



**California Health & Human Services Agency
Center for Data Insights and Innovation
Data Exchange Framework Stakeholder Advisory Group
Data Sharing Agreement Subcommittee
Meeting 3 (January 18, 2022, 12:00PM – 2:30PM 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 3. 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 Joanne and I'll be in the background answering any technical questions.

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If you experience difficulties, please type your question into the q amp a excuse me and a producer will respond.

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During today's event. Live closed captioning will be available, please click on the CC button at the bottom of your zoom window to enable or disable Alice will now cover the meeting, because the patient options, LLC now before.

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Thanks Joanne. Next slide please.

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There are a few ways attendees may participate today.

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First participants may submit written comments and questions through the zoom q amp a box, all comments will be recorded and reviewed by subcommittee staff, participants may also submit comments and questions as well as requests to receive data exchange

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framework updates to cdi@chhs.ca.gov. Next slide please.

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A designated times spoken comment will be permitted participants and subcommittee members must raise their hand for zoom facilitators to unmute them to share comments, the chair will notify participants and members of the appropriate time to volunteer

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feedback.

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If you logged in via phone, only press star nine on your phone to raise your hand and listen for your phone number to be called if selected to share your comment, please ensure you're unmuted on your phone by pressing star six.

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If you logged in via zoom interface. Press raise hand and the reactions button on the screen. If selected to share your comment, you'll receive a request to unmute, please ensure you except for for speaking.

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Next slide.

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Public comment will be taken during the meeting at designated times and will be limited to the total amount of time allocated individuals will be called on in the order in which their hands were raised and will be given two minutes.

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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 amp a to ensure all feedback is captured or again you may email comments to cdi@chhs.ca.gov.

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But that I would like to introduce Johansson, chief data officer at California Health and Human Services.

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Hello, good afternoon everyone. Perfectly afternoon.

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We have a very busy agenda so I'm going to jump into welcome and roll call. I want to welcome all of you to the third meeting of our data, green data sharing agreement subcommittee, I'd like to welcome all members of the public.

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And thank you, Alice for all that work at the beginning of the meeting for keeping a straight. So it will begin with.

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Roll Call.

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If I, as I introduce you if you can please let us know that you're present. We're going to begin with Ashish a train as it went from the American physicians groups, William build up Barcelona present from Wayne, Jen Brent present.

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Welcome bill Barcelona present from Wayne, Jen Brent present. Thank you.

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Attorney Shelley Brown.

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Hi, good morning john here like your background. Morning. San Diego there was only real.

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Good afternoon. Thanks for joining. From the County Board of Directors Association, California, Louie Qatar was President.

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Thank you. From manifest FedEx, Elizabeth killings work as a Kaiser Permanente Helen Kim here

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from Health Net Patrick Hurley.

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Hey john Patrick here.

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Hey, Patrick from the California Department of Developmental Services carrying control present

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from Sutter Health.

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Medical Foundation Steven late afternoon. Okay. Planned Parenthood of California.

Lisa much Barbara.

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Hi everyone.

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Hello.

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Kevin look Are you there. Yes, I am.

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Excellent, from the San Francisco department.

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Oh, Eric Ruffin.

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Good afternoon.

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The California Department of Health Care Services, Oregon State's captain and everybody

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from common spirit, health, Ryan Stewart.

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Hello, good afternoon.

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Bo from Electronic Frontier Foundation, the team.

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I am here.

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Hello Lee from Los Angeles County of health services Belinda Waldman president.

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And from health care partners terrible come present

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client.

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Okay, well, that's. Thank you everyone will move on to our meeting objectives.

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Our vision for the data exchange in California, is that every California, and the health and human service providers and organizations that care for them will have timely and secure access to usable electronic information that is needed to address their

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health and social needs and enable the effective and equitable delivery of services to improve their lives and will be.

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And today we have three major meeting objectives, and we're going to go through that right now discuss the threshold questions pertaining to the development of the data exchange framework, data sharing agreement.

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We're going to introduce a draft outline of the data sharing agreement and discuss an initial set of topics and draft language.

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Before we go into the meeting, we're going to have time for public comment and kind of make you familiar with that, when we open it.

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We will.

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You can use the raise hand feature in zoom.

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As we discussed earlier, already, and you'll be called in the earlier that your hand was raised. If you can please state your name and organization affiliation.

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And if you could keep your comments brief and respectful, we appreciate that. I will now open public comment.

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Thank you. I will first call on David Ford.

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David You should now be able to unmute.

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So for anyone doesn't know me David part of the California Medical Association.

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I'm absolutely sure I will not be the only one to mention this this morning but with the release of the trust exchange framework and common agreement by the ONC this morning effect right as I'm saying this I see Dr.

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Lane have had the had the time to digest it yet, but it obviously will influence and can suggest some directions for the work of this committee so I just wanted to mention it.

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Thank you.

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Thank you for your comments, we currently don't have any other hands raised.

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So maybe I can just step in for folks really quickly and kind of springboard from that last comment. Thank you.

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Yes, we're all aware that the common agreement was published today, and unfortunately we haven't yet had an opportunity to analyze that. And the changes from the draft to this published one to look to see where we need to make some modifications to the

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language that you've all reviewed and that we're going to be looking at today.

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So, unfortunately we haven't had that opportunity yet, we will be, and also of course you know we need to have some fair transparency to the public, and make sure that we still have a conversation around those things that we've already published so we

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are absolutely excited to hear from you if you've had a chance to look at it, but please keep that in mind when we go through some of the draft language and some of the things that will review later john did you have something you wanted to say, I just

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want to thank you very much. Thanks Jennifer and turn it back to see if we have any additional public comment.

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We have no hands raised now

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back over to Jen.

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Every go.

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Thank you so much. Click ahead and go to slide 13.

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Excellent. So let's dive in a little bit into the specials questions can you go to the next slide please.

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So, in this section we're going to talk about a couple of threshold questions or issues around discussion with respect to individual or proxy access as well as social services organizations as business associates.

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So let's go ahead and go to the next slide, and we'll dive in just a little bit more into issue number one or question number one. So, as everyone probably knows there are requirements in the law for access for individuals to who are the subject of the

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information so part, you know, patients, access to their own information, as well as proxy access or patient representative access to information, so we wanted to open up and hear from you with respect to, to what extent, the data sharing agreement, shouldn't
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require participants are signatories to provide access to individuals and their proxies.
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Would it be limited to direct relationships, and remember some of this languages, coming from the draft Africa, so that direct relationship piece came from, from that.
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And then, and if that is the case if we do want direct relationship.
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What is the direct relationship mean what does that look like. And then, in addition, should this requirement for access include social services organizations, or non-health provider organizations that are dealing with personally identifiable information.
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So I see that we have a raised hand already so let's see,
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I believe, was it
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looks like Devin you have one, go ahead.
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Okay, sure. So this is one where I think it'll be interesting to see the approach that they are taking in the tough cup, it's, Again I with you all I haven't read through all the documents, but I did have the time to sit through a couple of the webinars
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this morning so they have initially declared individual access and treatment to be the two priority use cases that will be sort of the initial use cases of the tough guy when they sort of get it into operation.
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At the end of this, by the end of this year, and they do use that concept of a direct relationship and essentially it doesn't necessarily mean that you're treating somebody as a patient but it could but it, but it does suggest someone who has sort of,
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whether it's a vendor relationship through an app, or a physician through, you know as a, as that, as that patient that there is some way that the individual that there's some connection to the individuals so that there's an ability
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to ID proof them to be able to get their consent, there's a lot that's in the tough crowd around individuals consent to query the network. The other thing that's interesting about the ticket is that it says that query has to be honored, but not every
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entity that is connected into the network has to be the one to provide that onboarding.
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So for example, if you have sort of a health care provider who says, I'll do it for my patients, I will query the network and get their data from wherever it, it's been, they've chosen to provide that service but they don't have to, but if they get pinged

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and requested for the information on behalf of an individual from someone else who's connected to that individual or an app act acting on the individual, then they have to respond to that so if that's helpful.

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I think it's interesting that they have established that mechanism and I'll also say that while patient access isn't necessarily delineated and at 133, it is absolutely, it's part of our mission.

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It's part of the mission statement in terms of access by California.

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Thanks.

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Absolutely.

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Does anybody else have something they want to weigh in here and it looks like Stephen.

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Yeah, I would just say that i think you know we all need to do our homework, but to review what is included in tough and determine whether we intend to point to that as a floor or not.

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Of course tough game itself, it remains voluntary for the time being. And, you know, but but clearly it. It points in the direction that we're going as a country.

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So, I just think we need to determine how we intend to manifest this, we certainly don't want to be and I would say that we don't want to be in conflict Stefka in any way.

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In our California agreements, because otherwise we'll just have to unwind those conflicts in the future.

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But whether we want to aspire to, to include somewhere all of the tough guy standards and requirements or referenda or reference them i think is something that we really need to address.

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Thank you, Patrick.

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Hey, Jennifer. Hey, can you give some insight on, and where you're thinking to the group is thinking about granting access to individual sub, as it as a regional slide to two things come at me and just wonder if you could explain it.

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One is, would there be like I represent a health plan with the health plan have a portal where members can go and look and get their information or providers office stood, or is there thinking maybe a centralized statewide organization where members could

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go and patients and individuals could go in and do their, their look ups and see their medical record based upon the entire network. So, do you have any, any ways you want to lead us to think where you're going and where we should be following you.

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That's an excellent question. So what is access.

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And what does it mean to get access right. And as you as you see this as a bit in a vacuum. And that's intentional, because we, we didn't want to box folks into preconceived ideas, since we have a lot of opportunity here to think about what works, what

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doesn't work what is missing and all of that. So, the way that I'm thinking of it. At this moment, and that's why I'm very interested in hearing from you is, in essence, I'm an actress by an individual or their process or their process proxy or

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their representative into some kind of system is a possibility, as well as asking for information based on written consent is another possibility so I'm wanting this information I have an authorization.

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I'm not the individual or their proxy but I do have written consent to have that information. So, what does it mean to you. And what do you see, we need should, and there isn't a thought yet, Patrick to answer your question a little bit more

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with more specificity around creation of one, you know, repository for example that's not something that I've heard any conversation about.

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But I think the goal here is to set up some parameters around what is required in terms of access by individuals and their representatives.

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And what's out there so we don't inadvertently limit something that is working really well.

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But we give a broad opportunities for more access greater access to individuals and their representatives, if that makes any sense.

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I recognize that that's pretty vague and in some ways it's in its intention is to be somewhat back to hear from you what what that looks like. So I see we have some hands Lisa, would you like to go next.

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Sure. Thank you, Lisa mots Barra for Planned Parenthood Affiliates of California. I think we're we're talking about this obviously agree with everyone on, you know, making sure that it's consistent and obviously simpler is better but I do you want to

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just as we're developing this really think about patient privacy, especially when it comes to proxies and how we separate out certain kinds of medical information that you may have a patient representative, that doesn't have access to certain kinds of

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information and then also confidentiality concerns about sort of sensitive services including mental health and for us, sexual reproductive health that have sort of additional confidentiality issues and how do we make sure that there isn't inadvertent

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disclosures of that information through the exchange on those kinds of disclosures can actually be really harmful for patients.

