California Health & Human Services Agency
Center for Data Insights and Innovation
Data Exchange Framework Stakeholder Advisory Group
Data Sharing Agreement Subcommittee
Meeting 2 (December 22, 2021, 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 December 22nd virtual meeting:

13:51:57 From Belinda Waltman, MD (WPC-LA) to Hosts and panelists:
Is anyone speaking, or is it my audio?
14:06:40 From Ashish Atreja to Everyone:
I have joined with Dr. Atreja's link - sorry about my confusion
14:10:58 From Kevin McAvey to Everyone:
Please find all draft materials on our website: https://www.chhs.ca.gov/data-exchange-framework/
14:11:04 From Kevin McAvey to Everyone:
To receive updates on the development of the Data Exchange Framework, email CDII@chhs.ca.gov.
14:13:37 From Lee Tien to Hosts and panelists:
I have one comment on principle 2 and timing.
14:13:39 From Steven Lane to Hosts and panelists:
I do not understand what makes a gap "disproportionate".
14:14:29 From Lee Tien to Hosts and panelists:
Also on accountability
14:15:18 From Belinda Waltman, MD to Hosts and panelists:
I have a comment when we get to Principle 3
14:15:34 From Ashish Atreja to Everyone:
could you just remove that word - and say that the data gap impacts disportionalteyl
14:19:23 From Ashish Atreja to Everyone:
Access to the data seems appropriate if we can accurately identify the patient - I think the privacy groups will have significant concern over a state controlled central repository vs federated data exchange and access
14:20:17 From Lisa Matsubara to Hosts and panelists:
Does principle 1 also include understanding diversity in providers and addressing their needs to effectively participate in data exchange towards addressing health inequities?

14:21:51 From Jenn Behrens to Hosts and panelists:

My “concern” or area in which I believe we should be particularly mindful is there is a greater implication of privacy risk to individuals from increased exchange/storage of data which could facilitate inappropriate surveillance and decision-making.

14:21:57 From Steven Lane to Hosts and panelists:

Meaningful access to and exchange and use of data does not require wholesale and certainly not centralized collection, consolidation or curation. Different data users have need for different data to support their use cases.

14:22:02 From Kevin McAvey to Hosts and panelists:

Friendly reminder to panelists: please send messages to "Everyone"

14:22:37 From Jenn Behrens to Everyone:

My “concern” or area in which I believe we should be particularly mindful is there is a greater implication of privacy risk to individuals from increased exchange/storage of data which could facilitate inappropriate surveillance and decision-making.

14:23:12 From Lee Tien to Everyone:

I agree with Jenn Behrens’ point on privacy (and security, too)

14:23:45 From Ashish Atreja to Everyone:

principle 5 seems to speak (or not speak) to centralized storage of data

14:24:15 From Lee Tien to Everyone:

As well as Ashish Atreja’s comment re “significant concern over a state controlled central repository”

14:24:22 From Steven Lane to Everyone:

Meaningful and valuable access to and exchange and use of health-related data does not require or necessarily warrant the centralized consolidation of data with the associated privacy and security risks that this entails.

14:24:26 From Kevin McAvey to Everyone:

DSA Members: thank you for your feedback on the principles, which remain under deliberation by the Stakeholder Advisory Group. If you have specific suggested edits to the principles, CDII would always appreciate your feedback. Please submit to the chat, to the CDII email, or via email to one of us directly. Thank you all!

14:24:27 From Morgan Staines to Everyone:

Kevin, can't locate the Subcommittee Charter on the wbsite

14:25:36 From Kevin McAvey to Everyone:

Hi Morgan - Please scroll down to the DSA Subcommittee, click on "November 8, 2021", and the final two links are for the charter.

