

Lessons Learned in Data Sharing & Care Coordination

June 2021

INTRODUCTION

Health centers have long embraced the factors of health occurring in- and outside of the clinic setting. This emphasis on whole-person care underpins the importance of integrated services meeting clinical and social needs along a continuum of interdisciplinary providers. While the goal is continuity of care, the fundamentals of this kind of service integration are the collection, leveraging, and sharing of data. Hopes for improving care coordination thus hinge on the appropriate, ethical, and efficient use of data.

The current landscape of data practices at health centers is wide-ranging. There is no one-size-fits-all approach to collecting and communicating data. Approaches are highly localized, depending on the resources, infrastructure, and partnerships available in their respective communities. Successful approaches in data sharing range from individual paper referrals to robust information exchanges, in which multiple kinds of service providers can share and receive relevant data.¹ Though some health centers have found success in pursuing this type of cross-system interoperability,² there is a persistent gap in how information systems are able to communicate with one another. This gap is especially apparent across systems (i.e., health, housing, justice, and legal) that reach underserved populations, including those experiencing homelessness and housing instability. Guidance around sharing data at these system junctures will help health centers make strategic choices to better integrate their services into an intersectional care continuum.

As with all health center functions, it is critical to include consumer voice in data sharing and decision-making. Despite having expertise in navigating different systems of care, consumers are often left out of conversations regarding health information. Traditionally underserved groups, such as those receiving services at health centers, also tend to be over-represented in data and are asked to share personal information repeatedly, regardless of whether that information is needed to advance care. Ethical and responsible decision-making must involve consumer leadership to guide the foundational *who, what, and why?* of data sharing.

To identify steps for advancing care coordination, the National Health Care for the Homeless (HCH) Council invited health center providers and consumers to participate in

ADDITIONAL RESOURCES

- [Community Information Exchange: Using Data to Coordinate Care for People Experiencing Homelessness: Addressing COVID-19 and Beyond](#)
- [Data Integration Best Practices for Health Centers & Homeless Services](#)
- [Community Information Exchange to improve health and advance equity in our region](#)
- [San Diego: What is CIE?](#)

targeted conversations regarding the challenges, opportunities, and recommendations for data sharing. This document summarizes the lessons learned from those conversations. Thanks to the expertise of the session participants, health centers and their stakeholders can use this document to consider substantive choices around the ethical and efficient use of data in various contexts.

HEARING FROM CONSUMERS

To ensure the consumer voice and perspective is included in programmatic recommendations, three listening sessions were planned, each with a different focus to ensure representation. These focus areas included a session for individuals from urban areas, one for those from rural areas, and one for individuals who identify as BIPOC (Black, Indigenous, and People of Color). In total, six individuals attended these sessions; three individuals attended the urban area conversation, three attended the session for individuals who identify as BIPOC, and no individuals attended the session focused on rural areas.

In the course of these conversations, two major buckets rose to the top: the importance of trust when sharing personal information, and the general perspective on data sharing. This can be further broken down into the key themes highlighted in the table below.

Key Themes	
<i>“I’m no longer interested in the problems. We have to start coming with solutions.” – Kendall Clark</i>	
Privacy and security options	<p><i>“The first page asks what providers you would want to share this information with and what is shared.” – Diedre Young</i></p> <p>There were varying perspectives and comfort level with information sharing, especially considering information shared across sectors. The consistent theme around privacy and security was to ensure that consumers had control and ownership over their information. Specifically, who has access to what information and how often. One individual expressed that they would be more comfortable if the information was shared point-in-time or if they had the option to review their data sharing settings at least annually.</p>
Only share relevant data	<p><i>“Who needs to know... the therapist doesn’t need what the allergist has to say.” – Charlotte Garner</i></p> <p>The overall consumer perspective, in-line with best practices in data sharing, was that only relevant information should be shared between providers, and especially across systems. While it may be helpful for a primary care provider to know about specialty care services or social determinants of health, it is unlikely that even the primary care provider needs all information in detail to make appropriate care decisions. Participants agreed that medications should be known to prevent contraindications, but that information like behavioral health session notes would not be necessary. Similarly, it may be</p>

