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Thank you for joining the webinar will begin shortly.

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

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

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During today's event, live closed captioning will be available.

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Please click on, click on the CC button at the bottom of your zoom window to enable or disable Emma will now cover the meeting participation options, the floor is yours.

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There are a few ways that participants may participate today.

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You can submit written comments and questions through the zoom q amp a box and all comments will be recorded and reviewed by staff, participants may also submit comments and questions as well as request to receive updates to CBI is the hhs.ca.gov.

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At designate a time spoken comment will be permitted participants in group members must raise their hand for zoom facilitators to unmute them to share comments, the chair will notify participants and members of appropriate times to volunteer feedback.
If you logged on via phone, only press star nine on your phone to raise your hand. Listen for your phone number to be called, and if selected to share your comments please ensure you are un-muted on your phone by pressing star six.

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

Next slide.

A public comment will be taken at designated times and will be limited to the total amount of time allocated individuals will be called on in the order in which they were raised and will be given two minutes.

Please state your name and organizational affiliation when you begin participants are also encouraged to use the q&a to ensure all feedback is captured or again you may email comments to CDI at ch hs.ca.gov.

And with that, I'd like to introduce John; John you have the floor.

Thank you. Good morning everyone and welcome to our second meeting of our data exchange framework stakeholder advisory data sharing agreement subcommittee meeting number two, welcome.

As you can see we have a packed agenda, as in last time so I'm going to just go straight to the next slide and do a roll call.

Excellent. Uh, first, I know that I just saw a note that Michael is is sitting in for Dr. Tria if you can just say president Michael.

Or he might not have the link so I know Dr Dre is not able to make it today so we'll keep going but Michael is is representing.

We have from American Physicians Group, Bill Barcelona isn't from lanes, Jen barons here just struggling to find the mute button. Thank you. Good morning.

From attorney Shelley Brown, President morning, California, sorry the county well for Directors Association of California Lewis, Kotaro, from manifest best met eggs, Elizabeth killings work as a Kaiser Permanente Helen Kim.

How's it from health that Patrick curly.
00:00:00.000 --> 00:03:59.000
I am present.
00:03:59.000 --> 00:04:08.000
Morning, California Department of Developmental Services Carrie, Corporal
00:04:08.000 --> 00:04:21.000
from Sutter Health Palo Alto Medical Foundation Stephen lane here with bells on
excellent you always are thank you so much Planned Parenthood Affiliates of California
Lisa Massara.
00:04:21.000 --> 00:04:24.000
Good morning. Morning.
00:04:24.000 --> 00:04:35.000
Devin McGraw Are you there. Yes, I am. Excellent. Morning, San Francisco,
Department of Public Health, or graphic
refund.
00:04:35.000 --> 00:04:50.000
Nope. Okay. Uh, oh actually sorry he is on the list of not able to attend from the
California Department of Health Care Services Morgan's things here morning
everybody.
00:04:50.000 --> 00:04:51.000
Good morning.
00:04:51.000 --> 00:04:59.000
Ryan Stewart I believe is not able to join today but I'll just pause, he was able to boost
pleasant.
00:04:59.000 --> 00:05:05.000
Okay, and then from the Electronic Frontier Foundation lead Tim here.
00:05:05.000 --> 00:05:07.000
Morning.
00:05:07.000 --> 00:05:15.000
From the Los Angeles County Department of Department of Health Services Belinda
woman president.
00:05:15.000 --> 00:05:22.000
And from health center partners Terry Wilcox.
00:05:22.000 --> 00:05:28.000
Okay, we can go to the next slide please.
00:05:28.000 --> 00:05:30.000
Excellent.
00:05:30.000 --> 00:05:44.000
I think here is well aware of our vision and goals, I just wanted to put that up there we
like to set our, our, our vision, at the beginning of each of these meetings so if you just
take a moment and understand that.
00:05:44.000 --> 00:05:49.000
We're here to advise but we're, we're really trying to achieve this overall mission.
00:05:49.000 --> 00:05:52.000
Please go. Excellent.
Excellent. So our meeting objectives today, as I said, we have quite an agenda, we are going to be sharing some latest updates to the subcommittee charter for this group.

We're then going to jump in and share with you the principles and how and how they relate to the data sharing agreement.

We are then going to jump into some considerations and questions related to the development of the data exchange framework involving both technology and other subjects.

So number three should be a pretty meaty item. And then we're going to discuss the process and timeline for the data sharing agreement development.

We all know that this is a key goal for the legislature to have this agreement, done by June.

We are on a full court press to get there and we really do appreciate all of your expertise and helping us shape, an agreement that's going to be achieving the goals that we've set out.

So thank you very much for joining today. And if we can go to the next item I think we're going to be going into public comment.

I just know that in public comment as Emma stated that individuals and public audience who have comment may inserted in the q amp a or otherwise you can raise your hand and use the Zoom teleconferencing options, and you'll be called on any order that your hand was raised, please state your name and your organization affiliation and if you can please keep your comments brief and respectful mo will recognize you as you raise your hand or go into q amp a, and we'll take you off mute at that time, so have about two minutes for public comment. And we are entering public comment now.

