



**California Health & Human Services Agency
Center for Data Insights and Innovation
Data Exchange Framework Stakeholder Advisory Group
Data Sharing Agreement Subcommittee
Meeting 3 (January 18, 2022, 12:00PM – 2:30PM PT)
Chat Log**

The following comments were made in the Zoom chat log by Data Sharing Agreement Subcommittee Members during the January 18th virtual meeting:

15:08:39 From Lane, Steven MD MPH to Everyone:

<https://rce.sequoiaproject.org/common-agreement/>

15:08:51 From Lane, Steven MD MPH to Everyone:

<https://www.healthit.gov/buzz-blog/interoperability/321tefca-is-go-for-launch>

15:09:03 From Lane, Steven MD MPH to Everyone:

<https://www.healthit.gov/topic/interoperability/trusted-exchange-framework-and-common-agreement-tefca>

15:11:11 From Lane, Steven MD MPH to Everyone:

<https://www.hhs.gov/about/news/2022/01/18/onc-completes-critical-21st-century-cures-act-requirement-publishes-trusted-exchange-framework-common-agreement-health-information-networks.html>

15:12:50 From Lee Tien to Hosts and panelists:

I have some questions about “breach” process, should I just send those directly to Jennifer/staff?

15:16:11 From Michelle Brown to Hosts and panelists:

I believe "access" is required under law.

15:16:25 From Lammot du Pont to Hosts and panelists:

Lee... feel free to include them in the chat and/or raise during today's discussion. The definition of "Breach" will be discussed during the next section of today's discussion.

15:17:22 From Jenn Behrens to Everyone:

RE: TEFCA - I agree that we should review and consider but that we should not require compliancy with TEFCA

15:20:45 From Lane, Steven MD MPH to Everyone:

A lot of work is ongoing to develop standards to be able to provide individuals with granular control over access to specific (sensitive) health information. The supporting technology for this work is in its infancy.

15:21:13 From Lane, Steven MD MPH to Everyone:

See specifically: <https://www.drummondgroup.com/pp2pi/>

15:21:32 From Deven McGraw to Everyone:

Good points from Lisa M re: “patient representatives” which at a minimum, under law, should be limited to persons legally authorized to make medical decisions.

Absolutely need to consider the adolescent use case.

15:23:50 From Lane, Steven MD MPH to Everyone:

There are multiple critical use cases beyond adolescents and reproductive rights. These are being teased out through the PP2PI effort, which is likely to become a formal FHIR accelerator under HL7 and ONC to advance the technical tools necessary to support this important need.

15:24:21 From Elizabeth Killingsworth to Everyone:

I have concerns about opening this up beyond individuals/proxies without a uniform, established consent process. I would recommend that such an expansion, especially as a requirement instead of an optional exchange, be considered at a later time

15:24:27 From Jenn Behrens to Everyone:

The recent ONC LEAP grants looked at some of these use cases and technical feasibility

15:24:49 From Ashish Atreja, MD, UC Davis Health to Everyone:

Overall, I totally agree with the approach of us keeping federal initiatives and specifications in mind as we draft data exchange agreement for CA so a) we are not in conflict b) leverage and build upon work already done rather than duplicating the effort and c) make it easy for organizations who have to comply with Federal mandates (across state data exchanges etc) in addition to California mandates.

15:25:01 From Eric Raffin to Hosts and panelists:

I might be helpful for all of us to see an analysis of health and social services laws (fed and CA) with specific disclosure rules so we can understand the complexity, challenges, feasibility of sharing in a broad manner.

15:25:54 From Helen Kim to Hosts and panelists:

I agree with Eric R.'s suggestion. That would be helpful to see that laid out.

15:28:00 From Deven McGraw to Everyone:

+1 to Elizabeth - Individual access should be defined to include individuals and their legal proxies.

15:28:29 From Lee Tien to Hosts and panelists:

+1 to Eric. The draft refers to “Applicable Law,” but do the Signatories agree on what they are?

15:29:14 From Lisa Matsubara (she/her) to Hosts and panelists:

Question as to whether the "proxies" would include other orgs outside of the state?

15:29:31 From Lane, Steven MD MPH to Everyone:

Agree with Elizabeth and Deven, but want to assure we address the challenge of adolescents and others who share their individual access credentials with their proxies, as this presents a REAL challenge in efforts to actually protect privacy in the real world.

15:30:07 From Deven McGraw to Everyone:

Administrators/executors - if they have the right to obtain records of a deceased person under state law, then they are essentially legal proxies (at least per HIPAA).

15:31:33 From Lane, Steven MD MPH to Everyone:

<https://jamanetwork.com/journals/jamanetworkopen/fullarticle/2784190> - Inappropriate Access to the Adolescent Patient Portal and Low Rates of Proxy Account Creation, 9/16/2021

15:32:53 From Lane, Steven MD MPH to Everyone:

As a family physician I can tell you that family members regularly access patient portal information and message providers using the individual's logon credentials.

