



All In Webinar: Navigating Consent

September 8, 2016

Purpose

1. Provide opportunities for communities to connect with thought leaders—each coming to the topic of consent with different expertise and perspectives
2. Address participants' questions related to consent and recommend various approaches or resources
3. Respond to specific use cases from communities on addressing consent
4. Stimulate active discussion that will help communities figure out concrete next steps

Questions Submitted by CHP and DASH Communities

- When is consent required, and what is the best process for deciding this issue?
- Related questions include:
 - Can I avoid having to obtain consent?
 - If I have to obtain consent, when does this have to be done?
- How do we coordinate data sharing with organizations that have pre-existing consent procedures?
- How do we determine whether the data we want to collect and share are consentable?
- When out in the community, how is consent typically obtained? When and by whom? Are there best practices for this?
- Have you seen effective strategies for working with pharmacies on consent? Other community partner examples?
- What are some effective strategies for empowering people to understand how their information is being used?
- In your experience, is the sharing of Behavioral Health PHI qualitatively different (more difficult) than Physical Health PHI? How are such barriers best addressed?
- How do we learn more about consent in mental health, specifically in California and/or among vulnerable populations?
- With respect to HIE, is there a "best demonstrated practice" that employs default "opt-in" versus default "opt-out" policies?

Use Cases Submitted by CHP and DASH Communities

■ All Chicago Making Homelessness History

This project's primary use case is data sharing from the Homeless Management Information System (HMIS) to the electronic medical record (EMR). The team aims to determine if a patient is homeless or is at-risk for becoming homeless.

- All Chicago (human and social services) is not a HIPAA compliant entity and is looking to enter into a business associate agreement (BAA) with a hospital. What does that mean for All Chicago when it comes to data sharing? Should we consider HIPAA certifications? What are the key aspects a BAA should entail?
- How should consents be written to handle data sharing across sectors? Can it be informed or should a client actually consent to every data element being shared? Would opt-in/out consents suffice?
- Depending on whether the Emergency Department (ED) workflow is universal screening (all ED patients) or selective (only those individuals that state they are homeless, or have characteristics that might indicate homelessness), we would like to change the ED Consent for Treatment and Authorization Form to include an opt-out selection. Is this feasible? If so, how?

■ North Coast Health Improvement and Information Network (NCHIIN)

Our project uses the Homeless Management Information System (HMIS) to send data on homeless or housing insecure clients served by our project partner, the Humboldt County Department of Health and Human Services. HMIS will interface with our local health information exchange(HIE) to share data across the social service and healthcare partners involved in our project. The HMIS is administered by the Humboldt Housing and Homeless Coalition (HHHC), which uses one standard release of information authorization document for all local organizations administering HMIS. While the team has been successful in adding our organization (NCHIIN) to the document, there is debate as to whether or not a separate document should be developed to capture client consent to participate in exchange. We are wrestling with two options:

- A. Keep the existing Return on Investment (ROI) and add additional language to provide more information about how client information will be exchanged with hospitals and clinics; or
- B. Have clients sign the existing ROI and a second ROI specific to the data exchange with hospitals and clinics.

While we think both scenarios are legally permissible, we are concerned about "one more consent" and/or "this needs a special consent." Our process will include detailed information about our program but we anticipated including that detail in the existing, standard multi-agency HHHC ROI. The existing consent does include articulated purpose of "medical/mental health treatment." In the past, we have had better luck with utilizing standard workflow and forms.

■ Louisiana Public Health Institute

- Are there communities that have set up health information exchange with any of the following organizations, and how have they handled consent?
 - o Jail and/or prisons
 - o Department of Corrections
 - o Police
- What are the special considerations for consent when working with the severely and persistently mentally ill, and are there variations by care setting/organization or provider type? How have other communities dealt with consent for this population?

Speaker Bios



Jane Thorpe, JD, George Washington University

Jane Thorpe is the Program Director for the Healthcare Corporate Compliance program and an Associate Professor in the Milken Institute School of Public Health, Department of Health Policy. Prior to joining the Department in 2009, Professor Thorpe served as the Deputy Director of the Office of Policy for the Centers for Medicare and Medicaid Services (CMS) within the Department of Health and Human Services and as Associate Vice President for Payment and Policy at the Advanced Medical Technology Association (AdvaMed). Prior to joining AdvaMed, Professor Thorpe practiced health care law representing a broad range of health care industry providers and manufacturers and provided counsel concerning fraud and abuse, corporate compliance, and other regulatory matters.



John Wilbanks, Sage Bionetworks

John Wilbanks is the Chief Commons Officer at Sage Bionetworks, where he leads the governance group. They have built open methods for informed consent that have enrolled more than 200,000 people into clinical studies since March 2014. He also works on getting donated data back to researchers, the impact of governance on data interoperability, and more. He is a Senior Fellow at FasterCures and has previously worked for Harvard's Berkman Center for Internet & Society, the World Wide Web Consortium, the US House of Representatives, Creative Commons (hosted at MIT's Project on Mathematics and Computation), and the Ewing Marion Kauffman Foundation.



Jennifer Bernstein, JD, MPH, The Network for Public Health Law

Jennifer Bernstein is currently the Deputy Director at the Network for Public Health Law's Mid-States Region and helps lead the Data for Population Health initiative. She received a J.D./M.P.H. dual degree from the University of Iowa. During graduate school, Jennifer was a research assistant at the National Health Law and Policy Resource Center and worked as a health law and policy intern at the District of Columbia Primary Care Association. Jennifer is a member of the Texas State Bar and completed a Hogg Foundation Mental Health Policy Fellowship at the University of Texas-Austin before joining the Network for Public Health Law - Mid-States Region at the University of Michigan School of Public Health.



Carrie Hoff, San Diego County

Carrie Hoff, Deputy Director with the County of San Diego's Health and Human Services Agency, currently manages the ConnectWellSD program, with a goal of enabling person-centered service through business process and data integration. Ms. Hoff's 17 years of County experience span managing programs and administering service contracts for a variety of departments. As a certified Lean Six Sigma Black Belt, Ms. Hoff excels in process improvement and project management. A graduate of the University of California at Los Angeles, Ms. Hoff taught in the Project Management program at San Diego State University College of Extended Studies for over five years. Ms. Hoff is a National Advisory Committee member for DASH and is a Board Member of the San Diego Community Information Exchange.