We are breezing through and giving lots of time to other points later on in the agenda so we will close public comment. And we move on to our next item on the agenda which is the data sharing agreement subcommittee charter, and go to the next slide.

So we thought that we just let you know that we've updated based on a number of your members feedback at our November meeting, and we've made a number of updates,
including number one is really just emphasizing the fact that when possible the data sharing agreement will avoid any duplication of existing laws and policies and we heard that loud and clear from a number of members that in your own world you're adopting your organization, or your members and educating them on how, you know, latest rules, laws, policies, our goal in this data sharing agreement is really to make reference to many of those but not to make it more work than we need to accomplish our goals.

We've also added the clause, including but not limited to one listing data, data sharing agreement subcommittee activities or the documents that may be reviewed.

And we've added clarifying language on the extent to the technical specifications and standards that are going to be included in the data sharing agreement versus other supporting documentation.

So, the, the lean the leaner that we can make this agreement by leveraging everything that's out there and really focusing on the areas that are not already in existence and policies or rules is really our approach in moving this forward as quickly as possible to get to the point where we have everyone participating.

So with that, if we can go to the next slide, please. No, by the way, I missed this is that the track changes version of the charter are available on our website.

And if you have additional comments as we're doing this we know we're moving pretty quick speed. And so we're asking folks to do is as we come up with these principles and these.

These frame, these framing documents, it's, it's a work in progress as a lot of this work is so we're not trying to, we are trying to move forward. And so we're trying to put things certain things to bed.

But at the same time if there's something missing or something that was missing during this process because it's so quick we really want to hear from you so please let us know and Kevin just put something in the chat to help reference, all of that.

So, we can go to the okay you already did go to the next slide.

As we talk about our guiding principles which is really shaping the scope of the work that we're going to be doing.
It really the the guiding principles states that it’s our responsibility as the data sharing agreement subcommittee to incorporate these principles in our work.

Please know that the principles as well our draft and are going to be finalized in the following weeks. But we thought that we would just take you through the principles where they stand as of now.

And if you will go to the next slide. We’ll start with that. So here’s our list. I'm just going to read them out so we can I know there's some people that are dialing in as well.

Our first principles to advance health equity.

And it’s to make data available to drive decisions and outcomes to support the whole person to promote individual data access reinforce individual data privacy and security, establish clear and transparent terms and conditions for data collection, exchanging

I'm just going to pause here for a moment, and I'm just gonna.

I don't believe we were going to do any.

I don't know if there are any comments or questions coming in with my feet up any of the items I'm pausing for a moment and turning to either Kevin, or am I just letting me know if there's any comments in the chat about the principles or anything is that want to be discussed before I go through all the more detail.

No hands raised at this time. A quiet group are we on the week of Christmas, okay. So in principle number one advanced health equity. I think that many of us are have equity at the top of our mind when we think about the work that we’re about to be doing, and ensuring that this is first is, is really critical to us and our administration as well, to, to know that we are filling the disproportionate gaps in data completeness, and we’ve been having a number of internal meetings here because not only at a statewide level with our external partners such as you, but also our own internal house in order.

We know that equity is something we all talk about, and we know that data collection is one of the critical components to understanding how we can make an impact in advancing equity.

I'm going to pause, because we start seeing some people come and I would rather not read these slides to you.
So I'm going to just kind of pause here, we're ahead of time, and open for discussion on principles John. This is Stephen Lane if I can just jump in.

There's this term here disproportionate gaps. And I don't know what makes a gap in data complete this or quality disproportionate under it. So can someone explain what that means? I mean proportionate to what I mean. I understand the sentiment and I'm totally for you know, doing everything we can to address the needs of underserved and underrepresented populations. I just don't know what disproportionate means.

Okay, and we mentioned that that's also on accountability John. Are you there? Do you want to?

You want me to.

I mean I can take a stab at what I believe we men. I think there's a lot of data that's out there.

I think that it's, it's, it's where we've identified only the most critical areas in advancing health equity. I don't know if there's an example out there Jonah.

I think the intent here is to note that there are there are gaps in data in terms of things like demographic information and they disproportionately affect certain populations because we have less of it, or impacts them more because for other reasons, that's an issue we can consider adjusting it. So it's not that the gap is disproportionate but the impact of that missing data is disproportionate could be that could be that there's more data being collected on certain populations than others say from our per capita perspective and we feel like there needs to be more about a particular group that's, I suppose that's possible.

So that's kind of worrisome to that you know that there's certain groups that we need additional data about. I mean it seems to me that you know we want comprehensive data for for all groups right anyway. Yeah I just wanted to raise that the other thing I wanted to raise in the wording in this first principle which which really jumps out here and throughout the latest version of this document is the focus on consolidating and curating information.

I think our charge from the legislature is to focus on the exchange of information, and you know and that's certainly plenty of work for us to focus on that specifically excluded from the legislation. I believe was, you know, a plan to consolidate that.
information, or two, or to curate it you know that our focus should be on exchange. This seems to me to extend the charge in, you know, whole new directions and dimensions.

