California Health & Human Services Agency
Center for Data Insights and Innovation
Data Exchange Framework Technical Advisory Committee (TAC) Meeting
Transcript (12:00 PM – 1:00 PM PT, June 12, 2025)

The following text is a transcript of the June 12, 2025, meeting of the California Health and Human Services Agency and Center for Data Insights and Innovation Data Exchange Framework TAC. The transcript was produced using Zoom's transcription feature. It should be reviewed concurrently with the recording – which may be found on the CalHHS Data Exchange Framework webpage to ensure accuracy.

[Alice K - Events] 15:01:43

Hello, and welcome. My name is Alice, and I'll be in the background answering any Zoom technical questions.

[Alice K - Events] 15:01:49

If you experience difficulties during this session, please type your question into the Q&A.

[Alice K - Events] 15:01:54

Individuals in the public audience who have a comment may insert it in the Zoom Q&A.

[Alice K - Events] 15:01:59

Public comment will also be taken towards the end of the meeting.

[Alice K - Events] 15:02:03

Live closed captioning will be available.

[Rim Cothren, CDII CalHHS] 15:02:11

Thank you, Alice, and welcome to today's tech meeting. As always, I encourage everyone to turn their cameras on if you're able. I'm expecting a lively discussion today, and it's nice to be able to see everyone's faces.

[Rim Cothren, CDII CalHHS] 15:02:25

Let's go on to the next slide, please. We start all of our meetings with our vision for data exchange in California.

[Rim Cothren, CDII CalHHS] 15:02:31

An important part of that data exchange is to make sure that we're following, whenever we can, the preferences of patients or clients in sharing their information, and so today, we're really going to be talking about Consent to share information.

[Rim Cothren, CDII CalHHS] 15:02:46

Um, and bear in mind, uh, how an important, uh, topic that is for, uh, trust in the system among those that we're serving.

[Rim Cothren, CDII CalHHS] 15:02:56

It's gone to slide 3, please. This is our agenda for today, so we'll start off with the welcome, which is where we are today. We won't do a roll call, a full roll call at any of our follow-on meetings, but we do have a couple of new members today that we might call on just to introduce themselves.

[Rim Cothren, CDII CalHHS] 15:03:12

Uh, our big topic today is a discussion on what should a model for managing and communicating consent be.

[Rim Cothren, CDII CalHHS] 15:03:19

Um, we'll pause for public comment at about 10 before the hour, and then there'll be next steps and short closing remarks.

[Rim Cothren, CDII CalHHS] 15:03:28

I'm just going to go ahead and warn people, I have an unavoidable conflict. The second half of today's meeting.

[Rim Cothren, CDII CalHHS] 15:03:34

So I'm going to be stepping out, I'll probably do that silently, just so that I don't interrupt the conversation and Cindy will be taking over for me.

[Rim Cothren, CDII CalHHS] 15:03:42

Do not abuse Cindy. I will listen to the recording, and I will know if you do.

[Rim Cothren, CDII CalHHS] 15:03:47

It's go on to the next slide, please. This is just a reminder of who's in the group here. We have a very large group, uh, and as I said, we have two new members. I'm not sure that I saw them join.

[Rim Cothren, CDII CalHHS] 15:04:00

Uh, yes, Sarah, do you want to… Uh, come on camera, introduce yourself and the organization that you're representing.

[Sara Rogers] 15:04:07

Good afternoon, uh, Sarah Rogers, I am with the California Department of Social Services.

[Sara Rogers] 15:04:13

Um, and the chief of the system of care branch. Within Children and Family Services.

[Rim Cothren, CDII CalHHS] 15:04:18

Thank you for joining us today, and Jessica, I'm not sure I saw Jessica, are you with us here?

[Sara Rogers] 15:04:27

From CDSS, she's not here today. I think I'm the only… I don't know if Shannon's here, but I… I am the only one from Children's today. I think Jessica's not joining today.

[Rim Cothren, CDII CalHHS] 15:04:38

Alright, well, I knew that we gave very short notice for her to join today's meeting. Thank you, Sarah, uh, for carrying the weight on your own shoulders.

[Rim Cothren, CDII CalHHS] 15:04:46

It's go on to the next slide, please. Also, as just a reminder, uh, there are opportunities for members of the public to comment or ask questions on today's meeting.

[Rim Cothren, CDII CalHHS] 15:04:58

Public comment. We'll pause for public comment at the place where it's listed on the agenda at approximately 10 minutes before the hour.

[Rim Cothren, CDII CalHHS] 15:05:06

Um, members of the public may also use the Zoom Q&A feature to ask questions or make comments. Anything that the public puts in that space is visible to everyone.

[Rim Cothren, CDII CalHHS] 15:05:17

So you may use that to make comments that other members of the public can see.

[Rim Cothren, CDII CalHHS] 15:05:21

Uh, members of the panel here can see those as well, and anybody that does see a question or a comment there that they want to bring to everybody's attention, feel free to mention that. I often try to monitor the Q&A as well.

[Rim Cothren, CDII CalHHS] 15:05:36

And then, just as a reminder, if you do use the chat feed.

[Rim Cothren, CDII CalHHS] 15:05:41

Feature, um, please make sure that you're chatting to everyone. But my strong preference is that you speak out loud.

[Rim Cothren, CDII CalHHS] 15:05:50

Um, one final thing before we really kick things off today. This is a very large group, and it was really obvious to us last time it was a very large group.

[Rim Cothren, CDII CalHHS] 15:05:57

Great conversation, and I want to keep that Um, moving forward, I'm going to shut up quickly here so that you guys have a chance to talk.

[Rim Cothren, CDII CalHHS] 15:06:05

But I would encourage people to make sure that you give everybody a chance by keeping your comments on point and short.

[Rim Cothren, CDII CalHHS] 15:06:12

Just because there are a lot of people here, and there was… I think at one point we counted 7 hands raised, so I just want to… Try to make sure that we keep things moving. Let's go on to the next slide.

[Rim Cothren, CDII CalHHS] 15:06:24

I just want to remind people the objective that this series of meetings, and that is to develop recommendations. You're actually making recommendations to CDI.

[Rim Cothren, CDII CalHHS] 15:06:33

For how to coordinate collection, sharing, and use of individuals' consent.

[Rim Cothren, CDII CalHHS] 15:06:38

Ensuring it is applied consistently when exchanged. When exchanging health and social services under… information under DXF.

[Rim Cothren, CDII CalHHS] 15:06:48

Let's go on to the next slide, please, and this is a brief summary of what we heard at our last meeting. I'm not going to read this slide to you.

[Rim Cothren, CDII CalHHS] 15:06:56

Pause here for a second, let you glance over things, and in particular, if you think that we got anything wrong here.

[Rim Cothren, CDII CalHHS] 15:07:02

I'd like to make sure that I hear from you. About, um, uh, how we should, um.

[Rim Cothren, CDII CalHHS] 15:07:11

Consider differently. One of the things that we noted here, or if there… it was difficult on one slide to summarize all of the conversation, but if you see something Of particular importance that's missing here, please highlight that, too.

[Rim Cothren, CDII CalHHS] 15:07:40

Yeah, David.

[David McCann] 15:07:41

Uh, so, Rem thought it was a good slide. On the 1, 2, 3, 4, 5th bottom bullet, I think what came out last time, both from your form.

[David McCann] 15:07:52

And the conversation, I believe, was that adolescent foster youth And people experiencing substance abuse and needing mental health treatment, I think they were also called out as tailored requirements.

[David McCann] 15:08:05

I don't know if you were adding a… adolescent and foster, but the other two were called out as well as somewhat unique.

