



All In: Data for Community Health Webinar Presentation

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

Thurs., April 7, 2:00 p.m. - 3:30 p.m. EST

00:45:54 Susan Martinez - All In: You can find out more about all of All In's offerings on our website: <https://www.allindata.org/>

00:48:46 Susan Martinez - All In: Download the full Modernizing Consent Report here: <https://stewardsofchange.org/13479-2/>

01:03:02 Susan Martinez - All In: Daniel's presentation will be included on our resource page, and you can also view the video clip here: <https://youtu.be/g6H9d1GsyE4>

01:03:54 Susan Martinez - All In: To learn more about SOCI, their website is <https://stewardsofchange.org/>

01:04:28 Susan Martinez - All In: Bronx Regional Health Information Organization website: <https://bronxrhio.org/>

01:05:58 Susan Martinez - All In: For more information on BronxWorks: <https://bronxworks.org/>

01:46:16 Greg Bloom: I'm not sure that my question was really answered, so to restate here, the 'Voices from the Community' section of the Modernizing Consent report points to a range of challenges that suggest that frictionlessness is not inherently a good thing, even if someone clicks a box to say 'yes.' For example, people might say yes under conditions in which they feel compelled to consent in order to access services; in this situation, consent is not given 'freely,' but the technology can't know that.

01:46:59 Greg Bloom: Also, the report says that both patients and providers have limited abilities to understand the implications of various decisions – meaning consent may not be truly informed – but a consent utility presumably would assume that if they say 'yes' they are informed. Yet we can easily see the flaws of this concept just by thinking about our own experiences consenting every day to share our information with web companies that we might not really trust and where we don't understand what will happen to that data.

01:47:29 Kathy Miller: @ Greg Bloom, I understand your question and that really comes down to training of the staff who are collecting the consent, which is a big part of our operation.

01:47:30 Greg Bloom: In other words, the mental model in which we say "individuals should be able to make decisions about what happens to their data" is necessary but not sufficient.

01:48:51 Greg Bloom: Kathy i don't think that's a satisfactory answer. I mean yes there should be training. But if the 'goodness' of a technology tool is entirely contingent on all the humans using it

doing so *correctly* then it's not a good tool because we know humans are flawed and will make mistakes even if they've received "training."

01:50:22 Greg Bloom: I think the 'Voices from the Community' expressed in the Modernizing Consent report point clearly to reasons why we should be skeptical of technology solutions, and why we should be investing in context-specific capacities to address these dynamics. And I don't think it's sufficient to say "we'll make the technology frictionless and expect others to figure out all the people stuff." We should expect such a situation to yield unintended results that are harmful.

01:51:44 Greg Bloom: This isn't to say there shouldn't be technology solutions but it seems like they should be secondary or tertiary to institutional solutions, and they should be designed specifically to account for human error, and to enable monitoring and redress. It's not clear to me whether the consent utility does address these concerns, so I'm eager to understand how the conclusion of the report follows from the concerns raised by the report.

01:54:05 Mary-Sara Jones: The goodness of any tool (tech and other) is dependent on how it is used. That said, the design of the tools can help alleviate some of the pressure on the individual, but it won't eliminate the issue.

01:55:03 Greg Bloom: But if we have reasons to believe that technology tools are inappropriate solutions for the nature of these problems (which is specifically stated in the report) then is it appropriate to start strategies of addressing this problem by building a technology tool?

01:56:17 Greg Bloom: I think one thing we often assume is that something will be better than nothing, but in this case we seem to have reason to believe that something might be worse than nothing. If we solve the friction problem without solving the problems of understanding, or the problems of context collapse, or the problems of my data being entangled with the data of someone else who can't consent... then we might make a frustrating situation into something worse.

01:56:25 Kathy Miller: The technology tool is being conceived of as an iterative process. Part 1 is automating and putting into the patients' hands a tool that gives them the ability to record consents and revocations and have access to where they have or have not consented, which doesn't exist today. So this will give the patient more control than they have today.

01:56:33 E Bu: To compare with the voting system, the decentralization of the system is what makes it a safer system. This massive data collection you are proposing is horrendously frightening & 1984-ish

01:57:04 Greg Bloom: I'd encourage the panelists to read up on the current literature about the insufficiency of privacy, and notice-and-consent, as frameworks for thinking about ethical data sharing.

01:57:13 Greg Bloom: For instance: <https://teachprivacy.com/the-limitations-of-privacy-rights/>

01:57:24 Greg Bloom: https://www.yalelawjournal.org/pdf/131.2_Viljoen_1n12myx5.pdf

01:57:39 Greg Bloom: <https://www.cigionline.org/articles/data-governances-new-clothes/>

01:58:16 Mary-Sara Jones: There are a handful of projects doing consent really well. There are successful approaches, they have not been commoditized. That's the gaps and it is getting filled.

02:00:57 Greg Bloom: What I was hoping to hear in this conversation was discussion about fiduciary responsibility and duties of care. Who will be responsible for making sure this happens in a client's interest? the idea that clients should be expected to manage these decisions and all their implications themselves, and that staff should be able to have all the training that's needed... it's very unsatisfying. Who decides whether the information has been appropriately conveyed? Who monitors whether the frictionless data sharing is happening in accordance with clients' interests? Who will be held responsible when something goes wrong? If we want to claim that these systems are ethical, these are the questions that we need to answer before technology solutions are implemented.

02:01:17 Greg Bloom: Yes we can, but should we?

02:03:36 Kathy Miller: @ Greg, I'm sorry you're disappointed in our focus, but our presentation was never intended to be an overall discussion of the real and gnarly issues you are raising. Our focus was designed to be on creation of a utility that will make existing inefficient processes more efficient and better enable sharing of consent information across sectors. I'm not at all trying to minimize your concerns, all of which I totally agree with. Those issues just were not our focus for this discussion.

02:04:24 Mary-Sara Jones: @Greg I think that is being done. This is evidently through the granularity of consent, the ability of the client to revoke or change at any time, using informed consent vs consent, and many other aspects of the design. In my experience, people are focused on the rights of the individual.

02:04:25 Greg Bloom: I think my questions are primarily for the authors of the Modernizing Consent report. I appreciate your efforts to find solutions to these problems in your context, and I am concerned about the prospect of generalizable scalable solutions to extremely context-dependent problems.

02:04:34 Miriam - All In: Thank you all so much for spending your afternoon with us!

02:05:06 Greg Bloom: Mary-Sara I encourage you to read some of the ample literature about how individual privacy rights are insufficient for the development of ethical systems of data sharing.

02:05:20 Greg Bloom: I shared links above and I would be glad to discuss further!

02:06:03 E Bu: You creators are looking at this from the caregiver role instead of the person being cared for

02:06:12 Daniel Stein: <https://hub.nic-us.org/>