California Health & Human Services Agency
Center for Data Insights and Innovation
Data Exchange Framework Stakeholder Advisory Group
Data Sharing Agreement Subcommittee
Meeting 4 (February 23, 2022, 11:00AM – 1:30PM PT)
Chat Log

The following comments were made in the Zoom chat log by Data Sharing Agreement Subcommittee Members during the February 23rd virtual meeting:

11:11:28 From Steven Lane MD MPH (he/him) to Everyone:
As someone who attends a lot of public Health IT and interoperability governance meetings, I am impressed by the fact that this group invites public comment at multiple points in the meeting, including at the very beginning. Perhaps this is routine with California meetings, but it is novel to me and quite inclusive. Bravo!
11:18:48 From Lee Tien EFF (he/him) to Everyone:
What is the definition of data quality?
11:20:16 From Eric Raffin to Hosts and panelists:
How about Usability, Availability, and Integrity (integrity = accuracy, validity, precision, etc.)
11:20:58 From Steven Lane MD MPH (he/him) to Everyone:
The Sequoia Project and eHealth Exchange have developed and continue to evolve testing tools related to Data Quality. These will continue to evolve, with the support of the ONC, as the TEFCA framework moves forward. As we can and should not try to define and manage this at the regional level, we should educate ourselves regarding the current state of this effort and engage with and guide it so that it meets the needs that we identify in CA. Another opportunity for us to help lead the national discussion and avoid creating an island in CA.
11:21:50 From Deven McGraw to Everyone:
As I recall, most of the existing data sharing agreements I'm aware of take an "as is" approach to this, trying to set expectations on both sides.
11:21:53 From Steven Lane MD MPH (he/him) to Everyone:
+1 @Eric. The relevant "outcome" of data quality is usability and actual use.
11:21:54 From Lee Tien EFF (he/him) to Everyone:
Facts differ so much in type. Name, birthdate, SSN, these are fairly static and "big"
11:23:10 From Lee Tien EFF (he/him) to Everyone:
Whereas I may have years of lab test results, and is there even a way to assess quality?

11:23:40 From Steven Lane MD MPH (he/him) to Everyone:

Regarding the quality of demographic data and the key role that this plays in accurate patient matching, new standards have recently been published and are making their way into regulations. Another wheel that we do not need to reinvent in CA and where we have an opportunity to lead by pointing to the standards that will, in time, apply to all.

11:24:33 From Eric Raffin to Hosts and panelists:

+! @Dr. Lane. Loads of good work already exists on how to test - no reinventing wheels. Too much detail in a DSA will require language to be updated frequently - suggest more broad reference to data quality standards that would be outlined in other guiding documents for participation.

11:25:29 From Steven Lane MD MPH (he/him) to Everyone:

Project US@ Standards for patient addresses, being considered now for inclusion in USCDI v3: • https://www.healthit.gov/buzz-blog/health-data/todays-the-day-for-project-us

- https://oncprojectracking.healthit.gov/wiki/pages/viewpage.action?pageId=180486153
- https://oncprojectracking.healthit.gov/wiki/pages/viewpage.action?pageId=180486153&preview=/180486153/237306191/Project%20US%40%20FINAL%20Technical%20Specification%20Version%201.0.pdf

11:26:44 From Steven Lane MD MPH (he/him) to Everyone:

Recently published and well conceived standards for managing Names: https://journal.ahima.org/ahima-releases-naming-policy-to-enhance-patient-identification-and-matching/

https://ahima.org/media/mezosx50/2022-naming-policy-v3-1-21-22.pdf

11:27:00 From Lee Tien EFF (he/him) to Everyone:

Are there standards for SDOH data?

11:28:12 From Eric Raffin to Hosts and panelists:

@Lee - USCDI v2 - https://www.hhs.gov/about/news/2021/07/09/hhs-updates-interoperability-standards-to-support-electronic-exchange-of-sogi-sdoh.html

11:28:27 From Steven Lane MD MPH (he/him) to Everyone:

Each data holder - provider, lab, HIE, public health, CBO - should have responsibilities for auditing and maintaining the quality of the data in there system.

