California Health & Human Services Agency
Center for Data Insights and Innovation
Data Exchange Framework Stakeholder Advisory Group
Data Sharing Agreement Subcommittee
Meeting 5 (March 22, 2022, 12:00PM – 2:30PM PST)
Transcript

> The following text is a transcript of the California Health & Human Services Agency Data Exchange Framework Stakeholder Advisory Group Data Sharing Agreement Subcommittee Meeting 5. 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 website – to ensure accuracy.

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hello and welcome. My name is Julian and i'll be in the background, answering any zoom technical question.

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You experience difficulties, please type your question into the Q. and A.

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And a producer will respond during today's event live closed captioning will be available.

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Please click on the Cc. button at the bottom of your zoom window to enable or disable, and we'll now cover the meeting participation options.

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Emma, you now have the floor participants based submit comments and questions through the zoom Q.

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And a box. All comments will be recorded and reviewed by some company staff participants may also submit comments and questions as well as requests to receive data, exchange, framework and data sharing agreement

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subcommittee updates to Cdii at Chhs.

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Ca: Gov: Next slide designated time, spoken comment will be permitted.

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Participants and group members must raise their hand for zoom facilitators to unmute them to share comments.

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The chair will notify participants or members of appropriate time to volunteer feedback if we can move it to the next slide. There, please.

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I had a delay on my end great thank you now we're head.

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I had a little bit ahead here. If you logged in by a phone, only press Star night on your phone to raise your hand.

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Listen for your phone number to be called, and if selected to share your comment, please ensure you are unmuted on your phone by pressing Star 6 logged in by the Zoom interface, press raise hand in the reactions area

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and if selected to share your comment, you'll receive a request to unmute, please ensure you, except before speaking, public comment will be taken during the meeting at designated times, and will be limited to the total amount of time

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allocated individuals will be called on in the order in which their hands were raised, and will be given 2Â min.

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Please state your name and organizational affiliation when you begin.

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Participants are also encouraged to use the Q. and A.

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To ensure all feedback is captured. Or again, you can email comments to Cdi at Chhs.

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Ca: Gov. And with that i'll hand it off to John Ohanyan, John, you have the floor.

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Thank you very much, Emma. Thank you. Manatt, team.

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Welcome everyone to our stakeholder, advisor, group data sharing agreement Subcommittee.

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My name is Shano Hanyan I'm. the chief data officer for CalHHS.

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As well as the director, for CDII and I want to begin by saying that you're hearing from me, and not Jennifer Schwartz, because Jennifer is on medical leave for at least the next 2

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months we wish for. Well, I know all of you do as Well, so i'm definitely no substitute for Jennifer or Chief council.

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I just want to thank our team for jumping in, and please let me know.

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Please let the team know if you need any assistance during this transition time.

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But I am happy to be here with all of you we are really coming down the wire, for now being I can't believe it's the middle.

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Some would say the end of March that anyone see that happening it's just been crazy speed both just in the world.

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But also with this project. so again welcome everyone. The other announcement is a very somber one for me, because we have lost one of our members.

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Patrick Privilege, who passed away recently. and I we just want to acknowledge his passing.

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I I've known Patrick. now for many years both in my prior job in San Diego, working with health that working with him, and he's just an incredible man.

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We deeply, miss him. and I will give more info i'll throw something in the chat for those who want to just get connected a little bit more with what happened, and it's still a little great But what i'll say is that from our

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standpoint, and the work that we're doing we want to kind of keep Patrick in our hearts in our minds, but also memorialize his work and contributions to this project, and his commitment to this work

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during during his time, and just let you know that we're gonna keys.

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Patrick is kind of a in absolute member of the subcommittee in his place Sanjay, John.

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Senior business analysts from help that is gonna be stepping in at least for today and and for the time for continuing.

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So 100. Thank you for being here and to your entire team.

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Please accept our heartville appreciation. for patrick and I thought, we will bely miss them, and our hearts go out to him and his family.

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So with that i'd like to move on to roll call to get our other members.

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Okay, I would like to begin with. You see, Davis health Ashisha.

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Okay, America's physician groups Bill barcelona present.

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Hello from Lee's Jen variance Hi I'm here, and just thank you for the statement about Patrick.

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It's quite a loss. absolutely thank you shelly Brown.

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Okay. blue Louis Kataro. Thank you.

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Alene epcot i'm here good afternoon Yes, and welcome. I sorry, Elaine Elaine is one of our 3 newest subcommittee members.

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We're gonna introduce and then our our next newest member is Diana for Tom.

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Good afternoon, hey? as it welcome. Welcome to our new members next We have Elizabeth Killingsworth.

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We're hello, Helen Kim Second thank you Carrie Kurturo here.

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Thank you, Stephen Lane. Good afternoon. Good afternoon, Lisa.

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Masbara. Okay, Devin Mcgraw. Here Morgan Stains present. correct today.

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Everybody, Brian Stewart and me present. Good afternoon.

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Good afternoon, leading here. I'll Have to drop off at one Thanks thank you for joining Belinda Waldman.

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Present, Terry Wilcox. present. Good afternoon. Good afternoon.

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Welcome. and Sandra Jane present. Good afternoon. Good afternoon.

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Okay, I wanted to. next go through for our meeting objectives.

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We like to start our meetings by keeping our focus on our vision for our our data exchange in California.

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You can see it on the screen I don't need to read it to you.

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But that's our north star and that's where we're headed, and I just appreciate everyone working towards this ambitious realistic.

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An important mission. Okay, So we go to our meeting objectives today.

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We're going to be discussing our v emerging data exchange for framework work that we've been doing related to governance of the framework.

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We're gonna have a Lammot cover that rim is then going to take us through the drafting the review of the data exchange framework data sharing agreement the policies and procedures. then give You an update on our

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digital identity strategy and the implications that we'll have on the sharing agreement as well as an opportunity for us to discuss and provide feedback on the content for the data sharing.

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One of the things I wanted to just cover real quick before I hand it over to Lamont.

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If we go to the next slide is we are moving back to in-person meetings.

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So as of March thirtieth. The governor's order that related to the Bagley Keen open meeting act is is going away so effective.

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April first. All meetings like this that need to follow Bagley team are gonna be in person, which means that we do escape one thing because this is an advisory group and not a decision-making. board.

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We do allow members to zoom in have however, we need to have a quorum. so we need to have the majority of the members in person to be able to hold the meeting, and so there's been thoughts about maybe rotating people that can

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come what we'd like to know is and maybe even put in the chat, if possible.

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So we can start Tracking So we've been trying to get a hold of folks is if you're able to make that in-person meeting on April.

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I have it right in my hands. 26, Thank you. April the 20 sixth. thanks, Jen.

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If you can make it in person, if you can please drop it in the chat that you can it's.

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Okay, if you can't just let us know as well and then we're going to try to do our best to make quorum.

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And then, if there are discussions around how we can maneuver ourselves back into this world.

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If you have suggestions, thoughts, please let me know but that is our goal. i'm gonna pause for a second to see if our team wanted to add anything.

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If I missed anything I want. pause for a second.

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I will just put my 2 cents in that. I think that while I know the in-person format might prove a little you know a little bit of a pivot, especially given the last couple of years in virtual I feel on a personal

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level. That would be great to be in person with many, with many of you, with all of you a of you.

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But it would be great to have that you know some in in-person fellowship with our with our experts.

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So if that's possible, we'd love to see you here. With that I will pass the meeting on to Lamont to take us through governance and feel free to check me on the side or email with any other followed questions well mine.

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Thank you so much. welcome, and handing it off to you.

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Thank you, John. Can you hear me? Okay, can hear you be great.

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Thank you. Fantastic. Okay. So During this portion of the meeting, we wanted to give you an update on the Advisor group's progress regarding the governance of data the data exchange framework So many of you may be

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aware that on the last advisory Group meeting on March the third, there was an initial discovery.

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Discussion of the governance considerations across 2 dimensions.

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The first was the potential structure of governance. What kind of entities would be involved?

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What kind of mechanisms the second was the potential scope for governance it's.

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And while the advisory group didn't get to weigh in and details with respect to the structure, they did have an opportunity to walk through a set of proposed governance functions that would constitute the scope so on this slide before you are

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the 11 proposed data exchange framework governance functions that were discussed.

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And today we want to highlight and focus on those functions that are going to have implications for our work on the data sharing agreement and the policies and procedures.

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So 3 of the functions that are illuminated on this slide addressed the creation and curation of the data sharing agreement and policies and procedures, and they're based on the notion that both documents

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or sets of documents that will released July first will likely, in our expected to evolve over time.

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So there needs to be an activity that addresses, not only the creation and release initially of those documents, but also it's ongoing curation.

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So the second function that you see on the slide speaks through the development and modifications of the policies and procedures.

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The third function addresses the potential need to develop an institute requirements for certain topics.
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The topics that they that were discussed during the advisory group meeting included an obligation to cooperate with respect to California's data sharing day extreme framework, and also for ensuring adherence
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to nondiscrimination. The third function that aligns in this cluster of creation curation is the function number 10 on the right hand column, which speaks to the the need to having ongoing maintenance of the
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data, sharing agreement, reviewing it, and refreshing it as necessary and as appropriate over time.
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In addition to creation, curation of the content that will need to be governed.
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There's also a second cluster of functions that have implications for, and will be impacted by our work.
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Because these functions involve enforcement and monitoring, and during the meeting in March the advisory group provided a lot of commentary on the functions Number 5.
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On this page 2 noting the importance of conducting additional stakeholder engagement before there's a formal establishment of an enforcement process.
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The advisory group also weighed in and provided feedback on function.
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Number 6 at the top column on the right-hand side, which speaks to the need to have the ability to file grievances and resolve disputes over time.
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Finally, the last governance aspect that that will need to be addressed is the identification and qualification of exchange.
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Intermediaries. Number 8. This speaks to the idea that there'll be networks that will be able to participate in data exchange, and on behalf of organizations that are participants in those exchange will be able to meet
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the requirements of the data, sharing agreement, and also policies and procedures over time.
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With that if they're quite about the process that the advisory group is undergoing.
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If there are any comments that the data sharing agreement subcommittee would would like to offer.
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We open the floor to you. I see a hand raised. Stephen.
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Yeah, I just wanted to hide what it is, put in the chat which was that you?
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These functions. Reference Review, where a couple of them really should reference review and ongoing maintenance in response to that view, especially when it comes to number 4 and Federal standards.
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And requirements. a very dynamic space, you know, which is chief regularly, and we do not want our State level requirements to do static while the world in which we live and in which we exchange data is is dynamic So I think a lot
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of this work is going to be, you know, whatever is the scope of our of our California data sharing agreement that it is remain very nimble and and responsive in the environment.
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Thank you, Steve, that's a great point an ongoing alignment is going to be a critical feature.
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As we move forward any other thoughts, observations, the deliberations of the advisory group on governance functions.
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Okay, thank you. With that we encourage you to listen to the extent that you can avail yourselves to either.
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The video recording of the governance section or the the summary is also a handy way to to walk through the discussion.
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The governance discussions going to continue at the advisory group's next meeting on April the seventh There'll be more to come.
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And more details will be shared at our final and sixth meeting at the end of April.
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So with that, John, I turn meeting over to Rim, to walk through some of the details on the DSA.
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And policies and procedures. Thank you, Lamont. can you hear me?
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All right, Thank you. So this part of the agenda we want to just touch very briefly on the process, as we see it going forward to develop the data sharing agreement and the policies and procedures that accompanied it just
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as a reminder. We have 2 talked about this process previously that A.
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B, 133 requires us to establish not only a single data sharing agreement, but also a common set of policies and procedures to govern data exchange on the data exchange framework we see the as

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we've discussed we see the data sharing agreement as the legal agreement with a broad spectrum of potential organizations that are required under a B 133 to sign it.

