

SOCIAL DETERMINANTS OF HEALTH DATA INTEROPERABILITY

A Concept Paper from the National Alliance to
Impact the Social Determinants of Health

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OVERVIEW

Creating a data ecosystem where social determinants of health (SDOH) data is shared seamlessly, privately, and securely is foundational to addressing the impacts of SDOH on individuals. It can also inform public and population health policy actions that impact SDOH upstream. The COVID-19 pandemic highlights the importance of data and information sharing as a valuable method of identifying and addressing social needs.¹

The National Alliance to Impact the Social Determinants of Health (NASDOH), with guidance from the work of the CARIN Alliance, developed this brief to describe a pathway to develop such a secure consumer- and community-centric, open, interoperable SDOH data ecosystem. First, we describe why identifying and sharing SDOH-related information will improve care. Second, we describe when this information should be collected and shared at the point of service, and what types of information are relevant in this context. Third, we identify key challenges that inhibit SDOH data interoperability, and highlight important considerations regarding the sensitivity and complexity of exchanging this data. Fourth, we outline five key opportunities to advance this work. Finally, we call on stakeholders to advance durable solutions and offer a draft set of guiding principles for stakeholders to embrace if they choose to work on addressing SDOH data interoperability.

VALUE OF IDENTIFYING AND SHARING SDOH DATA

Social determinants of health (SDOH) have a significant impact on health outcomes for all people, with a disproportionate impact on vulnerable populations.² Understanding and addressing SDOH downstream and upstream can improve the health of both individuals and communities. Sustained success will require a multidisciplinary, strategic approach that leverages policy, programs, and partnerships between the public and private sectors. These efforts must be built in partnership with communities through their meaningful engagement and involvement.

One important challenge to meaningfully address SDOH is the fragmented communication and coordination between the public and private sectors providing clinical, social, and human services, and with the individuals and communities served. This fragmentation has many unfavorable consequences, including limiting the effectiveness of resource availability and allocation, negatively impacting the quality of care, and damaging health outcomes. It can also be a source of frustration and confusion for individuals needing services and supports to address the impact of SDOH.

INFORMATION TO BE CAPTURED

It is important to identify key information that should be captured, maintained, accessed, exchanged, and used to meet individuals' holistic needs. Figure 1 depicts a simplified view of how this information could be shared to support SDOH upstream in the community and downstream efforts to address individual needs. These systems need to support consumer-mediated exchange and permissions for sharing in the following ways:

1. Individuals should be enabled to share their individual SDOH information at the point they interact with a service provider.

- **Program enrollment:** Whether in social services or health benefits program, initial collection of SDOH data should happen at the point of enrollment by the entity responsible for the program (e.g., the public agency or health plan).
- **Encounter with a health, social, or other relevant service provider:** Providers (e.g., public health, public program, social care providers) need access to existing SDOH data from different sources and the ability to capture new SDOH data or update existing data when an individual seeks services.
- **Individual access to all information:** Individuals must have access to their own care plan data and other relevant information. Putting this information in the hands of individuals enables them to be active partners in managing their care, and it can also improve the quality of the information.

¹NASDOH, 2020, "NASDOH Commentary: SDOH Issues in COVID-19," available at <https://www.nasdoh.org/wp-content/uploads/2020/06/NASDOH-Commentary-SDOH-and-COVID-19.pdf>.

²Healthy People, 2020, "Social Determinants of Health," available at <https://www.healthypeople.gov/2020/topics-objectives/topic/social-determinants-of-health>, accessed June 2019.

2. The information captured needs to be easily shareable with partner organizations, with appropriate consent and protections.

- **Referral:** When the provider refers an individual, there is a need to identify whether an individual is eligible and enrolled in human service programs (such as Supplemental Nutrition Assistance Program (SNAP)) and which services are available in the region. There is also a need to generate and submit a referral to the service provider.
- **Data exchange with referring provider:** After an individual encounter with a provider, information should be exchanged with the referring provider as necessary to facilitate follow-up. Bidirectional communication is critical in this case.
- **Public health and human service program enrollment exchange:** There is a need for public health and human service programs to exchange data with service providers after an individual has interacted with them. Enabling this exchange ensures that updated SDOH and encounter information is available for follow-up purposes.