15:33:02 From Elizabeth Killingsworth to Everyone:

I do agree that the adolescent question is a very difficult, but important, one. I also do not have a great answer for it. In other contexts, I have seen entities respond by simply never including the sensitive data in the initial response. There are obviously issues with this approach

15:35:46 From Lane, Steven MD MPH to Everyone:

In our organization we have decided, at this point, to not display online any potentially sensitive information to the adolescent (except those who are legally emancipated). Others have created multiple adolescent profiles so that those who specifically request access can have this provided.

15:38:42 From Michelle Brown to Hosts and panelists:

The agreement should be general... compliance with law. The policies and procedures can be used to get into these details.

15:44:49 From William (Bill) Barcellona to Everyone:

The agreement should be general and indicate compliance with law. Court appointment is often not required in estate matters and such a requirement could limit necessary activities by the executor or administrator, such as the completion of a death certificate.

15:46:20 From Michelle Brown to Hosts and panelists:

Definitely do not support this. Disclosure is driven by the authorization from the Client...

15:47:36 From Lammot du Pont to Hosts and panelists:

Although it is not an inventory of data sharing requirements, CalAIM released a draft of "CalAIM Data Sharing Authorization Guidance" for public comment in December

2021. <https://www.dhcs.ca.gov/Documents/MCQMD/CalAIM-Data-Sharing-Authorization-Guidance-For-Public-Comment-December-2021.pdf>

15:48:19 From Michelle Brown to Hosts and panelists:

Business Associates provide service to Covered Entities, whereas in the framework we are considering, Social Services need data to provide services to Clients independent of the Covered Entity.

15:51:33 From Belinda Waltman, MD to Everyone:

Similar to what Shelley is saying and Morgan was saying earlier, another approach would be to tackle this via client-level release of information, which may be necessary for segmented data beyond PHI like Part 2 data, LPS, HIV test results.

15:55:05 From Kevin McAvey to Hosts and panelists:

Friendly reminder: please address chats to "Everyone"

15:58:33 From Lammot du Pont to Everyone:

Although it is not an inventory of data sharing requirements, CalAIM released a draft of "CalAIM Data Sharing Authorization Guidance" for public comment in December 2021. <https://www.dhcs.ca.gov/Documents/MCQMD/CalAIM-Data-Sharing-Authorization-Guidance-For-Public-Comment-December-2021.pdf>

16:10:32 From William (Bill) Barcellona to Everyone:

The 24 page CalAIM Data Sharing Authorization guidance should be taken into account here. Public comment closed on January 7th and references AB 133 requirements at pages 4-5.

16:17:22 From William (Bill) Barcellona to Everyone:

Should we look closely at the 18 section format used in the Common Agreement?

16:19:24 From Jenn Behrens to Everyone:

+1 for FHIR

16:22:48 From Carrie M. Kurtural to Everyone:

Agreed. We are going to change so much in the future. Health exchange is a transaction like anything and this all might be on the blockchain within the next 5 years. I like being agnostic to not preclude any potential future tech options, but understand the need for a bare minimum standard as Ashish says.

16:23:26 From Ashish Atreja, MD, UC Davis Health to Everyone:

FHIR at Scale is now evolving as HL7 accelerator so lot of good standards to help us execute on CalHHS mission

<https://oncprojectracking.healthit.gov/wiki/pages/viewpage.action?pageId=43614268>

16:23:37 From Ashish Atreja, MD, UC Davis Health to Everyone:

All- Free and Open standards.

16:29:51 From Lee Tien to Everyone:

Relative to Eric R's point earlier, will there be an enumerated list of Applicable Laws (not necessarily all-inclusive)

16:37:33 From Deven McGraw to Everyone:

Are nongovernmental social service agencies covered by 1798.82 of the CA Civil code; or 1798.29 of the Civil Code w/r/t state agencies?

16:39:07 From Eric Raffin to Hosts and panelists:

+1 to Deven ... CA data breach law covers all businesses - we already are subject to this law in addition to HIPAA

16:39:41 From Elizabeth Killingsworth to Everyone:

I do not believe that there should be a tiered approach. My point is that, though many of this may be able to (or do today) comply with these provisions, we have to factor in the rest of the healthcare environment. Having tiers is not productive. There should be a floor set by this agreement that is compliant with law and reasonable for a wide range of entities. For some of us, we will have stricter obligations elsewhere that we must also comply with, but those do not need to be duplicated here

16:40:11 From Carrie M. Kurtural to Everyone:

I think social services need to at least be on the same safeguard and breach standards, except they don't have to report / liable to OCR. I agree with Elizabeth.

