AUGUST 2023

Stewards of Change Institute Consent Learning Lab

2023 Healthcare Information Management and Systems Society Annual Conference

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Executive Summary

Stewards of Change Institute (SOCI) has focused on the issue of informed consent to share protected and private data since 2018, when we created the National Interoperability Network (NIC) as a community network to advance information sharing and collaboration across diverse domains (including the expansive fields of health and social services). As part of NIC's work, we subsequently launched Project Unify and the National Action Agenda to Advance Upstream Social Determinants and Health Equity, which produced a set of six recommendations. In addition, SOCI produced an important, influential report relating to consent-to-share, titled Modernizing Consent to Advance Health and Equity: A National Survey of Key Technologies, Legal Issues and Promising Practices.

In April 2023, SOCI brought together 60 highly accomplished subject-matter experts – representing health care, social care, education, housing,

nutrition, and other sectors – for a first-of-its-kind Consent Learning Lab. The convening was held in collaboration with HIMSS at its annual global conference in Chicago. HIMSS' ongoing focus on expanding information sharing beyond medical care – in partnership with SOCI and in numerous other ways – is important because it demonstrates that the medical establishment understands the vital importance of sharing data across programs and domains.

The Learning Lab was designed specifically to address consent-to-share's challenges because of the national implications for better integrating the social determinants of health, improving person-centered care, and enhancing care coordination across sectors. *SOCI's full report on the Lab provides details about the day's activities, discussions, learnings, and recommendations.*

LEARNING LAB OBJECTIVES AND WORKGROUPS

- Examine existing practices and, especially, challenges to progress

- Identify opportunities to improve practices and harmonize standards

- Propose specific, actionable, near-term policy recommendations

Five Key Areas

Governance and Organizational Development

Equity

Legal, Privacy, and Confidentiality

Technology and Information Management

Interagency Systems & Administration

The primary themes discussed by each of the five workgroups at the Lab were:

- Obstacles and opportunities for better data sharing

- Improving consent-to-share practices

- Implementing consent management through technology and standards

- Legal and ethical considerations

- Patient/client engagement, equity and education

KEY POLICY RECOMMENDATIONS

The Learning Lab's discussions were designed to identify actionable policies and practices that could be applied in the near term (2023-2024) to advance consent, while protecting individual rights, promoting equity, and fostering ethical decision-making. Toward that end, participants made a series of high-level, longer-term, strategic recommendations, all of which are described in the full Lab report.

What became clear from our discussions is that progress can be made, but will require federal and state leadership, support, commitment, and resources. Against that backdrop, we highlight two particularly significant recommendations below because they could be advanced in the immediate term by focusing community efforts to:

- *Strongly encourage states to prepare/submit an Advance Planning Document (APD) to the Centers for Medicare & Medicaid Services (CMS) specifically requesting 90/10 Federal Financial Participation (FFP) to design, test, and implement consent-to-share initiatives.*

  CMS has said 90/10 FFP is warranted when the investment will "benefit the Medicaid Program." That clearly would be the outcome of improving a state's technical ability to share myriad health and social care data more effectively, securely, and ethically. States can also submit an APD to fund an initiative's Maintenance and Operations, requesting 75/25 FFP to operate it in perpetuity. Starting an effort with such secure funding would undoubtably improve its prospects for success.

- *Advocate and educate on the need to integrate consent-to-share practices for social care and other programs into key existing laws, regulations, and policies that address medical/clinical issues.*

  It is critical to seize the moment, while the overarching rules are being formulated and implemented into day-to-day practices and solutions. Examples include the 21st Century Cures Act, the Trusted Exchange Framework and Common Agreement (TEFCA), the Modernization Initiative of the Office of the National Coordinator for Health IT (ONC) and the Centers for Disease Control and Prevention (CDC), and Section 1115 Whole Person Care Waivers from CMS.

FRAMING THE CONVERSATION

The final section of this Executive Summary offers a glimpse of the Learning Lab's key speakers, listed here both to illustrate the breadth and expertise of the event's participants and to offer a few of their insights, which helped to frame the day's guided discussions.

- **Daniel Stein**, SOCI President, said the Lab's main goal was to encourage a shift from "admiring the problem" to finding and agreeing on actionable solutions.

- **Stephen Kony**a, Senior Advisor to the ONC Deputy National Coordinator and Innovation Portfolio Lead at HHS, said ONC is leveraging SOCI's work on this issue.

- **Valerie Rogers**, HIMSS Senior Director of Government Relations, cited interoperability and consent as two key aspects for successfully implementing Data Modernization program.

- **Alfonso Montero**, CEO, European Social Network, stressed consent as a fundamental human right closely tied to self-determination and the importance of seeking permission.

- **Lisa Green, M.D.**, Family Christian Health Center CEO (Chicago), discussed the adverse impacts of lacking consent on care coordination, including delays in care and higher costs.

- **Kristine McCoy, M.D., M.P.H**., SOCI Senior Consultant, identified the fact that consent is "nobody's job" in organizations, resulting in silos becoming more entrenched.

- **Brian Handspicker**, SOCI CTO, Project Unify Co-lead, emphasized a need for new mindsets, tools and standards – as well as demonstration projects – to work across silos.

- **Chris Alibrandi O'Connor, J.D.**, Deputy Director, Network for Public Health Law, outlined overlaps and conflicts between federal and state laws such as HIPAA and 42 CFR Part 2.

- **Sue Feldman, RN, Med, PhD**, FACMI, University of Alabama, spoke about the need for a systems approach encompassing people, processes, and technology.

CONCLUSION

The Consent Learning Lab provided a timely and unique opportunity to convene subject-matter experts from multiple disciplines to provide insights and formulate actionable recommendations to advance consent-to-share practices in the short and long terms.

SOCI recognizes that implementing solutions across the spectrum of care will likely require a decade or longer, comparable to the time it is taking to operationalize electronic health records. Furthermore, meaningful progress will require that federal, state, and local organizations work together to design, test, and disseminate successful tools and models that address the complex factors associated with obtaining, managing, and revoking consent to share.

In the near term, there are a several consent pilots already underway across the country that offer insights and promising solutions. There is no national leadership and/or coordination of efforts to harvest their collective learning, however, so that successful solutions can be developed, replicated, and customized to meet local laws, programs, and legacy infrastructures. Scaling promising solutions will require an enterprise, system-of-systems approach that addresses the complexity of the challenge and provides the resources and commitment from governments at all levels, as well as industry, academia, and the nonprofit communities.

SOCI's hope is that this report's findings and recommendations will contribute to the growing body of knowledge about consent-to-share issues; will be used to advance policy and practice over the next few years; and will provide useful guidance for long-term success.

