

The  
**BUILD  
HEALTH**  
Challenge

LEARNING  
SERIES

---

**DATA SHARING  
WITHIN  
CROSS-SECTOR  
COLLABORATIONS:**

*Challenges and Opportunities*

JULY 2018



# OPENING LETTER

The medieval proverb that “all roads lead to Rome” was not only about the importance of Rome as capital of the Western world, but also about the idea that many routes can lead to a given result. From my vantage point observing local collaborations working on community health, I can attest to the importance of sharing data across sectors to help them meet their community goals, and I can say that there are many paths that communities follow to get there. It’s worth noting that the way isn’t always—or even usually—clear, but many communities are discovering exciting ways to work together to share data.

*All In: Data for Community Health* is a national learning collaborative that includes the BUILD Health Challenge and other national and state-based programs that support the kinds of data sharing efforts described in this report. While this report specifically documents challenges and lessons from BUILD grantees, members of the *All In* learning network can confirm that these

challenges and lessons are representative of larger themes that we see repeated across the country as communities come together to share data with each other.

People new to this work often assume that the biggest problems in data sharing are technical or legal, but the initial challenges are familiar to anyone who is trying to build a collaboration: what problem or opportunity is so big that we need to work with others? Who can help us do this big thing, and why will they want to join us? BUILD addressed many of these concerns in their first learning series on collaboration <http://bit.ly/KeystoCollaboration>. Once we solidify our relationships, how do we start the complicated conversations about sharing data?

The cumulative wisdom from scores of *All In* participants past and present tells us that you have to answer these questions before you can tackle data sharing. We’re also learning

that data sharing is a natural next step for many community health improvement projects, even if that was not an original part of the collaborative plan.

This makes sense, in a world increasingly defined by data and information. There is no part of our society—cultural, political, economic—that is not being radically transformed by the management and integration of data. Data and information management is not just a bright and flashy tool and it’s not just for Silicon Valley startups; being able to understand and communicate the importance of data is a key strategy in our efforts to support equity and justice in our communities, and a powerful mechanism to combat the effects of racism, classism, and sexism. Across the country, communities like those supported by BUILD and *All In* are sharing their learnings to increase the capacity of others to understand their own communities, engage residents, build leadership skills, plan interventions, and identify new allies.

This work is hard; it takes time to build coalitions, it takes money to build systems, and it takes commitment to overcome the obstacles that you will discover along this road. Luckily, you are not alone. Somewhere, someone has already faced a problem like the one you face now, and many of those folks are already participating in *All In*. The purpose of this report, and so many

of the activities of *All In*, is to document the solutions so that you know where to find them, to acknowledge the mistakes that others have made so that you don't have to repeat them, and to encourage you to engage with us and with each other around finding common solutions that build your communities and the field of us working on this together.

We're glad to join you on this journey, where all roads lead to enlightenment and equity, eventually.



Peter Eckart

Co-Director, Data Across Sectors for Health (DASH)  
Illinois Public Health Institute



## ALL IN: DATA FOR COMMUNITY HEALTH

*All In: Data for Community Health* is a learning collaborative that helps communities across the country build capacity to address the social determinants of health through multi-sector data sharing collaborations. *All In* reflects the efforts and insights of over 100 community collaborations across the country.

Made up of individuals, organizations, and national initiatives, *All In* members join forces to coordinate formal and informal technical assistance, foster dialogue, and cultivate peer-to-peer learning activities for those tackling common challenges or employing similar approaches and tools.

The seven program offices and their communities that are in *All In* include:

- BUILD Health Challenge (funded by 12 national and regional philanthropies)
- Community Health Peer Learning (funded by the Office of the National Coordinator for Health Information Technology)
- Connecting Communities and Care (funded by The Colorado Health Foundation)
- Data Across Sectors for Health (funded by the Robert Wood Johnson Foundation (RWJF))
- New Jersey Health Initiatives (funded by RWJF)
- Public Health Innovation Lab (funded by the State of California and other funders)
- Public Health National Center for Innovation (funded by RWJF)

# INTRODUCTION

*Much of our health is influenced by social and environmental factors, such as employment opportunities, air and water quality, transportation, and educational attainment. Key to addressing these upstream factors—and ultimately improving community health—is better understanding the complex interplay between them and our communities. To do so, we must collect, share, and successfully manage data across sectors, in tandem with other forms of systems change, that will effectively transform health in America.*

While the importance of data in our collective efforts to improve community health is widely agreed upon, the way in which we leverage and apply data is not. During a series of interviews with participants from the first cohort of the BUILD Health Challenge (BUILD) about their data-driven approaches, we found that participants—although experienced in their respective fields, intentional about applying data-

driven approaches, and supported by technical assistance (TA)—still faced a wide variety of challenges surrounding data collection and usage. The reality is that data collection, sharing, and analysis is not a one-size-fits-all approach. While best practices are important to reference, how a group views the situation at hand, identifies a solution, and activates its resources in the real world is equally important.



The BUILD Health Challenge seeks to contribute to the creation of a new norm in the U.S., one that puts multisector, community-driven partnerships at the center of health in order to reduce health disparities caused by system-based or social inequity. A national awards program, BUILD represents Bold, Upstream, Integrated, Local, and Data-Driven approaches that help communities build meaningful partnerships among community-based organizations (CBOs), hospitals/health systems, the local health department, and other organizations. Together, these partners are driving sustainable improvements in community health. To learn more about BUILD, see page 41.



Therefore, rather than create a best-practice guide on data, we have collected stories of the five most common data challenges from the BUILD cohort and shared reflections and solutions from the practitioners involved.

In this case, the context for the challenge is just as important as the solution. How did the practitioner view the challenge? What circumstantial factors led to the team's decision on what to do? What tools did the organization have access to?

In this collection of stories, we aim to provide a guide for the real world—where even the most well-prepared and resourceful team may face a data challenge of its own. Whether it is developing ways to track patient progress across different dashboards, creating cross-sector referral systems to improve housing stock, or hotspotting in neighborhoods to curb youth violence, data-driven approaches are a central part of the solution. You'll find lessons you can identify with, ideas to inspire you, and

recognizable challenges for which we offer tested solutions.

As you read this, don't forget to:

- Laugh when you can relate to a data challenge you have faced.
- Discuss how you have handled previous barriers in your work with teammates.
- Distribute it to partners who have limited data skills and are working in a partnership dependent on data.

We invite you to creatively adapt any guidance presented in this report to your local circumstances in order to develop and maintain data collection and sharing mechanisms that improve population health partnerships. To learn more about the participating sites, see page 42.

Share your ideas and stories around collaboration with us at [info@buildhealthchallenge.org](mailto:info@buildhealthchallenge.org).



