



Resource Guide

Modernizing Consent: Creating a Replicable Model to Advance Health and Equity

Thursday, April 7, 2:00 p.m. - 3:00 p.m. EST

Extended dialogue from 3:00 p.m. - 3:30 p.m. with the presenters

Stewards of Change Institute (SOCl) recently published *Modernizing Consent to Advance Health and Equity*, highlighting the critical role of electronic informed-consent processes in enabling and accelerating cross-sector information sharing. SOCl and partner organizations are designing a new Consent Service Utility (CSU) tool as an open-source, open-standards technical solution and architecture to modernize the consent process and enable use across healthcare, behavioral health, and social and human services, including housing, and child welfare, among others. Two federally funded Integrated Care for Kids (InCK) sites in New York and New Jersey will be applying SOCl's recommendations through demonstration projects.

This webinar will increase understanding of the following:

1. How to use the Consent Service Utility (CSU) tool and understand its potential impact
2. How the CSU tool will facilitate the work of Bronx RHIO and its partners (care providers, community-based organizations and public agencies) to better address the behavioral and physical health needs of children covered by Medicaid.
3. How the information and insights developed at the pilot sites could be scaled/replicated to advance consent processes throughout New York City, the state and the nation.

Presenter Bios

[The Network for Public Health Law](#)

Chris Alibrandi O'Connor is a Senior Attorney at The Network for Public Health Law in its Mid-States Regional Office. Her work focuses on legal issues related to the collection, maintenance, use, and storage of data for public health purposes with a particular focus on cross-sector data sharing. She also provides legal technical assistance and training related to legal issues around data.

Prior to law school, Chris served on the political organizing staff of ACORN, then directed a state chapter of the National Lawyers Guild in Boston where she co-founded and led a Street Law Clinic for youth on their 4th Amendment rights when stopped by police. After law school she joined Atlanta Legal Aid, initially representing clients in housing conditions cases then public

benefits, domestic violence, and other civil matters, ultimately managing a community branch office. She later represented immigrants in tax controversies as the coordinator of a Low-Income Taxpayer Clinic in Boston and trained clients on US taxpayer rights and responsibilities. Transitioning to practicing health law, she became a SME on the Affordable Care Act for a dental benefits company and later its privacy officer and director of health policy, leading its compliance program and lobbying for greater recognition of oral health's role in overall health. Most recently she was Privacy Legal Counsel and Director of Solutions Integration on a CMS-funded DSRIP (Medicaid waiver) project in New Hampshire, connecting the legal issues in cross-sector data sharing with the technical ones.

Chris assisted in the development of the health sector section of the NH Endowment for Health's multi-sector Action Plan as part of its "Race & Equity in NH Series: Building Foundations for a More Equitable Future for All". Her other recent volunteer work includes providing humanitarian relief and legal information to detained immigrants. She received her law degree from Northeastern University School of Law.

[Stewards of Change Institute](#)

Daniel Stein is President of Stewards of Change Institute, a nonprofit "think-and-do-tank." He is also Principal Investigator for the National Interoperability Collaborative, an SOCI initiative designed to further collaboration and information-sharing among the multiple domains that impact health and well-being. SOCI's mission is to advance responsible, systemic change to achieve enduring progress in health and human services, person-centered care and socioeconomic mobility, especially for underserved populations. Stein has been a thought leader, educator and advocate for implementing interoperability at the local, state and federal levels for over 15 years. He also provides expertise to create strategies, tools, trainings and materials to achieve tangible results and fulfill SOCI's mission. He holds an MBA from Yale School of Management and a BA from The Evergreen State College.

[Bronx RHIO](#)

Kathy Miller's career since college has been spent working to improve health care services and service delivery to underserved, minority, low income NYC residents. She has done this through working 10 years for the NYC public hospital system – and another 20 in voluntary hospitals, developing new programs such as Teen Pregnancy Prevention, implementing continuity of care systems in hospital clinics and expanding access through off-site facility creation, improved language access services and extensive cultural competency programs for physicians and supporting staff members. Following her hospital career she worked for a private non-profit public health organization leading delivery of reproductive, primary care and early childhood health care services, including administration of the distribution of federal grant funding under Title X to other organizations throughout NYC. In 2012 Ms. Miller consulted to Title X grantees across the country on how to modify their services and systems to take advantage of the expanded health insurance coverage provided to their traditional clientele under the Affordable Care Act. In her current role as COO of the Bronx Regional Health Information Organization (RHIO) she has developed data driven population health services to support health care delivery system reform and a wide variety of quality measurement and improvement programs

in the Bronx. Her objective is to systematically find the actionable data nuggets in the RHIO's vast data lake and put them in the hands of health care, social and human service providers when they want them and in their work flow to enable efficient use of the data.

[BronxWorks](#)

Shauna Barry (LCSW, SIFI) is currently a Program Director at BronxWorks. She has worked in homelessness and housing services in the Bronx for over 15 years. She has worked and supervised in several supportive housing buildings, Medicaid funded health home programs and the Bronx based Homeless Outreach team. She recently opened up a new supportive housing building in the South Bronx for singles and families. She works with numerous databases, EMRs, and city and state funders to support people at all stages of their housing journey, and provides clinical hours and SIFI supervision for social workers. She fosters dogs in her spare time.

