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HOW TO SHARE DATA:
Practical Guide
for Health
and Homeless
Systems of Care

AUTHORS

Lauren Larin, PhD, and Julie Silas, JD, Homebase



CHCF

The Authors

Lauren Larin, PhD, is a directing analyst, and Julie Silas, JD, is a directing attorney at [Homebase](#), a nonprofit of legal, policy, and subject matter experts who work at the community, state, and national level to build capacity and develop and implement effective programs and systems to prevent and end homelessness. The content in this report is provided for informational purposes only and does not constitute legal advice. Homebase does not enter into attorney-client relationships.

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The Foundation

The [California Health Care Foundation](#) is dedicated to advancing meaningful, measurable improvements in the way the health care delivery system provides care to the people of California, particularly those with low incomes and those whose needs are not well served by the status quo. We work to ensure that people have access to the care they need, when they need it, at a price they can afford.

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Table of Content

| | | |
|-----------|---|------------------|
| 01 | Introduction | <u>4</u> |
| 1.1 | Alameda County | <u>6</u> |
| 1.2 | 211 San Diego | <u>7</u> |
| 1.3 | Benefits of Cross-Sector Data Sharing | <u>9</u> |
| 1.4 | Practical Tips for Cross-Sector Data Sharing | <u>11</u> |
| 02 | Data Sharing Agreements | <u>19</u> |
| 2.1 | Process for Developing the Data Sharing Parameters | <u>20</u> |
| 2.2 | Engage Legal Counsel | <u>23</u> |
| 2.3 | Scope of Data Shared | <u>24</u> |
| 2.4 | Data Sharing Rules | <u>28</u> |
| 2.5 | Elements to Communicate Through a Data Sharing Agreement | <u>30</u> |
| 03 | Client Consent and Release of Information | <u>33</u> |
| 3.1 | Key Elements to Obtaining Client Consent | <u>34</u> |
| 3.2 | Key Questions for Designing Client Consent Forms and Process | <u>36</u> |
| 04 | Understanding Technology Considerations | <u>37</u> |
| 4.1 | Establish Potential Use Cases | <u>38</u> |
| 4.2 | Tools to Facilitate Cross-Sector Data Sharing | <u>40</u> |
| 4.3 | Tips for Scoping a Technology Build-Out | <u>46</u> |
| 4.4 | Technology Development Steps and Processes | <u>48</u> |
| 05 | Different Approaches: Alameda County and 211 San Diego | <u>50</u> |
| 5.1 | Alameda County and 211 San Diego | <u>51</u> |
| 06 | Endnotes | <u>54</u> |

Introduction

This practical guide is intended to serve as a tool for communities at any stage of engagement in cross-sector data sharing between health and homeless systems of care. It is designed to help communities ready to start such efforts for the first time, as well as those that have room to grow their data sharing efforts. It is not intended to be a set of step-by-step instructions but rather focuses on providing practical tips for some of the more challenging components of robust cross-sector data sharing.

The guide is a follow-up to the report [Breaking Down Silos: How to Share Data to Improve the Health of People Experiencing Homelessness](#),¹ published in July 2021, which provides deeper background regarding the context and challenges of data sharing and lays out efforts underway to collaborate in many California communities.

The authors hope organizations and agencies across the state will use the guide to start or enhance their data sharing efforts. With focus and planning, cross-sector data sharing can facilitate more robust and effective responses to ensure that people with complex care needs can become stably housed and remain healthy. There is no templated approach to cross-sector data sharing that will work for all communities. Each community has unique partnerships, infrastructure, policies, and procedures that need to be considered when developing data sharing efforts. However, lessons learned from communities that have already implemented data sharing can guide others' efforts.

What is “cross-sector data sharing”? Historically, agencies and organizations have been siloed, working to promote housing or health care without recognizing or addressing that they may often be working on behalf of the same clients or patients. They collect information about their clients or patients separately. They analyze and report about their experiences separately. In the past few decades, efforts have been made to share data among similar organizations within sectors using shared or like technologies. The most well-known is the health care sector's commitment to electronic health records that allow data sharing between hospitals, physician offices, pharmacies, and health care organizations. Patients have become accustomed to having practitioners at different facilities open their computers to see what medications the patient has been prescribed or to read about a patient's medical history from when they were under another provider's care.

Introduction (cont.)

Data sharing across different sectors, however, has been embraced more slowly by some care systems. Often it is due to different legal, technological, historical, cultural, and disciplinary approaches to how each sector collects and analyzes data. Throughout this guide, the authors focus on cross-sector data sharing — encouraging agencies and organizations that work in the health and homeless systems of care to break down the silos and collaborate to better serve their clients and patients.

Throughout the guide, two cross-sector data sharing efforts will be highlighted, both in California: Alameda County and 211 San Diego. Each approach is unique — although there are some similarities between the two communities, there are some significant differences. The authors hope that information about what each community has undertaken can help others develop their own data sharing efforts to respond to their local conditions.

INTRODUCTION

1.1

Alameda County

Alameda County's cross-sector data sharing efforts started at the government level in the county's Health Care Services Agency (HCSA), which sought to better serve the thousands of people with complex care needs and those experiencing homelessness across the county, as part of their Whole Person Care (WPC) Pilot program.² They recognized that many of the people with complex care needs were experiencing homelessness and of those, many had unidentified or unaddressed needs.

With funding from the WPC Pilot program, Alameda County dedicated its efforts to develop a robust cross-sector collaboration between the health agency and other local partners serving people with complex needs. One tool they developed was a shared [Community Health Record \(CHR\)](#),³ which provides a curated and real-time view of events and developments in clients' experiences within the health and homeless systems of care. The CHR draws data from a central repository and allows providers to view a thin slice of information on client utilization, diagnosis, and information about who may be working with a client.

For the CHR to be able to securely collect and integrate people's medical, mental health, housing, incarceration, crisis response, and social services information in a way that allows collaboration across different agency and organizational partners, Alameda County established the Social Health Information Exchange. The SHIE is a central repository that stores data from an ever-growing list of partners, allowing the data, under all relevant privacy rules, to be accessible across many local sectors. The SHIE keeps data secure, manages who can see what, and matches identity when different data streams describe one person. The SHIE enables partners to conduct cross-sector care coordination and has an alert system that notifies participating providers when their clients are admitted to the emergency department or as an inpatient or booked into jail, as well as when they are discharged from the hospital or released from jail, helping ensure providers don't lose track of their clients over time.

INTRODUCTION**1.2****211 San Diego**

The San Diego [Community Information Exchange \(CIE\)](#)⁴ first focused on centering the patient and coordinating care across sectors for those experiencing chronic homelessness in an urban setting who were identified as frequent utilizers of costly health care and public safety programs. Unlike in Alameda County, the San Diego effort began outside the government, rooted in local community-based organizations. The CIE was originally funded by a local private foundation.

While the CIE began as a direct response to meet immediate needs as seen by on-the-ground providers, it has since turned into an elaborate case coordination and collaboration system that allows information sharing, referrals, and prioritization of care. The CIE began with a cohort of homeless service providers, then expanded to senior services, veterans organizations, and others. It now involves health care organizations including health plans, hospitals, and Federally Qualified Health Centers, San Diego County’s Health and Human Services Agency, individual cities, and other social service organizations and faith-based organizations that focus on issues ranging from food insecurity to transportation needs.

The CIE enables communities to have multilevel impacts by promoting proactive, holistic, person-centered care. At its core, the CIE centers the community to support anti-racism and health equity. Recently, 211 San Diego released an updated guide for using shared data to analyze the system, which addresses some of the equity issues they are focusing on.

Like some information and referral (I&R) platforms, the CIE has closed-loop referral capacity. But that is only one component of the CIE. In addition to being a referral platform, the CIE contains a single longitudinal record used for care coordination. It includes referral history, but it also offers other critical core components, including client demographics, care team information, assessment documentation, proactive alerts, and risk scores. Core to the CIE is data integration — the CIE’s person-centered record is populated by information from other data systems (like the Homeless Management Information System and clinical electronic health records). The “community” in CIE is critical — it’s built, owned, and governed by the community, not a software vendor or one health care system. San Diego is home to seven Medi-Cal health plans, each using multiple I&R platforms. The CIE integrates with those I&R platforms to streamline workflows.

