



**California Health & Human Services Agency
Center for Data Insights and Innovation
Data Exchange Framework Stakeholder Advisory Group
Data Sharing Agreement Subcommittee
Meeting 4 (February 23, 2022, 11:00AM – 1:30PM 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 4. 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.

11:00:58 Okay, Good morning. We're here for the excuse me Hello, my name is Julian, and i'll be in the background.

11:01:08 Entering any zone. technical questions. you experience difficulties.

11:01:12 Please tap your question into the Q. and A. and A.

11:01:14 Producer will respond during today's event live close captioning will be available.

11:01:19 Please click on the Cc. button at the bottom of your zoom window to enable or disable.

11:01:24 Alice will now cover the meeting participation options. Alice, you now have the floor.

11:01:28 Thank you, Julian. Next slide, please. There are a few ways. Attendees may participate today.

11:01:35 Participants may submit written comments and questions through the zoom.

11:01:39 Q. and 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 framework updates to cdi

11:01:52 at Chhs. ca dot com next slide designated times spoken time, comment will be permitted.

11:02:01 Participants and subcommittee members must raise their hand for zoom.

11:02:05 Facilitators to unmute them to share comments.

11:02:09 The chair will notify participants and members of the appropriate time to volunteer feedback.

11:02:13 If you logged in via phone, only press Star 9 on your phone to raise your hand and listen for your phone number to be called.

11:02:22 If selected to share your comment, Please ensure you are unmuted on your phone by pressing Star 6.

11:02:27 If you walked on via zoom, interface, press, raise hand and the reactions button on the screen selected to share your comment, you will receive a request to unmute.

11:02:35 Please ensure you accept before speaking. next slide public comment will be taken.

11:02:41 During the meeting at designated times, and will be limited to the total amount of time.

11:02:47 Allocated individuals will be called on in the order in which their hands were raised, and will be given 2 min.

11:02:53 Please state your name and organizational affiliation when you begin.

11:02:56 Participants are also encouraged to use the Q. and A.

11:03:00 To ensure all feedback is captured. Or again, you may email comments to Cdi at Chhs.

11:03:08 Ca: gov that i'd like to introduce Jen Schwartz. Jen, you have the floor. Thank you so much.

11:03:14 Good morning, everyone. I am certainly very excited to start our meeting today.

11:03:18 It's very good to see all of you today.

11:03:22 We have a very busy agenda as you can See? we're going to, you know, be very happy to hear from the public who are going to discuss sort of the data sharing agreement development updates have a conversation with some threshold

11:03:36 questions similar to how we have done it in the past meetings and again go through the second set of topics and draft language, and then we're going to wrap up with some next steps with respect to what's coming up and sort of the

11:03:52 timeframes with which we need your feedback. So, and thank you.

11:03:55 Thank you so much again for joining us it's very exciting So why don't we go ahead and dive into roll call so ashish a treasure from Uc.

11:04:06 Davis health. I believe I saw him are you here Yes, I'm here.

11:04:16 Thank you, William Barcelona from America's position groups I'm here.

11:04:21 Thank you, Jennifer. thank you. Jen barons from Lanes here are struggling off, Mute I'm here, Michelle Shelley Brown, private practice attorney.

11:04:36 Good morning, I'm here. good morning, Louise Kratara from County Welfare Directors Association of California.

11:04:46 Good morning. Good morning, Elizabeth Killingsworth from manifest medics.

11:04:51 Good morning. How long kim from kaiser permanente i'm.

11:04:59 Here, Patrick Crillidge from health net. Good morning up here.

11:05:04 Good morning. Carrie turned her off from the California Department of Developmental Services. Morning.

11:05:10 Jennifer. Good morning, Carrie. Stephen Lane from Sutter. Health Palo Alto.

11:05:14 Medical foundation. I am here with bell Zone you're excited too.

11:05:22 Lisa Mattibaro from planned parenthood affiliates of California, giving you just a second because of the the fun we had with mute.

11:05:37 You sorry there. Okay, Devin mcgrath from invite I'm going to start out in your tay.

11:05:47 Right? Yeah, it's Okay, don't worry about it I wanted to pronounce the Latin pretentious this morning.

11:05:55 So I apologize. No need for apologies. I am here, thank you.

11:05:59 Good morning, Thank you, Eric Raffin from San Francisco, Department of Health.

11:06:03 Good morning, jennifer i'm present thank you Morgan stains from the California Department of health care services all right, everybody Good to see you all again.

11:06:13 Good to see you, too, Ryan Stewart, from common spirit health.

11:06:22 1 s. Ryan, are you there? Okay, li tian from electronic Frontier Foundation?

11:06:30 Hi i'm here. Thanks. Good morning, Lee Belinda Waltman from Los Angeles County Department of Health.

11:06:37 Services. morning. Good morning, Terry Wilcox from health center partners.

11:06:43 Good morning, i'm here we're doing something a little different this morning.

11:06:48 I'm sure you've noticed clearly since I was so very excited to start the meeting.

11:06:55 We are not gonna have John, o'hanie and he's our executive sponsor today, so you are stuck with, or let's say, blessed with having a little bit more of my face during this meeting so thank you for

11:07:05 your patience, and we will continue to move through with our meeting of objectives.

11:07:11 If you go ahead and go to the next slide so as usual, I'm going to read from our vision that every California and the health and human service providers and organizations that care for them.

11:07:22 Will have timely and secure access to useable electronic information that is needed to address their health and social needs and enable the effective and equitable delivery of services to improve their lives. and well-being next slide please so today we

11:07:38 have kind of a packed, a packed goal. Here we have 3 sort of objectives.

11:07:45 First is to kind of go through that development and finalization approach again, because i'm sure folks are very keen on sort of understanding when you know the feedback comes in on the draft language.

11:07:56 2. we're gonna continue to discuss some threshold questions that will inform the development of the draft language.

11:08:03 And then 3. we're going to discuss that second set of topics and draft language towards the end.

11:08:09 Next slide, please. we're gonna go ahead and go to public comment period, and i'm going to hand it over to is it, Alice?

11:08:20 Or is this where I assist by saying those in the public audience who have a comment, please insert it in the Q.

11:08:29 And a or you can raise your hand. you the zoom teleconferencing options, and you will be called in the order.

11:08:34 Your hand was raised. Please do state your name and your organizational affiliation, and please keep your comments.

11:08:41 You know, somewhat succinct and respectful i'm gonna go ahead and hand it off to you.

11:08:50 And, at events, who can let me know if individuals have raised their heads so we can take them off neat.

11:08:58 Don't see any hands raised at this time Okay, Why, don't you just get a bit of an element.

11:09:05 Yeah, perfect. Okay, no hands raised, I think we can so please keep in mind if you're a member of the public.

11:09:27 You can go ahead and insert comments in the Q. and A.

11:09:30 So you do have an opportunity for feedback. you Can also, of course, provide feedback through other modalities, such as email.

11:09:38 Why don't we go ahead and go on to the next slide all right, and if we could go into the next slide, Okay, So we've talked a little bit about this in the past, where we are, We're sort of on a

11:09:53 parallel approach between the data sharing agreement and the policies and procedures.

11:09:59 So both the policies and procedures and the data sharing agreement, all need to be completed by July.

11:10:06 The first 2,022 according to a b 133, or that's our working law.

11:10:11 So the way, if it works of handling the these parallel tracks, because often you can expect, and as we've talked about the data sharing agreement is kind of a high level, you know, responsibilities document and policies and

11:10:26 procedures tend to be more detailed and more on the ground.

11:10:30 And so how we're treating this is as we go through the process, we are going to be doing a high level legal agreement with sort of all of those components that you would usually find in a legal agreement which can be

11:10:43 executed by the time of the statute, requires, which is January, the 30 first, 2,023.

11:10:49 The components are going to be, of course, a very streamlined document, and tended to not be 500 pages intended to leverage existing, sharing agreements that are already out there.

11:11:04 Such as Dersa and care quality, but avoid duplication, and conflicting with those existing agreements.

11:11:10 Example, content would be sort of the things that we've already discussed, and that are coming up definitions, uses and disclosures.

11:11:18 Who are the parties, You know. What is the intent around this?

11:11:23 And you know a lot of legal ease, the policies and procedures, because policies and procedures need to implement or operationalize the the structure of the framework, not just the data sharing agreement, but also the structure.

11:11:38 Of the framework itself. Those do need to be more detailed, and in some ways we need a little bit more information before we can finalize on this.

11:11:48 Policies, and procedures need to be flexible and need to be updated and upgraded and evolved with time.

11:11:53 So the way that we're approaching this is to create a set of foundational policies and procedures that'll come out by July the first 2,022, just like the statute requires and then continue to develop and work

11:12:05 on the policies and procedures necessary for implementation and operate operationalization of the framework itself.

11:12:15 So these are the detailed requirements again they're going to evolve through time.

11:12:21 They're going to you know, create the governance in more detailed way, and in essentially established modifying the the policies and procedures.

11:12:31 The sort of kinds of things in the pnps would be technical standards and specifications, compliance and penalties or enforcement or complaint process, governance process, dispute resolution.

11:12:42 So these were the kinds of things that'll go in the pnps next slide, please, and here's the process for how we're going to go through the rest of the time we have together and the rest of the time we haven't

11:12:57 sold July first in the development of the data sharing agreement.

11:12:59 So again today is the our fourth subcommittee meeting and we're going to have that conversation around the second set of draft topics, and then we'll continue to to iterate this as we move forward the final

11:13:14 draft that includes the entire draft will be released.

11:13:17 May, and that will be for public comment. It will be released to the subcommittee.

11:13:22 It will be released to the advisory group, which is kind of what we are.

11:13:27 The providing recommendations to and it'll be released to the general public for comments, and then, of course, we'll take in all those comments, and then by July, the first we will release the final data sharing agreement

11:13:41 which is, will be intended to be the one that folks I not to.

11:13:45 So I hope that's pretty clear are there any questions around how the visa.

11:13:53 This approach for development. Let me see, do we have any questions around this I'm.

11:13:58 Not seeing any hands. Yes, Devin. Yeah, So the so after April the 20 sixth does the does this Does this group's final recommendations have to first be blessed by the full group before it gets released to the public or is

11:14:17 it going to be released before group and the public simultaneously, because that's what it sounded like.

11:14:22 But I just wanted to check that's a great question and I believe, and I could be wrong.

11:14:31 So if i'm wrong I would appreciate somebody to jump in and let me and let me know if that's a mistake, because I don't want to give misinformation to the group, But I believe it'll be released at the same

11:14:40 time. Helen. Yeah. Who is developing the policy policies and procedures that document?

11:14:53 The details that's a great question to develop and so what we are gonna see is that there will be input from the advisory group from this subcommittee and from stakeholders.

11:15:06 And then the team will be developing those which will be sent out for public comments as well.

11:15:13 That might change a little bit, as we are sort of looking into.

11:15:18 How we develop that with the understanding that some of these pieces that we've been sort of creating on a parallel track need to be finalized a little bit before we can create policies and procedures to operationalize them.

11:15:30 So you'll there'll be an update around that process in the future as well.

11:15:34 I recognize that time is fast, and that's one of the reasons why we have the goal of putting out some foundational policies and procedures, and then flushing out and doing more development with time.

11:15:47 Elizabeth, so given that we can only go so in depth.

11:15:53 In our discussions here, and oftentimes elements are left unaddressed, or there's additional feedback that might be worth providing.

11:16:03 Is there a preferred path for each of us to provide written feedback on the potential documentation?

11:16:12 Do you want us to send it to someone in particular, Do you?

11:16:17 Does it need to be provided as part of this? Open me, What would be the best way for?

11:16:21 Not just me, obviously, all of us, to get our feedback to you.

11:16:24 Kind of after we've had a chance to digest the meeting. That's an excellent question, and at the very end of this slide show at the towards the end of our meeting where it's in the next step section there be an an email address

11:16:39 and one of our wonderful team members named qua and that's where we would like you to send the written feedback that you might have.

11:16:48 And so, and what we can do is we can, of course, remind folks that When we send out an email, we can let folks know this is the perfect way.

11:16:58 And we need to sort of document that information that comes in.

11:17:00 Of course you can send information, you know, through this forum you can send it, you know, any way that you'd like.

11:17:09 The preferred method, though, is to to have it come into one person, so that we can document.

11:17:14 We received it, and then we can process it in our in our process way.

11:17:19 So that would be the ideal way does that help thank you I'm, not seeing any other hands.

11:17:32 Let's see. So I think we can go ahead and move on to the next slide.

11:17:40 And why don't we dive into the threshold questions? So we do have 4 threshold questions to sort of dig into today data quality uses and disclosures especially protected information and minimum necessary the go ahead and move

11:17:54 into the next slide. So with respect to data quality there's a lot of conversation around the need for meaningful for useful information, so that that information can be meaningfully used, and the data quality has a real impact on the ability to use information however,

11:18:17 there there haven't really been a sort of national set standards for for data quality or for how data should be collected. In essence.