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We see it as a streamline document that really focuses on the key legal requirements, and that's those are the requirements that we've been discussing over time at these meetings and are seeking to avoid duplication

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or conflicts with other data. sharing agreements and organizations, may also have a responsibility of using and adhering to the policies and procedures.

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Add detail of how specific requirements under the data sharing agreement are to be implemented, and we see that while the data sharing agreement may change infrequently that components in the policies and procedures may evolve and be

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refined over time through participation in the governance processes we've just talked about what you might expect as we've been deliberating the DSA.

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Content includes things like the parties, the purpose for use, the intent of data exchange, etc.

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Whereas details that might appear in the policies. procedures would be items like the technical standards, specifications compliance with and penalties, or just are the processes for dispute resolution. let's go on to the

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next slide, please, and We've. talked a little bit in the past about a large set of potential policies and procedures that might accompany the DSA.

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As I said, we have a requirement to publish policies and procedures by July one, and the what we see is a need to release at least an initial set of foundational What we call foundational policies and

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procedures. on that date additional policies and procedures.

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Might be released in after July one, as we continue to develop them over time.

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What you see on the right hand side of this slide is the set of policies and procedures that we would see is our target for release.

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By July one that would include some aspects of governance, governance, and accountability, such as dispute, resolution.

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The change process for the DSA. and the change process for policies and procedures.
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It would allow us to move forward with creating new policies and procedures and making adjustments, as we need to, over the upcoming months.
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We would begin on technical specifications primarily with the data elements that are be to be exchanged, as some of those data elements are called out and and Ab 133, and therefore already established
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we'd start on privacy, and security with breach notification, and if we have time, we would include a requirement to respond as part of operations.
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Now, in no way are these different sections complete with just those items that are under them.
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For instance, technical specification will go far beyond just data. elements.
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Privacy and security will go far beyond just breach. notification.
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Operations will go far beyond requirements to respond. But those are the foundational policies and procedures we see as our focus over the upcoming couple of months for development and release.
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On July one. let's move on to the next slide, please, and this is just a reminder of the time frame and roadmap we see as going forward.
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So we are at DSA. subcommittee meeting Number 5 today, and we have a few things on our agenda today.
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A focus on digital identities and the third set of DSA topics, but in particular want to point out that at our next meeting we will discuss proposed drafts of the DSA.
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And this initial foundational set of policies and procedures.
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So that's what you should be preparing for at our April meeting.
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To be held in person. Those documents then, would be provided to the advisory group as well, and released for public comment, and would be revised as necessary over the following months.
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Again for release by July. one as required by ab 133 want to pause there for a minute and see if there are any questions about the planned approach here about the documents that we're planning to focus on
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as our foundational set of policies and procedures, or any thoughts on this very aggressive timeline that that we that we need to meet here?
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Are there any thoughts, questions, or comments we'll see none I think we can go ahead and bring on to the next item on the agenda?
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And I did see flashing by that. there were a few comments in the chat.
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Does anybody want? Are there any items in the chat that anybody wants to expand upon?
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Sorry to a gloss over that. Okay, Well, let's go on our next item on the agenda is also mine, and it begins to discuss the digital identity strategy.
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There are really 2 areas that we want to make sure that we discuss today.
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That may have implications on the data sharing agreement.
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Our policies and procedures associated with a strategy for digital identities is required under a B 133, and that is that we're going to be talking about privacy requirements that may need to be specified either in the
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DSA. or policies and procedures to protect personal privacy and security requirements.
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The need to be specified in the DSA. or policies and procedures to secure digital identities.
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We will start off with a brief introduction to where we stand in the development of a strategy for digital identities, and most of that will be the same material that was presented to the ag meeting last time.
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The advisory group meeting last time and we're and that bear in mind that that are our emerging concepts, and that the digital the strategy for digital identities is not yet complete.
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We have additional focus group meetings next week. and we'll be delivering some aspects of this, but at least the intent is to give you enough of a framework.
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To think about some of the implications on the slide. Here you see the call in Ab 133 for a strategy for digital identities.
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And this is the full language that appears in Ab. 133 is that CalHHS and consultation with the Stakeholder Advisory group is to develop a strategy for unique secure digital identities
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can capable of supporting masterpiece into, to be implemented by both private and public organizations.

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And this is the sum total of the requirement that appears in A. B, 133.

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Stephen, I see that you have your hands up. Did you have it had it up?

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Did you have a comment, and the Don't shoot the phrasing here is interesting insofar as we are looking for a strategy to support MPI, which says to be implemented.

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So I mean how much of this is about creating an environment where something can be done, and how much of it is actually a requirement.

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I mean, is there is there a requirement in this that says, there shall be MPIs that shall be implemented by both private and public organizations?

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Or are we talking about? You know there needs to be a strategy to support its secure visual identities?

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I don't know if I make my question clear But i'll understand what's the what's the you know shall in this absolutely and and yes, that was clear stephen the way we've introduced this topic to the

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advisory group, And the way we talked about it within the focus groups is that the strategy is what is meant to be implemented and digital identities requirement to be implemented.

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But masterpatient indices are not a requirement of this statement.

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Now, as I said, the strategy is still in flight, and we will talk a little bit very briefly about all of those aspects here.

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But I think that your question is a good one and I think it's important for us to understand.

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How we're what what the statement means and how the focus groups are interpreting the requirements under this statement to develop a strategy.

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So thanks for that question. let's actually move on to the next slide, because it starts to bear down a little bit on some of the requirements here.

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First of all, what the language does say is that we need a strategy for unique, secure digital identities.

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It does not call for a digital identifier, and that is one of the topics that we have continued to discuss in the focus group meeting digital identity for the purposes of our discussions has been defined as a collection of data that

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establishes an identity associated with a real person for a specific context.

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In this case it is in the context of exchanging data health and human services data on the data exchange framework.

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An example of a digital identity, for instance, would be my identity on CalHHS, which is my first in my last name, Robert Catherine.

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It is not rim, it is Robert. It does not include my middle initial or my middle name, and it also comprises an email address.

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Robert Catherine at the at Chhs. Ca: Gov.

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That is uniquely assigned to me that comprises my digital identity.

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For in the context, as a contractor to call a Tts.

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The call is for unique digital identity, which means that we really need to ensure that the digital identity uniquely identifies an individual.

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Again turning back to my example, Robert Catherine does not uniquely identify me, and, in fact, Robert Catherine, my date of birth and my gender, which is often used to exchange health information only potentially uniquely

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identifies me in aggregate. And there may be other Robert Catherines out there that were born on the same day that I was especially in more common names.

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That may be the case, however, in the context of my digital identity with CalHHS it is unique, not because of my name, but because of the unique identifier in that email, address.

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Robert Catherine at CalHHS. Ca: Gov.

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Is assigned to me only to me will never be reused for another person, and therefore my name and that email address constitutes a unique digital identity.

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The requirement here is also that the digital identity be secure and secure really means that it's protected against on unauthorized access or modification, or intentional or unintentional loss or corruption for

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the most part my digital identity at Caltech is also secure.

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It is maintained on a secure system. Changes to my identity are only authorized to specific individuals, and that control is is accessed.

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However, every time I send anyone on this list in email, my my address is included is plain text in the Clear without encryption, and therefore could be modified either unintentionally or specifically. intentionally, while it is in flight.

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So my digital identity is somewhat secure associated with Caltechs.

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Let's move on to the next slide. Please as we have discussed the strategy for digital identities across the focus group.

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I would say that there are 4 concepts that are emerging from that discussion that are represented here.

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First of all is the focus of that strategy should be on linking data to the correct individual.

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Specifically, it should not necessarily be on creation of a golden record that the intent here is to make sure that all of the health and human services information about Rim Catherine are correctly associated with me as an individual and that

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the goal is not necessarily to learn what is the best address for me, or only the correct phone numbers associated with me, that the digital identity itself, again, that that collection of information that can be used to identify me should first be a set

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of demographics that are taken from the USCDI.

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V. one that might include name data, birth, gender, address, phone number, some subset of those demographic information.

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It might also exclude some information. For instance, race and ethnicity might not be part of my digital identity, even though Us.

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Cdi requires it to be exchanged.

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But my digital identity might also include unique identifiers that are not part of us.

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Cdiv. one such as my medical Id or a Driver's license, or a state Id number Now, the exact content of digital identities is still under deliberation to the focus groups and at the Ag meeting that's

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upcoming will be proposing a set of data elements associated with the digital identity.

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There. The third aspect of that strategy is really a set of standards and guidelines around.

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How that those data elements should be represented at first would put include the value sets and Definitions in UsCD. i.

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V. one. So that would include, for instance, to code sets in any specific standards about representation of us Cdi data elements.

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It would also include national guidelines, that aren't encompassed in us.

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Cdi. v. one such as the representation of an address as is the subject of project us at.

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There may be cases where we lack sufficient definition of specific data elements, and the State needs to come up with standards that we will use An example of.

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That is, that there is not necessarily consistent on how to represent a two-word last name under any of the existing standards, and there may need to be guidance that we developed there.

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Then to Stevens Point. The fourth portion of this is that we should at least consider a statewide index to coordinate across different uses of data of digital identities and different repositories of health and human service information

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so that we can ensure organizations, share a common identity.

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And this is not envisioned as a replacement for masturpation.

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Indices that may or may not exist at organizations.

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Now, as you know, most Ehr systems have an index of the patients associated with the E.

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Hr: Most regional. Hes have a master patient index associated with them, but that there may be a need for a statewide masterperson index that coordinates across those master.

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The the Mpi's that exist at other organizations Stephen, to your point.

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I believe that the focus groups have intended that to be the meaning of in support of masterpatient indexes, that they be twofold as defining the data elements that might be used in regional Mpi and potentially a

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statewide mpi that would help coordinate across regional Mpis.

