

March 2023

**Michigan
Community
Information
Exchange (CIE)
Task Force
Interim Report**



**Social Determinants
of Health Strategy**
Michigan's Roadmap to Healthy Communities

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Executive Summary

The Michigan Social Determinants Health (SDOH) Strategy, entitled *Michigan's Roadmap to Healthy Communities*, was released in April 2022. The SDOH Strategy aims to improve the health and social outcomes of all Michigan residents while working to achieve health equity by eliminating disparities and barriers to social and economic opportunity. It includes several structural interventions – intended to be actionable mechanisms – to better advance health equity. Community Information Exchange (CIE) is one of the structural interventions included in Phase II of the SDOH Strategy.

CIE is an emerging priority for the Michigan Department of Health and Human Services (MDHHS) and stakeholders across Michigan. Efforts to build infrastructure facilitating the bi-directional exchange of social and clinical data are already occurring at the local level; however, stakeholders have expressed interest in exploring a statewide framework to support interoperability and development of data governance standards. Therefore, MDHHS established a CIE Task Force to develop consensus around practices to collect social care data, provide holistic treatment that addresses social drivers of health outcomes, and connect systems across communities through an interoperable infrastructure.

In August 2022, MDHHS announced the convening of the Community Information Exchange Task Force with the goal of developing a statewide plan for establishing CIE capacities. CIE facilitates the flow of information among organizations using different technologies to provide social care that supports people and families. CIE can also facilitate the aggregation of data about community resources and needs to inform policy change that promotes more efficient and effective distribution of resources and programming.

This report details the actions of the CIE Task Force to realize its goal of advising the development of a state CIE strategy. The CIE Task Force has brought together community-based organizations (CBOs), health care organizations, health payers, health IT, and governmental entities to align work that is best served by a coordinated approach to CIE. This report details efforts to understand the existing infrastructure of CIE activities in Michigan, analyze the needs of various stakeholders, the capacities of CIE that are needed in the field, and recommendations for actions that the state government can take to support the information ecosystem of health, human and social service providers in Michigan.

The CIE Task Force’s final goal will be to generate recommendations for the Michigan Health Information Technology Commission (MHITC). Through iterative and collaborative convenings, the task force will create actionable and operationalizable recommendations as to the prioritized capabilities for CIE, the appropriate balance between statewide and regional/local capacities and roles, prospective principles, and processes for governance, incentives and adoption support for CBOs, guidance for legal agreements, and a roadmap for implementation.

The Community Information Exchange (CIE) Task Force

The Michigan Community Information Exchange Task Force is authorized by the Michigan Health Information Technology Commission's (MHITC) 2022 annual report, as per the Michigan Health IT Roadmap (Bridge to Better Health, February 2022), referred to as the MHITC Roadmap.

Purpose

MDHHS has resolved to create and sustain statewide infrastructure to support the collection, exchange, and responsible use of information that can help address the social needs of Michigan's people and communities.

The CIE Task Force brings together CBOs, health care organizations, health payers, health IT, and governmental entities whose aligned work and interests are best served by a coordinated approach to Community Information Exchange. The task force is an advisory body that will make recommendations to both MHITC and the Michigan Department of Health and Human Services (MDHHS) on the development of capabilities for community information exchange.

Goal of the CIE Task Force

To promote health and social equity, and improve the well-being of all Michigan residents, CIE infrastructure can enhance capabilities for providers of health, human, and social services to coordinate care across sectors and technologies, by enabling information (such as information about people's needs, and the resources available to help them) to flow to the right people effectively and responsibly at the right time in the right context.

CIE Task Force Objectives

In service of the stated purpose, the CIE Task Force will:

1. Examine promising state, national, and global strategies, standards, metrics, and best practices that could accelerate, support, and improve CIE in Michigan.
2. Examine relevant perspectives from all interested parties and partners, with a focus on the priorities of communities that experience health inequities, the perspectives of CBOs that serve them, and the needs of people who have experienced the challenges of navigating these services.
3. Create a knowledge resource in service of MHITC Roadmap (Bridge to Better Health) and MDHHS SDOH Strategy (Michigan's Roadmap to Healthy Communities).
4. Advise the state on the development of a CIE strategy, including recommendations as to prioritized capabilities, the appropriate balance between statewide and regional/local capacities and roles, prospective principles, and processes for governance, incentives and adoption support for CBOs, guidance for legal agreements, and a roadmap for implementation, among other critical considerations.
5. Articulate scenarios for pilot implementations of key use cases that enable cooperation among prioritized stakeholder groups.

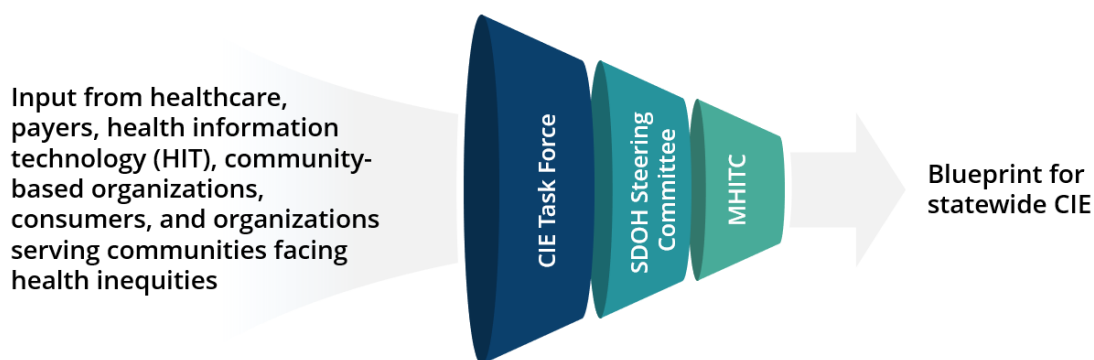


Figure 1. Input guiding the development of the statewide blueprint for CIE, with the CIE Task Force providing recommendations to the SDOH Steering Committee and the Michigan Health Information Technology Commission

Foundational Statements

Problem Statement

A wide variety of organizations provide health, human, and social services to Michigan residents, using a diverse array of data systems. These systems often do not share information easily, resulting in redundant processes for service users, duplicated efforts for service providers, barriers to critical resources, and gaps in service delivery – inhibiting our collective capacities to share information, coordinate care, and effectively meet people's needs to advance health equity.

Intended Result

By developing and promoting CIE infrastructure --including both technological and human capacities -- the task force will enhance the potential for organizations in different sectors, using different technologies, to coordinate care for their patients and clients. The task force expects such CIE infrastructure will make it easier for people to find and access services by removing obstacles to care, building capacities for service providers to provide holistic care, and informing efforts to address unmet needs – to ultimately improve health and social outcomes for Michigan residents.

Terms

What does the task force mean by Community Information Exchange?

In its first several meetings, the task force clarified what a CIE is *not*. For instance, a CIE is not a “closed-loop referral system,” a phrase that typically refers to a software system; rather, a CIE is **infrastructure** that enables **interoperability** among different software systems.

The Task Force has recognized two separate but non-conflicting definitions of a CIE. The task force utilized these definitions to inform its deliberations to date; the task force reserves the ability to arrive at a definition of its own in the future.