[Rim Cothren, CDII CalHHS] 15:08:13

Great, thank you, David.

[Rim Cothren, CDII CalHHS] 15:08:23

Are there any other comments here?

[Shannon Rohall, CDSS] 15:08:23

If I can tap onto that as well, um, this is Shannon Rojol from CDSS.

[Shannon Rohall, CDSS] 15:08:29

Um, I… not only was it mentioned to be unique, but Um, in appreciation of the fact that the, uh, existing concept is around an 80-20 split, where predominant, like, needs, 80% of the needs.

[Shannon Rohall, CDSS] 15:08:42

Would be prioritized over those more niche needs. Um, I think adolescent foster youth and those with mental health and substance abuse treatment fell into that category, and so recognizing that we want to have an efficient kind of, uh… consent flow, um, I think there's also the risk of, um, deprioritizing, um, or kind of sending the message that those other needs are deprioritized by focus on that 80%. So.

[Shannon Rohall, CDSS] 15:09:08

Don't have a recommendation, just uplifting that there's that kind of dichotomy, um, to balance there.

[Rim Cothren, CDII CalHHS] 15:09:12

Thanks, Shannon. Adam?

[Adam Davis] 15:09:16

Rim, uh, out of Davis Southern Health. The one other thing that I… at least I heard last month was some of the technical folks and myself sort of advocating for trying to come up with a specific and rather simple

[Adam Davis] 15:09:28

Like, first use case, um, because consent can be really tricky and large, and I want to make sure that we're keeping that in mind, because I think figuring out what should be our first thing, I think it's going to be one of the really

[Adam Davis] 15:09:40

Tricky decisions and recommendations that we're going to be making.

[Rim Cothren, CDII CalHHS] 15:09:44

Great. Thanks, Adam. Jim?

[James Shalaby] 15:09:47

Yeah, Rim, um, uh, the fourth bullet down, Consent Management System Must Support Reconciliation of multiple versions.

[James Shalaby] 15:09:55

Uh, with the most recent consent treat as, uh, authoritative. Uh, I think we may want to delve a little bit deeper into this, because there may be challenges with the subject of the consent, you know, the most recent may not necessarily represent

[James Shalaby] 15:10:12

Um, the topic of… of interest that the consent is focused on, and so… It might be worth it just to talk about that a little bit, just to clarify. I'm not sure I completely understand that.

[Rim Cothren, CDII CalHHS] 15:10:24

Okay, well, reconciliation is actually on our agenda to talk about today. Um, it is… and so we'll delve into that deeper today. We may… delve into it deeper next meeting as well. I do think it's one of the complex things.

[James Shalaby] 15:10:26

No. Sure.

[James Shalaby] 15:10:36

Okay. Great, thank you.

[Rim Cothren, CDII CalHHS] 15:10:38

Thanks, Jim. Lynette?

[Linette Scott] 15:10:41

I just wanted to, um, kind of echo behind Shannon, just to… to reiterate.

[Linette Scott] 15:10:47

From a DHCS perspective, certainly part of our priority is addressing consent needs for, um.

[Linette Scott] 15:10:55

Substance abuse, mental health, homelessness, um, and then, uh, foster care is another key area. Adolescents, obviously.

[Linette Scott] 15:11:03

Medi-cal has populations that are Um, uh, you know, about half or a third to half are in the children-youth category, so… Those are going to be critical to address for our population, so… In our world, those don't fall in the 20%.

[Rim Cothren, CDII CalHHS] 15:11:20

Thanks, Lynette. Hans.

[Hans Buitendijk] 15:11:23

Thank you. Yeah, there's one part that was… came up in the last meeting somewhat, and James started to allude to it for maybe further discussion as well.

[Hans Buitendijk] 15:11:32

Uh, we have this challenge of, are there multiple consent managers for a patient as they visit multiple places?

[Hans Buitendijk] 15:11:39

They must be centered to the patient, they must be able to reconcile.

[Hans Buitendijk] 15:11:43

There's one element that I thought came up, or if not, that we want to consider in our conversations as well.

[Hans Buitendijk] 15:11:49

That a patient may have the choice to use a, for them.

[Hans Buitendijk] 15:11:54

Centralized consent manager that other data holders can interact with. It's a mix of reconciliation and otherwise.

[Hans Buitendijk] 15:12:01

But I, as the patient, only have one place where I manage all my consents, no matter who it's for.

[Rim Cothren, CDII CalHHS] 15:12:07

Great, thanks, Hans, and I'm not… I think I may have missed that in our last conversation, so thanks for elevating this. We're also going to be talking about the components.

[Rim Cothren, CDII CalHHS] 15:12:15

Of consent and what it takes to exchange consent, and… that may come up in that discussion again, too.

[Rim Cothren, CDII CalHHS] 15:12:24

Joe, and I think I missed, uh, letting you to introduce yourself, because I think you missed our last meeting. You want to just… say hi to folks in what organization you're with, and then your comment.

[Joe Sullivan] 15:12:34

Sure, uh, Joe Sullivan, Chief Information Officer for California Emergency medical services authority.

[Joe Sullivan] 15:12:41

Um, my comment seems minor compared to the consent. Comments, but, uh, the last bullet about a Slack channel, can we not use Slack and… use Teams or something that, um… We have a government subscription for.

[Rim Cothren, CDII CalHHS] 15:12:55

So, I was going to touch on the request for a Slack channel, and we did take this back to leadership, and CDI is not going to do that. We also conduct these as Open meetings available to the public, and I think managing that through a Slack channel is just beyond our capabilities. If other organizations want to keep this conversation going

[Rim Cothren, CDII CalHHS] 15:13:16

Outside of these meetings, these meetings, I absolutely welcome that. However, um, this is the forum for a public conversation on consent, so we're going to… we're going to limit that here. Thanks for bringing that to my attention, Joe, and making sure I didn't slop…

[Joe Sullivan] 15:13:28

Okay. Black on it.

[Rim Cothren, CDII CalHHS] 15:13:31

Pass over that today. Yes, I'm not clever enough for the puns. Thanks, Joe. Ken!

[Joe Sullivan] 15:13:34

Alright, thank you.

[Ken Riomales] 15:13:40

Yeah, thanks. Um, this might be assumed, and not sure if it needs to be explicitly stated, but just a general alignment with other state initiatives.

[Ken Riomales] 15:13:48

Um, for example, DHCS's, uh. Up-and-coming release, then, and you ask me for them, as well as a potential CMP.

[Ken Riomales] 15:13:54

Uh, so if we're referencing consent management systems, I would think that weighs pretty heavily in terms of what's going to take, you know, precedence or whatnot as far as the management of several consent Uh, you know, potential documents being sent in. So, I would just kind of point that out.

[Rim Cothren, CDII CalHHS] 15:14:12

So, thanks, Ken, and Ken is not a plant, but if we do move on to the next slide. We identified really two assumptions that we wanted to talk about today. The first is an assumption that you should just take, and Ken alluded to the Ask Me Consent Management Platform.

[Ken Riomales] 15:14:13

Thank you.

[Rim Cothren, CDII CalHHS] 15:14:28

And the Ask Me Project, that is an ongoing Um, program, uh, operated by, uh, DHCS, and Lynette and Ellison both are Heavily engaged in that project, Ellison leads it, and they can talk more about it. We brushed on it.

[Rim Cothren, CDII CalHHS] 15:14:46

Very briefly, in our last meeting. And there is an assumption here that will be built, it will exist, and it will have the architecture and the processes that, uh.

[Rim Cothren, CDII CalHHS] 15:14:58

Were described there, will develop out of that description. Ken is part of some of those conversations, and Um, very aware of that. If Derek is here, he's part of those conversations as well.