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Now, again I would say that these are emerging concepts.
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This is not a final strategy and we'll group presenting the draft strategy at the upcoming advisory group meeting on the seventh.
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If we go on to the next slide. There are a few questions, however, become up as part of the the discussion here.
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As I said before, what the legislation Ab, 133 calls for is a set of standards to create a unique security.
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Digital identity, but does not say private. However, there has been a call for privacy in a number of the focus groups as we've been talking about them, and that it is they're there needs to be some way to ensure the data elements
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comprising the digital identity are only used to link data to an individual and might not be used for other purposes.
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Also point out that it at least in some context, the information associated with the digital identity may comprise Mpi.
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So, for instance, my name and my medical Id probably constitutes a Phi.
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So our first set of questions for you is, does the DSA need to stipulate the allowed purpose for use, or some restricted reuse of digital identities?
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Or are there allowable reuses of some data elements that should be allowed?
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And I would take as examples, for instance, could my Zip code or my address be used to assess equitable delivery of services?
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Because you have an area of residents associated with me and the services that are delivered to me?
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Or can my phone number used? If, for instance, public health receives a report of a positive test result that is absent.
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My phone name phone number in order to follow up as part of outbreak, investigation, or other follow-up. So i'll pause there, and I'm really interested in your thoughts on what the DSA or policies and
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procedures may have to me need to say specifically about privacy associated with digital identities.
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So, Devon. Yes, please. Yeah. So I have a couple of points, one being this: This digital identity sort of strategy is much more focused on the matching issue.

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Right, finding patients matching them appropriately to data to make sure that it exchanged it actually doesn't seem to address at all

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The need to identify the person who makes the query as being authorized to make that query which is typically in in exchange.

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Circumstances that occur in you know that We have already that exists in the country for treatment purposes.

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National exchanges that it's essentially a flow down expectation that the entities are the ones that connect, and then they take care of credentialing their individual staff or workforce members to be able to sort of launch queries

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push data, you know. utilize the network. it does, though.

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When you talk about patient access where patients may be remotely trying to get their data, where there's which is what some of the national strategies, for example, like the Karen alliance, are trying to develop some expectations around How do

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you credential, and an individual user who particularly in the context of a patient who isn't operating within a professional organization.

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So setting that aside that it doesn't seem like any of this work is geared toward addressing the question of sort of authenticating access, and the identity of the person who's requesting it and whether or not they have

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the authorization to be able to access that data Now, getting to the question that you actually asked Rim around the privacy.

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I I think it's it is I think it's important that we set some ground rules around this because the ability to sort of mind that those demographics in order to do marketing and order to do you know sort of

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outreach to give patients treatment. Alternatives could really sort of that.

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The kind of very sometimes gray line between what constitutes marketing and what constitutes a sort of legitimate use of somebody's identifying and contact information in order to reach out to them is tough.

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So it sort of begs the question about whether we want the data that we are exchanging in order to this demographic data that we are exchanging and order to facilitate the exchange of further data that

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we might do. We really need to depend on that for patient contact purposes, when the individuals care provider could be relied on to do that contact with the information they have versus make.

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You know, making network provided data per data provided for networking purposes, subject to, you know, sort of a laundry list of other potential uses.

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So, Thanks, Devin, I really appreciate that I would like to ask a couple of follow-up questions. If I can, on your first point, I would agree with you that for the most part, when we've been discussing ditch like identities with

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the focus groups. we haven't been talking specifically about authenticating or authorizing the individual that is seeking them.

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But that's part of the question that i'm asking here is well?

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Is, do we feel that there are required restrictions on that?

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And and are they the same as the restrictions that would authorize access to any data?

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Or are they special? Because we're talking about digital identities So that's one of my questions there and 2 years second point in particular.

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Think that for the most part the discussions that i've heard would agree with you is that a provider that has my phone number would be responsible for that outreach.

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The question is if that provider does not have my phone number like in the case of public health doing an outbreak investigation, it may not be on the lab report that comes in.

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Can they use digital identities to discover my phone number?

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Or is that an allowed process? And so I think you are absolutely touching on the questions here that i'm seeking to get some clarification on, and whether we need to work on privacy policies associated with digital identities

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specifically. Yeah, I I do think we need those policies.

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I see so many other hands up I feel like i've had my say so.

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I'm uninterested in the thoughts of others on the group.

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Thank you. Great thanks, Lee. I think your hand was up next.

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Yeah, thanks. So so versus like I think when we I seem to recall when we had our purpose groups a week or 2 ago, just on the identity stuff that we one of the the that that somebody and I thought it was me raised was

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we we want to think about how we authenticate everyone who has access to that data the more.

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But the broader point which dovetails, I think with what Devon was saying is simply that you know one of the comments we kept hearing on the focus group was, Wait a minute.

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What are, What are your use cases for this network Until we know what the new cases for that network are?

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It can be very hard to develop the proper sort of safeguards or policy responses to it.

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So the So in a way it's very this having the free floating question about how what is allowed is sort of almost hitting it from the wrong direction?

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And then the third point and then i'll stop here because I don't want to take up everybody's time is that when know from the public health we world already, and you and the experience we've all been through for the last

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couple of years that we haven't inadequate and messy system of privacy and security around information that's being collected for a public health purposes. right?

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It has a sort of way out of HIPAA into entities who are not covered entities, and therefore many of the assumptions we normally about how that data would be are simply falsified by reality, and even when they are in

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government entities right? The standards are very different in California.

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I always say this. but you know the State Government limited by the Ipa. but no city county is. and in my conversations with with county public health executives, they go.

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Yeah, you know, we all have our own rules. and none of These are like looked at by the State and the State Department of Public Health doesn't much care.

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And so we are looking at a situation which not only doesn't have clear sort of use cases, but also doesn't have any clear. We doesn't have as clear legal Redmond, and says as a privacy advocate would certainly want so

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Obviously it's you can't fix everything all at once which is the problem.

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But it is, it is especially especially seems dangerous to me. enter anything and have this kind of data.

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So even be thought about entering the public health. framework when we have such a Swiss cheese sort of of privacy and security for i'm looking there moment that that happens.

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I think you tremendous control of the data which and it would I would probably not.

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I'll i'll stop there great thanks Lee and we have had some discussion about use cases, and I certainly recall that discussion at the focus group that might indicate that we needed to be somewhat specific about those in the DSA or

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policies and procedures in some way. Lane, I see that you have your hand up.

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Thanks for being patient, of course. Hi I just wanted to chime in, and in my, this is my first meeting, so it might have already been discussed.

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But when I hear about digital signatures and privacy.

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And so if i'm from a different agency, or entity and I access information that was not given to me by the patient. but I need it for my services.

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I but I use it to reach out to the one of the first things that comes to my mind is often opt-out procedures. do. have have those been considered?

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Have those been are those in the works regarding this exchange the data exchange network that we're establishing

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I think, with the way that the privacy landscape is changing and it's definitely and especially in California, as we all know, is moving towards kind of creating a creating a a setting.

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For. but I think that can subject a lot of these entities to liability.

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If if there's a question about under the consumer level on the patient level, what sa do they have in how this information used, and i'm thinking i'm thinking also about like our population within dsh because it's

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not, you know the the average consumer that's on the advertisements outside, and has kind of independent the control over their information and the data, and what they agree to what they don't people that are actually you know

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removed from the general population. And then what that can mean if all of a sudden you're getting contacted by somebody that you never gave your information to to what extent is that being is that factoring into how these digit signatures are being

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used don't know I just that just kind of concerns me because I don't want I don't want this to

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Not have real world viability, because we're then cut off by litigation.

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Or just think that, like it's been said before and you know even the the 2 people that spoke before me were talking about the fact that privacy, the more that I learned about privacy, the more I realize and security the more I realize that the

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lines are not as clear. so how can we navigate that?

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Where we're not we're not so bogged up in my you know, being an attorney, my first thing is litigation that we can't even move forward with the actual use of this network so I think

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starting even with the use. The use case is a great way, because then we can.

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It can help inform us how what we need to notice what we need to notice what we need to.

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Yeah, I think the big thing is is is a notice issue too, because then we can say, well, we gave you the opportunity, and this is we let you know this is how we're using it.

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So I don't know but I I think my biggest thing was just on the patient level.

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How we considered what that would mean for opt-in, opt-out, or consent great thanks for your comments there.

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The one thing that I would say is that the concept of consent to share information often comes up in our discussion about digital identities, and it is it is an important topic, Morgan.

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I think you were next. Thanks. thanks Rim I think i'm at some extent at going, Louise and Elaine's comments about use cases.

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But I well, i'll try to put a slightly different lens on it.

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If you have to answer the questions, you've put forward I think most of most of the identifiers that will be used will all probably will already be in included the data elements that are that are going to be required to be shareable if

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that's the case then yeah and they're going to be usable for other for other appropriate purposes.

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Yeah, as long as the as long as as we know what those are, be hard to restrict those.

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If there are any that are not, you know identifiers that are not in the data set that's to be shared.

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Well, then, then, of a robust matching system that uses the identity. say yes.

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This person over here is that person over there same person, you know.

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So so yes, share that information then, you'd you'd want to be limited there.

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But as I say, a robust identifying system wouldn't share the details. wouldn't share the identifiers in the digital identity. it would say you got a match, you got to whatever you got to match it this level of

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confidence and and so it's a go I guess that's all I need to say.

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Thanks, Morgan. appreciate it, Lewis. I think you had your hand up next.

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Yeah, thank you, i'm i'm concerned about obviously informed consent.

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But I also recognize that our social services potion doesn't necessarily meet the criteria of always having a phone always having an address, or, you know, other characteristics as were described as a part of this my concern is that you know,

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we've we've had systems in the county some big counties have common identifiers to try and match most most systems trying to match coins who are receiving services on most most systems or many of the same different systems that nature

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just are doing probabilistic matching There are some unique identifiers in the State like a ssid and education, a sin number for medical or education.

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I'm Sorry I already said that immunizations I believe has a unique identifier.

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My my other point thing i'd like to point out here is when these rules give a certain percentage of a match to exchange that doesn't always mean it's still the same person, and usually we find that a human has to

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touch those to make sure, for example, that Luke, Frederickero, Lewis Ptero, or Louis Cratero are really the same person, so that information can be merged into a record or exchanged in

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and there's a lot of labor associated with that you know with that we've seen in the counties when even between our own systems.

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So I want that there's thursday at risk to that makes an argument for an master a statewide, master patient index.

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And that would if we could enter that with the systems that are are there to establish that digital Id and that that might help.

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And then we have to have some way that folks are being informed and what they're to regarding the exchange of that.