2-1-1 San Diego CIE toolkit:

“A CIE is a **community-led ecosystem of multidisciplinary network partners** that use a **shared language, resource database, and integrated technology platforms** to deliver enhanced **community care planning**. CIE enables communities to shift from a reactive approach to addressing social needs, to an approach that is more proactive, holistic and person-centered. At the very core of a CIE is the community it serves, and with the community as its compass, a CIE seeks to support antiracism and health equity.”¹

"Tackling Data Dilemmas in Social Care Coordination," (Bloom & Sorenson 2021):

“A [CIE] should encompass three elements of **primary infrastructure** that comprise a holistic ecosystem of health and social care: **Resource Data Exchange, Client Data Exchange, and Community Data Governance**. A CIE should facilitate the reliable flow of information about resources available to people in need to support service discovery and accessibility. A CIE should facilitate the responsible flow of information about clients as shared among various service providers to support cross-sector coordination of care. A CIE should ensure that the systems and activities associated

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

with coordination of social care are equitably developed and implemented according to the expressed interests of stakeholders in a local community.”²

² https://docs.google.com/document/d/1_fRYcPHYzwpv3EZEsf91DhAO34KO3pfAXjnB5BB0r4/edit

Objective 1: Landscape Analysis

Objective 1: Examine promising state, national, and global strategies, standards, metrics, and best practices that could accelerate, support, and improve CIE in Michigan.

To address Objective 1, the CIE Task Force gathered insights by inviting experts from Michigan and across the country to share their subject matter expertise in CIE. The task force also reviewed several summary reports (included in the Appendix) and engaged State experts in CIE to understand the Current State of CIE in Michigan.

Current State

This is a brief overview of initiatives that the CIE Task Force uncovered through a landscape analysis of existing social care initiatives in Michigan.

- **Michigan 2-1-1.** MI 211 provides connections to services, such as employment support, family support, housing, food, health, public benefits, and more. The MDHHS MI 211 state office coordinate a network of seven regional contact centers that help people in need of assistance access services. Notably, Michigan 211 utilizes an API to house its resource directory (with over 20,000 resource referrals) to allow third-party vendors access to its database of resources, including MiBridges and the Michigan Hope Portal.
- **MI Bridges.** MI Bridges utilizes the MI 211 API to provide resource navigation to local and state resources, as well as benefit programs. MI Bridges is an online platform where residents can explore potential eligibility for services, apply for Food Assistance benefits, apply for emergency relief, view their case information, or report changes to their MDHHS Specialist.
- **No Kids Hungry Project.** In 2022, MI Bridges launched the closed-loop referral pilot program - the No Kids Hungry Project - with the Food Bank Council of Michigan and several food banks across the state to improve community partners ability to support Michiganders facing food insecurity. Through the No Kids Hungry Project, MI Bridges Navigators and referral partners, as well as the client, can initiate requests for services that lower the incidence of food insecurity.

- **United Way Southeast Michigan-Henry Ford Health System-Gleaners Food Bank-Health Alliance Plan CIE.** In August 2021, United Way for Southeast Michigan (UWSEM) and the MI 2-1-1 regional contact center initiated a CIE with Henry Ford Health (HFH), Gleaners Food Bank for Southeast Michigan, and the Health Alliance Plan (HAP). Through this CIE, HFH and Gleaners act as initial “spokes,” connecting through application programming interfaces (APIs) to bidirectionally process and serve patients who have been identified through screenings at HFH facilities as food insecure.

HFH and UWSEM are also utilizing data to better connect at-risk populations with basic needs assistance and other support, improve health and social outcomes, and lower costs for health systems. Since this initial use case, the CIE’s capabilities have expanded to provide automated connectivity to other community partners, including local Volunteer Income Tax Assistance (VITA) preparation partners for real-time tax preparation service appointments, transportation assistance through a ride management broker service to Uber, and child care eligibility tests and subsidy application processing and submission to child care providers across Wayne County.

- **Michigan Community Network.** In 2021, Healthify, a private entity working with managed care organizations to address SDoH, initiated a CIE with Blue Cross Blue Shield of Michigan to coordinate nonclinical care for members. Healthify works on a closed-loop referral model to increase interoperability among formalized partners to the project.
- **Genesee County Community Health Innovation Region (CHIR).** In 2019, the Genesee County CHIR began working with providers to promote an SDoH screening tool. The Genesee County CHIR then began housing results in a central SDoH Repository to aggregate and analyze screening results to identify population-level SDoH needs. In addition, the CHIR implemented a Community Referral Platform (CRP) that provides closed-loop referrals between participating providers the CHIR Hub organization - the Greater Flint Health Coalition - and community/social service agencies.
- **Riverstar Community Care Hub - Jackson County CHIR.** In Jackson County, the Jackson County CHIR began working with the IT solutions company Riverstar to launch a virtual hub that hosts a SDoH screening tool. The application rolled out in Jackson County utilizes the MI 211 API to provide resource navigation to individuals in Jackson County. As of January 2020, the Care Hub has provided more than 80,000 SDoH screenings and provided more than 11,000 referrals.

- **Northern Michigan Community Health Innovation Region (NMCHIR).** The NMCHIR serves 10 counties in the northwest Lower Peninsula of Michigan. The NMCHIR developed and implemented a web-based, tablet-based screening and referral platform that screens patients for SDoH, refer patients for service navigation, and coordinate care between community services and clinical providers.
- **Livingston-Washtenaw Community Health Innovation Region - My Community Care.** In 2015, the Livingston-Washtenaw CHIR launched a free community-wide care coordination program in Livingston and Washtenaw counties. The program offers integration with regional medical providers, including Michigan Medicine and St. Joseph Mercy Health System, as well as shared consent form through an IT platform.

Physician Group Incentive Program (PGIP) Blue Cross Blue Shield of MI

Blue Cross Blue Shield of Michigan (BCBSM) is focusing efforts on the Provider Group Incentive Program, also known as PGIP to create the path for physicians and payers alike to better understand how social determinants of health impact health care outcomes.

In early 2022, BCBSM partnered with MiHIN to gather domain focused aggregated SDoH data from physicians' offices across the state. This partnership allows for providers to receive funding from the payer as they begin to transform health care screening practices in their offices. The current incentive offers infrastructure development funding to participating PGIP practice units. By late 2022, SDoH data informed the need for community health workers. Community Health Workers are considered boots on the ground workers when it comes to taking care of the patients. BCBSM launched an initiative to cover the cost of training for CHWs for participating PGIP organizations.

The current initiative offers funding to cover the cost of training to PGIP participating practice units. BCBSM is currently analyzing data and developing a strategy to further address health care disparities that impact members and the community.

Payor Involvement

Several payors in Michigan currently incentivize the collection of SDoH data from health care providers in a multitude of ways. The Michigan Payor Group has summarized the incentives in a table and made that available to providers on their website, and also made the information available to the 42 Physician Organizations/Physician Hospital Organizations

(POs) who act as fiduciaries of the funds to their physician provider members.³ The incentives are available to hospitals, physicians, and in some cases advance practice providers. The Centers for Medicare and Medicaid Services have begun to incorporate social care screening requirements and reporting into their Conditions of Participation for inpatient facilities with 2024 being the first year it's required.

These incentives encourage providers to utilize screening tools to assess social care needs, partner with Community Based Organizations, make referrals to those organizations, and track and report on the referrals. Some of these incentives are paid directly to the providers, while others are distributed through the POs for them to enhance and support infrastructure provided to their members. Managed Care Organizations themselves, in some instances, are currently required to collect and report SDOH data, such as social care screenings and number of patients screened.