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So just wanted to kind of put a flag on as we're developing this to make sure that there are some really clear parameters to prevent inadvertent disclosures, and you bring up an excellent point.

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Because you might have a patient representative making decisions for you for some things, but not for everything. There are a lot of instances in California law, in particular, where a minor has a right to make the healthcare decision on their own behalf

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for certain kinds of treatments, but not everything. And so I think what I'm hearing from you is that we need to be cognizant of those differences and make sure that we don't impact that and make sure that that information isn't inadvertently being released

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to an inappropriate proxy. Did I hear you correctly. Exactly, yeah I mean just, you know, a person's medical record is the record by, you know, even as a provider of, you know, we, we provide obviously sexual reproductive health care services and, as

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you said minors can consent to it without their parent or guardian who's technically their patient representative. And, you know, if the record is loaded up in full.

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We want to make sure the minor has access to their records, but their patient representative may or may not need, you know, may or may not have access to that particular information so just making sure that those sort of safeguards follow the information

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when it goes into the exchange.

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Thank you.

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Lee, did you have a comment. Well, yes I did thank you on and Lisa covered, really the first half of what I was going to say which is that there are so many really sensitive bits of this, and the granularity of authorization and clarity about who's

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really authorizing this is this is incredibly important especially given how how data about women's exercise of their reproductive rights is going to continue to become incredibly.
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Since I expect Supreme Court to overrule Roe vs. Wade i think that that we are looking at a situation whether it's a great deal of actual, real concern about the data about women in California, or women who receive abortions in California and being having
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their information exposed to the wrong people in other states who might bring actions either against patient or providers.

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For some reason so that that was Lisa's point she, she hit it hard. The other thing that I would say, wanted to mention is that this idea of proxy access to, to general personal information that is private is something that, you know, we've seen, we see

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in the, in the Zeitgeist of current privacy laws because GDPR has the strong provision for allowing subject access rights to be exercised on behalf of the data subject by some other organization that you know we've had experienced little bit of experience

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that in California with the CCP am CPR a because both of those also authorize consumers to have their privacy rights exercise, through a through a proxy.

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And so that has led to a lot of questions about what's the right balance of authentication against the needs to be able to provide consumers with access to their to their information and knowing that patients cannot be, you know, do not have the time

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to be their own you know sort of privacy manner. So, I think, I think that this is a typical implementation issue to get right now, we have to be really, really careful about how we do it.

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It is clearly as Devin said earlier part of our mission to get this information out to people, but only to the right people and the right information so it's that emphasis on precision and not over sharing though I think we have to really sort

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of go into this with very, very very open eyes. Thanks.

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Thank you. Lee.

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And then, Stephen.

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Thank you. I'll just echo some of those comments I think, you know, individual access is really important.

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We're dealing with this nationally we should definitely address it at the state level.

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It is also really hard because the technical infrastructure and standards don't really exist as a provider who cares for a lot of adolescence, I can tell you that there is good data showing that adolescents, often provide their login and password to their

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parents. And even though it looks like you're providing access to information only to the adolescent that you're not really doing that effectively or limiting that effectively so I think that we should keep in mind what our goals are, with regard to individual

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access, but not hold ourselves in debt don't expect this to be perfect. At this point, I put a number of links in the chat about the national effort that's going on to try to define technology standards to better control granular privacy.

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That will be needed to, to support this. But the timeline for this goes out a number of years to get this work done. So again I think perfect would be the enemy of good here.

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And we need to keep that in mind.

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Thank you. And I think some folks in the chat have commented on this as well that we do need to take a look at the common agreement and see what that says around this issue.

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We are kind of doing this.

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In the absence of having done that analysis but I think it's also kind of important for us to hear what all the thoughts are around this topic, without necessarily being limited by what might be in the common agreement, but with the understanding that

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it needs to be consistent with and not in conflict with the common agreement as well.

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I just want to make sure that we've hit all of the hands.

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There's some conversation, Elizabeth Am I correct in saying that you are thinking about how this would be a good topic to have at a later time after some other kinds of elements have already been discussed is that correct,

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Let's see.

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yes like I want us to understand what a consent framework would look like before we try to build out something that relies on a content framework that we don't have, if I just don't think that you can have this analysis, until that is already built.

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So individuals proxies that's one thing, but beyond that the expansion is more concerning to me because we really don't have a process that this entire group would be following that is consistent clearly implemented and obviously functional and until

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we have that in place.

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This makes me very nervous, and there's a lot of ways for it to go wrong.

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So, let me ask you this, so obviously this group hasn't had a chance to talk about policies and procedures yet.

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And we're sort of in conjunction with the advisory group kind of building something within the timeframe that we have set in the statute simultaneously.

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So my question would be, if this piece was to be carefully narrowed would some comfort be there to having it. Have some narrowing to it but still have some requirement around the ability for individuals to access their own information, and then have some

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conversation later in the future around policies and procedures, or would that be still that not provide comfort. No, I think that the requirement for individual access is correct should be discussed at this time should be part of this process up front

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what I'm concerned about is the expansion beyond the individuals and proxies to other consent options, and that's that's that's the discussion question rage can we take this beyond somebody, and that's where I kind of had a very physical reaction.

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I do not think that that is something we are capable of managing at this time. I absolutely believe that having individuals as kind of a baseline is appropriate right now.

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So just to flush that out make sure that I'm clear you also think with respect to the proxy. Don't folks with power of attorney conservators.

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You know guardians, you know, folks who have the legal right to make health care decisions would be part of that as well. So let me ask you, kind of push question then what about executives or administrators, if the patient is deceased, what are your

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feelings about that.

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I think that everything that deals with a deceased human being is incredibly complicated.

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Is the short version legal perspective, no i i don't have an interview right now I think that, in theory it sounds good, but in practice, again an executor if they are appointed by the court, like if it is something that is managed in the court documents

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then I'm okay with it but where we draw that line is a little bit complicated would I be comfortable with somebody who is appointed by the will, on the day after the decedent past coming in and getting the information that's a little bit harder so where

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do you draw the line, what is sufficient paperwork for them to have the right to reach into your medical records it's it's hard.

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That's for absolutely it is.

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So Morgan, you had some comments.

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Yeah, thanks. Jen, I think.

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Charlie Brown called this out in the chat earlier that that repository that has all this information.

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Couldn't lawfully withhold it from the, from the individuals to film it pertains.

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That seems like that seems like a given.

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And a scale and diverse it carries with it. All of the complexities of proxies, that it just doesn't seem optional, even about about the expansion that Elizabeth spoke to a moment ago I think this, it does.

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We are talking about a very complex system I'm reminded of the flow charts that sometimes come with with big technology projects where you could get a page of blocks of things, and every block is connected to every other block.

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In, in some fashion. And this is, this is kind of like that it's that complex especially if we, if we

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where we get to try and to expand it outside of, you know, outside of traditional healthcare. Where, where there's perhaps, nothing that that could be shared without consent is you have to have, you know, a system that will accomplish this even in existing

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in health care now it's going to have to have a fairly very sophisticated consent registry, what things has the individual consented to be shared with them, and what things not, but its own.

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And, and all that, the prospects for not having in that we need that in health in traditional healthcare side. And, and plainly will also needed if we want to expand into, you know the social determinants of their social services because those are not

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there isn't anything there that's, that's going to be readily amenable to the, to the, the, the channels that are available in traditional healthcare where something some information can be shared without consent.

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So a really highly sophisticated consent registry is a necessary component, and you need that to manage the proxies anyway.

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And that makes a lot of sense. So let's talk about the expanded then Morgan. Are you suggesting and I'm only trying to get clarification I'm not trying to put words in your mouth.

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Are you suggesting that the inclusion of the social services organizations piece should wait until we have more understanding and more work done on this particular content management piece, or are you saying that the potential solution would be sort

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of that.

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Carefully built repository with, you know, an algorithm or some way of making sure that validating, who is who they say they are, can you help expand on that.

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Yeah, I'll try I guess I'll say I'm, I'm, I'm eager for us to go down that path, you know, my department and much of healthcare is, is increasingly eager to, to, to look at social determinants of health and you have to take a much more holistic view.

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we have in the past him, and will need.

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You will need this kind of data exchange in order to really do that to deliver on that.

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So, so I say I'm a middle and about whether we have to do it now or, you know, or statutory charged only requires us to think about it.

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If I recall correctly.

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But I think it would be a mistake to, to, to contemplate building or describe what needs to be built without having it in mind.

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Because, because like we can anticipate that, that there are components that are going to be needed, and we should, you know we should we should anticipate those so that it's not difficult to add them on.

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If we don't do it early on.

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Thank you, Morgan Lee you had a comment.

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Yeah, that's right. I just wanted to, I, you know, first of all, I agree with the thrust of the discussion that it's incredibly is an incredibly difficult thing and that we want to get it right, more.

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I believe that we want to have to get it right first before we get sloppy.

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But the other thing I wanted to mention was people are referred to.

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Two more to the outside of medical sort of treatment of dead person's say communications or records and whatever I just wanted to point out that that is not well settled.

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As a matter of general sort of law in the United States. I mean, I worked on decisions assets to access to digital assets bills in in California I've looked at a bunch of, you know, the modern, the there was a model law that some states have pushed.

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But there are a lot of controversies over how that stuff is going to work especially when there are communications that are electronic communications and qualify as such under the Electronic Communications Privacy Act because then you have, you know,

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you have another federal law that can intersect with the way that things are treated and so we have had, I think, you know, people may recall that there have been issues with say persons who own email accounts, and died, and their parents tried to claim

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access to those accounts, essentially, but there were familial parental estrangement issues they because the, the son or the daughter was gay and they had a family break and you know so parents would deny access to the you know to the partner of

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the person etc and there were a lot of really difficult and complex generational and relational kinds of issues that came up around access to decisions records, even in a non sort of medical context so I don't want bulls to, to think that this has

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been solved well outside of this context it's, it's messy everywhere things.

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So let's spend, ask that next important follow up question. So we're talking about kind of a requirement for access right so do we really need to then require that access be provided for sort of the, let's call them representatives for a deceased person,

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or do we want to maybe move that out. And there are other ways of getting access to this information right so it's not necessary that this agreement say, you have to do it this way.

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There are other ways a person who has a right to obtain information can get that information. We're trying to essentially, in many ways, remind folks that the patient comes first and their access is absolutely part of, you know, being part of this partnership

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between a health care provider and an individual for their health, but also to help them make decisions around their, their health. and because you know people no longer own their records the health provider has sort of stewardship of that.

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So, let me ask let me throw that out there, and then definite looks like you have a comment.

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Sorry I was on mute. Um, I like. Sometimes I think about sort of, to what extent does all of the mechanisms for access of data today need to be ones that we want to be part of the network, as opposed to, you know, certainly the behavior of a healthcare

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providers and others, social service agencies in terms of how they deal with individual requests that are not necessarily coming through a network.

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And the other hand I might have too much tough call on the brain.

