Cross-Sector Data Sharing to Address Health-Related Social Needs: Lessons Learned from the Accountable Health Communities Model

Data sharing between clinical and community partners is a critical component of understanding and addressing health-related social needs (HRSNs), such as housing, food, transportation, utilities, and interpersonal violence that affect individual and community health. Effective data sharing can streamline referrals and improve care coordination for patients, as well as enable more systematic reporting and analysis of HRSNs at the community level.

From 2017 to 2022, the Centers for Medicare & Medicaid Services (CMS) supported Accountable Health Communities (AHC) Model awardees, known as bridge organizations, to screen Medicare and Medicaid patients for HRSNs, refer patients to community services to address identified needs, and offer community service navigation to those eligible. Bridge organizations represent entities such as health systems, health information exchanges, and community-based organizations (CBOs). They partner with clinical sites, such as emergency departments, primary care, and pediatric practices, to conduct HRSN screening and with CBOs to address HRSNs.

In February and March of 2022, Mathematica conducted a series of focus groups and interviews with 26 participants, including 19 bridge organizations, one health information exchange partner, three health care provider partners, and three CBO partners. Discussions explored whether and how HRSN data were shared with clinical and community partners, used to inform clinical care, or used to advance equity.

KEY INSIGHTS RAISED BY FOCUS GROUPS

- Providing HRSN data helps health care providers tailor care to accommodate social factors impacting patients. However, health care providers were uncertain about how to best use screening results to inform clinical care and whether sufficient resources are available to address HRSNs.

- HRSN data is essential to CBOs' efforts to apply for grants, inform program design, and understand the needs of their community. CBOs benefit from HRSN data specific to the populations and patients they serve.

- As a result of new referrals from the AHC Model, CBOs experienced increased workloads while still working with limited resources. Although the AHC Model did not allow bridge organizations to fund CBOs directly, bridge organizations made efforts to connect CBOs with other sources of funding to sustain their work.

- A lack of interoperability was a challenge for both health care providers and CBOs. For example, CBOs were often asked to participate in multiple referral systems that didn't align or interface with their existing case management and reporting systems. For health care providers, HRSN data were often stored in different formats within the same EHR platform, making it difficult to find and use data.

- Meaningfully engaging patients in the implementation of data sharing initiatives ensures that initiatives meet patient needs, and can support organizations in understanding potential unintended consequences.

- Encouraging CBOs and health care providers to give feedback on data sharing initiatives supported their engagement.

- Discussing aggregate data on HRSNs with community partners allows bridge organizations to understand findings and explore how systems and structures can contribute to identified inequities in needs and access to services.

DATA SHARING OVERVIEW

Among the 26 participants interviewed, eleven bridge organizations reported that health care providers (e.g., physicians, nurses, and other clinical care providers) within their organization, or that they partnered with, had access to patients' HRSN screening results through EHRs. Twelve bridge organizations shared HRSN data with CBOs. This was typically aggregate data, such as data from across clinical partners on rates of identified HRSNs among patients screened.

Nine bridge organizations were using a closed-loop referral platform to share information between these partners. Closed-loop referral systems allow health care providers to refer their patients to CBOs and CBOs to report back to health care providers on whether they addressed the patient's HRSNs. Figure 1 depicts an example of how partners in the AHC Model shared data using a closed-loop referral system.

As focus groups and interviews revealed, there are several challenges to health care providers and CBOs sharing and using HRSN data, even through closed-loop referral systems.