"TRUST ISN'T GIVEN, IT'S EARNED."
DR. LISA GREEN, CEO, FAMILY CHRISTIAN HEALTH CENTER

Stewards of Change Institute
Consent Learning Lab Full Report

2023 Healthcare Information Management
and Systems Society Annual Conference

INTRODUCTION

The Stewards of Change Institute (SOCI) Consent Learning Lab, was held in collaboration with the Healthcare Information Management and Systems Society (HIMSS) on April 17, 2023, during HIMSS' annual global conference in Chicago. The Learning Lab brought together 60 subject-matter experts to address the crucial topic of informed consent to share protected and private data across the spectrum of care.

By encompassing health care, social care, education, and other sectors, the Learning Lab addressed the challenges and opportunities surrounding consent across these interconnected domains. The discussions and insights shared during the convening were designed to contribute to the ongoing development of informed and actionable policies and practices that could be applied in the near term (2023/2024) to advance this type of consent, while also protecting individual rights, promoting equity, and fostering ethical decision-making.

The objectives of the Lab, and of this report, included:

- Examine existing privacy and consent practices and challenges associated with data sharing in health care, social care, education, housing, behavioral health, nutrition and other sectors.

- Identify actionable recommendations and opportunities for improving privacy and consent practices and harmonizing relevant standards.

- Propose specific, actionable policy recommendations to promote responsible and ethical data sharing in these sectors to impact near-term and longer-term programs.

This report examines the challenges, opportunities, and actionable policy recommendations to accelerate and advance informed consent practices and data sharing across the spectrum of care. It includes a brief background and historical context for SOCI's consent- related work; a short situational analysis of current issues/hurdles related to obtaining and managing informed consent to share information; a summary of remarks by Learning Lab planners and facilitators; a summary of recommendations; and a more-detailed outline of those recommendations derived from iterative breakout and whole-group discussions. It provides a general overview of process, observations and short- and long-term recommendations about the role of consent practices in overcoming structural obstacles and potential policy changes for 2023/24.

BACKGROUND

SOCI created the National Interoperability Collaborative (NIC) five years ago as a community network to enhance information sharing, collaboration, and interoperability across diverse domains, including the expansive fields of health and human services. Focused on local, state, and national partnerships, NIC's key objective is to promote systemic changes that improve the lives of those disproportionately affected by racial and economic disparities.

In August 2020, SOCI and Stanford University's Center for Population Health Sciences, along with other organizations nationwide, led a joint initiative, the National Action Agenda to Advance Upstream Social Determinants and Health Equity (NAA). The NAA was formed to instigate and implement tangible, systems-level changes across health, social services, education, public health, public safety, and other domains identified by NIC as relevant to its work.

Following the launch, six dedicated workgroups, each focusing on different social determinants, were formed in late August 2020. These teams engaged in monthly work sessions, synthesis, and prioritization meetings from September 2020 to January 2021. The NAA followed up with a national symposium on January 25-26, 2021, marking another milestone. The event served as an avenue to showcase six action recommendations developed by subject-matter experts; it also provided a glimpse into the planned activities at the first implementation site.

Focusing on consent emerged as the consensus priority among the 150+ participants who participated in the NAA. Consent was recognized as the single most-important action that could advance data sharing, interoperability, and care coordination. SOCI then published a comprehensive, influential report, "Modernizing Consent to Advance Health and Equity: A National Survey of Key Technologies, Legal Issues, and Promising Practices."

The aforementioned series of actions – propelled by the NAA, NIC and other efforts by SOCI and its collaborators – has led to our current focus on using the knowledge we've accumulated and developed to shape policy recommendations and drive genuine progress. We also want to underscore that the journey from NAA's launch to recent consent-related developments shows the critical importance of operating with a collaborative spirit, an embrace of technical innovation, and a shared commitment to social justice and health equity.

OPENING PLENARY REMARK SUMMARIES

The primary purpose of the Consent Learning Lab was to drive progress in service delivery, decision-making, care coordination, and collaboration. The following is a summary of the introductory remarks by the core team of the event's planners and facilitators.

- **Daniel Stein, SOCI President and Co-founder**, emphasized the day's opportunity for substantial insights and direction-setting, drawing on the attendees' collective knowledge and experience. Highlighting consent as a common factor in everyone's work, Stein said the Learning Lab's main goal was to encourage a shift from "admiring the problem" to finding and agreeing on actionable solutions. Despite the complexities involved, he expressed optimism based on several factors, including broad acceptance of whole-person care; generous federal funding opportunities, such as 90/10 Federal Financial Participation (FFP) from the Centers for Medicare & Medicaid Services (CMS); other governmental interest and support, including by the Office of the National Coordinator for Health IT (ONC) and the Office of General Counsel at the Department of Health and Human Services (HHS); technological advancements; shovel-ready pilot sites; and the presence of the right subject-matter experts in the room.

- **Stephen Konya, Senior Advisor to ONC's Deputy National Coordinator and Innovation Portfolio Lead at HHS**, echoed the sentiment that the time is right for addressing consent-related issues. He cited ONC's collaboration with numerous organizations to pilot and explore potential use cases, and highlighted the agency's efforts to understand the problem from a human perspective through a consent workshop based on personas. Rather than duplicating existing analyses, he said, ONC has sought to leverage the work done by SOCI and intends to distribute a Request for

Information (RFI) to gather feedback and responses. Konya also emphasized ONC's collaboration with payer partners and the FHIR At Scale Task Force (FAST). He acknowledged the tendency to table consent as a placeholder for later and stressed its continued importance in all of ONC's work.

- **Valerie Rogers, HIMSS Senior Director of Government Relations** cited interoperability and consent as two key aspects of public health data modernization. HIMSS has called for a $36.7 billion investment in digitization, standardization, and innovation in order to transform and interoperate state, territorial, local, and tribal governmental health agencies. Rogers raised the question of whether eConsent could be considered a low-hanging fruit in this regard. She identified maternal and adolescent health as important policy areas where use cases would be beneficial and highlighted the need to triangulate CDC, CMS, ONC, HRSA, IHS, and private sector data modernization efforts to ensure improved outcomes. She also advocated for health equity and the consideration of consent for caregivers, emphasizing the implications for families rather than only individuals.

- **Alfonso Montero, CEO, European Social Network**, emphasized that consent is closely tied to people's self-determination and the importance of seeking permission. He raised key considerations, including the process of withdrawing consent and the possibility of denying consent while still receiving treatment. Montero stressed the need to protect and empower individuals through consent, particularly highlighting the challenge of working with children. He outlined requirements for consent, emphasizing explicit recording and compliance monitoring. Montero provided an example of the tension that exists, questioning whether a social worker can gather information about a client from social media. He concluded that informed consent reflects respect for individuals' rights to self-determination, autonomy, and social inclusion.

- **Lisa Green, M.D.**, Family Christian Health Center CEO, discussed the adverse impacts of lacking consent, such as delays in care and increased costs. Green highlighted that consent is crucial for whole person care and care-coordination efforts and is one of the major barriers and issues facing the Federally Qualified Health Center (FQHC) that she leads in Chicago.