Given these needs, the information that would be useful to collect and share includes:

- **Individuals' social needs information:** An accounting of an individual's self-reported social needs or SDOH that impact them. For example, this report should include information on whether an individual experiences food insecurity. Note that in the aggregate, individual-level needs can be used to inform population-level opportunities for health improvement.
- **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. This information category would include, for example, data on whether the individual was connected with a food bank and received meals.

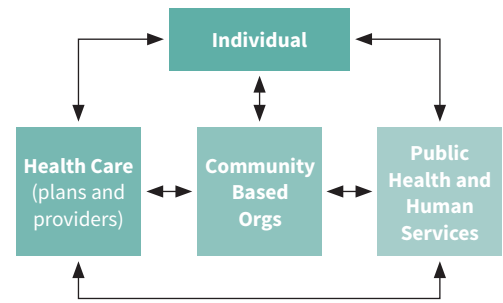


Figure 1. Individuals provide their individual SDOH information at the point they interact with a health care or social service CBO. This information is easily shared with partner organizations. For example, if an individual sees their health care provider and reports food insecurity, that information 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.

PREVAILING CHALLENGES IN CAPTURING AND TRANSMITTING SDOH INFORMATION

Despite the potential benefits of improving SDOH information sharing, there are technical and non-technical challenges that could potentially prohibit an interoperable SDOH ecosystem and must therefore be addressed. The range of issues to address include the following:

TECHNICAL CHALLENGES

CONSENT MANAGEMENT

SDOH data are crucial components of an approach to addressing individual needs, but entities covered by HIPAA may be hesitant about or restricted from sharing and exchanging this information with other providers (although not all SDOH data is subject to HIPAA). Defining parameters for the use and management of individuals' consent – consistent with HIPAA requirements and with individuals' expectations – is necessary. Accounting for dynamic consent management, which accommodates evolving individual preferences, can help alleviate individuals' concerns about having SDOH data automatically shared with new health care providers with whom they do not have an existing relationship, and entities' hesitancy to share this data. Dynamic consent management can also allay individuals' legitimate fears of bias or discrimination in subsequent interactions.

Another critical step is to adopt a set of transparent, responsible principles describing when and how an individual's personal information will be shared with entities that are not covered by HIPAA, and how these transactions will be communicated to and approved by individuals. NASDOH proposes a set of principles later in this paper, which address some of these issues; for example, the collection, use, sharing, and security of SDOH data should be known and consented to by individuals, and only the minimum amount of information necessary to fulfill that purpose should be captured or shared.

STANDARDIZATION OF SDOH DATA COLLECTION AND STORAGE

Facilitating communication and coordination between health care entities and CBOs must begin with a shared framework for collecting and storing SDOH data. Increasingly, health care entities and other organizations are collecting social need and risk

profiles at the point of service. Often, survey questions and modes of collection vary by entity. As population needs and survey psychometrics evolve, the questionnaires themselves also evolve. However, unless SDOH data are captured in a consistent, structured way using standardized terminology, they cannot be easily transmitted. Thus, standardization is essential to ensuring that information collected from an individual in one setting is meaningful when shared with another entity and in another setting.

DATA SHARING BETWEEN ECOSYSTEM PARTIES, INCLUDING THE CONSUMER

Just as with sharing of medical information, for SDOH data interoperability means seamless, bidirectional data exchange between two entities in a format usable by each system. If interoperability is achieved, it should be simple to identify an individual's social needs information, the programs for which they qualify, when they received an SDOH intervention, and what the outcome of that intervention was. The benefit of interoperability in this case is that SDOH risk can be incorporated into the care plan at the point of service, and interventions can be coordinated seamlessly. However, achieving and sustaining interoperability between health care entities and CBOs – in addition to including other social services (e.g. eligibility and enrollment systems for federal and state benefit programs) – requires technical architecture to describe how data and software relate. Additionally, there is a need to ensure that while information can be shared, it is done judiciously to maintain privacy. Access to data should be functionally limited to users for whom the information is relevant to provide or receive care, or be role-based. This may help foster adoption of interoperable solutions among service providers, who will be concerned about data security. Currently, several granular issues that inhibit data sharing within the ecosystem include:

- **Verifying individuals uniquely:** Verifying a person's identity and identifying that person across an SDOH ecosystem is a crucial component of sharing data and facilitating consumers' access to their own data. To enable seamless sharing, accurate identification of individuals is needed. At this time, there is no standard approach for identifying unique users across the health, public health, and social care electronic systems. Related, health care institutions are focused on individual records, while community-based service providers often have often use families or households as the point of reference for records. Their infrastructures are often engineered specifically to these purposes and create incompatibility. Verifying individuals uniquely is a challenge in these instances.
- **Proprietary technical infrastructure:** Currently, the tasks of sharing social need information between health and social care service providers, and then connecting individuals to services, are largely facilitated by vendor-developed digital platforms and, in some communities, by health information exchanges (HIEs) and community information exchanges (CIEs).³ These solutions are serving the important role of connecting health care and social care providers, but their proprietary approach precludes a standardized process for data transportation across the ecosystem. This requires local social care providers, who are often limited in capacity to begin with, to maintain connections with various platforms using individualized or proprietary technical infrastructures, or to limit with whom they work. An unintended consequence could be pushing critical CBOs with less technical capacity out of the community at the expense of individuals who require those services. Further, the lack of standardized data transportation solutions burdens proprietary platforms and HIEs/CIEs which experience barriers to entry in new communities because of the difficulty of building networks and connecting with public health and social care service organizations.
- **Lack of technical infrastructure:** Core to addressing social need is connecting with public sector human services programs, like housing or childcare assistance, to assess individual eligibility and enrollment in existing human service programs. Seamlessly connecting people to these resources requires access to human services administrative data, but to our knowledge, eligibility and enrollment information is not stored or shared outside of government agencies, and there is not existing modern technical infrastructure to support it.

NON-TECHNICAL ISSUES TO ADDRESS

ACCESS AND COMFORT WITH DIGITAL SOLUTIONS, AND CONCERNS ABOUT INFORMATION COLLECTION AND SHARING:

Vulnerable populations – including older adults, communities of color, those of low economic status, and individuals with limited English proficiency – are disproportionality impacted by social determinants of health. They may also have the greatest discomfort – justifiably – with their SDOH information being collected and shared because they are more likely to have experienced disparate or biased health care previously, are at greatest risk for misuse of SDOH data, and may face greater challenges accessing digital solutions. Relatedly, some individuals do not have the capacity to bear the responsibility for

³TAV Health, available at <https://www.tavhealth.com/solution>, accessed June 2019.

Modern Healthcare, "Addressing the Social Determinants of Health," available at <https://www.modernhealthcare.com/article/20170622/TRANSFORMATION03/170629956/addressing-the-social-determinants-of-health>, accessed June 2019; Healthify, available at <https://www.healthify.us/>, accessed June 2019.

HealthIT.gov, "What is HIE?," available at <https://www.healthit.gov/topic/health-it-and-health-information-exchange-basics/what-hie>, accessed June 2019. EHR Intelligence, "Texas HIE to Link Social Determinants of Health to Patient EHRs," available at <https://ehrintelligence.com/news/texas-hie-to-link-social-determinants-of-health-to-patient-ehrs>, accessed June 2019.

San Diego Health Connect, "The Story of San Diego's Health Information Exchange," available at https://www.healthit.gov/sites/default/files/data_sharing_care_coordination_and_population_health.pdf, accessed June 2019.

coordinating their data sharing, and we must avoid solutions which unfairly and inappropriately shift the expectation and burden for information sharing to individuals who may not have the resources or desire to do so. We must consider solutions that are sensitive to the concerns and circumstances of individuals, and technical solutions must accommodate individuals' needs and preferences.

SOCIAL CARE SECTOR CAPACITY AND CAPABILITY

The social safety net that stretches to support local communities' needs has persisted despite basic infrastructure and insufficient resources, and – in many cases – has adapted successfully through valuable, informal networks. Solutions, which are necessary and long overdue, must address both the strengths and the limitations of the very organizations that will be partners in meeting individual needs. The challenges go beyond technology gaps and include adequate resource availability, including workforce. The capacity of the social care workforce must be considered. Training, funding, and other supports should be considered in order for SDOH data collection and sharing efforts to be implemented successfully.