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And with respect to the Danish sharing agreement and the comments made early about earlier, I think we need to run the data sharing agreement through the County Council Association to have them.

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If you know, review that, so that we have an agreement in the counties about this framework.

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Great thanks, Louis, and a lot of the a lot of the considerations that Lewis brought up are part of the deliberations that are happening within the the focus groups and part of the discussions that are going on there it is

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a complicated process. I want to make sure at least for today's. Discussion is that we focus on things that we need to do in the data sharing agreement and our policies procedures associated with digital identities.

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So that we can have that discussion to the extent we can, and not ignoring the comments that have already come up.

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Considering. Use case and the ability to do that. Sanjay, I see your hand up.

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Good afternoon. You hear me? Yes, so I think we should not restrict the reuse of digital identities.

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But rather we should focus on listing down. what could be the appropriate uses of digital identities?

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And and the example given here is a perfect example where digital all the data elements which which are making a digital identifier could be very useful.

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We use it like, on alternate contact information to reach the member, and that is very helpful for us to, you know, to benefit the member, to reach out if we do not have the information or if we have the information, but we are getting a

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latest information in the data coming from the data exchange.

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Then we can have that information also as an alternate to contact and member.

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And there could be many more such use cases where we we can reuse the information coming and digital identifier.

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So maybe we need to brainstorm more. But I am in favor of putting allowing the reuse of digital Identifier for appropriate purpose. Thanks.

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Send you, Elaine. I wanted to acknowledge you.

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Your hand is up and I didn't know if you had another comment, and I didn't want to skip over you.

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Did you have another comment to make, or is it still up from before I I need to lower it

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Morgan. I did see your hand pop back up, though. Thanks. Yeah, Thanks.

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Very much I sanjay's comments start just give me a concern that I think we need to be.

00:56:14.000 --> 00:56:29.000
We need to be really clear that if a data element is allowed to be you shared and used that it's on the list of data elements that are allowed to be shared, and used, and let's say you know and and I think almost

00:56:29.000 --> 00:56:36.000
all of the data elements that will be part of a digital identity will probably be on both sides of that Ledger.

00:56:36.000 --> 00:56:46.000
But I think it's really important that we be conscious of that that we not assume that because it's part of the digital identity that it's free to be used for other purposes as the recipient sees fit

00:56:46.000 --> 00:56:54.000
all that that's that seems that seems dangerous leak to me to not conscious of.

00:56:54.000 --> 00:57:04.000
Yes, we're sharing this information and it can be used so, Morgan, I want to ask you a question before you mute yourself again here.

00:57:04.000 --> 00:57:12.000
If we look at some of the emerging concepts surrounding digital identities, it's not just demographics in Us.

00:57:12.000 --> 00:57:31.000
Cdi, but potentially some other identifiers as well, such as drivers, license, or your sin number for medica for medical and those aren't called out as part necessarily as part of the data elements.

00:57:31.000 --> 00:57:45.000
So what i'm hearing you say is that anything that is in digital identities should be covered under exchangeable data elements as opposed to being separated in some way.

00:57:45.000 --> 00:57:51.000

If they're, if yes, if there is if we articulate an appropriate use for it.
00:57:51.000 --> 00:57:55.000
Okay, i'll give me a great you know a great example with the you know a medical number.
00:57:55.000 --> 00:58:06.000
We have both State and Federal limitations that that our data can only be used in ways to support the administration of the medical program.
00:58:06.000 --> 00:58:12.000
So, and we tell our customers that we don't do marketing without their consent.
00:58:12.000 --> 00:58:16.000
So for someone else to use that to market. something to my customers would not be allowed.
00:58:16.000 --> 00:58:21.000
We wouldn't we would not participate if that were if we thought that was going to happen.
00:58:21.000 --> 00:58:24.000
We wouldn't be able to thank you morgan Steven.
00:58:24.000 --> 00:58:28.000
I see your hand up. Yeah, I just wanted to highlight.
00:58:28.000 --> 00:58:40.000
You know what I put in the chat, which is the fact that you know the addition of patient identifiers to the Usci data set is something that is very much on the table.
00:58:40.000 --> 00:58:50.000
And if this group or stakeholders crossed California feels strongly that the ability to be able to share this data is valuable, and we should ask for that.
00:58:50.000 --> 00:58:57.000
We don't have to you know just require that within the California framework, but we could get that added to the Us.
00:58:57.000 --> 00:59:04.000
Cbi, so that everyone can benefit. So I put the links in there where people can go in and and provide comment on that.
00:59:04.000 --> 00:59:08.000
If they feel that that would be beneficial great thank you Stephen.
00:59:08.000 --> 00:59:14.000
It's a good point bill I see your hand up Okay, thanks, Rim, hey?
00:59:14.000 --> 00:59:18.000
I've got a question for you about coordination here my money.
00:59:18.000 --> 00:59:29.000
Hk hpd advisory board and we're implementing a master patient index through a vendor right now.
00:59:29.000 --> 00:59:46.000
I don't see how you can have an opt-out policy that's applicable to that masterpatient index process, because we have to have everyone identified for the purposes of an accurate hpd in California
00:59:46.000 --> 01:00:05.000

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and and I think that that's a I think that's a good point is that the the organizations that are potentially involved in the data exchange network stated exchange framework will have different requirements both

01:00:05.000 --> 01:00:19.000
technical and procedural requirements as well as regulatory requirements, and we need to make sure that we meet that we address that variation in a way that allows them to participate.

01:00:19.000 --> 01:00:30.000
And so I think that You're raising a really good question that is going to make it difficult potentially to be very explicit in the strategy on the July.

01:00:30.000 --> 01:00:39.000
The one time frame. But may need I I think that It would be good for us to identify those issues that need to be worked out as we move forward.

01:00:39.000 --> 01:00:46.000
I Don't have a good answer for you but at least i'm glad that you're raising that issue because I think it is important.

01:00:46.000 --> 01:00:59.000
Let's move on to the next slide. we spent quite a bit of time on privacy, and we got ahead of we got some extra time on our agenda, so I think it was good for us to talk about privacy the other question that

01:00:59.000 --> 01:01:05.000
I wanted to touch on was just security requirements. Now, Ab: 133 does require digital identities.

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Be secure, and therefore protected against unauthorized access or modification, or unintentional or intentional loss of corruption?

01:01:16.000 --> 01:01:31.000
Is. Are there specific requirements that you believe need to be part of policies and procedures associated with digital identities, and beyond those that we might establish for Phi in the policies and procedures?

01:01:31.000 --> 01:01:41.000
I just want to remind folks that security and privacy are part of the policies and procedures that we do envision to be developing.

01:01:41.000 --> 01:01:46.000
Now, my question is, can we cover digital identities along with other data?

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Or does it need to be called out separately? Does it need special treatment, I think?

01:01:53.000 --> 01:02:07.000
Is my question we've had quite a robust to discussion on privacy here, and I think that that probably has some impact on the answer to this question.

01:02:07.000 --> 01:02:10.000
But I didn't know if there were other things in particular Devon.

01:02:10.000 --> 01:02:24.000

I see your hand up. Yeah, I mean one thing i'm not sure whether there needs to be any different different protections for the elements that we would use for for matching and for identity purposes.

01:02:24.000 --> 01:02:27.000
Then we would use to protect the underlying health information that flows underneath.

01:02:27.000 --> 01:02:32.000
I'm not sure about the answer that question but I do know it does take me back to conversation.

01:02:32.000 --> 01:02:44.000
We've had several times in this work group about the fact that we don't have privacy and security requirements that apply to all the actors in this data exchange framework, and that certainly we will need to make that sort of part

01:02:44.000 --> 01:02:53.000
of either the p's, and peas or or the agreement in order to sort of raise everyone up to at least one kind of consistent baseline level.

01:02:53.000 --> 01:03:04.000
But it feels to me that at a minimum that data should be as equally protected as as the sort of baseline health data elements that come underneath it.

01:03:04.000 --> 01:03:08.000
Thanks, Devin, and that's exactly the type of feedback that i'm looking for here.

01:03:08.000 --> 01:03:12.000
I appreciate that, Morgan. I saw your hand pop up for a minute and cut back down.

01:03:12.000 --> 01:03:29.000
Did you have anything? Are there any other thoughts on security? Well, if not, then I think that we can probably close out this discussion.

01:03:29.000 --> 01:03:45.000
I really appreciate it. That helped a lot in both helping inform me about continued deliberations that we'll have with the focus groups on digital identities as well as some thoughts about how we deal with digital identities in the

01:03:45.000 --> 01:04:01.000
DSA. and the policies and procedures I really appreciate that if you have any other thoughts, I would welcome them through email or some other means, and I'll point out that we do have upcoming focus group meetings with privacy

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with health plans and with social services next week, and they you can find the Times for those on the website.

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If your interest in attending is a member of the public to any of those in particular, I'm.

01:04:15.000 --> 01:04:24.000
Expecting another robust discussion at the privacy focus group is we had previously.

01:04:24.000 --> 01:04:29.000
We're still a few minutes ahead of schedule. but I think we can go ahead and move on in the agenda.

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This brings us to our place on the agenda for public comment.

01:04:34.000 --> 01:04:45.000
If anyone in the audience is interested in making a comment, would you please either in search your information and the Q.

01:04:45.000 --> 01:04:51.000
And a area in zoom or otherwise. Raise your hand as we discussed earlier.

01:04:51.000 --> 01:04:54.000
Using any of the zoom teleconferencing options.

01:04:54.000 --> 01:05:04.000
If if you do raise your hand, we will attempt to recognize you, and if you are recognized, you'd ask that you unmute yourself.

01:05:04.000 --> 01:05:10.000
State your name, you organization, and then keep your comments respectful and brief.

01:05:10.000 --> 01:05:15.000
Do we have any members of the public that wish to make a public comment?

01:05:15.000 --> 01:05:22.000
Do we have 2 hands raised at this time? i'm gonna start with Jonathan Bite?

01:05:22.000 --> 01:05:26.000
You did have your hand up first, and I saw you put it down and put it back up to Jonathan.

01:05:26.000 --> 01:05:32.000
I will go ahead and give you permission to add me Hi! thanks very much.

01:05:32.000 --> 01:05:35.000
Can you hear me? Yes, we can. Thanks, Jonathan.

01:05:35.000 --> 01:05:49.000
Hey, Ram Good to see you again. Yes, so real briefly. and since it was touched on earlier about the fact that our State has a wonderful habit of creating to in multiple parallel systems that then, need to be reconciled back to each

01:05:49.000 --> 01:05:56.000
other. I wonder if we could have some specific discussion around the unknown patient.

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And this is not theoretical at all i'm here on behalf of the California Fire Chiefs Association.

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The California Fire chiefs, Ems agencies, etc.