- **Kristine McCoy, M.D., M.P.H.**, SOCI Senior Consultant, stressed the importance of considering families, not just individuals, when managing consent. She underscored the mission of bringing people and organizations together to improve everyone's outcomes. McCoy also identified that consent is "nobody's job" in organizations and said that results in silos becoming more entrenched, which further erodes efficiency, effectiveness, and outcomes, especially for people who are the most vulnerable.

- **Brian Handspicker, SOCI CTO, Project Unify Co-lead**, stressed the need for new mindsets, tools, and models to work across silos, with the goal of minimizing duplication and leveraging existing promising practices. He proposed leveraging current and emerging tools, standards, methods, and experience to guide the design of proof-of-concept projects in consent management.

- **Chris Alibrandi O'Connor, J.D., Deputy Director, Network for Public Health Law**, discussed the overlap of and conflicts between federal and state laws such as the Health Insurance Portability and Accountability Act (HIPAA) and 42 CFR Part 2. She emphasized balancing individual rights with the need to share data and identified "the culture of no" as a prevalent problem. She also addressed the common mistake of requiring consent when it is not necessary, citing the variation in organizations subject to HIPAA. And she proposed the possibility of a "forcing function," such as a child's death, to catalyze change, referring to Scotland's national interoperability strategy.

- **Sue Feldman, RN, Med, PhD, FACMI, University of Alabama**, emphasized the need for a systems approach encompassing people, process, and technology. Her ultimate focus was on achieving better, safer, and higher-quality care outcomes.

Proceedings of Consent Learning Lab Sessions:

The Consent Learning Lab was a daylong event with a series of breakout sessions that brought together subject-matter experts to address consent-management challenges, identify opportunities for improvement, and recommend actionable solutions that could be implemented in the near and longer terms. The experts were organized into five workgroups based on key focus areas identified and refined since the launch of the NAA:

Five Focus Areas

Governance and Organizational Development

Equity

Law, Privacy, and Confidentiality

Technology and Information Management

Interagency Systems & Administration

- A standardized process was used to generate recommendations by the 60 participants from across the nation. Their expertise spanned pivotal aspects of consent, displayed in the graphic above. A list of participants and organizational affiliations is in Appendix 1.

- The workgroups used a structured worksheet to methodically, iteratively process discussions and capture ideas in a series of breakout sessions. The intent was to refine their thinking about the five major areas of inquiry.

- Discussions focused on using a standardized scenario and personas that articulated specific use cases that could be explored regarding a multisystem-involved family. The Thomson Family Case Study is in Appendix 2.

- Each group identified key barriers, opportunities, and most importantly, potential policy-related recommendations that could begin implementation in 2023-2024.

Summary of Key Themes:

The conference covered a range of themes that are applicable to the broad spectrum of health, human services, education, and other practitioners. Discussions examined consent models and frameworks, addressing their relevance beyond health care. Exploring various processes and mechanisms – such as informed consent, implied consent, and opt-in/opt-out models – provided valuable insights applicable to a broader audience.

Key points discussed included:

- **Obstacles to Data Sharing**. The structural obstacles identified included program-specific regulations, lack of trust among stakeholders, multiple consent forms, assessment fatigue, concerns about minor consent, and data silos.

- **Improving Consent Practices**. The actions suggested for improving consent practices included training, establishing durable trust, incorporating the social determinants of health, and empowering individuals with self-determination in their consent choices.

- **Technology and Standards**. The role of technology and standards in consent management resonated across professional domains. The Lab highlighted emerging technologies and their potential to improve consent practices, including smart contracts and consent management platforms and standards, offering practitioners novel ideas and solutions.

- **Legal and Ethical Considerations**. The legal and ethical aspects of consent management included addressing data privacy, consent for vulnerable populations, and legal frameworks such as the General Data Protection Regulation (GDPR) that have implications beyond health care.

- **Patient/Client Engagement and Education**. The significance of patient/client engagement and education in the consent process was emphasized. Sessions provided strategies for improving understanding, which can be translated to engaging students, service users, or justice-involved individuals in education, social care, and justice settings.

DETAILED SUMMARY OF FIVE BREAKOUT GROUPS

The Learning Lab utilized SOCI's interactive approach to engage participants in focused workgroups to discuss and dissect the intricacies of consent for the Thomson Family use case. The five groups explored barriers, opportunities, and actionable policy recommendations to drive immediate action. Leveraging the insights from their expert members, these groups utilized customized worksheets to structure, expand, and subsequently refine their thought processes and to generate policy recommendations.

1.   Governance and Organizational Development

The goal in this area was to create an integrative framework that ensures effective communication, delineates decision-making authority, and promotes harmonious cooperation among participating organizations and agencies. One way to achieve that goal is to weave these diverse entities into a comprehensive network that can recognize the synergies among providers and then meet the needs of the populations they serve.

Barriers and Challenges:

The obstacles identified that inhibit data sharing at a structural level were:

- **Lack of Trust**. This was found to exist systemically; that is, between service providers and between the providers and the people they serve. Without cross-sector collaboration and governance, multiple silos of individual data remain disjointed. Because of the many silos, providers across health and social service programs do not necessarily trust that their counterparts dealing with the same families/individuals are accurately collecting and recording important data that should be shared across programs. Furthermore, many additional trust-related challenges are related to race, socio-economic disparities and, especially in the wake of recent Supreme Court decisions and state-level

actions, the sharing of information for people who are trans/LGBTQ or pregnant.

- **Lack of Simplicity**. Consent forms and processes can be lengthy, complex, and vary greatly among programs, agencies, and organizations. This creates an obstacle to data sharing, as the many different providers helping a family are operating with differing consent practices that do not align. Participants also discussed that asking individuals or families to sign multiple consent forms that contain legal jargon and are difficult to digest undermines the "informed" component of consent.

- **Differing Regulations**. The laws, regulations, and policies regarding data sharing are unique to individual programs, and they vary from state to state and from program to program. Reconciling the different requirements can be a daunting task, for which no single person or entity has responsibility or authority. ("Consent is nobody's actual job.")

- **Differing Providers**. Because they operate independently, various care providers have developed and use differing consent forms but with a common denominator: They often include lots of dense, legal jargon that can impede achieving genuinely "informed" consent.

- **Assessment Fatigue and Re-traumatization**. The people seeking assistance have most often suffered from some type(s) of trauma. Having them repeatedly fill out forms or verbally relate why they need help forces them to relive their trauma and can make them averse to sharing information about it; worse, it can lead them not to ask for services at all. Additionally, since program eligibility enrollment often asks for the same or similar information people get fatigued by having to recount and submit the same information multiple times.

- **Minor Consent and Children's Rights**. Concerns were expressed about who has the authority and responsibility for providing consent on behalf of minors.

- **Multiple Data Silos**. The reality that information is contained is so many different systems complicates care coordination, among other problems. In most cases, it is due to the lack of standardized data collection and management of consents to share. A lack of secure, digitized, and computable data also contributes to this obstacle.