11:28:39 From Lee Tien EFF (he/him) to Everyone:

Thx Eric

11:29:26 From Steven Lane MD MPH (he/him) to Everyone:

@Lee - Happy to provide more detail. I co-lead the taskforce that helped bring SDOH into USCDI v2.

11:30:19 From Elizabeth Killingsworth to Hosts and panelists:

Language that can be found in the eHX DURSA, for example, specifically calls out that entities will provide data essentially as it is in their system, which is how some of Patrick's concerns have been handled previously

11:31:21 From Lisa Matsubara to Everyone:

We need to consider that the expectation is for ALL providers to participate in this exchange. Requirements in the agreement should not be such that it makes it impossible for smaller providers or those with less resources to participate.

11:31:46 From Elizabeth Killingsworth to Everyone:

+1 Lisa

11:33:11 From Steven Lane MD MPH (he/him) to Everyone:

+2 Lisa - Similarly we should not allow potential participants to NOT engage due to their or other's concerns about the quality of their data. We need to be able to pass reliable provenance data so that those who access, exchange and/or use data from others can consider the context before relying on that data for specific purposes.

11:34:17 From Deven McGraw to Everyone:

Can folks who are not speaking please mute their lines?

11:34:54 From Steven Lane MD MPH (he/him) to Everyone:

Inaccurate data is a constant in healthcare.

11:35:53 From Helen Kim to Hosts and panelists:

I would agree that the data should be provided "as-is" but with a floor of certain data quality standards, i.e., data comes unaltered from the data repository/system, non-corruption of the data, etc. Those details should be contained in the policy and procedures doc., not in the DSA itself.

11:36:31 From Steven Lane MD MPH (he/him) to Everyone:

+1 @Helen

11:37:03 From Shelley Brown to Everyone:

Data quality has a direct relation to trust and adoption. Data quality is subjective however. There is scientific data and there is observational or subjective data. Because there is a variation data types, the mechanics of addressing data quality should go in the policies and procedures.

11:37:52 From Deven McGraw to Everyone:

Yes, but we just need to make sure questions about whether the data are of sufficient quality doesn’t become the built in excuse not to exchange.

11:37:53 From Elizabeth Killingsworth to Everyone:

Helen: I think that's a reasonable approach, but it does introduce the question of what constitutes "altering" the data. Does converting from pounds to kilos trigger a violation? Or truncating a field because of transmission limitations?

11:41:25 From Morgan Staines to Hosts and panelists:

Data quality is important, of course, but I think it's very nearly out of scope for this effort. My department is primarily a receiver of data, from providers and plans that we pay. Since we are primarily a payer, we audit for that purpose, but auditing all data is simply not possible.

11:41:31 From Steven Lane MD MPH (he/him) to Everyone:

https://www.healthit.gov/isa/uscdi-data-class/provenance#uscdi-v1

11:41:39 From Helen Kim to Hosts and panelists:

HI Elizabeth, Yes, definitely questions, that need to be ironed out in the policies and procedures. My initial thought is that the data would be provided in the condition it is present in the systems, but non-material changes can possibly be permitted. Just a thought.

11:41:47 From Elizabeth Killingsworth to Everyone:

Ashish: Structured data is amazing, but I suspect that we would find that many smaller practices/EHRs have far less of that. Then we start running into issues where leaning on structured data could discourage certain elements from providing data

11:43:10 From Steven Lane MD MPH (he/him) to Everyone:

All data is "structured" to a variable degree. Text blobs, scans, PDFs ALL have value in addition to discrete labs, vitals, and coded PAMI data.

11:43:11 From Carrie M. Kurtural to Everyone:

For social services, mental health, and developmental services, I don't think we can clearly segregate structured v. unstructured data set - unlike w certain health data like lab info as indicated by @Ashish,. Diagnostic and characteristic data for developmental services can be quite subjective as well.

