CULTURE INCLUSION & EQUITY AND DIGITAL HEALTH ACTION COLLABORATIVES

Joint Meeting

Engaging Communities to Achieve Effective Health Data Sharing

April 13 Meeting Highlights

EXPLORING A VISION FOR COMMUNITY-WIDE DATA SHARING – OPENING SPEAKER SESSION

- Alonzo Plough stated the need for equity-centered data systems. The COVID-19 pandemic and recent racial and social injustices that have taken place underscored the need for a real-time data system that fosters equity and community engagement. To address this, the RWJF National Commission to Transform Public Health Data Systems was established in 2021, convening experts across multiple sectors to reimagine how private and public data are collected, shared, and used. The Commission reported three major recommendations: 1.) change the narrative to center on equity and encourage action by collecting data that is rooted in community experiences; 2.) prioritize equitable and consistent governance and community engagement, by working, for example, on trust-building in advance instead of amid a crisis; and 3.) ensure public health measurement captures and addresses structural racism and other inequities. Measurement should be conducted with the intent to monitor, improve, and address structural racism and other SoDH in an equitable manner. For a transformative change in the short term, governance structures must first be redesigned to include on-the-ground workers. In the long term, Alonzo emphasized supporting the community workforce to increase capacity to dynamically share data and collaborate and sustaining engagement with local and public health agencies.

- During Alonzo’s Q&A session, Reed Tuckson and Alonzo discussed the need to set a goal at the community level and evaluate progress toward that goal. There are benefits to standardization; however, creating a balanced data sharing system with common elements that is also modifiable can be challenging – the current system does not provide the needed granularity and interoperability. Federal action and a common and sustainable architecture would be helpful. Incorporating data outside the traditional scope (e.g., qualitative data, social services) would also be beneficial in addressing more complex local issues.

  - Dan Jernigan emphasized the importance of a high-level architecture to help local health departments acquire and share the right information. The CDC and ONC are considering this.
  - Karen DeSalvo commented about the need for federal action to harmonize data and create open data standards that allow more data flow and transparency in the public health ecosystem.

EXPLORING A VISION FOR COMMUNITY-WIDE DATA SHARING – MULTI-STAKEHOLDER DISCUSSION PANEL SESSION

- Craig Brammer presented on The Health Collaborative, which serves communities in Greater Cincinnati, Ohio. The Health Collaborative launched as a result of a merger between three health non-profits and has connectivity to major health systems, physician groups and community providers, and other partners at the federal, state, and local levels. They have access to clinical claims and public health data and move about 1.5 million clinical results electronically across the market each month. Crucial elements for demonstrating trustworthiness and developing trust include having a representative board, robust governance, trusted privacy and security programs, and operating via design principles that elevate the lived experiences of those closest to the issues and enable co-creation of solutions with them. Throughout the pandemic, they have focused their response efforts around stakeholder collaboration and developing a common language around aims and the use of data.

- Building off Craig’s presentation, Peter Margolis presented on the work of the Cincinnati Children’s Hospital Medical Center, which used The Health Collaborative infrastructure and resources to facilitate rapid regional responses across the Cincinnati region. Dashboards are created and are updated regularly on relevant COVID-19 data points, and when possible, the data is broken up and assessed within various sociodemographic categories to help people drive improvement. They countered issues experienced during the pandemic (including fragmentation, disconnection among stakeholders, delays in entry, etc.) by building a framework based on co-design and theory of action. They used data to build a shared purpose and inform action among collaborators.
• **Waldo Mikels-Carrasco** presented on Data Across Sectors for Health (DASH), a collaboration led by the Illinois Public Health Institute in partnership with the Michigan Public Health Institute, with support from RWJF. DASH is focused on building capacity to collect and share information needed to address issues of importance. The DASH model supports initiatives focused on collaboration, multi-sector partnerships, and data and information sharing across sectors to drive community health improvement, equity, and well-being. In sharing what does and does not work across communities, capacity and an evidence base form to create movement and, ultimately, systemic changes at the state and federal levels. Doing so requires placing community voices at the center of a thriving multi-sector community data ecosystem. DASH has worked with over 500 communities to learn from other active communities in this space and translate those learnings into new funding opportunities to increase collaboration.

• **Tiffany Gary-Webb** presented the Black Equity Coalition in Pittsburgh, Pennsylvania, operating since April 2020 to address disparities. Black elected officials advocated for health plans to provide testing resources to Black communities in Pittsburgh. Community leaders hosted social media town halls to increase awareness on COVID-19 risks for Black populations. Community funders worked with Black businesses, and data scientists assembled to know racial disparities in the COVID-19 outcomes data. Many stakeholders overlapped these spaces, and the coalition formed to create an equitable response to the pandemic. The Black Equity Coalition uses a “hub and spoke” model, with the Black Equity Coalition at the center and community organizations as the spokes. They also follow a data-to-action approach by translating and feeding data to communities, organizations, and other key stakeholders, using community conversations, locally-based events, and other tools to inform action quickly and effectively. To demonstrate trustworthiness, they support black leadership in their data working group, ensuring that there is community representation, ownership, and validation of the work being done. Creating trusting relationships, along with showing accountability and consistency, are all facilitators to local data sharing. Barriers to sustaining a data infrastructure are limited funding and resources, the spread of misinformation, and gatekeepers.