*Key to addressing these upstream factors—and ultimately improving community health—is better understanding the complex interplay between them and our communities.*

---



# ▶ TABLE OF CONTENTS

## **A. DATA SHARING: CHALLENGES AND OPPORTUNITIES**

Page 8

- HIPAA concerns
- Logistics of data sharing across a wide array of data systems
- Language differences between partners
- Lack of experience with data
- Difficulty finding methods or metrics to evaluate the intervention

## **B. SUGGESTIONS FOR COLLABORATIVE PARTNERSHIPS**

Page 30

- Suggested Practice #1: Plan the data process prior to data collection
- Suggested Practice #2: Collect data that impacts your role in the project
- Suggested Practice #3: Identify a data diplomat

## **C. CONCLUSION**

Page 40

## **D. APPENDICES**

Page 41

- About BUILD
- About the participating BUILD sites

# CHALLENGES

## SUMMARY OF DATA-SHARING AND DATA USAGE CHALLENGES

- Data sharing can introduce a new set of challenges for users, including:
  - › Aligning the integration of data across separate organization-specific data systems.
  - › Sharing a data system that was not developed with sharing in mind.
  - › Formatting and collecting data using disparate or incompatible methods.
- Integrated data systems can be expensive to develop and require upfront planning and significant resources.
- Partners from different sectors may use the same words to mean different things and use sector-specific terminology to describe similar ideas.
- Partners may use differing definitions for variables, which may lead to inconsistent data collection.
- Program professionals and data leads working on a project together may be at risk of miscommunicating with one another.
- Partners may be reluctant to share or collect data, especially if they are new to working with data.
- Partners may need significant training and technical support around data collection, use, or sharing.
- Partners may have limited or no experience with collaboration on data-driven projects.
- Partners may fall behind in data-related duties at varying points throughout the program, which can slow the progress of the overall collaboration.
- Partners should explore innovative approaches to evaluation methodology, but do so cautiously.

## SUMMARY OF DATA-SHARING AND DATA USAGE SUGGESTIONS FOR SUCCESSFUL PARTNERSHIPS

- Partners should have at least a surface-level understanding of the need for data and how it will fit into the overall project plan.
- Plan the data process as early as possible—definitely before data collection.
  - › The planning process should take into account capacity, financial resources, and personnel time.
  - › Discuss the type of data each partner has access to, the data-sharing policies within each organization, and the time and financial commitment necessary for data collection and sharing.
- Define data-specific roles for each partner to lead to clarity, increase capacity of partners new to data collection, create an atmosphere of collective data interpretation, and ensure that partners are not overwhelmed by their data-related role.
- Be aware of the downfalls of taking a siloed approach to data collection, sharing, or usage. It could cause partners to lose sight of the big picture.
- Every collaboration should have a “data diplomat”—a person responsible for all aspects of the data.

# BEST PRACTICES



# SHARING

**DATA  
SHARING**

*Challenges And Opportunities*



BUILD brings together partners from different sectors that work in different ways with different types of data. This breadth of backgrounds and approaches, while an asset to the overall partnership, poses unique challenges for data sharing like:

- Concerns around Health Insurance Portability and Accountability Act (HIPAA) Privacy Rule permissions.
- Logistics of data sharing across a wide array of data systems.
- Language differences among partners.
- Lack of experience with data.
- Difficulty finding methods or metrics to evaluate the intervention.

## HIPAA CONCERNS

*“[HIPAA] is prohibitive. [We were brought] to the realization that we weren’t going to get what we thought we could. [Not] having the actual data in front of us, the hard numbers, has been difficult. So, that is a need, a huge need.” – A CBO partner*

Successfully working with HIPAA is an important component of any population health collaboration. With the express goal of integrating data across several partner agencies and data sources, the BUILD sites faced various challenges with collecting, sharing, and analyzing personal health information as a collaborative while adhering to HIPAA policies. Many of the BUILD sites expressed concern about the potential for breach of privacy, especially with sensitive patient data. Some of this disconnect seemed to stem from a lack of experience in dealing with the nuances of laws that govern and protect personal health data. Sites we spoke with were able to adapt and evolve their existing processes to overcome some of these barriers.

Because HIPAA places certain restrictions on the sharing of personal health data, the great difficulty some sites experienced in sharing clinical data with all partners affected project timelines and partnership trust. This section

gives insight into how HIPAA can impact data sharing in cross-sector partnerships<sup>1</sup> and the concerns that organizations, specifically those that are not used to working with health data, need to address before beginning that process.

**The HIPAA Privacy Rule establishes national standards to protect individuals’ medical records and other personal health information. It applies to health plans, healthcare clearinghouses, and healthcare providers that conduct certain healthcare transactions electronically.**

**The Rule requires appropriate safeguards and sets limits and conditions on the use and disclosure of information without patient authorization. It gives patients the right to examine and obtain a copy of their health records and to request corrections.**

<sup>1</sup> Sharfstein JM, Chrysler D, Bernstein J, Armijos L, Tolosa-Leiva L, Taylor H, and Rutkow L. Using Electronic Health Data for Community Health: Example Cases and Legal Analysis. December 2017. Retrieved from <http://www.debeaumont.org/EHDforCommunityHealth>.

A number of our CBO partners reported frustration with the investment of time in, and the trial-and-error associated with, understanding HIPAA and working with individual-level clinical data. As an example, one site's CBO partner expressed great dissatisfaction with their lack of access to clinical data and concluded that the hospital partner failed to consider these data-sharing challenges before the BUILD collaboration was underway. Three other sites articulated the inflexibility of data sharing due to HIPAA, saying that electronic health records (EHRs), while available to the hospital partner, seemed useless to the collaboration due to their inaccessibility. One CBO-based partner wondered how anything could get accomplished with “so many people afraid of HIPAA.”

### ADDRESSING HIPAA-RELATED CHALLENGES

Many of the BUILD sites grappled with HIPAA challenges, and each site emphasized the need for creative approaches. Some aspects of each approach were beneficial, but others posed a threat

to the integrity of the work; all approaches had drawbacks. Despite this challenge being a fairly common one for many working in this arena, the sites found a limited number of solutions to receiving disease-specific data for their intervention:

- Two sites proposed **adding partners** that, in theory, could share data without being restricted by HIPAA. One site proposed working with a clinical laboratory partner, believing that labs might have a more liberal interpretation of HIPAA. Another site sought to add an insurance provider to get individual-level, disease-specific data. However, this site discovered that bringing in another partner solely for that purpose was just as “tricky”—the teams found that working with such a “big player” can be complicated.

The sites concluded that adding new partners is not a quick fix; HIPAA applies to all partner types, and these partners still need to invest

time in understanding one another and the HIPAA rules as they apply to their work. The teams eventually grasped these key points:

- › “Jurisdictional balance,” which includes “understanding what levers cut across our jurisdiction.”
- › Existing barriers to data sharing, and the need to “create data-sharing agreements and processes.”
- Another idea was to **compromise on the type of data used**. One site originally requested individual-level data from their hospital partner, but after negotiations they settled on the hospital sharing aggregated de-identified reports. While this approach helped ensure that the site had hospital data to drive the intervention, it introduced conflict. The CBO leading the collaboration expressed concern that the hospital partner

might not be providing raw data because the hospital lacked trust in either the partners or the collaboration.

A second site compromised on the level of data by working with their health department partner to review publicly available data at the zip code level after not getting individual-level data from the hospital due to HIPAA. This workaround, providing summary data, drew some criticism. One partner said this data was “too broad to be useful.” The site found that zip codes often crossed neighborhood lines and therefore were not as granular as needed, but the data did provide a general sense of the community’s health status.

- One site decided to **collect individual-level health data directly** from the intervention recipients along with all the other metrics collected for the intervention. This option provided the site with individuals’ health data,

but they noted problems with collecting self-reported disease-specific data:

- › Respondents may not know the correct details of their health conditions and therefore may report inaccurately.
- › They may purposefully answer incorrectly or in a way that attempts to please the interviewer.