Opportunities:

- **Trust**. Cross-sector governance to develop shared consent practices was discussed by participants as a strategy to improve trust. With a goal of moving toward a "single source of truth," this strategy would ensure buy-in across health care and social sectors to facilitate better data sharing through agreed-upon policies and procedures. It would also support trust-building among patients/clients and systems if individuals were not asked to re-share their personal histories – which is often retraumatizing – and if they knew their providers were following uniform consent practices.

- **Simplicity**. Simpler, standardized consent forms would better-enable people to provide truly informed consent. Additionally, standardizing consent-to-share practices with the goal of moving toward multi-program universal forms would likely lessen "assessment fatigue" and support individuals' self-determination via increased engagement and awareness.

- **Training**. Relevant workers at each provider organization should receive training to enhance their understanding of consent practices and how they should be explained, implemented, managed, and revoked.

- **Truth**. A single source of truth should be established to definitively identify the individual whose data is being accessed and shared. Having such a "golden record" would ensure that information

about the individual is up to date and accurate.

- **Self-determination**. Enabling people to participate in the process of providing (and/or revoking) consent to share private data puts the decision-making authority into their hands. Promoting this critical aspect for individuals in the consent process shows respect and builds trust.

Recommendations:

- Advance federal standards on the capture of detailed, granular consent and on the revocability of consent to build trust of health and social service systems, while also honoring self-determination for patients/clients.

- Create a model universal consent form with common, cross-sector information-sharing use cases at the federal level (i.e., sharing between health care, social care, education, housing, nutrition, etc.). Incorporate field testing with diverse audiences of patient/consumer groups to increase the readability of the model form.

- Simplify consent forms to ensure they are not too long and complex and are written in easily understood language.

- Incorporate consent to share for non-HIPAA entities and providers including social care, education, housing, foster care, and others as part of the 21st Century Cures Act and TEFCA. Ensure that data blocking is prohibited between organizations in the same way that Cures addresses information blocking as prohibited beginning 2023 for protected medical information.

- Introduce standardized tagging of sensitive data for better tracking and control of granular data.

- Develop advanced standards on how to revoke consent and maintain version control.

- Establish a federal age of consent as a long-term goal.

- Enable an expedited consent process for disaggregated data sharing to drive care and innovation.

- Address the need for granular consent capture to empower individuals to choose what is shared, what is not, with whom, and under what circumstances.

2. Equity

This area is rooted in the understanding that people with varying backgrounds and life experiences have unique perspectives and needs when seeking or receiving care, especially if they are involved with multiple systems. The goal is to surmount systemic challenges such as socioeconomic disparities, racism, homophobia, and other problems that can inhibit equitable access to services and supports. Those also include hurdles relating to stigma, misuse of personal information, and inequitable access to technology, among others.

Barriers and Challenges:

- **Lack of Understanding**. People often sign consent forms without fully understanding their contents, or the implications of doing so, or out of concern that they won't receive the services or other benefits they are seeking if they don't comply.

- **Conflicting Laws**. The sharing of sensitive data is impeded by conflicting state and federal laws (and sometimes local interpretations), which can lead to confusion and onerous compliance requirements. The result can also be to exacerbate disparities and implicit biases. The impact of opting out of data sharing, risk stratification, and willingness to disclose sensitive information

needs further study to develop and test solutions that improve services and care coordination.

- **Lack of Inclusion**. People with lived expertise are not routinely included in meaningful ways in the development and testing of consent forms and practices.

Opportunities:

- **Documenting and Widely Disseminating Best Practices**. Identifying such practices by authoritative sources for providers and consumers was seen as crucial. Providers often aren't aware of the difficulties faced by individuals in understanding information sharing and consent.

- **Building Trust among Marginalized Communities**. This goal was highlighted as a way to promote informed consent. Understanding the purpose behind data sharing requests and how the data will be used afterward was also viewed as important.

- **Simplifying Processes**. This was viewed as necessary not only for consent forms, but also the processes involved in changing consent preferences, removing paperwork burdens, and making it easy for individuals to revoke consent.

- **Simplifying the Regulatory Landscape**. The laws, regulations and other rules surrounding consent are complex; simplifying this landscape was identified as an opportunity to facilitate compliance.

Recommendations:

- Legislate funding and appropriations specifically for consent-related initiatives. Relatedly, states should be educated about accessing CMS funding to access 90% Federal Fund Participation reimbursement, as well as 75% maintenance and operations funding for long-term sustainability.

- Develop community-based user stories that are familiar to and resonate with individuals and highlight the importance of consent to build trust. Patient advocates and education campaigns targeted at providers and patients were seen as valuable.

- Assess existing pilot projects, such as the Authorization to Share Confidential Medi-Cal Information (ASCMI) initiative in California. This work could be conducted or authorized by ONC. Also, support/conduct/update a landscape analysis to capture learnings to inform policy and regulation.

- Advocate for a human-centered design approach, utilizing principles like standardized personas/user stories, leveraging consumer insight research to inform education, and incorporating insights and lessons learned from successful projects.

- Propose legislation for improving consent documents and processes by 2025, using previous examples like HIPAA to establish reasonable precautions and to incentivize compliance.

3. Law, Privacy, and Confidentiality

This key area covers the statutes governing the balancing act between individual privacy rights and the need for personal health information disclosure. It encourages a shift away from a risk-averse "culture of no" and calls for clearer and more synchronistic health data privacy laws. Additionally, it endorses the adoption of consent standards for the sharing of health-related information that are voluntary, informed, understandable, and meet competency requirements.

Barriers and Challenges:

- **Lack of Alignment**. Lab participants identified a lack of consistency and alignment in the application of laws as a primary obstacle to sharing information.

- **Broad Impact**. The lack of alignment includes what entities are subject to a law, what data would be shared, for what purpose the sharing will take place, and how the information will be shared.

- **Doubt and Confusion**. The result of the lack of alignment is uncertainty, an aversion risks to avoid making a mistake, and often the perception that data cannot be shared when it legally could be.

Opportunities:

- **Communicating the Law**. Data holders and consumers should be educated about relevant laws and regulations in digestible ways that take literacy into account.

- **Clarifying Organizational Policies**. Making these more understandable, along with other out-ward-facing materials, when uses or disclosures of information are made with or without consent.

- **Supporting Computable Consent**. This is vital when sharing data across sectors, considering the data elements needed, and whether data needs to be shared proactively or based on queries.

- **Building Understanding**. This applies to the extent to which certified Electronic Health Records (EHR) technology products are installed and/or modified to comply with consent laws.

- **Utilizing Minimum Necessary Standards**. This applies to all uses and disclosures beyond HIPAA requirements.

Recommendations:

- HHS should create an inter-agency workgroup to produce sub-regulatory guidance to stakehold-ers regarding privacy and confidentiality laws, using real-life data-sharing scenarios to illustrate a "pathway to yes."

- Inter-agency representatives should work with state program leads, where appropriate, to en-sure that guidance is put into practice.

- ONC's authority should be expanded beyond the regulation of EHR technology to include other types of technology that are utilized in social service settings.