• **Erikk Gilliam** presented on the West Philly Promise Neighborhood initiative in Philadelphia, Pennsylvania, which was formed in 2017 with support from a Department of Education-funded grant. Their overall goal is to improve education, health, and economic success for children, families, and communities. The initiative partners with various community-based organizations (CBOs) using a collective impact model approach to create a system that democratizes access to data and places it in the hands of the right people to use. People with lived experiences are the main subject experts, so this initiative ensures community residents are included in all levels of decision-making, from the design of the evaluation and development of survey instruments to the dissemination of data. Data is presented back to communities through stories, town-hall meetings, community briefs, and community-friendly data dashboards and codebooks. Challenges faced are integrating their program data with siloed data in city service systems, complex consent procedures, and finding ways to track data usage among community audiences, something the West Philly Promise Neighborhood is actively working to combat.

• **Panel Q&A session**
  - **Reed** asked **Peter** how community-based data can be integrated in a meaningful way when transitioning from one health care setting to the next, such as from the hospital to the home. Peter explained that, while they are not tracking data at the individual level, his team finds specific hyper-local trends and presents them at an aggregated level to help overcome fragmentation.
  - **Reed** turned to **Waldo** and asked how DASH builds its evidence-based best practices. Waldo said that communities are the central evidence base. DASH examines trends, lessons learned, and collects the knowledge in a system called DASH Knowledge Base. This information is also published and presented in webinars with partners.
  - **Reed** asked **Tiffany** how to navigate gatekeepers involved at each step of the data sharing process. Tiffany replied that one of the advantages of BEC was that many members were at the leadership level and could push to address issues publicly and behind the scenes.
  - **Reed** asked **Erikk** about the economics behind hiring and training community residents. Erikk explained that the curriculum the West Philly Promise Neighborhood initiative uses to train community surveyors was adapted from one developed in New Haven, Connecticut, by Dr. Amy Carroll-Scott, a Co-PI of the initiative. Also, although the process is expensive, it was important to them that surveyors are paid a livable wage and offered fair raises as they move up.
Creating Conditions for Achieving Community-wide Data Sharing

- **Karis Grounds** presented the Community Information Exchange (CIE) started in 2011 in San Diego. The CIE began as an effort to connect individuals to health and social services by simply asking them for consent to use their data. Over 10 years, CIE has expanded into a local data intermediary – a technical infrastructure with a shared governance model. This setup allows for a targeted focus on individual needs, experiences, and strengths which creates opportunities to provide more efficiently coordinated care across sectors and agencies and curate a response to community inequities via the available data. The process includes individuals consenting to share their information as a part of a longitudinal client record with role-based permissions and legal elements funded using a blended funding model. Key facilitators to successful sharing are implementing local/community governance, aligning with local infrastructure and initiatives, and building off existing relationships and capacity instead of attempting to reinvent the wheel. Conversely, a concentrated investment in tech over social services and operating in silos creates barriers. However, evaluation also presents challenges since a return on investment is difficult to prove when the focus is on public good vs. healthcare outcomes. Last, the consequences of a lack of interoperability standards continue to be evident in health care and within social/human services.

- **Paul Sorenson** presented the St. Louis Community Information Exchange, inspired by the San Diego CIE and led by United Way 2-1-1. Being a community/CBO-led initiative rather than health system or technology-driven initiative was a critical facilitator for success. Originally operating as a call center, the St. Louis CIE saw a need to respond to changes in the health care landscape (e.g., Obamacare) with a community-centered approach. They received funding from organizations investing in social services and health equity infrastructures to help connect the dots. United Way acted as the main convener, bringing partners to the table to reflect the goals of the CIE, including St. Louis health systems. They quickly adopted the Unite Us platform technology to help provide closed-loop referrals. Barriers to progress included a need for additional support, infrastructure, and standards to make adaptations at the local level, especially within the social services sphere.