[Rim Cothren, CDII CalHHS] 15:15:11

We are not here to re-architect ask me. Um, but we need to assume that it exists, and that it is a part of the DXF landscape. The assumption that we found ourselves making at CDI that I want to confirm today

[Rim Cothren, CDII CalHHS] 15:15:30

Is the DXF should converge on a shared model for consent management.

[Rim Cothren, CDII CalHHS] 15:15:34

That might include collecting consent, exchanging consent, having a repository for consent, identifying what consent means.

[Rim Cothren, CDII CalHHS] 15:15:43

Etc. So… If we can pull down the slides for just a minute so we can see everybody's faces, I want to confirm that with the organ… with the audience here. Can… so, can everybody just give me… A thumbs up, uh, if you believe that we should be identifying a mechanism within DXF to, uh.

[Rim Cothren, CDII CalHHS] 15:16:02

Coordinate consent.

[Rim Cothren, CDII CalHHS] 15:16:10

I see a bunch of thumbs up, I don't see all of them, so if you are questioning

[Julie Silas] 15:16:16

Like, what, like. You know, there's a lot of our organizations that we work with who are so divorced from DXF, and have no idea that DXF even exists, and so I'm just trying to understand, like, what's the alternative, and what's the benefit of it being housed here?

[Rim Cothren, CDII CalHHS] 15:16:33

Well, that'd be my question to you. The alternative may be the status quo, where every… where consent is.

[Rim Cothren, CDII CalHHS] 15:16:40

Fragmented and managed wherever it's managed today by every individual organization, and everybody is making disclosure decisions based on the local consent that they have So I would say the alternative is the status quo.

[Rim Cothren, CDII CalHHS] 15:16:54

Um, what that looks like is the big question for today. If the status quo is not good enough.

[Rim Cothren, CDII CalHHS] 15:17:00

Should DXF have a role in that? Um, so that's… that's the big question that I have. Robbie, I saw your hand… well.

[Rim Cothren, CDII CalHHS] 15:17:08

Let me… let me start by Julie… since you were the first one to, uh, mention something, I know you're the last one to raise your hand, but I'm going to turn to you first.

[Rim Cothren, CDII CalHHS] 15:17:19

Talked more about your thoughts on that.

[Julie Silas] 15:17:20

Thank you, thank you. Yeah, so it's just a very complicated process, right? And we have, like, and you work in the homeless system of care, they get a release of information, the county says that's not sufficient to release information with behavioral health, or with DSS, Um, then there's, uh, you know, who's on the release, and who… how that information could be shared, and…

[Julie Silas] 15:17:43

I love centralizing it, and I love the idea, like, conceptually, of it being managed at a state level in a in a streamlined way, that everyone accepts, uh, but that's a huge amount of work, um, for DXF.

[Julie Silas] 15:17:58

And it's not only create… I mean, sorry, CDI, it's, like, not only creating those forms, but making them accepted in the community, talking to all the county councils who don't have a lot of data and private expertise, so they tend to be risk-averse and say, no, there's just a lot of layers.

[Julie Silas] 15:18:14

Of implementation, um, to make this work and transition to a point 10 years from now.

[Julie Silas] 15:18:20

Great if it was a centralized place that everyone was socialized to use, and it worked well, I get it, but I'm just wondering if CDI and DXF has the capacity or the full understanding of what it means in practical terms, so that's sort of where I…

[Julie Silas] 15:18:36

Concern.

[Rim Cothren, CDII CalHHS] 15:18:36

So the full understanding, no, and that's why we're conducting these meetings. So I'm going to be looking for you to help us understand what this means, and what the steps might be.

[Rim Cothren, CDII CalHHS] 15:18:45

In a 10-year vision, but I'm hearing from you, though, is that there is a place for improvement.

[Rim Cothren, CDII CalHHS] 15:18:51

And I do want to say that people shouldn't assume that when we say coordinated consent for DXF, it means centralized. That is something for us to discuss as well, is what that ends up looking like Robbie, you've been very patient with your hand up.

[Robby Franceschini, Blue Shield of CA] 15:19:06

No, thank you, Rem. I think, um, a couple thoughts, and some of them jumping off of Julie's. One is, I think.

[Robby Franceschini, Blue Shield of CA] 15:19:12

First shared model, and I'm… I'm assuming, like, across… ask me plus whatever the DXF does, is that, you know, I think the rules and standards should align, right? Based on whatever use cases we're including, like an Ask Me.

[Robby Franceschini, Blue Shield of CA] 15:19:27

Or for the purposes of this DXF, consent management exercise, right? What's in and what's out?

[Robby Franceschini, Blue Shield of CA] 15:19:33

What are the technical standards? How are we thinking about things like the law? Most importantly, how does the law specify where consent is required, where it may be permitted for, you know, um, disclosures or uses.

[Robby Franceschini, Blue Shield of CA] 15:19:48

I think, as well, um, kind of, uh, with regards to, like, operations and workflow and uh, you know, implementing, um, these things. Like, if we have a centralized platform, say, for Medic, how, but not for you know, other uses for other members, right? I think that does create, certainly, workflow complexities for

[Robby Franceschini, Blue Shield of CA] 15:20:11

Payers for providers, for CBOs, who maybe, you know, if they're required to use it for Medi-Cal members.

[Robby Franceschini, Blue Shield of CA] 15:20:16

You know, they may be using it there and then handling consents in other places, so I think If that is to be the case, we want to think carefully about how we make compliance easier, so that ultimately, right, we can honor consents from, um, individuals.

[Robby Franceschini, Blue Shield of CA] 15:20:31

I think lastly, to that end, too, like, centering the patient or the member in this work.

[Robby Franceschini, Blue Shield of CA] 15:20:39

Um, I think, you know, as easy as we can make it for them to understand, right? You know, if you're on Medi-Cal one year, and then in the individual market the next year, maybe uninsured the next.

[Robby Franceschini, Blue Shield of CA] 15:20:50

How do you, you know, make, update, revoke a consent? Um, I think that that might be challenging if we have a centralized platform.

[Robby Franceschini, Blue Shield of CA] 15:20:55

For some members, but not all, right? And how do you… how do you manage all of those and understand how you can do so? And then I think, you know, underlying all that are the rules of the road for all of us that we need to comply with.

[Rim Cothren, CDII CalHHS] 15:21:08

Thank you, Robbie. David?

[David McCann] 15:21:20

So, good discussion. Um, I think in the previous meeting, I certainly pushed forward that

[David McCann] 15:21:26

I'm against the notion of the state mandating a central platform.

[David McCann] 15:21:26

The principle of DXF, which is about coordinating care across multiple entities.

[David McCann] 15:21:30

The 74 Paves Roadmap talks about innovate locally. I think that DXF is going to create common data models.

[David McCann] 15:21:37

Should the state absolutely influence the data model? 100% agree. I think where we ought to be headed in the cloud world is that everybody should be journeying towards a common data model.

[David McCann] 15:21:49

We've already called out there are 4 or 5 different consent types that we can envision for different cohorts.

[David McCann] 15:21:56

And given the thousands of entities that are operating across 58 counties.

[David McCann] 15:22:01

I would argue for a common data model. And then the state plays a role of guiding people to embrace the data model.

[David McCann] 15:22:09

But I don't buy into the notion that we should wait for the state to stand up a system.

[David McCann] 15:22:14

For which we don't even have a year.

[Rim Cothren, CDII CalHHS] 15:22:17

Thank you, David, and our next set of questions really starts to get to, so what are the components that we should be u- developing to advance this, what I'm hearing from David is that a common data model might be

[Rim Cothren, CDII CalHHS] 15:22:29

One of those components. Brian, I see your hand up.