After hearing about data challenges from the sites, BUILD provided the sites with TA, including alternate methods of addressing HIPAA challenges. For example, TA introduced the idea of a **data diplomat** to the sites. The data diplomat is a person who is knowledgeable about HIPAA laws and is tasked and trusted by all partners to read, understand, and implement their data policies.<sup>2</sup> Data diplomats are often helpful in cross-sector collaborations, aiding them in overcoming the obstacle of getting the right data at the most useful level.

## SUGGESTIONS FOR THE DATA DIPLOMAT:

- Develop the necessary data-use agreement so all partners can share data.
- Identify a safe, neutral place to store the data.
- Explain the value and use of accurate and complete data to all partners and stakeholders.
- Create a common language for data use and sharing.
- Facilitate conversations with vendors and data users to improve their collaboration.

See more about the role of the data diplomat in Suggested Practice #3, page 38.

<sup>2</sup> Castrucci BC, Hunter EL, Michener JL, Chapple-McGruder T, Bradley D, “*The Role of Data in Precision Population Health*,” in Solving Population Health Problems through Collaboration, Bialek, Beitsch, and Moran, Editor s, April 2017.

## STORY FROM THE FIELD: DEALING WITH HIPAA REGULATIONS

Sites ultimately figured out ways to work with hospitals to receive health information. At times, this meant revising their request from individual-level data to aggregate data or applying to the hospital's institutional review board (IRB) to obtain patient consent for the hospital to share their protected health information.

A specific project focused on reducing hospitalizations and lowering asthma rates due to housing hazards and poor indoor air quality struggled with getting patient-level data as a result of HIPAA. During the project's planning and design stage, the partnership discussed working with the local hospital to identify patients with uncontrolled asthma. The partnership proposed identifying potential participants by receiving identifying information such as addresses of emergency room (ER) and hospitalized asthma patients. Those patients within a certain geographic area would be targeted for home interventions. However, the partnership soon found that the hospital partner was "unable to comply" with the request to release such information, as they believed it violated HIPAA regulations.

To understand what they could do under HIPAA regulations, the hospital partners offered a series of suggestions and educated the collaboration on the legal limits to what they could and could not share. Collectively, they decided to address their issue of patient identification by employing a two-step approach.

- 1) The hospital provided de-identified and aggregate data to help with patient identification. This data included the addresses of the apartment or condominium buildings of people recently admitted or seen for asthma. However, it did not provide individual patient addresses. Program staff knocked on doors of the buildings with the highest prevalence of asthma and screened residents with the survey tool. Once screened, residents were eligible for a residential screening if they had asthma and had been recently seen at the hospital.
- 2) The partnership obtained IRB approval. This allowed the hospital to share data with the entire collaborative and enabled primary data collection through participant surveys. This provided some assurances for the entire project: data were collected and stored in a way that protected patient privacy, and no harm would be done to the participants of the study.

While the initial plan to identify patients was unable to be implemented, the site was able to come up with a HIPAA-appropriate recruitment plan. It did, however, add additional time and effort to the overall project. But once in place, it alleviated the initial stress of not having the data needed for participant identification.

# TAKEAWAYS *for* PARTNERS:

*Based on the findings from these sites, here are recommendations for addressing HIPAA-related challenges:*

**KEEP IN MIND:**



**1.** Invest time to understand HIPAA so you can work with individual-level clinical data.



**2.** HIPAA may pose an obstacle to the level of data the team initially sets out to use, as HIPAA violations can occur when linking identifiable data.



**3.** While compromising on the type of data used (e.g., aggregating data) can solve some HIPAA-related issues, these compromises may hinder the utility of the data.

**TAKE ACTION:**



**4.** Work with all partners (and lawyers) to ensure that everyone at the table is interpreting HIPAA regulations similarly, as HIPAA applies to all partner types.



**5.** Conduct primary data collection, while staying aware of the potential limitations to accuracy.



**6.** Consider asking partners with access to data under HIPAA to analyze and report aggregated results to the collaboration.

**HIPAA makes accessing individual-level, disease-specific patient data complicated, but not impossible. BUILD sites tried various options to gain the most suitable data and encountered many roadblocks.**

**ADVICE FOR COLLABORATIONS:**

• **Seek to understand HIPAA for yourselves.**

Work with all partners (and lawyers) to ensure that everyone at the table is interpreting HIPAA regulations similarly and no partner will be shocked at which data elements can and cannot be shared. The Advisory Board Company's how-to series includes a document entitled, "How To: Share data without breaking HIPAA," with data-sharing advice for collaborations working with hospital partners (<http://bit.ly/2sDp2JJ>). The Centers for Disease Control and Prevention's report, "Overcoming barriers to data sharing related to the HIPAA privacy rule," promotes collaborations that include state or local health department partners and provides a handy flow chart (<http://bit.ly/2stZG1x>). Collaborations working on housing abatement, lead, or asthma projects may find this quite helpful.

• **Reassess the level of data needed for decision**

**making.** Is individual-level data necessary? Could the questions be answered if the hospital or a neutral party such as the health department conducted the analyses and provided the sites with aggregated results (instead of hospitals aggregating the data from the individual level to the group level)? Or could sites get permission from their intervention participants to obtain certain aspects of their medical histories?

• **Have a clear ask, as well as a clear**

**rationale for why people or organizations should share their data.** Consider creating a data-use agreement in conjunction with your partners to ensure that the requests are feasible and all partners are in agreement. <http://bit.ly/2JusD7v>.



### LOGISTICS OF DATA SHARING ACROSS A WIDE ARRAY OF DATA SYSTEMS

All but one site mentioned technological issues with data systems as an inherent challenge of data sharing in cross-sector collaborations. Problems included integrating data across separate organization-specific data systems (a problem shared by four sites) and obstacles to user-friendliness within a shared data system across all partners (cited by two sites).

Some sites were unprepared to deal with the complexity of integrating data from multiple sources. One partner said, “We wouldn’t know where to start.”

A partner at a site without integrated data systems shared her frustration:

*“One of the challenges is working with multiple different enterprise systems. Legacy systems that you are saddled with in your organization are not designed to work together, not designed to be cross-referenced, not designed to capture the same data points. And each agency buys software and programs based on their needs without necessarily thinking of how the information they are collecting could be used by another agency to collaboratively move a program forward.”*

Sites addressing this challenge said the cost of developing an integrated data system was a barrier. They discussed the resources needed to develop such a system for collecting and sharing data, and the additional funding needed for technical expertise, for processes to protect patient health information, and for data sharing.

*“It is a cumbersome endeavor to link into any EHR. That’s going to take a lot of resources, money, and people’s time. Funding will be a big issue in terms of paying for people’s time and the capacity to make our EHR do things that it can’t do right now.”*

## STORY FROM THE FIELD: LOGISTICS OF DATA SHARING

One particular site was struggling with sharing data between partners in a timely and efficient manner. This site's work included physicians from three different facilities prescribing physical activity or similar interventions to their patients. The patients could then utilize community resources for free, based on physician referral. However, due to limited access to data, the community resources did not know why a patient was referred and only tracked in aggregate the number of people being served. As the intervention went on, the physicians expressed interest in knowing if their patients ever took advantage of the prescription program as well as their level of compliance. This was impossible to tell from the paper records retained by the community resources.