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You know, it's, this is a data sharing agreement and what we're trying to do is get entities to agree to share data for certain things, and the reason for the provisions around access to medical records by proxies which includes a legal, you know someone

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who has the legal right to information after death are for oftentimes very personal use cases around building familial history around investigating whether the care that was provided to the person, prior to their death was good care.

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I mean there are sort of a range of purposes I know we do a lot of work with people who have hereditary conditions where there is a desire on the part of the family member to also sort of pay it forward with the data, even though the patient might be

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deceased in terms of, you know, sort of continuing to contribute that data for research purposes for example again research not being one of them are prioritized use cases but when you put the, the information in the hands of, it's oftentimes family members

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who end up having by law the legal right to access this data, it can be very empowering for them. So, you know, given that we're depending on what we're creating here.

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I would hate to see us.

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Not wreck at least recognize that the law provides a pathway for access that is considered to be individual access, even when the person is deceased through legal proxies.

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Thank you.

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So, um, I think that, you know, this particular issue will come up again. And so we'll have more opportunity to have a conversation around this and where it fits in the DSA and to what extent we should be detailed about it, versus more high level in general.

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So why don't we do this unless I hear folks want to raise the hands I'm going to go on to the next threshold question.

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I'm going to give it just one moment.

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Eric, go ahead.

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Yeah, I, I put it in the chat a little earlier, but I think

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wasn't a question was a comment. But I think it's going to be really challenging for us to, to opine on this without actually seeing the full slate of programs that we might be considering for to be required.

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Having worked in a couple of counties now I can tell you that things like the public administrator and Public Guardian programs, just some of the things we're talking about here and there extent, but also many of the social services programs have very

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antiquated information sharing rules because the rules were probably written before there were a lot of very prominent information systems that help them get their jobs done.

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So I think if we want to review this question about proxy access and how individuals would gain access, I think it might be helpful to see like a catalog of what we know, especially within California, because if there's one thing that is happening with

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programs, coming out through medical like Kaleem, it is the joining or the bringing together of social services, and medical information that is a cornerstone of how those programs are designed to work, so I'm hoping that we can find ways to, to look

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really holistically.

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And when you say catalog of what we know.

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What are you, what can you define that a little bit, is that nerd so it's if you wanted to stay in the California example, we have a list of social services programs, they typically have governing statutes that may or may not address access

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proxy access etc. And I think it would be helpful to, like, look at a grid of how complex those different relationships might be, and they may answer some of our questions, but it also might point out where things might be really hard, and where maybe

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the reach of some of those items might be beyond what a data exchange agreement would look like in this case, I don't know, thank you john, you had something you wanted to say to.

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Yeah, I think that I'm having some sort of Compendium or catalog like was just discussed would be great and useful but I also would suggest that we not try to boil the ocean on this, we do have a very strong, you know, restricted timeline.

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And I would not want to go down a rabbit hole with all the edge cases, while forsaking the bulk of what we're trying to do here and so I, you know, while I do think it is worthwhile to set some boundaries on these edge cases.

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We do need to also make sure that we get through this because our timeline is somewhat restricted.

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Absolutely.

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Thank you.

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Okay, so give me one more second and then we're going to move on to issue number two.

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Caring nothing. Can we now go to the next slide please.

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And if I'm missing something in the chat, please don't hesitate to raise your hand and let me know I'm trying to capture everything and that doesn't always work out.

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So, issue number two. So, um, we've had a lot of input about this particular issue.

There's a little bit of a challenge behind organizations that do not actually meet the definition of a business associate, and do not have the ability to comply with a

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business associate agreement or a written agreement that is passing required terms from HIPAA and don't want to become business associates and yet there's also a need for the entities that have the bulk of the liability.

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When they release information such as healthcare providers to have some confidence in the fact that when they release information to a social service organization.

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There, there is an accepted reason for it, and that the that liability won't come back on them. When you know they have shared information. So there's a tension a little bit of attention here.

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So I think the the issue around this and definitely, I'll call on you in just a moment so no worries, is how do we ensure that organizations who are not business associates and don't want to be are not labeled as or given the status of a business associate,

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but also ensuring that confidence and comfort from entities that are provider entities or plant entities or whatever entities that hold the biggest challenge of the potential liability for sharing information if that sharing ends up being inappropriate.

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So Devon.

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Yeah, I was just going to say, um, you know a lot of entities that received that legitimately received health information due to sharing are not business associate so this isn't limited to social service agencies and in fact I've seen a lot of circumstances

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where you have enemies that won't share any information under any circumstances without a business associate agreement. And yet the business associate agreement is really only warranted if there's a contractual relationship that's in place so you're,

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you're spot on Jennifer that social services organizations are not going to be business associates but this is going to be true of a lot of entities that might receive data from any of the, of the data shares that are going to be sharing that are going

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to be signing on to this agreement we, I think we don't want to have a situation where you, you, you, you know, you need a business associate agreement with every person that you share with I think that would absolutely be contractually a nightmare.

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In addition to raising all sorts of issues. Having said that one of the approaches that is used by a lot of these national network agreements, is, is a sort of expectation around compliance with certain baseline privacy and security protections that are

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similar to those found in, you know, whether it's HIPAA, whether it's, you know, other, whether it's California law, you might not be covered by those laws but if you, but we have an expectation that you will adopt certain practices and then that's you,

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you are held essentially accountable for doing that as a condition of signing the agreement now how detailed those go i think is a really open question but that is the way networks have sort of handled this issue around the data might be going to somebody

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who isn't you know covered by a legal, you know some law that requires them to adopt certain safeguards. Thank you. And that's a really good point because some of this is to encourage social services organizations to sign on.

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And there may be a real challenge for very small organizations or community based organizations to have that infrastructure that is consistent with for example a HIPAA compliance framework.

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So, what are your thoughts Devon around that sort of balance between saying you will sign up for a baseline framework, while also trying to encourage organizations to join.

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Yeah, I think I think it's the same sort of give to get kind of dynamic, where if you have an interest in receiving information and and at you you you make those commitments to protect that information and you make that commitment to also share and kind

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it's it's the, the essence of what makes this whole enterprise and attractive one I mean we're, I guess we're fortunate or unfortunate depending on how you look at it to have a sort of legal requirement for certain entities in the state to sign this agreement

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right but but at the end of the day what you want to create is something that people actually not just feel forced to sign but actually want to sign because they they gain from receiving information that they that was hard for them to get before, but

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they also, but in return. We asked them to make certain commitments around protecting it and then also make certain commitments around sharing.

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Thank you.

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and then leave. Did you have a comment.

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Yeah, I did. And that's mainly that I'm always concerned in these sorts of situations when we're talking about folks who are not going to be subject to

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legal slash contractual binding this have a, status.

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What is, I realized that I do not understand what the lab, what the baseline liability framework for this is right i mean because at the end of the day, to say that that somebody is out of compliance with with HIPAA right since there's no private right

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of action under HIPAA patients or maybe you know a patient or an organization that represents a patient that finds that some signatory or some entity within this system has, has this has epically failed in in some way with respect to privacy or security.

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I would expect that somebody would be able to sue them hold them liable but I don't actually have a good understanding right now of.

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Where does what's the, where's the point, what's the point of the sharp end of the stick here that ensures that if somebody screws up that they're going to get more than a just a slap on the wrist that there's actually going to be opportunity for judicial

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redress and remedies and things, I don't have a good that's more of a question than anything else I don't really have a good understanding of how we contemplate all of the commitments in this data sharing agreement which is primarily among government

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and other participants, how that provides assurance to individual patients in the or paid groups of patients in who are actually, whose data is the one that's actually being thrown around.

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So, what I'm curious about. Yeah, that's, that's a really fair question. And so, the I'm what I'm hearing you ask Lee is where's the oversight, what is the oversight, what does that mean, And, you know, how does that.

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How does that relate to the patients, so there's oversight that, you know, it allows for a government entity to come in and do that sort of review and assessment and potentially sanctions but is there a place here for individuals as well, because they

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don't have that does not give a private right of action. But in my thoughts around this, we will be talking about oversight.

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We sort of, we have that challenge of trying to create this data sharing agreement at the same time, but the advisory group is creating the framework in the structure.

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So part of governance in my mind is sort of oversight. How do we know that folks are doing what they're saying they're going to do or promising they're going to do and they're doing it right.

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And everything is copasetic. And so, I'm, this is going to sound a little cheap but I'm going to ask that we maybe put a pin in some of the governance talk only so that we can see where the advisory group comes and then we can look at that and weigh in

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on that.

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I'm not saying we don't bring it up because I think it's really critical for us to talk through this is where that piece would be. And so, but I'm also going to say, let's, let's put a pin in it, where it will have time to also talk about that.

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And we know it's coming up, and unfortunately we're talking about some of this without having that that context, but it is coming. I'm happy to let that slide, if I can just make one more little detail point.

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And that is and this is one that we will, I think, get to. In the next section but it's, but this is part of why I wonder in the first place about the overall framework because I look at the draft language, and it talks about breach, and the big question

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for me as a litigator or as a former litigator it's always well who decides, like, whether or not the acquisition was in good faith, or for the purposes or whatever.

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Those go to the definition of a breach. But if they are decided by the participants, or whatever, then how, and it turns out that they were wrong or, it wasn't in fact good faith, you've got.

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How does anyone outside of that participant even know what the basis was for determining whether an X was in fact a breach that fit this definition or not.

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I mean just in the ordinary case of, of, you know, wanting to litigate something, one has to do discovery to get into that and yet.

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No, I think, I think there are some really interesting. From a from a perspective of someone who used to be a litigator timing and sort of back and forth questions about what's an affirmative defense what's in the prime of facia case etc etc in terms

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of thinking about all this. What kind of audit trail, do they have to keep maybe we keep that rule on the definition of the breach but they are required to memorialize there every decision.

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Every time that something was a potential breach. Why wasn't it, and that's discoverable if there's some if there's later litigation. I just, I just look at this I see so many ways in which a participant could hide and escape from any kind of governance

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so that's just not allowable. Thanks.

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Absolutely. So, you raise a really good point, which is that we are going to sort of talk a little bit about the definition of breach, and privacy and security later in this meeting, and so some of what I would ask folks to recognize is that there will

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be some additional information, and we'll get through in a moment to talk a little bit about the outline of the different elements of the agreement, and that some of it will be in technical specifications policies and procedures or some kind of attachment

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around confidential, you know information and security of information.

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So, but at the same time, I'm hearing you very clearly the with respect to adding comments around with that oversight and what that to governance looks like.

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So, some folks have it hands on what I'm hearing you say or suggest is there's a potential here for this, a group to make that decision or at least, if not, then a requirement that you know all of this be documented and a documentation be kept for a limited

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amount of time and available in case of an audit or some governance kind of responsibilities did I capture that. Yeah, I am that's just one idea I mean the general point is you have to have guardrails you have an audit trail so that people can review

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what decisions were being why decisions were made the way they were to the extent physicians are easily visible to the rest of especially to the patient.

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Well, thanks. Thank you.

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And then I want to say Jen was first.