	helpful for a housing provider to know if a consumer is connected primary care provider to document disability when needed for eligibility.
Talk about privacy and data sharing	<p><i>“It’s important for it to be understandable... I’ll shy away if it’s not clear and simple.” – Diedre Young</i></p> <p>Participants highlighted the importance of talking with consumers about data sharing in a way that is clear and understandable. The consumers participating expressed that their involvement in Consumer Advisory Boards and as staff at health centers has given them a knowledge of data protections and the Health Insurance Portability and Accountability Act (HIPAA) that others may not have since release of information forms may be difficult to understand, leading to hesitancy.</p>
Relationships and trust	<p><i>“It’s redundant to say the same thing over and over to different doctors... they don’t always get you... she knows me.” – ZsaZsa Floyd</i></p> <p><i>“I’m on the board and know all the providers, but there are only a few that I am comfortable with.”- DeeDee Blanchard</i></p> <p>Relationships and a sense of trust in a health care visit were essential. Individuals reported that they are more likely to share information with someone they trust and would follow that provider to another location if needed. The ability to provide holistic care hinges on the relationship between the consumer and the provider.</p>
Staff training	<p><i>“Make sure spaces are safe...Front Desk staff play a big role in this.” – Rodney Dawkins</i></p> <p>Ensuring staff are trained in areas of privacy, cultural humility, and trauma-informed care are essential to building trust. Participants reported instances of providers discussing sensitive health information in spaces where others can hear. It is equally important to ensure that front desk staff have the ability to discuss pertinent information in a way that does not allow those in the waiting room to hear sensitive information. Consumers also discussed instances where they faced discrimination and hostility from providers who made assumptions rooted in bias. To work towards addressing health disparities, individuals need to be able to access health care in anti-racist and trauma-informed settings.</p>
Key point of contact	<p><i>“It could be effective to designate a supervisory medical person.” – Charlotte Garner</i></p> <p>One solution promoted by participants is to allow consumers to designate someone they trust as the key point of contact. This person would have access to greater information and be able to support coordination without disclosing data that the consumer does not want shared. This could be a primary care provider, a behavioral health provider, a case manager, or other service provider.</p>

Overall, the listening sessions highlighted the importance in including the consumer voice in programmatic discussions, especially for cross-sector partnerships, including

conversations on data sharing. Consumer buy-in is essential for making these systems work, and the goal of any cross-sector work is to improve consumer experience and outcomes.

CHALLENGES AND OPPORTUNITIES

There are many considerations and potential challenges to instituting a cross-system data sharing process. These need-not prevent the process from happening but should be part of the planning process. It can be helpful to start with existing partnerships and those who have been on a partnership wish list. Using existing relationships and information that is already available can help to build the case for data sharing work and help with buy-in. It can also be helpful to consider the long-term and short-term goals and lift when developing an implementation plan. A shorter-term lift may be heavier but lead to longer-term benefits. Other challenges and opportunities include those listed below.

Challenge	Opportunity
<p>Workflow and capacity Health center staff often express capacity issues when new tools, requirements, or workflows are adopted in already stretched environments.</p>	<p>Identify what is already in place and build on it.</p> <ul style="list-style-type: none"> Start with existing structure and identify pain points. Start with incremental changes working towards the larger goals.
<p>Trauma-informed screening Some screening questions and processes can be re-traumatizing for individuals. Who, how, and how often sensitive questions are asked plays a role in this.</p>	<p>Engage consumers and peers in planning and implementation.</p> <ul style="list-style-type: none"> Ensure that screenings are completed by someone consumers trust. Review screening and data collection forms to ensure there is no insensitive language and to identify potentially triggering questions. If they are comfortable and interested, consider including consumers in this step.
<p>Staff buy-in Concerns for privacy and capacity may induce hesitancy among staff to adopt a data sharing process.</p>	<p>Build a team of champions to drive the work.</p> <ul style="list-style-type: none"> Identify the benefits based on staff needs and priorities.³ Use what you have already to build the case for data sharing.
<p>Privacy concerns Providers may want to protect the provider-consumer relationship and be cautious about the concept of data sharing. There are also concerns over who sees information and whether protected information remains appropriately private.</p>	<p>Train staff on how to discuss and address privacy concerns.</p> <ul style="list-style-type: none"> Implement and clarify specific privacy protections including limits on who has access to specific information. Only share what is necessary for care. Communicate protections with consumers.
<p>HIT Expenses</p>	<p>Look at existing structures and build on them.</p>