01:06:07.000 --> 01:06:15.000
Folks who are going to be engaging with patients out in the field, where they are possibly unable to speak for themselves.

01:06:15.000 --> 01:06:21.000
They may be of an altered mental status they may have that may be due to substances of one kind or another.

01:06:21.000 --> 01:06:25.000
Dementia, injury variety of different use cases.

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Certainly it brings in social equity issues, but also we are talking pretty aggressively in our room, of course, and I have had this conversation many times around pulsed end of life orders.

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So to the degree that you do not want to get the end of life order wrong because you looked up Rim Catherine instead of Robert Kaufman.

01:06:41.000 --> 01:06:46.000
So to the degree that we are talking about parallel tracks again.

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Different registries that will have different thresholds for identifying.

01:06:50.000 --> 01:06:58.000
And then you've got this massive population of people who are affected where they can't say here's my actual name.

01:06:58.000 --> 01:07:05.000
You may have a friend in nearby who says this person is written. I don't know you any other way for example.

01:07:05.000 --> 01:07:10.000
So can we talk a little bit about an unknown patient because the identity issues in a high triage.

01:07:10.000 --> 01:07:21.000
Environment can be everything and and you really don't have any room for error in those types of use cases where you might, in a in a more controlled setting of care.

01:07:21.000 --> 01:07:25.000
Thanks very much. Thanks, Jonathan, and what I would say is that I will.

01:07:25.000 --> 01:07:31.000
I'd be happy to take those questions and those points back to the focus groups that are deliberating how to create digital identities.

01:07:31.000 --> 01:07:46.000
Now to use them. Think that's the the forum for those discussions, and and we'll we'll try to address those there. and you're welcome to attend those as a member of the public as well images we

01:07:46.000 --> 01:07:53.000
have. Yes, thank you for your comment, Johnson great we do have Jerry Hall.

01:07:53.000 --> 01:07:56.000
Jerry, i'll go ahead and give you permission to unmute at this time.

01:07:56.000 --> 01:08:12.000
Okay, thank you. Hi, everyone. My name is jerry holland I don't see anygo and i'm an advocate in a number of areas around open government and and the data exchange between the criminal legal and

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behavioral health systems. but my comments here. i'll also email because they're much longer.

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But my underlying concern in the comments that i'm sending you focus on the potential misuse one's health data, especially by those in Government and the private sector and by those who would traditionally seek to continue

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to target our marginalized communities. Additional concerns include highly probable data use by corporate entities that may simultaneously upgrade in the health care marketplace.

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Yet also have business concerns that benefit from that same data for other purposes like targeted marketing, and which I believe would be much more difficult to track.

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So if they're using it for healthcare and then come in under a different umbrella, using the same data for their marketing, and I believe that we all know that data can be a double-edged sword it can both

01:09:11.000 --> 01:09:26.000
build and remove barriers. We should never forget that as a society, and in both private and government sectors we have traditionally, and will likely continue to seek opportunities that reinforce grow and sustain our biased and racist

01:09:26.000 --> 01:09:35.000
practices. So my ultimately, what i'm after is championing line level control of our data.

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So if I decide that either categorically or you know by practitioner, if I want to eliminate the ability for someone to use my data as I should have that control, no matter what the technological difficulties are today,

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if we, if we present the the ideas and framework, I think that that technology will be able to catch up pretty quickly.

01:10:00.000 --> 01:10:08.000
So not only have line level access, but also I went to know what entities are using my data.

01:10:08.000 --> 01:10:19.000
So if Google has a partnership agreement with a data exchange entity, I should be able to see that Google has access to my data.

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This isn't about you know eliminating control it's about making sure that consumers have the ability to know and and understand who's accessing their data.

01:10:30.000 --> 01:10:37.000
So they can advocate for themselves. Thank you, great, Thank you, Jerry, and we look forward to your written comments.

01:10:37.000 --> 01:10:47.000
There, too, Are there other public comments? We do not have any other hands raised at this time. Okay?

01:10:47.000 --> 01:10:57.000
Well, then, we will close the public comment period there. Thank you for your participation in that, and move on to the next item on the agenda.

01:10:57.000 --> 01:11:08.000
So like John. I am also not jennifer and i'm going to do my best to shepherd us through some of the next discussions.

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I'm interested in as much participation as people can give us to help move us forward to this discussion, and certainly welcome any of my colleagues to chime in with questions or clarifications.

01:11:22.000 --> 01:11:32.000
They would like as well. Really, The goal for this section of the meeting is to obtain feedback on our third set of DSA topics and draft language.

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You did receive some of that draft language in advance, going to start off with the next slide with the topic.

01:11:38.000 --> 01:11:41.000
Well, there are 3 topics that we're going to cover today.

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We're going to at least begin to cover today what constitutes a qualified network.

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And what that means. and then we'll talk about uses and disclosures and minimum necessary draft language that you received.

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So let's go on to the next slide and begin a discussion about qualified networks as you will recall Ab.

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133 calls for a number of specific organizations.

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That would be subject to and required to sign the data, sharing agreement and participate in the data exchange framework.

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So. However, some organizations may prefer to accomplish that exchange through some type of any intermediary, such as a regional hio to facilitate data exchange and and satisfy their requirements of

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A. B, 133 on their behalf.

01:12:36.000 --> 01:12:57.000
Our question to this organization is should the data exchange framework and its DSA include the concept of of a qualified network or qualified intermediary, and it's so should signatories only be permitted to use those

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intermediaries, if they are considered. and granted that qualified status.

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The second. question here is also: Should a qualified network be required to be a signatory to the data sharing agreement?

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Hos or other networks are not called out in Ab 133 as required signatories.

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So what are People's thoughts about qualified networks Steven?

01:13:24.000 --> 01:13:36.000
I see your hand up, please. Yeah. I guess the question line line is, should we be qualifying technologies and methodologies?

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Just say direct messaging, or should we be qualifying the specific networks or intermediaries that carry that those those exchange transmissions, because it seems like you know there's a whole bunch of regional hiv you know there's a

01:13:59.000 --> 01:14:04.000
whole bunch of you know intermediaries that can support direct messaging.

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I mean i've generally been or the idea of sort of saying, you know well if you're connected to care quality, you know, through common well, or through epic, or through whatever he health exchange, you know that that qualifies you for

01:14:17.000 --> 01:14:31.000
something in under California rules. but I think we just have to be clear that we don't want to, you know, be be creating a laundry list or a dynamic list that we have to maintain you know, as new actors you

01:14:31.000 --> 01:14:35.000
know. Come, come in and provide services, you know, every whatever week per month or thanks.

01:14:35.000 --> 01:14:43.000
Stephen, Helen, I see your hand up. Yeah.

01:14:43.000 --> 01:14:56.000
So in answer to the question, Yes, I do Think that these intermediaries need to be you know, qualified, or they would be a qualified network, because, you know, if data is going to be flowing through them.

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If they're going to be having access to it I mean they have to have some robust security requirements in place.

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And you know, industry accepted practices for safeguarding that data, especially in light of the cybersecurity cyber attacks and the cyber security environment.

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Right now as well as you know the ransomware.

01:15:20.000 --> 01:15:32.000
So I think this concept of having, you know a qualified network does need to come and play with this and what what that is, how we qualify them if they agreed to certain.

01:15:32.000 --> 01:15:36.000
You know, industry accepted, you know, standards and requirements.

01:15:36.000 --> 01:15:43.000
Maybe that would be it. But there needs to be some sort of qualifying factor in that.

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Thank you, Helen. Helen raised a point that I want to point out just very quickly, and that was some of these organizations.
01:15:53.000 --> 01:15:59.000
He's intermittent areas are going to have have access to the data from some of them may not.
01:15:59.000 --> 01:16:16.000
I would point out that, for instance, the c 10 is not a party to act, be able to access any of the data care. equality likewise doesn't access any of the data and we might consider whether the need to be a signatory is
01:16:16.000 --> 01:16:23.000
tied to ability to access data again access digital identities.
01:16:23.000 --> 01:16:29.000
As we talked earlier. Perhaps that's a question to talk about as well as I see your hand up.
01:16:29.000 --> 01:16:39.000
Yeah. So I mean obviously, i'm coming from an hiv So I do believe that qualified intermediaries need to be part of this process.
01:16:39.000 --> 01:16:59.000
I think that. And I think that it should be the organization's not necessarily the technology in part, because I think that if you try to qualify each individual element of technology that actually becomes a much longer and more difficult to manage list don't think
01:16:59.000 --> 01:17:06.000
that every participant necessarily is required to connect through the qualified intermediaries.
01:17:06.000 --> 01:17:17.000
I think that it is an easy on ramp right. It is meant to make it easier for people who have not set up their own system that exists today.
01:17:17.000 --> 01:17:27.000
It is not necessarily mandatory path. It is not if you are not using a qualified intermediary, then you are absolutely not in compliance.
01:17:27.000 --> 01:17:31.000
There's no universe in which this works I don't think that has to be the answer.
01:17:31.000 --> 01:17:37.000
If you have something that meets all of the requirements today, you don't have to go through a qualified intermediary intermediary.
01:17:37.000 --> 01:17:51.000
Most people, or at least enough people who who are being looped into this required framework will not meet all the requirements today, and you can say here's the list of qualified intermediaries that is going to be a dynamic
01:17:51.000 --> 01:18:04.000
list, Stephen, It is going to change if you are connected through one of these. Then you are kind of deemed to have meet met the basic requirements, and I think that that is it's a shortcut.
01:18:04.000 --> 01:18:11.000

It actually simplifies things for a lot of people and I think that's a material boon, thank you for that, Devin.

01:18:11.000 --> 01:18:23.000
I see your hand up Yeah, I we've had lots and lots of discussions about how you know there's no sort of single way that exchange is gonna you know that we're gonna be technology agnostic about the

01:18:23.000 --> 01:18:31.000
way that exchange occurs, but we have to recognize that that for a lot of enemies they will need some way to be able to exchange.

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There should be a menu of options that are available to them, and certainly exchange through one of the existing intermediaries, or maybe even some new ones that come on the scene later, could be a way to sort of be able to kind

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of check. the box you know i'm meeting the requirements there's there's also the potential for you know if these exchange intermediaries adopt sort of similar components in their agreements as are required in the main

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agreement. one could almost foresee a situation where it's like Okay. I'm.

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I'm signed up with this intermediary it's got it Come, you know, incorporated all of the provisions that are required of my data sharing agreement so that I could I should be able to check the box and

01:19:17.000 --> 01:19:30.000
sign the one agreement i'm an and and so that sort of presumes a kind of a review process to make sure that the intermediary is kind of meeting those standards around the policies and procedures and

01:19:30.000 --> 01:19:38.000
what's required in the agreement, but I think other than that it's just about making a menu of options available to people and allowing them to pick.