And in this sort of language. It was repeated multiple times throughout the latest document that was distributed. So I want to, you know, kind of check us right at the start here, you know, are we working on data exchange or are we, you know, suddenly trying to work on something totally different that was not included in legislation.

I think there are two different ways to look at that right so I think that you're correct in saying that we are not trying to build a central hub that has a complete source of information about everybody in the entire state that everybody must contribute to in a very narrowly defined way.

That said, if we just have exchange without any sort of structuring or consolidation or building of longitudinal records. It's just data, and its data that's very difficult to consume.

And I think we do have to consolidate it or clean it up in some ways it's just a question of what the limits of that are well I would argue that we've been having this discussion for a few years now.

And I know Elizabeth you're relatively new to the dialogue, but some of us have been at this for a while.

They're just really different things, you know this this central infrastructure consolidation.

Again, that's, that's not our charge from the legislature.

It's not really required to get the work done, and we could argue that you know for days we could have a three day conference just talking about about that.

So I again the fact that this got re inserted in principle one. And again, I think throughout the latest document it I just really want to highlight that and say that I think it pushes us in a whole different direction.

Let me interject here a couple things. One is that these guiding principles are guiding principles of the advisory group. And so, we want your feedback.

My hope is that maybe if you can submit comments to the team in the chat and online as written the suggested changes because I think in some cases it might just be word smithing if things are rubbing, so I appreciate if you guys could get that feedback here versus what's missing here.
The other part to Stephen's comment. I think there's some, some other items that maybe we want to have discussion and I'll turn to Jonah or Kevin if we want to tee up those that everyone kind of follow that.

That hopeful, I know there's a couple people with hands up leak.

I sorry, um, so I just wanted to make a real quick comment about what Stephen was talking about, which is, it's, it seems to me that, collecting by itself isn't very useful.

And to the extent that, that there are equity concerns in this part of the job is going to be understanding what the data tells us, and figuring out how to use it.

And so, my concern sort of opposite of Stephens whereas if we are collecting this sort of data, I'm not going to express an opinion on what the legislation required, then it seems that we also don't want to just be a collector and have no plans for how it is being used so that is sort of the first point on that and then on the accountability point. The one thing I wanted to point out is that within the state of California.

Holding state entities accountable to things is, is a different job than holding say county and city entities accountable because the state Information Practices Act, which has a number of privacy things does not apply below the level of state agencies and so that's something that, that it's just a weird aspect of California law that we have to address.

Thank you for that.

Other. Other thoughts. Now I'm going to just keep going them through so Principle number two is a really a big part of our mission here at CDI and obviously a colleague HS is to ensure that we're using data to drive our decisions and outcomes so whether or not it's specifically stated here, or kind of hit someone the right way or wrong way, please let us know kind of how we can wordsmith it to, to meet that.

But it is a key idea of why we're moving this work forward as well as to have that information at our fingertips in real time so that we can ensure that decisions are being made.
I’m going to go to the next slide if we can just kind of go through these everyone gets a sample of what we’re talking about another initiative of the Secretary is to move towards a more Person Centered way of caring for individuals.  
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So when we look how are we able to identify the not identify in terms of the person but identify areas where we can make improvements and service delivery efforts to ensure that we’re, we’re taking care of our citizens as best as we can collectively as  
00:21:47.000 --> 00:21:49.000  
a collective approach.  
00:21:49.000 --> 00:21:52.000  
Principle number four promote individual data access.  
00:21:52.000 --> 00:22:09.000  
I think I always think back to the days of the first concept of health information record and having individuals have that access when we talk about gaps and sometimes that is impacted disproportionately with individuals, not everyone has all of their  
00:22:09.000 --> 00:22:15.000  
information at their fingertips to advocate for themselves, or for care as a caregiver.  
00:22:15.000 --> 00:22:18.000  
In principle number five.  
00:22:18.000 --> 00:22:28.000  
I think that one speaks for itself that we have to always feel like you got one shot at doing something like this really well we want to make sure that we don’t have any issues with security.  
00:22:28.000 --> 00:22:34.000  
We can go to the next slide, and round three.  
00:22:34.000 --> 00:22:48.000  
So sorry, go ahead and click on principle three might be a wordsmith in common, but I think that the beauty of principle three. It’s kind of in the third bullet within the full guiding principles, but I think being able to emphasize here that this is  
00:22:48.000 --> 00:23:02.000  
really about being able to facilitate care coordination and communication across providers and disparate settings and inherently in doing that we can reduce fragmented, or redundancy or redundant care and inefficiencies and that’s again it’s kind of in  
00:23:02.000 --> 00:23:18.000  
the third bullet but it’s a little bit buried and I feel like, emphasizing that might not only, you know, highlight those other things that aren’t mentioned but also as we’re trying to increase adoption and buy in and that data reciprocity.  
00:23:18.000 --> 00:23:25.000  
Knowing that people can use this platform for real care coordination across, you know across providers may be helpful to emphasize.  
00:23:25.000 --> 00:23:34.000  
Thank you Bill and echoing a lot of the congrats to you and all the work he didn’t whole person Karen can la as well.  
00:23:34.000 --> 00:23:48.000
Okay. And I know there was a comment about Principle number five just making it sound like maybe there’s this movement towards like a central repository or one place for data to keep it secure so maybe there’s some words nothing there to help in that if we can go to the second, the third slide, I mean I would just say, California does, it's more than word smithing, I mean it's really a fundamental difference.