- ONC should develop a multidisciplinary training program approach to consent-to-share and should fund implementation projects at the local level.

- ONC and the Sequoia Project should prioritize consent-sharing use cases in TEFCA for social care, in addition to the current focus on clinical/medical care.

4. Interagency Systems and Administration

This area highlights the necessity for a systems approach to achieve whole-person care. Such an approach necessitates a shift in perspective and dialogue in order to instigate changes within and across systems and organizations to facilitate the neces-sary transformation. It also acknowledges the key role of technology as an enabler in the process.

Barriers and Challenges:

- **Who's in Charge?** Authority is often shared among different levels of administration and is some-times controlled by different government agencies/entities. This reality – rooted in the complexi-ty of American political culture, which favors distributed power structures – can cause confusion,

delays, and other impediments to information sharing.

- **Siloed Funding.** This longtime and often-entrenched reality impairs long-term commitment to clients/patients and discourages holistic allocation of resources. Savings generated by effective upstream interventions are rarely used to better-fund services.

- **Lack of Understanding.** The individual cultures within and across the health care and social service sectors function in silos; i.e., they have not kept up with technology that is available to facilitate their coordination. Instead, they work as though each provider's approach is independent of and should prevail over (rather than be in sync with) all others.

- **Resistance to Change.** Providers across sectors increasingly acknowledge the need for a holistic approach to care, but remain resistant to actually making the changes required for a variety of reasons. So the crossing of professional boundaries is still an elusive goal.

Opportunities:

- **There is broad consensus** among practitioners and experts that a change in perspective is needed to enable patient-centered decision-making. This approach would give individuals in need and their "care community" a true say in the decisions that affect them.

- **New technology makes it possible** to envisage a consent form that is common to all provider organizations and easily portable, even if patients/clients change location. Such a form could accompany an individual or family for years, while remaining up to date.

- **Advances have been made** in addressing cultural and cognitive obstacles, reducing criticisms related to fairness and literacy. This progress creates an opportunity to reach a consensus on the scope and language of consent.

- **Prioritizing consent to share** as a tool can drive cultural change and accelerate the integration of care, despite the interdependence between service integration and consent. That is especially true if champions of this movement in health and social care develop alliances with consumer and citizen groups seeking to increase individuals' control of their personal information.

Recommendations:

- Adopt a systems perspective for the governance of health and social services. This can be initiated by creating common templates for consent, with federal support.

- Develop a common legal framework for consent. This would replace the current regime of multiple and incoherent norms and standards with robust, well-conceived principles, respectful of each individual's social and cultural circumstances.

- Develop a common consent template, especially with federal support, to enable transparent accountability, rather than "negotiation" behind closed doors between bureaucrats and professionals. This approach would encourage all parties to share information, irrespective of their authority or professional culture.

- Develop a sustained advocacy/lobbying effort aimed at the federal government and other national stakeholders for a change in their approaches to consent.

- Hold a national conference on consent to inform progress and next steps, akin to those organized by SOCI over the last two decades. This convening would have a broad agenda and participants from the multiple impacted domains. It could also extend the borders of the conversation by including consumer associations, people with lived expertise, and other relevant groups.

- Apply a systems perspective to the governance of health and social services to circumvent detrimental competition among public authorities, which promotes a culture of blame and fosters disarray in standards, forms, and norms.

- Treat any entry point into health and social services as valid and meaningful, regardless of where contact is initiated. This approach benefits the user by ensuring equal support and protection, encouraging information sharing by different data systems, and guaranteeing the quality, integrity, and transparency of people's information.

- Highlight the connection between consent and funding, acknowledging that the funding method for services affects not only the services but also the ability to align them. Address the issues with siloed funding and zero-based accounting and consider the potential benefits of integrating consent and service funding for collaboration and coordination.

- Consider partnering with relevant organizations (e.g., the National Governors Association) to create a bipartisan program targeted at state legislators, with dedicated resources and capacity to reach out to all states in order to create uniformity for consent to share programs that can be utilized across states and counties.

5. Technology and Information Management

This key area emphasizes the need for the secure, responsible and accurate exchange of data within and across care domains, enabled through interoperability standards. It recognizes the unique needs of data sharing in social care compared to health care and highlights the importance of consent in the sharing of sensitive information. It also emphasizes the need for tools, models, and competencies that can facilitate effective collaboration across silos.

The technology group's approach, analysis, and recommendations are somewhat different than those of the other groups. Technology has been a key focus of SOCI's work with its NIC initiative for several years. The group therefore had a more-mature understanding of the technical challenges, as well as the potential solutions and standards, depending on business needs, governance, and legal constraints.

The consensus views of the technology subject matter experts in this group included:

- Consent standards have been defined by HL7 FHIR that enable the technical implementation of both record-level consent and sub-record-level privacy marking required for computed authorization to share protected health information (PHI) and other sensitive data. Those standards are maturing with their extension for use by IHE standards-based exchanges such as those supported by TEFCA's Qualified Health Information Networks (QHINs).

- Open-source software implementations have been created for HL7 standards-based consent services that enable consent-mediated exchanges for FHIR, HL7v2, and CCDA-based healthcare data sharing (e.g., LEAP-CDS and Consent2Share). These implementations need to be extended to support social care data sharing through the definition of specific rules and the integration of systems-specific enforcement services.

- Demonstrations of consent-mediated information sharing have been conducted for health care information and are being designed to demonstrate in 2023 how a general "consent utility" solution could apply to social care as well as health-related care.

- While technology can enable policy and governance, it needs to follow policy and governance

Thomson Family Case Study
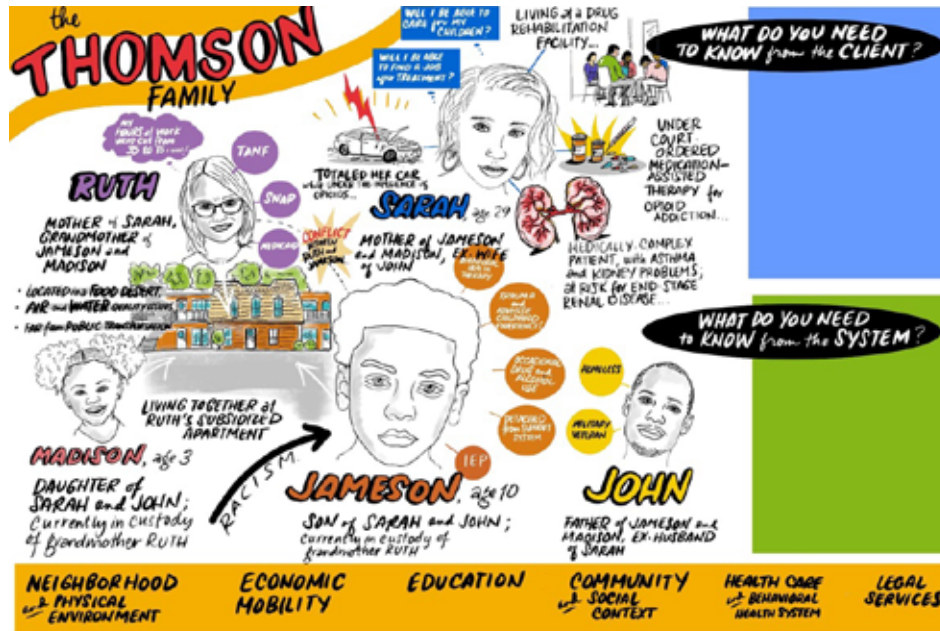
- What's going on with the family and individuals?

