Tackling Data Dilemmas in Social Care Coordination

Pursuing Open and Equitable Infrastructure Across a Fragmented Health and Social Service Landscape

DEVELOPED BY

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Overview

After the passage of the 2010 Affordable Care Act (ACA) – which included policy incentives for patient-centered care such as penalties for unexpected hospital readmission – health systems began to focus more carefully on what happens to patients outside of clinical settings in recognition that complex social circumstances (i.e. housing instability, food insecurity, inconsistent income) tend to play as substantial a role as medical care in the trajectory of patients' health. A vast web of governmental and nonprofit organizations exist to address needs associated with these "social determinants of health" (SDOH) — defined by the CDC as "conditions in the places where people live, learn, work, and play that affect a wide range of health risks and outcomes." Yet conventional healthcare services are often disconnected from such programs. Throughout the past decade, a flurry of software companies, data systems, funding programs and other initiatives have engaged in efforts to "address SDOH" — i.e. improve patients' social circumstances and overall wellbeing — by improving the coordination of health and social care.

This paper explores common challenges that hinder such efforts, focusing specifically on how data are — or are not, or could be, or shouldn't be — shared among organizations across diverse institutional contexts. We observe that new social care coordination systems are emerging in ways that echo the market patterns which yielded a fragmented, incompatible landscape of Electronic Health Records systems (EHRs). However, we assert that it is not too late to avoid the overwhelming costs, coordination challenges, and associated human and institutional harms that could emerge if this market fails to establish baseline capacities for interoperability and governance. Seeking clarity amid an overwhelming landscape, we delineate three primary elements of information infrastructure that would comprise a holistic ecosystem of health and social care: Resource Data Exchange, Client Data Exchange, and Community Data Governance. We also offer suggestions for future exploration — and we are eager to continue this dialogue and associated work with partners across the country.

These observations emerge from the collective experiences of the authors and their community partners in the field — a mix of technical, academic, and practical perspectives. Open Referral is a community of practice that has developed interoperability protocols, known as the Human Service Data Specification (HSDS), for the exchange of resource directory data across organizational and technological boundaries. The St. Louis Regional Data Alliance (RDA), housed at the University of Missouri–St. Louis, focuses on collaborative data sharing infrastructure and governance, including the development of the St. Louis Community Information Exchange: a care coordination effort led by United Way 2-1-1, the RDA, the Integrated Health Network, and a growing cohort of healthcare, academic, and social service partners. Throughout the drafting and revision of this paper, the authors were also in dialogue with national support organizations that are also grappling with these issues — including Data Across Sectors for Health (which helped fund this paper), the All-In Network, and the Gravity Project.

Unpacking the Concept of a "Community Information Exchange"

2-1-1 San Diego's Community Information Exchange (CIE) has set a precedent for many communities seeking to facilitate alignment among the health and social service sectors. 2-1-1 San Diego defines a CIE as "an ecosystem comprised of multidisciplinary network partners that use a shared language, a resource database, and an integrated technology platform to deliver enhanced community care planning." A CIE is analogous to the concept of a "Health Information Exchange" (HIE) in that it facilitates the sharing of

sensitive personal information across multiple information systems – but a CIE is also designed for use among community-based organizations, human service agencies, and other non-clinical care providers.

The term "CIE" has been adopted across the country as an overarching concept that can define social care coordination efforts.[1] However, the CIE in San Diego is quite different from the CIE initiatives emerging in different local communities and institutional landscapes; this is to be expected as every community is unique and no one single software tool or configuration can feasibly address all of what CIEs aim to accomplish. Given that challenge, this paper attempts to further define and delineate a specific set of core capacities that any CIE should incorporate.

A "Community Information Exchange" should encompass the 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**. Each of these capacities entails its own parameters, with unresolved — and perhaps irresolvable — tensions among them, which local communities should anticipate in their planning and evaluation processes. We define the objectives of these components as follows:

- **Resource Data Exchange:** A CIE should facilitate the reliable flow of information about resources available to people in need to support service discovery and accessibility.
- **Client Data Exchange:** A CIE should facilitate the responsible flow of information about clients as shared among various service providers to support cross-sector coordination of care.[2]
- **Community Data Governance:** A CIE should ensure that the systems and activities associated with the coordination of social care are equitably developed and implemented according to expressed interests and active participation of stakeholders in a local community.

After a brief definitional section discussing infrastructure and standards, the remainder of this paper examines the three above components in more detail, ending with an illustrative case study of how they are being explored in St. Louis. In short: we assert that a healthy information ecosystem must be built upon "open access" data infrastructure, using standardized protocols, so that any compliant platform can perform critical functions through interoperation with other connected platforms — and that these activities should be governed by local communities to ensure responsiveness to beneficiary needs (a critical driver of health and racial equity).

We fully acknowledge that this paper is only one starting point through which critical components of CIEs and their impact on local communities can be unpacked. We also recognize that other resources, like the National Alliance to Impact Social Determinants of Health (NASDOH), have also put forth definitions of key components of data interoperability that cover similar ground — and we are excited to add to this vital conversation. We invite readers with additional practical, technical, or academic expertise to add their own thoughts on this work, pieces we missed, and emerging hurdles through a "living paper" found here: bit.ly/socialcaredata.

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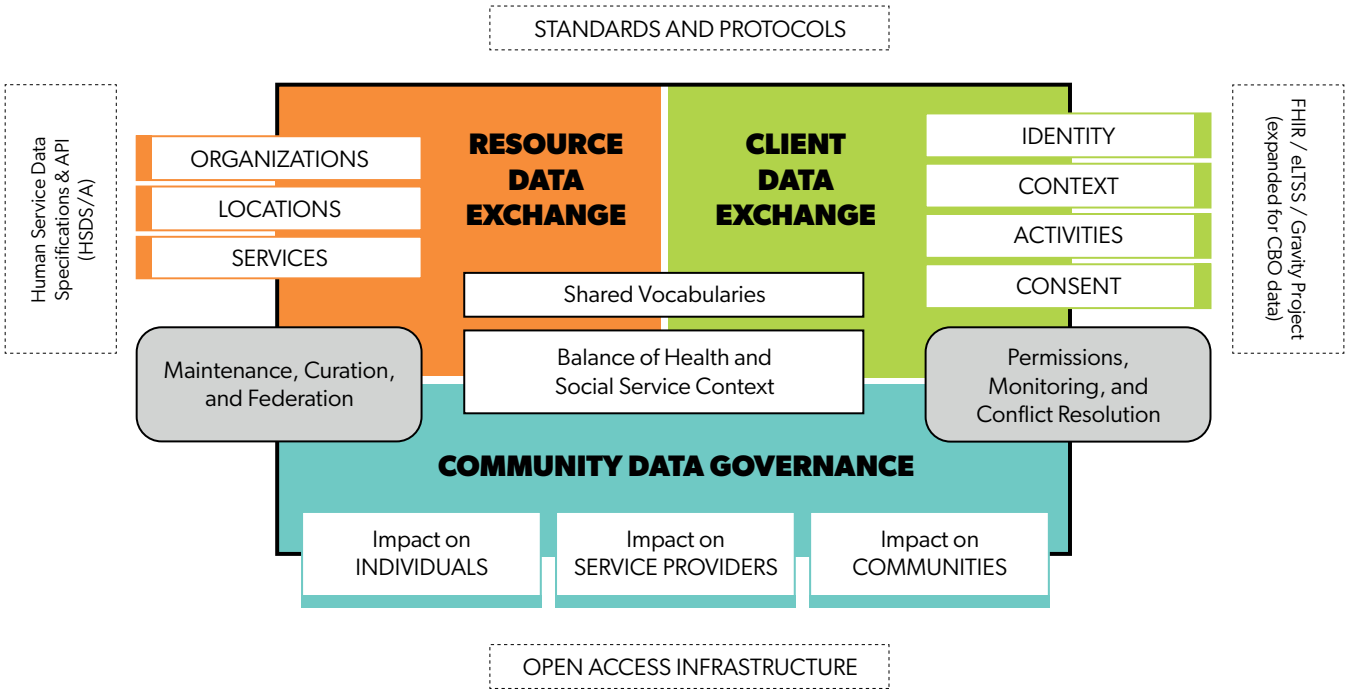
1 2-1-1 of San Diego has trademarked "Community Information Exchange" to avoid having vendors inappropriately using it simply as a function of technology. We use the term CIE like many communities across the country are using it, including St. Louis, as a part of the community of practice that San Diego has fostered.

2 In a clinical healthcare setting, the social services term "client" is synonymous with the term "patient." We use the term "client" throughout this paper, recognizing that patients and clients are often the same individuals.

Primary Components of "Community Information Exchange"



Infrastructure and Standards

*A Community Information Exchange is **infrastructure** that enables data about resources, people, and activities to be shared among a diversity of organizations and information systems in **standardized** ways.*

Infrastructure

Defining "infrastructure" can be a difficult task because the concept is inherently abstract. **Infrastructure refers to systems that undergird other systems.** Infrastructure is a systemic input to "downstream" activities — typically enabling autonomous actions while remaining in the background. People do things that use infrastructure all the time – drive on roads, make phone calls, etc. – but if infrastructure is working, users often don't notice it at all. They see and feel the thing they're using (the car, the phone) and not the underlying systems that make their activity possible (the truck that paints the lines that form the lane, the circuit switch, etc.).

One critical concept to grasp is that infrastructure is not a "thing." Infrastructure is relational, the result of the interactions between things, policies, processes, people, and so on. An essential step for any CIE initiative will be developing a shared mental model in which infrastructure is understood to be a set of relationships which include (yet are not contained within) technology.