And again, and one that that many people have weighed in on leading up to the legislation that led up to our discussion today. And I think we, we need to be careful if we’re going to try to go back and rewrite that history.

Are you referring to the history of, if we’re trying to try to be building some kind of central repository right i mean are we building right exactly correct.

I think that that number five is less about that and it's more about the overall framework.

If I'm incorrect please correct me. Kevin or john.

You are correct.

Hey,

Mj them to say that, okay so principle six, again, some of these to some folks are self-explanatory but I'll just pause after six if there's any comments there.

Okay. Principal seven I've kind of spoken about but I think this continues to pop up is not only adhering to the federal and state that's that that might be obvious to others, but it's really leveraging the best practices.

I mean, that's one of the things that I started asking at the beginning very beginning of this process is I continue to feel like we’re not the only place that's doing it, maybe we’re a little different, maybe California so special, but there are great best practices, there’s also the best practices within our own state within our different communities so whether we’re talking about social little term social determinants of health or other types of access.

It’s.

I think if we can really leverage some best practices that are out there and not reinvent would be terrific.
And then. Yes, please. I just gonna say a comment on this we identify these as federal and state standards. A really a lot of these standards are international standards, under under HL seven.

So I think we might want to say, international and national, as opposed to federal.

Some of them. The some there are some standards that are federal, you know, in terms of written into legislation but others have to do with international standards bodies.

Okay, thanks for that.

And then finally principle eight.

We, We need to hold ourselves and others accountable.

I think that there's a, you know, I don't know if there's a specific line that that calls out to me.

But we need to be responsible stewards.

I always come back to the the person that we're trying to serve is, is hoping that we're going to keep their data secure and use this information appropriately.

And, and as Lisa just said, and accessible to them, which speaks to the principal above as well that that goes that.

So with that, these are principles. This is where we landed. Again, we are going to continue to build and adapt, but I feel like we're at a pretty good spot to frame again these guiding principles are hoping to frame the work that we're doing to ensure that our work is, is, is good alignment with these principles. Now, another comment john again This is Stephen lane from Sutter Health sorry, but we have a number of references to individuals and individual access.

I think it is important that we also consider proxies, of those individuals certainly for the pediatric patients, and for, you know, many adults that proxy access and utility of data is pretty important.

And I think we should capture that in here somewhere.

That's a great point.

Other any other final thoughts they want to speak about I see the chat blowing up which is really fantastic. We appreciate it. Easy to capture and include.
If not, I'm going to go to the next slide, and give you someone else, listen to.
00:28:13.000 --> 00:28:17.000
I'm going to hand it over to Dr room popper room.
00:28:17.000 --> 00:28:19.000
Thanks john Can you hear me all right.
00:28:19.000 --> 00:28:22.000
Perfect. Thank you.
00:28:22.000 --> 00:28:25.000
So we're going to spend just a little bit of time.
00:28:25.000 --> 00:28:45.000
Starting a our today's conversation for the data sharing agreement on some of the assumptions we're making as we move into this, we'll touch base, a little bit on technology, the role of scenarios and exchange modalities in this discussion and I'll introduce
00:28:45.000 --> 00:28:53.000
each one of those and we'll pause for feedback, and any thoughts that you may have on each one of those in turn.
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It's gone to the next slide please.
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first from a technology standpoint.
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At 133 calls for the data exchange framework to be technology, agnostic.
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And so we're assuming that the DSA must be technology agnostic as well.
00:29:10.000 --> 00:29:15.000
That means that while we may consider infrastructure components.
00:29:15.000 --> 00:29:33.000
As an example, perhaps those that might be subjected suggested by our strategy for digital identities to be enabling, we are assuming that we should avoid requirements for any specific technology that must be included and that organizations must participate.
00:29:33.000 --> 00:29:44.000
in. We're also assuming that the DSA or more likely the policies and procedures that would accompany the DSA may stipulate technical standards.
00:29:44.000 --> 00:30:04.000
And then as we look at methods for participating at 133 calls out some very specific signatories to the DSA and participants in the data exchange framework and that's in the AB 133 itself, but we're assuming that we should enable labs, sharing directly
00:30:04.000 --> 00:30:21.000
with providers. Providers sharing directly with each other and plans and providers sharing directly with each other, but we are also assuming that we might accomplish this using either direct interfaces or nation-wide or state-wide networks or frameworks.
00:30:21.000 --> 00:30:40.000
However, we're also assuming that we must have provisions within the DSA to allow third party intermediaries to facilitate that exchange. So we're assuming that we might also support labs providers and plans, participating in organizations like a child's health information exchange organizations as a means to facilitate sharing their data.