[Brian Thomas] 15:22:34

Yeah, I think everyone has touched on this, but I think that if the question begins with.

[Brian Thomas] 15:22:41

Uh, should we be doing this as a group? I think the answer is yes, because I think we've heard structure we need.

[Brian Thomas] 15:22:48

We need common data sets. We need a common place and a way to think about this, uh, collectively And from my perspective, um, the state doesn't need to sort of own the direction or own a system.

[Brian Thomas] 15:23:01

But it needs to provide a place where folks like us can coalesce and agree upon structure.

[Brian Thomas] 15:23:07

And that structure is what will be layered probably over the next 10 years as this thing is built.

[Brian Thomas] 15:23:13

And is managed. Um, so whether or not it's a system or it's common data sets, it needs to be a place to coalesce all the ideas And all the things that really benefit our individual constituent bases. So, those folks that are going to benefit from this need

[Brian Thomas] 15:23:29

Representation, and we are those representatives, and we should be providing a way to facilitate consent. I would… love to see a digital model, something that we can all agree on in terms of passing that consent.

[Brian Thomas] 15:23:44

But I do think at the end of the day, this is where the voice of the… our individual constituent bases are represented in terms of their needs, and that this group should sort of make those decisions.

[Brian Thomas] 15:23:55

And the state should support that.

[Rim Cothren, CDII CalHHS] 15:23:55

Thank you, and again, we're going to be talking about, so what are the components, what I heard Brian add to us.

[Rim Cothren, CDII CalHHS] 15:24:02

Is structure, whatever that means, but I think it's good to be thinking about things at that level.

[Rim Cothren, CDII CalHHS] 15:24:06

And a common place to discuss these, which I think is an excellent discussion, uh, topic.

[Rim Cothren, CDII CalHHS] 15:24:13

We are going to be talking about this topic for, um, the next half hour here, and another two-hour meetings. Clearly, that won't be the end of it, and maybe there is some common place to continue these discussions that would be valuable as well. Hans, I see your hand up.

[Hans Buitendijk] 15:24:29

Thank you, Rim, and yeah, I want to add to that, and we'll wait for the rest of the conversation, but uh… The reason that I raised my hand on the, uh, on… in support of.

[Hans Buitendijk] 15:24:39

Is because of the term model. It did not use the term centralized. It has the opportunity to do that, so I think that next conversation on what's the model Which clearly has a data model, it has an agreement on standards and APIs that can be used to interact with that.

[Hans Buitendijk] 15:24:56

For the different parties, as the data holder, as the consent manager, other parties that need to be involved in it, I think that those are going to be relevant parts.

[Hans Buitendijk] 15:25:05

And as we go through what those components are.

[Hans Buitendijk] 15:25:14

I think we need to recognize is that the population that we consider They are mobile as well, so how do we align nationally, other states, otherwise, so that the management of this is very portable, um, that we are not shifting around to unnecessarily.

[Hans Buitendijk] 15:25:27

As we cross jurisdictions. So I think that element needs to be there as well, because the patient at the center implies that wherever the patient is, or is going to be, or came from.

[Hans Buitendijk] 15:25:40

Uh, so I think those are some of the elements that we will have to come back to, but key is its model, it's not centralized, it's federated.

[Hans Buitendijk] 15:25:45

And whatever that's going to mean.

[Rim Cothren, CDII CalHHS] 15:25:47

Thank you, Hans. So… An emphasis on model is what I heard there. Eric, we'll turn to your comment, and then we'll bring the slides back up and go to the next slide with our questions for today.

[Eric Jahn] 15:25:58

Thank you, Rem. One quick note, I do believe there's a role for the state in, kind of, cataloging the endpoints of the implementations of consent that are available across vendors.

[Eric Jahn] 15:26:08

And also to catalog the local governance rules that are intact, so that someone might be able to know what might be required. For example, a vendor like Bitfocus, where I work.

[Eric Jahn] 15:26:20

Uh, you know, it'd be great to have a quick reference. So, in other words, almost, you know, cataloging, um.

[Eric Jahn] 15:26:26

What's known, if possible, so that people can navigate the system.

[Eric Jahn] 15:26:31

Uh, and, um, so that might be a role for the state.

[Rim Cothren, CDII CalHHS] 15:26:36

Great, thanks, Eric. Let's go ahead and bring the slides up. I just want to build on Eric's comment a little bit that we've heard from some other places that a need to catalog endpoints is, um, suggestion in other areas as well, so it might…

[Rim Cothren, CDII CalHHS] 15:26:52

Meld with some of the other activities that we're exploring. These are really the questions that we wanted to, uh, guide the discussion today.

[Rim Cothren, CDII CalHHS] 15:27:00

Again, what are the components for a model for consent? For exchange of different types of information.

[Rim Cothren, CDII CalHHS] 15:27:07

Uh, with the emphasis on the model, but the model means whatever… whatever you want it to mean. I think that we need to discuss what what that is. Um… In our example, that might be… you know, the where, when, what, and who…

[Rim Cothren, CDII CalHHS] 15:27:23

Standard questions about um, involvement in consent.

[Rim Cothren, CDII CalHHS] 15:27:28

How do you reconcile consent collected at different places? And so, there's a discussion whether that is a common data model, whether that is Mechanisms or policies around how to exchange data.

[Rim Cothren, CDII CalHHS] 15:27:44

How you reconcile, uh… different consent forms, etc. We should discuss that.

[Rim Cothren, CDII CalHHS] 15:27:50

And how do you best establish trust So that we get to a place where I, as a participant on DXF, that am called upon to share data with another participant can act on that request based on consent that's collected

[Rim Cothren, CDII CalHHS] 15:28:05

Not by me, but by somebody else. What was necessary for me to trust the consent collected for a patient elsewhere.

[Rim Cothren, CDII CalHHS] 15:28:16

And then, as I said, I'm gonna have to leave here in a few minutes, so I am dumping, uh, this discussion on Cindy.

[Rim Cothren, CDII CalHHS] 15:28:22

And, uh, I will be listening in to the, um, the recording afterwards, and I'm really looking forward to that, so… Um, uh, Catalina, maybe you can dump these questions in the chat so that we can bring everybody on camera again and pull the slides down and have a wonderful conversation.

[Rim Cothren, CDII CalHHS] 15:28:45

Rita, I see your hand up, and then I'm going to turn things over to Cindy.

[Rita Torkzadeh] 15:28:50

Hi, yes, um, I might be jumping the gun a bit, um, because I know that a future Focus group is going to be focused on identity, but I do think that's actually a very key component to being able to

[Rita Torkzadeh] 15:29:04

Understand, like, who the… who… Provided the consent, um, who's recording it, you know, how it's… how it's captured, where it moves.

[Rita Torkzadeh] 15:29:13

Those sorts of things, and perhaps along with that, um, or maybe as part of that, um.

[Rita Torkzadeh] 15:29:18

Provenance, also. Um, so I would say that that's pretty, pretty key as one of the elements, and also a way to, um.

[Rita Torkzadeh] 15:29:28

Um… talk about, like, the whole validation question as well, because that's, um, would also enable that related item, so I'm… I'm… I'll let others speak to some other aspects.

[Cynthia Bero] 15:29:44

Thank you, Rita. Hans.

[Cynthia Bero] 15:29:52

Yeah, unmute. Sorry.

[Jonah Frohlich (he/him) | Manatt] 15:29:52

You're on mute, Hans.