- What and how many systems do the Thomsons interact with?

- What's it like for this family to get help?

- Whose stories/ personas does your group gravitate towards most strongly?

- Key obstacles (family, personas)?

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THE THOMPSON FAMILY SCENARIO

A 10-year-old boy named Jameson has recently been placed into the child welfare system because his single mother, Sarah Thomson, was incarcerated for driving under the influence of opioids and reckless endangerment. Her car was totaled when she crashed into a light pole.

As a result of her arrest, Child Protective Services placed Jameson and his 3-year-old sister, Madison, in the legal custody of Sarah's mother, Ruth, while social workers and the courts decide if either or both children will be reunited with Sarah, remain with their grandmother, or move to a foster family to await adoption.

Sarah, who is 29, was between jobs and cannot afford to buy a new car. The social service professionals now working with her (primarily at the drug rehabilitation facility where she is currently living) worry that it will be difficult for her to find another job once she's out of treatment, especially in the midst of the coronavirus pandemic.

They are also concerned because, even if she finds employment, there is virtually no public transportation in the area in which she and her children have been living

with her mother. Sarah is a medically complex patient with multiple chronic conditions: asthma and kidney problems that put her at risk of progressing to end-stage renal disease. She is also under court-ordered Medication Assisted Therapy for her opioid addiction.

Jameson, Madison and their mother moved into Ruth's subsidized apartment six months ago, after Sara divorced the children's father, John Thompson. He is a military veteran who is currently homeless; he provides no financial support to his ex-wife and children.

The family's total income – including Ruth's – barely exceeds the federal poverty level, so they receive TANF, SNAP and Medicaid benefits. Ruth's apartment is in a rundown area of town, a "food desert" with few services such as public transportation.

A furniture manufacturer and a large corporate farm in the area have contributed to air and water quality issues, and several lawsuits have been filed against them alleging that their activities undermine the health of local residents.

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#1. Using the Thomson Family scenario and the assigned lens of your group, identify the 1 or 2 most significant obstacles that inhibit data sharing at a structural level?

#2. In what ways can improving consent practices for sharing protected information address the key obstacles and/or opportunities your group identified in Q1.

 # 3. What policy related changes can be _realistically_ accomplished in 2023/24 that address the obstacles and opportunities your group identified? Longer term?

#4. Feedback and recommendations from 1st report-out.

requirements. The technology group therefore was dependent on the insights and requirements of the four other workgroups.

Barriers and Challenges:

- **Lack of a data model** that represents the family or household, as the focus of health care standards is primarily on individual patient data.

- **Challenges in caregiver** and/or parental authorization for data sharing.

- **Lack of a common identity** provider or identity standards for efficient data exchange.

- **Inconsistencies in data-exchange standards** that hinder interoperability between health care and social care.

- **Multi-domain involvement**, i.e., multiple domains with no common data model for health care, homelessness, social care, child welfare, education, etc.

- **Need to be able to find** where an individual's many various consents are stored/managed.

- **Need to be able to find** and revoke consent and keep privacy preferences updated.

- **Different levels of sensitivity** of data (e.g., 42 CFR, Part2, general PHI, social care sensitive information, etc.).

- **Different levels of authorization**, i.e., can you know a system has a record for an individual, and can you see an entire record/document (FHIR Consent) or specific sensitive fields (DS4P).

- L**ack of a trusted sharing network**, which inhibits building confidence by consumers/clients in their providers and care coordinators and safekeeping of their personal information.

Opportunities:

- **The ability exists** and could be readily implemented to conduct real-world testing of consent utility models before making them mandatory.

- **The ability exists** to establish governance frameworks and models to address inter-organization data-sharing issues; e.g., across multiple systems (servers) and multiple formats (FHIR, HL7v2, CDA, IHE, etc.).

- **The ability exists** for systems to track and update or revoke privacy preferences and consents across multiple systems.

- **There is a growing understanding** that there needs to be a balance in consent processes between professional control of data and the autonomy/agency of affected individuals.

- **There is a greater understanding** of the importance of levels of sensitivity and authorization for a broad range of use cases.

- **There is upcoming standards work** to provide FHIR support for families and households, in addition to individuals, and their associated privacy preferences and consents.

- **There is upcoming standards work** to provide FHIR support for caregivers (including parents) to be authorized to give consent on behalf of the individual patient/client.

- **There is open source software** that integrates consent management with privacy tagging and identity management.

- **Individuals should be the hosts** of their consents, i.e., using personally controlled "data lockers" (e.g., solid protocol) rather than a centralized or distributed system.

Technical Recommendations:

1. **Consent Service Utility (CSU)**. The creation and use of such a utility would expedite the achieve-ment of the most basic requirement of information sharing: the ability to discover all consents within a jurisdiction and determine privacy preferences, as well as the consents and authoriza-tions to share or reshare protected or sensitive information across multiple different organiza-tions and their multiple systems and providers.

2. **Identity Standards for Person/Client/Patient Matching**. Consent is impossible to associate with an individual if there isn't certainty about a person's identity – e.g., is the John Smith associated with healthcare records in EHR "A" the same John Smith whose healthcare records are in EHR "B" *and* the same John Smith as the person with social care records in housing system "C"? Only

> A CSU is a system by which individuals (patients, consumers, clients, etc.) autho-rize, deny, and/or revoke the exchange of their personal information across pro-grams such as health care, social care, behavioral health, education, housing, probation, and other social drivers that impact people's health and well-being.
>
> The CSU would be based on open-source, open-standards technology and architectures that can be replicated and customized to meet the unique legacy environments of different jurisdictions.
>
> It would provide a user interface, based on human-centered design, to create a common look and feel across programs and services. It would also include a configurable rules engine to enable cus-tomization to meet the needs of differ-ent domains and jurisdictions with their commensurate laws, policies, and codes.
>
> The CSU would be transformational by enabling and empowering individual deci-sion-making, while dramatically reducing duplication, lowering costs, streamlining processes, and improving outcomes.

when that can be determined with strong certainty can John Smith's consent to share his infor-mation be acted upon.

3. **A Data Model for "Family" and "Household."** The concepts of family and household are critical to many social care services. This requires the ability to define who is in each of those two units, which are not necessarily the same. It also requires the ability to distinguish between multiple groups with similar demographics – e.g., two different John Smith households and families in a post-divorce scenario – so it necessitates identity management to be extended to these types of groups, as well as to individuals.