Table 1. Components of Cross-Sector Data Sharing Efforts

| | Alameda County | 211 San Diego |
|--------------------------------------|---|---|
| Lead Entity | Alameda County Health Care Services Agency | 211 nonprofit |
| Cross-Sector Focus | Health care and homelessness | Health care and homelessness |
| Local Pilot Program | Whole Person Care (2015) | Project 25 (2011)* |
| Legal Experts | Outside privacy implementation specialist and county counsel | Outside privacy attorney and chief information security officer |
| Decisionmaking | Data Governance Committee composed of leadership officials representing each participating organization/sector | Community Advisory Board that reports to the lead agency’s board of directors; lead agency in consultation with participating agencies; and advisory groups as needed |
| Release Of Information | Information sharing authorization | Client authorization (release of information) |
| Agreements And Other Policies | Data sharing agreement, data privacy management plan, governance committee charter | Data sharing agreement, network participation agreements, business associate agreements, governance charter |
| Expansive Partnership | Health Care Services Agency, Continuum of Care (CoC), homelessness, behavioral health, public benefits, criminal legal system, homeless service providers | Hospitals, Federally Qualified Health Centers, CoC, city services, homeless service providers, county Health and Human Services Agency, social services providers, faith-based agencies |

Sources: Alameda County, 211 San Diego

* Lynn Reaser et al., [Project 25: Housing the Most Frequent Users of Public Services Among the Homeless](#) (PDF), San Diego Housing Commission, April 2015. See also “[San Diego County-Project 25](#)” from the Institute for Local Government.

INTRODUCTION

1.3

Benefits of Cross-Sector Data Sharing

Cross-sector data sharing provides each partner with greater insight into their shared clients' needs as well as the services their clients and patients seek and receive in systems other than their own. With the increased visibility, the culture of service delivery begins to shift away from the notion that a person “belongs to” a particular department or set of providers and toward a notion of collective, shared responsibility for each person. That cultural shift benefits both the people needing housing and health care resources and the systems set up to serve them. By focusing on the benefits to clients, partners can make the connection between the technical aspects of the work and the efforts to improve client experience and to achieve buy-in from stakeholders.

Engaging in cross-sector data sharing can create a strong collaboration that will:

- Build trusted partners to call upon to discuss a client's case
- Allow for coordinated care, providing varied sources of information and professionals collaborating to develop care plans for people with more complex care needs
- Increase the community's ability to address social determinants of health by beginning to address the impacts of poverty through greater collaboration and coordination across agencies
- Support higher-quality decisionmaking, which results in more accurate prioritization, greater accountability, and strong interdepartmental structures
- Result in better policies and strategies by building more comprehensive data sets, allowing for cross-system data analytics that can identify patterns, gaps, and system issues across the two sectors
- Develop administrative efficiencies to help maximize resources, braid funding from disparate sources, and build bridges across sectors
- Advance screening and prioritization of services for people with mental health and substance use disorders
- Provide an effective system that providers can use to locate patients for follow-up medical treatment or to notify providers when their patients are at the top of the waiting list for housing
- Enable providers to effectively advocate for housing for people with complex or severe medical conditions
- Facilitate access to clients' public benefits information (e.g., CalFresh, CalWORKS, Medi-Cal), which can identify individuals and households entitled to additional benefits but not enrolled
- Obtain more robust health information to help with prioritization decisions in the homeless system of care's Coordinated Entry System
- Create stronger systems to respond to emergencies like the COVID-19 pandemic

1.4 Benefits of Cross-Sector Data Sharing (cont.)

BENEFITS OF CROSS-SECTOR DATA SHARING FOR CLIENTS AND PATIENTS

1. Allows for warm handoffs between different agencies and systems, especially compared to traditional referral options that require people with complex care needs to follow up and make the connections on their own
2. Makes it easier to learn about other service options, as trusted clinicians and social workers have more understanding of available resources in other systems
3. Reduces the time, energy, and resources people expend repeating information, providing duplicate documentation, and being responsible for communicating between service providers
4. Increases the likelihood that people can access needed health care resources quickly and easily, reducing emergency department visits and hospital stays
5. Expands the community of providers supporting clients to access and retain stable housing
6. Allows for trauma-informed care for clients to allow them to share their histories but also to reduce the need to retell their stories repeatedly and recount their traumas

INTRODUCTION**1.4****Practical Tips for Cross-Sector Data Sharing**

The guide focuses below on some of the more complicated aspects of data sharing: introduction of a data sharing agreement, obtaining client consent, and developing technologies that enable cross-sector data sharing. Before diving into those areas, however, the guide lays out some steps to consider when planning cross-sector data sharing efforts:

1. **Build a cross-sector leadership team**
2. **Define clear expectations and goals for the collaboration**
3. **Engage people with lived experience of homelessness**
4. **Plan for data collection, evaluation, and analysis**

1. BUILD A CROSS-SECTOR LEADERSHIP TEAM

The composition of a cross-sector leadership team can be a key driver of success or a barrier to moving forward.

When developing the leadership team, it is important to be clear about who should be at the table for initial conversations. The team will vary based on the local community, the community's strengths, and the roles needed from each stakeholder group. Recognizing that initial plans may expand, and roles may change as the project moves from planning to implementation to ongoing operations, it is worthwhile to spend time developing a vision for a multidisciplinary team that will engage key decisionmakers and people with expertise across the sectors.

1.4 Practical Tips for Cross-Sector Data Sharing (cont.)

Here are some fundamental considerations for building the team.

FUNDAMENTAL CONSIDERATION 1 | Define the team

1. Identify leaders from different sectors familiar with the critical needs of residents experiencing physical and mental health challenges, economic uncertainty, homelessness, housing instability, substance use disorders, criminal legal system engagement, and social inequity.
 - a. Build a team that includes people with expertise on privacy, data sharing, and technology systems.
 - b. Add people with lived experience of homelessness and people with complex health needs to the leadership team who can help ensure that client- or patient-facing materials, trainings, and releases of information are clear, concise, and strategic.
3. Make sure there are team members who can advocate internally and with the community, identify executive sponsors or champions from partner organizations, and bring in additional supporters and resources as the project grows.
4. Keep the size of the team manageable: no more than 8 to 10 initial participants. As the work grows, the team can expand through committees, and even the leadership team can grow, if warranted.
5. Define roles of the leadership team and stakeholder partners, including consideration of whether they are voting decisionmakers, advisors, or something else.

1.4 Practical Tips for Cross-Sector Data Sharing (cont.)

FUNDAMENTAL CONSIDERATION 2 | Establish policies to govern the collaboration

1. Identify the resources each organization or agency has available to support staff time to engage in the collaboration. Consider equity across organizational size, capacity, and level of efforts on this project.
2. Establish norms and communication preferences that will guide the cross-sector data sharing efforts to ensure the collaboration is effective.
3. Create clear and regular mechanisms for communicating and obtaining feedback from the larger community of stakeholders.
4. Create a charter that defines the scope of the collaboration, which will help define the governance structure, roles of partners, and decisionmaking process.
5. Establish a governance structure that designates administrative or other staff who can carry out the day-to-day tasks of running the data sharing system.
6. Develop data sharing agreements, data use agreements, and/or memoranda of understanding.

STAKEHOLDERS AND GOVERNANCE MODELS

If stakeholders are county departments that take direction from board of supervisor priorities, an authorizing resolution can create a formal workgroup that supports each department in dedicating resources for the project. Alternatively, if the stakeholders are largely nonprofit partners, a more distributed model of shared direction and decisionmaking may be more appropriate.

1.4 Practical Tips for Cross-Sector Data Sharing (cont.)

2. DEFINE CLEAR EXPECTATIONS AND GOALS FOR THE COLLABORATION

Spending time up front setting clear expectations and goals can ensure shared understanding across all partners.