Michigan Health Information Network (MiHIN) Legal and Data Framework

MiHIN was established by the State of Michigan Health Information Technology Commission in 2006 to serve the state's health information exchange needs. While it serves as the statewide Health Information Exchange (HIE), there are regional HIEs that operate in respective geographical areas and send data to MiHIN. Providers and organizations can participate in the HIE by signing on to specific use cases, such as Admission, Discharge and Transfer (ADT) notifications. Organizations must first agree to a Master Use Case Agreement, then the Active Care Relationship (ACRs) use cases to establish patient/provider relationships and exchange data. Patient data is captured by the health care provider within the electronic health record and shared with other providers or organizations who are responsible for the care, treatment, or payment of those healthcare services as defined by HIPAA.

MiHIN was initially funded in part by federal funding from the Electronic Health Record incentive program. That program had three stages. Stage 1 paid incentives to hospitals and eligible providers for adopting a certified electronic health record. Stage 2 continued incentives to hospitals and providers for adopting a certified EHR and expanded the

³[Michigan Multipayer Initiatives \(mimultipayerinitiatives.org\)](http://mimultipayerinitiatives.org)

incentives for hospitals and providers that promoted “meaningful use” use of EHRs. The EHR Incentive Program established objectives for providers to demonstrate “meaningful use” that specified the functionality of the EHR necessary to access incentives. Stage 3 transitioned the EHR Incentive Program to the Promoting Interoperability (PI) Program that introduced requirements for participation including objectives for coordination of care through patient engagement, health information exchange, and public health reporting. The standards formed the guardrails for EHR adoption as well as the requirements that hospitals and providers must meet to receive incentives and avoid CMS penalties.

Lessons Learned from the Field

Community Information Exchange is still a new concept with few examples to reference in the field. To gather insights from experiences elsewhere, the task force has spoken with Alana Kalinowski, a representative from CIE San Diego. CIE San Diego is the first instance of a CIE, holders of the trademark for the term, and conveners of the National CIE Community Network. The task force also reviewed multiple reports from a range of implementations of “closed loop referral platforms,” and several summary reports that compile findings from the field of “community informatics.” The task force is still digesting pertinent information and working to formulate recommendations given the lessons learned. A few of examples are listed below in greater detail. The task force compiled references below in a set of common themes; citations and links are available in a bibliography in the Appendix.

1. Few precedents for success so far; signs of underperformance. This is a long-term challenge with few apparent models for sustainability.

2-1-1 San Diego’s CIE has shown some initial signs of success in facilitating community care planning that reduces hospital readmissions, as well as efforts to build capacities for data-driven advocacy. This is the one apparent precedent for successful CIE that the task force has found. Their infrastructure, however, took more than 10 years and more than \$10 million to develop.

Meanwhile, implementations of “closed loop referral systems” – one of the primary points of reference for many in the task force, and a major topic in the processes that preceded its formation – have generally reported disappointing results. A report from the “Highlighting

and Assessing Referral Platform Participation” (HARP), produced through a partnership with the Trenton Health Team and Social Interventions Research and Evaluation Network, found that “Trenton CBOs value the up-to-date searchable community directory, but the value of electronic referrals is less obvious,” and that “financial incentives to use community referral technology do not seem to motivate CBOs.”⁴

2. Technology is not a solution in and of itself. Effective CIE implementation needs to build trust and capacity, which requires investments in governance process, change management and organizational and human resources.

The report observes that “pre-existing referral systems and processes” conflict with attempts to start from scratch with a new software system. A report from HealthierHere in King County also found that a new closed-loop referral software system actually created “additional work to document referrals across multiple platforms.”⁵

The HealthierHere report echoes findings from Data.Org’s “ReCODE” assessment of the field of “community data ecosystems” which unexpectedly rejected common assumptions about the needs of communities for more technology to collect more data. The ReCODE report – which compiled interviews from more than 500 community leaders in surveys, interviews, and a Learning Council – sums up its findings with this statement: “We were wrong.”

“More data doesn’t mean better outcomes,” the ReCODE report states.⁶ “Throughout interviews and workshops, we heard over and over again that this work requires trust, transparency, empathy, and humility. When those with power don’t share it, nothing changes. Until data systems are overseen and owned by community, the systems who have

⁴ Cartier Y, Burnett J, et al. Findings from Year 1 of HARP. Trenton, NJ: Trenton Health Team; 2021

⁵ <https://healthierhere-org.webflow.io/our-work#connecting>

⁶ <https://data.org/reports/recode-report/>

power over these data ecosystems must begin to share and cede power back to that community.”

3. Closed-loop referrals are not the only use case for CIE (and not always appropriate). Other use cases involve anonymous referral, care planning and coordination, and benefits assistance.

The HealthierHere report is very explicit on this front: “Using technology to send electronic referrals is not appropriate in all care coordination situations.” They point to the wide range of instances in which social services are delivered anonymously – or, at least, without data collection – in ways that reflect important social and cultural contexts that ought to be preserved. Other situations like crisis response might actually be burdened by complex referral processes that obstruct other more direct and relational methods of coordinating care among providers.

CIE San Diego also cited a range of examples in which community information exchange supports coordination of care among providers without a “closed loop referral” ever being made – such as assistance in applying for benefits, care planning among providers, etc.

One of our task force members summed up this theme in the following way: “a closed-loop referral is a two-dimensional idea in a three-dimensional world.”

4. Interoperability as a core principle can reduce burden, decrease costs of change, and enable many efforts to be complementary not siloed.

HealthierHere, notably, has shifted away from its initial strategy of a referral software platform, and instead is developing interoperability capacities to enable exchange of information among systems. Interoperability as a core principle can address the challenges faced by the Trenton Health Team (as reported on by the HARP project mentioned up above in lesson #1) and other initiatives that found that simply implementing a new software system actually creates additional work and even erects new barriers to care. Instead of a new “centralized system” that inherently must compete with already-existing systems, *community information exchange capacities ought to be designed to enable existing systems to work together.*

In a paper commissioned by the Robert Wood Johnson Foundation’s Data Across Sectors For Health program, Bloom and Sorenson outline a set of interoperability objectives that face

CIE initiatives – such as enabling resource directory information to be shared among multiple systems; enabling identities to be matched across multiple systems; enabling personal data to be securely exchanged among systems; and managing permissions across systems.⁷

This paper observes that the same architectural design decisions that determine the structure of Health Information Exchanges also are relevant for CIE: such infrastructure can be “centralized” (in that data from multiple systems is aggregated in a shared database) or “decentralized” (in which data is exchanged among multiple systems but not centrally aggregated) or “federated” (a hybrid approach in which data is exchanged among decentralized systems and some data is centrally aggregated). The paper further outlines a range of governance questions that face communities considering these options.

5. Incentives are not naturally aligned, and power is imbalanced.

CBOs are typically not opting into resource referral systems, in part because of an absence of apparent benefits, a range of apparent risks, and a lack of trust.

Virtually all of the reports reviewed observe that there are significant prospective costs, and known risks, posed to CBOs by participation in data-sharing initiatives – whereas the prospective benefits are hypothetical, long-term, or otherwise uncertain. There is a clear need to engage in trust-building efforts that ensure CBOs and the people they serve develop capacity to participate, agency to make decisions, accountability for outcomes, and trustworthy institutional contexts.