4. **Standards/Processes for Caregivers/Parents.** Many individuals who benefit from health care or social services are unable to assert consent for themselves; for instance, children and people who are develop-mentally disabled or suffer from dementia. Caretakers need to be able to manage privacy preferences and to grant consent to share on behalf of such individuals and their families or households.

5. **Provider Management of Privacy and Consent.** Record-level and field-level privacy are critical for meeting the requirements of general PHI and sensitive social care information (SSI), as well as specialized information (e.g., SUD, BH, STD, etc.). This requires more-sophisticated means to identify and manage the varying levels of sensitivity and authorization needs in privacy prefer-ences and consents across the many systems managing that information.

6. **Consumer Management of Privacy and Consent.** Given the broad range of systems that now maintain protected and sensitive information, it is important to enable individual consumers to easily locate and manage their privacy preferences and consents across many different organiza-

tions and their systems.

Policy Recommendations:

To enable implementation of the basic requirements described above, direction and investment in policy, regulations, and standards will be needed, including:

- Federal agencies such as CMS, ONC, and the Administration for Children and Families, among others, should include HL7 FHIR Consent, HL7 CCDA DS4P, and FHIR DS4P standards in future notices of funding opportunities and federal grants.

- Congress and/or HHS should create regulations to clarify social care data resharing and to put teeth into the enforcement of privacy and consent regulations for exchanging information between health and social care.

- ONC should extend consent and DS4P standards to meet the potentially more-sophisticated requirements of social services, in addition to health care.

- ONC should add to its investments in a LEAP-CDSv2 Consent Service Utility to extend v1 to support social care rules and enforcement services.

- Professional and governmental entities should develop federal models for interagency data sharing and should incentivize their adoption.

- Providers, governmental entities, and other stakeholders should, as a matter of course, educate individuals (patients, clients, etc.) about the benefits of consent to them. This effort should include messaging that provides control over whether to share their data (or not) and reinforce that it is a nonpartisan decision that everyone should be empowered to make.

SUMMARY OF WORKGROUP RECOMMENDATIONS

These high-level policy recommendations are provided as guidance for all leaders and organizations pursuing innovative, comprehensive consent-to-share practices. The role of leadership is to evaluate relevance to each specific jurisdiction or organization, to incorporate applicable ones into the planning and implementation of consent programs, and to subsequently assign responsibilities, resources, and authority to incorporate them into practical solutions.

1. Harmonize consent standards and prioritize allocation of resources for implementation.
2. Ensure relevant stakeholders, including public health, social care, education, and justice sectors, are involved in shaping consent policies.
3. Encourage each sector to develop its specific consent frameworks that align with overall consent standards.
4. Establish clear guidelines for data sharing across the spectrum of care, ensuring proper consent practices are followed.
5. Implement technological solutions that build on promising practices and facilitate secure and efficient data exchange across these sectors, while respecting consent and privacy.
6. Develop training programs and resources to educate professionals across the spectrum/sectors of care about consent practices and their importance in data sharing.
7. Establish mechanisms for individuals to easily revoke or update their consent preferences across sectors.
8. Promote public awareness campaigns to inform individuals about the benefits and importance of consent in data sharing across sectors.
9. Establish oversight bodies or committees to monitor and ensure compliance with consent poli-

cies in these sectors.

10. Foster cross-sector collaborations and partnerships to address complex cases that require data sharing across sectors while upholding consent principle.

CONSENT IS NO ONE'S JOB,
THEREFORE NO ONE'S RESPONSIBILITY.

KRISTINE McCOY, M.D., M.P.H.

PRACTICAL WAYS FORWARD

The Consent Learning Lab provided a unique and timely opportunity to bring together a group of national subject-matter experts steeped in the many facets of consent. Participants identified a range of key challenges and opportunities, which are summarized above. They also proposed a number of actionable recommendations that are vital for advancing consent in meaningful, systematic ways. A summary of these recommendations follows. Unless considerable funding becomes available to support consent programs at scale, however, it will be necessary to prioritize the recommendations to select a few with the highest value and prospects for success to demonstrate a clear return on investment over the next few years.

It is critical to make progress in the near term to take advantage of existing policy opportunities and momentum. Therefore, given the lack of federal/national leadership and insufficient funded initiatives, SOCI recommends focusing on two areas.

- Leverage existing policy initiatives to incorporate consent-to-share practices; e.g., Cures/TEFCA, Data Modernization, Medicaid waivers that support Whole Person Care programs.

- Encourage states to apply for CMS funding to pay 90% of the costs to design, develop, and implement consent solutions, and 75% for maintenance and operations of such systems over time.

Focusing on a few key initiatives will be important to demonstrate progress and encourage persistence among innovators and early adopters. SOCI and its NIC initiative will continue will focus on distilling these recommendations, supporting demonstration projects, and advocating at the federal and state levels for improving consent-to-share processes.

Advocacy:

- Encourage federal leaders to incorporate consent for social care and other non-HIPAA clinical services into current strategic efforts such as Cures, CDC/ONC Data Modernization, TEFCA, and ONC Accelerator Projects (FHIR, Helios, Gravity, etc.).

- Ensure that people with lived expertise relating to the health care, social care, education, and justice sectors are involved in shaping and executing consent policies.

- Urge the federal government and national stakeholders to implement a bipartisan program aimed at state legislators, with targeted resources and materials to advance a multi-domain CSU.

Governance:

- Make cross-domain consent to share an actual job that is held by a senior leader with authority

in every jurisdiction/organization pursuing solutions.

- Adopt a system-of-systems approach to foster collaboration and accountability across domains, such as health, social services, education, behavioral health, nutrition, housing, etc.

- Establish/adopt/incentivize a common, standards-based universal consent template, with federal support from participating agencies.

Processes and Administration:

- Develop a common legal framework for consent to replace the multiple and often-incoherent norms and standards.

- Ensure that any entry point into the web of social and health services is treated as valid and meaningful, fostering collaboration and breaking down data-system barriers.

- Fund/implement/study/disseminate multiple proof-of-concept demonstration projects that build on promising practices and facilitate secure and efficient data exchange across sectors.

Funding and Financing:

- Leverage CMS 90/10% Federal Funds to design, build, implement, and maintain consent services. (Ongoing maintenance and operations costs are reimbursed at 75%)

- Allocate specific funding from federal and state agencies to support ongoing tracking and monitoring of promising practices and demonstration projects that advance the field of consent cross domains to support information sharing.

- Recognize the connection between consent and funding, and incentivize collaboration and coordination.

- Use savings generated by effective upstream interventions to provide incremental, sustainable funding for services and encourage proper resource allocation; i.e., focus on the "wrong pockets" problem.

Culture:

- Design ongoing research and communication strategies to centralize practices about promising technology that can be replicated and customized by jurisdictions; aggregate examples of universal consent forms that provide individuals the opportunity to update details and revoke permissions throughout their journey.

- Challenge the prevailing professional culture that favors one provider's perspective over others and prioritize the wholeness of each individual situation.