Stakeholders will likely have differing preconceived notions of what a cross-sector data sharing project will entail. Successful projects often find that the initial goals and scope may evolve over time. The evolution is important and useful. As stakeholders come together to share information, learn about partnering systems' needs and capacities, and uncover both challenges and opportunities, new ideas will emerge.

Fundamental considerations for defining clear goals and expectations include:

1. Determine if the community already has cross-sector collaboration or data sharing efforts in place that can be built upon, rather than starting from scratch. Are there existing programs that:
 - a. Focus on social determinants of health?
 - b. Participated in California's Whole Person Care Pilot projects?
 - c. Have agencies or organizations in the community already started sharing data? If so, what governance structures and policies are in place to guide the new collaboration?
2. Identify which agencies or organizations will be involved in addition to health and homeless systems of care.
3. Create primary goals for the data sharing effort, not only to ensure everyone is on the same page, but also to be able to measure success. Keep goals to no more than three to five.
4. Record goals in governance documents and review periodically as the project evolves.
5. Remember that flexibility, creativity, and adaptability are key elements of a successful project.

1.4 Practical Tips for Cross-Sector Data Sharing (cont.)

SAMPLE GOALS: CROSS-SECTOR DATA SHARING

- ▶ Enable/improve cross-sector care coordination
- ▶ Automate housing resource matching
- ▶ Provide care workers with a 360-degree view of a person's interaction with the care system across all sectors (e.g., services provided, care plans, and a timeline view to chart changes in need over time)
- ▶ Share outcomes
- ▶ Participate in community planning based on comprehensive data and identified unmet needs
- ▶ Create a technology platform to maximize resource utilization
- ▶ Decrease duplicate intakes and assessments
- ▶ Reduce the burden on people with complex care needs by minimizing the number of times and settings in which they have to share their stories
- ▶ Streamline referrals and better coordinate case management

1.4 Practical Tips for Cross-Sector Data Sharing (cont.)

3. ENGAGE PEOPLE WITH LIVED EXPERIENCE OF HOMELESSNESS

Robust data sharing efforts between health and homeless systems of care are strongest when they integrate the perspectives, priorities, and concerns of people with lived experience of homelessness and people with complex health needs.

Engaging people with lived experience of homelessness ensures collaborations are client-centered. They can help decisionmakers get information about the more needed or harder-to-find services in the community. Their involvement can facilitate identification of problems at the source on a programmatic level that might be difficult for providers to get at otherwise. They can build greater trust and increase the likelihood that clients are comfortable providing consent to share data. They can contribute to ethics conversations about benefits and possible harms in data sharing between health and homeless systems of care. Their involvement helps to create a framework that is empowering rather than paternalistic. They also help to identify language that can be triggering so that the content can be framed differently.

There are a few important considerations that can ensure people with lived experience can participate fully in designing cross-sector data sharing efforts.

- ▶ Compensate people for the time they are participating.
- ▶ Hold meetings, events, or review opportunities during different times of the day, not just traditional work hours, to accommodate people who have jobs, are in school, or who have other daytime activities.
- ▶ Take into account transportation barriers when determining where and when to hold in-person meetings.
- ▶ Take into account any technology limitations (e.g., ask participants if they have access to a computer, mobile device, unlimited data plan) to ensure people can fully participate.
- ▶ Create multiple opportunities for involvement, including participation in leadership and committees, and involvement in ad hoc workgroups, regular town halls, surveys, and other listening sessions.
- ▶ Develop a training initiative to equip people with lived experience of homelessness with the skills and knowledge to participate meaningfully in cross-sector data sharing activities.
- ▶ Provide accommodations that enable a diverse set of people with lived experience of homelessness to participate, including language and disability access.
- ▶ Invest in the time to build trust, especially when first starting out.
- ▶ Create professional development opportunities for people with lived experience of homelessness.

1.4 Practical Tips for Cross-Sector Data Sharing (cont.)

COMMON QUESTIONS ABOUT WORKING WITH PEOPLE WITH LIVED EXPERIENCE OF HOMELESSNESS

Q: Isn't this too technical for laypeople?

A: The leadership group needs to include people with technical expertise in a variety of fields: technology, medical service provision, legal frameworks, homeless service provision, and user experience of the services. Collaboration across all types of expertise requires breaking down assumptions and language while learning to communicate across disciplinary norms. It's critical to have leaders with service experience and a mission to balance the compliance and risk management folks. A small amount of risk can be worth it for the benefit of consumers. Zero risk cannot be the goal. In addition, the expertise of people with lived experiences is another of the disciplinary areas to integrate. Engaging with people with lived experience should be a consideration in all steps of the process.

Q: I'd love to integrate a person with lived experience with homelessness, but will it slow down the process?

A: Sometimes you have to go slow to go fast. Integrating the right experts from the beginning of the process can reduce the likelihood of missteps that must be corrected after the project has been launched and can increase the likelihood of success earlier in the process.

Q: How do I find people to serve in this capacity?

A: Consider recruiting from existing leadership groups within partner organizations. Often homeless system of care partners have Lived Experience Advisory Boards, Resident Advisory Boards, or similar. Health care systems often have Client Advisory Boards, Peer Education Specialists, or similar.

1.4 Practical Tips for Cross-Sector Data Sharing (cont.)

4. PLAN FOR DATA COLLECTION, EVALUATION, AND ANALYSIS

Collecting, evaluating, and analyzing the data that are part of the collaboration can provide insights about how data sharing impacts people's access to health care and housing.

Data review and analysis can help partners better understand the demographics of shared clients; identify patterns, trouble spots, and gaps that need to be addressed; and track outcomes of the collaboration.

Fundamental steps for collecting, evaluating, and analyzing data include:

1. Commit to using data to evaluate the project and learn about the community
2. Establish baseline data about the population, especially data elements that will be needed to measure success of the initiative
3. Establish key metrics at project initiation, adapting them as the project unfolds, and ensuring that metrics can be produced with the data collected
4. Establish a data governance committee that meets regularly to determine whether changes to the data sharing processes are needed
5. Invest in statistical analysis to be able to more easily and routinely learn from the data
6. Develop data dashboards that provide aggregate data to collaborative partners regularly (at least quarterly)
7. Implement data quality practices for data standards and validation
8. Evaluate the data across a diverse set of elements, including demographics (e.g., race/ethnicity, disability, gender, age, geography)
9. Establish feedback loops that allow users and clients to see the benefits of new workflows and that allow them to react to any cultural change



02 Data Sharing Agreements

A cornerstone in data sharing across health and homeless systems of care is exchanging personal information about those with complex care needs. Any time that personally identifiable information (PII) is shared, especially personal health information (PHI), enhanced privacy protections need to be in effect.

Policies and procedures need to be developed to identify the specific data elements that are exchanged, that delineate the people and organizations with access to the data, and that lay out the procedures that ensure the data are protected. It is essential to develop rules that clearly define who has access to the data and distinct guidelines on how the data are used.

The primary document that controls what data are shared between parties is called a “data sharing agreement” (DSA). While organizations and agencies look for template DSAs, they often are so unique to a community and the specific type of data that will be exchanged that it is difficult to create a template that every community can follow. That said, there are components commonly included in a DSA between health and homeless systems of care. Some of those components are highlighted below.

The DSA is the result of a very important process of communication between different sectors, as well as with legal counsel. In many ways, the process of creating a DSA is as important as the final product. There is great value in sitting down with partners to communicate clear expectations, provide opportunities to ask questions of one another, clarify terms, address concerns, and be transparent about assumptions. The resulting DSA may include a great deal of legalese and may even appear boilerplate, but the process that partners go through to come to agreement on the terms often is the foundation that sustains the relationship and the data sharing collaboration over time.

This guide identifies key areas to discuss about how data sharing will work in the community, which can both inform what needs to be articulated in the data sharing agreement and other policies documents, as well as solidify the scope and nature of the collaboration.

DATA SHARING AGREEMENT

2.1 Process for Developing the Data Sharing Parameters

There are two main approaches to develop data sharing parameters through data sharing agreements (DSAs).

In many communities there is a common DSA used by all partners that establishes the mutual agreements between all the agencies and organizations. Other communities have a template DSA adapted and customized specifically for each participating partner that addresses that partner's unique role in the data sharing efforts.