Figure 1. Example of data sharing flow between AHC partners

These include barriers with infrastructure and technology, as well as motivational barriers such as limited incentives to use HRSN data or participate in data-sharing systems. We describe these barriers, as well as uses of HRSN data and promising practices, in more detail below.
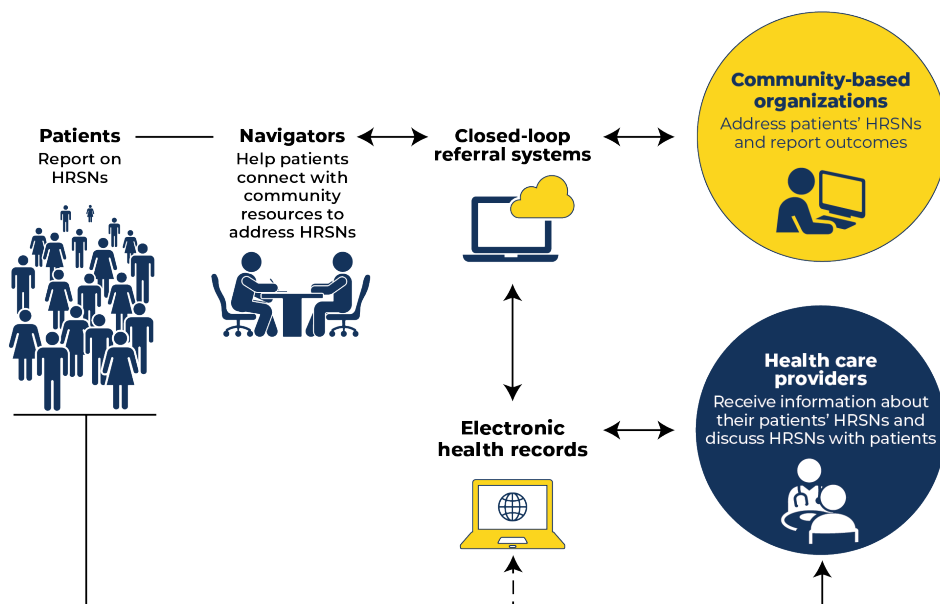
HRSN DATA AND EQUITY

AHC Model data have given bridge organizations and their partners insight into the social needs of the populations in their communities. By sharing HRSN data with partners, bridge organizations can inform community-wide strategies to address systemic and structural inequities. Participants shared the following considerations for using AHC Model data to advance health equity:

Apply data to better understand the distribution of HRSNs throughout the community. For a few bridge organizations, AHC screening data highlighted significant and sustained food needs and supported their efforts to address food insecurity in their communities. One bridge organization began stratifying social needs data by demographic characteristics such as payer, race, ethnicity, language, and federal poverty level. By breaking up the data by group characteristics, the organization can assess whether there might be unique considerations driving a need in a specific population.

Use aggregate AHC data to spark conversations about equity with leadership. One bridge organization noted that its Native American and Indigenous populations have higher social needs, which has generated conversation about gaps in care and resulted in a new organizational structure to support Native American and Indigenous populations who live off-reservation.

Share data with community partners to better understand the root causes of HRSNs. Several bridge organizations share aggregate data on disparities and HRSNs with members of the community and discuss drivers of HRSNs and investing in interventions based on the data.

Intentionally prioritize patient voices. Although sharing aggregate HRSN data with communities can support understanding of inequities, there are also important equity considerations for sharing patient-level HRSN data. Specifically, participants noted that it is critical to protect patients' privacy and safety and ensure that data sharing is ultimately to their benefit. Prioritizing patients' perspectives in developing data sharing systems can ensure that systems both protect privacy and meet patient needs.

HEALTH CARE PROVIDERS

Health Care Providers' Use of HRSN Data

Providing access to HRSN data helps health care providers address HRSNs and tailor care to account for social factors impacting the patient. For example, some health care providers addressed food insecurity by tailoring nutrition guidance for diabetic patients with limited access to food, making free food available on-site, and directly enrolling patients in long-term food security programs such as the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC). However, bridge organization participants noted key barriers to health care providers using screening data, suggesting that there is room for improvement in enabling health care providers to better engage with HRSN data.

Barriers to Data Sharing and Use

Some health care providers might be uncertain about how screening results can inform clinical care. Many health care providers were aware that their patients had social needs but were unsure how to use that information to improve care.