11:18:27 There are a lot of entities that have not had to necessarily collect data that is clean and validated.

11:18:34 But our collecting a lot of data that could be useful.

11:18:38 And so we engage in a need for some balance here between the need for high quality data that can be useful and that can allow for meaningful.

11:18:48 You know you use of that? and then there's the concern over the cost of how to clean it, how to validate it?

11:18:56 Who is responsible for the cost and and what that looks like.

11:19:01 And so we did get a question really quickly in the chat over.

11:19:07 And I want to hit this. because what is the definition of data quality?

11:19:12 Well, that is a fantastic question and I Think without going into sort of like a technical definition, because I don't think i'm capable of doing that at this moment.

11:19:21 What i'm gonna say is that data quality is it's it's accurate, and it is precise.

11:19:30 And so we're talking about data that how has maybe some things that are accurate.

11:19:36 But other things that are not so. maybe my name in the data is you know, Jennifer, sleep incorrectly, Schwartz. It's still me.

11:19:45 But maybe that data isn't perfect so that's a very very, very simple, you know.

11:19:50 Example of how data quality could matter. So there are as you can imagine a lot of jennifer's in this world, and a lot of people named shorts.

11:20:00 So when it comes to knowing that I'm the corrupt Jennifer Schwartz, a name that has a lot of people attached to it.

11:20:07 It's kind of important that you get that right and so quality can be an issue around that.

11:20:13 Now, obviously there are ways to validate who I am.

11:20:20 But in just trying to go into. then eric made a really great point with respect to usability availability, integrity, so accuracy, precision, and validity.

11:20:32 So that's kind of what we're talking about here is how accurate and precise!

11:20:37 And usable? Is it versus? Does it need some work?

11:20:42 Do we need to do work on it in order to have it be accurate, precise, usable, and valid.

11:20:48 So i'd like to open it up to conversation because this is A.

11:20:53 This is a challenging issue. To what extent should participants be responsible for the quality of their data?

11:21:00 Should requirements different depending on the kind of entity it is and the industry they're in.

11:21:06 For example, should there be a higher standard for health versus first social services, Should H.

11:21:13 los have a higher standard versus community-based organizations in the sense of the data quality.

11:21:19 What do we do about government entities? for example so we'd like to hear from you on that in addition, if we should address data quality, where should we address it?

11:21:30 Should it be, and the data sharing agreement? should it be in policies and procedures?

11:21:35 Or should it be through some other kind of mechanism so i'm going to open it up so that people can weigh in because

11:21:42 This is a huge sort of topic that has been debated in many other arenas, and so, hearing it now is really critically important. As we get down to, you know, creating the policies and procedures and the data sharing agreement, nuts there

11:22:00 we go, kerry Hi there, you know one issue that I'm thinking of just with my department and developmental services is the potential lag of data that's uploaded that we would have available to present in the Hiv

11:22:22 that would impact the data quality. So, for example, claims data may take up to 3 years to be inputted in to where we don't know the services and supports a particular consumer or patient received

11:22:41 From our system. That might be very relevant, you know, for purposes of the exchange.

11:22:46 Are we thinking of addressing these issues and policies? Or, you know, because I think some of the stuff is set in law on how long it takes to upload the data?

11:23:00 And whatnot, and i'm just kind of thinking broadly right now.

11:23:07 So let me make sure that I understand. Your question is your question the timeframe for a response.

11:23:14 Once you get a request for information, or is the question, How often do I have to refresh my data, So that it's the most recent exactly for purposes of the Hiv.

11:23:27 What are the expectations on? How fast to upload the information?

11:23:33 So that the information accurate and of the highest quality so that's an excellent question, and the A.

11:23:47 B, 133 talks about real-time sharing.

11:23:50 So I think that the goal of that that legislation was that we would have sort of the most accurate and most available. And so some health information organizations are are going to do this in real time, and and aren't going

11:24:07 to sort of have a lot of state entities, for example, that have information that comes in periodically, but not live or real time.

11:24:17 And so there are set limits on when that gets refreshed or updated with the more gathering versions. And so I think the goal is to be as real-time or live as possible.

11:24:29 Elizabeth. So how would you intend to deal with the different levels of responsibility for different entities in a data exchange?

11:24:41 So the I agree with Devon that generally speaking the standard today appears to be.

11:24:45 It's it's as is we will give you what we have we cannot validate all of it.

11:24:51 Different entities arguably Have different control over that if you're looking at an aggregator today.

11:24:57 If you're looking in Hiv today they're accessing data from hundreds of different points, and cannot necessarily go through and validate the data, how would they know if that was a correct reflection on a particular patient?

11:25:11 Right, whereas providers could but is that a reasonable expectation of them, if we're asking all of these small providers to go through of their records, bring up today, like it's what any given entity in this

11:25:23 in the system can do is very different and that that's sort of why the default today has been no negligence, right?

11:25:33 You. You have to give what you have, and you do your best not to include obviously erroneous data.

11:25:37 But essentially here's what I have and it's sort of on the providers who receive it at the end to validate that with their patient as necessary, and so on, and so forth.

11:25:49 So I i'm struggling with How you intend to address data quality here beyond the bare minimum of you cannot knowingly introduce errors.

11:25:59 So your question is our question. Is there a need for us to tackle this issue?

11:26:05 Maybe there, isn't maybe it's simply a matter of doing the businesses we've always done and wait for instead of doing it here in our small region, waiting for some kind of national approach to happen and that's perfectly

11:26:20 legitimate, but the the feedback we received was the data quality might be something that's an issue, and in that case it's really it was critical for us to hear from from you all in particular around.

11:26:34 Is it an issue? and if it is what's the solution and you know is the way we do business now adequate, and if it is, that's that's fine If it's not, then what we do need to know is how

11:26:47 it's not, and is is there a way to address it I don't know if that answers your question.

11:26:55 I just literally asked a question with a question so that wasn't really helpful in a way.

11:26:59 But it's really it's kind of that's what We're trying to elicit is is do we need to address this, So I want to say, Patrick, I think you Were next?

11:27:09 Hey? i'm. Good Good morning, good afternoon, thanks for the chance coming from a payer perspective.

11:27:16 I'm gonna start with the kind of the hub and spoke model with a health information exchange.

11:27:19 I think it's important that we address data quality in some generic terms for responsibility.

11:27:26 For example, a health information exchange is responsible for getting data may not be completely responsible for data in the source systems.

11:27:35 Whether that's accurate or not but we've got a responsibility to what we receive is stored in the Hiv systems, and is also used.

11:27:45 Their portals are passed on to others. So a health information exchange has a debt responsibility of maintaining the quality of the data that comes in to the point that it should be written saying, Hey, If you get a variable a in a

11:27:59 field, it should be stored in that variable in your systems, and it should be presented and as variable as an example.

11:28:08 The suppliers. I think There's there's the Slippery slope is. there? are different levels of suppliers, and every supplier for Elizabeth's comment was was great Hey don't introduce no errors

11:28:23 I think, is a great thing, but every supplier, I think, is responsible to to provide their data, to accurate.

11:28:30 In our systems, for example, if there's a mapping that's done like an extract.

11:28:34 If if I have column of field A and column B and I pass that on to an Hiv.

11:28:41 And I and I Mis map it i've got responsibility as the supplier, to make sure that it is accurate.

11:28:47 So, so, being silent, I think, is is easy to do. but I think we should have some, some benchmarks, or some wording that says that the the source systems that supply responsible for the data quality that They have it may not

11:29:01 be accurate like a phone number may not be accurate at the time, but it's the best that's available, but we're responsible for making sure we supply best known accurate data.

11:29:13 The the Hivs are responsible for getting that and mapping the correct fields and pushing it back out.

11:29:19 And then my organization is a pair. We may have a higher standard of data quality based on the the size, scope, and the it resources.

11:29:29 Then a small supplier was just beginning with an Hiv.

11:29:33 So I do think they addressing quality responsibility and expectations is a good thing in the contract and or in the legal agreement, and how we do it.

11:29:43 I'm going to leave it up to the experts thank you Patrick Stephen.

11:29:51 I'll just sort of select some of the things that We've been dropping into the chat I mean Patrick's point is well taken.

11:29:57 I mean each different data holder has different responsibilities for the quality of the data in their system.

11:30:03 If there's data that they're generating within their system they have one set of issues.

11:30:07 If It's data they're receiving into their system they have another set of issues.

11:30:11 If it's data that they're then realizing you know there's there's yet another set of issues.

11:30:17 So you know the the Hiv. Now you know has a whole set of data quality issues that we probably don't need to discuss in detail here. But I think we have to appreciate that that quality.

11:30:28 You know, runs across all of this. But we started out talking about sort of the quality of demographic data that were some comments made about that in the chat.

11:30:37 And and I just want to reiterate the fact that there are evolving national standards for data elements such as names such as address, that are working their way through the process of being being named in federal regulations.

11:30:51 So we kind of know where that Puck is going, and if we want to, you know, be be progressive and adopt, and point to those standards early on.

11:31:02 I think that would be. That would be a great opportunity for us at the state level.

11:31:08 Thank you, Stephen. Lee. Yeah, no it's great to to to learn about all these different sets of standards that I was not aware of of before, so that that's that's nice the the thing that I am concerned about

11:31:21 is that it's one thing, to have a standard to by which to evaluate, and it's another thing to actually have a applied them, or use them or to be able tested them against the data right I mean in the

11:31:32 in the old days when companies were sucking in and doing a lot of data data warehousing the so much.

11:31:40 So money and work was spent just trying to row the data sets they were getting to make sure that they were good enough for whatever direct marketing or whatever they were going to do, because accuracy matters, even in marketing and advertising so one of

11:31:57 the questions. So for me you know one of the things that i'm curious about is, I don't know how much what we know about the current level of of but what's our baseline in terms of accuracy and whether

11:32:11 it matters. So, for instance, one of the things you know we don't want to spend the time on things that don't really matter.

11:32:18 So if we're, generally confident, that the quality of at least health data held by most say covered down at ease, and you know hipaa payers, etc.

11:32:30 Is good, and we can't and we're able to back that up. And we then the questions we're having here about data quality made me more theoretical at least for for that kind of data like you know at lab core

11:32:44 and various other things, and then we you might say well, but then we worry more about whether or not the ask nation of a race or ethnicity or gender, which may have and which may have a Federal standard.

11:32:59 But I don't know that any person who is reporting their own race meets the you know the uses those standards, or anything like that.

11:33:06 So there's a number of places, where I think that the type of data to a different question about quality, and the effects are different, because it's not going to be about whether or not you necessarily gave the right treatment person but whether or not within the context of Hiv, and we were evaluating equity bias.

11:33:26 And you know, demographics, cost regions, and making decisions about that.

11:33:30 Whether or not there was sufficient accuracy for those sorts of things, or whether there was some sort of of skew.

11:33:37 And then the last point would would be that I agree. I mean it sound.

11:33:42 It makes sense to me that you know you can't fix all these things right now, and so that something like an as is is going to maybe gonna be the practical answer to this.

11:33:51 But then, in most areas, then there's a liability kind of of thing at the end, where yeah, everyone's responsible.

11:34:00 But at the end of the day, if a patient or if a person, or if a group is harmed because of inaccuracy, the there's going to be need for some kind of a remedial process, and it's not

11:34:18 clear to me how any of those kinds of things are are going to work in the context of of the Hiv.

11:34:27 Who would be you know who'd be who'd be soup?

11:34:31 What would the standards for liability be? how how would you actually work out that lawsuit?

11:34:37 So i'm you concerned about the at the end of the day we can talk about everybody's got the wrong responsibility. but as a lawyer, and as someone who used to sue people it's like Yeah, but that kind of does depend on

11:34:49 how, but where the rubber meets the road on damages and junctions and the lawsuit, So that's kind of my my general area of question.

11:34:59 Thanks. Thank you, Lee. So then, why don't I throw this out? a more threshold question, which is, do we have a problem with data quality in our existing systems. in the sense of the the way that we currently do business in sharing data is

11:35:16 this? Or is this a problem we need to do something about?

11:35:19 Or is the way that we've already? approached it adequate to a to handle our needs? For this we raise a good question, which is, Do we actually have a problem?

11:35:30 Is this something that we should be spending a bunch of time on, or our other people spending that time already?

11:35:35 And you know we can address this, maybe in the future, through policies and procedures.

11:35:41 When it comes down to that, Louis I believe you were next Lewis, you're on mute.

11:35:58 There you go, my apologies. Double music. Sorry I had some thoughts to to talking to a couple of speakers.

11:36:08 1 one. I I think the sender should be the primary response.

11:36:13 Have the primary responsibility for data quality. I believe it should be handled in the Davy sharing agreement.

11:36:20 I think it should be stricter for governments and health care and for a Community-based organizations, maybe less strict but expected in the data sharing agreement.