UNNECESSARY MEDICALIZATION OF SDOH

While making SDOH information available at the point of service is critical to providing individualized and equitable care, we must avoid approaches that medicalize SDOH. Medicalizing SDOH would be to the detriment of broader community and public health; instead, SDOH in partnership with individuals, their communities, and multi-sectoral partners, e.g. social care and public health sectors, which offer complementary strengths. Organizations that seek to advance technical solutions and benefit from SDOH interoperability must also consider when and where it is appropriate for the health care sector to partner with other sectors, and how SDOH medicalization can be avoided.

KEY ISSUES & OPPORTUNITIES TO ADVANCE SDOH DATA INTEROPERABILITY

NASDOH and the CARIN Alliance have identified five opportunities to address some of the challenges described in this brief. This is not meant to be an exhaustive list, but rather a recommended starting point for actions that can advance the development of the kind of open, interoperable data ecosystem that is critical to addressing individuals' needs, improving outcomes, and positively impacting SDOH.

OPPORTUNITY 1	OPPORTUNITY 2	OPPORTUNITY 3	OPPORTUNITY 4	OPPORTUNITY 5
Enable consumer-directed permission of SDOH information sharing	Ease collection of data on social needs	Support efforts to verify identity	Facilitate interoperability between service providers in SDOH ecosystem	Facilitate access to eligibility and enrollment in human service programs

OPPORTUNITY 1. ENABLE CONSUMER-DIRECTED PERMISSION OF SDOH INFORMATION SHARING

Previously, we described the need to secure individual consent (permission) while addressing privacy concerns in order to successfully share data across the ecosystem. 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. In some cases, approaches exist already, and we believe there are opportunities to adapt solutions in the field for transparent management of SDOH-related data, like the CARIN Code of Conduct⁴. Any solutions we adopt must account for diversity in consumer preferences and the likely evolution of those preferences over time. Further, technical solutions which enable information sharing, discussed below, must preserve privacy and security of the data so that it is consistent with individuals' preferences and so that it is not inappropriately or irresponsibly used and would harm individuals.

OPPORTUNITY 2. EASE COLLECTION OF DATA ON SOCIAL NEEDS

Simplifying the gathering and storage of an individual's social needs information could improve collection and reduce respondent burden. 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: the Gravity Project is identifying common data elements and associated value sets, and in North Carolina, the Department of Health and Human Services is collaborating with the National Library of Medicine's fast healthcare interoperability resources (FHIR) questionnaire app—an open-source tool that can be used to screen, collect, and store data gathered through questionnaires⁵. Any effort deployed should be coordinated and

⁴CARIN Alliance, "The CARIN Alliance Code of Conduct," available at <https://www.carinalliance.com/our-work/trust-framework-and-code-of-conduct/>.

⁵UCSF Siren, "The Gravity Project Charter," available at <https://sirennetwork.ucsf.edu/sites/sirennetwork.ucsf.edu/files/wysiwyg/Gravity-Project-Charter.pdf>, accessed June 2019.

standardized across sectors (e.g., housing and transportation) and should also be responsive to the individuals who may not want or be comfortable with their social need and risk information being collected and stored.

OPPORTUNITY 3. SUPPORT EFFORTS TO VERIFY IDENTITY

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. The CARIN Alliance and others, like the Office of the National Coordinator's FHIR at Scale Taskforce (FAST)⁶, are considering opportunities to advance identity solutions for health care, including the testing of identity solutions and the federation of identity credentials across the health care ecosystem. There is an opportunity to support these efforts so they may be useful in the context of SDOH information sharing.

