

Legal and Legislative Considerations for Cross-Sector Data Sharing

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NASDOH

National Alliance to Impact the Social Determinants of Health

COMMUNITY INFORMATION EXCHANGE SUMMIT

Sara Singleton, Principal
August 12, 2020



NASDOH WHO WE ARE

The **National Alliance to impact the Social Determinants of Health (NASDOH)** is a group of stakeholders working to systematically and pragmatically build a common understanding of the importance of addressing social needs as part of an overall approach to health improvement.



What We Do

NASDOH provides a bridge among sectoral efforts by **engaging organizations across the national system of health and in engaging the business sector to articulate the cross-sector value proposition for addressing the social determinants of health.**



Our Mission

The National Alliance to impact the Social Determinants of Health **seeks to make a material improvement in the health of individuals and communities** and, through multi-sector partnerships within the national system of health, **advance holistic, value-based, person-centered health care** that can successfully impact the social determinants of health.



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Karen DeSalvo, MD, MPH

**Former Health Commissioner, City of New Orleans
Former Acting Assistant Secretary
US Department of Health and Human Services**

Our Members

Steering Committee



General Membership



Our focus

is to advance public and private sector policy environments to support the advancement of the evidence base upon which work in the field can build, innovate, and be sustained. Specifically, our areas of focus are:

1. Issue framing in a way that promotes action
2. Elevating shared learnings across communities
3. Leveraging shared approaches to measurement and evaluation
- 4. Encouraging data and technology innovation**
5. Promoting a supportive policy environment at all levels of government and in the private sector

Issue Statement

- **One important challenge to meaningfully address SDOH is the fragmented communication and coordination between service providers and to individuals.**
- **This fragmentation has many unfavorable consequences, including**
 - Limiting the effectiveness of resource availability and allocation;
 - Negatively impacting the quality of care;
 - Damaging health outcomes; and
 - Creating frustration and confusion for individuals needing services and supports to address the impact of SDOH.

In an ideal world, the following data would be shared securely, privately, and with consumer consent

- **Individuals' social needs information:**
An accounting of an individual's self-reported social needs or SDOH that impact them.
- **Eligibility and enrollment administrative data:**
The health and social services programs for which an individual is eligible and enrolled, e.g. whether an individual is eligible and enrolled to receive home-delivered meals.
- **Care planning and experience:**
Whether an interaction between the individual and community-based organizations (CBOs) occurred, and whether an intervention was delivered.

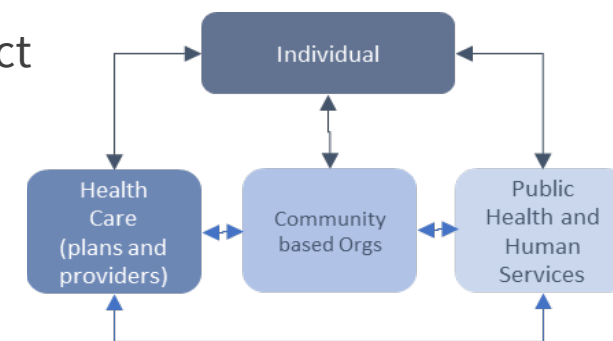
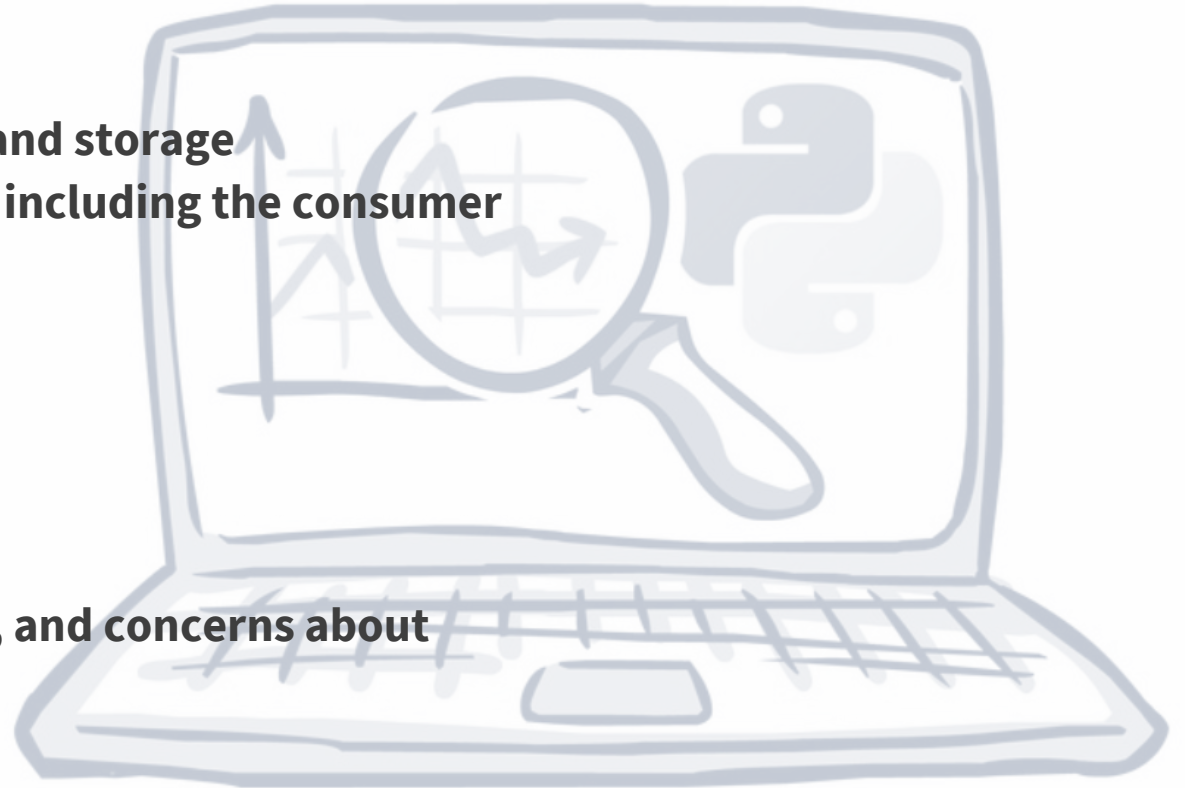