Health care providers were reluctant to discuss HRSNs when resources were limited. Some health care providers thought that asking patients about HRSNs without being able to offer assistance or community resources would be unhelpful, and could be perceived as unethical.

Sharing HRSN data across departments presented challenges. Health care providers in different departments sometimes used different methods for collecting and reporting HRSN data within the same EHR platform. This made it difficult to understand and share data across disciplines and care teams.

Facilitators to Data Sharing and Use

Integrating HRSN screening tools in EHR systems helped health care providers access patient-specific data. Health care providers were more likely to review patient-specific data if it was stored in the EHR. Several participants mentioned that they are working toward integrating screening information into their clinical sites' EHRs.

> "[We] really have focused a lot on training…we are really mindful about the biases in our clinical site staff and that their competence and their confidence in addressing social needs may not be that high."
>
> —*Bridge organization participant*

COMMUNITY-BASED ORGANIZATIONS (CBOs)

CBOs' Use of HRSN Data

Bridge organizations that shared HRSN data with CBOs typically shared aggregate data reflecting the prevalence of HRSNs identified and number of navigation cases initiated. CBO partners used aggregate data to apply for grants, inform program designs, and understand specific needs in the community. Some CBOs preferred to receive HRSN data for the specific populations that their organizations serve, or patient-specific and identifiable data. CBO partners found patient-specific health data particularly valuable for understanding the impact of their interventions on individual patients' health. However, sharing patient-specific data requires taking crucial measures to protect patients' privacy and safety.

Barriers to Data Sharing and Use

The inability of platforms to interface with existing data collection technology, align with workflows, and support reporting needs were issues for CBOs. CBOs juggle multiple platforms to receive referrals and various reporting requirements from funders and other interested parties. As a result, CBOs often input the same information in multiple systems. In addition, the closed-loop referral platforms adopted and promoted by health care systems often did not interface with CBOs' existing systems, and lacked the reporting, invoicing, and care-coordination tools to support CBOs' existing workflows.

CBOs face increased referrals and workloads with limited resources. HRSN screening and closed-loop referral systems allowed CBOs to receive more referrals, but the byproduct was often an increased workload. Bridge organizations noted that CBOs often have limited capacity and funding to support their work, and unlike health care systems, increased client volume does not equate to additional resources. One bridge organization noted that getting CBO buy-in for data-sharing initiatives is a major challenge because funding is going to health systems to implement these systems and not to CBOs. The combination of increased workloads and limited funding are factors that discourage CBOs from participating in data-sharing initiatives and in clinical-community partnerships more broadly.

CBOs lack staffing and technological capacity. CBOs faced challenges including lacking the technological infrastructure to use closed-loop referral systems, limited staff capacity, difficulty training staff to use data sharing systems, and challenges maintaining access to the systems for staff (particularly because CBOs often rely on volunteer staff and experienced frequent turnover among their volunteers).

> "The bigger picture is that we take referrals in 100 different ways and having to log into a health system [platform] doesn't give us what we need. It doesn't provide any reporting that I can use. I don't own that data and can't do anything with it."
>
> *—CBO partner*

CBOs lack clear incentives to participate in data-sharing initiatives. Several CBO partners explained that, although they share data with health systems, they do not receive aggregate or patient-specific data on health outcomes and were therefore not incentivized to participate in data sharing. One CBO partner noted that as long as patients have signed Health Insurance Portability and Accountability Act of 1996 (HIPAA) releases, they should be able to receive patient-specific data. However, CBO participants noted limited ability to access this information. Receiving health outcomes data for individuals could help CBOs support their clients. In addition, aggregate data on health outcomes could help them to demonstrate the impact of their work.