16:43:13 From Carrie M. Kurtural to Everyone:

Second that - I think the breach definition should just be the first sentence. take out the IPA stuff on that last line.. I don't think it's needed, state depts. will harmonize

16:43:36 From Deven McGraw to Everyone:

But why would a breach also include sharing information beyond an Exchange purpose? As long as the disclosure of that information is lawful, even if it's not a prioritized exchange purpose, shouldn't constitute a "breach".

16:45:00 From Elizabeth Killingsworth to Everyone:

I 100% agree with Deven, though it looks like at least some of that is solved for with the exceptions

16:47:32 From Jenn Behrens to Everyone:

I think differentiating b/w PHI and PII after the exchange is live is going to be exceptionally challenging from a functional perspective

16:47:45 From Lisa Matsubara (she/her) to Hosts and panelists:

I think the tiered approach does not take into consideration that Elizabeth raised which is that the capacity of various health care providers vary widely

16:48:00 From Deven McGraw to Everyone:

I wonder if there's a threshold question of whether we want or need this agreement to set new or even common standards for privacy/security/breach etc. On

the one hand, we're trying to trying to get entities to exchange data even under current conditions. What additional conditions need to be imposed?

16:49:57 From Eric Raffin to Hosts and panelists:

I would propose a comparison of HIPAA, CA Data breach notification act (has been amended several times) , CCPA and any other statute we find relative to determine which participants would not be covered properly wrt breach notification - narrow the approach to understand where some language might be required.

16:57:28 From Jenn Behrens to Everyone:

I propose that CA offer/provide a Technical Assistance Program to support smaller entities get through onboarding

16:58:59 From Patrick Kurlej to Hosts and panelists:

Jenn - I agree with your statement - Technical Assistance / consultive help

17:01:16 From Lane, Steven MD MPH to Everyone:

Agree with Jenn. We should be raising the floor, supporting those with technical challenges to utilize the tools that exist. As I have said before, the technology itself is no longer expensive nor does it require deep technical competence to access it. We need to help everyone get on board with the basic tools.

17:04:51 From Elizabeth Killingsworth to Everyone:

To Steven's point- Agreed that the technology for exchange is readily available, but I do have concerns that, in some/many cases, it is much faster/easier to implement a query functionality for outgoing requests and incoming data than it is to ready one's existing data for sharing and responding to the requests of others.

17:08:00 From William (Bill) Barcellona to Everyone:

I agree with your summary Jennifer

17:08:13 From Lane, Steven MD MPH to Everyone:

Agree that the first tools that participants need is the ability to pull data via the Carequality framework (which evolves into TEFCA) and to push data/messages via Direct. This can be set-up easily and cheaply, e.g., through

<https://kno2.com/interoperability-as-a-service/>

17:13:19 From Ashish Atreja, MD, UC Davis Health to Everyone:

To Lee's point, there are certifying agencies that can attest compliance with standards and best practices as well. We can leverage them and others for oversight function

17:13:42 From Louis Cretaro to Hosts and panelists:

funding may be a barrier to tech readiness

17:19:12 From Lane, Steven MD MPH to Everyone:

Reminder to committee members that there is a lot of valuable commentary being submitted through the Q&A channel. I believe that the organizers will capture all this content and post it to our website eventually.

17:20:52 From Michelle Brown to Everyone:

There needs to be a limit on Health Care Operations... these activities are really for the organization and not about sharing data to promote the wellness of the Client

17:21:17 From Lane, Steven MD MPH to Everyone:

Healthcare Operations needs to be broken down and addressed use case by use case.

17:21:31 From Lee Tien to Everyone:

+1 to what Michelle said about Health Care Operations

17:23:06 From Michelle Brown to Everyone:

good catch.... we need to allow research.

17:24:31 From Lee Tien to Everyone:

Agree with Deven's point about limiting to required responses. I always worry about over-sharing, and including "permitted" throughout makes it seem as though that's required by the agreement.

17:26:19 From Belinda Waltman, MD to Everyone:

If we do streamline the DSA per Deven's suggestion, we may want a complementary educational/TA/companion guide that does spell out the details, definitions, background, use cases, etc, for those less familiar or just joining this landscape.

17:26:36 From Louis Cretaro to Hosts and panelists:

The use case is critical to the dataset identified for each exchange in my opinion the DSA and the governing PHI or PII laws. Social services will contribute to various forms of prevention services as well as treatment.

17:28:55 From Jonah Frohlich to Everyone:

@Belinda: Agree with Deven's proposed approach and your response. I think we may need the state's governance process (TBD) to be responsible for promulgating this kind of state policy and data sharing guidance

17:29:13 From Deven McGraw to Everyone:

Thanks to staff for facilitating a great meeting!

17:29:23 From Lee Tien to Everyone:

Yes!