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Oh, I'm sorry, this may have been overtaken by the last part of the conversation that I was just going to recommend that we decouple if we're trying to think about how do we ensure security with organizations that are not classically governed by HIPAA

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than that we decouple the thought of security requirements or standards, from social service and community based organizations from a BA, because the BA really wallet includes those safeguards and that language, it's really about establishing governance

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of HIPAA, and so we could decouple those two aspects and talk about whether the social and community organizations should be part of the governed by HIPAA,

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and then also differently, how do we ensure privacy and security controls are in place with those organizations.

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So let me ask you this. Were you envisioning that piece to be sort of outlined a little bit more closely in the privacy and security kind of portions, or details what social services organizations would need to adhere to in terms of security or Privacy

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rules. Yeah, so I mean what I've done in the past, with these types of occasions, is have very clearly delineated security and privacy exhibits or data standard exhibits that walk through the controls.

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You know I love a good risk assessment so there's no harm also in asking an organization to participate in a risk assessment to ensure that they can achieve those standards, and then also having an exhibit, or an agenda, as part of a data exchange Participation

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Agreement or contract that then delineates their contractual obligation to comply with those controls, and that can all be done outside of a BA, but it can have the same level of assurance of standards.

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without putting those organizations within scope and PIPA.

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Thank you.

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And then Morgan.

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I'll be brief, I'm not sure if they think others may have may really have covered this but certainly, I think we should recognize that individuals are protected by keeping their debt but protect the data within the HIPAA umbrella.

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But clearly, so there's a pointed out some of the some of the, of the entities that we want to engage are not going to be appropriate for business associates that coming from come from the department who historically wants everyone to be our business

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associate.

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I've tried to unwind that some, but it comes back to and I and Glynis call this out in the, in the chat already to Mr. This comes back to, to that sophisticated management of consent from the individual that the only point, the real point of having a

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business associate agreement terms of data movement.

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There are many other factors of course for data movement.

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It lets you move data more readily without patient consent.

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10. And so, if everybody's not going to be our business so shooting everybody shouldn't be our business associate.

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Then we need them. We need good content management's.

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And then thank you working and then Lewis.

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All right, thank you I you know I was thinking about the three things that the consent.

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The agreement and then my security and, and I do recognize obviously that not everybody's going to fall under a BA. And I think that consent registry discussion earlier does play into this, and nobody wants to boil the ocean, but we already have a lot

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of need for social service data in healthcare and vice versa. For the you know the overall whole person care of an individual. So, if, If we end most of these

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programs are already co governed by some type of regulatory process privacy, security, even data exchange in the case of like the child welfare system.

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There's a whole, you know, CFR and citations covering privacy and in data exchange.

So, so for me, if we, if we're not going to this just my thought if we're not going to, you know, have a social services ba which would be incredibly complicated than

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Then I think we need to look at this business case by business case was applicable by there already is the governing regulations they already have and merge that into some kind of consent process, you know, so there's a registry of some type of so folks

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can be assured that that that that is the you know, as a person or entity that needs to is authorized to get that data and, and that.

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And each one of those scenarios, and they're very large or they're very small depending on the entity in the counties and they have some liabilities as well you know they do releases of information required to redact so there is liability there that thing

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you can do to reduce.

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Thank you.

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Thank you. So I've, I've heard some suggestion about a consent registry. And that's a fair possible solution. And also, I guess my question would be, then what about those disclosures that are legitimately exceptions in the law, where you don't need disclosure,

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you don't need express consent.

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So, what do we do with that, where social service organization does not need Express written consent for example, does need the information to perform a service or to do you know their appropriate legitimate work, and is not a business associate so I

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want to I want to push a little bit on that. And it looks like Carrie, you have something you'd like to add.

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Well, I was just going to go back to that idea on that topic about the looking at the program for that sort of solution is looking at the actual programs within social services, and perhaps I hate to segregate this and make this messy but, and you know

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for certain things like

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items that are touching waiver funding through Medicaid, which I don't I'm not an expert and social services on what those would be but for example like our community based organizations through Developmental Services.

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Are you know that that pretty much 40% of that comes from Medicaid through the waiver funding, and we were acquire our community based organizations, through the regional centers should be business associates.

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And so is there.

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Can we do a reef, look at the program level over whether you know maybe some of this should be grandfather under HIPAA for those types of uses, because I'm not so certain that you know yeah Social Services has community based organizations into the licensing

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licensing for them but you know I think we should do a relook to make sure that should they be business associates, I mean, there are some community based organizations that are huge like I'm thinking mentor and core and at Cole, Oregon and just some

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of these humongous private corporations, believe it or not, our San Diego that are spread out, you know all over the place. And yes, there's, there's individual ones but there's also individual health care providers.

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So if you look at it from that perspective and maybe you can connect for your operational type purposes for programs that have to be HIPAA covered. You know, it's an idea

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I'm to do a relook on those grants for those particular programs, things, and just so I'm clear, Carrie Are you saying that the look should be about organizations who have already been put into the business associate bucket and maybe looking to see should

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they belong there. Or are you saying that some of these social services organizations, because of the information they're getting and using and, and the services they're providing should be maybe considered business associates, what can you clarify a

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little bit. The second one that you just said.

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Okay, thank you. and then definitely.

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Actually I was glad. Glad to hear curious clarification because this was starting to sound like.

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I mean, there's rampant use of business associate agreements in health care where they are not needed. And I would hate to see us either reinforcing that through how we structured this agreement or causing entities to sort of aim in that direction

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when really what we ought to have is again a situation where if you are legally authorized to share data for one of the purposes for which you are required under this Agreement to share data, you meet those requirements, with respect to data sharing

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and that's your accountability and you, and you do it in the way specified in the agreement or, you know, including any additional privacy and security safeguards that we want to build in, in addition to compliance with law that's one of the advantages

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to a federated network right is that they're still there. We're not trying to centralize all of this, we're still kept you know we're still dependent to some degree on some decision making that's happening at the local level where the data sets.

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We certainly should try not to

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put business associate agreements, as an additional sort of criteria in the mix where they're not needed.

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please.

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It's just, it's just a lot of unnecessary work I think makes this more complicated than it needs to be.

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Thank you. So, I didn't open it up one more moment and then I'm going to switch now to the next portion of our sort of discussion so I'll give it just one more seconds and make sure that folks are good to move on.

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Okay. Hearing nothing.

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Why don't we go ahead and sort of give you a little bit of context around the topic so let me throw in my caveat, my required caveat. These are all draft topics and things are going to switch things are going to be deleted things are going to be added.

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So the goal here is to really help you get sort of a higher level context of vision of what it should or might look like. Or, you know where it's going.

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And again, as I said, these are all drafts so if we can go to the next piece.

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The next slide for me.

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Thank you. So, as you can kind of see here, we've parceled this donors or three sort of kinds of components.

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This is kind of what we have at this moment this is, again, it's draft. It gives you sort of a high level view though, of what it might look like. So that could be carried with you and kind of looking at these individual pieces because it's very difficult

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to understand how everything fits together. If you don't know what the actual thing looks like so, where we are trying to do here is give you some you know vision of what it might look like again, it's subject to change.

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So, the blue section are sort of that intro piece it's that typical beginning portion of a legal agreement, who was involved.

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The background for the agreement and sort of the definitions around what things mean.

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The second piece the orange piece is the sort of core components that's the meat and potatoes of the agreements. And here we're going to talk a little bit about technology agnostic, the you receive that language so you can get it get a sense of what that

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is.

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The special compliance provisions and a pic ability of public ability of HIPAA will be coming later. Today's discussion was to help inform that.

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And so you'll be seeing some of that in the future, potentially next time. Governance again that's that placeholder for what is, what is the governance, what does that look like that's a huge topic.

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And so, I just put it all under the word governance, for now, cooperation and non-discrimination that's exactly what you would anticipate which is that we agree that we are going to cooperate and that we're not going to discriminate against competitors

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in essence requirement to respond. We're going to look at that in a few minutes and talk a lot more about what that looks like and what should be their information blocking that is to acknowledge the prohibition on information blocking.

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And that is a placeholder for now, so we'll see that in a little bit. In, you know meetings to come expectations of participants that's intended to be a general sort of, what are the general expectations around what participants should do.

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That's a placeholder. We've heard a lot of conversation around what that might look like. And so, at this moment it's really trying to flesh out this so that we could, I could write some of that so we can take a look at that legal requirements kind of

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the same thing it's the, you know, sort of the the shells and shall knots piece that you would find in most legal agreements with data sharing and so that's a placeholder for now uses and disclosures, that's different from requirement to respond and said

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it's what to do in the future, can you use the input, what can you do with the information that you legitimately obtains, and what can't you do with it.

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And, for example, can you identify it.

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What about future users, what does that look like so that's a new shoes and disclosures privacy and security we're going to talk a little bit about today, that won't be the end of our conversation around privacy and security.

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Because, as you can see on the agenda portion there are pieces that we'll have more conversation around that their minimum necessary again that's a placeholder for conversations around what minimum information should be sent to fulfill the request and
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to achieve the purpose of the request data quality. That's a another question mark piece do we, what does that look like we'll probably have more conversations around do we need this, who's responsible for it.

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What does it look like in the future.

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authorizations if we have time today we'll talk some more about authorizations, and that's some of that draft language you saw individual access services, today's conversation that threshold question about individual and proxy access that will flow into
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this piece of course looking at the new published common agreement will also inform that, but that gives you a sense of what individual Access Services is terms of function and termination, that's what happens if something, there's a material, you know

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breach or what happens if I, you know, need to suspend or what happens if we want to suspend an organization's access to information, and how what does that look like.

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And is that needed. We'll have more conversation about that later compliance and penalties this gets into the idea of that governance piece. This is the placeholder to talk about what happens is we have an organization that is non-compliant and, you know,

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what do we do about that. So, the compliance and penalties piece is a placeholder for that discussion dispute resolution, clearly that's what happens if we have one or, sorry two or more organizations that have a dispute.

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What does that look like how much should be there versus how much should be in an attachment. That's a future conversation representations and warranties here's your typical.

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We don't, you can have access to the information but there is no guarantee that the information will you know serve the purpose for which you want it, things like that those general legal ease pieces of that belong in a contract.

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That's what that is. General provisions again that's more of that legal piece of the agreement, no third party beneficiaries a copy is as good as the original California level, take governance over other kinds of laws, that sort of thing that's in 22.

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And then the last piece are what's attached to the agreement we're more of the detail is, we kind of talked a few meetings before around the structure of what this would look like.

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and we talked a little bit about how some of this will be high level in the core components, but more information more detail will be put into other pieces and that one of them would be potentially policies and procedures or technical specifications,

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or whatever other kinds of piece onboarding implementation guide whatever that looks like. These are placeholders for what we will sort of flesh out in the future, and and when I say we, I mean this whole entire process not necessarily this subcommittee.

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So, that gives you a sense of what this looks like. Does anybody have a comment or question on the list of topics.

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Stephen.

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Yeah. One thing that strikes me about this is how comprehensive and large it is.

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We've talked in this group about, you know, whether we wanted to boil the ocean.

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The level of the state agreement, or whether we wanted to point to other's work, and just fill in the blanks with what might be missing or what might be necessary I've been teaching this for our use cases.

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This this kind of looks like it's more on the scale of boiling the ocean.