11:43:16 From Elizabeth Killingsworth to Everyone:

Just looking at how much work it has taken to move toward structured/codified SIG in eprescribing and the many loopholes that allow individuals to circumvent the industry preferred path for their personal preferences

11:44:43 From Ashish Atreja to Everyone:

Thanks Elizabeth- with TEFCA, structured data is built in as a federal requirement and every EHR would need to comply with it. Perhaps we specifically reach out to our partnering FQHCs and safety net institute to provide feedback on this. And language may need to be modified like structured data wherever possible? Would that help?

11:44:56 From Steven Lane MD MPH (he/him) to Everyone:

This is an incredibly slippery slope when we are dealing with entities that may or may not be covered by HIPAA and/or the Information Sharing requirements. I suggest that we start with data and uses that we can all agree on and expand from that as trust is built.

11:46:52 From Shelley Brown to Everyone:

I prefer language that limits use, re-use to a lawful "permitted purpose" that all participants agree to. There are "lawful" uses that may not be supported, eg. law enforcement.

11:47:44 From Steven Lane MD MPH (he/him) to Everyone:

Patients/individuals do not and will not understand the nuance of what entities are / are not covered by various laws. Once someone is burned by a misuse of their data they will lose trust in the system, government and civil society - something we are seeing all around us in the context of the Pandemic.

11:48:18 From Lisa Matsubara to Everyone:

Agree that this may raise legal issues as business associates are generally limited in the use and disclosure of the PHI to further the business of the covered entity - other uses for research or business purposes may require a separate data use agreement even when deidentified which usually must be for a specific purpose rather than a blanket agreement.

11:49:17 From Steven Lane MD MPH (he/him) to Everyone:

Recall that "deidentification" as this was defined in HIPAA, has no meaning today when data sets can be combined to reidentify individuals.

11:49:59 From Carrie M. Kurtural to Everyone:

I agree with your points Steven - so should the uses and disclosures be pretty limited? What are you thinking?

11:50:21 From Jenn Behrens to Hosts and panelists:

We should also look at relavent regulations such as CCPA for notice and permissions for secondary usages given we’re talking about the exchange of PHI and non-PHI.

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11:50:42 From Elizabeth Killingsworth to Everyone:

Last meeting we discussed requiring that any entity that joins agree to essentially comply with HIPAA as though they are a CE/BA, even if they are not. Do we agree with that as a baseline?

11:50:44 From Steven Lane MD MPH (he/him) to Everyone:

Like everyone, I want it all now; I just worry that this may not be in the best interest of our larger efforts to move interop forward to support state goals.

11:51:33 From Steven Lane MD MPH (he/him) to Everyone:

+1 @Elizabeth. This is the approach being taken by TEFCA.

11:52:08 From Morgan Staines to Hosts and panelists:

Agree with Steven's comment about the futility of de-identification.

11:57:15 From Shelley Brown to Everyone:

We should not limit disclosure to BAs, we do need to be able to share with CBOs and community information exchanges.

11:57:20 From Ashish Atreja to Everyone:

Perhaps we can also look at TEFCA and get this clarification from ONC for federal regulations

11:57:52 From Morgan Staines to Hosts and panelists:

HIPAA as a baseline is good, but not quite enough. E.g., each covered entity has to comply with its own Notice of Privacy Practices, which might include things such as "We don't do marketing without your consent." Data Exchange can't just steamroll these obligations.

11:58:45 From Carrie M. Kurtural to Everyone:

Agree re marketing and sales Morgan... And the concern of using data for research potentially without going through IRB approval.

12:00:00 From Carrie M. Kurtural to Everyone:

Well never mind erase that - HIPAA requires the IRB, but de-identification, and the concern raised about using that data for AI and marketing purposes..

12:00:37 From Helen Kim to Hosts and panelists:

Agree that HIPAA should be the baseline, but I would like to go one step further than HIPAA wrt the use of this data, especially around certain commercialization of that data.