Figure 1. Individuals provide their individual SDOH information at the point they interact with a health care or social service CBO. This information is easily shared with partner organizations. For example, if an individual sees their health care provider and reports food insecurity, that information is shared with their health plan, eligibility and enrollment for human service programs can be confirmed, and there is seamless care planning and experience data sharing between the service providers.

Technical Challenges

- **Consent management**
- **Standardization of SDOH data collection and storage**
- **Data sharing between ecosystem parties, including the consumer**
 - Verifying individuals uniquely
 - Proprietary technical infrastructure
 - Lack of technical infrastructure



Non-technical Challenges

- **Access and comfort with digital solutions, and concerns about information collection and sharing**
- **Social care sector capacity and capability**
- **Unnecessary medicalization of SDOH**

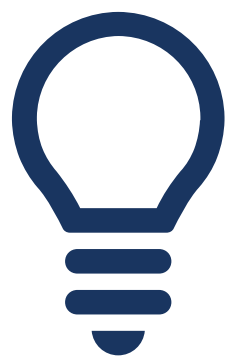
Five Key Opportunities

<p>OPPORTUNITY 1.</p> <p>Enable consumer-directed permission of SDOH information sharing</p>	<p>OPPORTUNITY 2.</p> <p>Ease collection of data on social needs</p>	<p>OPPORTUNITY 3.</p> <p>Support efforts to verify identity</p>	<p>OPPORTUNITY 4.</p> <p>Facilitate interoperability between service providers in SDOH ecosystem</p>	<p>OPPORTUNITY 5.</p> <p>Facilitate access to eligibility and enrollment in human service programs</p>
<p>There is an opportunity to overcome this challenge by developing or driving the adoption of existing principles and tools for managing individual permission to share SDOH information, and to govern the responsible management and sharing of SDOH data within and between service providers, as well as with consumers</p>	<p>There is an opportunity to develop a consensus around a set of technical standards for collecting social needs information using federated models, which can be scaled for national use. In fact, there are thoughtful approaches to standardizing and capturing SDOH data already underway or being tested.</p>	<p>The lack of a standardized approach for verifying unique users across electronic systems can be addressed through industry-wide framework for digital identity solutions. This would advance the ability to exchange data across systems electronically, including SDOH data.</p>	<p>There is an opportunity to facilitate bidirectional SDOH data sharing between social, health, and other service providers by building open standards to support a single digital infrastructure for accessing and exchanging this information.</p>	<p>There is an opportunity to build open standards for accessing and exchanging real-time eligibility and enrollment information for state-administered social and human service programs would support efforts to address social need.</p>

Call to Action & Principles



- **NASDOH calls upon our partners in the health care, technology, and social service sectors to consider these opportunities and establish durable solutions to advance SDOH interoperability.**
- **In support of these efforts, NASDOH offers a set of core principles that we believe can help instill the trust and build the capacity needed:**
 - Collaborative approaches
 - Individual-centric and purpose-specific
 - Transparency
 - Open standards-based
 - Flexible architecture and operational structure
 - Interoperable, federated exchange model
 - Multi-directional exchange approach
 - Strict privacy and security practices



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Data Sharing and the Law: Overcoming Health Care Sector Barriers to Sharing Data on Social Determinants

Manatt Health

Community Information Exchange Summit

August 12, 2020

Project Background

Increasing Focus on Social Determinants of Health Requires Cross Sector Data Sharing

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The health care system increasingly recognizes that patient care involves linking patients to social services.



Coordinating care across health care providers, community-based organizations (CBOs) and other entities requires data sharing across entities.