And I just note that this might mean that we should perhaps consider whether this assumption has implications on potential potential signatories beyond those explicitly mentioned in a be 133.

I'll pause there for a second and see if there are thoughts or comments on those technology assumptions that we're making.

I think we have to assure that we are facilitating the use of intermediaries where that adds value, and is desirable to the parties involved, and not crossing the line to requiring these such intermediaries because so much of this data and you mentioned lab data in particular, so, so much of this is as accomplished today through peer to peer arrangements of various sorts and the technology supporting that directed exchange is only becoming more and more robust and available as time goes on.

So we shouldn't assume that there is a requirement for intermediaries. When that it's being done without that today.

Thank you, Steven Lee I see your hand up.

Yeah, I had just one comment on the thought on this notion of technology, agnostic, because I was wondering if I understand, not wanting to pick winners and losers at the other.

On the other hand, technologies are not all fun, or not fungible right they have different characteristics.

Things may be different things may be appropriate for different tasks and so does agnosticism mean that there's not going to be any evaluation or assessment of whether or not, some particular technology or a way of doing things, is appropriate or properly privacy protected or properly secure etc etc I want it.

I think you can be both agnostic, and evaluative but I want but doesn't say anything about the evaluations. I think that's a very good point Lee and I think that we should remember that as we move forward with discussing items in the DSA that there may
be evaluation or requirements that speak specifically to security or privacy that we may want to include there so let's continue to think about that. I think that's a great point we Thanks, Bill I see your hand up.

Yeah rim I agree with the wording, you know, in the conjunction between the peer to peer arrangements and the exchange arrangements because when you get down to the individual provider level a small group level or even the contracted IPA level is going to be very expensive for us to start to meet the interoperability and patient access rule. We may need it may be a cheaper alternative to use intermediaries and to establish that kind of infrastructure. So I'm going to make sure we do preserve that.

Great. Thank you, Bill. I'll just call attention to Shelley's comment in the chat also about remaining agnostic on technology, but encouraging uniform standard standards and data structure and vocabulary is something to consider as well.

Patrick I see your hand up a room Hey, I like the slides you got support the agnostic, the peer to peer also the centralized model and the network, network so very supportive, it will switch into implementation thoughts is once we develop the framework that guidelines, we say hey it's set. Is there any thought about developing some best practices to say hey this is how we, we recommend it to be implemented to give people a head start.

Once once the agreements out there, or trying to figure out is what I envisioned My head is there's a two to three year model out there to say hey once this is out there. or we could do an HIV connection but I'm wondering is there any thought to say hey once this is going to be published, is to outline here's our recommendations and how to satisfy and accommodate that requirements.

I think that's a good question Patrick and I don't really have a good answer but I think it's a good thing for us to consider as a group.

Devon I see your hand up.

Yeah, I was actually commenting on Patrick's question since this follows on nicely I, you know, I think that to the extent that we are looking to sort of leverage existing models that are out there already, that one of the easy sort of wins right off the bat would be to point to existing models of exchange that are consistent with the standards that we're creating and say, when you're connected using this model that and assuming that you've got that you signed an agreement.
As part of that connection in some way that meets whatever standards we, we recommend or that get it.

That gets adopted by the group that that you can check that box, essentially, so rather than a sort of a single set of best practices there's sort of recognized models that that meet the requirements and that exists already in the universe and if nothing sort of fits the bill writ large what are the tweaks to those existing sort of networks and and mechanisms of exchange that will need to happen in order to facilitate that but i think that that allows us to move this forward actually quite quickly once, once we've got sort of those requirements set.

Right. Thank you, Devin.

Let's go on to the next slide please.

The next set of assumptions is, if you've been following the advisory group meetings, you know that we've been talking about a set of scenarios as part of those meetings, and the six scenarios, juicy listed here.

We're assuming that they are not however the definition of the total scope of the exchange participants modes of exchange triggers for exchange or data definitions for the data exchange framework, nor for the data sharing agreement, instead we assume that we are taking them as minimum to be that is established by the advisor gu group, and should be supported by the data sharing agreement.

We're also assuming that they, that we may consider and enable additional exchange patterns and participants that are not included in these scenarios and therefore we're really talking about that they establish a floor for our discussions, but not a ceiling for our discussions.

Are there any questions or thoughts about that.

Yes, Devon.