[Hans Buitendijk] 15:29:55

Double muted, sorry about that. I had to control the Um, so the, uh, the second question is what I'd like to focus on, where, um, on reconciling consent.

[Hans Buitendijk] 15:30:05

Um, and, uh, depending on how one wants to view it, federated.

[Hans Buitendijk] 15:30:09

Centralized, multiple places. Otherwise. Um, two things that jump out that we need to look at. One is the notion of How do we know where the patient has consents, whether it's one or multiple places?

[Hans Buitendijk] 15:30:22

So there is the need for associating a patient with the address or addressees of where the consents are. That can be shared with the relevant data holders that may need to act on it, or not act on it.

[Hans Buitendijk] 15:30:36

Uh, based on what it is. So I think that's an important element.

[Hans Buitendijk] 15:30:39

Uh, the second part is that as that information changes. In either one or multiple, is that other data holders, including the ones that have consents on record.

[Hans Buitendijk] 15:30:50

Just need to know about it, so that they can act or react accordingly.

[Hans Buitendijk] 15:30:54

That means the subscription notification method of sorts. That when things change, the right parties that are data holders for that patient that need to be aware of those changes.

[Hans Buitendijk] 15:31:05

Hora made aware of them, and then can appropriately act. They can pick it up, or otherwise.

[Hans Buitendijk] 15:31:09

So those, I think, are the two main elements to enable whatever variety of architecture or federation we come up with, because I have the ability to notify everybody else Beyond that, I think it's going to go back to question one, topics.

[Hans Buitendijk] 15:31:24

I'm curious to hear from others, and just offering that element.

[Hans Buitendijk] 15:31:29

Hl7 Fast is really trying to address with the consent management, so that the standards on how to interact, how to request concerns.

[Hans Buitendijk] 15:31:37

How to be aware of it, subscriptions otherwise, how to do it. So I don't want to go into details there, but that's something to consider.

[Hans Buitendijk] 15:31:43

Uh, in the future discussions.

[Cynthia Bero] 15:31:47

Great, thank you. Derek?

[Derek Plansky] 15:31:53

Sorry, coming off mute. Yeah, um… generally agree with everything that Hans has mentioned, and from a technical infrastructure I think there's a danger on the quote-unquote innovation side that if we allow too much innovation, we're not going to have a standard set of definitions of what everything

[Derek Plansky] 15:32:10

What the consent, uh, pieces that people are actually uh, asserting are their preferences mean the same thing to everyone else, so… From a governance perspective, we have to absolutely have some sort of common set of definitions, like, does an opt-out mean everything?

[Derek Plansky] 15:32:27

You know, there's a lot of nuance, and there's a lot of different types of data.

[Derek Plansky] 15:32:32

But the more complex it becomes, the more likely there's someone who will not interpret the consent the way that the patient originally intended. So.

[Derek Plansky] 15:32:41

Even if we have this federated system, there needs to be a common set of definitions of what we're what the rules are, what we're articulating are our patients' preferences around the sharing or not sharing of data.

[Cynthia Bero] 15:32:55

Sort of that shared understanding concept that… that is essential. Thank you, yeah. Eric?

[Derek Plansky] 15:32:58

Yeah.

[Eric Jahn] 15:33:02

I had, uh. Regarding the components, I think the two main components would be something like a web ontology that sets up the semantic.

[Eric Jahn] 15:33:10

Terms, entities, workflow. Uh, and… I'm sorry, the entities and the relationships between those entities and the various data types fields.

[Eric Jahn] 15:33:18

And then, um, and that could be shareable publicly, and it could go through many versions, and it's, you know, it's a flexible tool used for logical modeling, you know, across the U.S. And the world.

[Eric Jahn] 15:33:28

The other aspect, though, is we need a sequence of, you know, who are the actors, and what are the uh, the… what would you call it, the archetypal steps that would occur in a standard workflow.

[Eric Jahn] 15:33:41

Uh, and then also, you know, along the lines, I think, of what Hans was saying, you know, with the publish and subscribe, the PubSub aspects of this, I think one key thing that interaction would be revocability, so that if consent is retracted, that then all the actors' systems are updated as well.

[Cynthia Bero] 15:34:00

Those are all great features. Jim?

[James Shalaby] 15:34:08

Sorry, uh, was on mute. Yeah, um, just to echo, um, you know, what Derek and Hans have been saying, is that Um, I think, uh, consent management rules, along with the model, is going to be, uh.

[James Shalaby] 15:34:21

Kind of a really important piece, because Um, the notion of, you know, most recent consent, you know, kind of wins.

[James Shalaby] 15:34:28

It's a little bit difficult, even in a… even more so in a federated model, because Um, the most recent consent may have been, you know, a complimentary or you know, there might have been an older consent that's more broad in scope, and…

[James Shalaby] 15:34:42

And actually still applicable, so… so consent… Consent management rules at least some guidance rules around how to interpret, um.

[James Shalaby] 15:34:53

What would be considered the most you know, most valid or most recent consent might be, uh… a good thing to accompany the model, because, um, you know, I think development of the model Uh, we'll have, you know, some implicit, uh.

[James Shalaby] 15:35:08

Assumptions around how you're going to use elements in that model.

[James Shalaby] 15:35:13

Best to make them explicit. Sure.

[Cynthia Bero] 15:35:15

Great. Thank you. Diane?

[Diane Dooley] 15:35:21

Yeah, I appreciate this discussion, and also the… the questions about the exceptional populations that were brought up, such as foster care kids, and Um, adolescents.

[Diane Dooley] 15:35:32

Um, when I look at the idea of the components for a logical model for these special populations.

[Diane Dooley] 15:35:39

I would see it being that at a particular age, for instance, at adolescence 13, there would be a new consent offered one to the parent and one to the child.

[Diane Dooley] 15:35:52

And both of the child-adolescent. And both of those would be consistent with the laws that we have in California right now.

[Diane Dooley] 15:36:01

As to what are the privileges of confidentiality for teens, um.

[Diane Dooley] 15:36:07

And they would be… they would be somehow synced. This is the part I haven't heard yet.

[Diane Dooley] 15:36:12

With a medical record that has segmented information when you enter your teen year. So, some of the EHRs right now are using a confidential component of the medical record, where either the provider identifies it as being confidential, or it's automatically considered confidential through AI.

[Diane Dooley] 15:36:33

So, the teen would be asked about their acceptance of the standard legal structure for confidentiality, for teens, but also it would be supported by some type of requirement that the medical record has to have a segmented section for teens, so that's a big step right now, because that's not standardly available.

[Diane Dooley] 15:36:55

So I think this is a long-term implementation, because Just giving a teen a new confidentiality form to sign every time is not going to be enough.

[Diane Dooley] 15:37:04

It has to be consistent with state law, and it also has to be something that can be extracted from the medical record, and that's going to take a while, so… I think both… this is a long-term process, because many of the legal, um.

[Cynthia Bero] 15:37:06

Yeah.

[Diane Dooley] 15:37:21

Many of the laws that we follow right now in confidentiality in California are very confusing and interpreted differently by every agency in California. So that would have to be worked out through some changes in the legal structure.

[Diane Dooley] 15:37:34

And secondly, there's no compliance… no expectation that electronic health records have segmented information. So, I really admire what we're trying to do, because it is… it is not going to be easy, but I do think it's really important to do.

[Cynthia Bero] 15:37:50

Yeah, it will not be easy, that's true. Thank you. David?

[David McCann] 15:37:57

Great discussion, and I think this forum is our tool for refining these dilemmas.

[David McCann] 15:38:03

I think there's a noun that we've actually been given in the DXF roadmap that I think about in these meetings.

[David McCann] 15:38:10

Which is program. We keep talking about the person. We assume they are a patient.