11:36:32 And I think we you know we have to acknowledge that some organizations have limitations on the data they're able to collect, and their size and the complexity of their system.

11:36:43 I think we have to augment somehow or recommend augmentation with funding for source system, improvements and data quality management tools.

11:36:55 That can be applied on the sending or the receiving end for some fundamental data.

11:37:02 And I do believe we have data quality issues and a a career observation of mind that a lot of systems will have duplicate clients clients with aliases.

11:37:19 Constantly to match or have multiple people in the same system with different designations.

11:37:28 Just because of data entry errors and although there are allowed and new tools out there, and things are getting better.

11:37:35 Historically. i've seen that be be a problem in a lot of system.

11:37:42 That we have. We have data quality issues to address. I also know that there are limited opportunities to get some data from some folks depending on their life.

11:37:59 Circumstances, and the times that we're engaging and then what we can collect, and we have to account for that because we're so not going to get every single thing about every single person in which we're engaging them, and so we

11:38:15 have to account for those. Those are my thoughts. Thank you, Lewis.

11:38:20 We have time for 2 more, Stephen, and then Ashish, Stephen, go ahead!

11:38:23 Great. Yeah, there's been a really rich content in the chat. So I encourage people to continue to monitor that, you know, I think data quality is just inherent in health related data, you know, as a primary care physician

11:38:39 you know we are constantly relying on what's reported by the patient.

11:38:43 What's reported by caregivers you know what comes from, You know all manner of outside organizations, be they sources or collectors. so I think it's critical.

11:38:53 That we maintain a focus on provenance, that that we know where the data has come from.

11:38:58 You know who was the author? How how has it made its way to me, you know?

11:39:04 Did it go through an h ie. or somebody else who might have done something to it, you know, and then we need to take that into account when we're looking at that data, but keeping that provenance information front and Center you know not

11:39:15 only the the minimal provenance data that's now required in us Cdi version version.

11:39:22 One, but also, you know, additional provinance characteristics that I think we might want to consider defining as we go forward.

11:39:31 Thank you, Nashish. Yeah, just for to build on what Steve was saying. I am wandering.

11:39:37 We need to save wherever structured data is available that should be shared, because structured data is much more reliable than unstructured data which is in documentation and physician notes or faxes or papers in that

11:39:52 regard. There is already a lot of initiatives in Emrs to increase the quality of structure data.

11:39:58 So we don't have to dovetail into that like medication.

11:40:03 Reconciliation labs are nearly always accurate.

11:40:06 Right with certain exceptions. So So I think if there is an ask for the data, and that data can be brought in a structured format which is basically using standards which are now national channels, we are inherently than having

11:40:21 a very good standard in terms of quality of the data we would not be, I presume, able to, and we don't want to go to a level where we can say data accuracy should be checked.

11:40:30 That's such a big barrier and burden for most of the sites who do not have tools to look at unstructured data and the quality before sharing right, but adding Metadata like Stephen

11:40:43 mentioned. Who is the primary source of the data? right? Is it patient reported in some cases at that comes, is it?

11:40:50 Ehr report is coming through. Hiv and timeliness of the data are very good kind of definitions which can actually carry carry forward along with the data exchange.

11:41:04 Thank you. Thank you all for the robust conversation we are monitoring the chat.

11:41:11 We will be looking through that. So please feel free to continue adding items to the chat.

11:41:17 Don't feel like we're ignoring that Why don't we go ahead and go to our next topic.

11:41:21 Please. Okay, so uses and disclosures. and this is intended to be different from sort of the required responses we we saw earlier in.

11:41:33 You know our meetings. This is really about how participants might want to retain use, reuse, repurpose information that's received through the framework.

11:41:43 For example, we've heard a lot of stakeholders talk about how they would like to de-identify data for use in research or in business planning.

11:41:52 For as an example of what to do with data that has already been received.

11:41:57 So part of this conversation around future uses of data. To what extent should participants be able to retain, use, reuse, repurpose data received through the framework?

11:42:12 A lot of existing data, sharing agreements of limit, retention, use, and redisclosure.

11:42:18 Should the framework data sharing agreement include any additional requirements for data use for tension or redisclosure?

11:42:27 Or instead, should it just say comply, you know, comply with applicable law.

11:42:31 So you need to follow applicable law with respect to whether you can retain it, use it or redisclose.

11:42:39 It. Should the ability to retain, use, reuse, or repurpose data be limited to business associates only, for example, often business associates are performing functions on behalf of a covered entity.

11:42:53 They have an explicit agreement with the covered entity over the kinds of functions.

11:42:59 The uses of the data that can, they can perform. And so should it be limited to just business associates.

11:43:07 If not, are there other types of participants that it should be limited to?

11:43:11 So these are the kinds of conversations around future use that we were hoping to to elicit from you.

11:43:17 And I see we have already somebody who's raised their hand Morgan, do you want to go ahead and jump in?

11:43:24 Yes, thanks, Jim. I have pretty strong feelings about this one that that this needs to be a closed container.

11:43:33 Indeed i'd say for my department's purposes we're we are subject to Federal limitation.

11:43:41 That only allows our data to be used for purposes that further the administration and Federal level, the further administration of the Medicaid program.

11:43:51 So if we we think that this state is gonna go other places for other purposes, that we don't have any me say so about

11:44:00 I don't know that we would think that we would put our data into such a system.

11:44:08 Thank you. Morgan Devon. Yeah, this is a tough one.

11:44:16 Because I think it does create. I I think I we will have to sort of explore the legal limitations on some of our, some of the participants in this network.

11:44:26 With respect to downstream uses of data for sure but where there are no such legal limitations, but just a desire to kind of control the downstream uses.

11:44:40 It gets very difficult to do that, because it essentially requires every single data holder to kind of create a separate cash.

11:44:46 C. A. Ch. of the data they've gotten from the network versus the data that they have, you know, gotten through other sources in order to make sure that they are not using it in a way that is that might be completely consistent with

11:45:02 law, but is but is forbidden by the terms of disagreement.

11:45:08 I think that that it's just not workable from an exchange environment.

11:45:14 So generally. What you see in the existing exchange agreements is this sort of an expectation that data received through the exchange is going to be treated in accordance with raw in terms of its further use or disclosure

11:45:28 generally is my recollection, although folks can certainly chime in if there's a piece that i'm missing.

11:45:37 But one other piece we could consider is where we have endpoints that are receiving data through the network, who, in fact, are not subject to subsequent strong laws regarding how they might be using the data.

11:45:52 They're receiving through the network that They kind of agree to abide by a certain legal framework with respect to that data.

11:45:59 That's actually the approach That's being taken in the common agreement with the Tefca is sort of an expectation of kind of minimum minimum requirements regarding treating that data frankly, They they model

11:46:13 hipaa which is which might be one way to to go about it.

11:46:17 But it but admittedly it's it's extraordinarily tricky to to try to cabin the downstream uses and i'd want to explore morgan's concerns about the

11:46:28 constraints on how recipients of his data. need to be further constrained to allow them to participate in the in the network. because obviously, that's something we need to pay attention to.

11:46:40 Thank you, Helen. Yeah, I think I would go. I think I feel strongly about this one.

11:46:49 I I think that what's the tookable law would be the base, the floor of what these are recipients would need to.

11:46:58 The here, too, but I I looked strongly you know, encourage a prohibition against, you know.

11:47:08 Secondary use for certain purposes like for or private benefit and it's only because there are so many organizations.

11:47:15 Now that even healthcare organizations that that use data for building artificial intelligence or machine learning capabilities and that sort of thing.

11:47:28 And even if it's de-identified and aggregated that's valuable data that for example May as a patient would not necessarily think my dad would be used to be creating.

11:47:44 So I I think that there I think it is tricky in terms of being able to the cabin.

11:47:49 The downstream uses of this data. But to think that the secondary uses of it be unrestricted, and building commercialization and going potentially, I and be very careful.

11:48:05 And want to happen. Restrictions that i'm that is the secondary.

11:48:12 So, thank you, Helen Lee. Yeah, so helen said what I was going to say from sort of a a values of intent approach.

11:48:26 I think it's it's really and to the extent to be very careful about the downstream uses recognizing that it's incredibly tricky as Devin was saying I also but a friend, I think from a twist standpoint, which

11:48:40 comes up a lot right I mean patients and the citizens have to be able to trust that when their data is going into the Hiv. that's not being used in ways that they don't expect, and i'll and you know I

11:48:52 use the phrase that they don't expect they are pretty meaningfully, because it's not what we expect.

11:48:58 It's a lot of things frankly the folks on this call will know much more about the way health data moves than I do.

11:49:05 As a generalist. They wouldn't be shocked by lots of things, but consumers would be consumers.

11:49:10 Will. I had no idea that you that this would allow my data to go with you there.

11:49:15 So I think that in the early, if we are in the early days depending of getting consumer and patient trust in the system, we have to double down on not allowing any potentially unauthorized, or you know un understood you uses of

11:49:35 this data elsewhere, and also because there are bad actors, or at least acting ways, you wouldn't necessarily have expected doctors and insurance companies. The other thing that I wanted to throw in here is that I I have a sympathy as

11:49:50 a lawyer for requiring compliance with applicable law. but I think the applicable law part of what we're talking about is extremely unclear and big, and you know I I can talk about that more.

11:50:03 When we actually get to that in the section on authorizations.

11:50:06 But I mean I see stuff in there that's fine Oh, yeah governmental entities, and like applicable law which you you know, even the city of California.

11:50:15 So varies depending on whether you're the state agency or you're not you know there there's a reference at 1,798.24 in you know in these documents and that doesn't

11:50:29 apply to anybody at the county city level. right I mean and if people don't know that.

11:50:34 Then they're thinking, oh, look them a lot there's hipaa level strength protecting this when in fact, there isn't there isn't anything even like that and similarly though it everything we've talked about in terms

11:50:45 of public health data, you know, when stuff moves out of an end covered entity into a Pha.

11:50:52 You know the rules tone sharply, unless you're gonna now stick in it's like, and you're still going to be restricted under cmi or hippos.

11:51:01 So I I feel like I feel everybody's pain in terms of this is being this being very, very tough to do it's. I think it's really important to to make sure that we don't have you know data.

11:51:12 About these is coming out of this in your in the first 5 years, because that's just going to crash everything.

11:51:20 I mean it's better to do it right from the beginning than to have an error that just causes the whole thing to blow up.

11:51:26 So I worry about these things. Thank you, Lee: Ashish: Yeah, hit to be had raised a little tougher challenge.

11:51:37 I think, Jenny, for you outline. we have a timeline to deliver by June some of the issues we are talking right now, which are so important, but probably are out of our comfort zone to be able to

11:51:53 decipher when there's no line clear in that space and there's a lot of other possibilities right?

11:52:00 So. so we may have to balance the the need for timeliness, because we cannot create laws while it is unclear.

11:52:08 But we can refer to it. I just want to and I want to share one aspect, and maybe we need to consider clinicians or healthcare organizations, providing care and how they're going to be using the data as different

11:52:21 and a research organization, or something outside, like an insurance company or something.

11:52:28 The reason being data by nature. is not limited to one entity.

11:52:31 Data can be owned by a patient which is always they have the ownership.

11:52:37 And the same data can be owned by multiple health system.

11:52:40 Because if a patient gets care in multiple health, systems right so i'll give an example.

11:52:45 Suppose we have one patient who seeks care at Uc.

11:52:47 Davis health get scared at Mayo for certain disorder.

11:52:50 The mail does a data exchange with us. They have that set of the data for the patient.

11:52:55 We have the same etc. They have the right to do Ai and other algorithms on the node, 5 data to have a better prediction model to help.

11:53:05 And we have that right as well. Right? So So I think there is that situation where we need to have complete set of data, and that will be inevitably there in multiple organization.

11:53:18 And they they have their own processes to how to do.

11:53:21 Second reuse of the data, but but if there's a non health care entity, which is there, we anyway need some kind of a way to.

11:53:28 We're not only requested that data is there the purpose of the data is identified.

11:53:32 I think that we can say, and then whatever processes are there we can have some guidance on that.

11:53:39 But we can't go and define every single use case in my mind, because that will be something that's taken.

11:53:46 We're gonna take us 5 years completely Understand and we do have a timeline.

11:53:53 Thank you ashes, Elizabeth. I actually agree with the fair bit of what was just said.

11:54:00 I just want to kind of echo a couple of points.

11:54:03 We did, I think, discuss something remarkably, similar to this in our prior meeting, where we all sort of came around by the end of this discussion that we're okay with saying if you're not a covered entity or Ba we're

11:54:14 still going to make you agree to essentially pretend that you are for purposes of getting data off of this health exchange.

11:54:25 We're not comfortable with that anymore I think that that's a very different discussion.

11:54:29 But that seems like a reasonable baseline. The second question becomes, Do we then add on to that?

11:54:34 And I have a bit of an allergic reaction to that, because part of what a shush was saying.