12:00:46 From Elizabeth Killingsworth to Everyone:

Overall, I a very much in the camp of removing hurdles to adoption, but this is still PHI and I think that it is reasonable to expect everyone able to properly protect it. If they cannot comply with security expectations, do we want them to have the ability to receive the data?

12:01:14 From Morgan Staines to Hosts and panelists:

Shelley, hopefully, anticipated HIPAA amendments will clarify the conditions under which CEs can disclose to CBOs. But absent clear federal guidance, at least some of them may need to become BAs.

12:01:43 From Terry Wilcox to Hosts and panelists:

Elizabeth, I agree with you. Anyone receiving PHI should be expected to protect it.

12:03:28 From Deven McGraw to Everyone:

@Morgan, a little known FAQ from OCR already allows for disclosures to CBOs for treatment purposes — can't seem to share the link in the chat but could e-mail it to you. Shouldn't require a BAA even today.

12:04:17 From Louis Cretaro to Everyone:

Consent must be informed and there must be accountability. What concerns meis the ability of systems to prevent data from being sent for those who did not consent to sharing

12:05:29 From Morgan Staines to Hosts and panelists:

@Deven, the OCR guidance on this topic that I'm familiar with completely ignored the question of whether the recipient needs to be a BA.

12:05:48 From Elizabeth Killingsworth to Everyone:

Some of these potential "weak links" (state entities that do not comply with HIPAA) will potentially have enormous quantities of PHI

12:06:04 From Lee Tien EFF (he/him) to Everyone:

Yes, sigh

12:06:18 From Deven McGraw to Everyone:

@Morgan, it says pretty clearly that such disclosures are considered to be treatment — hence no BA required.

12:08:14 From Shelley Brown to Everyone:

I believe most agreements do not spell out every law that may apply. New laws are passed all the time. Generally speaking, every person that collects and shares personal information should know what laws apply to them.

12:11:18 From Helen Kim to Hosts and panelists:

I think we need more than just requiring adherence to applicable law, but may include something like "participant will adhere to applicable law, including but not limited to 42 CFR Part 2, etc." But I think it would be very difficult to list all applicable laws, esp. with changes in law. This would be very difficult to maintain. I don't think the DSA should set forth a comprehensive list of laws and where they apply.

12:13:23 From Morgan Staines to Hosts and panelists:

Unless & until SAMHSA modifies the 42 CFR Part 2 rules, we have little choice but to restrict this data, or withhold it.

12:15:07 From Deven McGraw to Everyone:

HHS has actually tasked OCR (not SAMHSA) with creating the new Part 2 regulations.

12:17:41 From Elizabeth Killingsworth to Everyone:

The changes to Part 2 are moving slowly, though. They are working to revise the rules and make sharing simpler, but the timeline keeps extending

12:21:42 From Jenn Behrens to Everyone:

+1 for a state group/entity/org to provide technical oversight/guidance
12:23:27 From Lee Tien EFF (he/him) to Everyone:
I personally think that we should list all known applicable laws, updated on a periodic basis
12:23:30 From Elizabeth Killingsworth to Everyone:
Again: this goes back to using HIPAA as a baseline. Is there a reason we shouldn't?
12:24:46 From Lee Tien EFF (he/him) to Everyone:
Data minimization is “spreading” as a standard in consumer privacy, although the standard itself is less than clear
12:26:38 From Bill Barcellona to Everyone:
Agree with Elizabeth on Minimum Necessary standard
12:27:29 From Morgan Staines to Hosts and panelists:
Agree that sticking to HIPAA's minimum necessary makes sense. We can't disregard it - that would put us out of compliance with HIPAA.
12:30:21 From Helen Kim to Hosts and panelists:
Provide data that is minimum necessary to the extent feasible(?)
12:30:54 From Morgan Staines to Hosts and panelists:
Agree with Deven that both parties should practice minimum necessary, and with the observations that delivering on this can be difficult and messy.
12:35:06 From Shelley Brown to Everyone:
In general agree, however, shouldn't we allow the recipient to decide what is necessary... how would you enforce this provision. I would prefer to allow recipients access to data they believe is necessary for the intended -permitted use.
12:36:50 From Justin Yoo (he/him) to Everyone:
The draft language and other meeting materials are available at: https://www.chhs.ca.gov/data-exchange-framework/#data-sharing-agreement-subcommittee-2022-meeting-materials
12:40:02 From Morgan Staines to Hosts and panelists:
But the party who shares is responsible if the authorization is inadequate.
12:44:13 From Belinda Waltman, MD to Everyone:
A universal authorization could lower the barrier to share information - so that the sender of the data isn’t required to evaluate the legal validity of every different organization’s authorization
12:45:04 From Deven McGraw to Everyone:
Absolutely, Morgan. FWIW, the way that the Info blocking rules deal with that is the requestor is obligated to provide the authorization - if it is deficient, not legally compliant, the data source does have an obligation to let the requester know why the authorization is insufficient - to give them a chance to correct it - but ultimately a