The design of infrastructure might vary significantly from one context to the next, even if its purpose is similar. There are some common patterns that are worth highlighting:

- **Centralized infrastructure:** A single point of access – and control – to which all nodes in a network submit. Centralized infrastructures can offer economies of scale and predictability of uniform policies and procedures.
- **Decentralized infrastructure:** Many nodes in a network that are able to interact without any central structure, controlling their own operations. Sometimes described as "distributed infrastructure," decentralization may pose more friction for certain kinds of processes at large scales, yet may more readily adapt to change and remain resilient in the event of failure.
- **Federated infrastructure:** A "hybrid" of centralization and distribution, federation implies that many systems in a distributed network are linked to each other through some central coordinating mechanism(s).

Information infrastructure trends seem to go through cycles of centralization and decentralization. Today, many people's online activities take place largely upon massive, corporate-owned centralized data infrastructures like those operated by Google, Facebook, Amazon (AWS), and Microsoft (Azure). Yet despite decades of corporate consolidation of web activities, the internet itself remains decentralized

infrastructure: anyone can deploy a server and put data online, and this data can be accessed by any compliant third party system that knows the correct address. (Of course even in this modern classic example, the infrastructure is not purely decentralized: The human-readable web domains that comprise the World Wide Web, for example, are registered in a centralized Domain Name System – enabling federated address management and retrieval across an otherwise-decentralized system.)

In healthcare, these different approaches to infrastructure can be seen in the field of Health Information Exchanges (HIEs). Some Health Information Exchange systems are centralized repositories of patient data shared among multiple Electronic Health Record (EHR) systems; such centralization offers various benefits of scale. However, centralized infrastructure can also be difficult to implement politically and may pose considerable risk as a "single point of failure" among other challenges of scale. Some HIEs have been designed as decentralized infrastructure — which enable the routing of data from one system to another but do not themselves aggregate patient data. The most common HIE models seem to be a hybrid or federated approach to health data exchange, which centralizes some core data (like a Master Patient Index) without trying to capture all data about all patients.

CIEs may be successful pursuing any of the three models of infrastructure outlined above; in any case, they should be intentional about leveraging the benefits while mitigating the risks of decentralization and/or centralization. Given the complexity of health and social service data ecologies — and learning from missteps and promising practices in the healthcare landscape — we encourage CIE initiatives to carefully consider alternatives to centralization that may be more feasible and appropriate.

One final concept worth defining with regards to infrastructure is the principle of "Open Access." Open access is a technical term for infrastructure that can be used by any compliant system. Open access does not mean that "anybody can do whatever they want" — presumably, open access infrastructure has rules, requires protocols, and possibly even levies fees. Open access merely entails that use of infrastructure is not subject to private discretion of the party that built and/or operates the infrastructure. Airports are usually "open access" infrastructure (usable by any number of airlines), as are most fiber networks, utility poles, railways, etc. In most cases, it is in the public interest for infrastructure to be established as open access — i.e. as a public utility — which reduces dependence upon a single vendor while enabling a competitive market and fostering innovation.

Standards

Often considered to be a core component of infrastructure, **standards (or protocols) are common ways of doing things**. Standards enable predictability within complex processes and interoperability among complex systems.

Grammar itself is a kind of standard: A set of rules that govern relationships between words so that they can be assembled in meaningful sentences. We don't tend to notice grammar unless it's wrong.

As such, activities enabled by distributed infrastructure (such as decentralized or federated models) is made possible by standardization; even centralized infrastructure will operate through use of established protocols, but such protocols may be established unilaterally by the centralized operator.

There are, of course, different kinds of standards – which establish different types of interoperability:

- A **data standard** is a format for structuring data in a predictable way, which enables data from one information system can be received and processed by a different information system. This is known as "technical interoperability" in which different technologies can "read" the same data. This report outlines several emerging data standards that enable data exchange among diverse information systems (such as Open Referral's HSDS for resource directory information exchange and HL7's FHIR for patient information exchange).
- A **standardized vocabulary** (like a taxonomy) is a formal set of terms that define concepts and their relationships with each other. Standardized vocabularies enable "semantic interoperability," in which different people in different contexts can use the same words to describe the same things. This report describes several kinds of standardized vocabularies — from the 2-1-1 taxonomy of services, to clinical terminologies that describe personal conditions and clinical methodologies like ICD-10, LOINC and SNOMED.
- **Operational standards** are agreed-upon processes for performing tasks**.** Operational standards enable "organizational interoperability" – such that different institutions are able to reliably align their functions in predictable and efficient ways that reduce the likelihood of errors such as miscommunication or worse. Operational standards are critical for effective implementation of institutional governance. In the context of new kinds of institutional behaviors (such as exchange of information among previously-siloed systems) new operational standards will likely need to be developed to enable both performance and the evaluation of performance.

This paper attempts to outline the elements of open access infrastructure and standards that can enable the equitable development and governance of CIE infrastructure in diverse communities. While the purported efficiency of single-software solutions offered by private vendors may be tempting to institutions that seek to address the social determinants of health, we strongly encourage them to consider the models and concepts outlined throughout this paper — stepping back from the tactical concerns posed through comparison of various vendors' software platforms to instead consider strategies that can bolster the entire ecosystem in ways that are adaptable to community conditions and concerns.

Resource Data Exchange

Objective: *A CIE should facilitate the reliable flow of information about resources available to people in need.*

Resource data are comprised of information about the health, human, and social services that are available to those in need – as typically provided by governments, government contractors, or tax-exempt charitable organizations. Resource data includes information about:

- **Organizations**: Entities that provide services to those in need.
- **Locations**: Places where those services can be accessed.
- **Services**: Details about the purpose, eligibility, and accessibility of resources.

The term "resource data" is synonymous with "service directory data." "Referral data" is sometimes used to refer to resource directory data, but this is incorrect; to avoid confusion, "referral data" should be used only to describe data about activities associated with people who are referred to services.

Aggregators of resource data are often known as "information and referral" (I&R) services – information intermediaries that compile resource directories to use in referring people to services over the phone or web. It is not uncommon for a given community to be serviced by a 2-1-1 call center as well as sector-specific I&R providers (for mental health, childcare, veterans, older adults, etc); at the same time, a community also might include a variety of additional print and online directories produced by community-based organizations organizations and grassroots groups. Recently, web-based resource referral platforms have emerged to offer their own resource directories. These efforts to maintain directories typically struggle to sustain themselves — in isolation from and even competition with each other.

One reason this remains an unsolved (even worsening) problem is that community-based organizations (CBOs) have few tangible incentives to keep their information updated in any directory; such providers are typically not paid by their clients, and furthermore are also typically not compensated per-client-served by their funders — or, at least, not compensated enough to cover the costs of service. (This incentive structure, or lack thereof, is often similar for human services provided directly by a government.) As more resource directories emerge, and more referral providers make more requests for information from service providers, this incentive problem is exacerbated. As a result, communities face the dilemma of more and more sources of less and less reliable and sustainable information.

The Open Referral Initiative (launched in 2014) has created data exchange protocols that enable standardized resource data to be frictionlessly shared and simultaneously used across multiple systems. In 2018, the Human Service Data Specifications and API protocols (HSDS and HSDA, respectively) were endorsed as industry standards by the Alliance of Information and Referral Systems (AIRS, which certifies I&R providers), and have since been adopted by a broad range of technology vendors, governments,

and referral providers. The emergence of such standards makes possible new kinds of solutions to the resource directory maintenance problem.

Our first recommendation for development of Resource Data Exchange infrastructure is to promote adoption of these standards for resource data exchange among primary stakeholders that already aggregate resource directory data in a given community, and/or among any platforms seeking to enter the CIE's market. This can be done through RFPs and procurement policies, as well as "innovation challenges," collective impact processes, and old-fashioned negotiation. Once a critical mass of actors "speak the same language," it's both cheaper and quicker to integrate systems — as well as easier to develop mutually-beneficial data sharing agreements.

That said, *resource data interoperability* is valuable inasmuch as it is an *enabling precondition* for the development of effective and equitable *resource data supply and maintenance arrangements*. The most important questions regarding resource data that a CIE must answer are about responsibility and sustainability: *Who should be responsible for ensuring accuracy of resource data in the CIE? And how can these efforts be sustained?*

These are questions that a CIE should answer through research, development, evaluation and deliberation. CIEs should experiment with various sustainability strategies – including partnership with governments and philanthropic funders that can require their own grantees and contractors to update information in official "service registries," revenue models that provide value-adding "data services" for premium fees on top of open resource data, and federated "data collaboratives" that facilitate cooperation among multiple resource directory maintainers. These approaches are outlined in more detail in this paper (pending publication in The Cambridge Handbook of Commons Research Innovation).

On this front, there are still several open questions that require further research and development:

- **What role should service providers, and funders of services, play in resource data management?** It is a common mistake to assume that service providers can be expected to update information about their own services in a resource directory. Many providers do not have strong incentives to do so; with each new directory requesting such information, these incentives further weaken. Perhaps more importantly, information about services can be complex and nuanced, and may be expressed in subjectively variable ways; which is to say that when two different staffers at the same organization are asked for information, they'll likely give two stylistically or even substantively different answers. Hypothetical long-term market incentives that a CIE might someday provide – such as data analytics, or potential fee-for-service compensation – also should not be assumed to present tangible near-term solutions to these problems. CIEs should encourage service providers to participate in sharing information about their own services, but *consider this to be merely one input among others in an established institutional system of resource data aggregation, verification, and curation.*

- **How will resource data stewardship be delegated and sustained?** The only reliable way to ensure accurate information is for humans to produce it – preferably, humans who are trained, paid, and supported. For an average metropolitan area, AIRS estimates that the equivalent of one to two full-time employees is required to maintain a reliable, comprehensive directory. Data collaboration and expanded user feedback might decrease these costs over time, but will not

eliminate them. More detail about potential sustainability models can be found in Open Referral's white paper on the subject. We want to highlight in particular its emphasis on resource data as "open access" infrastructure. Care coordination is greatly inhibited if various care coordination tools each maintain different resource directories that differ from each other and/or are only accessible as reusable data to paying customers. Inconsistent and siloed resource data creates inconsistent and siloed referrals. Meanwhile, resource data-as-a-commodity has not proven to be a viable business model in the market, as the value of resource data is directly related to the scale of its use, and charging fees for even basic access inherently decreases its use — paradoxically rendering it less valuable. Open access resource infrastructure can become sustainable through the services associated with its use (from "guaranteed" levels of "premium" services, to value-adding analysis of resource data usage).