Privacy laws, however, were not written with disclosures across service sectors in mind:


- The Health Insurance Portability and Accountability Act (HIPAA) envisions data sharing among providers and plans re: protected health information (PHI)
- Substance use disorder (SUD) confidentiality regs rarely allow exchange w/o written consent.
- Criminal records laws typically assume data will remain in the criminal justice system.

See appendix
for a list of
complementary
resources on
related topics

- In consultation with others, we developed four hypothetical situations (referred to as “use cases”) that reflect real-life experience where a health care provider shares information with another sector:
 - Clinicians and housing providers
 - Health clinics and school health programs
 - Health clinics and prison health services units
 - Medicaid managed care organizations and states re: food stamps
- We examined restrictions on data sharing under federal law and in three states: California, Louisiana, and New York
- We studied bi-directional data sharing and the implications for using an electronic information exchange to share data

Our analysis is intended to provide insight into the issues, but is not legal advice. Anyone wishing to share data should seek legal counsel

Data sharing by the health sector with other organizations is often permitted

- 
- Information can almost always be shared if the individual signs a consent form; in some cases, consent is not required
 - The ease of obtaining written consent varies based upon the circumstance
 - Requirements on information that must be included in consent forms can complicate efforts to share data
 - Clarification of legal requirements can promote data exchange



Health privacy laws

- Health Insurance Portability and Accountability Act (HIPAA)
- 42 C.F.R. Part 2 (“Part 2”), the federal substance use disorder confidentiality regulation
- Family Educational Rights and Privacy Act (FERPA)
- State laws (e.g., mental health or HIV laws)



Benefits privacy laws

- Medicaid
- Supplemental Nutrition Assistance Program (SNAP)



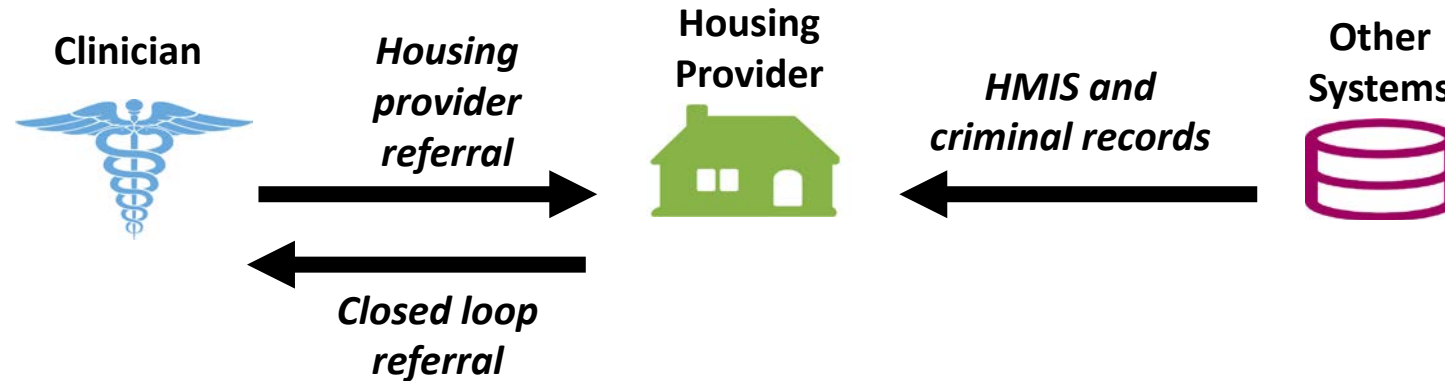
Criminal records laws

- Federal Criminal Justice Information System (CJIS) regulations
- State criminal history laws



Homeless Management Information System (HMIS) regulations and policies

Use Case Analysis



1. Clinician treats homeless adult patient with a serious mental illness
2. Clinician refers patient to a housing provider
3. Housing provider seeks data (including behavioral health) from clinician
4. Housing provider also seeks housing-related data from HMIS and criminal history information
5. Clinician asks for closed loop referral




Clinician Connecting Patient to Housing: Conclusions

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Is data disclosure allowed? Yes, written consent sometimes required

- Clinician's ability to share clinical health information with the housing provider without written consent depends on the state:

California 	Louisiana 	New York 
Written consent generally needed, unless both clinician and housing provider are members of a homeless MDT	Written consent is not needed, except if one of the providers is operated by the state Health Department	Written consent is not needed (unless clinician is subject to mental health law), and clinician must inform patient of referral

- Written consent needed if certain SUD information (Part 2) is disclosed
- Housing provider may confirm receipt of services ("closed loop referral")
- Housing provider must enroll in HMIS to receive HMIS housing-related data
- Housing provider may obtain publicly available criminal records

Concluding Thoughts

Recommendations for Developing a Plan for Data Sharing Across Sectors

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Begin with detailed model for data flow



Develop a common understanding of applicable laws



Create an effective authorization form and consent management system, if necessary



Use workarounds to address legal restrictions where practical (e.g., use publicly available data)



Consider clients rights in privacy that go beyond minimum legal requirements



Determine how to maintain data exchanges over the long term



Confer with regulatory agencies when guidance is needed

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