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And I just, you know, I observed that I'm a little surprised I didn't think that was the direction we're going in, so curious sort of what your overall thoughts are on that.

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That's a really, really great question, And I think what struck me the most when we've actually talked through this and this subcommittee as well as input, input we've received from other venues, is how do we do that.

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How do we sort of transfer the sort of responsibilities and all of that to another agreement. And so I think what you're seeing is the in some in some respects the original sort of get everything down so we can understand what we need to put in this.

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And like I said, it doesn't necessarily mean that it will end up looking like this. And as we talk through how we refer, and how we, you know, you know, sort of tie back, other agreements that are already in existence, you know, leveraging those agreements

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for this work, how we do that. And so this gives you a sense of what it might be, that's not necessarily what we think the finished products that look like so let me, let me put it in right there that we're not necessarily saying this is the way it has

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to be like this is the potential scope. Correct. Got it. Thank you. Absolutely.

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And then she's.

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I Jennifer thanks for framing it that's still a draft, and it is more inclusive draft, and as we go to different sections we can say hey this is covered in this section policy elsewhere and refer to that that that helps a lot.

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I want to take a other stand I've been for this running the risk of adding more stuff I feel there's one part, which perhaps worthwhile to be added. I really like the approach of being technology agnostic.

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So we are giving people, you know, we're not managing one technology versus other. At the same time, I think there are a lot of very good standards for data exchange now, and 2022, and if we just completely make a technology agnostic we run the risk of

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And if we just completely MAKE IT technology agnostic we run the risk of nothing working because people may say hey I have this data format and and the people who really, you know, get the short end of it, other people who have least capacity to change

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different data formats. And those are the organizations FQFC which need the data the most. Right. So I think we also need to somehow blended. While we support multiple ways of handling data, we generally favor data standards such as we can list three

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or four or five or six you know these are five standard I sit on fire, fire at scale committee from ONC. And that's becoming ubiquitous. But we can also have other experts having another standards, but not having any mention of standards.

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I feel will take us a lot backwards and execution stage, and we need to see that people not only believe this in concept, but organizations are able to execute and data exchange really becomes a reality.

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That's an excellent point. Thank you so much.

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I appreciate that. and then Devon.

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Yeah, I mean I know it looks like a lot but i i think that we have to, to accommodate the fact that there will be a number of providers who will need to execute this agreement that don't have any other executed exchange agreements that exist, I think

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we do need to think about what we're going to do with how we're going to accommodate entities that are already dairy data sharing through, through an infrastructure so that there doesn't need to necessarily be duplication but we could do that down the

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road and it's also a lot easier to to decide that things are not necessary. Once you've sort of got them in and you see how the whole agreement hangs together versus forgetting something, and then remembering and realizing you forgotten it and putting

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it back in so a minute in agreement that we start with something big, but we, we should always be mindful, do we really do we really need this provision as we start to sketch this out.

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Thank you.

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And I think that we heard folks say smaller is better Mahler can suffice. And so having too much doesn't necessarily make it better.

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You know when we don't have to have too much and so what you are seeing really is an attempt to get everything out there so we don't forget anything, so we have a chance to talk through everything.

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And the goal is not to have a 500 page agreement, but rather to do what we need to do. Just, just throwing it out there in case folks are a little concerned that the agreement might be overly long and I think everyone has a concern that the agreement

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might be overly long, and then we yeah hi I just wanted to sort of agree with, to some extent, what he was saying about the concerns on yes, we want to be technology agnostic, but at the same time.

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You know there's a lot of technical solutions out there. People can put together lots of things, and we do need to have minimum, some sort of minimum interoperability and utility and efficacy.

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We've seen certainly with the growth of machine learning and AI, there's a lot of snake oil, there's a lot of stuff that is claimed to do X, and it may do X, but it may also do YNZM, and all sorts of other things that are actually inimical to privacy

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or security and I'm and I am concerned from, you know, from what we have seen in terms of lots and lots of independent analysis of how apps work how devices work, how much technology out there is really not particularly well secured, or, you know, is

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allowed to leak information and so I don't know what the right answer to do that is I admit it's certainly not with wiring. Only x wires, the better. It seems like you also have to acknowledge and build in some sort of technical technology evaluation

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component.

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If you're going to allow any thing to be used, then you got to be able to tell whether or not it's actually worth putting into onto the network so I'm just I don't know how much that would add, or how expensive that would be or maybe that's a deal breaker,

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in some way.

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But, but it would, it seems like a real gap to not be able to actually say oh that technology actually isn't suited for what we want say I'm because I've seen.

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I see a lot of things in the D identification world for instance that I don't think has really been subjected to proper analysis by you know properly certified statistician so it's hard to know whether or not something actually meet, say, the identification

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standard without actually studying it. And that's a really fair point, especially around efficacy and around privacy as well as around, you know, having some minimum standards, so that we all can be on the same playing field.

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I think the reason why you're seeing technology agnostic is really because that's what the statute requires is that it's technology agnostic. That being said, that piece, we have an opportunity to look at and define what that means, and to kind of define

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how it applies to this agreement, and how it applies for example in policies and procedures or technical specifications. So, I want to say that while we're starting from the standpoint of technology agnostic and we keep using those words because they

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come from the statute So, and that's kind of a strange phrase to be using to describe an element of this agreement, but it's used intentionally because it came from there.

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And so we'll have a chance to talk a little bit later about that particular piece. And I'm very excited to hear what you have to say about it because in some ways it definitely needs comment, so I'm going to ask folks.

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Is there anything else we kind of want to discuss with respect to the topics, because we can get right into the meat and potatoes.

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Next,

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your your appetizer. And, okay.

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Hearing nothing, Billy you do still have your hand up. So I just want to make sure you're good.

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Okay. Oh I thought it took it down, sorry. Okay, no worries.

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Okay, if we can go to. I believe we should be on slide 20.

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I can't see the numbers.

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That's right, yeah, we're there, the title page.

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Okay, great. Okay, if we can go to the next slide.

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And then the next one.

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Right there. Okay, so, um, if you give me just one second to share my screen, and pull up

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the draft language so that we can have a, I'm going to drive a little bit. So

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I'm thinking you can see this, and I'm going to go to

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shoot.

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I was trying to give myself the ability to put the participants up so I could see folks can you see this.

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Shoot, it's gonna be a little challenging for me to have the participants up at the same time.

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So, if folks could be patient with me while I try to navigate the hands up that would be awesome. So let me just go ahead and move this. Is that better.

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Okay, so let's kind of let me give some context first before we dive in, because, as you see, there are some definitions, but not all definitions. Some of the definitions were added to provide context to some of these pieces so you could get a better

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sense of what they mean that these sort of things that are capitalized, those are intended to be defined things.

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And as you see we didn't give all of the definitions, but as we walk through this I can give you an understanding of what a part of that means, for example, authorization means pretty much what you would expect it to me.

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And essentially, you know, a valid written document that meets the laws requirements for consent for disclosure of information signed by the individual or their, you know legal proxy.

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So, and I'm saying it vaguely like that because a lot of this includes this as you'll see, which is often together.

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And it's intended to be separated, specifically so there's a sort of differentiation between protected health information and personally identifiable information, which is, sort of, I'm doing as we walk through this as kind of an understanding between

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health information covered by HIPAA and information that the social services organizations might have, or information that is identifiable, and confidential but may not be covered by HIPAA, does that make sense is PII is broader than PHI.

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And, for example, there are also pieces that are highlighted, as I'm sure you've noticed, these are placeholders what they are is sort of a call back to that governance portion that hasn't yet been built, but clearly there's a hole here and so some of

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this is to provide sort of that space where we know that there needs to be more detailed pieces here. We know that there's some kind of governance entity what that looks like.

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We know that there's going to be technical specifications of some kind, potentially, and so that's what's referenced here and these, these yellow pieces.

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In addition, the numbers at the very top mean nothing right now, as it, it's organized I needed to put numbers up so that we could do and forgive me for the seasickness of scrolling, but this kind of thing.

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These this piece and then it's yellow to remind us that these pieces need to be appropriately filled in, at an appropriate time. But it refers back to another section in the agreement so numbers are important from that perspective.

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So does that help with folks, and then I'm happy to walk through this, and I'm also happy to open it up for comment immediately. I know that there are folks who've had a chance to read this and then you know and really would like to provide some explanation

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for it so why don't I do this because I don't see any hands. And that might just be because it's harder for me to do that because I'm not driving.

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But why don't I walk through some of this. So this definition is from primarily from the culture set and so I'm going to give you a sense of where these things come when we walk through it so you can kind of understand where they came from, many of them

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have been altered, some of them are combined between different agreements. And so what you'll see is there's that piece. And so with this the intention here is to combine federal and state law, as well as to sort of give a little bit of a carve out to

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governmental entities as you can see from the text. And so,

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I know that there are a lot of agreements moving away from the word breach and moving towards the word security incident. So what I'd like to do is I'd like to hear from folks around, you know, this definition, you know, is it adequate, is it, you know,

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what are your thoughts around this.

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And just open it on up.

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Devon. I have a question it would help to know.

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Bree is said we need to define breach because there's going to be some sort of requirements in the agreement regarding breach Is that why we're, we're seeing this I just wanted to put it in the right context.

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Yes. Sorry.

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And I'm not sure who's had a chance to sort of look at this language. Before we talked today, but breach this definition is here so that we can have a larger conversation around privacy and security.

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And in the privacy and security peace, there is a section on notification. Got it. Yeah, I went back through my list of maybe I've missed it. I didn't see this as something to review and advance of the meeting so my apologies for not having done so.

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So the slide to saw the agenda so the charter but didn't see this document so I'm okay, that's helpful. I mean it's one thing, and I guess another thing to consider is why the breach notification would not just become something that we would expect people

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to comply with under law.

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Given the scope that we actually have a pretty broadly worded state Breach Notification law that covers health information.

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Because it seems like maybe a rabbit hole we might not have to go down. If we think that most of the entities that are signing this already have an obligation to, to make that report.

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So that's an excellent point.

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And so my question would be, there, there is, to a certain extent, some sort of comfort level that's associated with having a contract, a little bit more specification around what to do in the event of a breach.

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And so what I'm hearing you say is, these entities are already subject to requirements under the law so why not just say comply with your whatever law covers your breach notification is that what I'm hearing Devon.

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Yes.

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And so I think that the thought here is a while that's true that there is you know a requirement to comply with that. Do we need more standard, a more standard system in terms of timeframes for example, or how that works.

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And is there a need for government entities to have a little bit faster noticed, or is there, is that unfair.

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And what does it look like. So, I'm going to then take it through because we have a bunch of folks who have some comments so Lisa I think you're next.

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And yeah I think just kind of what Devon was saying to just having multiple different requirements is very difficult from the provider perspective, and also some of the like requirements here I mean one hour of learning that a breach occurred.

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I don't think is reasonable at all.

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You know, that's, that's doesn't give anybody, the entity time to even, you know, figure out what's happening internally.

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Like, and definitely not enough time to like get it together to do any sort of reporting.

Um, and I as I said you know they as Devon said.

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Most of these health entities are already covered under a breach notification having multiple different layers, just makes it a lot harder.