- **How can multiple, subjective vocabularies (such as service taxonomies) be aligned around shared resource data?** Service classification, as established through taxonomies, is a deceptively difficult problem. The variability of types of services is vast and granular, and the vocabularies used to describe services differ across contexts. Appropriate categorization is critical for both service discovery and also performance analytics; however, categories that might be appropriate for users who are seeking help (in clear and non-technical language) would likely be inappropriate for users who are conducting technical analysis and operations (for example, a researcher or program evaluator). This is a tension with which communities can cope, though perhaps not fully resolve. The 2-1-1 Taxonomy is an industry standard used by the majority of I&R systems — but it is a proprietary schema, which presents a significant barrier to entry for a system such as a CIE that might be used by many different actors as shared usage would hypothetically require an exponential number of licenses. The lack of such a comprehensive, non-proprietary taxonomy is a significant challenge for the entire health, human, and social service sector. (Open Referral's HSDS/A is taxonomy-agnostic and can be used in conjunction with multiple categorical schema.) We recommend that CIEs consider using the 2-1-1 Taxonomy as "core infrastructure" while developing methods of aligning this controlled technical vocabulary with other user-facing / partner-managed vocabularies. We also recommend that national institutions should invest in R&D for non-proprietary stewardship of service vocabularies as "open access" infrastructure.

Recommendations

- Stipulate the use of the Human Service Data Specifications and API Protocols in any RFPs, contracts, and MOUs with technology vendors involved in the CIE.
- Work with existing and emerging resource directory maintainers in the CIE's community to develop an equitable and sustainable resource data supply chain.
- Ensure that the CIE has human resources and institutional processes to manage the challenge of service categorization – balancing the need for terminology standardization against the reality that different contexts necessitate diverse vocabularies.
- National institutions should invest in the development of non-proprietary resource data classification and taxonomy systems as open access data infrastructure, perhaps as part of broader efforts to standardize SDOH terminology.

Further Reading

- AIRS Standards: https://www.airs.org/i4a/pages/index.cfm?pageID=3371&activateFull=true
- "Averting Tragedy of the Resource Directory Anti-Commons," Bloom, G. *The Cambridge Handbook of Commons Research Innovations*, ed Foster, S and Swiney, C. (Cambridge University Press: publication pending.) Pre-publication text available at http://bit.ly/ResourceDataCommons
- "Miami Open211: Developing New Business Models for Resource Data As a Service," published January 20, 2020 on openreferral.org: https://openreferral.org/miami-open211-developing-new-business-models-for-resource-data-as-a-service/
- "The DC Community Resource Information Exchange: Phase One Report," published January 9, 2020 on openreferral.org: https://openreferral.org/the-dc-community-resource-information-exchange-phase-one-report/

Client Data Exchange

Objective*: A CIE should facilitate the responsible flow of information about clients as shared among various service providers to support cross-sector coordination of care.*

Clients frequently receive many types of services from a variety of providers for a number of health and social needs — often across fragmented sectors and data systems — leading to the repeated sharing of the same (sensitive) information and disjointed records that make it hard to coordinate care over time. This same problem has long inhibited efficiency and effectiveness in healthcare, where it is now being addressed through the development of electronic health record (EHR) interoperability protocols and Health Information Exchanges (HIEs). The personal data exchange problem becomes even more complex when involving social services provided by government agencies and CBOs. As their primary design objective, CIEs typically aim to enable client data sharing for such use cases as "warm referrals" (i.e. a referral of a client made by one provider directly sending information to another) and "closed loops" (i.e. feedback that follows from the making of a referral) for the purposes of connected, person-centered coordination of care.

A single software system cannot solve this problem. The various kinds of human services and social services are vast, and the context for "a referral" might vary widely among them — the context of a referral made from an emergency room to a homeless shelter, or from one legal aid provider to another, is significantly different from that of a person applying directly to receive a service, or a case manager suggesting a job training program to their client – and such differences cannot be reconciled through a "centralized system" that is "friendly" for all possible users.

The establishment of warm referrals and closed loops is above all an institutional process. Technology can enable solutions (if it is designed to work with other technologies) or technology can inhibit solutions (if it is incompatible with other technologies), but *technology is not in and of itself a solution*. A CIE facilitates interoperability among technologies as only one part of a broader institutional process of alignment among organizations.

In light of that broader context, we will focus in this section on the technical dimensions of the client data interoperability challenge. We observe the following four primary challenges posed by the exchange of a client's information across systems:

1. Establishing a person's **identity**
2. Describing that person's relevant personal **context** (i.e. their social circumstances)
3. Sharing information about **activities**, such as the making of a referral
4. Soliciting a person's **consent** to collect, share, store, and use any of the data outlined above

Healthcare Precedents

Within the healthcare sector, a variety of established solutions — such as Health Information Exchanges — have largely addressed these technical problems. For the identity problem (#1), EHRs can match patients information using a master patient index as frequently mediated by an HIE. EHRs can use controlled vocabularies (such as ICD-10, LOINC, and SNOMED) to structure and communicate a patient's contextual data (#2); activities like referrals and service outcomes (#3) are increasingly shared across systems through protocols like HL7's Fast Healthcare Interoperability Resources (FHIR). Consent management (#4) varies, though parameters are largely defined by the Health Insurance Portability and Accountability Act (HIPAA), which establishes the terms by which protected health information (PHI) is stored and shared. These solutions are far from perfect or complete, but nonetheless they establish important precedents — and potentially can be repurposed as functional infrastructure by human service systems.

Social Service Challenges

Data sharing precedents do not exist at any comparable scale within social service sectors. At least two major structural differences contribute to this disconnect. First, these sectors are tremendously variable — housing, food, legal, employment, childcare, eldercare, etc. provided across independent nonprofits, governments of overlapping jurisdictional levels, and even for-profit entities — without consistent coordinating functions among them. Healthcare has the advantage of common payers and services (Medicare and Medicaid most prominently), as well large insurance providers, that necessitate a level of standardization across systems and geographies. Hospitals may compete around how they provide oncology services, but the basic building blocks are the same. In contrast, social service delivery varies wildly from place to place, even in sectors that receive similar federal funding.

Data standards sometimes exist within specific sub-sectors, like homeless services, where providers are often required to share coordinated data through a housing management information system (HMIS), as well as long-term services and support for eldercare and disability services, where eLTSS serves as a standardized framework for care planning and provision information as established by the Centers for Medicare and Medicaid Services (CMS). Outside of the institutional remit of such federal agencies, however, data standards (or large-scale coordinated service delivery systems of any kind) are notably scarce within and across social service sectors.

Pursuing Client Data Exchange Standards

These challenges may seem overwhelming, though recent progress within the exchange of healthcare data — particularly though the development of HL7's FHIR protocols, and the establishment of federal policy that requires adoption thereof — might be leveraged to catalyze similar alignment for client data exchange among non-HIPAA-covered entities in human and social service sectors. Our initial recommendations build upon NASDOH's concept paper on defining components of data interoperability, and seek to further refine relevant community context and data component parts:

Identity

Can different systems correctly match data from different records to the same person? This problem has been addressed with mixed results by regional HIEs (through Master Patient Indexes and algorithmic matching services) and nationwide industry infrastructure

such as Commonwell and Care Everywhere, though these approaches are not uniform or federated at scale. The Seqouia Project offers a significant framework for patient matching, Pew proposed a set of standardized fields, and HL7 also publishes its own modules for MPIs. In many cases, CIEs may also be able to leverage an HIE's MPI and other data sharing protocols instead of creating their own standalone MPI — though modifications may need to be made to account for the variety of service delivery contexts that a CIE encompasses.

OPEN QUESTIONS:

- Are there already-existing identity-matching infrastructures that might be available for use by a community information exchange, such as a regional HIE's Master Patient Index?
- How can CIEs evaluate identity matching frameworks across care management systems with a minimally-viable set of fields and processes (name, birthdate, etc.) as recommended by national institutions such as the Pew Charitable Trusts and Sequoia Project?
- How can a CIE establish the human capacity to facilitate the ongoing quality improvement of its patient-matching service beyond technical infrastructure?
- How will the CIE monitor for, address, and redress instances of false negatives (i.e. failure to match an individual's existing records, resulting in duplicates) and false positives (i.e. incorrectly matched individuals)?

Context

Information about a person's social situation – their demographic context, their needs, their goals, and other salient details about their situation – is a critical element of care coordination, and also poses problems that may not be fully solvable. This is also often imprecisely referred to as "SDOH data."[3] The major challenge for exchanging data about a person's social context is that different people in different contexts might describe the same person in different ways, and the "right" description or label will often be a subjective consideration.

Demographic factors like income, race, ethnicity, and disability status, for instance, may have common definitions already established by the Census and other Federal agencies (such as CMS's Functional Assessment Standardized Items for the aforementioned LTSS domain), alongside non-governmental standard-setting bodies in various service domains. These definitions put forth by different frameworks may not align with each other, and may or may not have any bearing on

3 We observe that the term "SDOH" is increasingly used as shorthand reference to concepts that are not, in fact, "social determinants." SDOH refers to macro-level patterns observable in aggregated data about population health. An individual's health outcomes, however, are not solely determined by their social needs and social risks. Likewise, personal information cannot accurately be described as "SDOH data." Social services are not "SDOH services," and resource referral tools are not "SDOH solutions." The misuse of this term causes confusion and opacity in many contexts where clarity is urgent. Gottlieb and Alderwick have offered helpful clarifications of this terminology in the Milbank Quarterly. In this paper, we offer clarifications when helpful; in general, we encourage practitioners, policy-makers, funders, and technologists to relegate the use of this jargon to its appropriate, narrow context of population health research, and instead use simple, clear language such as "social needs" and "social care."

terminology used in the field by service providers, clients, and patients. Such terminology might also vary across geographies and communities in ways that might not easily be resolved through apples-to-apples comparison.