⁷ [Social-Care-Data-Whitepaper-October-2021.pdf \(stldata.org\)](#)

Objective 2: Stakeholder Analysis

Objective 2: Examine relevant perspectives from all interested parties and partners, with a focus on the priorities of communities that experience health inequities, the perspectives of CBOs that serve them, and the needs of people who have experienced the challenges of navigating these services.

To address Objective 2, the CIE Task Force identified three primary types of stakeholders whose interests should be centered in the design of Community Information Exchange capacities: 1) individuals and families in need; 2) community-based organizations; 3) and communities. The task force has also identified a range of secondary types of stakeholders, such as government agencies, healthcare payers and providers, and research institutions.

For each of these stakeholder types, the task force has analyzed needs, prospective benefits, and potential harms associated with this work. The task force is continuously engaging perspectives from individuals representing these groups which has, and will continue to, guide recommendations, including prioritization of CIE capacities.

The following is a summary of the analysis for each type of stakeholder type:

People (Individuals and Families)

The task force is guided by the goal of improving data sharing between health care and social services providers to address the needs of people and families. Community information exchange that successfully serves people and individuals must facilitate better information about what services are available and, more importantly, how to access those resources in a direct way. In addition, people want to know what information is being collected about their health and social needs, what entities have access to it, and how their information is being utilized, including how it is being changed or removed.

Successful CIE capabilities would support many technologies that accommodate individuals with differing abilities, diverse languages, and a variety of social needs. Individuals and families should be able to access health and social records, change and/or update health record information, and, if desired, opt-out of data collection and/or exchange. In turn, people will have a system they can trust and is responsive to their needs and concerns.

Establishing trustworthy systems is critical because people fear a lack of transparency of data practices, and the potential for improper disclosure of sensitive information can ultimately put people at risk. Apprehension about surveillance might disincentivize people from seeking help. Multiple requests for more or redundant information from different service providers reinforces distrust and is cumbersome to individuals.

Community-Based Organizations

CBOs need to know what services are available in their local community and how to access those services in order to share that information with their clients. CBOs vary in degrees of reach, scope, and capacity. The primary focus of local CBOs is to meet people where they are and meet their needs. Some work in partnership with other local CBOs to do this work. In addition, CBOs want access to aggregated, population-level data to demonstrate their program's effectiveness and justify needs for additional funding.

A critical capacity for CIE is appropriate levels of funding to train and support CBO staff in processes of collecting, assessing, sending, and using information in new ways that are relevant to their organizational mission. Social service providers want to be able to seamlessly coordinate care for individuals without burdensome worry that the individual will be lost in the system or unable to access the service they are directed to. CBOs also want to be able to convey actionable information about the benefits of individuals' participation.

Organizations are concerned that a lack of sustainable funding to meaningfully collect data, and establish the technical capacities to share client data, will result in more costs and burdened, overworked, and underpaid staff. There is also concern that CBOs might lose the agency to choose what technologies, tools, and workflows will work for their organization and the community they serve.

There are also concerns about conceptual mismatches between social care organizations, healthcare institutions, and their clients; for instance, the question of when a need has been effectively "met" may be answered very differently by a healthcare provider, social care provider, and a client. Without ways to account for differences in meanings across contexts, system integration and automation could yield unintended inequitable outcomes.

Diverse Communities (Population-Level Analysis)

Community information exchange networks must also support healthy and diverse communities. Communities and their leaders need access to information about the resources available, to whom they are available, and resource capacities and restrictions.

More importantly, communities need access to information about the gaps in resources specific to their communities to understand where there are unmet community needs.

Successful CIE would provide timely and relevant information to support community-level and culturally competent interventions that improve health outcomes and socio-economic well-being and reduce inequities while respecting the values and safety of the community.

Mistrust in communities might yield unequal or nonexistent buy-in, siloing resources and perpetuating inequities in care and disparities in outcomes. To build trust, CIE must be flexible in supporting the varied needs of diverse communities. Without such commitment to meeting diverse communities where they are, and addressing their unique needs, CIE initiatives might result in uneven participation that perpetuates inequities.

One example of a risk that community leaders are concerned about is the unaccountable use of algorithms in predictive analytics; for example for processes like risk adjustment. Without accountable data systems that are monitored for bias and undesirable outcomes, flawed data could result in inequitable access to resources and funding.

Health Payers and Providers

Health payers - such as health plans, Medicare, and Medicaid - and providers utilize patient data to coordinate with service agencies and target social drivers of health. Health payers and providers want to know what services are offered by CBOs in their local community. At an individual level, they want real-time understanding of a patient's existing referrals and treatment plans, and a patient's ongoing needs (i.e., from patient records or screening results), risks, and treatment priorities.

Through effective CIE, health payers and providers could reduce the amount of duplication in the administration of assessments at the client-level and duplication of referrals. Health payers could access aggregated data about the effectiveness of supporting social drivers of health and utilize that data to reimburse social care providers. Finally, health payers and providers could support individuals in accessing coordinated, holistic care.

Without effective CIE strategies, health payers and providers can only access incomplete data on individuals, which limits effective care management. At a systems level, lack of systemwide buy-in and participation could lead to health payers and providers being forced to maintain old processes while implementing siloed efforts to incorporate social care. The absence of coordination on the community side leads to inconsistency in the identification and services to address social needs across providers, payers, and health systems, which can increase costs and undermine patients' wellbeing.

Government Agencies

Government agencies can support local community information exchange to become more efficient and equitable through funding support, resource allocation, and strategic guidance. In order to allocate resources, government agencies need information about the availability of services, gaps in services, redundancy of services, as well as demand for services and unmet needs. More importantly, government agencies need to understand the successes and failures of its resource allocations.

CIE should support government agencies in defining “Who is accessing services? Who is not? Why not? How much does it cost to provide specific services - e.g., housing vouchers in this community?” In turn, government agencies should be able to identify systemic issues and support frontline CBOs in closing gaps and addressing unmet needs. The role of government agencies is to utilize CIE data to influence policy, funding, and programming, including at the state and federal level.

Government agencies also play a key role in alleviating population and organizational concerns about privacy of data. Government should provide clear and ongoing guidance on data-sharing. More importantly, government agencies have an opportunity to effectuate clear guidance by providing information technology (IT) solutions for CBOs to ensure affordability and promote interoperability. That includes ensuring that terminologies are standardized across sectors, such as for definition of “needs met.”

Finally, government agencies play a role in equipping CBOs with the tools to do this work. In addition to funding and data guidance, government agencies should support with standardized trainings for staff, capacity building support, guidance on using and sharing data for organizations, and access to guidance on IT solutions. Ultimately, wherever a person is entering a system, information should be available to meet their needs, and government agencies play a key role in cutting through silos to promote access to needed data.

Government agencies face limitations in supporting CIE work. They must maintain compliance with complex federal rules and regulations (e.g., 42 CFR pt. 2, HIPAA, etc.). The scope of CIE work happening across the system creates extricate complexity that dissuades meaningful state participation. In addition, government agencies must maintain the role of neutrality and empower community-level leadership; that is most difficult with reluctant on-the-ground partners. Requirements to demonstrate positive health and financial outcomes from CIE projects detracts from addressing system-level CIE concerns leading to unsustainable or time-limited funding. Lastly, there continues to be a lack of sustainable funding models to support CIE.