APPROACH 1 | Common DSA shared across all partners.

For communities that strive for a common DSA shared among all parties, there needs to be investment of time and resources to develop the agreement. The process to create the single DSA requires that all partners are fully invested and they commit staff (both legal and policy) with the authority to speak on behalf of the organization or agency. They also need to be flexible, open to compromise, and willing to think outside the ways the organization or agency normally works. The advantage of a single shared DSA is that partners share a common set of goals and principles and a common understanding of expectations for all participating organizations. Any differences in data sharing (either in terms of access or what data are shared) must be understood and agreed to by all partners.

2.1 Process for Developing the Data Sharing Parameters (cont.)



ALAMEDA COUNTY

Alameda County began its data sharing efforts by bringing a group of agencies and organizations to the table to define the goals and vision of the data sharing efforts and to guide the development of the original data sharing agreement. From the outset, the participating agencies were asked to identify those who could represent their organization and who had organizational decisionmaking power. While Alameda County hired outside legal counsel with expertise on privacy and security, participating agencies and organizations were welcomed to include their own legal counsel at the meetings. The process to develop the terms of the DSA was arduous but it was also transparent, collaborative, and foundational to the future collaborative efforts and adjustments to the agreement as new opportunities arose.

The initial development of the SHIE focused on entities covered by HIPAA (Health Insurance Portability and Accountability Act) and maximized the data that can be shared between those providers for the allowable purpose of care coordination without consumer consent. In the past year, Alameda County has started to add non-HIPAA-covered organizations to the system (mostly housing providers, though others focus on various social supports). Those organizations get no access to any data until the consumer consents to the SHIE sharing that information. Some data, such as those from the Social Services Agency, required a signed consumer consent that allowed the SHIE to share those data with HIPAA-covered entities, as those data were not under the HIPAA umbrella but had separate requirements for sharing.

2.1 Process for Developing the Data Sharing Parameters (cont.)

APPROACH 2 | Customized DSA for each partner.

Other communities have taken a wholly different approach when crafting DSAs. Rather than have a common DSA that applies to all partners, they have developed a common template that they adapt and customize for each participating partner so the DSA addresses its unique role in the data sharing efforts. This approach reduces the time needed to negotiate data sharing across all partners. It provides flexibility to organizational leaders to craft individual DSAs with all other agencies and organizations specific to each organization and the types of data it will share. While efficient, customized DSAs require more time investment by the lead organization or agency and can require that changes made in the vision of the partnership get reflected and updated in many individual DSAs. It also minimizes the opportunity to have a shared process to agree to data sharing terms that can be the foundation for longer-term collaboration.

DATA SHARING AGREEMENT**2.2****Engage Legal Counsel**

Sharing private information about people, especially health information, is a sensitive subject. Communities use DSAs to protect clients and organizations involved in data sharing efforts. The perceived and actual difficulties around different rules for different types of data and the need to preserve personal privacy are often barriers that need to be addressed when sharing data, to improve services for people with complex health needs.

Many county and city agencies have lawyers on staff available to develop policies needed for the agencies to conduct their business. That is not the case for most community-based nonprofit organizations, who often hire legal consultants to help them establish the policies and procedures that govern how the organization and board do their work.

Given the specialized area of practice governing cross-sector collaboration, communities that have taken up efforts to exchange data across different agencies and organizations have benefited by engaging expert outside legal consultants. Even in government agencies where lawyers are on staff, communities have engaged external legal consultants with the privacy and security expertise required to develop data sharing policies and procedures, especially in early steps of the process.


ALAMEDA COUNTY

Alameda County hired outside legal counsel with expertise in privacy and data exchange to help them develop their initial DSAs and accompanying policy guidance. At the same time, their county counsel was prepared and willing to become more expert on privacy rules and policies around data sharing. Over time, the outside legal experts were able to transfer knowledge to internal county counsel, who developed expertise. While Alameda County still engages outside legal experts occasionally, their own lawyers are now fluent in these laws and regulations and can revise or update their DSA and other policy documents used to govern their data sharing efforts.

DATA SHARING AGREEMENT

2.3

Scope of Data Shared

Different types of information to be shared in cross-sector collaboration are governed by different laws and policies. When discussing and drafting the DSA, partnerships will need to have a clear understanding of which types of data will be shared. Some communities choose to start by limiting data sharing to simplify the regulatory environment in which they're working. As they develop more experience with data sharing, they expand to share other types of data.

For some communities, that might mean that they limit the data they share to basic data, personal information that does not trigger more strict rules and accountability, such as name, date of birth, and other identifying demographics (e.g., gender and race/ethnicity). Simpler data sharing may limit the partnership and collaboration, yet even basic data exchange can help identify the patients and clients they have in common.

The more data that partners agree to share, the more potential for greater collaboration and better outcomes for patients. Because HIPAA has strict rules on sharing PHI, communities are often reluctant to share PHI outside of the health care sector. It may take more time to negotiate the DSA when the community seeks to share PHI. The additional time and investment, however, may be well worth it to equip partners with better, more in-depth information about the individuals and families they serve.

2.3 Scope of Data Shared (cont.)

ALAMEDA COUNTY

When the Alameda County Health Care Services Agency (HCSA) initially sought to undertake data sharing between the health and homeless systems of care, they limited the data exchange to health care partners and those homeless service providers already covered under HIPAA. Once the data exchange between those partners was in place and happening smoothly, they expanded the data sharing to partners who were non-HIPAA-covered entities. By that time, the partners had greater facility to develop technologies to create rules and algorithms to restrict non-HIPAA-covered entities from seeing HIPAA-protected data. The effort to include a broader set of partners required Alameda County to develop more sophisticated technological processes that could differentiate data that were accessible based on the type of user through algorithms and role-based access. Working with both outside and internal counsel, the HCSA and its partner organizations worked to revise the DSA to include policies and procedures to govern the broader efforts. The expansion of participating entities was considered by their governance committee, and as new agencies were added, other policy documents were updated as needed.

211 SAN DIEGO

When 211 San Diego first launched the CIE, they used off-the-shelf software and shared approximately 40 data fields. Over the past decade, the number of data fields has expanded to thousands. With every new network partner and data integration, whether it's HMIS or a Federally Qualified Health Center, the data dictionary expands and the longitudinal client record expands. CIE offers role-based permissions and data source fields.

Definitions

Algorithms are rules that guide software in how to treat data. In the context of cross-sector data sharing, algorithms ensure that only specific users can view specific, privacy-protected data, which allows entities to collect and share data carefully and thoughtfully without violating privacy rules.

Role-based access restricts access to information based on the role someone has in an organization or partnership. It is used to limit the number of people with access to private information held by an organization so as to better ensure the information stays confidential.

It is important to limit the scope of data shared to only those data necessary to achieve quality outcomes of patients and clients. The community will want to decide what data elements are necessary to share to achieve the identified goals. It is best to start out with a narrow list of data to share and expand it as needed as the project grows (**Table 2**).

Table 2. Types of Information and Governing Laws for Data Sharing

| | Definition/Example | Governing Laws* |
|--|--|--|
| Personally Identifiable Information | Name, date of birth, Social Security number, gender, race/ethnicity | Many |
| Personal Health Information | Health status, health conditions | Health Insurance Portability and Accountability Act (2013)⁵ Health Information Technology for Economic and Clinical Health Act (HITECH Act)⁶ Confidentiality of Medical Information Act⁷ California Health and Safety Code § 1280.15⁸ |
| Behavioral Health | Mental health diagnoses, mental health treatment information, substance use disorder records | Lanterman-Petris-Short Act⁹ Confidentiality of Substance Use Disorder Patient Records, 42 CFR Part 2¹⁰ |
| Homeless Status and Services | Homeless status, services provided | Homeless Management Information Systems (HMIS)¹¹ Data and Technical Standards Final Notice,¹² The Privacy and Security Standards section |

* For more detailed information on Federal and California laws to share with legal teams, see “Appendix C: Applicable Privacy Laws,” in [Addressing Homelessness in the San Francisco Bay Area: A Framework for Regional Data Sharing \(pdf\), Homebase](#).