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But making sure that all of those options meet sort of the general expectations around again.

01:19:44.000 --> 01:19:52.000
Policies and procedures, and and you know the elements of the agreement, so that people don't necessarily have to sign 2 agreements.

01:19:52.000 --> 01:20:08.000
They could just sign the one. Thanks. kevin i'll point out that Stephen has been dropping some items in the chat about at least one network that does some qualification of the participants on that network morgan

01:20:08.000 --> 01:20:22.000
I see your hand up. Yeah, Thanks. Thanks for me. This seems like like quite a double-edged sword, unless unless we point to something like the resources that Stevens identifying.

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Point to something else. But if if we whoever we is if we're going to to determine who's who's qualified to do this?

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Yeah, that that implies that you know that that's that's a licensing operation that has to be able to grant and withhold approvals and take them away when there's when something goes wrong

01:20:45.000 --> 01:21:03.000
that's a that's a pretty significant operation that would need to be resources the flip side of that is like this. A couple of others have alluded to also is and don't hear me as is not being supportive of high standards I am supportive of high

01:21:03.000 --> 01:21:20.000
standards, but we're also going to make sure that the all participants can participate. we have to be mindful of the costs We impose also that you know that small providers rural providers the the social services

01:21:20.000 --> 01:21:23.000
the folks in the social determinants of health zone.

01:21:23.000 --> 01:21:31.000
We may, you know, if we we, we need to be mindful of.

01:21:31.000 --> 01:21:40.000
How do we include those participants in the system where they're their ability to resource?

01:21:40.000 --> 01:21:46.000
Some of these needs may be very different than what some of us are accustomed to.

01:21:46.000 --> 01:21:52.000
Thanks, Morgan Stephen, in an attempt to answer your question.

01:21:52.000 --> 01:21:57.000
Depending on how you count. There are probably more than a dozen H.

01:21:57.000 --> 01:22:04.000
Ios in California that are currently operating. I think there are 16 signatories participating on the C.

01:22:04.000 --> 01:22:10.000
10 that includes some State agencies and organizations like your own, as well.

01:22:10.000 --> 01:22:20.000
So depending on how you count there's probably more than a dozen, but not the 30 that you identified as members of the direct trust network.

01:22:20.000 --> 01:22:28.000
So if we were going to, you know, qualified folks, for you know, to support exchange in California.

01:22:28.000 --> 01:22:36.000
Between the various, you know, public and private and nonprofit national networks, the hits they change and the chos.

01:22:36.000 --> 01:22:39.000
We're still probably in doubled digits you know We're not.

01:22:39.000 --> 01:22:45.000
We're not going to triple digits, yet I would say that that's a good estimate.

01:22:45.000 --> 01:22:49.000
Yes, Blenda, I see your hand up and thanks for him.

01:22:49.000 --> 01:22:52.000
So when I saw this slide, This the word qualified over the weekend.

01:22:52.000 --> 01:22:58.000
The first thing that came to mind was the the qualified surface organization concept under Part 2.

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So as the non lawyer, Can I ask a naive question?

01:23:00.000 --> 01:23:06.000
Does that? does that play into this at all and i'm thinking from the lens like what Morgan was saying.

01:23:06.000 --> 01:23:16.000
If there's any way to lower the threshold or the barriers to certain entities participating and being able to exchange part 2 data in a permissible way, can that be leveraged?

01:23:16.000 --> 01:23:26.000
Here are these completely different constructs? Well, i'm not a lawyer, either, and I so I can give you a definitive answer for that.

01:23:26.000 --> 01:23:33.000
I know in my mind what came to mind when I saw qualified was a term that Dhcs.

01:23:33.000 --> 01:23:40.000
Used during the Calhoun program and some other programs where they qualified participants in that program.

01:23:40.000 --> 01:23:44.000
And it was a very different bar than the one you're talking about.

01:23:44.000 --> 01:23:51.000
But I think that's a question for us also is what does it mean to be a qualified organization?

01:23:51.000 --> 01:23:55.000
And to. you know some of the discussions that have come up.

01:23:55.000 --> 01:24:06.000
What is the barrier to organizations What is the cost, and what is our ability to actually license, or withhold licensing from them to be qualified?

01:24:06.000 --> 01:24:19.000
I'd be interested in any thoughts that anyone else has on Belinda's question, Guest Morgan.

01:24:19.000 --> 01:24:31.000
I think I I think the safest horse would be to say that the use of the word qualified, and 42 cfr part 2 doesn't really connect to this it.

01:24:31.000 --> 01:24:36.000
Doesn't there isn't any standard for that it's you know.

01:24:36.000 --> 01:24:43.000
I think they made it up a long time ago. Oh, I I think under I don't know where either.

01:24:43.000 --> 01:24:51.000
Obviously under the kefka. right? I identifying as a qualified health information network.

01:24:51.000 --> 01:24:58.000
They have to be both the logistical, administrative, and then technical requirements that are agreed upon right.

01:24:58.000 --> 01:25:15.000
So if the D, you know, if we decide under our exchange that have certain technical standards, administrative standards agreed to for data sharing. and as long as you meet those and you they are then quote qualified the health information network within this data

01:25:15.000 --> 01:25:29.000
sharing organization or trust, if you will. thanks John and I would also point out that and correct me if i'm wrong, if somebody knows better than I do.

01:25:29.000 --> 01:25:37.000
But the qualified health information network. Senator Tefka are also signatories. Are these signatories to the common agreement?

01:25:37.000 --> 01:25:41.000
So. there is a stipulation there, and I at least see Devon nodding her head.

01:25:41.000 --> 01:25:50.000
You had your hand up to Devon, I did only to say, You know we use the word qualified in health care a lot, and it really just depends on you know.

01:25:50.000 --> 01:25:57.000
What are the standards that we would want someone to meet in order to be quote, unquote, qualified for this particular purpose?

01:25:57.000 --> 01:26:05.000
It's not clear that other sort of qualification systems that exist in health care would necessarily make you quite qualified to do this.

01:26:05.000 --> 01:26:13.000
You know what's interesting about the tefa is that That is a that is a network that where they're making architecture choices right.

01:26:13.000 --> 01:26:23.000
There is, you know, the one network you're gonna you're gonna it's, you know, you're gonna abide by this sort of one sort of common way of exchanging at the top you know with some room for

01:26:23.000 --> 01:26:26.000
flexibility underneath that kind of q hint framework.

01:26:26.000 --> 01:26:41.000
I'm not sure that we can get there. with this data sharing approach that we're taking because of our requirement to sort of be technology exotic agnostic. But again, I do think we need to put options in front of

01:26:41.000 --> 01:26:58.000
people that would work for a range of entities that we have in the State for which we want to encourage data sharing that allow for folks to use their local Hiv or use direct or use sort of a menu of options But all of

01:26:58.000 --> 01:27:01.000
them sort of, I think, ideally coming from a list so we're not so.

01:27:01.000 --> 01:27:10.000

We do have some sort of loose organization and understanding of how it's all going to knit together, thank you

01:27:10.000 --> 01:27:21.000
So what i'm hearing when I look at the 3 questions from this slide is, should the data exchange framework include a concept of an intermediary.

01:27:21.000 --> 01:27:29.000
I think i'm hearing a yes, there that there should be options to participation, and I think we've had that conversation many times.

01:27:29.000 --> 01:27:42.000
Whether It's a qualified intermediary is a maybe whether the qualified intermediary needs to be needs to be a signatory to the DSA.

01:27:42.000 --> 01:27:51.000
Is a maybe. are there So first of all, am I hearing that writer?

01:27:51.000 --> 01:27:58.000
Do people believe that we've come to a different place on these questions?

01:27:58.000 --> 01:28:04.000
And what would we need to do to turn the babies into yeses or no, so that we knew how to proceed here.

01:28:04.000 --> 01:28:14.000
Yes, the babies are all contingent on the framework, right?

01:28:14.000 --> 01:28:25.000
So depending on how we set up the reality. It may be that because of the way you become a qualified intermediary, that hoops that you have to jump to.

01:28:25.000 --> 01:28:28.000
It is not necessary to be a signatory to the agreement.

01:28:28.000 --> 01:28:42.000
If the hoops are not sufficient or they they miss critical elements that are covered by the agreement, then you're going to need the signatory to need the individual organization to be a signatory to the agreement so to to resolve

01:28:42.000 --> 01:28:51.000
those last 2 means we have to decide how we're going to let this process work, and then that will that will necessarily answer those questions.

01:28:51.000 --> 01:28:57.000
100 we have to have. How are they being qualified? Kind of set out?

01:28:57.000 --> 01:29:10.000
Great. Thank you. And so that might identify that. we need a policy and procedure associated with that as a framework to deliberate on those questions.

01:29:10.000 --> 01:29:20.000
Perhaps i'm seeing them maybe and i'm just trying to make sure that I understand how to summarize your point.

01:29:20.000 --> 01:29:24.000
There. Morgan, I see your hand up. Yeah, Thanks.

01:29:24.000 --> 01:29:32.000
I think the the having these networks or intermediaries sign the DSA.

01:29:32.000 --> 01:29:43.000

You a little problematic to me, because the because the purpose of the DSA is different than than qualifying the entities that are going to participate.
01:29:43.000 --> 01:29:49.000
So that seems a little problematic to me. But But to the question of how do you you?
01:29:49.000 --> 01:30:02.000
How do you manage? sort of a enforcement? having having some kind of a commitment from from the networker intermediate is is, could be a way to do that.
01:30:02.000 --> 01:30:09.000
But I think it's not the same instrument most likely it's a different instrument There they have.
01:30:09.000 --> 01:30:13.000
They're playing a different role unless unless they are actually playing 2 roles.
01:30:13.000 --> 01:30:17.000
But I I think those are probably 2 different pieces of paper.
01:30:17.000 --> 01:30:24.000
Thanks, Morgan Dev. And I see your hand up. Yeah, I would agree with that, Morgan.
01:30:24.000 --> 01:30:34.000
It feels like for the intermediaries we want to at least they have to agree to exchange with each other under under in the same way that that the Tefca is set up for the Cubans to exchange with
01:30:34.000 --> 01:30:50.000
one another. But we've really been talking about this agreement all along as an assuming that individual organizations or individual providers, if they're not part of an organization, would sign it so it's got a lot in it that's geared toward sort
01:30:50.000 --> 01:31:03.000
of individual actors or nodes on the network, there might need to be something separate for for for the networking intermediaries, and that could just be part of their qualifications. standards as opposed to signing the participation
01:31:03.000 --> 01:31:12.000
agreement. Great, Thank you, Devin. Appreciate that. Are there other thoughts on this topic?
01:31:12.000 --> 01:31:19.000
If not, why do we go on to the next topic on the agenda?
01:31:19.000 --> 01:31:25.000
And I think that this is a review of some of the draft language that came out.
01:31:25.000 --> 01:31:44.000
So if I can share my screen I think i'm driving to the language, if that's isn't correct so hopefully you can see my screen.
01:31:44.000 --> 01:31:59.000
This is the draft language that was distributed earlier in the margin are the sources of the information of the language that was used in each one of these sections for your reference.
01:31:59.000 --> 01:32:18.000

I think that was also in the copy that you received. The first topic here is on the uses and disclosures, and the question before people here is, is, Do you feel comfortable with this language?