Feedback from Task Force Members: Qualitative Interview Key Findings

To address Objective 2, the CIE Task Force also conducted interviews with members of the task force. In January and February of 2023, MDHHS conducted 30-minute qualitative interviews with members of the task force to understand their experience participating on the task force, assess perceptions on the application of equity, the effectiveness of organizational tools and facilitation methods, progress on task force objectives, and the overall vision for the work.

Key Findings:

1. **Expand efforts to engage diverse stakeholders.** Task force members acknowledged positively the diversity of representation on the task force, one member noted there's representation from "frontline staff to Vice Presidents from big organizations," yet TF members did identify additional stakeholders that could be engaged in the conversation around CIE, notably:
 - Community based organizations (CBOs) in rural areas of the state
 - Local on-the-ground organizations doing client-level work, particularly CBOs serving populations that experience health disparities (for example, organizations representing immigrant populations, communities of color, and/or indigenous populations)
 - Direct consumers of services
2. **Improve processes of the task force.** Task force members identified structural and technology process improvements for the task force to better streamline feedback and increase active engagement across membership.

Structure: The CIE TF convenes in 2.5-hour meeting sessions led by the Executive Committee, which consists of the two co-chairs, MDHHS staff, MPHI administrative support, and the facilitator. TF members recognized the limitations of longer meetings to foster continued engagement and suggested opportunities to create more individual small groups to consult on specific task force objectives.

Additionally, TF members noted opportunities to increase engagement outside of meeting times, through tools like direct surveying or shorter targeted meetings between the full convenings of the task force.

Technology: Beginning in 2022, the task force began working in the visual collaboration platform, Miro. TF members noted positively that it creates a real-time virtual space for all members to participate (through tools like live sticky notes, etc.)

which is a particular challenge during virtual meetings. TF members also felt the Miro board provides a high-level visual of the work done.

TF members also noted the Sharepoint site pairs well with the Miro board as a secondary resource for materials. TF members did identify the need for technical support when implementing a technical tool, like the Miro board, such as tutorial videos or Frequently Asked Question guides, before implementation.

- 3. Build consensus on operationalizable recommendations as to actions that the state can take to support local activities.** TF members were solicited to provide feedback on the most important work of the task force to accomplish. Consistently, TF members noted the need to finalize recommendations that will support the state of Michigan in its work to develop a state Community Information Exchange strategy that supports the range of existing and emerging activities on a local and regional basis.

Task force members noted the opportunity provided by the diversity of stakeholders convened through the CIE-TF and recognized that this group must provide guidance on the most critical considerations of a state CIE strategy. TF members noted key areas that the recommendations should offer critical guidance on:

- The legal challenges around privacy and consent (i.e., clarity on 42 CFR and DHHS-5155 Authorization to Release Confidential Information, etc.).
- The appropriate balance between statewide and local/regional capacities and roles, especially in processes relating to governance.
- The need to support CBOs role as the infrastructure of people who provide connections to services on-the-ground.
- The role of the state-designated HIE in supporting CBOs, and the ability of these organizations to maintain autonomy from a health data exchange infrastructure.
- The challenges facing the Michigan workforce that impact CIE work.

Objective 3: Creating a Knowledge Base

Objective 3: Create a knowledge resource in service of Michigan Health Internet Technology (HIT) Commission five-year HIT Roadmap (Bridge to Better Health) and MDHHS Social Determinants of Health (SDoH) Strategy (Michigan’s Roadmap to Healthy Communities)

To address Objective 3, the CIE Task Force developed a “Knowledge Base” of compiled materials from programs across the state of Michigan along with findings from across the field of health and human services, as well as general guidance for data system integration processes. These materials have been variously reviewed by task force members to inform deliberations, and key themes are reflected in the findings above and recommendations below. The materials in the Knowledge Base are listed along with links to publicly available documents in an index which can serve as a centralized repository for collateral materials about CIE in Michigan and beyond. This Knowledge Base Index can be found in the Appendix.

Objective 4: Develop Recommendations

Objective 4: Advise the state on the development of a CIE strategy, including recommendations as to prioritized capabilities, the appropriate balance between statewide and regional/local capacities and roles, prospective principles, and processes for governance, incentives and adoption support for CBOs, guidance for legal agreements, and a roadmap for implementation, among other critical considerations.

To address Objective 4, the CIE Task Force utilized the analysis of prioritized stakeholder groups, that might use a variety of software systems, to assess the capacities of key stakeholders and key software systems that support CIE. The CIE Task Force also undertook an analysis of legal frameworks for CIE, specifically around the role of the state and of local organizations in establishing legal frameworks.

The CIE Task Force will utilize findings from the capacities analysis and the remaining period (through June 2023) of the CIE Task Force's work to continue the process of inquiry and information gathering, while shifting our focus to the process of making recommendations on the state CIE strategy.

The task force has identified the following capacities that can enable community-based stakeholders to exchange information among various technology systems to achieve success and/or avoid unintended harms.

Resource Information Directory Capacity

Resource directory information consists of data about the health, human, and social services that are available to those in need. Task force members asserted that community stakeholders need a comprehensive supply of reliably updated information about resources. The information supply should be responsive to stakeholder feedback about quality and accuracy so that when users find information that is unclear or incorrect, they can request a correction and have that issue resolved in a prompt manner. Task force members assert that this information should be available in multiple languages.

Task force members have discussed the potential capacity of gathering feedback about the quality of services themselves; there is not yet clear consensus, however, as to whether this

should or should not be a core capacity of the CIE itself (as opposed to a functionality that can be developed independently by organizations or networks that use the CIE).

The task force will produce a synthesized output of analysis and recommendation on this issue, for review by April.

Personal Information Exchange Capacity

The following capacities are associated with the exchange of information about people among multiple providers.

- *Identity management capacities*

Identity management services enable records about a person in one system to be matched with records about the same person in another system. In the task force's discussion with Alana Kalinowski from CIE San Diego, she identified this capacity as one that may be especially important to establish statewide to reduce the barriers to entry for local initiatives and ensure consistency and accountability.

- *Consent and permissions management*

Community organizations that provide care are only likely to support a CIE initiative if they can trust that their clients will have the ability to control how their information is used. But the decisions associated with consent may be difficult to make because various factors are technical and difficult to understand. More active requirements for consent (i.e., "opt-in") and restrictive approaches to permissions may decrease participation in activities associated with CIE. Less active approaches to consent (i.e., "opt-out") may increase participation but also increase the risks that clients' data is used in ways that they did not anticipate and might consider to be against their interests.

Initial assessment through rounds of discussion with the task force is that there may need to be different requirements in different scenarios for managing consent and permissions. On the other hand, there needs to be common understanding among providers across sectors about legal requirements and consent management processes. More research and deliberation are needed to make specific recommendations.

- *Data exchange capacities*

APIs (application programming interfaces) and other data exchange capacities enable the transmission of data among different information systems so that different people at different organizations can access the same information. By establishing common standards

for APIs and protocols for data exchange, the state government can ensure that various technologies can interoperate in the same ecosystem. This may entail policy changes such as procurement requirements; for instance, there also may be need for capacity building for CBOs and government agencies to be able to adopt such new approaches to integration and collaboration.

- *Vocabulary standards and translation*

Terminologies (i.e., vocabularies, taxonomies, etc.) enable different people in different contexts to use the same terms to describe the same contexts. Task force members observe that the government can take action, for example, to make eligibility rules for various programs more consistent through standardized terminologies.

- *Monitoring and assurance capabilities*

Task force members observed that any CIE activities should be monitored, with capacities to discover and alert parties to breaches, as well as capacities (in part human resources) to evaluate the results of activities to ensure alignment with intended goals.