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So what about social services organization so by the inclusion of PII here, this, this is what we mean when we say we're including the social services organizations piece.

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So, what do you think about that, do you think that that still should be, you know, follow what your law says, and are we confident that they're that each of those laws actually say what needs to be done.

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When it comes to social services information.

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Yeah, I think that's part of that wider conversation right about whether or not they're considered business associates and then if they are not.

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You know what laws are going to be applicable to them.

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Okay, thank you, Elizabeth, to kind of continue on that last piece I absolutely agree that it is part of the broader conversation of can we just set a floor like, okay, technically, you're not covered under HIPAA but you still have to meet these basic

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HIPAA requirements technically you may not be covered under this notification law, but we're going to pretend. Once you sign this you're pretending that you are.

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And all of those same requirements which I agree that the one our timeline is not acceptable.

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I don't, I don't think that, so we have to look at this from the perspective of the huge range of entities involved here. These aren't plans, I mean there are plans but they aren't just plans that have millions of lives covered by medical.

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You're also dealing with at Bidy systems and anybody provider groups and as we were talking about earlier potentially fairly unsophisticated very small social services organizations, in addition to the behemoths out there, and what they can do, is not

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the same. and I think that the more we push to make it faster and stricter and harder than is already required under law.

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And the more we're kind of running those guys off it makes it infinitely more difficult for them to comply. And, and I think that some of the terms of this are really pushing the lines of what can realistically be expected if not blatantly over them of

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the smaller groups like, yes. Many of us in this conversation represent organizations that can absolutely comply with all of this because it is what we do today.

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That is not the group retargeting, or at least it's not the entire group retargeting.

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We have to factor that in, I think some of this language and he doesn't. And I have major concerns about that.

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So let's talk about those areas of concern let's go down to one of them, the one that I heard several people bring up, which is all the way down here.

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I'm going to stay here. Right here, so there's this one piece that says no later than two calendar days. And then there's this other piece down here that says, but if it's government, you have to do it within an hour.

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where did this come from the calendar.

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Some of this is, let's talk about what should be changed, is this appropriate. Is this reporting piece appropriate.

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And what I'm hearing is, this is, this is unreasonable.

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Again, several of us comply with this today, right, we are all able to do these things because we're doing it today.

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That's not true of everybody we're trying to bring in from the outside.

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And that's why we're trying to expand it right now and I think that some of this is, it's pushing it too far.

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So am I hearing. And let me just raise this I don't want to put words in folks mouth Am I hearing that maybe there should be a tiered approach. One approach for health entities, and one approach for social services entities.

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And so I'm going to throw it to Ashish.

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Yeah. First I want to really resonate with Elizabeth said, I think.

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While we're framing this I need to we need to look at the concept of empowerment, empowering the patients and families but also health systems social service organizations have to add see all alike.

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Right, and and the moment we, and this is such a great spirit of we are able to work on it. But the moment we put some things which one group cannot comply, and then the whole thing fails right so looking more specifically at the security but having been

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been part of multiple. I shouldn't call breaches but multiple concerns and CSOs meeting.

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I think it's also very unclear when the webinar starts to take.

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Because sometimes in one hour we know something is down, we do not know the cause and the teams are running to find a cause. So, why we are trying to find the cause.

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It's very tough, and the extent of the leak or the breach or the security thing. It's very tough to comply because we don't we are still trying to do fact finding ourselves.

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So if that is okay Jennifer it helps, we can get back to our respective CSOs the chief information security officer and get back to you with more specific guidance on what they already frameworks they have in place to further inform this committee.

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And that's fair.

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And then I don't see why that's not fair. That's what kind of feedback we're looking for.

And then Shelley,

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Shelley you're on mute in case you were talking.

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Yes, I was Thank you think a reminder, apologize.

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So two points I do agree with Elizabeth we need to we need to, to kind of make this broader, and we need to set the standards, I guess, broader as well so that different types of entities can comply, a one hour reporting requirement, I think has always

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been unreasonable. I really honestly don't know how anyone, or that I'm not speaking for health plans I suppose they're different, but I've always thought that was just incredibly, you know, to, to shorter timeframe.

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So I you know know in the law does have a time frame which is much broader. So I think we have to move the needle out a little bit on that requirement.

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They the other comment is, you know, HIPAA has one reporting requirement for pH I and that's because pH I technically isn't, you know, patients don't consent to disclosure pH i.

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So we have a different security framework for pH, then we do for PCI.

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And I think that the framework that we're contemplating patients and clients of social services agencies, expect to share their data, and under California law security incident doesn't occur just because someone's name got disclose.

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We have only special kinds of data combinations of data that would require notification if it was breached. So we have a different standard for PCI than we do for pH I.

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And so I think are really all centers again around what kind of data are we, sharing what classification is that data and is there an authorization in place.

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Then we have different standards for whether or not a breach or security incident is correct.

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That's a really good point. Go on.

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And then scrolling back up to the top, I think that trying to define breach so many different ways is too confusing.

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We could just find the common, common ground here with these different laws which is basically think your first sentence, we can eliminate a lot of the other language in that definition.

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And so then I would think that perhaps this would need to be defined.

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Is that what you're saying, Well I think your first sentence actually does a good job of defining what a breaches

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and others we don't have to go into a California State Department's.

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You know with with regulations or the definition of a breach for California State Department, or you know what is not a breach below.

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I'm just trying to look for ways to simplify this agreement so that's that's the extent of it. Thank you.

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Thank you.

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Emily.

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All right. Yeah. Um, so this is definitely the definitely a messy, messy thing right because there are a lot of different standards here, even under California law.

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Yes, we have the old from like 90s vintage Breach Notification rules that cover both, you know that came out of the first major breach in the state that involved lawmakers, we now also have right the SES combined CCP ACPRA, which has a different private

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right of action with respect to security, let's call them incident, because the standard is not the same as that in the one that has that has more of a focus on financial and medical information and requires certain pairings.

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But the CCC gay CPR a statute is not quite, not that limited also point out that, you know, under TCP and CPR a only certain businesses are covered. It doesn't cover noncommercial doesn't cover nonprofits.

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So if we're talking about the social services agencies that are on profits that are not governmental agencies, they will be only subject to the first sort of the older set and not anything under the new finally also point out that, you know, as we see

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see with 17 98.24.

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That doesn't apply to all government agencies either right. I mean, that's only if you're a local city or county stadium. That's not going to that, that that standard doesn't apply to you.

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So, even under existing law.

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There's, there's a multiplicity of interesting standards that also point out, even for if you're a commercial business records of employees. Employees aren't covered right now.

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Under CPA CPR a that will expire in 2023 or 20 and 24 but we're expecting the labor force to put in new standards, there so it's going to continue to be sort of be a little messy on the brief side of things, and I think we just have to recognize that

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actually the elite status quo of the law. It's a mess. And I don't know what our powers are here to to smooth any of that out but I think that we need to know, with great specificity, what we're talking about in terms of all of those standards, before

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we do, you know top level amount and I admit I know nothing about compliance on this side for, for all the folks who are in this, in, in the conversation now so on.

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actually trying to implement in compliance. Thank you. Certainly, do you mind if I push a little bit on some of what you said. So what do you think about, and maybe I mischaracterizing Listen If so, somebody should pop up, and when.

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What do you think about sort of a different tiers, depending on whether it's phi or personally identifiable information. So for example, that the pH I would be this standard minimum standard but the PII would be the standard.

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I mean, it sounds unworkable I worry that it wouldn't.

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I mean, that's always my question right I always have this, this one football here's what the perfect set of rules would be, but then they meet reality and you can't have that.

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That's why we're, we're here, I, I, you know, I read Elizabeth's comment

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it.

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I am concerned that that that's just going to be a mess. On the other hand, I don't know if it's accurate or, or proper or normatively right to just sort of like slap, just have one Tier I I defer to those of you who are much much more deeply involved

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with implementation. I can only say what I what I worry about and not what how I think it should be solved.

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Thanks.

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I'm just taking a moment to check the chat out, Shelly, I think you have your hand raised.

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No. Okay.

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So why don't we do this.

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Why don't we put a pin in that. There are a lot of concerns around this definition. This is the kind of feedback we're looking for. So there's no ego here, what we're interested in is how to make this workable and how to do everything we can to do what's

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best for the state of California. So let's move down a little bit and talk about some of these pieces here. So, as you saw, this is pretty high level in terms of some of the sort of baseline requirements for privacy and security.

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So safeguards, and safeguards are defined a little bit different. In an attempt to address that difference between social services organizations, and health organization so safeguards for example and I'm pinpointing us here because this kind of flows

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from some of that conversation we've heard about this tension between social services and our organizations and health organizations. So here, your typical, you know, standards set by HIPAA, let's just call it that for now.

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For those that are covered by HIPAA, and then for government.

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There may actually be more or also mandatory policies. So, for example, the state has mandatory policies related to Information Privacy and Security. So that's where you see some of this regulations or policy.

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Here's that tension clickable law mandatory policies for example a lot of organizations are required to follow departmental letters, so it's not a regulation, but it's a it's essentially departmental or or government agency guidance that says these are

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the ways that you need to do the implementation. And so that would be kind of a mandatory policy.

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And then the third piece would be a contract piece. So, whatever your contract with a government entity. If your social services organization for example, or your, your agreement with an entity around this your contract piece would also often define privacy

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and security requirements within it. So, what do folks think about these different pieces here at Do we need them, should they be the same.

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Should there be kind of this sort of understanding that these folks are used to the folks in the healthcare piece are used to and have sort of very clear, technical requirements and in number three, for example the social services organizations may not

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have that kind of fleshed out sophisticated understanding of some of these requirements, Devon.

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Yes, thank you. I put this in the chat because I'm. I'm.

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I'm.

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I'm. And I don't have an answer for this so I'm just sort of putting this before the group to flesh it out I, I'm really struggling with, whether the goal of of at 133 and and having a data sharing agreement should be to get enemies sharing under, under

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current conditions, or whether there's a need for this agreement to cover gaps in the law.

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In order to bring all the participants that will share the agreement, up to some certain level.

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Because, you know, an approach that as a former just says, Look, you've got legal requirements today that you need to comply with and we, you need to comply with them before you share data, but other, but you need to share lawfully and that's what this

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agreement is intended to achieve versus what we seem to be aiming for here is the latter approach which is trying to raise the bar of what protections need to be in place, through contract.

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And I guess maybe it comes down to whether we think that one of the primary reasons why information doesn't get shared today when it's legally permissible or even in some cases legally required to do so, is because of uncertainty around the recipients

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privacy and security policies that given that most of these laws don't hold you accountable for that downstream uses as long as you are doing the right thing when you share.

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I just want because this is, if, if, in fact we're essentially creating a kind of a common privacy and security framework. Through this agreement, it is going to be very long.

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And it's going to be very potentially complicated and and is going to make our task a lot harder, but I don't know whether how people feel about that.

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I mean I, you could make this these agreements a lot shorter to say, you need to comply with applicable law around breach privacy and security etc.

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Maybe even to say to use other law as reference if you're not covered by those laws, you at least have to, to buy contract, agree to comply with a B and C, as opposed to having to spell them all out in the agreement.