[David McCann] 15:38:15

Patient is a status, not a person. I can be David calling 2-1-1 for homelessness. It doesn't make me a patient in the database until I'm attached to a medical record.

[David McCann] 15:38:26

I think we need to really think about the noun program. In Orange County, you know United Way is in a county where there are 2,500 programs Delivering some form of social or medical care to over 300,000 people.

[David McCann] 15:38:42

The program is a filter for the kind of consent we need for the person.

[David McCann] 15:38:47

We're capturing consent in 211 already. I would propose to the group that we embrace a model I go back to Eric Yan's comment from Bitfocus. I think we need to think about a person Needing a certain type of consent specific to the program.

[David McCann] 15:39:03

And then if the person is in the program. The other thing that DXS has given us is the notion of a population of focus.

[David McCann] 15:39:10

So if we use the tools we've been given linguistically, population of focus, program, person, and consent.

[David McCann] 15:39:17

I think this group can quickly come to a model. I'm an optimist, Diane, that we can refine it with good guidance.

[David McCann] 15:39:26

And then let people adopt it county by county. So I think we have the tools, and this discussion is actually the mechanism to improve the thinking, and I welcome all the great comments.

[Cynthia Bero] 15:39:39

That's a great concept shared in that one… that one statement, David. That was terrific. Shannon?

[Shannon Rohall, CDSS] 15:39:48

Thank you, yeah, I really appreciate the conversation. One of the things, uh, and I acknowledge that I come to this with, I think, perhaps a little bit less, um, experience, uh, on this topic as others.

[Shannon Rohall, CDSS] 15:39:58

Um, so one of the questions that comes to mind for me is this point about kind of cataloging endpoints and kind of backtracking that all the way to, like, the initial user experience.

[Shannon Rohall, CDSS] 15:40:07

And so, conceptually, would this be… I saw the note of a form. Would this be, like, a long… fully comprehensive range of different, uh, services to which you could consent to share your information about.

[Shannon Rohall, CDSS] 15:40:22

Um, or would this be conceptually applicable to each of those individual entities?

[Shannon Rohall, CDSS] 15:40:28

Um, for instance, I guess to David's point about homeless services.

[Shannon Rohall, CDSS] 15:40:32

Um, and other, um, community services that are available, right? That would be a consent model or consent form within his infrastructure that would be different from healthcare, which would be different from social services.

[Shannon Rohall, CDSS] 15:40:42

And then all of those build up and aggregate together. Or is this one massive form that's going to end up resulting in an individual having this, like.

[Shannon Rohall, CDSS] 15:40:52

Novel to flip through and consent into, which I think would… create a lot of concerns and problems around reconciliation, so…

[Cynthia Bero] 15:41:01

That's a great point. I think, you know, try to embrace all of it in one is overwhelming, I think, for the individual in some ways. So, uh, breaking it up into pieces does make a lot of sense.

[Cynthia Bero] 15:41:12

Sarah?

[Sara Rogers] 15:41:14

I really love, Shannon, how much what you said was, like, reflective of what I was wanting to say almost exactly. Um, and I think it is… I just wanted to say it resonates with me, what I was hearing from Eric, as then also from David in terms of Starting from a place of.

[Sara Rogers] 15:41:29

Trying to understand the endpoints of implementation, backtracking in a way that's accountable to user experience, and then logically, the step we're trying to take would be this web ontology with, you know, defining the terms, the entities, the fields.

[Sara Rogers] 15:41:45

Using that to inform a logic model. Building that… that basic decision-making infrastructure, seeing how far we can go with that.

[Sara Rogers] 15:41:55

And then at that point, we'll know more information about whether that is achievable in the tech we have available.

[Sara Rogers] 15:42:01

In the era that we are in with AI, probably in another year, it'll be even 10 times what it is now. So, um… you know, that… but… but it does resonate that actually what we're needing is the decision-making infrastructure for people on the ground who are really close to that person.

[Sara Rogers] 15:42:18

Because for child welfare, I'll say, our attorneys, those who are responsible for protecting children's rights.

[Sara Rogers] 15:42:24

Will tell you that they need to be able to control every piece of information and where it goes and to whom, and, you know, so making that real.

[Sara Rogers] 15:42:32

I don't know how hard that will be. And I just wanted to affirm that what I'm hearing there feels correct from my… from my vantage point.

[Cynthia Bero] 15:42:42

Great, thank you. Ken?

[Ken Riomales] 15:42:45

Yeah, so, um, one of the things that I'm… and we may have touched on it really quickly, Shannon brought it up, but segmentation.

[Ken Riomales] 15:42:52

Um, we haven't really discussed the correlation of the consent to the actual data that it correlates back to.

[Ken Riomales] 15:42:58

So, sorry, Lynette, I'm bringing to ask me back up now, but if we're going to implement as a state.

[Ken Riomales] 15:43:03

A consent model or framework that segments all types of consents from SUD, homelessness.

[Ken Riomales] 15:43:09

You know, judicial, education, et cetera, et cetera. The data for which that consent governs must correlate back directly to that consent.

[Ken Riomales] 15:43:17

So right now, we don't have a framework that allows for that level of segmentation. It's a very linear process. Do you have consent? Yes or no?

[Ken Riomales] 15:43:26

If it's a yes, great, here's the data that's available. Now we're going to a model where Do you have consent? Yes or no, for SUD?

[Ken Riomales] 15:43:32

Yes or no education. And then we add additional flavor of yes or no juvenile.

[Ken Riomales] 15:43:36

Has that juvenile consented. So… There's lots of different use cases that we have to consider, and I think we do need to be reverent to the technical capacity of facilitating the data segmentation requirements that will honor, be reverent.

[Ken Riomales] 15:43:50

To the type of consent that we ultimately recommend. That's a pretty significant lift.

[Ken Riomales] 15:43:59

And I want to make sure that's… that's very… very clear that the type of expectation or, you know, turnaround time that's required in order to facilitate that.

[Ken Riomales] 15:44:05

It's fairly unprecedented right now. All of our national networks are not built on that, so we can't say TEFCA eHealth exchange or care quality can easily facilitate that. So, I just want to point that out.

[Ken Riomales] 15:44:16

It doesn't invalidate anything that's being said here, it just adds that additional consideration to ensure that We're looking at things holistically.

[Ken Riomales] 15:44:24

And not just looking at the first aspect of it, of just capturing that consent.

[Cynthia Bero] 15:44:29

Really good points raised there. Thank you. Eric?

[Eric Nielson] 15:44:34

Yeah, I think just building on this series of conversation, it really seems that as we move forward.

[Eric Nielson] 15:44:40

And establish some type of model for consent that, you know, we're not going to cover everything all at once, and that we're going to be living in a world where we have paper consents.

[Eric Nielson] 15:44:49

And the old process that, you know, many of the folks on the ground who provide services, you know, in counties.

[Eric Nielson] 15:44:52

Or seek services for clients, um, you know, or coordinate it, are going to be using paper consents in conjunction with whatever old, you know, existing system we have for consents in conjunction with, you know, this new model, and so…

[Eric Nielson] 15:45:05

You're really being cognizant that as we're growing this, you know, that we're going to have, you know, kind of parallel processes that we're going to have to be reconciling and being cognizant, you know, of Sarah's… to Sarah's point of the the, um, you know, the administrative burden of the… or Shannon's point, sorry, that may fall onto workers in terms of, you know, managing electronic consents in addition to, you know.