You're on mute unmute and put my hand down, let's do here, is it, where's the patient access to data set i is that presumed to be included in all of these scenarios because they look very
provider and service both, both healthcare provider and social service provider centric a
patient might need their data to attend to an acute need but they might just need their
data for their own purposes, and since that's a required sort of data sharing
00:38:36.000 --> 00:38:43.000
parameter I'm a little bit worried that it does not that not expressly called out it gets lost.
00:38:43.000 --> 00:38:59.000
Great, thanks for that Devin Jonah I don't know if you want to speak to that if individual
access is specifically called out any of the scenarios.
00:38:59.000 --> 00:39:04.000
I would have to go back and check whether or not.
00:39:04.000 --> 00:39:14.000
That was actually incorporated into anyone listeners, I'm not sure I don't remember
either and I'm sorry for calling on you like that. Jonah but Devin will make note of that.
00:39:14.000 --> 00:39:23.000
Again, this is a floor. So we might make note of that just for our own discussions to
make sure that it's something that we consider as we move forward.
00:39:23.000 --> 00:39:27.000
Okay, thanks for that Devon.
00:39:27.000 --> 00:39:33.000
Are there any other comments or questions on this assumption.
00:39:33.000 --> 00:39:45.000
I guess one other comment that I would toss in, is that we should think about the
reciprocal ality and by directionality within each of these scenarios.
00:39:45.000 --> 00:39:55.000
Oftentimes with public health response with you know we're talking about a one way
valve data going into public health. And I think we need to think about and with
emergency response as well.
00:39:55.000 --> 00:40:07.000
And I think we need to think about how the data comes back out of those systems to
support various users who could benefit from gaining that data.
00:40:07.000 --> 00:40:08.000
Great.
00:40:08.000 --> 00:40:13.000
Thank you, Stephen.
00:40:13.000 --> 00:40:28.000
If there aren't any other questions or comments there when we go on to the next slide
and this is our third set of assumptions here and it dies in a little bit deeper on our last
discussion associated with scenarios.
00:40:28.000 --> 00:40:46.000
So we're assuming that the DSA must support all of the exchange motet modalities that
the scenarios require, and that might include any or all of the following and the first is
that it might include requests for health information such as query based
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document exchange that is often the focus of many of the statewide and nationwide frameworks and networks, but it also might extend to requests and queries to do not result, only in the exchange of a CCD a document.

It might include unsolicited delivery of health information, such as direct secure messaging results delivery from a lab or other ancillary service encounter other event notification reporting to public health or other registries.

It might include publishing so subscribe arrangements, or participants in the data exchange framework may request updates on specific information or specific patients or members.

Subscribe to specific types of notifications, or otherwise play standing requests for notifications and help them formation transfers.

It might also include exchange of data on from multiple consumers to support population health analysis assessment of outcomes and interventions, public health research and effectiveness of the health care system.

So as we assume that we may be considering all of these modalities, we must also assure the patient remember privacy is protected. And we assume that we will be defining the allowed purposes for exchange and use that address the needs of any or all these modalities.

Now that's a bunch to kind of bite off.

Why don't we pause there again for thoughts or comments and Stephen I see your hand up. Yeah, I'll just put voice to my comment in the chat that one thing that's not included in this list which is facilitated by the you know the evolving fire architecture and standards is the opportunity to to query for or push a very limited data set specified to the needs of a particular use case or scenario that we don't have to limit ourselves to hold document exchanges, or bulk data exchanges in order to facilitate these.

Thanks, Steven. Shelley I see your hand up. Yeah, and I'd like to just add that the mortality should also include access that's view only, so it's not actually an exchange.

And that would allow you know practice practices that have limited technology to access data.
I think that's an excellent point and I am guilty of often thinking about our work here as the flow of information rather than the access of information, but at 133 is explicit about access and exchange and we should bear that in mind as well.

Thank you, Shelley, and just to pile on there briefly, I think with evolving cloud storage solutions for health related data, oftentimes the access is truly just you know providing access to the data, the data never moves anywhere.

And that access can be limited it can be temporary. It can be use case specific, I totally agree with Shelley that we should be thinking about that in addition to wholesale copying and moving of data.

Thanks Stephen, and Lee I see that you have a note here in the chat we're a little bit ahead of schedule so do you want to add your voice or perhaps expand upon your note in the chat.

Sure, I just think that the more we are talking about a lot of different types of groups and stakeholders who will have access to data, and the more the more centralized repository like that is it just raises the stakes on privacy and security and that one of the things that that you kind of have to do I think is to have a very very robust systems for oversight audit trails, etc to make sure that when things go off the rails for some reason that we haven't anticipated that it can be debugged otherwise it's just going to be a bad spills.

Thanks Lee.

Are there any other thoughts, questions comments.

Yes, Lucas,

you're still on mute Louis. There you go.

Thank you. Oh double muted.

Well I've been trying to relate this, you know, to the environment that I've worked in in the counties and, you know, I want to say that each data exchange would have its own transactions that you know, based on the the purpose or even legislation behind the exchange between health and the social services system are two social services systems or a law enforcement exchange and I've been trying to, you know, develop a list of of the types of data that goes between the agencies, and I was, I was feeling
that says, you know, here's the data exchange with its own transaction said using a
standard transmission framework or modality then all covered by this standard data
sharing agreement, the need for the exchange itself may be governed by its own
legislation

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and access to the data may be governed by policy or procedures of the sending or the
receiving application for, for example, if I sent data to a health system then access to a
personal health record fortunate that person's records might be governed by,

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know the way they would request, do a records request for that agency or that entity. So
I'm trying to, you know, from my vantage point, identify what those exchanges are and
I'm trying to put in my mind at guard Bray of, you know, guardrail up on, we're

00:46:58.000 --> 00:47:16.000
talking about the the way we trance net this data, and the and the universal data sharing
agreement about it and then the access to the data, maybe, follow the reason for the
exchange may be governed by legislation.