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But there's a threshold question here of whether we in fact.

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Does everyone agree we need to raise. Raise the raise the floor.

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For all the participants. And in, in some sort of common way.

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So you you raise two really great points.

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So, let's put a pin in the sort of large one, which is.

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Okay.

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This is the kind of discussion we should be having, which is what are we trying to do and what what should we do, and so I guess my thoughts are you made a good point earlier when you said that many folks have already signed on to an agreement with some

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other entities, but many have not right. And so, to a certain extent we do need some minimum pieces, and I don't know about folks who have practiced on this subcommittee, but in my experience, there are folks who really want to say five times, you know,

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you have to comply with the law, and you have to comply with this law you have to comply with that law you have to comply with every law and then do it over and over and over again, which we've all seen, and which we've talked about also earlier in our

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subcommittee days.

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Kind of this sort of rehashing of what that says, and so I guess the question I would have would be in. In the case where, you know, we're trying to do something that hasn't quite been done yet.

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Is there a need to maybe be a little bit more careful around this, so we can build trust or is that more, it would it be more appropriate instead to say you have to follow the law, period.

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And then, you know, maybe there's, there's a place for oversight.

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And it should be, you know, that should be the focus, what do you think what have people think about that.

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Can I share, I think another perspective is if we're trying to get a low threshold of participation, especially for our social service organizations that if you say there are these lies in laws, you need to comply with will have to provide so much technical

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assistance and a reassurance to help those organizations that may not have legal counsel or may not have access to other large organizations would have access to, to reassure them that maybe they aren't compliance or what do they need to do to be in compliance,

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that I wonder if there's a way this can also address that so that we're not, you know, I think there's an important thing about setting the floor here, but also not prohibiting people from participating because they're so worried about not being able

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to meet some of the baseline guidelines.

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That is an excellent point. So to what extent are. Is there a responsibility here to assist organizations that are small, that maybe don't have a lot of money for infrastructure to to sort of come up to a certain standard that they're not necessarily

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required to comply with but they want to be part of this. and would there be an issue here with respect to prohibitive costs or prohibitive need for workload or for resources around how they would do that.

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So, in other words, would we be. And while I grasp that you know the the sharing piece is really valuable.

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I also have heard from a lot of small organizations, the pain points they have around a lack of capacity with their current workload. In other words, being able to do extra functions, lack of resources, lack of funding and time.

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So I'm wondering if maybe we, there are some spots around that and I want to say I think Belinda you had your, you might have had your hand raised.

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I think I meant to take it down but I think just to add like something I was going to mention earlier is, is there an opportunity here just to spell things out and again at the risk of a longer document but to spell things out more so more definitions

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that might actually inherently provide more reassurances so for example with PII pH I, are we going to spell out where social determinants data part to LPs all those things fall in so that the smaller organizations that may not even be used to handling

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it know what that means for them. I think when when we get into the details of actually how this data is going to be exchanged and Jen I think I mentioned it earlier in the chat.

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You know, and we're thinking about can we do this without consent. Some of those data depending on how technically sophisticated these organizations are some of those data elements may be mixed, they may not be tagged or easy to segment and so we may

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end up getting them anyway. And I think organizations need to know what that means for them if they are going to be sharing data that may not be really clean.

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So for me it's adding maybe more definitions and almost some of the background education into a document like this or maybe in a tandem that can provide some of that those reassurances.

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Thank you.

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So I'm in the interest of time, I'm going to scroll down to our next piece, and move off of privacy and security for now.

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You have to text. We are absolutely happy to see whatever comments you might have, so feel free to send us something in writing to after Have you have a chance to look at that.

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So this isn't your only bite at the apple so let's talk about technology agnostic because this is this is that balance between getting folks to come on board, folks who may not already be technologically ready to do so because now they're, you know, legally

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required to do this as opposed to before when they were not as well as organizations so services organizations that may not be technologically ready. Also, but also we want to have meaningful participation.

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I've we've heard a lot about reciprocity and the need for reciprocity or bilateral sharing, and also we've heard about the need to ensure that whatever we do here does not justify or allow an organization to access information but then failed to send

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because their quote hiding behind technology or or not technologically ready when they could be sharing information. So as you may read through this, there is a bit of a circular piece to this and that is because it is really challenging to do what I

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just said, in terms of a purpose. Say you have an opportunity here where a tiered approach to getting to become technologically ready but we're not going to hold it against you if you're not technologically ready and also you can't hide behind your lack

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of technological readiness to not do bilateral sharing. So, to a certain extent, what you're seeing in this language is an a circular approach, only because this is a challenge.

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And so what I really would like to hear from is, do we need this, do we need a tiered approach to technological readiness. And here, Here's that approach right here.

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What this says first let me go to the first because I recognize that some folks maybe hadn't had a chance to look at it is that you know, We don't care what kind of method you use in other words this agreement doesn't specify how to do the data sharing,

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right, it allows you to leverage other arrangements other agreements whatever kind of technology, but that, you know, you have to engage in meaningful health and social services information exchange, whether that is your own or through another agreement,

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whatever that looks like. So it's, it's somewhat broad. The second pieces, what the tiered approach might be, again this is a possibility. We're, we're here to talk about whether it's necessary where you have organizations that in number one, our that
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this is what they do, they've done it for a while, or they can do it. No problem, they are technologically ready. Then you have the sections to which is essentially those newer potentially newer organizations that have not done this, but are required
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to sign on to the DSA they're listed here.
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And then you have down here.
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Right here government participants. So government participants include state federal and county and local.
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So we've heard about how you know county organizations, local organizations. They may not be technologically ready and they administer a, you know, the bulk of services when it comes to social services in conjunction with a lot of nonprofit organizations
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as well. So they're critical partner, and yet they, many of them are not technologically ready so might be. So here's the section for governmental participants.
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The last piece would be social services organizations, and I recognize if I'm going through this too fast, let me know where social services organizations not required by law to sign this not really involved in this, Some might be part of a community
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information exchange. Some might not be the majority will not be and so what do we do with them, how do we how do we achieve that.
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So, and then there's this part here, which is essentially saying you can't use it as a justification to fail to meaningfully participate, but we aren't necessarily going to penalize you either.
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So in Section seven refers back to what we will talk about in a moment which is requirement to respond.
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So, I'm going to pull it back up and ask the threshold question of do we need, do we need this 5.2, or is 5.1 enough where it says we expect meaningful participation.
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And, you know, but you may not know this, but you can do it in through having a contract with another entity, meaning you would create a business arrangement and share information that way or you would do it yourself.
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So what our folks thoughts on this.
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See if I missed hands.

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I'm not seeing any have Jen Patrick hand is up. Oh.

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Hello everybody, a bit more of a comment in support of what's been written here so in paragraph 5.1, from my perspective I support the last half of that paragraph, I support the whole paragraph, but particularly the last part because it, it does describe

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Hey, get connected anywhere you want, but it leads us to a scenario where we have a team of experts many organizations in California called health information exchanges that can help do that.

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So it alludes to health information exchanges. And I think that's a good statement the way it was put in their second part is another comment is, I think through either this document or through some supporting documents, we should be leading our participants

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to say hey here's, here's one or two or three recommendations on how to do it and I think just by giving people a roadmap will help people get there faster for example if we've got a small organization that doesn't know where to begin, giving them a roadmap

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and say hey contact an HIE or implement your own fire server to everybody, you can do either one, pick which one and go there, but I do, I do like the last pair part of the paragraph and supporting documents Let's help lead some of our organizations,

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and what the solutions, or what are some potential ways of connecting and sharing could be without prescribing it so you must do it. Thank you.

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So what I'm hearing Patrick let me just make sure that I understood you is as part of to help flesh out what meaningful exchange means, and meaningful exchange, you know, provide some recommendations or some suggestions around what this looks like it

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may be, you have a contract with another entity to do data sharing on your behalf, or, you know, and didn't provide some options that I hear that right.

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That's right.

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And Eric.

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I thank you. I think one thing I would propose would be this might be a time and to sort of re amplify as she says comments earlier about standards, is that rather than us focusing on the term, you know, technology agnostic to talk about Standards and

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Technology and that Well, no, we're not saying you have to use a certain technological path, there are standards that we should adhere to that are sort of baseline acceptable standards for this type of information exchange today and.

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And I think as Stephen pointed out in the chat a little while ago that you know their tools are out there, they can be accessed by. Bye, bye all.

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And while it's true that would probably be a heavier lift for social services agency that's never done this before.

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The bottom line is that the standard is still attainable. The health part it's more of a more procedural or more technical support related but a little bit less in my opinion, tied to the agreement itself, but I think if we get too deep industry and tried

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and tried to stratify what would mean by technology agnostic.

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It might be, it might make people shy away from looking at this rather than just saying look, there are standards let's, let's talk about how everyone could use those standards, the same way.

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So am I hearing that 5.1. Looks good.

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However, 5.2, and maybe 5.3 are not necessary, but rather flush out 5.1 a little bit more with respect to some suggestions of how to meaningfully participate.

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And then maybe add some, you know, language with respect to standards for technology or refer to technical specifications around that said I heard that right.

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Mostly I think there are part parts of 5.3 that are are important for different reasons but I think five dot one and five, two and I think she says hand is up so maybe I'll let him a chime in since he brought up the standards topic a little bit earlier.

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She's.

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Thank you, Jennifer Thank you, Eric. I think it would be good to mention standards explicitly within this main document.

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And if there's not much space, or we believe this there we can always have appendix which can save which those standards are in that regard. But at least mentioning standards, at least shows that we are supporting a federal policy as well which is bipartisan

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to adopt those standards in that regard.

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While it is not in the purview of this committee to talk about how to support the standards and others. I do believe you know a rising tide lifts all boats.

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So standard is something like that.

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If outside this organization we need to create some advocacy, so everyone can get on board with the standard I think that is probably a very meaningful advocacy to do.

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But just because few organizations cannot adopt the standard which are open and free.

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We should be able to train them so everyone is efficient like a USB.

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If we do not have a USB multiple devices cannot connect to each other.

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That's an example of a standard.

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So everyone wins in that regards.

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So I will leave up to you, Jennifer.

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We mentioned for sure if that's our recommendation is if most of people feel. But if we feel it's getting too much nitty gritty mentioning either standards here in this section, we can have that in appendix and how about maybe a separate sub charter which

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can come back with technical specifications for that, thank us Yes.

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We

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yeah Hi, thanks three.

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I am sort of gnostic about the utility of of 5.2. But the thing that. But if you use 5.2.

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I don't understand how you evaluate how who evaluates or what the meaning of quote technologically ready and able is and who sort of determines that or technologically able and ready to the extent that that if that is really just quarter toys on the whole

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whole section really has no hasn't got much meaning in the first place.

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The thing that I do not have enough of a knowledge background in this who actually, to know but when I look at three and four we're talking about two separate entities governmental participants and social services organizations and I'm curious if, for

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instance, our government mental participants in this going to be any of them going to be a bottleneck. I mean like they're not required to disclose information under this until they are technologically able and ready.