[Eric Nielson] 15:45:27

Other paper consents that may be needed. You know, if the framework that we're developing doesn't cover everything. And so, just just, I think… what we're doing is a big lift. I think it's definitely headed in the right direction, but… but want to be mindful that we're going to be living in a world where there's going to be some type of hybrid consent model that we have to be aware

[Eric Nielson] 15:45:47

That, you know, folks are going to be dealing with, so…

[Cynthia Bero] 15:45:52

Thank you. Lynette?

[Linette Scott] 15:45:54

Um, so… so Ken, uh, admittedly, you kind of called me out.

[Linette Scott] 15:45:58

Um, but in terms of thinking about, um, consent, one of the principles that Um, I think we've been thinking about it at Healthcare Services.

[Linette Scott] 15:46:09

Is the provenance component. So, much of our consent is tied to provenance of data.

[Linette Scott] 15:46:15

And where did it come from? So, certainly within our department, we received data from different places.

[Linette Scott] 15:46:22

Our use of that data, um, and requirements related to permissions are tied to provenance, depending on what data sharing agreement or what agreement was in place, you know, in order for us to receive that.

[Linette Scott] 15:46:33

So, when we think about, um, various types of data, knowing the provenance is going to be critical in terms of how we parse out consent So, as we thought about ASCME, we thought about it in the context of provenance.

[Linette Scott] 15:46:47

That we could potentially map to in a relatively straightforward way.

[Linette Scott] 15:46:52

And that… that's where, sort of. I don't really like the framing 80-20, but that's where some of that was coming from. We're not going to try Even remotely try to think about consent for I want this part of my medical record versus that part of my medical record.

[Linette Scott] 15:47:08

There's no way we can do that, automate it, and, like, do that in a standard way. If somebody wants to tease apart.

[Linette Scott] 15:47:13

That level of detail, they're gonna have to do a one-off.

[Linette Scott] 15:47:17

Specific consent managed separately. Right? But if it's substance use disorder treatment.

[Linette Scott] 15:47:23

It has to have a specialized consent, a specific checkbox that has to occur.

[Linette Scott] 15:47:28

So to speak, doesn't necessarily have to be a physical checkbox, but… the, right, so you need to know provenance that it's SUD data.

[Linette Scott] 15:47:36

You need to know Providence, that it's homeless data. You need to know Providence.

[Linette Scott] 15:47:39

That it's standard HIPAA data. Those kinds of things, and so that's how we've been thinking about it in terms of you're giving consent for those Bodies of data that are tied to specific provenance.

[Linette Scott] 15:47:51

And then, even if we can't do it right now, that becomes something we can build to.

[Linette Scott] 15:47:56

And we can segregate that data, and that… that need to segregate or be able to distinguish data of particular types of provenance.

[Linette Scott] 15:48:03

Has very much been part of this conversation around high-tech for the last decade, right? But it's getting more and more real because we're now going to have to figure out how we actually do that.

[Linette Scott] 15:48:14

And then be able to tie the turning on and off of data sharing.

[Linette Scott] 15:48:17

Related to consent. To tie to those… those components.

[Linette Scott] 15:48:22

So, that's how… I just want to share that's how we've been thinking about it, because several of you have mentioned different aspects of that.

[Linette Scott] 15:48:28

Um, and… and again, the… Ask Me form. We've been trying to keep it as simple as possible.

[Linette Scott] 15:48:35

As few pages as possible is least overwhelmed as possible. But that does mean that if you want your consent to have a lot of specificity, it's not going to work.

[Linette Scott] 15:48:46

Um, it is going to hit the big… buckets of things so that we can coordinate care, deliver services, and provide better outcomes.

[Linette Scott] 15:48:54

Um, so, thank you.

[Cynthia Bero] 15:48:56

Thank you, Lynette. Uh, Rita?

[Rita Torkzadeh] 15:49:01

Yeah, I want to go back to a point that I believe it was David, um, made earlier about, um, um, starting from, like, the program base, because When we… when we talk about consent, and I don't know if this has come up, but are we…

[Rita Torkzadeh] 15:49:15

Framing it in any particular way with regards to whether we're talking, you know, about, like, whether the consent is being, for example, captured in a clinical environment versus the community setting and things like that, and I don't know if that's at all relevant to how we approach also the question of.

[Rita Torkzadeh] 15:49:31

Identity in terms of, like, how the record, um, is being, um, defined for any particular type of entity, so…

[Cynthia Bero] 15:49:39

Yeah, I think… I think the… the lens is all of the data exchange framework, which would include multiple environments and a pretty broad, you know, set of services. So I think… and so rightfully so, a lot of folks have called out the challenges of of that kind of, um, solution.

[Cynthia Bero] 15:49:56

But I'm hearing some of the themes being the, you know, segmentation of the data, being very clear on who the patient is, where was the consent collected, I mean, so just a lot of component parts.

[Cynthia Bero] 15:50:08

To really make this happen. Um, so this is… this is all great information.

[Cynthia Bero] 15:50:13

Um, let me take a couple more, maybe I'll take Eric and Hans, and then we'll pause for, uh, public comment.

[Eric Jahn] 15:50:20

Okay, thank you. I just want to say that what Lynette Scott mentioned really resonates with me about the context, and that will require the data and model to also know what the different domains are of the logical model, which would be the same as a web ontology, not two separate things.

[Eric Jahn] 15:50:34

Although there's a workflow. But, um… as far as that, um… the context. I think that really gets at what Muhammad Jafari was working on with the Sequoia document that's been linked in these papers as far as, um, or in these, um, meetings, as far as the computable consent. So that's going to look at the context and then figure out, is this something that's shareable or not? And I just had one other quick comment that I think we also need, and this is related to that. We need a record locator or URL by which, if you have the credentials and the key or whatever, you're authorized in that context to retrieve

[Eric Jahn] 15:51:07

That's… that… that context from whoever collected the consent information, you could then review it and verify that you are authorized to access that information in some way.

[Eric Jahn] 15:51:19

Um, so

[Cynthia Bero] 15:51:22

Great. Thank you, Eric. Hans?

[Hans Buitendijk] 15:51:26

Completely agree with Erzloff's comments of URLs, addresses, we need to know where the data holders need to know where they, uh, they, uh, the consents are that apply to them.

[Hans Buitendijk] 15:51:35

Um, sharing certain consents, you can't share it with everybody, either, because that might give them insights that are not supposed to have, so it's still an interesting, challenging, complex area.

[Hans Buitendijk] 15:51:44

There were two other thoughts that were raised that I wanted to respond to confidentiality and segmentation.

[Hans Buitendijk] 15:51:53

I think we… we at times need to be cautious that how do we do that, because with consent, rules can change, revocation is in play.

[Hans Buitendijk] 15:52:03

Uh, so we always need to figure out how… I think that on how can we figure out what's the latest state of the consents for patients.

[Hans Buitendijk] 15:52:11

So, segmenting data, if that means physically separating data, one can always do it, but you have to be careful. Therefore, it should not be a mandate.

[Hans Buitendijk] 15:52:21

Um, the other part of flagging data as confidential can be done inside the system.

[Hans Buitendijk] 15:52:28

But be careful sharing that, because the moment that the data is shared, today it's confidential, tomorrow it's not, depending on who it is.

[Hans Buitendijk] 15:52:35

Uh, so I think we always have to, as we need to do for private, uh, sensitive data can send data, we need to figure out around other ways that how can we associate the consent rule Um, express it in a computable fashion that the data subject to it is clearly understood, and what that scope is.

[Hans Buitendijk] 15:52:55

How do we do that? And so that somebody else that is looking at the data understand what applies, what doesn't.

[Hans Buitendijk] 15:53:04

Uh, and it's not always confidentiality flags, and it's not always segmentation.