Building new infrastructure can be a cost-burden. Costs for software and staffing can be a challenge.

- Work with the local continuum of care to allow the health center access to HMIS.
- Work with other service coordinating entities, like an agency running 2-1-1 to determine other lighter-lift options.¹

RECOMMENDATIONS

Based on conversations with consumers and providers, as well as existing best practices, recommendations for starting a data sharing initiative can be broken down into three buckets, privacy and consent, relationships, and partnerships and infrastructure building, each broken down further in the table below.

Privacy and Consent

Build in privacy and security options that allow the consumer control over their information – even between departments within an organization

Ensure only relevant and necessary information is shared

- Embrace the HIPAA ‘minimum necessary’ standard at all levels of data sharing⁴
- Require partners that are non-covered entities to follow the HIPAA privacy rule and minimum necessary standard

Discuss privacy and data sharing with consumers

- Is information shared on an ongoing basis or is it just point in time?

Work with staff to ensure that conversations with and about consumers are held in private spaces

Relationships

Relationship building and trust are key

- Work with staff to ensure that implicit bias is addressed and to implement anti-racist and trauma-informed practices
- Ensure that issues with confidentiality and bias are addressed immediately and appropriately

Encourage consumers to designate a trusted key point of contact in coordinating care and sharing private information

Allow for time to discuss consent during appointments and meetings

- E.g., What is/is not included in a release of information?

Build on trust to ensure buy-in from consumers

- Identify care coordination champions who share excitement in improved provider collaboration

Partnerships and Infrastructure Building

Identify care coordination champions interested in cross-sector collaboration

Establish internal priorities based on conversations with consumers and providers

Using signed agreements, such as memorandums of understanding (MOUs) or data sharing contracts, define the exact breadth and depth of data that will be shared within a partnership

- Build upon templates and examples of data sharing contracts agreements online⁵

Identify what technology is already available in the community

- What infrastructure can be built upon to limit the initial data sharing lift?
- What are the capabilities of your electronic health record (EHR) software for exporting information?

Invite partners to the table that are familiar with health information technology (HIT) and system interoperability (i.e., Health Center Controlled Networks, HIT Vendors)

Establish community priorities based on the needs and interests of all interested organizational partners

CONCLUSIONS

Cross-sector data sharing offers the opportunity to provide coordinated, holistic care that addresses the social determinants of health. It strengthens partnerships and reduces duplication of services. Communities working to implement cross-system data sharing should be aware of the importance of including the consumer voice in planning and the role of relationships in not only care planning, but also data collection and sharing processes.

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¹ <https://ciesandiego.org/what-is-cie/>

² <https://mehi.masstech.org/programs/mass-hiway/hie-use-case-stories/boston-healthcare-homeless-puts-meaningful-use-perspective>

³ <https://www.healthierhere.org/wp-content/uploads/2019/10/CIE-Opportunity-Onepager-2.0-103019.pdf>

⁴ <https://www.hhs.gov/hipaa/for-professionals/privacy/guidance/minimum-necessary-requirement/index.html>

⁵ <https://d155kunxf1aozz.cloudfront.net/wp-content/uploads/2015/12/CSH-Health-Housing-Partnerships-Guide.pdf>