Both Alameda County and 211 San Diego have DSAs that articulate the types of data the partnerships agree to share across sectors.

Table 3. Current Scope of Data Sharing, Alameda County and 211 San Diego, January 2022

| Type Of Data Shared | Alameda | 211 San Diego |
|--|---|---------------------------------------|
| Personally Identifiable Information | ✓ | ✓ |
| Personal Health Information | ✓ (limited to certain providers based on consumer consent) | ✓ (limited to certain data fields) |
| Mental Health Data | ✓ (limited to certain providers based on consumer consent) | ✓ (limited self-report) |
| Substance Use Disorder Data Covered by 42 CFR Part 2 | (waiting for rule changes) | (limited) |
| Homeless Status and Services (from HMIS) | ✓ | ✓ |
| Social Services Information (e.g., Medi-Cal, CalFresh, CalWORKs) | ✓ (with consent) | ✓ |
| Criminal Legal System Information | ✓ | ✓ |
| Municipal Data | | ✓ (limited) |

DATA SHARING AGREEMENT**2.4****Data Sharing Rules**

Most data sharing systems will need to restrict access to data in some fashion so that only the right data are available to the right people at the right time. Sharing sensitive data across different agencies and systems requires robust security across all elements of the data sharing spectrum. The DSA will need to outline not only which data are shared, but the rules for who has access to which data.

Legal experts can help determine what systems need to be in place to protect privacy and establish security measures. But the community wishing to undertake data sharing will want to develop clear facts and information to guide the experts, to seed policies, and to govern decisionmaking. They need to be prepared to answer the following questions:

- ▶ Which data elements can be shared between all agencies and organizations? Which data elements will need to be specially restricted and in what circumstances (e.g., behavioral health or HIV/AIDS status)?
- ▶ Will all users have equal access to the data, or will there be different access depending on the user's role (e.g., HIPAA-protected health providers, system administrators, etc.)?
- ▶ How long will the DSA be in effect before it needs to be revised, updated, or renewed? How will those revisions be drafted and agreed to?

In addition to the DSA, the partners may want to develop additional policies and procedures to govern their data sharing efforts. The collateral documents will not necessarily have the same force of law as the DSA, but they can be an important component to capture the mission, vision, and goals of the collaboration.

Additional policies might include one or more of these:

1. A partnership charter
2. A shared memorandum of understanding
3. Business associate agreements
4. Operations or policy manuals

2.4 Data Sharing Rules (cont.)

Definitions

A partnership charter is a document that spells out the specific roles, responsibilities, and authority of each partner.

A memorandum of understanding is an agreement between two or more parties that sets out the scope of the relationship, describes the intentions between the parties, and sets out the parameters of the partnership. Like a charter, it also spells out the roles and responsibilities of each partner, but also clearly sets out the resources each partner will contribute to a project.

A business association agreement sets out each signatory's responsibilities for dealing with personal health information. It is a required document for HIPAA-covered entities when they partner with other organizations to share data.

Operations and policy manuals set out an organization's or collaboration's rules, policies, and procedures.



211 SAN DIEGO

211 San Diego's partnership for data sharing through its Community Information Exchange (CIE) extends across a number of local and regional organizations and agencies. In addition to customized DSAs for each of the partners, all partners sign a partnership agreement, a business associate agreement, a service level agreement, an implementation toolkit, user guides, client release of information forms, and training materials. The collaboration is governed by a number of policy documents, including a partnership inclusion policy (PDF),¹³ and Security Breach and Notification Guidance (PDF).¹⁴

DATA SHARING AGREEMENT

2.5

Elements to Communicate Through a Data Sharing Agreement

DSAs and other policy documents identify the responsibilities placed on partners to communicate clearly and accurately with the people whose data will be shared. The responsibility should include providing people with the right to opt out of data sharing and not authorize sharing their individual data (see Client Consent and Release of Information section for more information). The DSA should also spell out to partners the rights of clients to revoke an authorization and the steps required to do so, setting expectations and processes that govern requirements of partners to ensure client consent is informed and voluntary.

The companion policy documents should:

1. Ensure that client data are kept private and secure.
 - a. Develop policies that govern PII and PHI to allow for data sharing without violating federal or state laws.
 - b. Consult with security experts to help determine what practices need to be in place to ensure datasecurity — two-factor authentication, role-based security, etc.
2. Describe any uses of technology that help protect privacy, such as special algorithms that provide for different access depending on whether a user is a HIPAA-covered entity or a non-HIPAA-covered entity or where there is a care relationship.
3. Guide technology team members regarding the rules, and also provide them with the context for why the rules exist. Doing so can help them better understand the uses of the rules so they can create algorithms and other functionalities consistent with partnership intentions.
4. Establish a data governance committee that will take primary responsibility for monitoring the development of the data sharing process to ensure it is consistent with policies and guidance.
5. Establish clear data quality standards.

2.5 Elements to Communicate Through a Data Sharing Agreement (cont.)

Other components of DSAs that communities will want to ensure are included are these:

1. A definitions section that defines terms, programs, and partners
2. Processes for establishing as well as for terminating authorized users
3. Any technology requirements that must be in place to participate in data sharing
4. Plans and requirements for training authorized users on privacy and security
5. Provisions regarding ownership rights of the system and the data
6. Limitations, if any, regarding how often data will be transmitted between agencies
7. Provisions that delineate responsibilities for ensuring data accuracy and data quality
8. Details about permissions for use of the data by all partners
9. Processes required to adhere to security protocols when/if there is a breach of security

Table 4. Data Sharing Partners: Alameda County and 211 San Diego

| | Alameda County | 211 San Diego |
|---|----------------|---------------|
| Adult and Aging Services | ✓ | ✓ |
| Behavior Health Care Services | ✓ | ✓ |
| Child and Family Services | ✓ | ✓ |
| Continuum of Care | | ✓ |
| Criminal Legal System | | ✓ |
| Emergency Medical Services | ✓ | ✓ |
| Emergency Shelters | ✓ | ✓ |
| Faith-Based Organizations | | ✓ |
| Federal Qualified Health Centers or Other Community Clinics | ✓ | ✓ |
| Fire Department | | ✓ |
| Food Banks | | ✓ |
| Health Care Services Agency | ✓ | ✓ |
| Health Insurers | | ✓ |
| Hospitals | ✓ | ✓ |
| Homeless Service Providers | ✓ | ✓ |
| Housing and Community Development Agency | ✓ | ✓ |
| Housing Commission | | ✓ |
| Information and Referral Organizations | | ✓ |
| Legal Services | ✓ | ✓ |
| Medicaid Managed Care Plans | ✓ | ✓ |
| Social Services Agency | ✓ | ✓ |
| Veterans Organizations | | ✓ |



03 Client Consent and Release of Information

Client consent is an important element of any data sharing project. Having clear permission from patients and clients to share their personal information protects them and preserves client choice. Long documents packed with legalese that don't help people understand what they are agreeing to, do not serve communities well. Rather, documents that are simple and clear, that share with the person the intent of the data sharing, the restrictions and protections in place, are the most useful.

Most importantly, people need to have clear communication about what they are agreeing to and how the information will be used. It's not just the piece of paper that supports client consent. It is also how the consent is presented to patients and clients — the collateral information that agency and organizational staff provide through outreach, education, and one-on-one interactions.

CLIENT CONSENT AND RELEASE OF INFORMATION

3.1

Key Elements to Obtaining Client Consent

Successful data sharing includes robust efforts to obtain client consent.

- ▶ Develop releases of information (ROIs) written in simple language so they are clear, easy to read, and include understandable directions.
 - Ensure releases are co-created or reviewed by people with lived experience of homelessness and people with complex care needs.
 - Limit data sharing to only that information necessary to improve quality of care.
 - Clearly spell out the differing legal implications of sharing PII, PHI, and other types of information that includes special client consent (e.g., HIV/AIDS status, mental health, and substance use information).
 - Make ROIs available and accessible to all patients and clients, including in multiple languages.
- ▶ Provide clear protocols for terminating and for revoking consent.
- ▶ Make available policies, procedures, and forms for collecting and documenting consent through multiple means (i.e., verbally, on paper, and electronically).
- ▶ Train staff to be able to fully explain the benefits and potential risks to clients from sharing data across sectors that help staff better communicate to patients and clients.
 - Include scripts for staff to use to explain the purposes of the ROIs that can be used when speaking with clients and patients.