14:25:46 From Kevin McAvey to Everyone:

CLean version: https://www.chhs.ca.gov/wp-content/uploads/2021/12/CalHHS_DxF-DSA-Subcommittee_Charter_v2_Clean_12.13.21.pdf

14:27:00 From Lisa Matsubara to Everyone:
On principle 4 - we will need to be mindful of protecting the privacy of minors and others who may not want information about certain sensitive health care services to their "caregivers" or guardians.
14:27:21 From Lisa Matsubara to Everyone:
accessible to them
14:27:32 From Lee Tien to Everyone:
But if the standards are not legal, how binding are they?
14:28:30 From Lee Tien to Everyone:
And how much can we assure patients that the standards will hold if they are not legally binding? We should be clear on the differences.
14:28:34 From Ashish Atreja to Everyone:
I also believe there may be some conflict as we move outside traditional healthcare providers and organizations
14:28:51 From Ashish Atreja to Everyone:
for what laws and standards are impacted
14:29:12 From Lisa Matsubara to Everyone:
please see my comment above about "proxies"
14:29:34 From Deven McGraw to Everyone:
We can make the requirement to adhere to exchange data using accepted international/national data standards part of the agreement.
14:30:16 From Steven Lane to Everyone:
For the written record, we should determine where in the principles we can identify and acknowledge the needs and rights of legal representatives and authorized proxies to access, exchange and use health-related data on behalf of individuals.
14:34:14 From Michelle (Shelly) Brown to Everyone:
While agnostic on the technology used to process information, we should encourage uniform standards for data structure and vocabulary
14:36:15 From Lee Tien to Everyone:
In my privacy legislative work, we've seen policy makers be less than clear on distinctions between pseudonymous and de-identified data
14:39:12 From Jenn Behrens to Everyone:
Agreed, Lee. Good point.
14:39:26 From Steven Lane to Everyone:
Individual/proxy access should be called out specifically.
14:39:46 From Steven Lane to Everyone:
Its role in each scenarios is a bit different.
14:41:48 From Michelle (Shelly) Brown to Everyone:

it should also promote access where exchange is not feasible - e.g. view only access

14:42:30 From Steven Lane to Everyone:

Should add to this list the focused query for or push of specific (minimum necessary) data elements required to support the scenario/use case.

14:43:54 From Steven Lane to Everyone:

+! @ Shelly

14:44:15 From Lee Tien to Everyone:

All these really heighten the need for access controls, robust authentication, data granularity, and audit trails, to bolster accountability.

14:45:40 From Steven Lane to Everyone:

Those raised stakes are not specific to a centralized repository data model but will also apply with access to cloud-based data.

14:45:46 From Lisa Matsubara to Everyone:

agree with Lee on importance of access controls

14:48:04 From Ashish Atreja to Everyone:

assume Pub/Sub is related to event driven exchange?

14:48:19 From Ashish Atreja to Everyone:

Like admit nofitications?

14:48:33 From Lee Tien to Everyone:

Minimum necessary is a great concept, but I worry about good mechanisms for implementing it.

14:52:14 From Jenn Behrens to Everyone:

Perhaps going down a rathole, but it could be interesting to conduct a risk analysis applying the privacy-engineering discipline to identified workflows, such as the one highlighted in the NISTIR 8062…which could drill down on mechanisms/controls to tackle some of those concepts such as minimum necessary.

14:52:26 From Steven Lane to Everyone:

HIPAA specifies certain exchanges where the exchange of Minimum Necessary is a requirement. Providers, at least, have decades of experience with this concept.

14:53:04 From Rim Cothren to Everyone:

Yes, Michael (aka "Dr. Atreja"), at least my use of the term pub/sub in the slides would include a standing request for notifications, such as a PCP's request for ED admit notifications on their patient population.

14:54:20 From Patrick Kurlej to Hosts and panelists:

I support the 4 uses identified - Treatment, Payment, Health Care Operations, Public Health. Look forward to hear other opinions and perspectives - many nuances to this.

14:54:55 From Morgan Staines to Everyone:

The need for robust controls also raises questions about who exercises granular control. I.e., HIPAA permits but does not require most disclosures. When patient authorization is not required, will we assume that the disclosure should be made without the patient's voice?