01:32:18.000 --> 01:32:24.000
Is this: Does this seem appropriate? Are are there changes to this language that we need to consider?

01:32:24.000 --> 01:32:44.000
Give people a minute to to kind of look through. so Why are you continuing to read there.

01:32:44.000 --> 01:33:04.000
I'll draw. Our first attention to perhaps as section 2 on future use is, is, is that appropriate recipients may only retain use and redisclose information to coordinates with applicable law.

01:33:04.000 --> 01:33:17.000
Yes, Steven. Yeah, I mean, this is been a point of contention for a long time.

01:33:17.000 --> 01:33:23.000
Because, of course, applicable law does allow a lot of reuse of data.

01:33:23.000 --> 01:33:28.000
You can paying it to one purpose in the it for other permitted purposes to.

01:33:28.000 --> 01:33:41.000
So this is a very permissive approach, you know. and then, of course, in some situations people suggest, and you know that you can utilize the data only for the purpose for which it was released.

01:33:41.000 --> 01:33:48.000
You know, or for some more limited set of purposes and I think it's a key question that we need to address, you know.

01:33:48.000 --> 01:33:53.000
Do we want to be more permissive or more restrictive as we define?

01:33:53.000 --> 01:34:03.000
You know our use in California, or just you know I mean I think most most of the national frameworks they're working on this do default to applicable law.

01:34:03.000 --> 01:34:15.000
But there were a couple of comments earlier about. You know the the role of privacy and and the feelings about privacy in California is Is that really any different than the the national State?

01:34:15.000 --> 01:34:21.000
And I think Stephen really is focusing on the the key topic here.

01:34:21.000 --> 01:34:38.000
So, Morgan, I see your hand up. yeah I said that say 11, 2 bakes me makes me a pretty uncomfortable. that in effect, that particularly I focus in on the it's not just the applicable law but the

01:34:38.000 --> 01:34:53.000
recipients privacy and security P. andps that that that could completely undermine the promises that each participant has made to its own customers.

01:34:53.000 --> 01:35:07.000

Thanks, Morgan. So so perhaps we should be asking ourselves what to additional restriction should be putting on things here.
01:35:07.000 --> 01:35:15.000
Shelley, I see your hand up, Shelley if you're talking.
01:35:15.000 --> 01:35:27.000
We cannot hear you. I did see you come off mute but we still can't hear you.
01:35:27.000 --> 01:35:41.000
You may be double muted. Maybe one of the folks from Menac can see if they can help. Shelley get off mute Helen.
01:35:41.000 --> 01:35:47.000
Why don't we go on to you and we'll come back to you, Shelley, as soon as we can.
01:35:47.000 --> 01:35:58.000
But yeah. As I was reading this, I saw a conflict between 11, not 2 and 11.4, or they talk.
01:35:58.000 --> 01:36:11.000
Am I not reading it right? Only because it Seems like 11.4 does have a more narrow restriction on You know the secondary use of this data that's coming across.
01:36:11.000 --> 01:36:17.000
It seems like there is more you know it's not just you can
01:36:17.000 --> 01:36:26.000
You know you did importance to applicable long recipient information private security, but there's also the requirement that it cannot be for their own benefit.
01:36:26.000 --> 01:36:37.000
And so it seems like there's a conflict there between 11.2 and love that 4, and I you know I I do agree, my little uncomfortable for 11.2.
01:36:37.000 --> 01:36:42.000
It just seems to be, you know, from my perspective, too broad.
01:36:42.000 --> 01:36:55.000
Considering how much data is trying is being mind for different uses, and it seems like 11.4 has more limiting parameters around that for their own.
01:36:55.000 --> 01:37:07.000
For you know a participant's own own benefit and then There's these 1, 2, 4. So I thought that either they're talking about 2 different things.
01:37:07.000 --> 01:37:12.000
Or they're or talking about the same thing and being contradictory.
01:37:12.000 --> 01:37:25.000
Oh, and and I guess I would tart turn to some of the lawyers on the phone here, and if they share that that concern, that things appear to be controversial, contradictory there, and I see Devon Sh nodding her
01:37:25.000 --> 01:37:32.000
head, and Morgan and Stephen that both felt uncomfortable with 2 as it stood now.
01:37:32.000 --> 01:37:38.000
Whether for helps that in some way. Thanks, Helen and Devin.
01:37:38.000 --> 01:37:44.000
I see your hand up. Yeah, I think I mean I mean I think it's interesting that the these were pulled.

01:37:44.000 --> 01:37:57.000
It's good that that justin remarked the sources, because they were pulled from 2 different documents, which means they may, in fact, have been provisions aimed at a similar thing, but just taking a slightly different approach in each one

01:37:57.000 --> 01:38:07.000
I think the tough part about. I think the tough part about all of these kind of downstream restrictions is, how do you enforce them?

01:38:07.000 --> 01:38:21.000
And what does that, then? what kind of additional burdens does that place on a recipient organization to separate the data it's received through the network versus the data that that that it can treat in accordance with applicable law and its

01:38:21.000 --> 01:38:26.000
commitments to to pay, you know public commitments to patients and policies, etc.

01:38:26.000 --> 01:38:36.000
That that may be slightly different than than what the generating the data holders policies might have been.

01:38:36.000 --> 01:38:43.000
And so it you know, and and and if you're making sort of commitments to people that your data will never be used for X.

01:38:43.000 --> 01:38:49.000
It's going to make it very very difficult if x is a permitted a use permitted by law.

01:38:49.000 --> 01:39:05.000
It's going to make it very difficult to participate in exchange, because essentially, being able to sort of make that make those protections essentially stick to the data wherever it goes, is a nearly impossible task But my main question with number 11.4

01:39:05.000 --> 01:39:16.000
is what is owned benefit, and who determines that excellent question that I do not have the answer to.

01:39:16.000 --> 01:39:30.000
Then we can ask care quality, since it came from them if they've had any policies just sort of define this, or if they've ever had an occasion to enforce this and I don't know the answer to that question and that

01:39:30.000 --> 01:39:46.000
is something perhaps we can, we can discover. Is there alternative language that anyone would suggest other than own benefit to clarify that what I mean?

01:39:46.000 --> 01:39:52.000
And as I, as I commented here, I think benefit can be monetary.

01:39:52.000 --> 01:40:02.000
It can be all sorts of things. I mean people can be training their Ai algorithms using the data that they you know told you for a payment treatment or payment.

01:40:02.000 --> 01:40:05.000
Purpose I mean there's there's just there's so many ways to define benefits.

01:40:05.000 --> 01:40:19.000

So I think you know you either sort of agree that privacy is dead, and once you look less a day ago, it's just going to Why, over at once, or you try to create some guardrails, and perhaps think of it as an iterative

01:40:19.000 --> 01:40:42.000
process, thanks to you. So if we look at the the language under for if there's concern about 2 and a conflicts, is there other than the lack of a clear definition of own benefit, are there Are the provisions?

01:40:42.000 --> 01:40:49.000
The exceptions. one through 4? Are they appropriate? Is there something else that is missing?

01:40:49.000 --> 01:41:05.000
Is there something that should be altered with them? Yeah, Devon, I kept watching your face and thinking.

01:41:05.000 --> 01:41:24.000
Yes, I can see the wheels turning might come up there. Well, just because so there's you know, essentially number one is if what people are trying to get at with the prohibition and 11.4 is not allowing sort of further monetization of

01:41:24.000 --> 01:41:32.000
data collected through this through this network, which is largely done with D identified data because it's it's almost impossible to do it with identifiable data.

01:41:32.000 --> 01:41:39.000
Essentially number One is a gigantic loophole, because it allows a participant to authorize their business associate to do it.

01:41:39.000 --> 01:41:44.000
And then the business associate can do it, because number one exempts that entirely. So you know.

01:41:44.000 --> 01:41:52.000
Again. I I think I under. I totally get the desire to sort of place downstream restrictions.

01:41:52.000 --> 01:42:05.000
I just think it's it's not it's really hard to do, and it's very hard to enforce again, because data once, you if you're a you're every participant in this network is both going to give and

01:42:05.000 --> 01:42:09.000
get right. you're both going to be providing data into the network, and you're going to be getting data from the network.

01:42:09.000 --> 01:42:15.000
If it's successful, right do you does does each node on the network want to.

01:42:15.000 --> 01:42:18.000
You're the protectionist instincts come from the data you're pushing out.

01:42:18.000 --> 01:42:33.000
Do you then want to have the data you're taking in be something that you have to hold separately to make sure that you're treating it consistently with with the agreement versus setting a providing a set of standards and

01:42:33.000 --> 01:42:43.000

policies and procedures that apply to all holders of this data across the network, and not trying to sort of control how that data gets used by by.
01:42:43.000 --> 01:42:51.000
And it in this way requiring it to be separated that's that's my main concern.
01:42:51.000 --> 01:43:05.000
It's just I don't I could see provisions like this just being in the agreement, and then being in name only because it's hard to enforce It would be hard to enforce thanks Kevin Yes, Tiana
01:43:05.000 --> 01:43:29.000
you are still muted every day. I agree with Devin. that the the downhole, the downstream control of data is you're impossible at a certain point, not having limitations on how data can use I just want to you know put
01:43:29.000 --> 01:43:38.000
this out there. So it's known that there that may restrict what systems and what databases can participate.
01:43:38.000 --> 01:43:43.000
Because if there are limitations on how data that is collected can be used, that would limit.
01:43:43.000 --> 01:43:53.000
If we can participate without having the ability to control further use and you're talking further, you're talking downstream.
01:43:53.000 --> 01:43:56.000
Use that you need to be able to control downstream. Use?
01:43:56.000 --> 01:44:02.000
Yes, correct. Yeah, great, thank you, and devin I still see your hand up.
01:44:02.000 --> 01:44:05.000
I don't know if it's still up or if you had another comment.
01:44:05.000 --> 01:44:07.000
You wanted to mail. Sorry I just didn't want to skip over you.
01:44:07.000 --> 01:44:12.000
If you did. Are there other thoughts about the provisions here?
01:44:12.000 --> 01:44:34.000
Other recommendations about how we might alter this if not I'm gonna go on to the next section of this document, and I would encourage people to think back about that last discussion.
01:44:34.000 --> 01:44:40.000
And any thoughts that anyone has about how the language might be changed or tightened up.
01:44:40.000 --> 01:44:56.000
Please please feel free to suggest The minimum necessary section is relatively short, and we have had some topic, some discussion about minimum necessary before.
01:44:56.000 --> 01:45:08.000
I'll give you a chance to read through this and interested in people's thoughts about whether this captures your your your thoughts about our earlier discussion.
01:45:08.000 --> 01:45:21.000