11:54:39 It becomes quite difficult to get into the nitty gritty of each thing you can and cannot do.

11:54:43 And also, just as a practical matter, especially for smaller organizations. it's much harder to manage working with a data exchange.

11:54:52 If you have to have sort of 6 different buckets of where the data can go, and how it can be used in all of these to different little formats.

11:54:59 So think that the simple baseline that seems to be pretty prevalent nationally is everyone pretends that they're covered by Hipaa and and state laws in our particular case, right?

11:55:12 And we stick with that is i'm curious from the group if there's an appetite to then go steps further, or if that's where we're comfortable. or if that's too far for some people so you raise a

11:55:26 really good point, and we did hear from folks last time have especially concerns around social services, organizations, or small entities, being able to sort of comply with hip.

11:55:38 But they're not already covered by It but It does look like we have somebody with a raised hand.

11:55:45 Stephen. Sorry I was typing at the same time, but I would just say I would consider I think it's a great suggestion.

11:55:53 I really do. I think the idea that that actors participants in this framework be expected to, you know, Comply with Hipaa requirements.

11:56:03 I would suggest that we might also consider asking them to comply with information sharing requirements.

11:56:10 So that it goes both ways. you know and again. these are these are requirements that we can look to the feds, for you know that we know they're they're evolving.

11:56:18 But I think it really does raise the floor for everyone, both in terms of making data available.

11:56:27 As well as for how they're going to take care of that data as they access exchange and use it.

11:56:38 Let me just check and see don't see any other hands Okay, Lewis, I'd just like to clarify that we're talking about agencies that may not all under hipaa Now, applying with

11:57:05 exchange, using the hipaa for regulations of exchange.

11:57:11 The data versus the whole umbrella of Hipaa on their systems.

11:57:19 So I think that could get pretty heavy for those as was stated earlier for the small Cbo's and agencies we're talking about.

11:57:29 That's a good question. So what are we saying when we say we want to use Hipaa as the Baseline.

11:57:37 Are we saying that the security rule for example, applies or are we saying that the exceptions for use in disclosure are the baseline of what we're talking about?

11:57:50 Stephen. Yeah, I I would tend to be pretty broad, you know, as we as we think that through as we interpret it. you know.

11:57:57 What does it mean that you know you're limited in you either your access, your use, your exchange, but but that you know, once you've got the data, you don't have to actually take care of it I mean I think

11:58:07 the The community as a whole has a lot of experience, you know, dealing with the requirements of Hipaa.

11:58:14 I would exclude any of those requirements, you know, on only after careful consideration. Because this is important data, you know.

11:58:23 It means a lot to people. It can hurt them in all kinds of ways that we could talk about.

11:58:30 But I think these are. You know these are tried and true standards that so many have come to live with, you know, while they are imperfect.

11:58:41 I think they do establish a really reasonable floor for us to consider.

11:58:50 Well, I guess my question would be, would Then the public health entity is at the local level or the state level that are not covered by Hipaa.

11:59:00 Would then that be something that would be a bit burdensome for them to adopt order to get them to be part of this framework, because now they have all of that infrastructure that they have to build and all of that

11:59:15 compliance. you know I don't want to use the word burden.

11:59:18 But let's call it resources that now have to be found in order to do the compliance that would allow them to be part of the system.

11:59:30 I mean public health has, you know, the opportunity of a bunch of funding coming their way.

11:59:35 That could. you know that, hopefully is being used to update their systems, you know, which includes policies, procedures.

11:59:40 You know, etc. You know, when you think about the community based organizations, they're, you know, there are going to be other challenges.

11:59:48 But but truly, I mean, what we want to build is a framework of data exchange.

11:59:52 That is going to meet the needs of an extensive group of participants. and we don't really want to build it on a shaky foundation of privacy, security, and the resultant trust upset.

12:00:11 And then, Lewis, did we finish all of your comments?

12:00:13 I apologize if I interrupted you you sell your Henry I'm. i'm concerned because I think they're and you touched on it with social services agencies in the in and out of the

12:00:28 public sector, having to become hipaa compliant in all their practice.

12:00:37 Many of May so already fall under P. I high laws and regulations, and I think that the this may be a barrier to them exchanging data versus you know an opportunity.

12:00:58 And that's what Mike my concern is I mean I I fundamentally we want informed consent and accountability.

12:01:06 I'm worried about just say the weight of other portions of Hampa.

12:01:14 That may they may already be meeting in some area but there's an administrative piece of this that I think it may become a are too much for a burden for small agencies, and concern i'm not the

12:01:32 authority on it. But my! but but I think that that's probably what would happen is that there there there would be a lot of time to have to move to something like that and and cause of a delay in and adoption

12:01:51 was trying to ascertain whether or not, you know, flying with framework for exchanging data meeting with some of those requirements.

12:02:03 If we were bifurcating that we, from the other administrative overhead associated with with Hipaa, especially, the data may already be protected by a 100 different privacy.

12:02:17 Laws, which may, in fact, be more stricter. Thank you, Lewis.

12:02:25 We have time for one more. Lee. Yeah, Most of what I wanted to say has has roughly been said.

12:02:33 I think it is really important to make sure that we have the right level of protections through the system.

12:02:41 The the thing that I am that I wanted to to to highlight was when we talk about Hipaa.

12:02:46 We're talking about a you know a fairly well-known standard that in many ways is burdensome for for many of the potential participants.

12:02:54 I do not. I am, you know, all the going to advocate for this, stronger rather than weaker.

12:03:00 But at the same time I worry more. about worry about a situation where, say, 90% of the participants are operating under a solid good hipaa.

12:03:13 But there's some some small fraction which is just at a such a low level that basically they're not they're they're really not regulated in any meaningful way, and I fear that public health is one of those areas

12:03:26 especially at the at the local county level. I think that's just something that is reality.

12:03:34 For for right now that there have been many years over which we didn't not put where they were.

12:03:38 The system did not have the political or financial will to actually be get a model, say public health privacy law that would bring up everything on the public health side, so that we'd be ready after the past public health crises and instead we

12:03:55 ran into this one, which was worse than anything anyone could expect, could have expected and exposed many, many failures.

12:04:05 Or we this is in the legal framework that i'm that you know I've been staring at I 2 years.

12:04:11 So it's hard now as we're looking at not this project to say, Yeah, let's just ignore everything we've learned about all the the weaknesses in the exchange system. and work on the on the stronger practice So

12:04:23 I think the thing that I, my counselor, the thing that I wish we were able to do is to shore up the worst.

12:04:32 The the bottom of the of the the worst actors the were the ones that have the fewest reason to protect privacy and security and help them, you know.

12:04:46 Yes, they're gonna be out there are gonna be large actors who may not be able to handle full-parently, Hipaa.

12:04:52 I worry less about them than small actors who can't handle even the smallest sort of yeah lowest level of of privacy and security.

12:05:01 Weak link is where things where things where data data always runs out.
Thank you.

12:05:08 Thank you, Lee. Okay, thank you so much for that and Why don't we go ahead and go to our next threshold?

12:05:17 Question specially protected information. So one of the things we haven't really focused on.

12:05:24 Yet. has been information that has some special protections around it We've talked a lot about hipaa and protected health information, but we haven't really talked about substance use disorder treatment.

12:05:39 Information rules, such as the Federal, you know, 42 Cfr.

12:05:43 Part 2 to the California equivalent, but health and safety code, 1, 1, 8, 4, 5.5.

12:05:48 We Haven't really talked a lot about behavioral health, restrictions in California, such as the legendary Petro, Short Act for involuntary behavioral health or the management developmental disability, services act for developmental disabilities and intellectual

12:06:04 disabilities, services, records. So there are some special information that is protected in California in particular, that we really need to find a way to address.

12:06:18 And so the question becomes, Do we need to point this out and sort of address it in the Dsa.

12:06:26 Or in the policies and procedures should. instead, we say, you need to follow all laws again.

12:06:35 That applicable law piece of you know you are responsible for knowing what those laws saying.

12:06:40 You're responsible for complying with everything should there be some kind of mechanism to inform people of what laws cover this specially protected information.

12:06:50 For example, these are just examples. Should every person or entity that is signing onto this, you know, provide a list of the kind of data with the types of laws that we cover.

12:07:03 It should the metadata be tagged with.

12:07:08 For example, this is covered by Lentum and Petra short.

12:07:12 Should there be some kind of mechanism that helps folks know?

12:07:15 Hey, this is this is not the same, you know, Phi, that maybe. but dealing with this is different, because it has different requirements or different limitations around it, and different protections.

12:07:30 So i'm gonna open it up to the conversation because We talked a lot about Hipaa, but we haven't really talked so much about the more challenging pieces with respect to behavioral health.

12:07:40 And one of the goals of A. B, 133 was for the framework to include behavioral health as well as this developmental and intellectual disabilities. services, records.

12:07:53 So. i'm gonna open it on up and looks to me like Belinda has her hand race, so please blend up.

12:07:59 Go ahead. Great? Yes, so I have strong feelings about this one as i'm sure others do, especially as a pertains to part 2 data.

12:08:07 So my responses to the following would be pretty emphatic.

12:08:11 Yes, with some caveats. The number 3 and I think if we're going to do this.

12:08:15 Well, I think the data sharing agreement really has to call out these especially protected data elements, especially part 2 separately and and not lump them together.

12:08:26 This is coming from the programmatic perspective. of just the vast number of hours that it took us to really develop a thoughtful approach, including training our end users.

12:08:38 And and how we're gonna actually implement and ingest part 2 data into our care management platform for whole person care not even an h ie.

12:08:45 Because when you or your organization becomes the lawful holder of that part to data whether you intended to or not, Obviously, all of those rediscovered rules are so stringent and so cumbersome.

12:09:01 And so nuanced so the so I think we have to call it out.

12:09:03 I think we have to set everybody up for success, especially the organizations who are not used to dealing with this data, and the social service organizations may actually be more sophisticated with some of this than than some of the other you

12:09:15 know organizations who don't deal with this and then the last 2 points to make a number 3, you know if we can tag this and and be able to compartmentalize, or segment.

12:09:25 This at the metadata level that would be ideal because, as we know, part 2 data is not about the data element.

12:09:31 It's really about the data source and It's dynamic.

12:09:35 So that same data element like Stephen was saying when it's self-reported by the patient maybe Phi, and you can exchange it under Hipaa.

12:09:42 But when that same element is either corroborated, by or then provided by the part, 2 provider, it suddenly changes, and you've got the hot potato and all those rules apply, and that part of it is so complex so I

12:09:55 think at the thoughtful approach to Metadata. It would be great, you know, maybe at the organizational or like role-based level, not at the data element level.

12:10:03 And then, lastly, I know we're going to get to this. but I think this speaks to the need for a universal authorization that really addresses all of this, because, having organizations rely on other organizations authorization especially

12:10:16 with part to data. just put a huge on on them. Thank you, Belinda.

12:10:22 I believe, Devon, you were next. Yeah, I think belinda's points are well taken, although it does occur to me that there are some changes to part 2 that are currently that were part of I think the cares not the cures act

12:10:39 of the cares act least on the Federal level, and that Ocr is currently working to implement through regulations.

12:10:49 Which hopefully we will start to see some proposals.

12:10:53 Soon to see what that looks like so that that doesn't that doesn't negate the need to think about how you know this data, which is particularly sensitive, needs to be protected.

12:11:04 But it but it it it might open up the aperture a little bit in terms of

12:11:11 How we can facilitate exchange of that data in a responsible way.

12:11:14 That is at least compliant with law. my in terms of the data tagging and other folks on the phone may know a little bit more about this.

12:11:23 There's been a lot of effort on the part of o Andc.

12:11:26 To sort of recognize some HI. 7 standards regarding tagging of particularly sensitive data.

12:11:33 I'm just not sure in in how widespread they use is of that data tagging, and how effective it is at both communicating the sort of set of expectations that come with the data downstream.

12:11:47 But also self executing on those on those commitments i my impression, and I got my knowledge of this is a little bit stale is that it's mostly in a kind of notification that the data are specially protected

12:12:03 versus way of necessarily prohibiting further uses. But

12:12:07 But i'm not sure you know my knowledge might be a little outdated. So I think it begs the question overall of whether this is just about making sure that entities that the that where there are special protections in the law that

12:12:24 follow, the data can actually be honored throughout the network or whether we want to impose additional requirements on certain data types that might go above and beyond the law.

12:12:34 My own opinion is I don't think We should because what that tends to create is nondisclosure of that data at all, because people are sort of Oh, we can't handle the additional expectations around this so we just won't

12:12:47 exchange it at all, and I think that's what we all recognize with respect to certain kinds of information is that a lot of existing networks are actually not sharing behavioral health information of various types because of the challenges surrounding

12:13:04 the differences in the laws. Yeah, and and making sure that they're not liable for inappropriate sharing. Yeah, and so.