The data need was threefold:

- 1) The community resources needed data that described the medical reason for the referral in order to gear appropriate classes and programs to meet the needs of the participants.
  - Individual-level health data needed to be transferred in a HIPAA-compliant way from three different medical facilities to a community center.
- 2) Physicians from different facilities wanted to know the outcomes linked to the patients they referred.
  - Individual-level data on program usage needed to be transferred from the community center to three different medical facilities in a secure manner.
- 3) The community program's paper records needed to be more specific and able to provide individual-level data.
  - Individual-level data specific to program usage and outcomes was needed. It also needed to be linked back to the referring physician.

Faced with these data needs, the site decided that the best approach would be to train the community staff on HIPAA requirements so they could become HIPAA certified. This would allow them to access the medical reason prompting referral from the medical provider. In order to address the need for all involved partners receiving real-time data, a data system was proposed that could both transmit individual-level data from all three medical facilities to the community resource and transfer data from the community resource to three different medical facilities in a secure manner.

While the proposed solution of a new two-way data system that could interface with all three hospitals and the community resource would have fixed the problem faced by the site, it introduced new challenges. Would those entering data from the hospital side need to do dual data entry (i.e., enter the data into their hospital's EHR system and then again into the program's data system)? Or would the data system be able to pull directly from the hospitals' EHRs? They soon found out that each hospital used a different EHR and that it would be time consuming and overly cumbersome to try to create a data system that could interface with all three EHRs. Also, there would be no easily scalable way to grow the data system to allow new hospitals that joined the intervention to access the data system.

The route suggested by the computer programmers, and ultimately accepted by all partners, was to create a fillable PDF document. This document could be sent securely from the medical providers to the community resource staff, as well as the reverse. This fillable PDF was able to connect to disparate EHR platforms, allowing physicians to view and edit it as if it were a part of the overall EHR system. This cut down on dual entry and eliminated the need to use and learn an entirely different data system.

*“One of our solutions that seems to be working well is to send individual PDFs—one page per referral in a zipped file so that those individual PDFs could be attached to the electronic health record (EHR)—and that has now crossed the two big [EHR] systems; the people that work with Cerner and the people that work with Epic, those two different medical record systems. They both asked for that and it can be done. So, from their point of view, that's interesting that [it] can fit into their processes. So that has been, I think to me, an unexpected outcome. That's an integration really of the two systems because they sent us a referral and the community partners send them back something that gets attached directly to the patient's electronic medical record.”*

“Every single clinic is collecting their evaluation data differently, and I don’t know how the evaluators are going to keep it all straight. But we’re developing process maps for every single one, and every process map is going to look different.”

---

### SHARED DATA SYSTEMS

Two sites were actually able to either integrate their data systems or jointly create a shared data system. Sites found this path to be expensive and time consuming, and the only partner who found the data system to be useful was the partner who housed it. Technology concerns did not end once a decision on data systems was made. Sites found that variations in how information was collected and formatted also presented challenges. One partner expressed frustration with “keeping the data straight” as a result of varying formats:

*“Everybody in our BUILD partnership is collecting data. Sometimes those are corner stores; sometimes those are healthcare facilities; and sometimes they are people like us. We are developing procedures for how all this data will be collected, but it has been challenging because every setting is different. Every single clinic is collecting their evaluation data differently, and I don’t know how the evaluators are going to keep it all straight. But we’re developing process maps*

*for every single one, and every process map is going to look different.”*

One site chose to use BUILD funds to provide TA on the use of data to all partners. They worked closely with their evaluators to create a data dictionary and ensure that all partners understood the meaning of variables and the correct way to enter data. They also instituted the role of a data diplomat to aid in future data issues or concerns.

To address the issue of usability or incompatible data systems, some sites used award dollars to jointly create a shared data system. Sites recommended that each partner be given adequate training on the system and that they create clear processes for data collection. Two sites highlighted the need to be deliberate in planning the data process before starting collection, to ensure that all partners are aware of and prepared for potential pitfalls. Partners who opposed this solution cited cost, time, and maintenance of the new data system as obstacles.

# TAKEAWAYS *for* PARTNERS:

Based on what we learned from these sites, here are some suggested practices for addressing shared data systems challenges:

## KEEP IN MIND:



### 1. Data sharing can introduce a new set of challenges for users, including:

- Aligning the integration of data across separate organization-specific data systems.
- Formatting and collecting data using disparate or incompatible methods.



### 2. Integrated data systems can be expensive to develop and require upfront planning and significant resources.

## TAKE ACTION:



### 3. Use grant dollars to enable partners to jointly create a shared data system.



### 5. Create clear processes for data collection.



### 4. Provide each partner with adequate training on the data system.



### 6. Be deliberate in planning the data process before you start to collect data.

## WE RECOMMEND THESE RESOURCES FOR ADDITIONAL INFORMATION AND SUPPORT:

- **Practical Playbook:** This publication includes implementation tools, guidance, and resources to improve population health through collaboration among public health, primary care, and other organizations. [www.practicalplaybook.org/section/expert-insights/working-data](http://www.practicalplaybook.org/section/expert-insights/working-data)
- **Data Across Sectors for Health (DASH):** Launched by the Robert Wood Johnson Foundation, DASH identifies barriers, opportunities, promising practices, and indicators of progress for cross-sector collaborations that connect information systems and share data to improve community health. [www.dashconnect.org](http://www.dashconnect.org)
- **ALL IN:** This nationwide learning collaborative helps communities build capacity to address the social determinants of health through cross-sector data-sharing collaborations. [www.allindata.org](http://www.allindata.org)
- **Academy Health:** A national organization for health services researchers, policymakers, and healthcare practitioners and stakeholders, Academy Health increases the understanding of methods and data used in the field and enhances the professional skills of researchers and research users. [www.academyhealth.org/evidence/topics/data-sharing](http://www.academyhealth.org/evidence/topics/data-sharing)
- **Using Electronic Health Data for Community Health: Example Cases and Legal Analysis:** This white paper by Sharfstein, J.M., et al., gives six examples of how a public health agency might use electronic health data to make progress on childhood asthma, a common and preventable chronic illness. These use cases cover a range of potential data applications, including surveillance, geographic analysis, identification of high-risk patients, engagement with clinicians, and evaluation of interventions. [www.debeaumont.org/EHDforCommunityHealth](http://www.debeaumont.org/EHDforCommunityHealth)

## LANGUAGE DIFFERENCES BETWEEN PARTNERS

Of the seven sites interviewed, five disclosed that lack of a “shared language” hampered data collection, sharing, and/or use.

- At times, partners were using the same words to mean different things—or using sector-specific terminology to describe similar ideas—but the terms failed to resonate across sectors.
- Variables were defined differently by partners and across data platforms.
- Partners who focused on the program aspects of the work felt that their data partners spoke in “esoteric terms.”