3.1 Key Elements to Obtaining Client Consent (cont.)

Well-developed client consent documents will be responsive to the particular needs of the partnership and applicable laws. **Table 5** describes sections included in the client consent documents of Alameda County and 211 San Diego communities.¹⁵

Table 5. Sections Included in Client Consent Documents, Alameda County and 211 San Diego

| | Alameda County | 211 San Diego |
|--|----------------|---------------|
| Client Name, Contact Info, and/or Personal Identifier | ✓ | ✓ |
| List of Information To Be Shared | ✓ | ✓ |
| Right of Refusal | ✓ | ✓ |
| Process For Revoking Consent | ✓ | ✓ |
| Notice of Privacy Practices | ✓ | ✓ |
| Client Signature | ✓ | ✓ |
| Expiration Date of Consent | ✓ | ✓ |
| Right To Obtain Copy of Information | ✓ | ✓ |
| Benefits of Participation | ✓ | |
| Special Consent For HIV Test Results and/or Mental Health Services | ✓ | |



ALAMEDA COUNTY

Alameda County engaged with people with lived experience of homelessness and a health literacy expert to ensure the processes and consumer facing documents were understandable and effective. AC Care Connect had a team of peer-to-peer advisors who had lived experience and supported many parts of Alameda’s program development. A senior member of Alameda’s Data Exchange Unit took the version of the client consent that had been agreed to by the lawyers and walked the peer-to-peer advisory group through the consent form. They gathered the group’s nuanced feedback, areas of concern, and specific language they flagged that might be triggering or confusing. The team then went back to the lawyers and then back to the peer-to-peer group to review the updates. A plain-language literacy expert was involved throughout.

CLIENT CONSENT AND RELEASE OF INFORMATION

3.2

Key Questions for Designing Client Consent Forms and Process

When developing ROIs and corresponding policies and procedures, consider:

1. What forms and processes are already in use by either or both the health and homeless systems of care?
 - Can any be expanded to cover the additional type of data sharing?
 - Do any need to be supplemented or replaced?
 - Have they been reviewed and revised based on feedback from people with lived experience of homelessness and people with complex care needs?
 - What legal or other expertise is needed to inform any expansion of or addition to existing forms or processes?
2. Can several systems of care share the same ROI form, or are separate forms necessary?
3. How will input from people whose data will potentially be shared be incorporated into the development of policies and forms?



SAN DIEGO

A key component of San Diego's success is the strong partnership they have had since the very beginning of the process with the homeless system of care's Continuum of Care (CoC), which manages the Homeless Management Information System (HMIS) in San Diego. The integration of HMIS data directly into the CIE record provides robust data for individual care coordination and for community planning.

The community reached critical mass when most HMIS users were also CIE users and filling out two consent forms with clients. The CIE legal team worked collaboratively with the CoC and HMIS legal team to design the form, process, and trainings. The CoC board adopted the common consent form after an approximately two-year process. The partnership established a shared release of information, allowing a person's consent to apply to both HMIS and CIE activities. Data integration feeds from HMIS share valuable data points to support a more comprehensive CIE client profile, creating the opportunity to leverage the data to help highlight [housing instability \(PDF\)](#)¹⁶ inequities and opportunities for systems change.



04 Understanding Technology Considerations

Technology is an important tool that can facilitate cross-sector data sharing. When considering technology, it is important to match the solution to the problem that needs to be solved. Each community will have different goals or areas of focus for its data sharing projects and will use different technological tools to achieve its required results. This section covers key principles to incorporate when considering technological solutions and provides examples of solutions used throughout the field.

UNDERSTANDING TECHNOLOGY CONSIDERATIONS

4.1

Establishing Potential Use Case

A use case is a way to describe how a user might interact with a system. Developing a use case can establish what successful interaction with a data sharing system might look like, as well as identify potential pitfalls in the system. Use cases are a valuable way to identify the inputs needed for developing a data sharing platform. They are particularly helpful for technologists to best understand the functionality needed in a data sharing system so that the design and functionality meets the needs of the community. For example, if the use case is to simply provide internal data sharing across two departments under the same agency, the technology and rules required may be very different from a use case where government agencies will be sharing data externally with community-based partners. Not only is the technological functionality different, but the design of the rules for privacy and security will be different as well. For more in-depth information about use cases, see the box about 211 San Diego's program and its [Community Information Exchange Toolkit \(PDF\)](#).¹⁷

In addition to creating a framework and definition for building technology, the process of creating use cases can help stakeholders to gain an understanding of the settings their colleagues from other sectors work in and the systems different sectors engage with, as well as to help build empathy and a culture of understanding and collaboration as similarities and differences across the needs of users are identified.



SAN DIEGO

In 2018, 211 San Diego's program developed a [Community Information Exchange Toolkit \(PDF\)](#)¹⁷ to respond to the growing state and national interest in data sharing and San Diego's experience developing and growing the CIE. The toolkit provides background information and strategies for developing use cases and defines the core components of a Community Information Exchange. Given the rising interest in social determinants of health and funding of technology vendors focusing on cross-sector connections, the toolkit was released to highlight the importance of data integration, interoperability, and a single client record for care coordination, community voice, and shared governance.

4.1 Establising Potential Use Case (cont.)

Fundamental elements for developing a use case:

- Be very specific when developing a use case.
- For each use case, identify the specific data needed to enable effective data sharing and to avoid sharing more than what is required or adding unnecessary complexity.
- Ensure that use cases take into consideration the needs and goals of all stakeholders.
- Be sure that use cases align with the vision and goals for the effort.
- Create composite use cases. Remember that use cases are generalizations and not meant to describe every individual exactly.

Key questions to consider:

- Who are the potential users of the shared data? What is their day-to-day work like? What are the challenges they face in working to serve their clients or patients?
- What will motivate users to interact with the system?
- What problems are users trying to solve by accessing the shared data? How will they use the data they find in the system?

UNDERSTANDING TECHNOLOGY CONSIDERATIONS

4.2

Tools to Facilitate Cross-Sector Data Sharing

While robust and regular data sharing across systems is best enabled by having comprehensive structures in place, communities have successfully shared data using low-tech processes, as well. Technological limitations should not prevent communities from taking advantage of data sharing.

The options in **Table 6** are listed in order of required technological capacity, from least to most intensive. Capacity, data sharing type, availability of resources, and the partnership will together determine the best approach in each community.

All options allow for cross-sector sharing of information, which require data sharing agreements and client releases of information.

Table 6. Pros and Cons of Data Sharing Options

| | PROS | CONS |
|---|--|---|
| <p>In-person or virtual meetings, where people from different sectors discuss those they mutually serve, often through case conferences, by name list reviews, or both.</p> <p><i>Technology:</i> Face-to-face or virtual meeting capacity (e.g., Zoom, Microsoft Teams, etc.)</p> | <ul style="list-style-type: none"> • Brings people together to discuss complex cases and builds relationships between providers. • Establishes a good starting point for further and deeper collaboration. • Allows for in-person collaboration and dialogue. • Provides opportunity for creative care coordination. • Enhances ability for direct service provider collaboration rather than just systems collaboration. | <ul style="list-style-type: none"> • Performed manually (i.e., requires people to identify needed information to bring to each meeting and request from others). Often requires significant preparation by the facilitator. • Requires providers to wait for problem solving or needed information about clients and patients until the next scheduled meeting. • Limits who can collaborate to those available to attend meetings. • Limits the type of data that can be shared and collected to information brought about specific cases, likely without uniformity. • Unrecorded qualitative data sharing limits the ability to comprehensively collect and analyze data to help improve the care system. |
| <p>Shared spreadsheets, by two or more organizations to enable data matching of a broader set of data.</p> <p><i>Technology:</i> Shared lists, spreadsheets</p> | <ul style="list-style-type: none"> • Quickly and readily identifies when different systems share in caring for a person. • Identifies when people are falling through the cracks of one or more systems. • Can share more data than just name and date of birth. | <ul style="list-style-type: none"> • Performed manually. • Paper-based data sharing (not automated) prohibits sharing data for a large group of people. • Often the size of the data set and the way it’s stored is inadequate to allow the team to comprehensively analyze a large breadth of data to help improve the care system. • Requires ongoing work to keep current. |