Presenter Resources, Websites & Ideas

[The Network for Public Health Law](#) The Network for Public Health Law provides visionary leadership in the use of law to protect, promote and improve health and health equity.

[Stewards of Change Institute](#) Stewards of Change Institute is a unique, not-for-profit, think tank, advocacy and implementation organization.

- [Modernizing Consent To Advance Health and Equity](#) SOCI strongly believes that modernizing the consent process would significantly accelerate progress on many fronts. Our new report focuses on the nuts and bolts of improving consent, such as legal and technical issues. It also explains our open-source proof-of-concept initiative, the Consent Service Utility (CSU). Most importantly, it gives voice to “people with lived expertise,” those in underserved communities who stand to gain the most from this work.
 - Download the Executive Summary [here](#)
 - Full report [here](#)
 - Promoting Data Sharing Approaches [People Should Have a Say](#)

[BronxWorks](#) We empower Bronx residents by providing them with the services they need to uplift their lives and communities.

[Bronx RHIO](#) The Bronx Regional Health Information Organization (Bronx RHIO) is a clinical information exchange established by the borough's leading healthcare organizations.

- [Bronx RHIO Playing Key Role in N.Y. Integrated Care for Kids Project](#) RHIO staff are helping define data needs for primary care integration for sickle cell disease and reducing out-of-home placement for at-risk children

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- [Subscribe to the All In Newsletter](#) (Subscribe)
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 - Centering Racial Equity throughout Data Integration
 - Data Law, Navigating Legalities of Multi-Sector Data Sharing
 - Health and Housing Data Integration
 - Governance Models while Centering Community
 - Re-imagining Technology in Support of Cross-Sector Referral and Care Coordination

[Data Across Sectors for Health](#) DASH is a national initiative that looks for new and better ways to help organizations in the public health, social services, and health care sectors share data with one another.

- [Interconnected: Data, Knowledge, and Action for Community Health](#). The publication details the important data-sharing work from the first two funding rounds of DASH's Mentor Program.

Resources on Navigating Consent

[The Limitations of Privacy Rights](#) The article critiques the effectiveness of individual privacy rights generally, as well as specific privacy rights such as the rights to information, access, correction, erasure, objection, data portability, automated decision making, and more.

[A Relational Theory of Data Governance](#) Data governance law—the legal regime that regulates how data about people is collected, processed, and used—is the subject of lively theorizing and several proposed legislative reforms. Different theories advance different legal interests in information.

[Data Governance's New Clothes](#) When citizens, consumers and stakeholders can't hold institutions accountable for their promises, there's little reason to trust those promises.

Tools to Address Racism and Implicit Bias

[TalkAbout Trayvon: A Toolkit for White People](#) Five years ago, a teenage boy went out for a snack but never made it home to his loving family. A grown man took it upon himself to patrol his neighborhood and to shoot dead an unarmed, unassuming boy.

[Black Lives Matter resources, toolkits & downloads](#)

[Data for Black Lives](#) Data as protest. Data as accountability. Data as collective action.

[CLASP](#) is a national, nonpartisan, anti-poverty nonprofit advancing policy solutions for low-income people.

[Working in the community?](#) Check out the Healing in Action Toolkit by Black Lives Matter. This toolkit was created to collate, condense and share the lessons we have learned in ensuring that our direct actions are centered on healing justice.

[Stop AAPI Hate](#) The coalition tracks and responds to incidents of hate, violence, harassment, discrimination, shunning, and child bullying against Asian Americans and Pacific Islanders in the United States.

[Dolores Huerta Foundation](#) The Dolores Huerta Foundation is a 501 (c)3 organization on a mission to inspire and organize communities to build volunteer organizations empowered to pursue social justice.

Data Sharing to Address Racial Equity

[Centering Racial Equity throughout Data Integration Toolkit:](#) This body of work seeks to encourage shifts of awareness and practice, by centering racial equity and community voice within the context of data integration and use.

[Our Data Our Bodies](#) We are a five-person team concerned about the ways our communities' digital information is collected, stored, and shared by government and corporations.

[Why Am I Always Being Researched?](#) A Guidebook for Community Organizations, Researchers, and Funders to help us get from the Insufficient Understanding to More Authentic Truth

Upcoming Events

April 5: [2022 Health Datapalooza and National Health Policy Conference](#), Taking Steps Toward More Seamless Data Exchange and Health Equity By Modernizing Consent

April 20: [BronxWorks Job Fair](#) at 1130 Grand Concourse from 10 a.m. – 2 p.m.

April 25 - 28: [Public Health Law Summit](#), Strengthening Protections for Community Health & Advancing Health and Racial Equity

May 1-4: [2022 Annual Technology and Business Conference](#), Accelerating Progress through Modernized Consent

October 12-14: Climate Change, Health Equity and Public Health Law, Minneapolis, MN
Deadline to [submit proposals](#) is April 8, 2022

October 25-26: 6th Annual All In National Meeting Brings together a diverse group of practitioners from public health, community-based social service, healthcare, and others at the nexus of working across sectors to leverage data to improve community health.