Screening tools will likely vary — and likely should vary — across provider types, service types, and community contexts. There are many high-quality, evidence-based screening tools under consideration or already adopted by CIEs and their partnering healthcare and CBO providers. (For instance, 2-1-1 San Diego and Health Leads developed the Comprehensive Social Continuum Assessment [CSCA] specifically for CIEs.) Calls for a single, all-encompassing screening tool (with associated semantic standards) are common, but this is not feasible (or responsible) given the complex needs of individuals and the variety of health and human services available to them.

Given our interviews and experience with social service providers, we believe strongly that providers should remain able to gather information from their clients in variable, context-appropriate ways. Instead of forcing a "standardized screening" method upon all providers, semantic interoperability can be pursued through encoding the answers to providers' questions — i.e. the outputs of screening processes — in standardized ways for structured data exchange. Such semantic interoperability could also be enabled through shared service taxonomies and common domain definitions as highlighted in the Resource Data Exchange section above. This challenge manifests in ways that are highly context-dependent and therefore requires localized solutions. CIEs will need capacity to facilitate alignment around shared vocabularies, and translation across vocabularies, in ways that are appropriate for their community. To reiterate our recurring theme, this work of clarification, curation, etc, is largely work that needs to be done by humans; technology can inhibit or facilitate such human labor, but despite the hype about machine-learning and artificial intelligence, technology can only work with humans in the loop — and such humans need training, capacity, accountability, etc.

To some extent, collaboration at a national scale can enable and support regional and local efforts to facilitate semantic interoperability for personal information sharing. The Gravity Project (which is a "FHIR accelerator") is currently facilitating a collaborative process of "identifying and harmonizing social risk factor data for interoperable electronic health information exchange" — which entails the extension and alignment of already-existing clinical terminologies (i.e., LOINC, SNOMED-CT, ICD-10) to describe social circumstances such as risks, goals, and interventions. Gravity has received various forms of endorsement and support from critical federal institutions such as the Department of Health and Human Services' Office of the National Coordinator of Healthcare Information Technology (ONC), the Centers for Medicare & Medicaid (CMS), and the Administration of Community Living (ACL). That said, while Gravity is currently facilitating this articulation and alignment of the healthcare sector's terminology to describe social circumstances and related human service operations — and while Gravity plans to address additional use cases beyond that of healthcare providers referring to social services in the future — the question remains open as to how such alignment might be facilitated *within* human and social service sectors themselves.

OPEN QUESTIONS:

- How will a CIE foster semantic interoperability (via shared taxonomies and vocabularies) for data about types of people and types of situations?
- How will a CIE use existing standardized terminologies (like LOINC, SNOMED, ICD-10, etc.) and how will these terminologies be locally adapted to reflect the needs and culture of the community?
- To what extent will the CIE's strategy depend upon changing members' behavior to enforce adoption of standardized terminologies — and to what extent will it depend upon processes of translation, alignment, and clarification across a diverse landscape of service provision? (Given a vast empirical record of how interoperability succeeds or fails, we advise against strategies that are overly dependent upon the former approach.)
- How will a CIE establish methods by which stakeholders – primarily service providers and ultimately also service users – can participate in these processes of vocabulary definition and alignment? How will stakeholders be able to challenge and improve the formulation and application of terminology about themselves?

Activity

The current discourse about data exchange among health, human, and social service providers is narrowly focused upon the prospect of "warm referrals" and "closed loops" across a broad array of services. In this mental model, a problem – i.e. a person's social need – can be addressed when one provider makes a referral to another provider who can subsequently meet the person's need. This process can be monitored, presumably, such that the service provider who makes a referral receives some kind of information back from the referred-to provider about the result of the referral.

We observe that this concept of coordination of care is overly simplistic: "making a referral" is only one use case in a wide range of possible "activities" that involve providers exchanging information about their clients to coordinate care. Other activities — such as program enrollments, documentation, situational changes, and a client's own decisions about what actions they are taking toward their goals — are equally vital for holistic care that supports a client's path to health and wellbeing. By narrowly focusing upon "warm referrals" as a simplified concept for coordination of care among health and human services, communities may unintentionally develop "solutions" that are not in fact holistic or "user-centered." More work needs to be done to define a common set of activities that can encompass shared care management data — as well as what should remain outside the scope of standardization.

For the purposes of this paper, we will focus on this primary use case of "warm referrals" and "closed loops." Given our framework as outlined above, a warm referral might occur when an *identified* individual articulates their social *context* and associated needs to a provider who then identifies a relevant *resource* that can address such needs, and in turn provides information about their client to the other provider. (There are of course differing variations on this scenario: a provider can make a referral to another provider without sharing any personal information, clients can directly refer

themselves, etc.) Healthcare has established protocols for exchanging clinical information — such as the C-CDA (Clinical Document Architecture) template — and emerging protocols for making referrals from one healthcare provider to another, such as the IHE 360X protocol and the FHIR Bi-Directional Services eReferrals Protocol (BSeR). The Gravity Project is also developing implementation guidance to support the use of FHIR for API-based exchange of client information from healthcare to non-clinical providers such as social service CBOs. As seen above, however, data sharing protocols within healthcare are likely not appropriate for human service providers who are not using EHR systems.

To fill in the blanks, Client Data Exchanges will require standard protocols that health and social service providers can use to share the right information with the right parties at the right time. This "referral protocol" might include as standard elements:

1. Packaging information about a client (structuring information about their identity, relevant context, relevant activity, and their consent)
2. Transmitting client information from one provider to another
3. Providing a receipt of received information to the originating provider
4. Returning information about the result of the interaction (including the reason for the result) for shared use

In fact, healthcare-centered data sharing models may pose disconnects and risks in their application to social service contexts. For instance, assigning an extension of Current Procedural Terminology (CPT) or Healthcare Common Procedure Coding System (HCPCS) Codes to social services may seem like an ideal solution, but they struggle to define services that are not individually delivered to individual patients. Social services are often relational, intermittent, and sometimes involve more than one person (such as families, caregivers, etc.); healthcare constructs might fail to function for these purposes — especially as social services are often not designed to receive referrals from an open set of outside actors like in healthcare. A CIE should facilitate interactions beyond service transactions to encompass information about networks of people and ongoing case management. Concerted efforts are needed to adapt and align healthcare conventions such as C-CDA and exchange protocols such as FHIR for non-clinical contexts, including the possibility of complementary methods of data exchange that can be made compatible with FHIR while remaining feasible for use by non-clinical institutions in governmental and community-based settings.

Centralized client data? On longitudinal records

Some Community Information Exchanges, such as 2-1-1 San Diego, may seek to establish "longitudinal care records" by aggregating the history of a client's contextual assessments, referrals, and case activities across a spectrum of social care services. In 2-1-1 San Diego's case, this entails a centralized repository of client data that includes data about all activities conducted among the nodes of the CIE's network over time.

There are many potential benefits that can come from such centralized aggregation of client data — and there are also notable risks and liabilities. Centralization of longitudinal client data, for instance, may be more politically fraught as it concentrates control and power within the data holder; this strategy presumes a high degree of trust and accountability that may not be present in a community. A centralized data repository may also pose liabilities as a single point of failure – organizational or technical – for an entire network.

2-1-1 San Diego's achievement is impressive and worth considering; we also believe that a community could pursue most if not all of the same health equity objectives without choosing to centralize client data. Even longitudinal data analysis is hypothetically possible through purpose-oriented partnerships among specific nodes in a network; the result may not entail a single repository of "all" data, yet may still deliver sufficient value for the given purpose. Communities ought to be involved in the process of evaluating the various tradeoffs involved with different methods of data management — and that begins by recognizing that there are options from which to choose.

OPEN QUESTIONS:

- Given the proliferation of care management systems, each with their own methods of facilitating care coordination, how will a CIE ensure that some basic capability of sharing information about clients is established *among* diverse platforms, rather than just *within* one platform or another?
- What are the "minimally viable" protocols and processes that will enable exchange of data about patients across platforms and sectors? How might the CIE (and its associated partners) establish compliance with interoperability protocols through procurement policies – such that, for instance, adoption of open standards is required as a condition of executing a contract?
- In a shared system, to what extent should healthcare protocols be imposed upon social service sectors and to what extent should data exchange about social service clients reflect the needs and conventions of social services?
- How will a CIE facilitate access to information about resources that don't "fit" within the conceptual box of "closed-loop referrals"? To what extent do various stakeholder groups "want to have" — as opposed to "need to have" – loops closed? To what extent should these distinctions inform the priorities, design, and evaluation of the CIE? What kinds of activities other than "warm referral" and "loop-closing" might improve social equity and health outcomes in a community if facilitated through cross-platform data exchange?
- How does the maintenance of a longitudinal care record augment the technical requirements for client data exchange as outlined above? What additional consent and governance considerations are required by the creation of such a record? How can communities navigate the risks and potential benefits of centralized, decentralized, or federated approaches to client data exchange?

Consent

The challenge of ethical management of consent for data sharing — especially through systems that integrate across institutional and technological boundaries — is particularly difficult. There is near-universal agreement that clients should have control over what information is shared with whom and in what context. There is not broad understanding, however, of the tradeoffs and tensions that make it difficult or even impossible to fully uphold such a principle.

We uphold the framework for "Consentful Technology" articulated by the Our Data Bodies project, which references the FRIES model as a set of principles as an ideal: Consent should be Freely Given, Reversible, Informed, Enthusiastic, and Specific. We know of few examples of data exchange systems that appear to achieve more than one or two of these criteria; we know of none that achieve all.