14:55:06 From Lee Tien to Everyone:

How is the system addressing patients who are in certain programs that are protective of their identity (e.g. domestic violence survivors)?

14:57:48 From Michelle (Shelly) Brown to Everyone:

treatment to extend to school nurses and clinics not only for K-12 but also college- I realize this may also fall under use case.

14:58:51 From Steven Lane to Everyone:

Yes Shelly. Treatment happens in all sorts of different settings that each have their own workflow and privacy issues to consider.

14:59:16 From Elizabeth Killingsworth to Everyone:

To me it seems that some comments are suggesting that we extend the definition of Treatment beyond that found in HIPAA, is that actually what we are considering?

15:00:50 From Michelle (Shelly) Brown to Everyone:

prior authorization for treatment

15:01:19 From Deven McGraw to Everyone:

Not necessarily, Elizabeth - IMO we can still use the definition of HIPAA but just acknowledge that we may need to add purposes for social service sharing vs. assuming that “treatment” (based on HIPAA) would take care of it. Creating a more expansive treatment definition would be one approach - but we could also add purposes that assure sharing for meeting social service needs.

15:03:10 From Ashish Atreja to Everyone:

where would SDoH fall in these categories - like housing or food insecurity

15:03:24 From Steven Lane to Everyone:

I guess my question is are their services that are not being delivered or accessed because payment-related data exchanges cannot occur.

15:05:14 From Elizabeth Killingsworth to Everyone:

From my perspective, HIPAA-defined TPO and public health would make an excellent floor. I don't object to including other items, but I would want to separate that (and possibly put them on a different timeline) from the "traditional" TPO definitions

15:06:21 From Deven McGraw to Everyone:

I absolutely would not put individual/proxy access as “sub” to any other priorities. Not consistent with the vision as currently articulated, IMO

15:07:20 From Belinda Waltman, MD to Hosts and panelists:

Related to prior auth, a potential use case would be increased identification of patients eligible for the new statewide benefit, ECM, under CalAIM.

15:10:08 From Ashish Atreja to Everyone:
Thanks
15:12:00 From Deven McGraw to Everyone:
Definition of Health care operations includes the following (per HIPAA) includes a lot of activities. Not sure we want to mandate all of them.
15:13:08 From Lee Tien to Everyone:
I share Deven's concern about the breadth of the HCO def'n
15:14:05 From Steven Lane to Everyone:
Providers broadly are anxious about and may be resistant to the required sharing of health-related data for all of these HCO uses.
15:14:49 From Steven Lane to Everyone:
In particular, contracting and underwriting are HCO purposes that make providers concerned that data exchange could be used against them or their patients.
15:15:12 From Michelle (Shelly) Brown to Everyone:
exchange of data, meaning it is sourced from other providers, should have a very limited role here.
15:15:48 From Steven Lane to Everyone:
+1 @ Elizabeth
15:15:51 From William (Bill) Barcellona to Everyone:
Providers are concerned that costs of sharing the broad information under the TEFCA definition of business operations could be significant, without generating much value to the healthcare system.
15:16:04 From Michelle (Shelly) Brown to Everyone:
HCO - data is most relevant to an organization when it truly concerns their own internal operations, so I would support limited used cases here.
15:17:46 From Steven Lane to Everyone:
Some HCO uses involve comparing one's internal operational data to similar (benchmark) data from other organizations. This has not historically been an required reason to access/exchange/use data.
15:23:34 From Steven Lane to Everyone:
As with all of these exchange purposes, Public Health includes multiple specific use cases: Clinical Treatment, reporting, case investigation, research, resource planning, etc.
15:23:59 From Steven Lane to Everyone:
+ contact tracing
15:25:00 From Steven Lane to Everyone:
We also face the significant challenge in CA of different counties/jurisdictions making different requests/demands for data in different formats.
15:25:06 From Deven McGraw to Everyone:

Lee is correct that public health defined in the HIPAA Privacy law is limited to sharing with public health authorities or their designees, for purposes relevant to allowing those authorities to do their jobs, essentially. But the issue of whether any recipient of data (public health or otherwise) is subject to appropriate controls regarding how they subsequently use and share information is something we should consider whether we can address as part of the agreement (i.e., agreement to abide by certain privacy & security safeguards even if not otherwise covered by law).