In an earlier BUILD report, “Keys to Collaboration” <http://bit.ly/KeystoCollaboration>, there’s a section dedicated to creating a shared language across partners. However, a few sites found that this remained a problem months into their BUILD project. One hospital partner discussed their experience with not understanding public health phrases:

*“I think ‘social determinants of health’ is the language used in the community through the*

*public health department. It's just that our hospital system does not use that language. There is a long way for them to go to understand some of the public health terminology."*

The lead partner at that site shared his astonishment that some of the confusion among the collaborators was because they lacked a shared lexicon:

*"One of the things we realized in one of the meetings [was that] everyone was using a different language and it was mucking up what we actually do and our focus. So we had a touch point where we brought in different definitions, where people were saying, 'No, we are doing community organizing work,' 'Oh, we're doing chronic disease management,' 'Oh, we're doing community capacity building,' and at the core of it we realized, when we went back to our notes, the co-chairs and myself said, 'people are using seven different words [for the same thing]!"*

This finding led the site to focus on developing a shared language among all partners, which led to a common understanding of the topic and more effective conversations around appropriate metrics.

Four other sites faced the problem that data terms or variables had multiple meanings. This led to inconsistent data collection. For instance, one site realized that partners interpreted the word "year" differently; some partners were collecting data by fiscal year, while others were collecting by calendar year. Similar interpretation issues occurred around differing methods for coding a hospital visit; some partners included ER visits as a hospital visit, while others only included hospital admissions.

Another source of confusion was how to count outcome measures (i.e., whether to count cases or events). One site with multiple healthcare facility partners said their various data systems collect data differently—some by events and others by unique patients. For example, partners at this site interpreted the following case differently: One child was admitted to the hospital for three asthma attacks. Some partners counted this as three events, while other partners counted it as one case. Once the site realized this inconsistency, discussions centered on the need for a data system capable of both counting unique cases, and tracking unique events.

Lastly, at least two sites noted communication difficulties between program professionals and data leads. One interviewee felt the data analysts used esoteric language that others could not easily understand, while a data lead lamented "the lack of basic data knowledge" among the partners. A public health department partner from a different site was also concerned that varying levels of data understanding on her team would pose a barrier between collecting and sharing data and that the quality and completeness of data would be affected, introducing a "percentage of error." To address this issue, sites would often either depend on their data lead to conduct training for partners lacking the experience, or the site lead would request TA through the BUILD project. While this issue was always resolved, it did impact the validity of data collected early in the project and cause delays in data collection.

These examples illustrate how different perceptions from different sectors can inhibit a project's success, and how, once identified, methods can be put in place to mitigate potential complications.

A photograph of a person's hand holding a black pen over an open notebook on a desk. In the background, a computer keyboard and mouse are visible. The image is partially obscured by a purple diagonal overlay.

## INSIDE LOOK AT BUILD: DATA LANGUAGE

Sites suggested several ways to develop a shared language around data. While some have implemented these suggestions, others were presenting plans or describing lessons learned.

One of the sites that had a problem with silo-specific terminology and differing interpretations proposed the creation of common definitions and a data dictionary. This document would describe the content, format, and structure of each variable relevant to the project.

Sites expressed the need to be very deliberate in their data collection processes by creating these “living documents” to be continually updated throughout the project. One partner emphasized the importance of using these documents as a tool to facilitate shared understanding:

*“Making sure that we’re all working within the right definitions of data sharing and compliance and breaking down what the different acronyms and jargons mean across the different jurisdictions has been really helpful. We’ve been building [a data dictionary] in real time and it’s been comprehensive. Maybe a lesson learned is if we could do this again, I would have spent more time doing that breakdown of jargon and growing understanding across the different jurisdictions before we dived in.”*

A site that started out with partners having varying levels of data proficiency relied on their evaluation arm to teach all partners about appropriately handling and interpreting data. This built capacity and allowed all partners to feel vested in the data process.

# TAKEAWAYS *for* PARTNERS:

*Based on what we learned from these sites, here are some suggested practices for addressing language differences and challenges:*

**KEEP IN MIND:**



- 1.** Partners from different sectors may use the same words to mean different things and use sector-specific terminology to describe similar ideas.



- 2.** Partners may use differing definitions for variables, which may lead to inconsistent data collection.



- 3.** Program professionals and data leads working on a project together may be at risk of miscommunicating with one another.

**TAKE ACTION:**



- 4.** Create, use, and continually update a data dictionary to ensure common definitions for variables and facilitate shared understanding among partners.



- 5.** Be deliberate and consistent in data collection approaches across partners.



- 6.** Build capacity and shared understanding by having the evaluation team teach all partners about appropriately handling and interpreting data.

## STORY FROM THE FIELD: VARYING EXPERIENCES COLLECTING AND UTILIZING DATA

One site had partners that ranged from neighborhood corner store vendors, to food bank distributors, to graduate-level, public health–prepared practitioners, researchers, and evaluators. As such, the levels of understanding, knowledge, and experience collecting public health data varied. The public health–trained partners wanted detailed data from the corner stores on buying and browsing behaviors of customers as it related to the impact of the healthy food signage on purchasing nutritious snacks. Most corner stores were not equipped to provide more than sales data, nor did those partners understand the importance of changing their data collection techniques for the purposes of the initiative. This limited the data, as it was only clear that healthy food items were sold, but not clear if they were consumed by one person, shared with the family, or ever eaten.

Similar limitations were found with the data from the food bank. Anecdotally, the researchers heard that the food purchased through food vouchers was often not solely consumed by the purchaser. They tended to share the food with whoever provided them with transportation to redeem the vouchers or others in their home, or they used it to barter with other students in exchange for goods. This limited the researchers' ability to describe the reach of the food program, understand the impact of providing food on the overall health of the participants, and calculate a true return on investment.

Additional training of corner store or food bank staff could have resulted in the collection of more specific data. However, partners would have needed to be trained on collecting data as well as on ways to inform participants that their responses would be kept confidential and not impact any of the food services they received as part of the intervention. It is unclear whether staff in the partner agencies would have been able or willing to undergo that level of data collection training.



### LACK OF EXPERIENCE WITH DATA

Most BUILD partners had limited or no experience with collaboration on data-driven projects. Some were reluctant to share data because they were new to the process and unsure where to start, while others did not know how to collect data in this type of project. A partner representing the evaluation arm of one site said:

*“We are relying on our partners in our BUILD partnerships to have feet on the ground collecting the data. But that might be new to them and not traditionally a role that they’ve done. We will be doing a lot of trainings around data collection and how to do it in the best way possible.”*

One of the partners on the evaluation team revealed that its BUILD partners needed more training and technical support than the evaluators expected. This interviewee said partners needed capacity-building support to collect data using best practices and the evaluating team needed more lead time to prepare them for that role.

At another site, a partner organization was grappling with the question of how to collect and use data to inform decision making about

services rendered to the community. They mentioned having access to EHRs but not knowing the best way to use them or even what questions to ask about them.

### INSIDE LOOK AT BUILD: VARIATIONS IN DATA USE AND SHARING

There’s great variation among sites in data use and sharing, despite partnerships with organizations known for using data and TA offered to all BUILD awardees. This variation may be due to the different sectors that are collecting data—some in controlled environments and others in more dynamic community settings, such as corner stores. It could also be due to certain partners’ differing expectations about the amount of labor and equipment required. One site was unprepared for the time commitment and ended up slowing down the partnership due to the backlog of unentered data.

Sites addressed the problem by:

- Giving in-depth training on data collection and usage to partners new to data collection.
- Taking advantage of TA opportunities offered by BUILD.
- Shifting resources to allow one site—whose data collection delays threatened to derail a project—to hire temporary workers to aid in data entry and collection.