To the extent that consent challenges are technical — entailing cybersecurity and effective permissioning systems — there are some established frameworks such as HL7's Data Segmentation for Privacy and the All of Us consent protocol project by the National Institute of Health upon which CIEs can build locally-appropriate solutions. The Consent2Share project sponsored by SAMHSA offers a "proof of concept" implementation of these frameworks. In the UK, the concept of "dynamic consent" has been articulated in ways that hypothetically address the broader array of criteria for consentful data sharing. These frameworks should not, however, be considered mature.

Furthermore, there is very little understanding of the need to solicit and maintain *collective consent* of communities from whom data can be aggregated for the purpose of policy-making, resource allocation, and other matters pertaining to health equity. Communities should have meaningful control over how aggregate data is used to construct population-level representations and processes, such as structuring algorithms that might be used to allocate resources and make other kinds of critical decisions about who should have access to what under which circumstances.

Amid the vast array of regulatory, technical, and ethical challenges inherent in this problem, CIEs need to compensate for the ethical immaturity of consent frameworks through investment in the development of governing processes in which stakeholders – including both service providers and service users – are structurally empowered to co-design, monitor, audit, evaluate, and sanction the various methods of consent solicitation and preservation throughout the lifecycle of various projects conducted through the CIE. We will further explore this objective in the Community Data Governance section below.

OPEN QUESTIONS:

- *Opt In vs. Opt Out:* What kinds of activities should require users to actively agree to participate (i.e. "opt-in") and what kinds of activities should merely offer an option to "opt out"? Should these decisions be associated with different levels of permissiveness and sensitivity of the resulting data exchange and use?
- *Granularity:* How can users retain specific control over what kinds of data they do or do not agree to share, with whom, and for what purpose?
- *Comprehensive vs Comprehensible:* How will the CIE ensure that users are presented with an appropriate amount of context to inform their decisions? If a multi-page "Terms of Service" presents "too much information" to be properly understood, how will the CIE strike the appropriate balance between transparent and user-friendly?
- *Revocability:* How will the CIE ensure that consent is sustained over time and revocable as necessary? How can clients retain the ability to change their data sharing relationship with their providers and associated institutions over time?
- *Relational Data:* How will the CIE address the entanglement between one person's data and data about other individuals in primary, secondary, and tertiary relationship with them? How will consent to share be ethically managed among a connected cohort of individuals, families, caregivers, and communities?
- *Collective Consent:* How will the CIE solicit and sustain the consent of its community for data about the community to be extracted, used, and governed — especially for policy-making and resource allocation purposes?

Recommendations for Client Data Exchange

- Leverage data infrastructure already developed within healthcare — like HIEs, MPIs, and FHIR protocols — while recognizing their limitations across social services.
- Build complementary tools for social services that leverage the Gravity Project's codified terminologies of social needs, social risks, goals, and interventions.
- Require interoperability between referral platforms during the contracting process.
- Develop processes for facilitating semantic interoperability of client information shared across screening, case management, and referral systems — including shared taxonomies at large scales, and human resources for clarification, curation and alignment at local levels.
- Define the components of a referral record that are shared across providers, while recognizing the disconnects between transactional clinical standards on relational social services, and mitigating the risks of overriding the former by asserting the latter.
- Elevate the importance of client consent within CIE technology platforms and governance, prioritizing client data protection and control over institutional constraints.
- Place referrals within a broader context of shared activities needed for holistic, person-centered care management — some of which will resist uniform standardization, and instead require ongoing institutional collaboration.

Further Reading

- "Social Determinants of Health Data Interoperability, A Concept Paper from the National Alliance to Impact the Social Determinants of Health." Published by NASDOH, August 10, 2020. https://www.nasdoh.org/wp-content/uploads/2020/08/NASDOH-Data-Interoperability_FINAL.pdf
- "A Framework for Cross-Organizational Patient Identity Management." Published by the Sequoia Project, updated 2018. https://sequoiaproject.org/resources/patient-matching/
- "Enhanced Patient Matching Is Critical to Achieving Full Promise of Digital Health Records." Published by the Pew Charitable Trusts, October 10, 2018. https://www.pewtrusts.org/en/research-and-analysis/reports/2018/10/02/enhanced-patient-matching-critical-to-achieving-full-promise-of-digital-health-records
- *Sorting Things Out: Classification and Its Consequences.* Geoffrey C. Bowker and Susan Leigh Star. MIT Press: 1999.
- *Building Consentful Tech*, published by The Consentful Tech Project, Oct 24, 2017. http://www.consentfultech.io/wp-content/uploads/2019/10/Building-Consentful-Tech.pdf
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Community Data Governance

Objective: A CIE should ensure that the systems and activities associated with the coordination of social care are equitably developed and implemented according to expressed interests and active participation of stakeholders in a local community.

The final component of a Community Information Exchange — arguably the most important, most difficult, and least understood — is governance. We adapt our definition of "data governance" from Sage Bionetworks' green paper about data governance mechanisms:

Data Governance is the process of establishing and ensuring the freedoms, constraints, and incentives that determine how two or more parties agree to conduct the ingress, storage, protections, use, and egress of data, tools, methods, and knowledge amongst themselves and with others.

In the context of a Community Information Exchange, however, we also recognize that "data governance" itself ought to be considered a secondary component of an equitable governance process. Consider, in light of the definition above, the following questions: Which parties are involved? How did these parties come to be involved? Who represents the parties in decision-making processes? Who decides what decision-making processes will take place? What are the values and principles that guide all parties in the making of decisions pertaining to freedoms, constraints, incentives, etc.? How are criteria established by which these decisions will be evaluated? How might such agreements change as more parties enter into the process? What happens when everyone acts as they agreed but something still goes wrong?

The equitability of data governance is highly contingent upon the ways in which these and other questions are answered — which itself is highly contingent upon the ways in which these questions are asked — and these questions are about much more than data. All too often, however, governance is largely relegated to, and contained within, chains of "data use agreements" established (often bi-laterally) between parties — such as between a vendor and the institution that purchases its software, between the vendor and the users of its software, and between providers and their clients. This ad hoc approach to governance is a recipe for failure or, worse, unintended and even harmful consequences.

Legal agreements, like technologies, are most successful when designed to *reflect* the nature of existing relationships — not to determine them. So legal agreements, while essential, ought to be one of many *outputs* of governance processes, which themselves ought to be embedded within standing institutional arenas through which stakeholders establish context-specific arrangements that can evolve over time.

These arrangements ought to be designed to facilitate and preserve alignment among incentives and behaviors across multiple types of stakeholders. To the extent that institutions stand to benefit from improvements to the health and wellbeing of their clients, institutional interests can be aligned with the

interests of clients and their communities as a whole. But it would be a grave mistake to assume that such alignment occurs naturally through well-intentioned plans made in good faith – even when those plans are sealed by a contract that establishes compliance with all relevant legal frameworks. Agreements to share data through legally sound and highly secure systems can still yield significant harm to involved parties or others who are not even party to these agreements. Such risks are especially concerning in situations where there are significant asymmetries in power and information among stakeholders — such as asymmetries in resources between healthcare systems and community-based organizations or asymmetries in knowledge between lawyers, technologists, and service providers. As a result of these asymmetries, there are various risks of disconnection between the desired goals of technology-enabled interventions and their eventual results.

In order to mitigate these risks, a CIE's governance processes ought to be designed to deliberately build and carefully preserve trust. Community leaders and decision-makers need to develop methods for the participation of key stakeholders — especially service providers and help-seekers themselves — in processes of defining priorities, establishing agreements, monitoring activities, evaluating outcomes, and (re)making decisions. This entails thinking beyond focus groups and community visioning sessions. It requires processes of *institutional governance*, and processes of *administrative governance*, which then subsequently yield *data governance agreements*. (We further define these terms below.)

These processes are time- and energy-consuming by their very nature and must be resourced appropriately. The costs of development and maintenance of effective governance systems should be considered on par with a CIE's technology costs. Likewise, as much care should be dedicated to the process of monitoring data activities and enforcing data sharing agreements — and the process of improving those agreements over time — as to the initial set of agreements themselves. At the risk of stating the obvious, technology vendors should be subject to these processes — and therefore, responsibility for their facilitation should be held by some other established party or set of parties.

Some key objects of CIE governance have already been outlined above — including consent protocols, taxonomies and associated vocabulary management, resource data stewardship, and service provider participation. Each poses choices with various tradeoffs, which therefore should be subject to negotiation among stakeholders, with a commitment to equitable alignment of costs and benefits, as well as risk mitigation and prevention, reduction, and remediation of any harms that might result from CIE activities.

While creating an exhaustive list of governance considerations is unrealistic in this paper, we offer the following framework for communities to consider in the process of developing a CIE:

Institutional Governance includes the processes by which:

- "The Community" is constituted and represented
- Leadership is instituted, evaluated, and removed
- Priorities are set and adjusted
- Policy-making processes are established
- Outcomes are evaluated
- Institutional conflicts are faced and resolved

Questions to be asked within institutional governance processes include:

- ☐ **System Purpose:** Who is the CIE designed to benefit, and what outcomes does it aim to produce? What are the values and principles of this system?
- ☐ **Membership:** What does it mean to be "in" the CIE? What are the responsibilities of membership? What are the rights of membership? How does one join? How does one leave? Under what circumstances should members be expelled?
- ☐ **Decision Making Authority**: Who is able to determine the direction of the CIE and the result of questions or conflicts that arise? Who will decide who will have this authority?
- ☐ **System Funding:** Who supports the CIE financially and what impact will this have on systems design and incentive structures?
- ☐ **Incentive Structures:** How are providers and individuals incentivized to join or use the CIE, and where may these incentives present opportunities for, or barriers to, equitable service delivery?
- ☐ **Conflict Resolution:** How will we articulate, address, and resolve disputes? Who will solve problems that we can't?
- ☐ **Change Management**: How will we monitor, evaluate, amend, and enforce these agreements? Who participates in that process?