OPPORTUNITY 4. FACILITATE INTEROPERABILITY BETWEEN SERVICE PROVIDERS IN SDOH ECOSYSTEM

The proliferation of proprietary vendor platforms or HIEs/CIEs to share social need and connect individuals to services introduces burden to providers to be equipped to work with differing systems. There is an opportunity to facilitate bidirectional SDOH data sharing between consumers, and social, health, and other service providers by building open standards to support a single digital infrastructure for accessing and exchanging this information. One potential approach could be developing a FHIR-based application programming interface (API) to support interoperability between the various service providers in the SDOH ecosystem, and with consumers and caregivers. The development of an API allows for connection and exchange through a HIE, or another proprietary platform, based on their needs and preferences (See Figure 2 – the exchange of this data is exemplified by the orange connections), and eliminates the restrictive and individualized interface common now. This approach would also enable individuals to access their own information, facilitate information access at the point of service (which is essential for high quality and safe care), reduce the burden on service providers to connect to multiple digital infrastructures, and provide each stakeholder in the ecosystem with equal market access. However, open-source, FHIR-based API present unanswered questions about necessary privacy safeguards and consumer protections, and may still present barriers for CBOs, depending on their technical capacity. Thus, it is important that privacy and security preservation issues, including the digital infrastructure capacity of CBOs, must be understood and addressed before technical solutions are implemented.

OPPORTUNITY 5. FACILITATE ACCESS TO ELIGIBILITY AND ENROLLMENT IN HUMAN SERVICE PROGRAMS

Real-time eligibility and enrollment information for state-administered social and human service programs would support efforts to address social need. There is an opportunity to build open standards for accessing and exchanging information with states. One approach is developing a FHIR-based API to support interoperability between the various actors in the SDOH ecosystem and state governments to access real-time eligibility and enrollment data. This facilitates the sharing of information about an individual's social needs and eligibility/enrollment in human service programs, which can positively impact their health and wellbeing (See Figure 2 – the exchange of this data is exemplified by the green connections). A technical architecture to guide verification of eligibility and enrollment in government programs may already exist.⁷

However, this opportunity may be the most challenging to solve. Because of the sensitivity of eligibility and enrollment data, any approach must adequately account for granular permission and consent, so that information is shared only when and with whom consumers approve, and data privacy and security to prohibit irresponsible and unethical data use. The FHIR standard adopted in health care may be less common across the human services.⁸ Finally, states take diverse approaches to implementing programs, including reliance on contractors and community organizations, which can make implementation more complex.

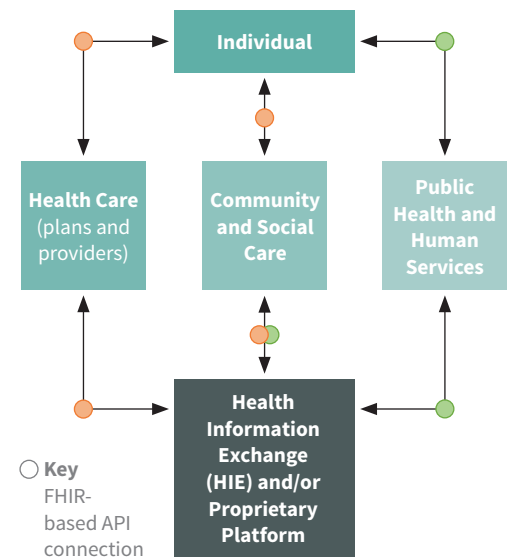


Figure 2. Health Information Exchanges (HIEs) and/or Proprietary platforms could connect health care services providers, to community and social care service providers, and eligibility and enrollment administrative data using FHIR-based APIs. Patients would consent to any data sharing.

⁶National Library of Medicine, "Addressing Social Determinants of Health with FHIR Technology," available at <https://nlmdirector.nlm.nih.gov/2019/10/22/addressing-social-determinants-of-health-with-fhir-technology/>.

⁷Section 1561 of the Patient Protection and Affordable Care Act (ACA) required the federal government to develop interoperable and secure standards for "providing individuals and third parties authorized by such individuals and their designee's notification of eligibility and verification of eligibility required under such programs." Currently, ACA Section 1561 is not operationalized. Given the Administration's recent emphasis on interoperability, there is an opportunity to develop a public-private partnership with government agencies that seek to provide beneficiaries with more direct access to information about social programs. Source: Protection, P., & Act, A. C. (2010), Patient Protection and Affordable Care Act, Public Law, 111(148), 1.

⁸Stewards of Change – Let's Get Technical Workgroup (2019), "Reconciling NIEM and FHIR for Data Sharing," video available at <https://www.youtube.com/watch?v=UCeiRhiETNQ>.