12:13:12 But that's one of the reasons why perhaps the writers of Ab, 133 wanted in particular as to work on this issue, challenging that it is is that that these folks also deserve the same access to care and quality

12:13:29 care as folks who are, you know, not experiencing these kinds of challenges or health conditions.

12:13:35 And so how do we provide that equity while still protecting their information, is, of course, the the challenge.

12:13:45 And so you know, Lee, I think you might be next Devon where you finished.

12:13:49 I just want to make sure I didn't interrupt you know you didn't interrupt at all they think the only thing that was running through my mind is, you were talking about this jennifer is adolescents.

12:13:57 Is another category where the the the data does have special protections attached to it, and as a result, there's there, there is very little exchange through typical networks of adolescent data that's

12:14:10 a really good point, and when we didn't add to the slide, which is essentially minors or minors, 12 or 14, and over in particular places where they're entitled under California law to make their own healthcare decisions I believe devin that's

12:14:25 what you're referring to yes, it is so lee I think you are next.

12:14:33 Yes, and not surprisingly, the you know what Devin said sort of Segways into what I was gonna say, because you know, especially to protected information on Federal law is not the same as what's specially protected in California I

12:14:48 mean. I've been lately operating in the space looking at mental health and mental health apps, and Paul, by how much companies like that are in the commercial side of this the hock space.

12:15:05 And these folks are just shitting the data around. that they're getting from through the apps all over the place, and yet you know folks who are from who sort of know here.

12:15:16 But say oh, doesn't HIP have something for psychotherapy notes!

12:15:19 But of course we know that doesn't actually mean anything and for practical purposes, mental health isn't very protective.

12:15:25 Is it really protected, especially under under HIPAA.

12:15:29 But it is in California right under Petteco, and we have a lot of State constitutional privacy rights that attach to that.

12:15:34 And similarly that's the we that's the exercise the reproductive rights and stuff like that.

12:15:40 But that Devon was talking about, and and especially in a context of today, where I expect you know.

12:15:47 And I said this last time, you know, a road to be overturned by the Supreme Court.

12:15:53 There are even now there are battles around who has access to information about providers of abortions, or patients seeking them, of how medicines or other primary schools used in this in these kinds of procedures are being moved so there's a lot

12:16:11 of very, very adversarial political politically sharp interest in this kind of data which isn't unusual right.

12:16:24 We've always known that all this kind of data is that's why it's sensitive it's especially sensitive today.

12:16:30 And then I'll add just add to that we've got mental health.

12:16:33 We've got road type data and then we have still have all of the issues about how does How does that sort of data?

12:16:39 Then move into possible health, and and how control is it in the hands of of the public health entities.

12:16:47 I don't actually have any idea myself, but I feel like There are so many different pieces of this, and that there are enough very well in communities that understand the stigma are afraid of this thing of We have to actually take that super super seriously in

12:17:05 the California context, and be aware of all of the think of all the things that people could abuse.

12:17:13 The you know, access the data for somewhere I mean like I have political threat models that maybe we wouldn't have had if we were having this primary years ago.

12:17:24 But it's now. so things are definitely different thank you nee Carrie.

12:17:34 Thanks, Jennifer. I have I'm going to kind of repeat what you had already said.

12:17:40 I really do have concerns that there will be an issue with use and disclosure.

12:17:49 In the case of emergencies with folks that have intellectual and developmental disabilities.

12:17:55 As well as those with mental health, to call out the lps act as well as a landman.

12:18:03 Act with those specific provisions I think we'll be able to do a workaround, whether that you know, is obtaining consent from the consumers in advance.

12:18:15 Or something like that to the effects separate from the hiv I mean we'll have to think creatively, but I certainly would advocate not pointing those out if segregating that for purposes of ensuring equitable services and

12:18:32 supports, and in particular an emergency situations. and so I would advocate for following all State and Federal laws.

12:18:45 In case you know, part 2 might be a little bit different.

12:18:49 Hiv information might be different, you know, and those sorts of things.

12:18:56 But I would advocate specifically for mental and developmental services for it not to be segregated out.

12:19:03 So we ensure equitable services. Thank you absolutely and then Carrie also raised another type of specially protected information that wasn't on the slide, which is Hiv test results.

12:19:18 California does have some special protections for Hiv test results as well.

12:19:22 And so all of these things that presumably are desirable information, because they give you a complete picture of a patient.

12:19:29 And so I think what i'm hearing is that nobody's saying we ignore California law or Federal law, and that we need to find a way to where everyone has the same treatment the same access and also want to just sort of push a little

12:19:52 bit on folks, because i'm not sure that i've heard Do we?

12:19:59 Do we call this out, maybe in the policies and procedures, and then say you, you are responsible to comply with the law.

12:20:08 And then we mention some of the laws. But of course we can imagine all of them, because some things change with time, especially California law tends to change every year in some ways, although some things you know stay the same, or or what is the what is

12:20:24 the potential solution to how we address some of this specially protected information.

12:20:32 Do we, for example, have technical assistance or guides as to part of the framework where we would help, especially folks who are not used to, you know, handling this kind of information.

12:20:46 You know what the rules might be around it? how to treat it? how to protect it? What the limitations are, What or you know, do we do we, As you see what I'm: saying, So do we is there a place separate from the data?

12:20:59 Sharing agreement, or even the policies and procedures where there might be some technical assistance with entities to ensure that they understand the limitations of the data.

12:21:10 Just a thought, not something. We have to do i'm just throwing it out there as a as a thought for the conversation.

12:21:19 And Shelley, I think you are next no i'm just gonna plug this shig one more time.

12:21:24 I think that's an excellent resource it's already out there, and available.

12:21:28 So I just don't think all of this detail should go into an agreement when things change so often.

12:21:35 But that we can provide the community or participants. signing these agreements with those resources, so they can understand the laws and how they have been, how how they can be applied.

12:21:47 So, if that would be my vote. Thank you, shelly, and thank you for raising the State Health Information guidance, which, of course, Cdi is heavily involved in publishing, and has multiple volumes of including hiv a developmental

12:22:03 intellectual disabilities, minors or adolescents, and behavioral health.

12:22:09 So I appreciate you bringing that up. Do we have anyone else who wants to weigh in on this topic, Kerry, You still have your hand up.

12:22:18 I just want to make sure you've about that and i'm.

12:22:26 Obviously we are monitoring the chat so we do see what's happening in the chat.

12:22:30 Even if I don't necessarily bring it up sometimes it's faster than I can respond to.

12:22:36 So if we don't have anything more to discuss on this one we can go to the next topic.

12:22:40 I'll leave it open for just 1 s Okay, can we go ahead and go to the next topic.

12:22:46 Then for the next slide. Please sorry that's it perfect took a moment.

12:22:54 Sometimes there's like, Okay, so minimum necessary. so there are there are limitations in terms of how information can be provided.

12:23:09 And Hipaa has one such limitation where you know you can only provide the information that is reasonably necessary to achieve your purpose, and it doesn't apply in all instances.

12:23:21 For example, it doesn't apply treatment but it does apply to many disclosures that you know, are lawful disclosures that we've talked about previously.

12:23:31 So should this standard apply to many organizations, even those not covered by Hebu, such as social services, organizations.

12:23:43 In in, especially in California. law. there's already some kind of built-in limitation.

12:23:49 For example, you might see in California law to the extent necessary to achieve the purpose of the collection, or to achieve the purpose of the disclosure something like that where it's essentially very complicated, But it in essences it's the
12:24:05 minimum necessary to get it done, and so should we instead create a default, or add, not just instead.

12:24:12 But perhaps 2 defaults where all participants have to only ask for what's needed.

12:24:20 So, instead of you know, putting all of the burden on the the entity disclosing which of course, is where the liability is to to have it be on both entities.

12:24:32 The one That's asking for it and the one that's just closing it, and that would be obviously through the data sharing agreement.

12:24:39 So what what expectations here do we have with respect to limiting the amount, that of information that is disclosed?

12:24:49 And do we need this, and so that's kind of what we're looking to have a conversation around.

12:24:53 I see that we have some folks who have their hands up.

12:24:57 Elizabeth I mean, as Stephen was saying earlier, Why are we not just saying broadly, Hipaa should apply here, which includes the minimum necessary standard?

12:25:11 I understand that i'll bring these other entities into the same world that all the rest of us have been operating under for decades.

12:25:18 It. It makes sense. it solves more problems than it creates.

12:25:24 I truly believe. And is there a particular reason that we wouldn't want the minimum necessary standards?

12:25:31 Is there, because by definition, if you need the data, you can ask for it.

12:25:36 So why would we want a standard that says, actually, you can ask for way more than you.

12:25:42 Strictly speaking, meeting just in case you think it's helpful like I don't see that being beneficial and generally speak.

12:25:49 We want to limit the data to the intention for the exchange.

12:25:55 Bring everybody into the same world. we're already in thank you Elizabeth Stephen.

12:26:01 So I really support that. I I love being in meetings with Elizabeth, because I almost always agree with her.

12:26:09 But but minimum necessary is hard and it's hard in part because of the technology limitations, you know, depending on the the tools you're using to access exchange data, whether it's a V 2 interface whether it's

12:26:24 a file transfer. Whether it's a ccda exchange, whether it's a fire exchange, you know it can be really challenging.

12:26:32 So I think that the direction we, I hope, are going at California and and across the globe is towards fire based exchanges where you can literally ask for what you need.

12:26:44 You know, and then the respondent can send you just what you asked for, or some subset.

12:26:50 Thereof. it's difficult in an era where I mean all all I can request from a lot of data holders is a CCD.

12:26:59 And and oftentimes that has more than the minimum necessary.

12:27:06 So you know. Where do we give on that I mean again?

12:27:07 I think we've been striking a generally conservative tone here today, you know.

12:27:14 So I think that if the if the data holder can't provide the minimum necessary data as requested does that mean they're off the hook.

12:27:26 Does that mean they have to come up with some alternative means of doing it, of responding to the request?

12:27:32 I think it's tricky so I I totally agree you know minimum necessary makes a lot of sense that we should we should endeavor to incorporate that it.

12:27:41 Also like a lot of the other things we've talked about today may limit the you know.

12:27:48 The impact of this framework early on, while we wait for technology to catch up and for everyone to get on board with the technology that, will, it really will support that in a robust way.

12:27:58 Thank you, Steven Devin. Yeah, I think so i'm not a disagreeing.

12:28:05 We seem to all be sort of in agreement with each other.

12:28:07 That that minimum necessary is a standard that should be part of this.

12:28:12 I will say, though, that hipaa actually does not impact minimum necessary on requesters.

12:28:18 And one thing that I actually really like about the way that this is framed is that it puts the obligation on both sides of the transaction. right?

12:28:26 It's you should only ask for what you need and you should be disclosing

12:28:34 The information that either responds to that request, or I mean, you do sort of get some situation where there could be dueling on, you know.

12:28:42 Dueling determinations as to whether it's minimum necessary or not.

12:28:47 And there's a lot in hipaa about how that you know that you can resolve that in the fate in favor of the requester in what the requester is asked for.

12:28:54 In many contexts the technical piece is is one that will. you know, that does create some hiccups here.

12:29:02 If you cannot segment data in a way that allows you to share only what's requested and and particularly if it's even easier to share structured data as we talked about earlier, and that structure isn't the entirety of, a document

12:29:16 that has both the needed elements and some elements that are not needed.

12:29:19 But nevertheless, I don't think that any of that argues against a sort of expectation that people treat this data with respect, not ask for more than is needed, not disclosed more than is needed.

12:29:32 Given the context, but I but what I really like about the way that this is framed is that it flips it It doesn't exactly flip it because it's on both sides.

12:29:40 But it does create a set of expectations around requests that's not necessarily part of Hipaa.

12:29:46 Thank you, Devin Lee. Hi: Yeah. So my main point here is that a a while?

12:29:54 2 point. one. I agree that we should have some sort of minimum andes necessary.

12:30:00 I've always liked that aspect, of i'll hipa even though, as Devin says, once, I started really getting into it, I realized how little it actually applied to, and also how it wasn't really something that anyone ever enforced in any

12:30:14 sort of way it's like if somebody did seated it it wasn't like there was anyone who was gonna run around going.

12:30:21 You gave you hand. It over too much and that's actually my my main. The main value, I think, of this is that it is a presumption.

12:30:33 It is it is stating the expectation that we don't overshare, because the information is and sensitive to someone not you.

12:30:42 And you don't actually have it's about you're not the boss of that data in any meaningful way.

12:30:48 It's Still, you know, patient data. and So the thing again, I have an experience that comes from the non health area.

12:30:58 And what I see is in Federal statute all over the place.

12:31:03 If you do not limit what people allowed to share to what they should be, then the incentives in the system always tend to go.

12:31:14 Maximize the sharing. They just share more more and since no one is saying, don't.

12:31:21 Then everyone just keeps adding to it, and there is no way for unless you use something like minimum necessary, it is not possible for the E.

12:31:31 Liberia state of of sharing in this substitution anything but continually so.