00:47:16.000 --> 00:47:35.000
And the other access to governance certainly governed by legislation and by policy of
each agency or entity, and the private sector. And I'm just trying to confirm that my
understanding is that and it seems like we're, we're going to just my interpretation

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we're going outside of the guardrails that I'm putting up I'm just trying to, you know,
figure out where I can best serve this this subcommittee in terms of, you know, the
business need, and the type of data that actually.

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on my comments. Well, I will, I will start there, Louis, and then maybe other folks on the
phone will have thoughts about this as well I think that one of the reasons that you're on
this group is to make sure that we consider questions like the ones that

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you're raising that it will be important as we move forward in the data sharing agreement
activities to make sure that we accommodate those different scenarios that you're
listing.

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I don't think that there's necessarily a blanket answer to your question but it is
something we'll need to consider as we go through specific terms or language in the
data sharing agreement.

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Are there any other thoughts on Louis's questions.

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Okay, thanks for that Lewis and raising that hard tension I'm sorry that I don't have a
good answer for you but I think that that's an important point for us to consider, to
continue to consider as we move forward in our, in our discussions.

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Thanks for that.

00:48:54.000 --> 00:48:57.000
Thank you.
00:48:57.000 --> 00:49:05.000
Are there any other questions or thoughts.
00:49:05.000 --> 00:49:21.000
If not, I would encourage the group here to remember this discussion but it's something that we can continue to challenge it starts to set a baseline for the assumptions as we move forward in our discussions, but it may be something that we want to revise
00:49:21.000 --> 00:49:26.000
or, as I said challenge as we move forward
00:49:26.000 --> 00:49:34.000
with that. I think that next on our agenda is discussion with Jen, so I will turn it over to you.
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Thank you can go ahead and go to the next slide please.
00:49:42.000 --> 00:49:57.000
So for this portion of our meeting, we would like to discuss some threshold questions on a few definitions. The reason or purpose for exchange, what are the permitted uses of the information exchange, who should find on to the agreement, and how to recognize an address that some entities are more technologically ready to exchange than others, especially those who have not been involved or had limited involvement and health information exchange.
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Next slide please.
00:50:13.000 --> 00:50:29.000
Thank you. So let's first look at the legislation to see what the legislation fed about what information should be exchanged. So, Ab 133 from that we see that entities listed in the legislation are required to share or provide access to health information
00:50:29.000 --> 00:50:44.000
in real time for treatment payments and healthcare operations. In addition, the legislation also makes it clear that states and local public health authorities will exchange health information in real time with healthcare entities.
00:50:44.000 --> 00:50:52.000
So the exchange purposes appear to be a minimum of treatment payment healthcare operations and public health activities.
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Next slide please.
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And that's why we want to have a conversation about what those mean because those are undefined in the legislation. And so what we'd like to do is first focus on the legislative required props that prop purposes or reasons for exchanging health information.
We will discuss other purposes a little later. So let's focus here on the statutory ones. I think that many people are comfortable with treatment and what that means, which at this time is being defined as the definition of treatment and HIPPA.

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each one of these. So are there any thoughts on treatment.
00:51:58.000 --> 00:52:02.000
Yeah, I think, you know, within treatment.
00:52:02.000 --> 00:52:18.000
There's this concept of care coordination, which you know when you're a provider, you think of that as treatment. And when you're a payer I think that's defined as healthcare operations, and clearly since care coordination is so central to the situations that we're trying to address I think we need, we need to be. Be sure to clarify, you know what, what pieces fall into each of these statutory purposes and for what user categories.
00:52:38.000 --> 00:52:45.000
And forgive me if there's a little bit of a delay I am taking some notes down.
00:52:45.000 --> 00:52:49.000
Okay. Are there any other thoughts on treatment.
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Stephen you still have your hand raised. I just want to make sure I hit, in case there was some additional thoughts.
00:52:56.000 --> 00:52:58.000
No but doesn't Belinda.
00:52:58.000 --> 00:53:11.000
How does that go with Stephen said I think it's worth thinking about social service providers who may not view themselves as you know medical treatment providers that care coordination piece will be really important to define.
00:53:11.000 --> 00:53:15.000
Thank you. Yes.
00:53:15.000 --> 00:53:18.000
Okay. Lewis.
00:53:18.000 --> 00:53:22.000
All right, I think that to augment those comments.
00:53:22.000 --> 00:53:26.000
An example would be.
00:53:26.000 --> 00:53:44.000
In the case of Child Welfare which would meet says threshold of an emergency response that we talked about previously, where they're responding with law enforcement perhaps to an allegation of child abuse, and then their court ordered services that are medical or our social in nature that PX will will need to exchange between behavioral health providers and physical health providers.
00:53:56.000 --> 00:54:15.000
So when I look at a treatment. Certainly the services the counseling the other other services, besides what you may think of in treatment in a medical world, are, are some of the types of data that we, you know, intend to exchange rather new state child welfare system. So, just wanted to add that.