# TAKEAWAYS *for* PARTNERS:

*Based on what we learned from these sites, here are the suggested practices for addressing variations in data use and sharing levels of experience:*

## KEEP IN MIND:



- 1.** Partners may be reluctant to share or collect data, especially if they are new to working with data.



- 2.** Partners may need significant training and technical support.



- 3.** Partners may have limited or no experience with collaboration on data-driven projects.



- 4.** Partners may fall behind in data-related duties at varying points throughout the program, which can slow the progress of the overall collaboration.

## TAKE ACTION:



- 5.** Provide in-depth training on data collection and usage.



- 6.** Consider hiring temporary workers to aid in data entry and collection.



- 7.** Encourage partners to take advantage of the TA BUILD offers all grantees.



### DIFFICULTY FINDING METHODS OR METRICS TO EVALUATE THE INTERVENTION

BUILD awardees have the opportunity to innovate initiatives for upstream solutions that address the health of their target communities. Yet this outside-of-the-box thinking means there may be a paucity of methods to evaluate these initiatives.

One site had difficulty finding the right metrics on social and economic impact to measure a project's return on investment. One partner said:

*“We have a couple of CDFI [Community Development Financial Institution] partners who are also very interested in that [outcome], especially if they start investing in us. It’s also very challenging. We consulted with health economists at some of our local universities. We put a call out to 20 different places to ask who is doing this, who is monitoring, who is measuring return on investment for a social impact intervention like BUILD. Nobody! And it’s very hard to measure.”*



### INSIDE LOOK AT BUILD: EVALUATING NOVEL INTERVENTIONS

While only one BUILD site has reported challenges with their evaluation, we expect that as more community partnerships seek novel approaches to address community health, this issue will spread. Additional interviews did not reveal any potential solutions; however, one site noted that it used the Practical Playbook as a framework and guide to develop evaluation metrics for process and outcome. Also, all sites prepared detailed listings of secondary data sources and described the data collection methods they use to support their work, as shown in the following table.

**Sample Data Collection Methods and Data Sources Utilized by BUILD Sites**

“While only one BUILD site has reported challenges with their evaluation, we expect that as more community partnerships seek novel approaches to address community health, this issue will spread.”

	QUALITATIVE	QUANTITATIVE
<b>Primary data collection</b>	<ul style="list-style-type: none"> <li>Focus groups</li> <li>PhotoVoice</li> <li>Video mapping</li> <li>Storytelling</li> <li>Key informant interviews</li> </ul>	<ul style="list-style-type: none"> <li>Count data (e.g., sign-in sheets)</li> <li>Surveys</li> <li>Health screenings</li> <li>ER return data</li> <li>Fresh food consumption data</li> </ul>
<b>Secondary data collection</b>	<ul style="list-style-type: none"> <li>School cafeteria menu data</li> <li>Housing remediation data</li> <li>Dietary patterns</li> </ul>	<ul style="list-style-type: none"> <li>Demographic data</li> <li>Biometric data</li> <li>Disease-specific data</li> <li>ER data</li> <li>911 data</li> <li>Housing remediation data</li> <li>Ambulance runs</li> <li>Health insurance billing and claims data</li> <li>Citizenship data</li> <li>Quality of life data</li> <li>Environmental data</li> <li>Educational attainment data</li> <li>Food insecurity data</li> <li>Linguistic isolation data</li> <li>Food bank data</li> <li>American Community Survey</li> <li>Comprehensive Housing Affordability Strategy data</li> <li>Section 8 housing voucher utilization data</li> <li>CoStar data (e.g., real estate data, rental prices, blighted properties, etc.)</li> <li>Median home prices from Zillow and Rentometer</li> </ul>

# TAKEAWAYS *for* PARTNERS:

*Based on what we learned from these sites, when evaluating novel approaches, consider the following:*

**KEEP IN MIND:**



- 1.** Take innovative approaches to evaluation methodology, and use caution to ensure that approaches are methodologically sound.

**TAKE ACTION:**



- 2.** Consider routes to primary data collection as well as taking advantage of secondary data sources (Appendix I).



# PARTNERSHIPS

## **SUGGESTIONS FOR COLLABORATIVE PARTNERSHIPS**



### **SUGGESTED PRACTICE #1: PLAN THE DATA PROCESS PRIOR TO DATA COLLECTION**

All sites underscored the importance of planning the data processes as early as possible, and definitely prior to data collection. While integrating this type of planning may seem natural, too often it is overlooked. Sites described the planning phase as an opportune time to discuss the type of data each partner has access to, the data-sharing policies within each organization, and the time and financial commitment necessary for data collection and sharing.

One site mentioned the need to be “deliberate in all matters concerning data,” including data collection, sharing, and use, and in taking the time to get to know and understand the data each partner brings to the table. The partner remarked:

*“Getting the right partners to the table early on is the important lesson learned, and making sure that folks understand where they want to go, and what information other partners may already collect without realizing the impact the information can have.”*

In particular, sites hoping to tap into hospitals’ EHRs mentioned the need to think about which variables would aid their work and to develop a plan for how the data will be used. One partner said everyone at their site wanted EHR data, but the only person who could say why it was needed was the hospital’s data analyst. Other partners described discomfort in not knowing why certain data sets were needed and suggested that all partners should have at least a surface understanding of the need for data and how it fits into the overall project plan.

Another site said it was vital to think about EHRs early in the planning process to evaluate potential challenges in accessing patient records. Learning the details of each partner’s data-sharing policies could eliminate frustration and help sites create reasonable roles and expectations about what data each partner will bring to the collaboration. One partner said that when planning the data collection process, sites should also take capacity, financial resources, and labor into account.

## STORY FROM THE FIELD: ROBUST DATA PLAN

One BUILD awardee had a very detailed and advanced data collection plan that enabled the collection of both qualitative and quantitative data at the individual, Census Tract, zip code, and clinic levels. It was designed as a three-phase plan that assigned a role to each partner in each phase, based on what they defined as “jurisdictional data” (i.e., data owned by each partner). The group met in its entirety every two to three weeks to discuss data and tackle problems as they arose.

The plan was designed so that no partner would be overwhelmed by data collection. For instance, in Phase One, each partner collected primary, intervention-specific data corresponding to their role. The hospital would collect basic demographic data on the patients they saw as part of the project, while the CBO partners would collect data on program usage and home visits, and the health department partner provided information on referrals and uptake of nutritionist visits by program participants. Phase Two was led by the partners who worked for the city and added secondary data sources to provide a broader context on overall mortality, obesity, and other quality of life measures citywide. Phase Three involved working with intervention participants to create a PhotoVoice-like project, using pictures or videos to tell a story from the participants’ perspective.

This process gave the partners an opportunity to think through each component of the project and identify the corresponding data needs. It also provided the necessary time for each partner to be trained in data collection.

While the initial plan to identify patients was unable to be implemented, the site was able to come up with a HIPAA-appropriate recruitment plan. It did, however, add additional time and effort to the overall project. But once in place, it alleviated the initial stress of not having the data needed for participant identification.