12:31:38 It is necessary, as a break against oversharing to have something like this.

12:31:45 I don't know what level of enforced compliance or attention to trying actions, to actually cause it to be effective.

12:31:53 But if you don't have have at least the basic expectation norm and standard on it, it will never happen So that's enough.

12:32:03 Thank you, Lee Louis. Hi! thank you first i'd like to say that there, I think there's some significant difference between social services.

12:32:16 So healthcare systems and so I do think there will be significant impacts, hypnot, as I stated earlier, with respect to minimum necessary.

12:32:30 And there's a lot of access controls within these systems. for cases that are deemed sensitive, or in the cases where the court has sealed the records of an individual cell.

12:32:45 Certainly practice of access controls, so that folks can only see and have privileges to see what they're supposed to within those case management to different degrees of sensitivity.

12:33:01 So my question about what a request you might ask for it's kind of how do they?

12:33:06 How's the requester know what they can see or not see on a social services system when they're asking for a record that may be sealed or sensitive on that system for the business of business needs and how does this apply

12:33:21 so i'm a spirit of minimum necessary I agree people should only see what's minimally necessary.

12:33:26 But in the terms of the next age, where somebody may request information.

12:33:32 How do we have these access control also they're not just given us and on the exchange missing some but that there would be my concern that we have those kinds of access controls and i'm not sure how

12:33:52 technically, you know, if we we, we need to put something in that you give me a bring that

12:33:58 Whereas the this data is not released where you know every other record might have been there's exceptions it kind of goes along with the my concern about the system being able to nuts and things that people didn't

12:34:16 consent. i've seen that before with immunizations forming more.

12:34:22 You know people don't consent to have that that data sent, and if somebody is and check the box their data gets sent, and we have an issue

12:34:33 So along those lines I would be concerned about any of the requester for information when they may not know if they don't, They're not entitled to that, because our minimum necessary on and those other systems does that make sense that's a

12:34:55 fair question. but with respect to how this would pragmatically be applied, and and that's fair.

12:35:04 So we do have just when you need to move on to the next piece.

12:35:07 I just want to make sure that folks got their say. It looks like Devon, Lewis and Lee used to love your hands up.

12:35:14 Did you? Okay, Sorry, Lewis. Thank you. Okay, Thank you.

12:35:21 So much for this conversation again. we are looking in the chat So if you still would like to put something in there feel free, we do need to move forward, because now we're going to be discussing the draft language.

12:35:35 So thank you. Go ahead and thank you. And now I am going to share.

12:35:46 Okay, can everybody see this? I see nods perfect. Okay. So just some background information.

12:35:57 V. As you would expect, the capitalized words, like participants, or authorization or applicable law, are defined terms.

12:36:05 They are at the very bottom of this language that you hopefully had a chance to read, and in the definition section.

12:36:14 And so the highlighted sections here, where, for example, this says Section 14.1, there are other highlighted sections.

12:36:22 Those are place folders They don't mean anything in particular They are reminders of.

12:36:27 We must do something with this in the future. and so just keep in mind that they're placeholders.

12:36:32 The numbers again are meaningless. We just needed a way. of you know, mapping everything out. And so please don't take the numbers as being, you know, at all, representative of anything that matters.

12:36:43 So let's dive in with authorizations and i'm. Sure you saw we tried to do something a little outside the box, and and maybe that doesn't work Maybe that does work what we were trying to do was to streamline the

12:36:59 ability of an individual to have their information that they want shared shared in a streamlined way.

12:37:06 And so again, Maybe it works. Maybe it doesn't work but that's why we're asking for your opinion about it.

12:37:14 And so I saw there was kind of this way of two-part kind of system.

12:37:20 One is, you know you validate your own receipt of an authorization.

12:37:26 The other way is you. accept assurances that it is valid and so i'd like to open it up to hear from folks about what they think on this.

12:37:36 And so It's going to be a little bit more challenging for me to see the chat so feel free to jump on in.

12:37:43 I'm going to see if I can I don't see it hands can't possibly be perfect.

12:37:55 Okay, Devin, just I just have a few questions. So this is in a context where an authorization is required.

12:38:05 And are we presuming that the whose responsibility is it?

12:38:11 In a circumstance where the author we're an authorization is required to obtain that authorization Is it the requester's obligation?

12:38:19 Or is it the data holders obligation? so I just want to set the scenario because I see where you're going, which is to sort of say, let's get this once.

12:38:34 And some, but by some party involved in the transaction, and and and and hopefully enable reliance on that downstream.

12:38:42 But I just want to. sort of get a sense of sort of when the supplies and who's expected to get the authorization in in a context where that's required. that is very That's a very fair question and So we

12:38:55 did not expressly add, whose responsibility that was because if you want the information.

12:39:02 And you have to have an authorization you're gonna need to get the authorization.

12:39:05 So I think impliedly, the responsibility is on the entity or person that wants the information, and so not on the party.

12:39:14 That is providing information, and that is because often terms of how it's collected.

12:39:21 It could be collected by the party that wants it, the authorization you, I mean.

12:39:27 And then it would be sent to the party that has the information now, if that's not that doesn't work, or if we need to be very clear about who's responsible.

12:39:37 Then then, that's a great point and we should sort of sort of flesh that out a little bit, because, as you saw from this there wasn't an express who is responsible.

12:39:50 It was, You can send it on over the entity with the information that is requested determines in their mind whether it's Val or not, and then says yes or no, or you can do this assurance system, and so does that help provide

12:40:04 some context, it does. and I and I actually think the way that you frame this in terms of the requester meeting to sort of put force that they've met all the legal requirements for for getting that information makes a lot of sense.

12:40:19 I will say that I do think it needs to be spelled out only because what we're creating here is a term into a legal obligation to disclose.

12:40:26 So where it's silent about who's responsible for getting that authorization.

12:40:31 I think, could create some some kluginess or some confusion about that. and my recollection is that in in the early information blocking rules.

12:40:43 It wasn't clear who was responsible, for actually presenting a required consent or authorization from the from the individual who's whose data was subject was requested, and they clarified that and they clarified it in exactly the way

12:40:58 that you framed it, which is, if you want the data it's your responsibility to meet the legal requirements to to disclose it.

12:41:06 But interested to hear what other folks think about that. So So my comment here was actually sort of in the same vein, Devin.

12:41:24 So I I took that first son to the line Oh, wow they're mandated to disclose, and then i'm going, then, I said, and obviously the key variable is is it illegally valid authorization in the first

12:41:36 place, because it is not there's no duty to chair and indeed!

12:41:40 Then I went, said I, I can actually write a second rule.

12:41:44 Participants shall not disclose Phi or P. I.

12:41:48 To another participant without illegally valid authorization and I don't know whether that would also be appropriate to put in there, put in here.

12:41:56 But the main question seems to me what do you do what when you're not.

12:42:04 If if somebody has data and they have an uncertain so like level of authorization, it is, you know.

12:42:12 Maybe they believe in good faith that is a legally valid authorization.

12:42:20 But you know they haven't, actually gone and and completely down So is that a situation where a participant in fact has the quote weekly valid authorization, and therefore shall and is supposed disclose or not and that's and that's

12:42:40 why early on I in this discussion I asked about Well, you know really in most areas of the law, the answer to that question falls on who the bag, if they were being, if some, if everyone were being sued because someone got her who's holding

12:43:01 the bag, and I don't know the answer to that question yet, and if I don't know what the answer to that question is, then I'm not sure that the incentives are where they're supposed to be so to me this whole

12:43:12 thing is about what happens when you are not sure when you have a confidence level somewhere between 2.

12:43:20 You know 75 to 90% you know fairly sure but you're not a 100%.

12:43:25 Sure and the way. and these days the way that you get data you can't even you.

12:43:31 You don't necessarily know. but on the province so I am sort of concerned about how the where the chain of liability ends up.

12:43:41 That's what I would want the skeleton flow Once I had that that I could go back and write the rules to match the incentive structure of the liability.

12:43:51 But until I have the incentive structure of the liability it's kind of difficult to know how you should craft that agreement cost up there.

12:43:57 So let me ask you Thisly, because you brought up a really great point about that first sentence.

12:44:03 What about the section here where you have an insufficient authorization, where it says, If you've determined, it's not legally valid, then you shall not disclose, Do you feel that that adequately addresses

12:44:18 so you concern that you raised your original concern, which was, what do we do about legally invalid, or legally inefficient or legally insufficient?

12:44:28 Excuse me authorizations. Yeah, I looked at that and I said that might be the that might be the language that I that we needed to have in there.

12:44:37 I don't actually know. Still, though we where where the reliability land, if there is about it, or someone is wrong about whether it was legally sufficient, does it does good faith is good faith that defects or or what and I

12:44:56 don't know you know what level of diligence you know what is the standard by which a provider or other participant in the network has to what they know when when when is there a red flag for them but the sort of stuff

12:45:14 that we deal with in the privacy world and all sorts of other sort of areas.

12:45:20 So I don't know the the answer to those questions thank you Lee Morgan.

12:45:28 Thanks, Jennifer, I I think you've made a really good effort to address to the address of you know, an nasty problem here a bit as if you put the the other option is put the burden

12:45:42 on the the party that has the data to have the authorization, and that will cause the data to stop moving.

12:45:51 If I have the data, and somebody else wants it I don't have any incentive to to chase down the patient to get that authorization.

12:46:00 If I don't already have it i'm just have I won't get to it.

12:46:05 It won't happen and won't happen timely but but the as the party that has the data if I give it out, and there isn't a good authorization, it's hard for me to avoid responsibility for that know as Lee

12:46:20 points out you know we'll see you in court we don't know how this to play out until until some mistakes are made and people are hurt and and and the and the private bar helps us figure this out. but I think you've made

12:46:33 a good effort to do so, and and and to with the burden the burden on the party that wants the data as much as possible. They're the ones that are going to be motivated to take the steps necessary to make it happen Thank

12:46:51 you, Morgan Belinda and I can move this around and I'm, hoping to type on to this document, some notes, or even modify language.

12:47:03 If you know, based on our conversation. So just so folks know, feel free to tell me to scroll up or scroll down.

12:47:10 Linda Belinda you're still on mute there might be a lag.

12:47:22 Sorry my Internet just cut out. I just wanted to to add up with those things, and I put something in the chat.

12:47:28 It seems like pragmatically, the barrier to exchange data will just be raised if you're putting the onus on the sender of the data, like who is going to evaluate the legal validity of other

12:47:37 People's authorizations especially for small organizations who don't have that sort of expertise, and so then they might just say, Well, I don't know so I can't share so I just posed you know can there

12:47:48 be that the concept of a universal authorization that everybody participating in the Hiv like it, would be the same one that everybody has to sign.

12:47:57 So you feel confident if it was signed that you can move forward and share.

12:48:03 Thank you, Glenda. I think Devon was next yeah I'm.

12:48:09 I'm not opposed to coming up with a with a with some sort of authorization form that's gonna work in a wide variety of contexts.

12:48:17 I think the Social Security Administration actually tried to do that with respect to, you know, creating a sort of authorization for the Ssa.

12:48:26 To get data in the case of disability determinations that would work across multiple states, across multiple different types of data.

12:48:34 It's a very long authorization, because of that but at least you know there have been efforts to do that, and I'm not opposed to it.

12:48:41 But but but for what it's worth the only thing you know your approach that you've got in this language, Jennifer mirrors.

12:48:48 I think the set of expectations that we're put forth in the Federal information blocking rules that the you know when when you've got an authorization that's deficient.

12:48:58 They're there. you know you inform the requester that It's deficient, I think the only piece that's missing. is that the information blackening rules require the data holder to provide a bit more information about Why,

12:49:10 it's deficient like if you think it's deficient it's deficient, because right it doesn't have all the elements that are required.

12:49:17 It's not in the right font size in a circumstance where that's a requirement under the law, it, etc.

12:49:24 That gives. That gives the request an opportunity to cure it But if they ultimately don't pick up that thread and actually follow through and get you get get the data holder.

12:49:33 The request the type of request that they need then then yeah then they shouldn't share because they, the the data is not legally allowed to be shared, because the requirement for consent has not been met.

12:49:46 And it also occurs to me that we we have been thinking of this issue through the lens of a query based transaction right where I'm requesting data in a push.

12:49:56 Of course it would be the obligation of the of the data holder if they're pushing, if it's their initiative to share that data to get the proper consent.

12:50:07 And then Morgan. Yes, thanks, Jen. I write on the palm of my hand.

12:50:13 Of every data meeting I go to consent registry until someone builds builds the consent registry.

12:50:20 We're gonna struggle with this one just endlessly that that that is just real. it's just such a such a naughty problem, and we should note, as I think I think, some folks some folks on the on the panel know but

12:50:35 maybe not all that that jennifer your agency has has led some efforts to try to to aid and pilot a universal consent, but sadly still without building the consent registry that's that's how we're looking for

12:50:53 here. Yes, and unfortunately we did not get you know funding to sort of continue our efforts on building that universal consent.