disclosure could refuse to share in a situation where the authorization doesn't meet legal requirements.

12:48:12 From Ashish Atreja to Hosts and panelists:

Support that! A universal authorization would solve a lot of problems.

12:50:32 From Carrie M. Kurtural to Everyone:

Need to change WIC 4514 and 5328.7 - strike each separate use. Then a universal consent works for mental and dd records @Ashish.

12:50:37 From Carrie M. Kurtural to Everyone:

I mean 4515

12:55:11 From Lee Tien EFF (he/him) to Everyone:

This is the section that I was alluding to earlier, the different government entities are subject to very different standards, and state agencies are regulated in ways that city/county bodies are not

12:58:14 From Morgan Staines to Everyone:

Louis, I don't think the receiving system has any meaningful obligation unless we try to establish it here. There's no penalty for asking for protected data, only for improperly giving it.

12:58:31 From Ashish Atreja to Hosts and panelists:

How does this impact research... why limit to HIPAA covered activities?

13:02:13 From Deven McGraw to Everyone:

Elizabeth, can you provide more details on what aspects of this you feel are onerous on smaller entities?

13:02:56 From Lisa Matsubara to Everyone:

+1 Elizabeth that the participants here and in CalDURSA are not the same and we must be careful when we use those agreements as a template.

13:05:47 From Morgan Staines to Everyone:

Ashish, if we were building a data repository, how to handle research would need to be on the table, and reasonable minds would differ. But without a data repository, we are arguably only committing to/obligating one-to-one exchanges, and research was not part of our statutory mandate.

13:11:10 From Louis Cretaro to Everyone:

Morgan, I am reacting to a universal authorization that may be in conflict with a sealed record or a lack of consent on the social services system. That receiving system would have to validate before responding in my opinion. I think we may have circumstances that may override the request.

13:21:00 From Morgan Staines to Everyone:

Louis, I agree there's a problem if the person who signs an authorization doesn't have legal authority to do so -- e.g., if a sealing order applies to that person, then the attempted authorization itself may be unlawful. The party sending data will always have

to decide if they believe the authorization is sufficient. Question remains about how high that burden should be, including whether to rely on an assertion by the requesting party that a sufficient authorization is in hand.

13:23:19 From Steven Lane MD MPH (he/him) to Everyone:
LOL

13:23:29 From Elizabeth Killingsworth to Everyone:
Fair enough

13:23:35 From Lee Tien EFF (he/him) to Everyone:
reality

13:24:05 From Elizabeth Killingsworth to Everyone:
This is one of those things that we'll figure how the holes over time and have to clean it up

13:24:31 From Elizabeth Killingsworth to Everyone:
*figure out

13:26:01 From Deven McGraw to Everyone:
+1 to Elizabeth's comment

13:27:09 From Ashish Atreja to Everyone:
+1 Louis

13:31:03 From Deven McGraw to Everyone:
HIPAA treated as Penicillin in a Petri dish - Lee, when I use that next time I'll quote you

13:31:05 From Bill Barcellona to Everyone:
Thank you Jennifer

13:31:15 From Deven McGraw to Everyone:
Yes, thanks Jennifer!