Facilitators to Data Sharing and Use

Encouraging CBOs to provide feedback on data sharing initiatives supported engagement. One bridge organization highlighted the collaborative nature of its data-sharing process. Its CBO partners expressed concerns about the ethics of data sharing, particularly sensitive topics such as interpersonal violence, one of the five core HRSNs collected in the AHC Model. In response to the CBO partners' concerns, the bridge organization created community-based groups to discuss best practices and protocols for designing data platforms to protect patient data.

Identifying additional funding to support CBO efforts. Although the AHC Model did not allow bridge organizations to pay for community services using CMS funds, bridge organizations described efforts to connect CBOs with other sources of funding to sustain their work and encourage data sharing. For example, one organization identified funding sources to provide stipends for CBOs to participate in data sharing initiatives, and another helped CBOs to identify funding from local philanthropic organizations. Participants also noted that community members often feel more comfortable disclosing their HRSNs in a community setting than in a clinical setting, and CBOs are therefore well-positioned to screen for HRSNs. Additional funding for CBOs could bolster their efforts to screen and enable them to share HRSN data with health systems.

FOCUS GROUP RECOMMENDATIONS TO REDUCE BARRIERS

The focus group and interview participants suggested the following strategies to improve data sharing with health care providers and CBOs:

Engage patients in the development of HRSN data sharing initiatives and use patient feedback to improve data sharing practices. Participants noted that data-sharing initiatives should not cause harm to patients and should protect patient privacy and security. They also suggested that HRSN results should be shared with patients using terms that they can understand and that do not feel judgmental. To help achieve these goals, patients and community members should be consulted and engaged when developing data-sharing initiatives and processes.

Clarify the role of health care providers in using HRSN data to support patient care and provide guidance. Many health care providers were uncertain about their role in using HRSN data to support patient care and how to appropriately discuss social needs. Providing access to HRSN data through EHRs is helpful but does not always facilitate health care providers' use of the data. Using EHRs to make linkages across teams requires technological, clinical, and operational adjustments. Information application teams can help make connections across care teams (for example, by allowing navigators or community health workers to flag specific HRSNs for physicians to integrate into care plans). Care teams could also identify ways to share guidance through the EHR on adjusting care to accommodate social factors impacting patients. Organizations can consider defining health care providers' responsibility for using HRSN data and providing training on appropriately discussing HRSNs.

Integrate HRSN screening results into EHRs in a consistent format. Having HRSN data available in EHRs helped draw health care providers' attention to the data. Identifying a common way of displaying HRSN results within EHR platforms, providing access to care teams, and educating staff that these data are available would facilitate coordinated whole-person care and interdisciplinary understanding and sharing of HRSN data.

Referral platforms should consider CBO priorities in their design and align or interface with CBOs' existing referral processes when possible. CBOs are often asked to participate in multiple referral systems that don't align or interface with their existing case management and reporting systems. Having a streamlined interface that enables them to receive referrals from and share results through multiple platforms without logging into each platform individually could help ease their burden. Involving CBOs in system selection or design can also help systems meet their needs.

To encourage CBOs to participate in data-sharing initiatives, invest in CBOs and facilitate their access to health outcomes data. CBOs play an important role in addressing HRSNs, and monetary investments that reflect and sustain this role are critical. In addition, health systems can consider establishing reciprocal relationships with CBOs, sharing data on health outcomes, and making customizable dashboards specific to the populations CBOs serve.

CONCLUSION

As organizations look to sustain programs to address HRSNs beyond the AHC Model, they emphasized that collecting, analyzing, and disseminating data are pivotal to the continued implementation of HRSN screening and navigation efforts. While closed-loop referral technology can support data collection and sharing efforts, our work revealed important gaps in implementation of this technology, including limited incentives for CBO participation. This underscores the point that technology alone is not a solution. Relationships across care teams, within health systems, with CBOs, and with community members are necessary to equitably and effectively address HRSNs. Technology can facilitate and support these relationships, but in order to do so effectively, it must be designed and implemented with each partner's needs in mind.