NEXT STEPS

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. Most critically, NASDOH calls for these partners to promote individual-focused approach to SDOH data interoperability that protects the most vulnerable and the privacy and security of this extremely sensitive data, and develop technological solutions which ensure an individual's privacy, consent, and data sharing preferences are accounted for and respected. Practically, some early actions should include considering SDOH data as part of a future version of the USCDI core data set and development of open standards for exchanging information between consumers and service providers.

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 for all stakeholders to be effective partners in improving national health.

- Collaborative approaches: Successful projects will involve key stakeholders across the ecosystem (plans, providers, proprietary digital platforms, CBOs, and potentially governmental human services agencies, working in close concert with patients, consumers and advocates), which can identify local needs and engage community partners effectively.
- Individual-centric and purpose-specific: Data sharing will be in service of meeting an individual's clinical and social needs. Only the minimum amount of information necessary to fulfill that purpose should be captured or shared, and the entire process should occur only with the individual's knowledge and permission.
- Strict privacy and security practices: SDOH information on individuals should be protected from risk using reasonable safeguards, and confidentiality should be maintained.
- Transparent: The collection, use, sharing, and security of SDOH data should be known to individuals. This information should be understandable and easily accessible to individuals.
- Open standards-based: Technical standards should be based on open standards. Open standards are publicly available and the right to use is unrestricted, which allows for interoperability and easier implementation.
- Flexible architecture and operational structure: The data architecture and governance structures should be inclusive and capable of advancing as technology, service models, and needs evolve.
- Interoperable, federated exchange model: The model should support hosting of consumer data at the location of an individual's choice.
- Multi-directional exchange approach: Multi-directional exchange allows for better data accuracy and ensures that data is consistent across the ecosystem. It also promotes sharing and use of consumer-generated data.

CONCLUSION

Understanding an individual's social needs and making their comprehensive care plan available to them and to other providers at the point of service is crucial to improving individual wellbeing.⁹ Securely storing this information makes it readily available when needed and reduces the burden on service providers to collect – and on individuals to report – the information repeatedly. Sharing this information among health, social, and human service providers and with the individuals they serve has the potential to make care delivery more efficient and effective. There are still important technical issues which must be addressed to facilitate SDOH data interoperability. However, any solutions must be implemented responsibly and in individual-centric ways. Perhaps even more critical are the non-technical considerations which must be accounted for – the sensitivity of SDOH information, its appropriate use and disclosure, and the necessity of proceeding only when an individual has consented – before SDOH interoperability can be implemented. If pursued, we believe the five opportunities we have identified in this paper can improve wellbeing and health.

ABOUT NASDOH AND THE CARIN ALLIANCE

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. NASDOH brings together health care, public health, and social services expertise, local community experience, community-convening competence, business and financial insight, technology innovation, data and analytics competencies, and policy and advocacy acumen to assess and address current regulatory frameworks, funding environments and opportunities, and practical challenges to implementing and sustaining social determinants of health efforts. One of NASDOH's guiding principles underscores the importance of leveraging digital strategies to improve health and well-being including promoting bidirectional information flow with appropriate attention to privacy, proper use, and data security. For more information, please visit www.nasdoh.org.

The CARIN Alliance is a non-partisan, multi-sector alliance led by distinguished risk-bearing providers, payers, consumers, health IT companies, and consumer advocates who are working collaboratively with other stakeholders and leaders in government to overcome barriers in advancing consumer-directed exchange of personal health information across the U.S.¹⁰ The CARIN Alliance seeks to rapidly advance the ability for consumers and their authorized caregivers to easily get, use, and share their digital health information when, where, and how they want to achieve their goals. For more information, please visit <https://www.carinalliance.com/>.

⁹NASDOH (2019), "Identifying Social Risk and Needs in Health Care," available at <http://www.nasdoh.org/wp-content/uploads/2019/01/NASDOH-Social-Risks-Issue-Brief.pdf>.

¹⁰Consumer-directed exchange occurs when a consumer or an authorized caregiver invokes their HIPAA Individual Right of Access (45 CFR § 164.524) and requests their digital health information from a HIPAA covered entity (CE) via an application or other third-party data steward.



ABOUT NASDOH

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