Administrative Governance includes the processes by which:

- Policies are designed, implemented, monitored, and enforced — including those pertaining to regulatory compliance
- A community's expressed interests and concerns are addressed through fair and enforceable rules and processes
- Operational standards are established
- Clients' rights are enumerated and processes are established through which those rights will be adjudicated

Questions to be asked within administrative governance processes include:

- ☐ **Referral and Care Coordination Workflows:** How does information flow from individual to provider and from provider to provider, and how are stakeholders expected to act upon that information?
- ☐ **Client / Patient Experience:** How do clients (/patients) experience the CIE and the providers in its network, and how does their experience inform CIE design and incentive structures?
- ☐ **Consent Management:** How do individuals give consent to share data and receive services from the CIE, and what happens if they deny consent or if their wishes are disregarded?

- ☐ **Service Provider Experience:** How do different types of health and social service providers experience the CIE differently, and what processes or incentives may be aligned to improve their experiences? How are service providers' needs articulated and addressed by the CIE?
- ☐ **System Monitoring and Evaluation:** Who monitors the ongoing performance of the CIE, how is it evaluated, and how do these processes account for equitability across the CIE's various stakeholder groups?
- ☐ **Harm Prevention, Reduction, and Remediation:** How are risks of potential harms identified, assessed, and mitigated? How can different stakeholder groups identify harms that do actually occur, and how can such harm be reduced and/or remediated?
- ☐ **Continuous Improvement:** How does the CIE make improvements over time based on client experience, service provider experience, and overall system monitoring?

Data governance includes the processes by which policies established through administrative governance are implemented — such as rules for data collection, management, storage, exchange, verification, validation, contestation, and deletion.

Questions to be asked in data governance processes include:

- ☐ **Standards:** What technical and operational standards are required? How will adherence to these standards be assessed and validated? What are the consequences for non-adherence?
- ☐ **Data Lifecycle:** What data is being collected about the individuals and providers who are using the CIE, and how is that data being managed and used over time? Under what circumstances and timeframe is data destroyed?
- ☐ **License:** Who has rights to do what with which kinds of data? Under which conditions? For what period of time?
- ☐ **Data Protection:** How are data about individuals and providers protected within the CIE, and what happens if such a protection is breached? How should these protections extend to data presented in aggregate for resource allocation, research, and planning purposes?
- ☐ **Technology Procurement:** What technologies most closely align with the governance decisions outlined above, and how can these affordances be instituted through the policies and processes of technology procurement – both for the CIE as a whole and for its members?

We encourage readers to add additional Community Data Governance items to the checklists above, as well as provide insight or examples regarding how these considerations were addressed in their communities.

These considerations should each be assessed through three separate lenses through which to gauge their impact individually and collectively: *Impact on Individuals* (clients/patients), *Impact on Service Providers* (such as CBOs), and *Impact on the Community* at large.

Impact on Individuals

It is increasingly recognized that the mental model by which individuals can and should "own" their own data is often impractical and in many cases can be paradoxically inequitable. This default mode of data governance through personal choice shifts a tremendous amount of responsibility to individuals – expecting clients (as well as care providers themselves) to be able to make informed decisions in extremely complex situations in which information about the implications of their decisions is likely to be either incomplete or overwhelming, if not both.

These choices are often framed simply ("opt in," "opt out") when the range of possible subsequent actions across various contexts may be both unpredictable and extended long into the future. Such binary consent does not provide an individual with significant agency in the process of determining what should or should not happen, and instead leaves individuals with only the options to "take it or leave it." Furthermore, especially in the context of social services, an individual's data is often entwined with that of family members, caregivers, and others in their community; one person's consent to share information about their household status, for instance, might affect others in the household without providing any method by which those others can themselves consent. Finally, the ability to access services may come to be contingent upon consent to share data — meaning such consent may not be freely or enthusiastically given.

Communities should beware of promises that technology will be "user-centered"; we must question the value of this phrase, especially when referring to *infrastructure* that enables many different systems serving many different kinds of users. Different users have different kinds of needs — and one system cannot "center" all of the different kinds of users in a community. Any number of prospective interests and concerns might fall outside of the scope of a given system's initial design considerations, complicating who is centered in which context at any given point in time.

For example, in one prominent case study about an HIE governance model, the HIE governing board reached a conclusion that the unexpectedly low level of participation from clients was due to the HIE's "opt in" method of soliciting consent; the board decided to change the model from "opt in" to "opt out." Accordingly, participation increased. This is described as a positive example of governance for the HIE, but it very well may be an instance of governance failure for users. When the consent method changed from "opt in" to "opt out," were any other measures of protection and constraint put in place to protect clients who were now more likely to share their data but less likely to consider the implications of sharing their data? Should there have been? The case study does not say; in fact, it does not address the question of ethics at all, and instead focuses entirely upon regulatory compliance. One can imagine either affirmative or negative arguments that could be made as to whether such a decision was "human-centered": the "opt-in" choice centers the human as a person who is especially interested in this decision, whereas the "opt-out" choice centers the human as a person with limited time and energy to make a decision that's presumed to be in their self-interest.

Rather than merely handwaving these serious tensions all away with a broad, misleading assertion that "individuals will own their own data," CIE proponents need to design institutional systems of trustworthy *data stewardship*. **Stewardship entails responsible management of data that the steward does not own.** We assert that the challenge of a CIE is to ensure that individuals do not have to assume the entirety of the responsibility of assessing the risks of various kinds of actions with regard

to shared data — even if they should have more control over their own information in many cases, including the management of consent over time. Instead, focus should be directed to designing a process through which responsible choices about people's data are collectively and accountably made by CIE stakeholders, including but not limited to individuals receiving services.

While technology cannot "center" every type of person, people can build institutional systems by which any given type of person's interests can be identified, evaluated, and addressed in accordance with common principles and fair processes. Community data governance entails the establishment of institutional responsibility for the interests of individuals whose data is subject to exchange and use across contexts. This might often involve deliberation over the implications of various methods of consent solicitation; some decisions about what can, should, must, or must not happen with people's data may be most equitably made on their behalf — without expecting individuals to be able to process all of the information and implications of data sharing on the spot. Such deliberation should also include methods of soliciting perspectives that are representative of different groups of individuals to develop these processes. An effective governance system would synthesize the outputs from such deliberation into decisions that weigh these priorities and account for their various trade-offs. Some potential governance models are discussed below, though each will need to be tailored to address the context and concerns of local communities.

Impact on Service Providers

In CIE discourse, it's commonly asserted that social service providers can benefit from participating in a CIE in various ways — such as access to data about community needs and the impact of their services as well as the prospect of reimbursement from healthcare payers for non-clinical services that demonstrably improve health outcomes (thereby reducing health payers' costs). It should be asserted, in turn, that these prospective benefits are hypothetical, uncertain, and projected across a long time horizon.

In the meantime, it also must be observed that there are real and near-term prospective costs for social service providers to adapt their processes in order to engage in CIE — even if the software being offered to them is "free." Those costs include time and energy for behavior change in the short-term and unknown additional costs in the long-term (such as the expiration of free software licenses in addition to various liabilities risked by new forms of data sharing and shifting funding structures in the wake of the CIE's development).

This does not mean that social service providers will refuse to engage (though some might). It does, however, mean that there is likely to be an imbalance in incentive structures (as well as power) between healthcare and social service providers in the CIE's development, and perhaps also among larger and smaller social service providers.

CIE governance models need to anticipate this imbalance — and design to correct for it.

For example, actors in the healthcare sector have strong incentives to demonstrate measurable impacts on health outcomes that yield financial returns on investment either in the form of generated revenue (like payer reimbursements) or reductions in expenditures — this is a value proposition that may be easily measurable in output even if not truly equitable in patient outcome. Meanwhile, value propositions for social services are not as clear. Social service providers want to positively impact the health and

wellness of their clients and communities, but much of their funding comes from grants and donations that are not on a fee-for-service or reimbursement basis. Even when social services do receive fee-for-service compensation, this compensation is often not enough to cover the full costs of service. As a result, an increase in referrals from healthcare providers (commonly cited as a primary objective by CIE proponents) might actually decrease social service capacity and/or burden them with medicalized frameworks of care that don't correspond with their often more relational, holistic approaches.

These power imbalances, often reinforced through misaligned incentives, can be addressed through effective governance that ensures social services have a central role in establishing CIE rules and incentives that account for their perspective and needs. There is at least some precedent for organizing governance through a membership association for CBOs such as "Independent Practitioner Associations" representing individual healthcare providers for collective bargaining with insurance companies like the Alliance for Better Health's Healthy Alliance IPA.

Impact on Communities

In addition to consideration of a CIE's impact on service users (clients) and service providers, effective Community Data Governance also considers the prospect of a CIE's impact on the community as a whole. How does the alignment of institutions through integrated technology systems affect, for example, the allocation of resources to different groups of people in a community?

Most data use agreements and consent procedures focus on personally identifiable data protected by HIPAA and other standards, but some of the purposes of many data sharing activities — especially in the context of CIEs — are about population-level concerns. Data sharing agreements frequently do not address the use of metadata, anonymized aggregated data, and algorithmic processes that may be applied in unanticipated ways — sometimes with harmful (even if lawful) effects. A broad array of literature and journalism has revealed the unexpected ways in which entire groups of people are disadvantaged when data about their respective individuals are aggregated and used through algorithmic decision-making processes that might replace or overrule other more human (and therefore accessible) processes.

Communities as a whole may only realize after the fact (if they realize at all) that aggregated data from a given program may be used to make decisions on their behalf about resource allocation, risk adjustment, etc. — meaning that the aggregate effect of individuals' shared data may pose a risk to collective autonomy and dignity. Furthermore, correlation across datasets may mean that the aggregate effect of data gathering among consenting families may in turn generate contextual inferences about non-consenting families. Thus, data shared by a consenting set of individuals may adversely impact some other non-consenting set of individuals.

These problems cannot be addressed at the level of individuals and their private choices. Given that health equity is to some degree a function of collective well-being, CIEs need to design mechanisms for monitoring the use of aggregated data, assessing the impacts of that use, and making and enforcing rules that preserve the communities' related interests and agency.