15:27:20 From Steven Lane to Everyone:

While we are attempting to identify where we might do something important and innovative iN CA let's consider requiring that exchange for Public Health purposes be bidirectional - allowing providers, individuals and perhaps payers and/or researchers to be able to access data collected and maintained by Public Health.

15:28:35 From Lisa Matsubara to Everyone:

We should consider private third-party contractors that a public health agency contracts with for PH purposes and what those contractors can to with regard to retention and use of the data they collect

15:29:01 From Steven Lane to Everyone:

Short of innovating in the space of Public Health exchange, let's take this opportunity to raise the floor so as to get all PH jurisdictions across the state up to using modern technologies to exchange and use core data for core purposes.

15:30:21 From Michelle (Shelly) Brown to Everyone:

research

15:35:24 From Michelle (Shelly) Brown to Everyone:

yes - broaden to include determination of eligibility by local governments - county and city

15:36:00 From Elizabeth Killingsworth to Everyone:

I would not mandate research, permit, yes, but not mandate

15:37:47 From Steven Lane to Everyone:

Agree that Research uses should be permitted and supported by whatever we put in place at a statewide level, but not required.

15:39:00 From William (Bill) Barcellona to Everyone:

I agree with Belinda's points as well. If it is at least permitted that would help establish the floor that Steven was proposing in order to standardize public agency capabilities.

15:39:19 From Steven Lane to Everyone:

Research may be public or private, clinical or business-focused.

15:44:48 From Elizabeth Killingsworth to Everyone:

Are we, as a group, comfortable with permitting any exchange allowed my law with a narrower list of required exchanges or does anyone wish to limit the permitted purposes further?

15:45:22 From Michelle (Shelly) Brown to Everyone:

directly related to the principles to detect and address gaps

15:49:22 From Lee Tien to Everyone:

My understanding of public attitudes toward research these days is that the public is more suspicious that “research” is somewhat euphemistic for profitable pharmaceutical research regardless of patient objections.

15:49:45 From Michelle (Shelly) Brown to Everyone:

agree

15:50:22 From Ashish Atreja to Everyone:

agree, need to determine where the line of optionality lies

15:50:26 From Lisa Matsubara to Everyone:

agree

15:51:02 From Deven McGraw to Everyone:

Agree with @Elizabeth

15:51:26 From Steven Lane to Everyone:

No need to enumerate exchange purposes already permitted by others.

15:51:47 From Steven Lane to Everyone:

Research data is NOT always deidentified.

15:51:57 From Elizabeth Killingsworth to Everyone:

My goal is the cleanest, easiest to understand document that we can possibly have.

15:52:24 From William (Bill) Barcellona to Everyone:

Agree with Elizabeth's point.

15:52:30 From Michelle (Shelly) Brown to Everyone:

Agree with @Elizabeth... makes the agreement much simpler... the data needed for use cases can be tailored in a policy and procedure

15:52:45 From Steven Lane to Everyone:

Much data required to support research done under the Common Rule is specific to the individual research subject.

15:53:12 From Jenn Behrens to Everyone:

Regarding individual access - there are limitations to some records by agencies we are including in this framework for legal, policy and protective reasons - such as certain records by social services

15:55:07 From Steven Lane to Everyone:

We should point to the Information Sharing requirements of the ONC Cures Final Rule specifying that (1) providers (2) health information networks/exchanges, and (3)

developers of certified HIT MUST exchange data upon request if that access is allowed by HIPAA.