National Collaboration:

- Organize a national conference with participants from multiple domains to serve as an accelerator for the next phase of consent work. A strategic, coordinated approach focused on advocacy, legislative reform, and collaboration with various stakeholders holds promise for driving meaningful change in consent practices and the integration of care.

- Strengthen the national collaborative through additional partnerships and diversified funding to continue supporting multi-domain consent services.

- Develop training programs and resources to educate professionals in the social care, education,

and justice sectors about consent practices and their importance in data sharing.

It is evident that the current system of health and social services requires an urgent, comprehensive transformation to accomplish the goal of integrated, coordinated, whole-person care. The challenges inherent in governance, administration, financing, and ingrained cultural differences, however, pose significant hurdles to achieving an integrated, responsive system of care. To clear these hurdles, the needs of the individuals being served should be prioritized, providing them with an active role in decision-making about sharing their personal data that has potential to positively impact their lives, health, and well-being.

The critical question is whether consent can be a catalyst to spark systemic change, thereby fostering better interoperability and seamless integration of services. It seems clear that taking this consent-focused approach could indeed empower people (patients, consumers, clients) and providers to more-consistently and uniformly manage and appropriately use sensitive data.

The barriers are very real. There is no cohesive national framework for data sharing, for instance, nor are standardized digital methodologies for individual consent within the health and human services fields. Current consent processes are notoriously redundant, confusing, and challenging to monitor or manage, largely due to their continued siloed, paper-based nature. This disconnect obstructs the necessary flow of personal data across the diverse programs, systems, and domains that collectively contribute to every individual's health and well-being and adds significant cost and complexity to delivering quality services.

Perhaps the biggest challenge is how to build the political will and leadership at the federal, state, and local levels to realize the potential of consent in order to enable a paradigm shift.

Creating a streamlined, patient-centered approach to consent to share would provide health and social services with a historic opportunity for genuine progress toward meaningfully better outcomes and greater equity. To effect this level of big, bold, and disruptive change, we must seize the moment, rethink our systems, confront the complexities head-on, and collectively design a future that respects individual autonomy while fostering integrated, efficient care.

We also must set our expectations appropriately and assume that the consent-to-share journey, much like the one to broadly adopt and use electronic health records, will take a decade or more to accomplish. The path forward will be laden with challenges, but the potential rewards – in terms of

trust, efficiency, equity, outcomes, and many other benefits – are so big and so numerous that we should all agree it's a trip worth making together.Appendix 1

List of Attendees/Participants

First Name	Last Name	Title	Agency/Organization	State
Syeda Shehirbano	Akhtar	Fulbright PhD Scholar	University of South Carolina	SC
Chris	Alibrandi O'Connor	Deputy Director, Midstates Region	The Network for Public Health Law	MA
Pooja	Babbrah	Practice Lead	Point-of-Care Partners	AZ
Courtney	Baldridge	Business Strategy	Usaging	VA
Matt	Bishop	President & CEO	Open City Labs	NY
Gregory	Boone	Program Manager	Our Healthy Community	IL
Hans	Buitendijk	Director, Interoperability Strategy	EHRA (and Oracle Health)	PA
Jessica	Cintorino	Planning Analyst	Hennepin County	MN
Theresa	Cullen	Health department director	Pima county health department	AZ
Evan	Dunne	Specialist	HIMSS	VA
Sarah	Esty	Senior Advisor for Technology and Delivery	Department of Health and Human Services	Washinton, D.C.
PG	Forest	CEO	Inspq (quebec public health agency)	Quebec
Robby	Franceschini	Director of Policy	Bluepath Health	CA
Jonah	Frohlich	Senior Consultant	SHVS Princeton	NJ
Hannah	Galvin	CMIO	Cambridge Health Alliance; Shift	MA
Lisa	Green, MD	Physician/CEO	Family Christian Health Center	IL
Brian	Handspicker	CTO	Stewards of Change Institute	MA
Mohammad	Jafari	Subject matter expert	Independent	BC
Eric	Jahn	CTO	Alexandria Consulting LLC	FL
Mary-Sara	Jones	HHS, Interoperability & SDOH leader	AWS	AZ
Jung	Kim	Director of Product & Analytics	Gainwell Technologies	CA
Susan	Kressly	MD	Shift	FL
Alfonso	Lara Montero	Chief Executive Officer	European Social Network	Brussels

David	Lee	Director	Leavitt Partners/CARIN Alliance	Washington, D.C.
Ross	Lemke	Director, PTAC	AEM Corp/U.S. Department of Education	VA
Alana	Lerer	GR Manager	HIMSS	Washington, D.C.
Nancy	Lush	President, Patient Centric Solutions	Patient Centric Solutions, Inc	RI
Madison	Lyman	IIS Data Quality Scientist	MA DPH	MA
Sally	Mabon	Director of Programs	State Health and Value Strategies	NJ
Ida	Mantashi	AVP, Software Regulatory Compliance	EHRA	All states
Kristine	Mccoy	Senior Consultant	Stewards of Change Institute	NJ
Kaye	Meier	Senior Global Policy Counsel	Masimo	CA
Eliel	Oliveira	Director, Research and Innovation	Dell Medical School	TX
Adam	Pertman	Senior Consultant	Stewards of Change Institute	MA
Ivy	Pool	Senior Consultant	Stewards of Change	Chicago, IL
Carol	Robinson	Founder, CEO	Midato Health	OR
Valerie	Rogers	Director, Government Relations	HIMSS	VA
Jessie	Roushar	Principal Planning Analyst	Hennepin County	MN
Elizabeth	Russo	Epidemiologist	MA DPH	MA
Sumit	Sajnani	Health Information Technology Officer	State of Connecticut	CT
Ben	Schooley	Associate Professor	Brigham Young University	UT
Aaron	Seib	SVP Strategy and Innovation	Saffron Labs	MD
Sheetal	Shah	Chief Strategy Officer	EMI Advisors	IL
Sristi	Sharma, MD MPH	Medical Informatics Consultant	CA Department of Health Care Services	CA
Bren	Shipley	Strategy, Community Engagement, Programs	The Sequoia Project	CT
Jessica	Simon Koch	Principal, Government Initiatives	Hennepin County	MN
Vivian	Singletary	Executive Director	Public Health Informatics Institute	GA

Daniel	Stein	President	Stewards of Change Institute	NY
Scott	Stuewe	President and CEO	Directtrust	Washington, D.C.
Sue	Feldman	RN, med, phd, FACMI, Professor	University of Alabama, Birmingham	AL
Stephanie	Thornton	Policy Manager	Bluepath Health	CA
Jaffer	Traish	COO	Findhelp	TX
Amit	Trivedi	Dir Informatics and HIT Standards	HIMSS	CA
Greg	Wass	Business Manager	State of Illinois hhsi2	IL
Chantal	Worzala	Principal	Alazro Consulting	MD
William	York	CEO	211 San Diego/CIE	CA
Julia	Zarb	President	Zarb Consulting	Ontario