12:51:02 But it doesn't mean that we can't leverage that work in the future.

12:51:05 So just want to make sure that I've hit everyone with their hands up.

12:51:12 I think Devon and Morgan did you have additional things to say, Okay.

12:51:18 So i'm gonna move down so free to open it up to any of these.

12:51:26 This special compliance section is the about acknowledging that the businesses associate agreement which will be attached to the datash sharing agreement applies to those entities that are covered entities business

12:51:41 associates are covered components of a hybrid entity, and that not all participants want to become or intend to become, a business associate.

12:51:53 This language is from I want to say it's a care quality it could be dersa I leverage some of that, and combine some of it here, and I recognize we've had conversation around.

12:52:07 You know, should a hippoly to everyone at the same time, what we do contractually may not necessarily be what is intended.

12:52:17 The sense of imposing regulatory enforcement.

12:52:21 So I want to ask folks you know what your thoughts are with respect to this section, because it's true that an entity who is not covered by Hipaa.

12:52:32 Might choose to be part of this framework, and sign on to something, and make agreements contractually to comply with certain standards.

12:52:39 But at the same time they may not necessarily want you know the regulatory oversight entities coming in and enforcing those standards that they're not legally required to comply with outside of the contract does that make sense

12:52:54 to folks, so that's one of the reasons why this is here?

12:53:00 So. Are there any thoughts around this piece? or is this standard language?

12:53:08 And then I can scroll. down for folks I don't know if somebody's reading it, or if yeah, it could. I don't know how fast folks read. I don't want to you see sick either by scrolling too quickly

12:53:36 And then, of course, this was to acknowledge that we still want to support privacy and security.

12:53:44 Said so. This was meant to be an acknowledgement of that, and it was meant to.

12:53:53 For example, the challenge comes in with entities that are regulated differently.

12:53:57 So for social services, a lot of let's call them regulations come in through departmental letter or departmental guidance, because the State administers the program and counties and entities often with contracts administer the services

12:54:14 or provide the services. And so here often these policy requirements are. Contracts often have sort of requirements that are set by the State.

12:54:26 But they're not necessarily in regulation or in law and So that's why in Number 4, where it talks about social services, We're it also says applicable contracts and policy requirements because some departments have the ability to

12:54:41 issue policies that are mandatory on these kinds of entities through the contract or through just the way it works.

12:54:49 But it's not the same as being a regulation or a statute. I hope that's kind of makes sense.

12:54:54 Why that was written the way that was i'm going to continue to go down.

12:54:59 And then here's the end. Let me make sure you can so we learned any thoughts around this section 7.

12:55:32 I think one of my only questions around the the social hipaa should apply to all participants has been with respect to entities that help patients and individuals get their own data, and this is because the Hipaa privacy rules are

12:55:47 kind of built, with some sharing presumptions in mind like you can share for treatment, payment, and operations without consent.

12:55:56 You can share with you know there's like 15 different categories of permitted sharing without consent whereas. you know, when you're talking about a tool that a consumer is using there ought to be some more control and we

12:56:10 don't necessarily want to to Override that necessarily This is definitely something that the the Tefca common agreement tries to accommodate by kind of cherry picking a little bit among the privacy rule provisions

12:56:25 and the security, the whole of the security rule would apply but only certain provisions in the privacy rule that that don't necessarily undermine the the content. The con that that consumers should have the kind of control even over a treatment disclosure if you're talking about

12:56:43 the data coming that their copy that's that's theirs to use and share.

12:56:48 So I just just putting that out there can you maybe that maybe they're not participants in the network, and maybe rather just the obligation on the participants to disclose in response to individual access and that makes sense, participant is

12:57:03 solely a signatory entity that an individual user is the person who's the subject of the information. Okay, and so, and you will see that a little bit more when we go into the definitions.

12:57:15 But but yes. The reason why this is focusing on participants and not on individuals is because the individuals and their access is contained in the individual access services.

12:57:24 Section that makes sense to me. Thank you. absolutely. so. are there any comments about this section?

12:57:33 And I recognize that you know there. Yes, ashish ashish and she's here still on mute, so what she's I can't tell if you have a comment.

12:58:02 You want to make, or if or if there's a lag happening?

12:58:11 Okay, if you can come jump in we'll make sure to make time for your comment.

12:58:18 As soon as you're able to jump in i'm gonna go ahead and move forward.

12:58:23 Just go ahead and take yourself off meat and jump in when you can. and I'm moving down because I assume that that last section was just amazing.

12:58:32 And all of you loved it, and i'm just joking because I know you need time to process it.

12:58:36 So this next piece is really the cooperation and nondiscrimination is really intended to be about how competitors behave towards each other.

12:58:47 And so there's this obligation or responsibility that you know every participant will cooperate, and will essentially treat every participant the same such that you know, if i'm in competition with you I still have to treat

12:59:04 your request for information the same as I do an entity i'm not in competition with, and that's what this particular section is really intended to be about where we cooperate we engage in exchange

12:59:20 there's no inappropriate behavior, just because we're competitors, or we're not trying to restrict or to impact another entities business through our behaviors.

12:59:33 And so that's kind of what this is intended to be really exciting stuff Again, the yellow highlight committee is a placeholder.

12:59:41 When the discussion on governance takes more of a you know a form then there'll be some additional information put in there, and i'll continue. Move down.

12:59:52 Well, we know if i'm going too. fast elizabeth so I like to think i'm not an idiot, and I did read this prayer to this meeting, and what you just said is not what I got out of this to me

13:00:16 This reads much more broadly than don't refuse to basically work with your competitors, and it looks incredibly onerous for small prep.

13:00:30 For either the smallest practices who don't do this on a regular basis, or arguably the largest participants who would be working with so many people that have become completely overwhelming.

13:00:41 I think we need to really clarify the definitions of what we're trying to get at here.

13:00:45 We need to be a little bit more clear. about the outer boundaries of what is expected of the participants, and what sort of requests are reasonable to make of other participants.

13:00:56 You can't just say, Oh, well, you have to help me with this thing, because I I just it would be great

13:01:04 This just read is very, very broad and potentially onerous.

13:01:08 On a large number of participants in a way that I don't think is strictly necessary to achieve the goals.

13:01:12 You just stated. So you're actually I apologize you're actually right.

13:01:16 It is not intended to just be about competitors it's also intended to sort of outline some of the general ways in which participants will cooperate with each other.

13:01:29 And I will say that this came in large part from Dersa and Kerr quality.

13:01:35 But you do have to keep in mind that the target audience for this is not the same target audience as is is for the durasa.

13:01:44 Right it is. I mean that the calendars in particular has a very specific subset of of signatories right.

13:01:52 The care quality versus the e health exchange shirts that is obviously there's a huge amount of overlap between those 2, and it does have a broader audience, but it's not nobody's required to sign that

13:02:06 first firstters and and I do think that it's it's focused on a slightly different universe like we are talking here in some cases about very small practices.

13:02:18 Or entities that frankly aren't really engaged in this universal exchange at all today.

13:02:24 And they're they're in being introduced to something new. This is so broad as to be confusing, and again, I I think, pretty difficult to meaningfully comply with.

13:02:38 I agree that entities have to be able to work with each other, and they have to be willing to have conversations.

13:02:43 And if there's a question about you know where did this data come from, how did this happen that that needs to be there?

13:02:49 I understand. I do think we can put some boundaries on this that are not there today.

13:02:54 That would be productive. and Devon just asked me a question.

13:02:56 Home Honestly, devin the generality, the generality is what I find confusing.

13:03:06 It is everything they will work with anyone's anybody about any question and that can inspire a lot of control really quickly.

13:03:18 So would you think that this should be higher level in the sense of then pointing to policies and procedures for more detail with respect to what that looks like.

13:03:31 So streamline make this shorter. then refer to policies and procedures for little bit more detailed around what this means.

13:03:42 I'm fine with that, because it is probably going to be a moving target.

13:03:46 But I do. I do want to make sure that we're not just pulling the language from here, and dropping it into policies and procedures, and saying the exact same thing.

13:03:55 I think that the basis of this needs to be looked at from the eye of what?

13:04:02 What do we really want from people? What do we really expect from them as opposed to just such a broad swad?

13:04:11 Because again, we have a slightly different target audience. and I Think that We're not always taking that fully into consideration.

13:04:20 That go? Okay, Thank you. Okay. So yes, patrick a good Good afternoon, hey?

13:04:32 What's what's the perspective the thoughts the direction on delegating the access and providing data.

13:04:39 Let me let me give an example here. if i'm a large facility that I've got all the resources in the world.

13:04:45 I may, this may imply directly to me that i've got to communicate with everybody, so I, a large university health system, or just a large for-profit provider system.

13:05:01 We would have resources to to provide fire api's or provide that type of technology to say, Hey, come to us, and we'll give you the data versus someone a small community provider who's whose main intention is to help the community

13:05:15 and they've got no interest in and providing these services but they can delegate it out to a health information exchange.

13:05:23 Is there any any thought to say, Hey for the small, or even the large, and say, Hey, we will!

13:05:29 We will serve. Satisfy the the request in the competition by going directly to our delegate and you contact them.

13:05:37 We'll provide the data to them and they will provide the data to whoever requests it.

13:05:43 That's an excellent question and I think to respond it's going to be that there's sort of an expectation that the information is exchanged consistent with the Ab.

13:06:03 133, which we're what we're trying to get at.

13:06:06 When we talk about the technology agnostic piece that we've sort of had a conversation about in the past, and I recognize this was weeks ago was really the method.

13:06:15 And what you described is in some ways the method right i'm i'm utilizing the service to be this data sharing on my behalf.

13:06:24 And so that piece I don't see that we have a problem with that. I think what we're trying to do is not not create an obligation for 4 and tease to do that or have a major impact on businesses by

13:06:40 adding obligations to do that kind of work.

13:06:46 But at the same time, you know allow for entities. to use a system that's already in existence, because they don't want to create infrastructure, and they don't have you know they don't want to do all that so

13:06:57 I I'm not sure that that fully answered your question it helps, and at least gets the the interest.

13:07:08 And in our team discussion, where we could say, How might we start solving some of these?

13:07:14 And in part of it, through the cooperation nondiscrimination, it triggered a bunch of How can we realistically apply it?

13:07:20 The the laws are phenomenal the worrying is great as long as we have a way of implementing it. That's what I'm trying to figure out what is and also see is there anything that is against the spirit of what we're

13:07:31 trying to do and I haven't heard that so that's that's good. i'm a big fan of health information exchanges a huge fan of that they play a vital role and they will evolve as

13:07:42 our change, and i'm also a big fan of the fire technologies, and that will be a phenomenal a place in our industry, and there's there's a ton of room for both thank you and then I

13:07:56 want to see if I shish, is able to connect with us again before we move down, Ashish for any chance.

13:08:04 Were you able to come log back on doesn't sound like it But, Helen, you have your hand raised.

13:08:13 Yeah, I had a question on point number 6 Yes, so that's information regarding the investigation of the breach of this mute.

13:08:24 That must be provided in the tfca. they mentioned some information around cybersecurity, risk information sharing.

13:08:37 And when I looked at the definition of breach was not fair.

13:08:41 That that would include any of that type of information so i'm concerned about.

13:08:45 If there's a cybersecurity incident or risk of that, would that be included in an obligation to share cooperate to show under this investigation for breaches and disputes that's a really Yeah, And I

13:09:06 would be a proponent of of sharing that type of information, because when there is a cybersecurity incident, you know, you do want to gather as much information with the the value of the the risk pencil Thank

13:09:37 you, Helen. Okay, all right. So we come to the last bit of draft language.

13:09:53 The definitions. and so i'm gonna open it on up to folks to make comments about all this. so go ahead.

13:10:03 And and I can continue to scroll down. Can you just say where you copied these from?

13:10:12 Wow! that's a great question and i'm not sure that I can do that off the top of my head.

13:10:24 You know we all like provenance metadata.

13:10:26 Yes, understood actually need someone else to drive. so I could go back to the original document, because I actually did tag every single piece with where the original language came from.

13:10:42 That that's fine maybe when you post the next version, or you know just to Yes, i'm happy to do that.

13:10:51 Please know, though, that it may not be the exact language it might have been originally, for example, from Dersa, but in some, in some respects some things have been heavily modified, because it may not apply to what we're doing so

13:11:03 do keep, Keep that in mind, but i'm happy to do that we can.

13:11:07 I can tag these and send out where they were leveraged from can definitely do that.

13:11:18 The I can tell you that the breach definition came from the Calgary stuff, but has been modified after our last conversation together around that definition.

13:11:30 So, as you see it's much shorter we're trying to be consistent with what we hear from you.

13:11:39 I might be going a bit fast. so let me know, Elizabeth, this is a quick one.