# TAKEAWAYS *for* PARTNERS:

*Based on what we learned from these sites, when preparing a data process, consider the following:*

## KEEP IN MIND:



- 1. All partners should have at least a surface-level understanding of the need for data and how it will fit into the overall project plan.**

## TAKE ACTION:



- 2. Plan the data process as early as possible—definitely before data collection.**



- 3. Take capacity, financial resources, and personnel time into account during the planning process.**

Discuss the type of data each partner has access to, the data-sharing policies within each organization, and the time and financial commitment necessary for data collection and sharing.



- 4. Plan appropriate usage for the data.**



- 5. If planning to use EHRs, consider potential challenges in accessing patient records and learn the details of each partner's data-sharing policies.**

Partners were typically in charge of bringing data that they were used to capturing; one site referred to this as each partner’s “jurisdictional data.”

**SUGGESTED PRACTICE #2:  
COLLECT DATA THAT BEST SUITS YOUR  
INTEREST AND EXPERTISE**

While not all sites had detailed processes in place for data collecting, sharing, and use, they all had clearly established data collection roles for each partner. The table on the next page represents the variety of approaches by partner type across all sites.

Partners were typically in charge of bringing data that they were used to capturing; one site referred to this as each partner’s “jurisdictional data.” Often, this meant that the community-based partner collected data specific to the intervention, the hospital partner collected disease-specific data, and the health department partner provided access to secondary data. Additional partners, such as external evaluators or academic partners, were enlisted to help with data collection or analysis.

One partner explained how defining each organization’s role enabled them to be very strategic. A CBO member described their role in data collection:

*“We have a Zumba class too, and we have a monthly calendar that we use to figure out how many people are going to each of the Zumba sites to participate in the classes. Through the use of sign-in sheets, hand calculation of the data, we’ll count how many people went to a specific Know Your Numbers event or how many people went to the Zumba class. We’re all responsible to report on our piece of the information.”*

Another partner explained that each partner collected very specific data. For example, the hospital tracked the number of ER returns as well as disease-specific details. The health center collected non-emergent health information, and the community center both tracked the resources used by each patient and explained how that information helped determine the need for various resources at the health hub.

## Inside Look at BUILD: Each Partner's Role in Data Collection and Analysis

Partner Type	Role
<b>Core Partners</b>	
CBO	<p>Collects:<sup>a</sup></p> <ul style="list-style-type: none"> <li>Intervention-level data (number of people utilizing the services)</li> <li>Resources utilized and needed for participants</li> </ul> <p>Manages:<sup>b</sup></p> <ul style="list-style-type: none"> <li>Data collection, analysis, and interpretation process</li> <li>Tracking of data collection process (e.g., dashboards)</li> </ul> <ul style="list-style-type: none"> <li>Case management data</li> <li>Data storage</li> </ul>
Hospital	<p>Collects:</p> <ul style="list-style-type: none"> <li>Patient-level, disease-specific data</li> <li>Social determinants (e.g., employment)</li> </ul> <p>Analyzes:<sup>c</sup></p> <ul style="list-style-type: none"> <li>Aggregated individual data</li> </ul> <p>Creates:<sup>d</sup></p> <ul style="list-style-type: none"> <li>Evaluation design</li> </ul> <ul style="list-style-type: none"> <li>Demographics</li> <li>Insurance status</li> <li>Community health needs assessments</li> </ul>
Health Department	<p>Collects:</p> <ul style="list-style-type: none"> <li>Health department clinic usage</li> </ul> <p>Analyzes:</p> <ul style="list-style-type: none"> <li>Sensitive data and provides aggregate results to partners</li> </ul> <p>Provides:<sup>e</sup></p> <ul style="list-style-type: none"> <li>Population health statistics</li> <li>Medicaid insurance data</li> <li>Cost data</li> <li>Contextual, social data</li> </ul>
<b>Additional Partners</b>	
Other City Departments	<p>Provides:</p> <ul style="list-style-type: none"> <li>Housing sales data</li> <li>Housing condition data (mold, etc.)</li> <li>Home ownership and rental data</li> <li>911 data</li> </ul>
Other Research Partners (evaluators, university partners)	<p>Collects:</p> <ul style="list-style-type: none"> <li>Project-specific survey data</li> </ul> <p>Creates:</p> <ul style="list-style-type: none"> <li>Evaluation design</li> </ul> <p>Provides:</p> <ul style="list-style-type: none"> <li>Family structure data</li> <li>Poverty-level data</li> <li>Qualitative data (focus groups, PhotoVoice, storytelling)</li> </ul>

\* Each partner did not actively participate in every aspect listed in their corresponding role section, but they did undertake at least one.

a) Collects: Actively seeks data to compile.

b) Manages: Takes a leadership role and all responsibility for ensuring data collection in a timely and accurate way from all partners.

c) Analyzes: Conducts data analysis before sharing with partners.

d) Creates: Makes something new specifically for their BUILD project.

e) Provides: Agency has access to data that is already compiled, and the partner is sharing the data with the BUILD collaboration.

A DOWNSIDE TO DATA COLLECTION WITHIN SILOS WAS THE POTENTIAL FOR PARTNERS TO ONLY HAVE A VESTED INTEREST IN THE DATA THEY WERE COLLECTING AND LOSE SIGHT OF THE BIG PICTURE.



Sites said that determining data-specific roles has advantages, including:

- Clarity that can prevent partners from becoming overwhelmed.
- Increased capacity of partners who were not initially well versed in data collection.
- Creation of an atmosphere of joint data interpretation, where every partner has an equal opportunity to help shape the narrative around the data.

However, a downside to data collection within silos was the potential for partners to only have a vested interest in the data they were collecting and lose sight of the big picture. As one partner put it:

*“We are all doing our own thing in terms of data use, assessment, and planning around the BUILD health partnership. [Amongst the partners,] it is all about ‘collecting for my piece.’”*

Before implementing this approach, sites must ask themselves if they are doing it so that everyone will have a clear role or because they lack trust in each other to enter raw data into a shared repository.

One method to ensure that sites had a vested interest in the big picture was to involve all sites in interpreting the data. Multiple sites held a meeting where the lead data analysts would walk through all the data collected during a specific time frame and the partners would interpret the data as a group. One site even included their target population in these data discussions and used the findings from these meetings to drive the next steps of their collaborative work.

# TAKEAWAYS *for* PARTNERS:

*Based on what we learned from these sites, when collecting data, consider the following:*

## KEEP IN MIND:



1. Defining data-specific roles for each partner leads to clarity, increases capacity of partners new to data collection, creates an atmosphere of collective data interpretation, and ensures that partners aren't overwhelmed by their data-related role.



2. A siloed approach has the potential for partners to lose sight of the big picture.

## TAKE ACTION:



3. Each partner should take charge of bringing data that they're used to capturing to the collaboration.



4. Involve all partners in interpreting the data. Meet as a group, include representation from the target population, and use the findings to drive next steps.

**SUGGESTED PRACTICE #3:  
IDENTIFY A DATA DIPLOMAT**

Across all sites, the CBO partner employed someone to serve as the data diplomat. While the role's definition varied across sites, one partner captured its essence as “the weaver of the data.” Others defined this role as one who advocated for accurate and complete data. For the majority of sites, the data diplomat served as the intermediary between the partners and the data by:

- Confirming that each partner had a clear understanding of their role in the data.
- Creating data-use and data-sharing agreements.
- Ensuring all partners submitted their assigned data components in a timely manner.
- Hosting data “visioning sessions” for group interpretation of the data.