Table 6. Pros and Cons of Data Sharing Options

| | PROS | CONS |
|--|--|--|
| <p>Data matching, which includes identifying whether a person is touching both the health care and homeless systems. Usually uses a minimal number of data points (e.g., name and date of birth) to identify whether the same person appears in more than one database.</p> <p><i>Technology:</i> Shared lists, spreadsheets, statistical analysis systems, master patient indexes, data matching software (open source or proprietary)</p> | <ul style="list-style-type: none"> • Quickly and readily identifies when different systems share in caring for a person. • Identifies when people are falling through the cracks of one or more systems. • Can be done electronically (i.e., without manual effort of multiple providers). • Often a first step in a larger project that can help scope the range of partners to participate for biggest impact. | <ul style="list-style-type: none"> • Limited to a few data points (usually name and date of birth) mostly used to find where there is overlap between systems. • Insufficient to enable collaboration around care between systems or individual service providers because data shared is limited. • Limited data set prevents teams from comprehensively analyzing a broader data set to help improve the care system. • Not all teams have the technological functionality that enables communities to share data electronically across systems. • One-time match, so in some cases must be done repeatedly to stay current. |

Table 6. Pros and Cons of Data Sharing Options, continued

| | PROS | CONS |
|--|--|--|
| <p>Shared care platforms, which are used by staff from multiple agencies to enter data directly into a database, app, or tool about the people they mutually serve (e.g., many communities have created care management portals to centralize and coordinate care). They are created specifically to manage care across different partners, and data can be entered directly into the platform or pulled into the platform from a central repository. San Diego’s CIE is a shared care platform. Alameda County’s Community Health Record (CHR) is a shared care platform.</p> <p><i>Technology:</i> Typically, stand-alone care management software, and in rarer instances, an electronic health record</p> | <ul style="list-style-type: none"> • Allows a wide breadth of data about each person to be shared and stored in the system. • Provides one platform to share data across two otherwise discrete systems. • Facilitates more efficient use of resources by having one central place for data. • Offers access to a diverse group of service providers. • Enables staff to enter notes and communicate directly with staff from other systems. • Provides stronger ability to respond to emergencies that impact multiple systems of care (e.g., COVID-19 pandemic). • Organized around the person seeking services, so enables them to be treated as a whole person. • Helps providers locate or track clients. • Enables systems to comprehensively collect and analyze data to help improve overall care. • Updated information can be accessible in real time by system users. | <ul style="list-style-type: none"> • May require users to enter duplicate data into the system, in addition to data entry required for their own systems. • Needs investment of funding for dedicated IT or vendors to develop and design the platform. • Requires technological upkeep to keep current. • More costly to develop. |

Table 6. Pros and Cons of Data Sharing Options, continued

| | PROS | CONS |
|--|---|--|
| <p>Central repositories, which pull data from disparate databases into one shared central system, can allow all providers to have full access (or limited access, depending on privacy concerns) or can be used to pull data from different sources and then share that data in a separate shared care platform. Alameda County’s Social Health Information Exchange (SHIE) is a central repository that pulls data into the shared care platform (the CHR).</p> <p><i>Technology:</i> Often off-the-shelf or custom-built data warehouse systems</p> | <ul style="list-style-type: none"> • All the pros of the shared care platforms, plus... • Automatically pulls data from other systems, so no need to do duplicate entry. • Can pull data into a shared care platform, if desired. • Can pull data from multiple systems, to expand collaboration. • Can pull data based on cohorts of concern (people in a specific zip code, people of a certain age, people enrolled in a specific program, people overlapping two specific programs, etc.). | <ul style="list-style-type: none"> • Needs significant investment of funding for dedicated IT or vendors to develop, design, and maintain the repository. • Most beneficial when working with more than two systems. • Requires technological upkeep to keep current. |

4.2 Tools to Facilitate Cross-Sector Data Sharing (cont.)



SAN DIEGO

The CIE platform of 211 San Diego shares client-level data integrated from diverse data systems and facilitates community case planning and care team communications. It is a community-led ecosystem composed of multidisciplinary network partners using a shared language, a resource database, and integrated technology platforms to deliver enhanced community care planning. Through the use of comprehensive screenings and assessments across 14 domains of social determinants of health, the CIE calculates a Risk Rating Scale to assess client strengths and needs. Data on clients are tracked longitudinally and include referrals to other partners, program eligibilities and enrollments, care team members, and proactive status change alerts to providers to facilitate care.

UNDERSTANDING TECHNOLOGY CONSIDERATIONS

4.3 Tips for Scoping a Technology Build-Out

There are basic decisions about technology that communities should be clear about before engaging with their own IT departments, consultants, and third-party vendors. There is no single template solution that will work for every community or data sharing project. It will depend on the current technologies used by the partners involved or available in their community, additional resources available, and whether partner organizations have capacity to develop technology internally or will need to identify a technology partner.

One key aspect that should be discussed and decided upon very early in the process is the fundamental structure of the data sharing functionality desired. There is a correlation between the collaborative model the community chooses and the level of technology and tools needed.

Collectively, key partners need to decide which one of these the technology will be:

- ▶ Built in-house from scratch by one of the stakeholder organizations
- ▶ Collaboratively built from scratch with technology staff from multiple stakeholders
- ▶ Built in-house from something that already exists in the community (through one or more stakeholders)
- ▶ Purchased as an off-the-shelf product and possibly customized
- ▶ Developed with an outside technology firm

There are pros and cons for each option, and the considerations are specific to the community, the resources, and staffing. What might be a con for one community could be a pro to another. It is important to consider the community's particular resources, data sharing goals, long-term investment opportunities, and sustainability.

Below are some key considerations to help the community decide upon the basic structure and approach to developing data sharing functionality. Knowing the answers to these questions will help inform decisions about which approach from the options identified above will work best:

1. Can the data sharing functionality be built on or into an existing data system (e.g., Homeless Management Information System or electronic medical records system), or will it require new functionality to be created to allow for data sharing across sectors?
 - Does the current system have the functionality to communicate with other systems (e.g., technological capabilities designed to help separate systems engage in two-way communication)?
 - Are there expert staff at partner agencies or organizations with the IT skills and capacity to make the needed adjustments, or will third-party vendors need to be engaged?

4.3 Tips for Scoping a Technology Build-Out (cont.)

2. If it is possible to use an existing system, what adjustments or adaptations are needed to allow for the desired cross-sector data sharing?
3. Does the community want the data to remain in each of the current individual systems and also be uploaded into a shared system? Or should data be stored only in the new system?
4. What kind of access should partners have?
 - Will users be able to see real-time data?
 - Will there be customizable data and/or dashboards viewable to partners?
 - Will they be able to download data for analysis?
 - Should different sectors have different access to the data?
 - Should data be made available in aggregate form for public consumption?
5. What changes will need to be made in current systems or built into new systems to ensure appropriate privacy protections are enforced for PHI and PII?
 - Should limitations be established within the technology on what data can be shared?
 - What data elements are desired to be shared by all systems?
 - Should the system be able to use machine learning and/or predictive analytics to improve service delivery or interventions?
6. If a new system will be built, in addition to the above, communities will want to consider:
 - If a customized solution is needed is there an out-of-the-box system option available to purchase or license?
 - If funding exists to not only set up a new system but to operate and maintain it?

UNDERSTANDING TECHNOLOGY CONSIDERATIONS**4.4 Technology Development Steps and Processes**

After the data sharing approach is determined, processes and documents need to be developed to ensure clarity, transparency, and accountability around the technology components of the data sharing system. Clearly defining the process will also help establish timing and expectations.