Data Aggregation and Analysis Capacities

The following capacities have been identified as potentially relevant for aggregating data for the purpose of analysis such as needs assessment, program evaluation, etc.:

- Longitudinal record-keeping
- Normalization
- Anonymization
- Aggregate reporting and analytics

The task force has initiated discussion on these issues and will produce a synthesized output for review by April. Definitions for the above terms can be found in the Glossary of Common Terms and Acronyms.

Organizational capacities

Task force members have repeatedly insisted that CIE should not be considered “a technology” but rather a system of technologies, organizational processes, and human resources. The following have been identified as essential organizational capacities to support CIE activities.

Monitoring bodies: Empower monitoring bodies with responsibilities for ensuring that CIE capacities are conducted in alignment with intended goals, values and principles. Such a body or bodies should be able to receive complaints and apply mechanisms for recourse in the event of undesirable outcomes for individuals, CBOs, and communities.

The task force has begun discussing the prospective role of “coordinating entities” (i.e. backbone organizations), and is expected to produce a synthesized summary of analysis and preliminary recommendation by April.

Training and support: Task force members insist that capacities for training and support will be essential to facilitate change management processes among CBOs that might need to collect new kinds of data and effect new workflows and organizational processes in order to participate in CIE activities.

Governance processes: Task force members observe the challenge of ensuring that stakeholders interests are represented in decision-making processes associated with CIE at a local and state level. Institutional design of appropriate governance systems will be a critical process in successful development of statewide CIE capacities.

Legal frameworks: Task force members have prioritized this capacity for analysis and recommendations. An initial draft of analysis and recommendation is included below.

Summary of Legal Frameworks: Equitability and State/Local Analysis

Regulatory frameworks establish guardrails for data usage that can protect people.

But ... existing legal frameworks don't offer clear guidance for important cross-sector exchanges involved in use cases of CIE. Furthermore, different regulatory frameworks might be difficult to align across sectors – i.e., HIPAA and FERPA have requirements that differ and may even conflict. For another example, there is confusion about the requirements of 42 CFR pt. 2, which inhibits action around substance use disorder (SUD) services and mental health services.

This compounds the challenge of organizations' legal compliance. There's a high cost of legal frameworks. There are also high costs for maintaining compliant security in ways that might conflict with the culture of social care organizations (i.e., locked access, etc.). In general, the prospect of data collection and exchange poses significant risks to organizations of unintentionally breaking the law.

Finally, legal compliance tends to stand in for ethics by default; however, there are various bad outcomes that might result from actions that are legal but not ethical.

In addition, expectations are largely localized and vary across communities. Most implementation capacities need to be local because trust is best established locally, through local institutions. But local communities don't have funding or legal capacities to drive this work. And it's challenging – and in some cases unworkable – for statewide institutions to develop unique legal agreements with every locality that does things in a different way.

To some extent there needs to be consensus across communities to establish a baseline framework that can work for the state as a whole. The framework should align with the “umbrella” legal framework for health data exchange that is already established; it should also accommodate the differing interests, needs, and capabilities of both state and local entities across the social service sector. The framework should reflect both the necessary conditions for regulatory compliance and also a set of ethical principles that reflect the interests of social care stakeholders.

In response, the state of Michigan should engage social care sector stakeholders in a process of deliberation around an ethical framework – i.e., a “Bill of Rights” – that can establish normative principles for data collection, exchange, and use among social service providers.

Outputs from this “Bill of Rights” process should be synthesized with the outputs from other, already-underway processes to develop legal frameworks for data exchange, such as that being conducted by the learning networks and the multi-payer alliance.

This process should further engage CBOs to consider the operational challenges associated with both legal requirements and ethical requirements. In this process, various scenarios should be described in easy-to-understand language that paint the picture of what's possible in terms that are not too legal or technical. The process should consider a range of scenarios, including:

- Health care entity shares personal data with CBO.
- CBO shares personal data with health care entity.
- CBO shares personal data with another CBO, or a group of CBOs.
- CBO shares data with government agency (health care).
- CBO shares data with government agency (public health).
- Government agency shares data with other government agency (i.e. health care to public health).

For each scenario, stakeholders should articulate kinds of outcomes that should not happen involving specific kinds of actors, actions, and data types. Given these criteria, the state can initiate the development of a legal framework that should specify what methods of consent solicitation and permissions management must be established across various scenarios. The

framework should further specify how these rights will be adjudicated. The framework should be drafted and reviewed with CBO stakeholders through rounds of input and revision until a sufficient threshold of agreement is reached.

The result should yield a templated “CIE Services Agreement,” which should serve as a baseline standard framework for all business agreements associated with a CIE. Extensions to this baseline Services Agreement can be developed locally and/or across specific domains (i.e., behavioral health, education, etc.) through modular agreements that establish additional conditions or exceptions to be submitted and reviewed.

Through this framework and alongside other processes of capacity-building, the state should empower and support “backbone agencies” that can assume the risks of liability and hold responsibilities for coordination of associated activities on behalf of entire networks of CBOs. These local data aggregators (i.e., backbones, like CHIRs) can facilitate partnership development, use case design, compliance, ethical oversight, and quality assurance.

State government should establish and fund processes for auditing, and monitoring compliance of legal frameworks. In pilot phases, the state government ought to pay for an organization’s legal and operational costs – evaluation, change management, assessment, etc.

Objective 5: Where does the task force go from here?

Objective 5: Articulate scenarios for pilot implementations of key use cases that enable cooperation among prioritized stakeholder groups.

To address Objective 5, the CIE Task Force will utilize the remaining period (through June 2023) of the CIE Task Force's work to continue the process of inquiry and information gathering, while shifting our focus to the process of making recommendations on the state CIE strategy and articulating pilot scenarios for pilot implementations of key use cases.

The task force will generate recommendations through an iterative process of proposal and polling: in future meetings, task force members will offer actionable proposals regarding the range of stakeholder needs and prospective CIE capacities; for each proposal, task force leadership will gauge the level of consensus among task force members. Proposals that receive strong consensus will be further assessed to determine the level of urgency – is this an action that the task force thinks MDHHS *should* take eventually, or is it an action that the task force *must* take as soon as possible? When a proposal does not find consensus, task force members will be further prompted to offer revised proposals that may achieve more buy-in. In instances where proposals are strongly supported by at least two task force members but fail to reach consensus, task force leadership will take note of the proposal as a prospective action that has been tabled yet could be considered in future processes.

Questions for MDHHS

- What are some examples of public health use cases for CIE that MDHHS would prioritize?
- What kinds of already-existing state initiatives – like MI Bridges – does MDHHS expect to be leveraged through the CIE? Can we get an update about MI Bridges Integrated Service Delivery and can MDHHS offer prospective use cases in which such existing systems could be integrated with other systems through the CIE infrastructure?
- How else might MDHHS directly leverage / benefit from CIE capacities? Can MDHHS specify any agency sections that might participate in initial phases of a CIE pilot?

- What kind of guidance can the agency provide now for legal frame-working around consent and exchange?
- What capacity does the agency have to establish funding for this work, and what would be the process thereof?

Conclusion

This report details the actions of the CIE Task Force to realize its goal of advising the development of a state CIE strategy. The CIE Task Force has brought together CBOs, health care organizations, health payers, health IT, and governmental entities to align work that are best served by a coordinated approach to CIE.