One hospital partner mentioned that relinquishing control of the data to a community partner was a departure from the way they typically collaborate. While doing so initially caused some discomfort, the hospital understood the need to try different methods in order to get different results.



# TAKEAWAYS *for* PARTNERS:

*Based on what we learned from these sites, when collecting data, consider the following:*

## KEEP IN MIND:



- 1. Across BUILD sites, the CBO partner served as the data lead.**



- 2. This process may be new and cause discomfort for hospital partners or those accustomed to managing their own data in any collaboration.**

## TAKE ACTION:



- 3. The data diplomat's role includes:**
  - Serving as the intermediary between the partners and the data.
  - Confirming that each partner has a clear understanding of their role in the data.
  - Creating data-use and data-sharing agreements.
  - Ensuring that all partners submit their assigned data components in a timely manner.
  - Hosting data “visioning sessions” for group data interpretation.

# CONCLUSION

When it comes to addressing the root causes of our most pressing health challenges, there are no simple solutions. There is, however, one consistent factor that is key to maximizing efforts: integration of data. As we saw with the BUILD sites profiled in this report, programs must intentionally and skillfully practice data collection, sharing, and analysis. Otherwise, no program can effectively understand, measure, or validate its impact—or share its learnings with others.

The integration of data can also present its own set of challenges. In the case of the BUILD sites, as with other community collaborations operating today, they were inundated with data. They had to parse that information, interpret it as a group, and use it to drive decisions. It played a critical role in not only catalyzing, but validating the work of the sites at both local and national levels. Despite the fact that they all had a clear vision for the usage of their data, many struggled with language barriers, lack of experience, or alignment of the right metrics. Data in this case was much easier to discuss in theory than apply in practice.

An unanticipated result of understanding how BUILD sites leveraged data was discovering how the sites' intentional focus on data helped to shed light on various other elements of their project. That intangible element ultimately helped contribute to each site's ability to advance its own efforts. For example, at some sites, working with data helped to reveal the need for stronger cross-sector partnerships within the collaboration. In others, communication among partners became an area in which to improve. And of course, data also helped to show where progress was being made and where it was not, so that real-time, program-wide adjustments could be made.

In addition to informing one's own program efforts through data, inherent in BUILD is the aim to share information with others across sectors. With upstream issues as diverse and widespread as housing, transportation, food insecurity, violence, and education, data sharing has proven to be a valuable approach. For the BUILD sites, and others like them, data is and will continue to be one of the key elements that unite all issues, all actors, and all approaches in the fight for healthier communities. Are you ready to join us in this fight?

# APPENDIX I: ABOUT BUILD

*The BUILD Health Challenge is a national awards program designed to support community collaborations that are working to give everyone a fair chance to be healthy. BUILD encourages communities to build meaningful partnerships among hospitals and health systems, community-based organizations, their local health department, and other organizations to improve the overall health of residents.*

## **BUILD STANDS FOR:**

- **BOLD:** Partnerships that aspire towards a fundamental shift beyond short-term programmatic work toward longer-term influences over policy, regulation, and systems-level change
- **UPSTREAM:** Partnerships that focus on the social, environmental, and economic factors that have the greatest influence on the health of a community, rather than on access or care delivery
- **INTEGRATED:** Partnerships that align the practices and perspectives of communities, health systems, and public health under a shared vision, establishing new roles while continuing to draw upon the strengths of each partner
- **LOCAL:** Partnerships that engage neighborhood residents and community leaders as key voices and thought leaders throughout all stages of planning and implementation
- **DATA-DRIVEN:** Partnerships that use data from both clinical and community sources as a tool to identify key needs, measure meaningful change, and facilitate transparency among stakeholders to generate actionable insights

# BUILD IMPLEMENTATION SITES OVERVIEW

*Seven of the (18) BUILD sites from the first cohort participated in the learning series initiative. To learn more about all of the BUILD sites, visit [buildhealthchallenge.org](http://buildhealthchallenge.org).*

## **Albuquerque, NM**

Primary care providers and community development enterprises are working collectively to address some of the nonmedical factors that impact health in low-income, minority neighborhoods with high rates of heart disease mortality, high blood pressure, and childhood obesity. The goals are to equip core partners to act on the social drivers of poor health and to use feedback to measure the impact of nonmedical interventions.

## **Bronx, NY**

This project serves residents of multifamily buildings in neighborhoods with the lowest median income in the metropolitan area, overwhelmingly populated by Medicaid-eligible, working-poor people. This partnership brings together core partners to address root causes and triggers of asthma, including working with tenants and landlords to improve the quality of multifamily buildings and enact necessary upgrades.

## **Cleveland, OH**

This multidisciplinary partnership of community health and housing organizations addresses the health challenges of asthma, chronic obstructive

pulmonary disease, and lead poisoning. It focuses on three neighborhoods with the largest Hispanic and uninsured population and a disproportionate share of disease. The initiative will expand the asthma home visit assessment program and address deteriorating housing in the target communities.

## **Des Moines, IA**

This project brings together health and housing partners to conduct necessary home repairs to address asthma triggers. Residents ages 2 to 12 with a history of asthma-related medical visits can be referred to this program to receive housing assessments and home repairs. This initiative also includes education for families on how to manage asthma and maintain a healthy home.

## **Ontario, CA**

This partnership is working to increase wellness among individuals and families that face a variety of economic, social, and language barriers to good health. The project targets the area's lowest-income neighborhoods, where large numbers of residents speak English as a second language and educational attainment among parents is low.

## **North Pasadena, TX**

This partnership is working to alleviate the impact of food insecurity in five predominantly Hispanic and working-class zip codes that have higher rates of poverty, lower educational attainment, and more language barriers compared to surrounding areas and the rest of the county.

## **Oakland, CA**

This collective action by grassroots and institutional stakeholders seeks to achieve health equity in an area of historic divestment and physical decline. The project plans to improve health and well-being by improving community safety, supporting strategies to increase affordable housing, pursuing policies and programs to promote local economic growth and workforce development, and performing health interventions to lower the prevalence of high blood pressure among residents.

# BUILD PARTNERS

This report was made possible by the generous support of funders from the BUILD Health Challenge: Advisory Board\*, The Blue Cross and Blue Shield of North Carolina Foundation, The Colorado Health Foundation\*, The de Beaumont Foundation\*, The Episcopal Health Foundation, Interact for Health, The Kresge Foundation\*, Mid-Iowa Health Foundation, New Jersey Health Initiatives, The Robert Wood Johnson Foundation\*, Telligen Community Initiative, and The W.K. Kellogg Foundation.

\* Denotes original founders and funders of the first cohort of the BUILD Health Challenge.

This set of funding partners—coming together across sectors and national geography—aims to inspire similar teamwork among diverse organizations at a community level, add to the knowledge base for community health, and discover new best practices for the field.

To learn more about the BUILD Health Challenge, visit [BuildHealthChallenge.org](http://BuildHealthChallenge.org).



The Colorado Health Foundation\*



## SPECIAL THANKS TO:

- The first cohort of BUILD Health Challenge sites for sharing their experiences and learnings
- The BUILD Health Challenge Executive Steering Committee for their contributions to the report
- The Mendez team for conducting the research

The  
**BUILD**  
**HEALTH**  
Challenge

[buildhealthchallenge.org](http://buildhealthchallenge.org)