[Hans Buitendijk] 15:53:09

So I think those are going to be the hard parts, and it's going to be analogous to what We need to figure out the privacy rule side, where certain data is subject to restrictions. It's effectively the same thing that's happening. A party, jurisdiction, or patient.

[Cynthia Bero] 15:53:16

Great, thank you. Um, Julie, if you could… just, um, share quickly, because I do want to get to public comment. Oh, you… okay, all right, great. So, thank you, Hans, and thank you all. I mean, this has been a great conversation, and you raised a lot of key issues that I think are critical for us to think about as we think about consent management more broadly.

[Hans Buitendijk] 15:53:23

Tells us what we can or cannot share. How do we do that in a computable fashion?

[Hans Buitendijk] 15:53:28

That is transportable, and that we can keep track of as the rules change.

[Hans Buitendijk] 15:53:33

A regulation might take longer. A patient might do it overnight.

[Cynthia Bero] 15:53:59

Uh, but let me pause now and ask if we could go to public comment.

[Alice K - Events] 15:54:05

Thank you, Cindy. Participants may submit written comments and questions through the Zoom Q&A box.

[Alice K - Events] 15:54:13

All comments will be recorded and reviewed by CDI staff. To make a verbal comment, members of the public must raise their hand for Zoom facilitators to unmute them.

[Alice K - Events] 15:54:23

If you've joined via Zoom interface, you can click Raise Hand at the bottom of your screen, and if you've dialed in by phone only.

[Alice K - Events] 15:54:31

Press star 9 to raise your hand, and listen for your phone number to be called.

[Alice K - Events] 15:54:37

There are currently no hands raised from the audience at this time.

[Cynthia Bero] 15:54:40

Okay, we'll give folks a minute or two to find out that button. Um, but I, you know, again, wanted to comment on what a great conversation this is, and the issues that you all identified are very, very helpful. Um, I would also comment that the The Q&A and the chat is very lively, so this is obviously a topic that, um, is near and dear to everyone, so again, I appreciate it.

[Cynthia Bero] 15:55:06

Um, Alice, any up… any raised hands?

[Alice K - Events] 15:55:09

Yes, uh, Mark M, you should now be able to unmute.

[Marc Mar-Yohana (OtisHealth)] 15:55:14

Hi everyone, thank you so much for this great conversation, and this is an awesome opportunity. So, I put a bunch of questions in around some of the the details of some of the things around consent, but in particular, one of the cool opportunities is this really gives us

[Marc Mar-Yohana (OtisHealth)] 15:55:28

An opportunity for providers or organizations that need to reestablish consent to actually potentially message the consent holder, the actual person that's providing the consent. So we can actually build something here, new.

[Marc Mar-Yohana (OtisHealth)] 15:55:41

That would send a notification back to somebody saying, hey, it looks like you revoked consent, we need it for this purpose.

[Marc Mar-Yohana (OtisHealth)] 15:55:47

Can you… can you provide your consent again? So this isn't just something where we just have somebody fill out a dry form.

[Marc Mar-Yohana (OtisHealth)] 15:55:54

Electronically or otherwise, and then… store it somewhere for folks to use. It can actually be a way to reach out and establish consent without having somebody come back in an office.

[Cynthia Bero] 15:56:05

Great, thank you.

[Alice K - Events] 15:56:08

Thank you. Kevik N, you should now be able to unmute.

[Gevik Nalbandian (IDENTOS)] 15:56:19

Hello? Oh, I didn't see the unmute button, sorry about that. Great discussion, absolutely. So, some, some comments and suggestions One, uh, I think we were talking about certain groups that might have specialized requirements for consent.

[Cynthia Bero] 15:56:20

Yes. Yes.

[Gevik Nalbandian (IDENTOS)] 15:56:34

Um, I think we should also include in that group a women's productive health consent around that, especially with the, uh, the sensitivity around cross-state movement of of our citizens, and… or within the state.

[Gevik Nalbandian (IDENTOS)] 15:56:50

Or coming… coming from other states. So that was one top… one thing I wanted to just comment out. And the other one was.

[Gevik Nalbandian (IDENTOS)] 15:56:57

Hans and Julie had a point about how consolidation of, uh, consent could have challenges and be a heavy lift, and having everybody to agree, and we have jurisdictional variability in terms of policies and so on, so I agree with Hans that

[Gevik Nalbandian (IDENTOS)] 15:57:13

Uh, each patient can have their own consent stored or managed.

[Gevik Nalbandian (IDENTOS)] 15:57:19

Within some… locale, but, um, it could be accessible.

[Gevik Nalbandian (IDENTOS)] 15:57:23

From anywhere, so I want to do a thumbs up. There, and David made a comment, uh, on considering a patient as a state, I… I would like to… I would like to say that we should consider a patient or a person or a citizen

[Gevik Nalbandian (IDENTOS)] 15:57:40

Uh, the patient is a persona. Provider is a persona. It's, uh, you can think of it as a relation.

[Gevik Nalbandian (IDENTOS)] 15:57:46

And as opposed to a state, because we don't stop being a patient just because we act as a citizen or somebody calling 2-1-1, or being a doctor ourselves, and so on and so forth.

[Gevik Nalbandian (IDENTOS)] 15:57:58

Thank you.

[Cynthia Bero] 15:57:59

Great, thank you.

[Alice K - Events] 15:58:03

There are no other names raised at this time. Oh, there, we just got another one.

[Cynthia Bero] 15:58:07

Okay.

[Alice K - Events] 15:58:09

Uh… Kachi, you should now be able to unmute.

[Rajib Ghosh] 15:58:16

Hi, uh, yes, this is Rajiv Kosher, and thank you for, uh.

[Rajib Ghosh] 15:58:20

But the opportunity to, uh, express my comment here. Um, you know, as somebody who has worked on this consent piece quite extensively.

[Rajib Ghosh] 15:58:31

Uh, in, um, in Alameda County, in a multi-sectoral way. Um, and having, uh… Uh, some real-life experience, uh.

[Rajib Ghosh] 15:58:41

How difficult it is to do this work.

[Rajib Ghosh] 15:58:45

With a large community of multi-sectoral providers, uh… I can have a… One recommendation for this group.

[Rajib Ghosh] 15:58:56

And that is, uh… Uh, if you plan for a… Longer-term implementation.

[Rajib Ghosh] 15:59:04

Uh, maybe one way… to think about it is… Um, sectors at a time.

[Rajib Ghosh] 15:59:12

Because every sector One challenge that we had is tackling everything together.

[Rajib Ghosh] 15:59:19

And, uh, that created a lot of barriers. Because, uh, a social… services versus the criminal justice.

[Rajib Ghosh] 15:59:31

Versus behavioral health. Uh, it's very difficult to bring these stakeholders together to agree on, uh… What can constitute a… universal consent model.

[Rajib Ghosh] 15:59:44

That's it. Thank you.

[Cynthia Bero] 15:59:47

Good, thank you. Um. I… first, I want to thank everyone for a very, very robust conversation. Alice, I hope that may be the end of the… Okay, great. Um, because we are right at the top of the hour. So again, I want to thank everyone for a very lively conversation. Um, in terms of where we go from here, um, as usual, we will put the materials and recordings on the webpage so that you have an opportunity to reflect on it. Um, we will try to summarize everything we heard, which was a lot.

[Cynthia Bero] 16:00:18

Um, and share it with you, um, before our next gathering, and then we will continue to push forward on this conversation about, um, how does the DXF support consent management, uh, going forward. Again, I thank you for all of your contributions. Our next meeting is Two weeks from today, same time, same place, um, and I appreciate everything that you brought to the table. So, thank you, and have a