13:11:51 There are some exemptions to The definition of breach that is in the Durza that I think are actually pretty important that are not here. I'm wondering if they're going to be elsewhere in the document

13:12:03 so. So some of those exemptions a lot of that.

13:12:08 Was that a lot of that language was removed after our conversation last time, where it essentially means unauthorized acquisition, access, disclosure, reviews, and if there are exemptions, and that means that it wasn't

13:12:21 unauthorized. No, not necessarily so the one that i'm Currently noticing is There is an exemption in at least that you health exchange or I believe also the count actually Yes, definitely also the

13:12:40 Caldersa that specifically says that for purposes of this agreement a breach is not triggered.

13:12:46 If it is not subject to data that is basically covered by this agreement pieces like that, it's there are other ways to cover that exemption.

13:12:56 But it's, I think, relevant because if there is If Tiny provider has a technical breach of 2 people.

13:13:06 Right. It has not that's not the data that was that came across this or that.

13:13:11 They have not submitted. Then do they need to follow all of the various breach procedures that are in this document?

13:13:15 I don't think that makes sense. but so again.

13:13:20 There are other ways to handle that than just the definition if you've got that tugged up somewhere else.

13:13:24 Fantastic. no problem. It can just be in the definition of data, frankly.

13:13:29 But I it's something that I want to flag and i'd be definitely might want to compare this again to the acceptance that you specifically deleted.

13:13:39 I'd like a little bit like. Yes, i'm always happy to know if what we've just changed actually is for the worse.

13:13:47 So it was a much longer definition it did include more I guess what i'd ask is, if you come help me understand the just a little bit more about what you would like.

13:13:57 So what i'm hearing you say is you would like something that says and let me know if I captured it right, that the information that a signatory to this or a participant to this which wasn't through the framework they got

13:14:12 it from somewhere else. Clearly, they shouldn't have to follow the procedures for this framework. If it wasn't something that came through the framework.

13:14:22 Did I capture that right? Yes, and that is specifically spelled out in both the calendars and the Eat Health exchange drivers.

13:14:29 I think, because there is some confusion on this pretty regularly.

13:14:32 Because the language, in in at least both of those agreements and obviously it's not built here yet.

13:14:37 About what is required in case of breach is very broad and very, you know, demanding and so everyone they they spell out a number of exemptions.

13:14:49 That's one that I happen to be mentioning it is not the only one, and I think that there is something to be said for making sure we are clear on points that everyone else seems to think we need to be clear on I love shortening language

13:15:04 very much, but I want to make sure that we don't lose something that matters, or accidentally impose a requirement.

13:15:10 We don't intend to obviously never intend to impose breach requirements on something that was not from the framework, but it can accidentally happen if it's phrase certain ways.

13:15:20 Agree, thank you, elizabeth no we don't want to be doing things that add additional burdens on an entity.

13:15:27 Agreed that's not the intent So and and we really appreciate when you point these things out. So please speak up more important, definitely, not perfect.

13:15:35 But we do want to get it right so i'm going to continue to go down.

13:15:41 There's still plenty of time for anyone to jump in I recognize I'm going a bit fast.

13:15:51 I can slow down, but or quite a few devon this is This is not a question that pertains to any particular definition.

13:16:05 I'm seeing but just just one that just occurs to me overall.

13:16:09 Is, you know, one thing that would keep the agreement much shorter would be if we just reference to definitions that are already in law.

13:16:17 Right. Say, you know the the meaning of business associate, as you did with business associate, for example, same thing with respect to breach and things of that nature.

13:16:26 But that give that makes the that makes the agreement much shorter, which could be a very appealing thing.

13:16:33 For you know, sort of the audience that we are trying to reach with this We're not asking them to sign multiple pages.

13:16:38 We're all asked, or they will be multiple people in terms of the volume of of paper that it gets taken up.

13:16:43 On the other hand, when you put the definitions themselves into the agreement, it makes it much than the guidance for what it means.

13:16:52 You don't have to go looking around and searching in another place to get the actual definition.

13:16:57 And so i'm just curious whether our goal is to have an agreement that is that kind of stamps on its own in terms of people reading it and and understanding their expectations. or is is is our goal to try to make

13:17:12 the agreement as short as possible, with lots and lots of references to supporting materials like policies and procedures like legal definitions, where we're incorporating them.

13:17:22 That might make the agreement shorter right up I don't know how folks feel about that.

13:17:27 I I have sort of sense that we've been trying to keep this short, and I have expected policies and procedures to carry some more of the weight of some of the details. but it does occur to me that it's really hard to

13:17:38 read an agreement where every single definition requires you to go find something else.

13:17:45 That's a really fair point that's a very fair point I think what you're seeing. The goal is to allow as much flexibility as possible, because there are so many entities that are required to sign on and we

13:18:01 don't want to try and do this every year or over and over and over again to revise this that what you're seeing is an attempt to put what's necessary in the contract, and put things that are not necessary in the policies

13:18:16 and procedures which we expect will be changed very quickly as we work through things, or as we get more input. while these are open stakeholder meetings, as you may have noticed, not every representative of every kind of entity is able

13:18:34 to attend. And so, while we're doing our best to try and get all of the perspectives through this process and reach out to get perspectives, we are not capable of being perfect in that, and so the goal is to make it as flexible as

13:18:48 possible without having to constantly re-execute with all of these entities, but have the ability to still have some basic framework, legal framework.

13:18:59 Where then we can ensure that the policies and procedures can evolve appropriately for the entities that are very disparate that you know some things may not work that we've tried to do for them and we need

13:19:12 to make it work, and so that that frankly was the goal.

13:19:15 So some things were trying to smash Federal and State law together like reach, and some things were a recognition of.

13:19:23 We should just go there instead of trying to define this, because it might change.

13:19:28 And then if we refer it to the Federal law we don't have to worry about it changing that. and and frankly that's kind of what you're seeing, and and it doesn't have it's essentially a how do we make this work in a

13:19:42 way where we don't have to constantly revise this but we can, you know, have a more flexible platform to do some revisions when we need to.

13:19:51 I hope that makes sense. It may not be the best way but that's kind of what you're saying.

13:19:56 It does. Thank you, and then, Ashish are Are you back with us?

13:20:04 I could have sworn I saw your Yes. Did you have a Did you have a comment?

13:20:09 You would like to share. Welcome back. No, thank you I think Devon point is very well taken.

13:20:15 I think that's a there's a struggle and a challenge how to keep it succinct while referendum policies, but not being something that people can't even read because there's so much reference i'm

13:20:26 hoping if we have to make reference, we refers to death.

13:20:30 Kind couple of other major documents, and also borrow as much as possible, the language where they have gone through such a arduous process of getting it, and that there's 2 things for us it first aligns us completely with the

13:20:44 Federal standards which we anyway be supporting many of the organizations.

13:20:49 Most of the organizations have to plus it helps us be very consistent, and saves our time as well, and builds on that.

13:20:56 So maybe looking at def kind of gaps it has, and covering those gaps could be one area and also strategy to keep the documents accent.

13:21:05 Thank you. Then I just want to make sure you were able to say everything, because you do have your hand up.

13:21:13 No, I think I don't have hand-up on this one, I think there was another phone call.

13:21:18 I made, and that has a hand up I was trying to figure out what is my other device which is already has a done?

13:21:25 I'm sorry for that. for no worries i'm really trying not to go too fast, and and recognize that i'm kind of moving through this.

13:21:47 I apologize. we're getting close to our time so I just wanted to make sure that you had a sense of what some of the said so you could provide feedback here's another piece, where we have combined Federal and State law where that

13:22:24 whole specially protected information comes into play. If you look at the protected health information or Phi definition.

13:22:57 And then here's some sections we would love to hear of your thoughts on I mean, I could not find and i'm sure there is.

13:23:06 So forgive me in advance definitions for social services and social services organizations.

13:23:13 So this is just made up, and if there's a better a better definition that could be used.

13:23:22 Please let me know You know we do our best, but I could not find one.

13:23:27 That sort of met what we were looking for, kind of a universal way that we were looking to use it as and then we're almost through it.

13:23:49 It seems, you know, as is. you are making that up. I know we No, I love it.

13:23:56 I love it very human, You know the question is should we be more specific and narrow, or should we endeavor to be very broad and inclusive?

13:24:06 I mean that's really the question you know We talked a lot about community-based organizations social service organizations.

13:24:14 I mean it's interesting to me as a clinician who's relatively new to this domain.

13:24:20 You know that there aren't you clear definitions or boundaries between who's who and providing what services and whatnot.

13:24:28 And clearly this is such a focus of what we're here to Do you know, as part of this project? I think it's worth putting some real thought into this, and especially getting the input of the people who represent those organizations to make sure that

13:24:45 we accurately reflect. You know they see themselves and the work they do, and and it's relevance to health data sharing absolutely agree.

13:24:58 And then Elizabeth I agree with that as per usual.

13:25:04 But what I will say is I think that, how broad or narrow We want to be in this definition will hinge at least in part, on whether we're saying we are, in fact, going to require everybody who joins including these guys, to come up to

13:25:17 the standards of Hipaa I know I keep repeating myself, but that's sort of its own filtering mechanism.

13:25:24 I think it's safer to have a broader definition. If anybody who wishes to join under that definition has to jump through the hurdles of getting themselves up to the standards whereas if we don't adopt

13:25:37 that, or we have materially different or lower standards for social services and social service organizations.

13:25:44 Then I think we have to be much more tailored as to our definition here to protect the data, and that makes a lot of sense.

13:25:54 Does anybody else have a thought about that the before we move into our next piece, because we're going to need to go as much as I love our time together.

13:26:06 We are getting very close to 1 30, so does anybody have anything they want to add to what Elizabeth or Stephen just said.

13:26:14 With respect to social services. Okay, Lewis. Yes, I will see if I can speak out another definition and send it to you.

13:26:32 Successful, but I also think, you know, social services are already subjected to other privacy.

13:26:40 Laws and practice. So I know we keep trying to say we're raising it to the level of Hipaa.

13:26:47 But I think they're already subjected to numerous privacy. so i'm not sure that we would benefit by some subjecting them to all of the weight, as I said earlier. I'll leave that as it is but I will look

13:27:04 for to see if the Social services agency has. Another definition can consider.

13:27:11 Thank you so much. Lewis Okay, i'm gonna stop sharing.

13:27:17 Now again there is an opportunity to provide feedback. and then i'm gonna hand it on over to are wonderful but not folks.

13:27:33 I'm sorry. just need a second. okay so next. steps We, of course, will do what we always do, and Li I do see.

13:27:49 And Lewis, I think you might also have a comment.

13:27:51 I do just want to, quickly, though. Make sure folks know that we need your feedback.

13:27:57 We really want your feedback on that written language and we're very much hoping that you will provide that by Wednesday March the second, and your written feedback can come on in and why don't we go ahead and go to the last

13:28:13 slide, please, the one with quas email on it, so that Lee, you can have the rest of the time here.

13:28:20 Is that that email address I mentioned earlier what Elizabeth asked, which is the preferred method to give written feedback.

13:28:26 And so please go ahead and feel free to submit your written comments to Quavone, and then leave.

13:28:33 If you want to go ahead. And yeah, I just wanted to very, very quickly note that it is not at all clear to me how how much organizations in this space would in fact, be covered by other to see laws.

13:28:50 Because one of the things That's happening when we see comprehensive State privacy bills coming through like California as well as other States.

13:29:00 Whether It's Virginia, Washington, Etc. they typically have a massive exemption where they basically say you know, Ccpa or for Cpr.

13:29:13 Does not apply to you know information that is being processed under the auspices of, and by an entity, that is say, defined in Hipaa or in Cmia, or in the clinical trials act or in

13:29:30 the common world. Many of the State laws that are purported to be comprehensive actually start by exempting hipaa, Glb. Fcr.

13:29:42 And a whole slew of other privacy laws so that they because the fear of a lot of those State bills is that if there's already some other law you don't have to add it so I just wanted to to say that because

13:29:55 people have been saying, Well, gee! there may be other privacy laws on this, but and there may well be older ones.

13:30:02 But i'm just saying that as you watch state privacy laws unfold across the country in the last 2 years, there is a consistent exemption of because nobody wants to mess with Gibb's state level, and they don't and every

13:30:16 Hipaa covered identity comes to the legislature and says we're already regular.

13:30:19 We don't need to. so so there is a real tendency actually, for the presence of health data to sort of act like a penicillin in the peach.

13:30:28 We do, and so the legislators just don't go there.

13:30:32 Thanks. Thank you, Lee. Thank you. Everyone very much. Appreciate all of your feedback.

13:30:38 Your time. We know that you are busy people and that you don't have to spend your time on this, so we very much appreciate it.

13:30:45 We can't do this without you our next meeting is march the 20 s.

13:30:49 Please provide your written a feedback on that draft language by March the second, so that we can continue to revise these things because surprise we do listen to you that we do revise things based on your feedback.

13:30:59 And so I just want to again say, thank you so much for everything, and I hope you have a fantastic day.