Scoping and feature development:

- ▶ Identify what the data sharing system should look like and the functionality desired. Be clear about what features and data will and will not be included. Ensure the system can data match and deduplicate records for those that touch more than one system, especially nonstandard data sets from nonclinical organizations.
- ▶ Conduct design sessions with a leadership team or committees to ensure the community has consensus about expectations of the platform. Include people with lived experience of both the health care and homeless systems of care.
- ▶ Share those expectations with the developer of the technology (whether internal staff, contractors, or third-party vendors). Create a written description of needs, which can inform contracting and development.
- ▶ Put a process in place that includes a small team of stakeholders who will work with the developer as the project moves forward. Ensure that the developers are sharing their progress and communicating clearly changes from the originally recommended design. It is best to have a process of iteration as the product unfolds to ensure the final product meets the program's needs.

Establish the technology development team:

- ▶ Develop a request for proposals or request for a quote if using an outside vendor or contractor.
- ▶ Create a job description that defines the role and specifications (of both the organization and the staff member) if an existing staff person will take on this role.
- ▶ Identify at least one person from the project leadership team to be the liaison with the technologists. This person will manage scope, ensure ongoing questions are addressed by the leadership team, and share challenges uncovered during development that may require scope, budget, or timeline changes. Ensure the roles and division of responsibilities are clear between the program leadership and the technology team.

4.4 Technology Development Steps and Processes (cont.)

Key considerations during the development process:

- ▶ Identify any changes that fundamentally change the original expectations, and be prepared to communicate those changes to the broader stakeholder group. Build time into the process to allow for discussion and adaptation so everything is transparent.
- ▶ Develop a plan for pilot testing the technology functionality with the IT team and with users of the platform, clarifying how much time will be needed from what types of people. User testing should be designed not only to ensure the product works the way it was designed from a technological point of view, but also that the product works well in the way users need it to work (e.g., on the various devices they will use — desktops, laptops, phones, and other mobile devices).
- ▶ Identify training needs and create a plan to develop a curriculum and training materials. Identify which components of training materials will be the developer's responsibility and which will be the community's responsibility.



DIFFERENT APPROACHES:

05 Alameda County and 211 San Diego

While San Diego County and Alameda County efforts have some common elements, each approach was developed differently. Most fundamentally, Alameda County’s efforts were initiated and are led by a government agency (Alameda County Health Care Services Agency). In contrast, San Diego’s efforts were led by a community-based nonprofit 211 agency.

DIFFERENT APPROACHES:

5.1

Alameda County and 211 San Diego

Other differences between the two efforts include:

The type of information shared:

- Alameda shares HIPAA- and non-HIPAA-governed data, as well as cross-agency data.
- San Diego shares HIPAA- and non-HIPAA-governed data. Both self-reported and provider-verified data are shared, with the data source visible to the end user. Some health care data are shared from individual health clinics and health providers. Limited county agency data are part of the CIE.

Population prioritized

- Alameda primarily shares data about Medi-Cal and uninsured health consumers.
- San Diego has a shared-loop referral program for people experiencing homelessness that enables the 211 team to access a broad set of shared data to expedite and facilitate referrals for assistance.

Technology platform

- Alameda uses a Social Health Information Exchange.
- San Diego uses a Community Information Exchange.

Table 7. Data Sharing Efforts Compared, Alameda County and 211 San Diego

| | Alameda County | 211 San Diego |
|--|---|--|
| Leadership and governance structure | County — government agency | Nonprofit backbone with shared community governance |
| Types of information shared | <ul style="list-style-type: none"> • Care team members and social contacts • Medi-Cal coverage status and health plan • Clinical encounters, programs, providers, diagnoses, and assigned primary care medical home • Mental health services (including county hospital and crisis), programs, and utilization • Housing programs and Coordinated Entry System information from HMIS • Current county jail incarceration • Public benefit information from Social Services Agency, including CalWORKs, CalFresh, General Assistance, and Medi-Cal re-enrollment due date • HIV test results, if opt-in • Detailed hospital info, including discharge summaries | <ul style="list-style-type: none"> • Client demographic data • Eligibility • Current and past program enrollment including benefit programs, renewal dates, housing programs, and community-based organization programs • Medi-Cal coverage status and health plan • Current and past care team members • Housing programs • Social determinants of health screenings and assessments • Discharge data • Self-reported care data • Some health care data shared from individual health clinics and health providers • Limited county agency data are part of the CIE • Care team communication feeds • Status change alerts • Data source auto-history • Predictive analytics • Data entered into the platform by participating partners |
| Population prioritized | Medi-Cal and uninsured consumers | Initially, people experiencing homelessness, now all San Diegans needing assistance navigating resources and coordinating care |

Table 7. Data Sharing Efforts Compared, Alameda County and 211 San Diego

| | Alameda County | 211 San Diego |
|----------------------------|---|---|
| Shared platform | Social Health Information Exchange (SHIE), which keeps data secure, enables the team to manage who can see what data, and to match identity when different data streams describe one person. | Community Information Exchange (CIE), which is a community-led ecosystem composed of multidisciplinary network partners using a shared language, shared resource database, and integrated technology platforms to deliver enhanced community care planning. |
| Technologies used | <ul style="list-style-type: none"> Community Health Record (CHR), which is a portal that allows providers to view a thin slice of actionable information about consumer utilization, diagnosis, and information (including who else is working with them). CHR data are curated with consumer consent, consumer information, and real-time data. Uses a best of breed platform supported by Thrasys/UpHealth that integrates Verato, data from Collective Medical Technologies, signature management from DocuSign, and risk-tracking system John Hopkins ACG. | Built on Salesforce with middleware Informatica, CIE integrates data from other source systems into a single person-centered record that displays past and current demographic information, referral history, program enrollment, risk scores, and care team and chart changes over time. |
| FUNCTIONAL ELEMENTS | <ul style="list-style-type: none"> Patient matching (deduplication) Algorithm for user-based access to manage different users and different permissions (HIPAA vs. non-HIPAA) Attribution between a consumer and an organization where there is evidence of a care relationship | <ul style="list-style-type: none"> Detects and merges duplicate records Ensures the accuracy, completeness, and consistency of multiple domains of enterprise data Reads data from a database Converts the data for the new database Loads into the new database Read-only data (users can see the data but cannot manipulate it), which requires users to enter the data into the system. |

Endnotes

1. Erika Siao and Julie Silas, [Breaking Down Silos: How to Share Data to Improve the Health of People Experiencing Homelessness](#), California Health Care Foundation, July 2021.
2. See [Alameda County Care Connect](#).
3. “[Alameda County Community Health Record Delivering Consumer-Centered, Data-Informed Care](#),” Alameda County Care Connect, July 26, 2018.
4. [CIE San Diego](#).
5. [HIPAA Administrative Simplification: Regulation Text — 45 CFR Parts 160, 162, and 164 \(PDF\)](#), US Dept. of Health and Human Services, March 2013.
6. [HITECH Act, Pub. L. No. 111-5 \(2009\)](#).
7. [Cal. Civ. Code §§ 56–56.37 \(1992\)](#).
8. [Cal. Health & Safety Code § 1280.15](#).
9. [Lanterman-Petris Act](#).
10. [42 C.F.R. Part 2 \(2017\)](#).
11. [Homeless Management Information System](#).
12. [Data and Technical Standards Final Notice](#).
13. [CIE Partner Inclusion Policy \(PDF\)](#), Community Information Exchange, last updated February 1, 2018.
14. [Security & Breach Notification Guidance for Community Information Exchange Partner \(CIE\) Network: 2021 \(PDF\)](#), CIE, last updated June 1, 2021.
15. For full ROI documents, please see [Alameda County Information Sharing Authorization \(PDF\)](#), Alameda County Health Care Services Agency; and [Multiparty Authorization to Use and/or Disclose Information \(PDF\)](#), San Diego County CoC, last updated March 31, 2020, [CIE Authorization Forms](#).
16. [Housing Instability in San Diego County \(PDF\)](#), CIE/211 San Diego, September 2019.
17. [Collaboration and Cross-Sector Data Sharing to Create Healthier Communities \(PDF\)](#), CIE/211 San Diego, November 2018.