Through the investigative work of the task force, it is apparent that CIE remains underdeveloped in the state of Michigan. More importantly, the development of CIE infrastructure is not solely contingent on dedicated, sustainable funding sources. Effective CIE implementation needs to build trust and capacity among the ecosystem of stakeholders involved. Without trust, CBOs are not opting into resource referral systems. In other words, technology is not a solution in and of itself.

Any CIE investments must prioritize building interoperability among different software systems, capacity to participate among stakeholders, and systems of accountable governance to ensure equitable process and outcomes. The task force, through discussions with stakeholders from across the country, has identified a set of capacities that can be prioritized to facilitate CIE activities across local and state levels. In the remaining months of the task force's operations, we will analyze priorities among these capacities and make recommendations for action.

Through development and promotion of community information exchange infrastructure, organizations will be better able to coordinate holistic care for individuals and will lead to improved health and social outcomes for Michiganders.

Appendix

Membership of the Task Force

Membership includes 15 representatives of entities or communities with a stake in CIE, up to two designated liaisons from the Michigan HIT Commission, and no less than two consumers.

Members of the task force can make recommendations for expansions to the membership, for consideration and approval by the MDHHS SDOH Steering Committee.

Name	Title	Organization
Ammar Alzuad	Community Health Worker	Medicaid Health Plan
Bob Kreha	MI211 Technology Consultant, Principal & Co-Founder, BrightStreet Group	Michigan 2-1-1
Dawn Opel	General Counsel and Director of Research & Strategic Initiatives	Food Bank Council of Michigan
Ed Worthington	President/Owner	Advanced Technology Health Solutions/NMCHIR
Janée Tyus	Senior Director, Genesee Community Health Access Program	Greater Flint Health Coalition
Joyce Fetrow	Project Director	Northern Michigan Opioid Response Consortium (NMORC)

Julia Aronica	Director of Plan Initiatives	Blue Cross Complete
Kelly Stupple	Program Manager and Child Health Advocate	Washtenaw Health Plan
Marissa Ebersole-Wood	VP, Regulatory Implementation and Data Governance	Blue Cross Blue Shield of Michigan
Nadeem Siddiqi	Executive Director, Technology, Development and Data Strategy	Wayne Metro CAA
Patrick McNeal	Director	North Flint Neighborhood Action Council
Renee Smiddy	Sr. Director, Policy	Michigan Health & Hospital Association
Sarah Kile	Mi211 Director of Outreach	Michigan 2-1-1
Steven Grulke	Chief Information Officer	Mid-State Health Network
Tim Pletcher	Executive Director	MIHIN
Tyler LaPlaunt	Tribal Council Member	Sault Ste. Marie Tribe of Chippewa Indians

Stewardship of the Task Force

- The co-chairs of the task force are Janée Tyus and Ed Worthington, as representatives of Community Health Innovation Regions (CHIR).
- The task force is supported by the Michigan Public Health Institute (MPHI) and Greg Bloom of the Open Referral Initiative.
- The task force has been convened and staffed by MDHHS.

Meetings

- Task force meetings are held once a month through at least June 2023. Members are expected to attend all task force meetings.
- Members shall engage with materials and complete necessary preparation in advance of meeting
- Members are expected to engage in discussion during meetings
- Members are invited to facilitate progress by self-organizing additional ad hoc meetings as necessary and appropriate; outputs from these meetings should be documented in SharePoint and shared with the Executive Committee.
- Members are expected to respect others, recognizing when to lean in and lean out

Documentation

- All documents are stored in a shared space accessible to all on SharePoint
- When editing documents during discussions, MPHI will document comments, concerns, revisions and provide a revised document for consideration at the following meetings
- Members may provide feedback and revisions by email to MPHI and MDHHS between meetings
- Members may also suggest edits in shared documents on the SharePoint site
- Revisions will be made by committee and brought back to the group for final approval

Methodology

The CIE Task Force meets monthly, during which members learn about existing initiatives, prioritize topics for discussion, and when possible, engage in deliberation within facilitated small groups. Notes from these discussions are synthesized into summaries and shared back with the group for revision and clarification. Task force members are encouraged to gather input from their respective communities on key topics between meetings. Members are also able to form breakout group conversations between meetings to generate input for

consideration by the whole. Notes are maintained in a running document on our group's SharePoint, and we also engage in discussion in reference to a work board (Miro) where participants can generate notes, identify patterns, and comment on each other's ideas in real-time. In between meetings, these notes are summarized, documented, shared out, and the work board is prepared for the next discussion. Previous iterations of the work board are viewable through Miro, and all content is aggregated in the SharePoint.

Knowledge Base Index

Title	Summary	Link
MI Community Care Washtenaw Health Initiative	Overview of MI Community Care (Livingston/Washtenaw region)	MI Community Care (MiCC) (mi-communitycare.org)
Impact and Vision in the Livingston/Washtenaw Region	Impact and vision report in the Livingston/Washtenaw region	MiCC 2022ImpactReport (002).pdf
Collaboration and Cross-Sector Data Sharing to Create Healthier Communities	CIE toolkit highlighting insights and strategies on how San Diego approached development of a local CIE.	2-1-1 San Diego CIE Toolkit
Michigan Health IT Roadmap: "Bridge to Better Health" Report	Summary of the Health IT Roadmap; the engagement and long-term planning efforts in how care systems can leverage health IT in Michigan to improve the health and wellness of all Michiganders.	CY2022 Bridge to Better Health Report Adopted Final Aug22.pdf
Michigan's Roadmap to Healthy Communities	MDHHS social determinants of health strategy.	FULL SDOH Strategy 04.04.22.pdf
Findings From Year 1 of highlighting and Assessing Referral Platform Participation (HARP)	Project highlights from community resource referral platform among Trenton CBOs.	HARP-Year-1-Highlights-1 referral platform.pdf https://trentonhealthteam.org/projects/harp-p-research-project/

<p>Connect2 Community Network Unified Network Infrastructure Request for Proposals</p>	<p>Request for Proposal for Connect2 Community Network CIE.</p>	<p>HealthierHere Connect2 CIE Phase 1 RFP.pdf</p>
<p>MiHIN Interoperability Pledge</p>	<p>Michigan Health Information Network Interoperability Pledge</p>	<p>MI Interoperability Pledge.docx</p>
<p>Rising Equitable Community Data Ecosystems (RECoDE)- The Voices We Trust: Building Equity-Centered Community Data Ecosystems that Work for Everyone</p>	<p>Findings from the Rising Equitable Community Data Ecosystems project, seeking to better understand how we can undo antiquated and dangerous data systems that limit the power over where when and how data is used to improve individual and community outcomes.</p>	<p>ReCode-Report.pdf</p>
<p>Tackling Data Dilemmas in Social Care Coordination</p>	<p>Summary of common challenges that hinder SDOH efforts, focusing on how data are shared among organizations across institutional contexts.</p>	<p>Social Care Data Whitepaper (October 2021).pdf</p>
<p>Who Has the Power? An Analysis of Where Power Lies Within SDOH Interventions</p>	<p>An analysis of where power lies within SDOH interventions.</p>	<p>Who Has The Power CIE FollowUp.pdf</p>
<p>Michigan Multipayer Initiatives: Guiding Principles for Data Sharing in Performance-Based Payment (PBP) Models</p>	<p>An overview of data sharing principles in performance-based payment models.</p>	<p>Michigan Multipayer Alliance LAN Data-Sharing Principles 12.22.pptx</p>
<p>The Community Bill of Rights</p>	<p>The Community Bill of Rights was created by community leaders with support from the Full Frame Initiative. The Community Bill of Rights is a guiding tool to bridge the gaps between what truly matters to the community and the systemic injustices they endure while navigating institutions and services.</p>	<p>The Community Bill of Rights Full Frame Initiative</p>