15:55:25 From Ashish Atreja to Everyone:

the other aspect of consent is whether is can be conveyed to another organization - in current exchange - data may move from one provider to another and then a 3rd - with provenance - might need to agree to how much that consent moves from org to org in a particular TPO dynamic or other?

15:57:16 From Steven Lane to Everyone:

Jennifer - You are doing a great job moderating. Thanks!

15:58:55 From Steven Lane to Everyone:

How can we support and advance reciprocal exchange if these other entities are not also required to participate?

16:00:38 From Steven Lane to Everyone:

Can we create some incentives for the non-required entities to sign on?

16:00:43 From Deven McGraw to Everyone:

Should be a quid pro quo - if you want the benefits of accessing through the network, you have to be willing to share back, subject to any legal constraints

16:01:18 From William (Bill) Barcellona to Everyone:

Agree with Deven's point. Wouldn't that help facilitate CalAIM for example?

16:02:34 From Steven Lane to Everyone:

The technology hurdle here is really quite low. Anyone with a charged device and Internet access can participate with a low barrier to entry.

16:02:38 From Ashish Atreja to Everyone:

Really need to understand patient identity - matching amongst organizations - could be required to exchange, but tighten the patient matching logic to make it almost impossible to find a match - and exchange - may need to weigh in on identity and matching to ensure the reciprocal exchange

16:02:56 From Steven Lane to Everyone:

We are no longer limited to 20th Century Big Iron technology solutions.

16:04:38 From Steven Lane to Everyone:

This is California, for goodness sakes. Let's get some simple apps out there to support low budget stakeholders to participate in standards-based federated exchange. The technology solutions are readily available.

16:06:15 From Michelle (Shelly) Brown to Everyone:

CIEs can serve to fill the gap between sophisticated EHR used by a Covered Entity and a CBO that operates off an Excel spreadsheet. But requiring a CBO to provide data exchange rather than allow them access will deter adoption.

16:10:34 From Lee Tien to Everyone:

Is there any way to get the broadband infrastructure $$ to involved local entities?

16:13:33 From Steven Lane to Everyone:

f we are to support closed loop referrals between CBOs and providers the CBOs will need to be willing to send as well as to receive days. This data exchange can be skinny at first but will be revolutionalrily impactful.

16:14:18 From William (Bill) Barcellona to Everyone:

I agree with Shelley's verbal comments. CalAIM has incentive dollars, for example that would allow smaller providers to ultimately participate in data exchange, after a period of data access.

16:17:09 From Steven Lane to Everyone:

This architecture appears to be consistent with how this is being addressed through Carequality today as well as by TEFCA, as we expect it to function in the coming year.

16:18:44 From William (Bill) Barcellona to Everyone:

I like your approach Jennifer. I assume that you would include a governing body that would periodically address the need for updates to the P&Ps. Perhaps more than one body, based on differing areas?

16:20:31 From Steven Lane to Everyone:

P&Ps in particular will need to have a rapid amendment/update process to respond to changing needs and technology.

16:21:26 From Patrick Kurlej to Hosts and panelists:

Curiosity question - How will each organization be tracked / requested to sign whatever is in the DSA? Who is the oversight organization?

16:24:22 From Lee Tien to Everyone:

This may be a very dumb question. Who, if anyone, can enforce the DSA? What does the enforcement process look like?

16:28:00 From Belinda Waltman, MD to Hosts and panelists:

Will we be doing a deeper dive in subsequent meetings to discuss potential participants/actors for data exchange? i'm thinking specifically about the Coordinatted ReEntry use case and whether branches of law enforcement may request to sign onto the DSA. In the LA experience, we had requestss from probabtion for some data exchange because they felt they were providing care coordination.

16:28:02 From Steven Lane to Everyone:

Thank you all and HAPPY HOLIDAYS!!

16:28:02 From Morgan Staines to Everyone:

Lee, that's a fine question. Not a dumb one at all.