Moving Community Data Governance Forward

The considerations outlined above do not have clearly established or simple models for redress, but must be grappled with across a CIE's development cycle. Tensions between individual, provider, and community interests will likely remain present — and likely should remain present — due to changing local conditions, emergent policy constraints, and the complexity of human and institutional systems of care. Other resources like CHOIR's Accountable Communities for Health Data-Sharing Toolkit outline additional approaches to community data governance that can also be engaged; there are a variety of productive approaches to wrestling with governance considerations within a local CIE.

Whatever the approach, however, we believe that Community Data Governance must go far beyond the "secure data systems plus informed consent" model that is frequently implemented through legal agreements. The larger questions outlined above — *what data should be collected in the first place, according to whose interests, and under what oversight?* — must be addressed for CIEs to avoid unwittingly creating or concealing power imbalances or erasing important community context and lived experience. Being able to share data legally (and technically) does not automatically ensure that data will be shared ethically and equitably.

Some legal frameworks, however, are emerging to close gaps between legal parameters and equitable decision-making. One of the most promising is that of a Data Trust, which can structure how a community places their data and data rights under the control of a trustee or board similar to the structure of a Community Land Trust. The particulars of Data Trusts vary depending on the context and intent of an initiative, though they nonetheless provide a structure for the type of holistic data governance outlined above where many stakeholders come together to balance their shared data interests as a collective. Some organizations, like BrightHive or DigitalPublic, can help communities establish their own Data Trusts — though the concept is still relatively new and many critical details will need to be explored within the local context of a CIE.

Recommendations

- Recognize that equitable Community Data Governance goes far beyond the establishment of fair data sharing agreements.
- Governance must include ongoing institutional processes with all impacted stakeholders, including structured leadership roles for clients/patients who are accessing services.
- Data governance should receive as much investment of resources and duty of care as the data and technology systems to be governed. Monitoring and evaluation of data use agreements should receive as much attention and care as the initial design of those agreements themselves.
- Decision making will require tradeoffs that should be negotiated through the equitable alignment of incentives, with provisions to mitigate the risk of harm however possible.
- Consider a framework such as a Data Trust and/or membership association as a legal and fiduciary vehicle for governance.

Further Reading

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- *Race After Technology*, Ruha Benjamin. Polity: 2019.
- CHOIR's Accountable Communities for Health Data-Sharing Toolkit

In Summary: *Community Information Exchange* is a Verb

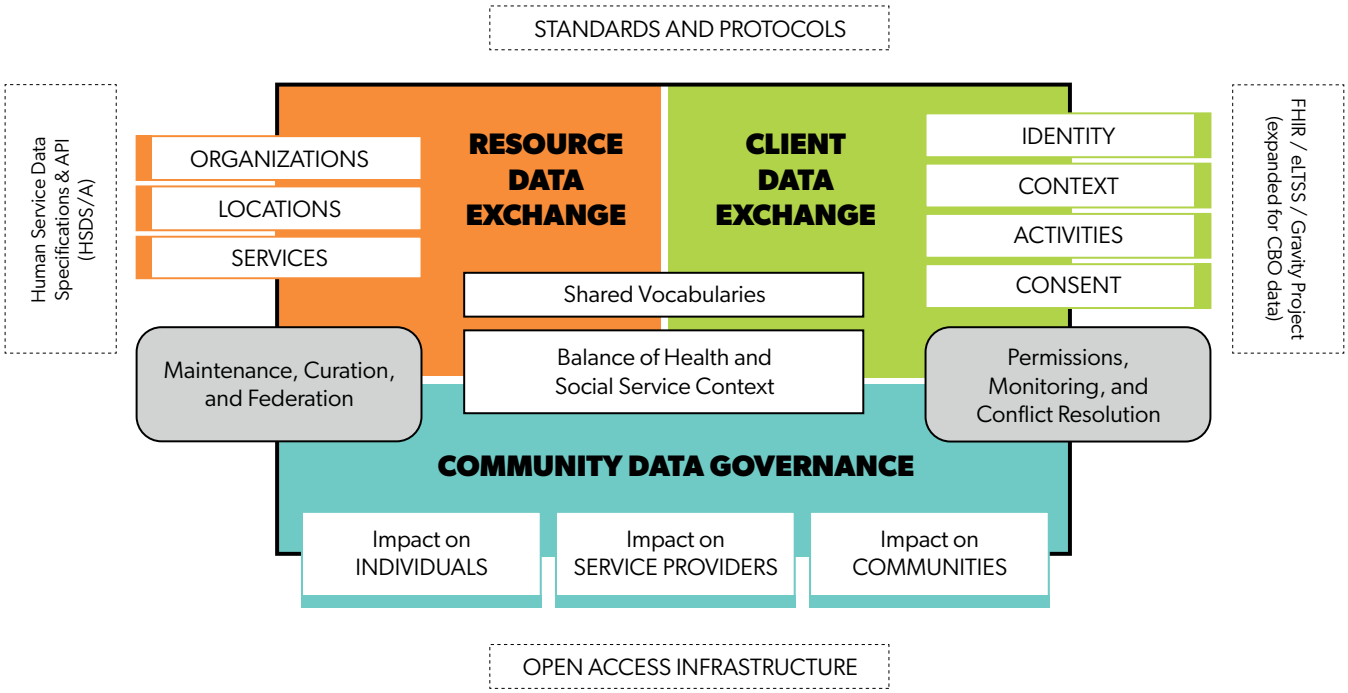
In this paper, we've explored a range of challenges and opportunities that present themselves to communities that seek to share health and social care information among providers, help-seekers, and stakeholder institutions. We've outlined a set of interlocking functions that are implicit in the concept of a "Community Information Exchange" — specifically, infrastructure that facilitates the exchange of information about community resources and information about people ("clients"). The set of emerging standards identified in this paper can make it significantly easier to achieve technical interoperability of data exchange in each of these domains.

We've also argued that some critical challenges for CIEs may not be technically solvable at all — such as challenges of semantic interoperability among diverse vocabularies and challenges relating to consent. This is not to say that communities cannot effectively cope with these challenges, but rather to emphasize that technology is a secondary or even tertiary consideration after the primary concerns of community governance. Equitable and sustainable decisions about technology and data can only be made after questions about power and accountability have been appropriately asked and satisfactorily answered among stakeholders and beneficiaries. We offer these final summary recommendations — and encourage you to share your own experiences so that these insights can evolve over time across the health and social care landscape through the "living paper" at: bit.ly/socialcaredata.

- Shift away from thinking of a CIE as an "SDOH solution." A CIE is not a solution; it's a context in which communities can work together to design solutions.
- Likewise, do not assume that enabling "closed-loop referrals" will "solve for SDOH." This shorthand jargon can obscure a broad array of value propositions, as well as challenges and risks, posed by the many kinds of collaboration that can be enabled through interoperability. One kind of use case entails "making a referral" and "closing the loop" — but there are many others.
- Understand that a successful CIE may have to tackle different problems that each require different strategies — and likely need to be engaged by different people and managed with different technologies.
- Shape the market to encourage cooperation and interoperability by requiring these qualities as a cost of doing business — mandate the use of open standards for data structure and exchange as a condition of contracting. By requiring open standards as a procurement policy, institutions can preserve freedom of choice in the market and work toward interoperability at scale.
- Start small and stay iterative — design your initiatives to learn and change over time, and start by focusing on simple problems before trying to develop complex systems.
- Build upon what already exists whenever possible and appropriate. For resource information, develop partnerships with those organizations that already maintain resource directories in a community, and design strategies that align their interests with the broader ecosystem — rather than competing with them. For client information exchange, explore the potential to leverage existing infrastructure like HIEs.

- Prioritize the capacity of the people (community members and care providers) who power the CIE — including their labor of maintenance, translation, monitoring, assessment, deliberation, and decision-making. Technology can facilitate these efforts, or, if deployed with the goal of circumventing the need for such human capacities, it can easily get in the way.
- Consent is primarily a social problem that requires institutional solutions. Regulatory compliance is a secondary attribute of "consentful" technology; exchanges of personal information *must* be legal, but this alone does not make them ethical and responsible. Security systems are a tertiary attribute of "consentful" technology; well-designed tools can be badly used and cause harm, so prioritize the context in which a tool is used and the practice in which it is used. The ethics of data collection, exchange, and use are extremely context-dependent — which means they need to be considered by humans in social contexts.
- Governance systems should be designed with community stakeholders' priorities and perspectives as the primary input. Data governance agreements are merely one output of institutional and administrative governance processes.
- Intermediaries need to be held accountable through each phase of the project's lifecycle. Put as much care and effort into developing capacities for monitoring and evolving agreements over time as is put into designing the initial agreements themselves. Anticipate that things will go wrong and have a plan for equitable harm reduction and remediation.
- Each community is different — while infrastructure and standards can be open and shared, they cannot replace the community-driven processes needed to establish an equitable and sustainable Community Information Exchange.

Primary Components of "Community Information Exchange"



Case Study

Developed in Collaboration with Ben Cooper, St. Louis Regional Data Alliance

St. Louis Community Information Exchange

To illustrate how the recommendations above play out in practice — as well as the remaining tensions that still need to be resolved — we are including a short Case Study documenting the development of the St. Louis Community Information Exchange, an emerging effort led by United Way 2-1-1 and a variety of partners to "to share information and coordinate efforts to maximize resources in the delivery of holistic, person-centered care." The St. Louis Regional Data Alliance (RDA), one of the authors of this paper, is helping facilitate this initiative alongside United Way of Greater St. Louis and the St. Louis Integrated Health Network (IHN).