<p>Is that even legal? A guide for builders experimenting with data governance in the United States</p>	<p>Drafted by Mozilla Insights, this research provides builders with an overview of the current legal landscape governing the collection, management, sharing, and use of data; and to identify opportunities for alternative data governance models in existing legal landscapes.</p>	<p>builders_guide_USA.pdf</p>
<p>Leveraging Community Information Exchanges for Equitable and Inclusive Data: CIE Data Equity Framework</p>	<p>CIE systems-change work requires a community to adopt an anti-racist framework. The CIE Data Equity Framework will help institutions, organizations, and communities to understand, acknowledge, and reconcile systems change work in their communities.</p>	<p>RWJF_211-CIESanDiego_DataEquityFramework</p>
<p>Data Sharing to Build Effective and Efficient Benefits Systems: A Playbook for State and Local Agencies</p>	<p>Benefits Data Trust has designed this Playbook as a "how-to" guide for using data sharing to make benefit systems more effective and efficient.</p>	<p>Data Sharing to Build Effective and Efficient Benefits Systems: A Playbook for State and Local Agencies</p>

Glossary of Common Terms and Acronyms

Term	Definition	Source
Community Information Exchange (CIE)	<p>A CIE is a community-led ecosystem comprised of multidisciplinary network partners who use a shared language, resource database, and integrated technology platforms to deliver enhanced community care planning. CIE enables communities to shift from a reactive approach to addressing social needs to an approach that is more proactive, holistic and person-centered. At the very core of a CIE is the community it serves, and with the community as its compass, a CIE seeks to support antiracism and health equity.</p>	<p>211 San Diego CIE Toolkit</p>
Community Information Exchange (CIE)	<p>A [CIE] should encompass three elements of primary infrastructure that comprise a holistic ecosystem of health and social care: Resource Data Exchange, Client Data Exchange, and Community Data Governance. A CIE should facilitate the reliable flow of information about resources available to people in need to support service discovery and accessibility. A CIE should facilitate the responsible flow of information about clients as shared among various service providers to support cross-sector coordination of care. A CIE should ensure that the systems and activities associated with coordination of social care are equitably developed and implemented according to the expressed interests of stakeholders in a local community.</p>	<p>"Tackling Data Dilemmas in Social Care Coordination," Bloom and Sorenson 2021</p>
Health Equity	<p>Health equity means that everyone has a fair and just opportunity to be as healthy as possible. This requires removing obstacles to health such as poverty, discrimination, and their consequences, including powerlessness and lack of access to good jobs with fair pay, quality education and housing, safe environments, and health care. Health equity also means reducing and ultimately eliminating disparities in health and its determinants that adversely affect excluded or marginalized groups.</p>	<p>Robert Wood Johnson Foundation</p>

<p>Social Drivers of Health</p>	<p>The conditions in the environments where people are born, live, learn, work, play, worship, and age that affect a wide range of health, functioning, and quality-of-life outcomes and risks. These forces and systems include economic policies and systems, development agendas, social norms, social policies and political systems. Social determinants of health refer to macro patterns pertaining to population health that are observable in aggregated data.</p>	<p>“Meanings and Misunderstandings: A Social Determinants of Health Lexicon for Health Care Systems,” Milbank Quarterly</p>
<p>Infrastructure</p>	<p>The underlying systems and resources that are required for public works [and associated activities].</p>	<p>Dictionary</p>
<p>Stewardship</p>	<p>The careful and responsible management of something entrusted to one's care. [as distinct from ownership].</p>	<p>Dictionary</p>
<p>Governance</p>	<p>The process of establishing and ensuring the freedoms, constraints, and incentives that determine how two or more parties agree to conduct their behavior.</p>	<p>Sage Networks on Data Governance</p>
<p>Resource Data</p>	<p>Information about the health, human, and social services that are available to those in need, including the organizations that provide them, the locations at which they are available, and associated types of information about the accessibility thereof.</p>	<p>"Tackling Data Dilemmas in Social Care Coordination," Bloom and Sorenson 2021</p>
<p>Federated HIE</p>	<p>Enables sharing of data among systems, given common patient identifiers; does not hold data itself, data remains locally stored.</p>	<p>"Tackling Data Dilemmas in Social Care Coordination," Bloom and Sorenson 2021</p>
<p>Centralized HIE</p>	<p>Maintains a single shared 'clinical data repository' to which all member systems contribute.</p>	<p>"Tackling Data Dilemmas in Social Care Coordination," Bloom and Sorenson 2021</p>

<p>Hybrid HIE</p>	<p>Some shared clinical data is stored in an HIE which facilitates exchange among a network of local data sources.</p>	<p>"Tackling Data Dilemmas in Social Care Coordination," Bloom and Sorenson 2021</p>
<p>Application Programming Interface (API)</p>	<p>A set of software code, protocols and tools that enable developers build applications that interact with a database. APIs do not have a user interface; rather, they offer instructions that enable software developers to embed interactions with the given database through their software programs.</p>	<p>Office of the National Coordinator APIs 101, 4/2021</p>
<p>Closed-loop Referral Platforms aka Social Health Access Referral Platforms (SHARPs)</p>	<p>Software designed to enable care coordinators to screen for social risks, needs, and protective factors, connect members to community resources to address social health and then understand the impacts on members' clinical health outcome - with the shared aim of enabling health care organizations to identify and refer patients to social service organizations more easily.</p>	<p>UCSF Social Interventions Research & Evaluation Network (SIREN), April 2019</p>
<p>Service Request</p>	<p>A record for a request for service such as diagnostic investigations, treatments, operations, outreaches, or interventions to be performed.</p>	<p>http://www.hl7.org/fhir/servicerequest.html</p>
<p>Identity matching capacities</p>	<p>Capacity to associate records about a given person in one system with records about the same person in another system.</p>	<p>https://sequoiaproject.org/resources/patient-matching/</p>
<p>Consent and/or Permissions management</p>	<p>The processes by which users agree to collection, sharing and use of data about themselves, and the related processes by which third parties are permitted to conduct such activities.</p>	
<p>Data Exchange Capabilities (APIs, etc.)</p>	<p>Enable the transmission of data between different actors at different organizations using different technologies.</p>	

<p>Terminologies and translation capacities</p>	<p>Enable the standardization of vocabularies across contexts, and/or translation between different vocabularies to support semantic interoperability.</p>
<p>Longitudinal data collection</p>	<p>Aggregation of information about people’s social context, care activities, and results over time. Data can be aggregated longitudinally about individuals, like in a shared client record used for “community care planning.” Data can also be anonymized in longitudinal aggregation of population-level data for reporting, analytics, and evaluation of community needs, program effectiveness, etc.</p>
<p>Normalization</p>	<p>Organizing data entries to ensure they appear similar across all fields and records.</p>
<p>Aggregate reporting and analytics</p>	<p>The ability to combine data across organizations to look at overarching social care trends for a population of community.</p>
<p>Anonymization</p>	<p>Organizing data entries to eliminate personally identifiable information.</p>