Are there any concerns or suggestions associated with this language?
01:45:21.000 --> 01:45:36.000
Yes, son Jay, all right. So i'm thinking you know, with respect to getting the data through intermediaries like Hiv.
01:45:36.000 --> 01:45:41.000
So if we get data through them, and we are getting, for example, Ccds.
01:45:41.000 --> 01:45:46.000
That is a huge set of data, and it just gives us everything about the member.
01:45:46.000 --> 01:45:53.000
So. i'm just wondering how the minimum necessary would be applicable in those situations.
01:45:53.000 --> 01:46:09.000
I think that's an excellent question and care summaries grew up largely, and a care coordination environment largely exchanged for treatment purposes.
01:46:09.000 --> 01:46:16.000
But we are talking about other participants on the network here, and I think that's an excellent question, Sunjay.
01:46:16.000 --> 01:46:29.000
Are you suggesting, then, that receiving did a health? plan? like yours, receiving a seatCD a care summary would be inappropriate and would not meet a minimum necessary standard?
01:46:29.000 --> 01:46:43.000
That's what I was thinking. Yeah great devon I see your hand up, and you're still muted there to myself.
01:46:43.000 --> 01:46:56.000
Thank you. Rim I I made a comment in the chat. but but but the the point that's being raised is one where the document-centered architectures of exchange that that that do exist in in a lot of
01:46:56.000 --> 01:47:07.000
settings make it sort of hard to do more granular requests. So there might need to be some caveats here, for you know, if if what I need is the lab data.
01:47:07.000 --> 01:47:13.000
But what have but the way that you? the only way you can get me the lab data is in a document that also has a bunch of other data in it.
01:47:13.000 --> 01:47:27.000
That we may be sort of we may have to deal with the the technology we've got as we sort of evolve to more mature ways of exchanging data that's based on data element only that this happened
01:47:27.000 --> 01:47:39.000
in during Covid. I remember distinctly a lot of public health departments being wanting to sort of tap in directly to to their local Hiv in order to get data, but only being able to get a CCD.
01:47:39.000 --> 01:47:51.000

Which had a lot more data than they necessarily which had all the data they needed, plus a bunch of other data that couldn't be carved out efficiently in order to get the data to where it needed to go thanks for that

01:47:51.000 --> 01:48:00.000
Devon, and and I guess I would. The question that I would put before the folks here is so what do we do to the language here to acknowledge?

01:48:00.000 --> 01:48:05.000
Implemented technical standards that may make it difficult to meet this.

01:48:05.000 --> 01:48:09.000
This need, Stephen. I see your hand up. Yeah. Thanks.

01:48:09.000 --> 01:48:14.000
You know this has come up a lot. The issue that the CCD.

01:48:14.000 --> 01:48:19.000
As it is created and provided by a number of healthcare team.

01:48:19.000 --> 01:48:25.000
Developers, you know, can continue more data than these, or more data than is useful or wanted.

01:48:25.000 --> 01:48:42.000
Would we, you know, insofar as we are trying to be fully looking and looking at where the technology is setting? Would we want to be more specific And look at at varying our expectations to depending on the technology that

01:48:42.000 --> 01:48:47.000
we're using you know if you're talking about an hl 72 feed, you know. you can be very specific.

01:48:47.000 --> 01:49:00.000
It's a talking about a fire data request you can be very specific, whereas with you, you know, you can't, and I know a lot of Hiv have built their infrastructure around the CCD.

01:49:00.000 --> 01:49:04.000
You know, so far have you yet to transition to fire.

01:49:04.000 --> 01:49:19.000
But you know, perhaps, what We're. looking for is only, going to be so portable in in a more modern world of Fire, or a more expensive world of a multitude of V 2 interfaces, and that just you know taking the

01:49:19.000 --> 01:49:24.000
CCD. Paradigm is is perhaps not what we want.

01:49:24.000 --> 01:49:30.000
At this point. Thanks, Stephen, so I guess i'd put my question out there again.

01:49:30.000 --> 01:49:42.000
So what do we do during this transition? period? where fire hasn't been widely implemented and adopted by all of the players that we anticipate being here?

01:49:42.000 --> 01:49:47.000
Or how do we take advantage of what is implemented in CCD documents?

01:49:47.000 --> 01:49:56.000
Devin, I see your hand up. Yeah, I put it. I just put a small suggestion in the chat, which would be, you know, any use or disclosure, or Phi or P.

01:49:56.000 --> 01:50:10.000
I would will be Pi or Phi will be limited to the minimum necessary to achieve the purpose for which the information is shared to the extent technologically feasible, and to still ask people to be careful in their requests but

01:50:10.000 --> 01:50:19.000
in terms of producing the information requested. you know the technology may may may win the day you need to.

01:50:19.000 --> 01:50:26.000
You need to provide what's requested and and in the minimum necessary when went to the extent technologically feasible.

01:50:26.000 --> 01:50:34.000
Thank you, Devin. How do people feel about that? I guess my only concern Devon would be.

01:50:34.000 --> 01:50:43.000
Would that be disincentivizing folks from moving towards the more specific granular technology solutions?

01:50:43.000 --> 01:50:49.000
Because then they could just say well take's invisible to me because I haven't set up a fire server. I'm just gonna stay where I am.

01:50:49.000 --> 01:51:04.000
I would think that we should use other mechanisms to sort of move people towards the more sophisticated technological approaches versus holding their holding them in violation of their contract because they're their current technical capabilities, won't let

01:51:04.000 --> 01:51:18.000
them exchange it will. It will take some time for people and protect under resource entities, to be able to to migrate their tech something that allows more granular data elements.

01:51:18.000 --> 01:51:26.000
I got I i really I don't see this minimum necessary provision as being the the thing that people cling to as an excuse for not upgrading their tech.

01:51:26.000 --> 01:51:35.000
I think it'll be a lot more complicated than that thanks Devon. Steve Elizabeth.

01:51:35.000 --> 01:51:37.000
I saw your hand up for a minute and then go back down.

01:51:37.000 --> 01:51:42.000
Did you have a comment you wanted to make really just going to say almost exactly what Devon did, So I think we're good.

01:51:42.000 --> 01:51:57.000
I was reading her mind she's great at that i'm always happy to also hear people just weigh in and underline what other people have said that's that helps us understand if we're reaching consensus on a

01:51:57.000 --> 01:52:05.000
topic. Are there other thoughts about me, the minimum necessary for these provisions?

01:52:05.000 --> 01:52:16.000
If not, that brings us largely to the bottom of the agenda.

01:52:16.000 --> 01:52:30.000
I think that the manat team can take over slide sharing again, And, John, we're a little bit of a head of schedule, but I think that we really have largely gotten to the bottom of our agenda and if you would

01:52:30.000 --> 01:52:36.000
like to close this out. i'd welcome that I will take it thank you so much.

01:52:36.000 --> 01:52:40.000
If everyone can give Rim a thumbs up or something, give us some information.

01:52:40.000 --> 01:52:48.000
Get a great job. this is not easy. work. it's not easy to do over zoom, and all of you make it look so easy, so well done to all of you.

01:52:48.000 --> 01:53:02.000
We have a just a couple quick updates next, we will obviously get all these notes back to you as we continue to draft our data exchange data, sharing agreement as well as the Pmps.

01:53:02.000 --> 01:53:08.000
And the next request for feedback is Tuesday, March 20, ninth.

01:53:08.000 --> 01:53:23.000
So you got 5 business days on the topics, the language discussed today, and if you can please give us feedback, we're happy to take that, and if you have any questions, let us know as well with that. if you can.

01:53:23.000 --> 01:53:33.000
Also if sorry, I decided I tried to raise my hand but I know you're You're on a roll, so I have to just jump in.

01:53:33.000 --> 01:53:37.000
You know you mentioned the challenge of doing this on Zoom.

01:53:37.000 --> 01:53:43.000
I think realistically, it might be even more challenging doing this in a hybrid mode.

01:53:43.000 --> 01:53:47.000
One of the nice things about zoom is that everybody's seen the chat having a chance to contribute to it.

01:53:47.000 --> 01:53:52.000
And I think what you got you know 2530 people in a room looking at each other.

01:53:52.000 --> 01:54:08.000
You know it's harder to participate in that way. So I just think we need to think ahead. You know, as we try to re-enter a new, a new hybrid world that that we maintain full participation hangs a really

01:54:08.000 --> 01:54:18.000
good point and it's funny i've thought about that with a couple of meetings that i'm involved in knowing that you know there's usually people that participate usually people that maybe aren't not that they don't have

01:54:18.000 --> 01:54:20.000
something to say. but you know we have more introverts.

01:54:20.000 --> 01:54:23.000
That that might be comfortable at a different vein.

01:54:23.000 --> 01:54:29.000
So how we can maybe take some of the things that we've done well and worked well together, because I agree with it.

01:54:29.000 --> 01:54:35.000
It's really multi-task. in our community and people are gonna be on their phones or or laptops, anyway, even at some in-person meetings.

01:54:35.000 --> 01:54:39.000
So if we have that chat maybe it's a way to keep people engaged as well.

01:54:39.000 --> 01:54:50.000
So if you have thoughts we'll look as well to to figure out how you know, I know that i've been a part of meetings where i'm not necessarily in the room and it's a little hard to follow as

01:54:50.000 --> 01:54:58.000
Well, so let's if you have suggestions that's great one is, how do we kind of keep the chat active and keep everyone in in that? in the hybrid?

01:54:58.000 --> 01:55:02.000
Model. there's others let me know and you know we're gonna go through our first meeting.

01:55:02.000 --> 01:55:10.000
We'll do our hybrid. and let us know what's working, and what's thought as well, and we'll kind of get our legs under us.

01:55:10.000 --> 01:55:15.000
So our next meeting April the 20 sixth, face to face, Hope you can make it.

01:55:15.000 --> 01:55:19.000
We need a majority to be able to hold this meeting so as soon as you can.

01:55:19.000 --> 01:55:29.000
Please get qua a yay or nay and then even if you're a maybe you're a no but a possible maybe let us know the distinction.

01:55:29.000 --> 01:55:36.000
So if we get down, and if you are a yes, please know that we're counting on you to be a Yes, So with that I just want to thank you all for your time.

01:55:36.000 --> 01:55:52.000
Give you 5 min back, and see you and i'm on take care for joining.