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Well, if that's the case, and if a governmental entity somewhere just doesn't isn't pulling its way of how much harm, for instance, what does that do to, to our mission of trying to move this information around I mean, I guess the question I have is,

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if you're going to have something like this in here then that starts to say well we need to get agency a on board, or we don't need agency. And if we don't have any metrics we don't have any guidance, we don't have any sort of direction that's created

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by this section then it does seem sort of functionally worth pointless. But if you do have the section. It seems that it, it really kind of militates in favor of a number of things that that we would want to do either to evaluate the meaning of these

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words, or even to use them as as milestones, or for planning. I mean, it's one or the other. It's either nothing or it's something. And, and right now I'm not true what what something is, is there in the first place.

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That's.

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Thank you.

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So that, that's another sort of way and where does the oversight come in, does it come in, or, you know, is this something that we want or is this something that we don't need.

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And so I'm going to move on to the next topic, but I'll give you just one second to tell me.

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I mischaracterize what folks are thinking. And what I'm hearing is that, you know, that 5.1 is definitely good with maybe some expansion. And then 5.2 really only matters if we have some sort of oversight kind of looking to evaluate that tech readiness

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and whether or not it's, you know, reasonable and appropriate or what that looks like.

And that 5.3 is, you know, part of it might be useful but maybe not the whole piece and that maybe we should look a little bit more into technical standards, as, as

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sort of something that we should be out of here or referring to in an attachment.

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Did I get, did I capture that right.

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So,

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okay, I'll give it one second.

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All right, let's move on to the next piece I recognize we don't have a huge amount of time so I apologize.

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So exchange purposes. This piece was a sort of combination of the draft tough Gaza and the dosa. So, obviously, that's not going to be exactly the same, but as you see some of these are defined terms like treatment and payment utilization review, so some

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of these terms would be defined consistent with the Tosca depending on whether they're still in the tough guy I'd have to look at that but they were in the draft tough class so you'll see some of them here like utilization review or quality assurance

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and improvement business planning and development for example. So, let me just sort of scroll through so folks can see again this is pH I or PII.

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So trying to capture both that social service plus the health.

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And then down benefits determinations was in the dropped tough got as a specific defined term, but this piece here on five is more broad, it talks about some of the things we've already had a conversation around, which is that more entities do these benefit

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determinations than government, a lot of non-governmental entities in fact to do this work, and so five would be trying to capture that outside of tough God but in acknowledgement of that important world, public health activities, this was, this is defined

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a little bit lower and I'll show you that in a moment. And then, Meaningful Use here.

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Is this something that we still need

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doesn't need to be parceled out because I'm Laura pretty much talks about permitted by law. So, and do we need to call it out this was something that was directly called out by the dosa, which is why it's here.

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So I'm, I'd love to hear from folks on that. And then authorization, something a little different where it says it's pursuant to an authorization individual access.

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And then, government participants acknowledges that some government participants have users and disclosures that the law allows for, and then your general otherwise permitted or required.

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So that's the exchange purposes.

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public health activities. Pretty standard very Hippo based. So, you know, doesn't reflect necessarily California law, but this came from the draft Tesco.

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And then if I scroll down, we get into the meat of it, which is what are you required to respond. And as you may have seen there was a talk about how technological unreadiness was a way of being appropriately, non compliant with this section so here it
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talks about how there are certain purposes that you are required to respond to.

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And not all of them, all of them may be permitted you may, you know, share information for lawful purposes but for certain purposes.

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There's a requirement to respond. And I'd like to sort of bring your attention to the fact that this doesn't say, if you're if you're asking for treatment you must share for treatment.

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So, it's not limited to Treatment it could be. I asked for payment information, and I have to share treatment information for example. So it's not giving in terms of a prioritization of what comes first, it but it is saying in a prioritization

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of a type which is that these purposes are important, and you are responsible to reciprocate.

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And so I'm going to open this up and I'm going to scroll down a little bit, and then I'm going to Stephen you have a comment.

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Yeah, I was just going to comment on your use of the term meaningful use, and the reference to the legislation that that brought that to us, simply to say that that legislation isn't you know that that term has now been co-opted or incorporated into the

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promoting interoperability efforts. And I just think it could be confusing if something that we published in 2022 looks back to terminology that that is no longer being used by by its authors.

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So we just might want to think about that.

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Thank you.

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And this is what we needed to hear, whether we should call this out specifically or if it's antiquated, And I'm hearing that it might be integrated.

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So Stephen Did you still have something you wanted to weigh in on your hand is still up.

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Good. Sorry, I dropped it.

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Belinda pretty, I was just gonna say under number one is we've talked about a lot today and last time just to make a plug for including potentially treatment, including the care coordination, so that it's clear what that means to all organizations.

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Thank you.

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An excellent point.

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And Devon.

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I don't think we need to put permitted uses in this agreement.

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I think we should the agreement is a contract, where people are committing to sharing information that we that we presume they're legally authorized to share if they're not legally authorized to share it then of course they wouldn't have to do so but

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otherwise we're basically deciding that there are some use cases that bump up from being just permitted to being required and that should really be the purpose of this agreement and that will also help to streamline it what's required everything else.

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Yeah, if you're permitted to share it under law and then share it under law, right but we should focus on again trying to those use cases that we want, actually, for people to share, not to just say that they're permitted.

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Okay, so let me repeat what I thought I heard you say, so what I'm hearing you say is we don't, we don't need this piece here this definition of exchange purposes and said, these individual pieces treatment payment healthcare operations, etc.

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are defined terms and instead what we should do is in this section here. Forgive the sickness again from scrolling, it should just say, these, these purposes are required and we don't need to talk about exchange purposes, did I capture that.

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Yes. Yeah, yeah, I mean now that breach definition Now I see why it was worded the way it was. But otherwise we're, it feels more boil the ocean to have a contract that everyone signs it says what their product to do when they, you know, that should be

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covered by law. This agreement.

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What are those things. What are those purposes for what which we want people to contractually commit that they will do not that they are permitted to do.

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Yeah.

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Thank you. Let me push just a little bit on what you just said so.

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Understood. And also, uh, what about to a certain extent, that we're, we're moving forward in this space, and a lot of folks joining this agreement will be new in this space, as well as the largeness of it being something new to the state of California.

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Now there are a lot of individuals who are going to be hearing about this for the first time and may have some concerns around their information. Do you think carving out some things and I recognize that it also does literally say up here, you know, any

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any lawful purpose right so there it is right there. It doesn't it, it does do some narrowing but it also says, any purpose that is permitted or required.

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So, but it does. So I guess my question would be, is there any value in having this as an expansion, or any value in narrowing it just for the need to move trust forward and the need to move comfort forward and we have had some conversations around this,

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but now you're seeing the language so this is another chance to weigh in on that. Devon did you want to respond to that or yeah I mean I just, I don't feel like we should use this contract as an educational opportunity right it's the cons The purpose

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of the contract should be to mandate data sharing for those purposes for which we think it should be mandatory versus just permitted and and and I think, you know, we've said all along there there are lots of, there's lots and lots of room for education

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about what's permitted by law what's covered by law, but we shouldn't use that contract for that purpose, I don't think. Thank you. Absolutely.

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So Devin, of course you know that's.

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And that is going to become much more as we start seeing patients being in participatory research.

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So, either. We follow what Devon is saying in terms of we definitely the purpose of this, but if we do include it. we may have to call out.

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Do we have the same framework for data sharing the purpose can be research. Now in a way you can say a patient can request it and they can use it for research or not, but it does have an implication, because patient may say I delegate this organization

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to have access to this data on my behalf.

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And that may be a CIO, or some other research organization so I think at some stage we need to see that is in or not and how to fall that then and there can be more use cases which may not be mentioned here.

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So having a general statement like this is very useful. If we do decide to use it.

Otherwise, I also want to point out what Steve mentioned before that meaningful users, not use that often at the stage because it's kind of being censored.

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But I'm wondering, it's okay to have a statement of for reporting and compliance reasons.

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If something has to be done because those we don't see the that those are going to end.

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And it will come in one shape, or the other. So having one of those kind of a line item being covered in general, may be helpful.

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Thank you.

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Morgan.

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Thanks, Jen.

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I would add to the Linda's comment that may we expand care coordination and treatment to coordination of services if we want to capture social services, eventually, that what they do might or might not fit into treatment to maybe broaden that

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a little bit, and Devon raises a really significant

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question for us about what's permitted and what's required and then the construct of HIPAA, that other, other than things that are directed by the patient.

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Most almost everything in HIPAA for HIPAA purposes anyway is only permitted. And it's not HIPAA doesn't require do anything it only allows things, some of which is combined with other things that are required course but.

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But I think we need to, if, if we are going to say what we think is permitted is required.

That's what it means to participate in this event and we need to we need to be really, really clear about calling that out, I think, particularly, particularly

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if we're talking about say again, to use the context. If we're talking about, about saying that that exchanges there disclosures that are permitted under HIPAA are going to be required.

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If you're participating in this in this agreement.

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And that, in the end, and then the ultimate question there is, is how much patient control, do we do we propose to infuse into the system.

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Do we want do is, is the patient going to go into control the movement of their information, pretty much across the board, again, potentially, again, potentially, including disclosures that could be made under HIPAA without patient consent.

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Do we want you to we say we want to have a space for that.

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Or, or is it that I don't mean to put a dark spin on it.

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But, but, or do we mean, know the system now the system knows better and then this kind of move your information.

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So you bring up a really good point, hugely important, which is to what extent are we, requiring things that are not necessarily required. And so what we heard we heard a lot of folks talk around reciprocity being so, so important that you can access

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my information but I need information from you to do my work but I can't get that even though it's legally permitted. And so what we heard a lot was that a lot of existing agreements, already have some requirement for bilateral exchange for treatment

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for example. And so the question then became the there is a lot of neat out there for information for more than just treatments.

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And what should that be, if, if there should be any because if we have an agreement that everyone is required to sign that just says you can share, well they can already share, and we find though that a lot of folks don't already share.

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So, if, am I hearing that maybe some of these purposes are too many under the label required purposes, should there be less of them.

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Because even if we don't say they're required, they're still permitted. Right. And they might be required under a different contract, or they might be required under different law but you know they're if they're still permitted they're still allowable,

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so if something else is requiring that exchange, you can still do it. So, um, so can you maybe I recognize we're out of time so

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that's kind of the balance that we're sort of struggling with, and as you see, and so I think at this point we're going to we're going to move forward to next steps.

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I'm going to stop sharing.

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We just got into such a great conversation.

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Let it became hard not to continue so I forgive me for that. And instead, why don't we go ahead and put it up on, I believe we're at slide 23, so that folks can pull that up and Donna Hadean can talk through what sort of the next steps are.

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Thanks Jennifer I always feel like I'm interrupting a heated conversation, interesting conversation so you guys will be back on February 23 but in the meantime, we do appreciate everyone's participation today, we will get you out of here on time.

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Please take a look at the notes as we get them back out to you, the revised agreement will take this as we usually do and take your advice and input and coalesce something that we can give to you to react to before the next meeting.

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So thank you all for being a part of it. If we can get to the next slide you can see the date, February 23 and following that will go monthly until April, really appreciate everyone's willingness to bring this major project forward, and everyone's time.