- **Moderated participant discussion:**
  - **Mary Naylor** asked meeting participants to reflect on the facilitators and barriers heard thus far and propose potential solutions. Participants spoke about the pressure to measure the success of an initiative and assess whether health improvements are the results of program efforts. Increasingly available publications on niche interventions could serve as a collective example to follow in the future. There are also growing efforts to create and evaluate short-term interventions. However, it is difficult to demonstrate impact in a short period of time. It is crucial to take the time to develop a shared vision, gather stories and indicators earlier on to provide guidance, show commitment, focus on listening before moving immediately to action, and refrain from shutting operations down prematurely just because the funding stops before results surface.
  - Participants observed that the pandemic was the first time initiatives, in their efforts to deploy pandemic mitigation resources, connected with underserved communities in generations. Continuous and consistent outreach to communities should be a key part of data modernization.
  - The political barriers stemming from local public health resistance provided the impetus to conduct activities outside of the ordinary, such as building community engagement and improving data collection and analysis.
  - **Jamie Bland** provided perspectives from CyncHealth’s data sharing efforts. The past three years have consisted of intentionally bringing individuals together to identify best practices for community interventions, determining who has access to data, and applying governance to ensure appropriate access. This work requires complex technological and interpersonal processes and frequent engagement.
  - **Mary Naylor** asked about the data and measurement milestones that could be implemented to assess the level of community engagement and determine if an effort is valuable to communities. **Waldo** replied that DASH has learned that community organizations/people with lived experiences want to participate in collaborations from the outset to identify what they feel to be the problem. Asking communities to respond to predetermined questions that decide the problem for them creates barriers to assessment. Creating community councils that allow communities to rotate in and out to discuss issues with decision-
makers on an ongoing basis would allow them to effectively articulate and elevate issues they would provide support. We need to leverage people working in the community already to act as ambassadors and natural connectors to these issues. Tiffany and Ed encouraged having diverse data workers who can connect with different perspectives. Karen DeSalvo agreed that there needs to be a focus on building relationships, not just data infrastructure. The data itself cannot be stale by the time it gets to public health. Rethinking data sources and mixing qualitative and quantitative information would also help, rather than relying solely on the quantitative for novel signals. One challenge Paul and his group have encountered are how to present the qualitative data so that it is treated with importance and used instead of appearing as a simple pull quote in a report. This data could explain why certain health conditions are encountered and what was missing. The suggestions for model improvement included the following:

- Mary Naylor concluded the session by emphasizing the foundational nature of trust and having communities see themselves as assets. The narrative must change – we must listen to communities and use what we have learned as guidance towards a shared vision, and develop metrics that they can value.

**Creating Conditions for Achieving Community-wide Data Sharing**

- Bill Novelli presented a composite model representing a compilation of existing community data sharing frameworks and models developed by those with experience in engaging diverse communities and sharing local data across those communities to improve health. The composite model presents elements of the data sharing process and the common environmental factors impacting the ability to share data across a community successfully. The goal was not to suggest that this model is the ideal, but to share for feedback and discussion.

- Mary Naylor asked the group for thoughts on the model – whether anything about the model resonated with them and what was missing. The suggestions for model improvement included the following:
  
  - Incorporate the critical role of a supportive regularity environment in the success of data sharing and include the ethical, legal, and social implications of data sharing
  - Clarify the placement and purpose of economic drivers (i.e., drivers for improvement)
  - Leverage community contributions established in the field and use this initial work as a scaffold or exemplar for best practices
  - Consider necessary standardizations (i.e., data collection practices, coding for race and ethnicity, developing a shared language)
  - Consider how the model can be adapted across diverse communities and what training and monitoring would resemble. Think about the effect of different policy contexts (i.e., state, federal, and local levels).
  - Include workforce, talent, and ongoing capacity building that reinvests in the community-wide data sharing process
  - Rework the model design so that it does not appear one-dimensional
  - Determine the target audience – is this technology for health systems, public health, or CBOs?
  - Embed equity throughout the model
  - Add a complementary visual focusing on the value proposition or ROI for leaning into community-driven narratives over the traditional data sharing practices

- In addition to the development of a conceptual model, identifying practical best practices to cultivate local level data tracking and sharing will be paramount to any future action. A number of possible elements were identified as important common issues on which to provide facilitative guidance. The example was given for a 10-category “checklist” of compendium elements to be used for assessing community capacity:
  
  - Sparkplugs: Which organizations and individuals provided important impetus?
  - Stakeholders: Which organizations formed the core stakeholder action and consultative group?
  - Vision: What were the common aims, goals, philosophy, and approach stages envisioned?
  - Services: What were the key system services provided to stakeholders?
  - Platforms: What were the candidate platforms for sharing and the relevant choice implications?
  - Finances: How were the development and operational costs estimated, and what were the cost-sharing principles?
  - Governance: What structures were developed for stakeholder guidance and oversight of the operations?
  - Barriers: What obstacles to progress were/are notable, and how were they approached? (e.g., availability/fragility of data from social services components)
- **Qualitative impact**: What qualitative evaluation approaches and methods were helpful? How could broader evaluation help?
- **Quantitative impact**: What quantitative evaluation methods were applied in estimating Return on Investment?