Origin and Development

In 2016, IHN convened local healthcare, behavioral health, and social service partners (including United Way 2-1-1) to apply for a Federal Accountable Health Communities grant — focused on holistic care coordination as a vehicle to address systemic health and racial disparities as highlighted in the work of Forward Through Ferguson after the killing of Michael Brown. While the grant application was not successful, this partnership has evolved into the St. Louis Community Information Exchange over the past four years. Exploration of the CIE model (inspired by San Diego) officially kicked off in June 2018 led by United Way 2-1-1, with a cross-sector steering committee and detailed exploration of best-fit technology platforms. The RDA was an early thought partner in the CIE's development focused on data and technology capacity. The St. Louis CIE is now a collaborative multi-stakeholder initiative which is currently exploring sustainable operational models and institutional forms. Alongside a core team made up of committed service providers, healthcare, and academic partners, the CIE is fiscally sponsored by United Way as the "lead backbone" and is bolstered by the St. Louis Regional Data Alliance and the St. Louis Integrated Health Network as "support backbones."

In early 2020, the CIE team was preparing to launch its next phase, including an RFP for a referral technology platform and a transition into long-term governance structures, when the COVID-19 pandemic hit. A group of funders and partners challenged CIE leadership to respond to the urgency of the crisis by selecting a referral platform that was ready to deploy. The CIE team chose Unite Us as the platform that seemed to most closely align with the scope of St. Louis' technology needs, as well as their eagerness to partner with St. Louis in exploring needed enhancements to their platform. Unite Us went live in St. Louis in late August 2020 as a "rapid response" pilot to help manage CARES Act emergency housing funding distribution in St. Louis City and County. Throughout 2021, the CIE has been working to onboard a broader spectrum of health and social care service providers, develop more robust governance structures, and conduct deeper community engagement.

Resource Data Exchange

2-1-1 led the development of the CIE concept with a recognition that offering telephone referrals and a web directory alone was not enough to deliver holistic, equitable care across a broad swath of needed services. Local coalition partners also recognized that 2-1-1 is the most significant piece of resource data infrastructure in the St. Louis Region as well as the State of Missouri, maintaining information for nearly 25,000 services across 99 counties.

2-1-1 uses Wellsky as its Information and Referral technology backbone, which uses the 2-1-1 Taxonomy and recently adopted the Human Service Data Specifications and API (HSDS/A) to facilitate interoperable resource data exchange. Significant questions remain around how 2-1-1 resource directory data can be seamlessly integrated with the Unite Us referral platform – and, relatedly, how this partnership can be mutually beneficial with shared funding and staff time. Resource listings are not currently exchanged between Wellsky and Unite Us, presenting a potential duplication (and inconsistency) challenge for social service and health providers. These challenges may lead to a higher cost of resource data upkeep and alignment for 2-1-1 with the potential to further fragment resource data instead of positioning 2-1-1 as a trusted resource data utility. St. Louis is in the process of learning from models like in North Carolina that successfully aligned data across 2-1-1 and referral platforms.

At the moment, Unite Us is currently the only referral platform with significant adoption in the St. Louis region (though a number of additional platforms have taken root across Missouri) — and 2-1-1 holds a strong central presence as the most prominent I&R platform in the state, with cooperative relationships with adjacent systems like Behavioral Health Response. However, this advantage may not continue as additional health systems pursue technology platforms (referral and analytic) to address population health, including those covered by 2-1-1 in other parts of Missouri.

Client Data Exchange

Because St. Louis is in the early stages of CIE formation, it has not yet encountered some of the Client Data Exchange challenges outlined above. Unite Us was launched only with community-based organizations in St. Louis instead of its typical approach of contracting with healthcare providers or payers — its first such implementation. (Local healthcare providers joined the CIE in early Fall 2021, though the CIE leadership team hopes to maintain a CBO-centered approach long-term.) All client data is currently contained within Unite Us and governed by its internal data storage and protection protocols. However, this reality will quickly change as more data is able to be shared across Unite Us, EHRs, and social service data systems — leading to governance and ethical considerations around who has access to what data for which purpose across the CIE.

New questions emerge each week about how to best facilitate exchanging client data to meet the many goals, concerns, and parameters of CIE partners. CIE leadership is pursuing at least two potential solutions to address key challenges. First, it is exploring relationships with Health Information Exchanges in Missouri to help facilitate data sharing between the CIE and healthcare institutions, particularly by utilizing their Master Patient Index and protocol for data exchange. Second, it is working to clarify,

extend, or even in some cases create client data standards within social service subsectors — starting with case management systems for older adults and the unhoused — that can facilitate interoperability while avoiding costly (and time-consuming) manual connections between fragmented data systems. This work is also being supported by the ACL's Social Care Referrals Challenge, where both the RDA and Open Referral are active participants.

In current data exchange configurations, consent solicitation currently defaults to policies set by Unite Us, which offers clients a binary point-in-time opt-in decision to allow their providers to share their personal information with another provider that is subject to HIPAA-compliant protections. The CIE Leadership Team believes that the consent and permissions management framework should be more nuanced and dynamic for individuals sharing data with the CIE, such as granular controls and revocability for at-risk individuals and sensitive service areas like domestic violence and behavioral health. While some early conversations with Unite Us seemed to highlight an interest in enhancing consent management features, they do not seem to be prioritized as their platform rapidly expands — a concern that the CIE Leadership Team will continue to monitor and push on over the coming year.

Community Data Governance

The CIE Steering Committee and Leadership Team that emerged over the past two years has strong representation across health and social service providers as well local funders and support organizations like the RDA. The fast-moving development of the CIE due to COVID, however, necessitates additional governance considerations that are actively being explored and implemented. The St. Louis CIE strives to embrace the broader definition of Community Data Governance outlined above that extends beyond legal agreements and technology platforms. However, the recent focus on launching Unite Us during a pandemic can make it difficult to consider the full range of CIE data governance priorities outside the implementation of this specific technology.

Most of the considerations outlined above remain active conversations — particularly around long-term system funding, data ownership, access, and usage, and improving CIE practices based on new information. The CIE is also exploring how to build an intentional leadership structure for clients that elevates their experiences and concerns given their central importance in establishing an equitable and effective CIE, as well as a potential role for community health workers to serve as a dedicated bridge between service providers and the clients they are ultimately accountable to. The CIE is also dedicated to retaining local governance even as Unite Us and others make a statewide (and national) push to stand up care coordination networks — recognizing that the unique dynamics, challenges, and lived experiences of people in the St. Louis region cannot be equitably addressed by a one-size-fits-all approach.

Next Steps

The St. Louis Community Information Exchange continues to evolve — particularly as Community Data Governance and Client Data Exchange considerations expand alongside its user base of providers and clients. The St. Louis Regional Data Alliance is happy to answer any additional questions about our work-in-progress alongside United Way 2-1-1, the Integrated Health Network, and the CIE Leadership Team — please feel free to reach out anytime to rda@umsl.edu.

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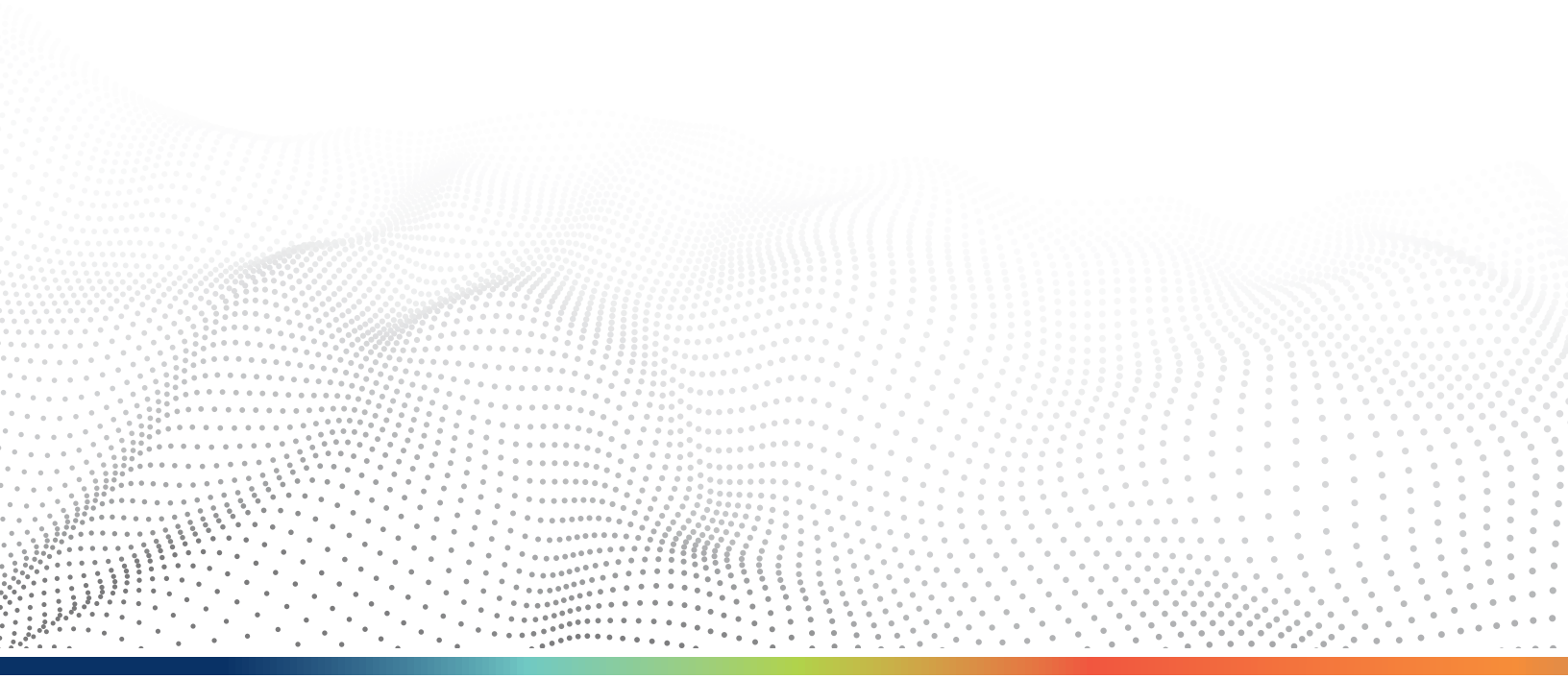

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