And Kim,

and then let me go to the chat really quickly.

So do folks want to talk through any of their comments in the chat.

For this particular use treatment.

I don't want to put anyone on the spot.

Louis, or are you still wanting to raise a question or concern or, or comment, or are you still having your hand up from last time.

Devon, go ahead. Yeah, so, you know, raise the hand raising function it's it's a challenge to, to keep toggling it on and off.

But I'll go ahead and take it down right now, if you if you wanted to rely on the treatment definition and HIPAA, you're not necessarily going to pick up purple Linda's point, the sharing with social service agencies for treatment of the whole person.

You know OCR which enforces HIPAA has done some limited guidance on the application, you know, the ability to sort of use treatment. In order to share to meet a patient social service means, but it's but it's relatively limited, and they had some proposed changes to the rules that has not been fully implemented yet so so to the extent that we endeavor to sort of encourage or facilitate whole person care with this data sharing agreement we may not be able to rely on the definition.

Okay.

Okay, thank you. So let's move into the next piece so what have you got more, you got some more hands on I know, go ahead. Sorry, Lewis, Stephen.

Okay.

Yeah, I think it you know as a, as a provider, you know who does treatment, all the time.
Again the privacy issues Ender intersect with treatment, use cases, and really do have to be kept in mind I made a comment earlier about pediatrics there's adolescence there's you know adult proxies there's, there's a lot of real complexity in terms of maintaining appropriate privacy in the treatment context and, and a lot of work being done on this nationally with the p2p I effort, etc.

So I just think that we need to keep in mind that the treatment is not even though it's certainly the most well established use case and the one that probably engendered the greatest volume of current exchange.

It's not just black and white it's like oh it's treatment therefore we can start thinking about it it's still quite complex.

Thanks Jennifer. Yeah, I would echo the comments from Belinda, and Devin about, about the social service aspect of it I think in some respects that may be that may be the most important part of what we have in front of us given, given the, the many other efforts that already exists and already due to the fact that, that are active in health information exchange that interoperability activities that on the, you know, on the traditional health side are this work doesn't seem to me to be groundbreaking.

But to figure out how to, how to add that whole person aspect to capture the social service issues that are not within traditional healthcare, that that remains missing from from most other activities, and I think maybe the most important aspect that we can deliver.

Thank you.

And are there other folks with hand raised.

Some organ you still have your hand raised. And I think that might be, everyone.

Okay jump in if it's not the case.

Or else we're going to move on to the next piece which is payment.

So, can we go back to the far side, please, we're not we're not quite finished, so about payment. This could be a very broad topic.
So far, the draft trust exchange framework, common agreement limits payment to utilization review, although other agreements such as there so allows more than utilization review.

If the data sharing agreement will require exchange of health information for certain purposes such as treatment, should there be any limits on payment, I believe, although I would love to hear from you that the tough call limits payment to you are because the comments received by stakeholders, were about feasibility over, requiring more payment uses.

So what we'd really like to hear is your thoughts on what does payment mean what's feasible. And what does that look like Stephen It looks like you have your hand raised.

Yeah, I just, I think that, you know, payment, arguably, was the very first use case for electronic information exchange in the healthcare space, you know, sending sending bills and getting paid is central to the majority of healthcare in America.

And I, and I think that it's a system that that has evolved, you know tremendously continues to evolve. And I don't think that we necessarily have a list of particular problems that need to be solved, you know by us in california i don't know that we have, you know, unique payment use cases in California or whether there are unique payment needs related to addressing the inequities or the social services etc that we are focused on here.

So I just, I just don't know how much I think the reason that if God didn't include lots of payment use cases is probably the same it's like it's, it's working, it's up and running.

So I think we just need to think about are there gaps in the existing exchange that occurs to support payment that we should be addressing especially with our equity lenses on.

Elizabeth.

So are you saying, are you saying that you're not necessarily in the camp, that we should require exchange for payment because you believe it is already covered.

Are you saying you only want to require it if there is a specific gap, or you're okay with a requirement but you want to dig into it a little bit more.

So what we're saying is we'd like to kind of define it and I assume I was for me, rather than for Stephen, I was actually asking student but okay so I will accept it from either or both.
I can't say that I've given this deep thought, so I'm going to sit back and listen to you guys talk for a little bit longer.

So, where we're coming from with kind of moving through these different topics with treatment payment health corporations and public health is to ask, are there gaps What are those gaps, what's working, what's not working.

Do we need to limit some of this because the business processes or technology isn't ready for it what what is working, what's not. we're looking to hear from you.

Do these needs to be limited do they need to be broadened, do they just need to be the words themselves as written or do they need to be aligned with existing or with future agreements.

Does that make sense.

I think it makes sense to answer your question. But back to the payment I just wonder and I'm not sure. Hopefully not, you know, stabbing myself but would payment and expansion of these, you know areas of payment would consider include access to data for pre authorization.

I think that's a really great question, and I think what we would like to hear from you is should it.

And if it should, why should it. Does that make sense. So what we're really looking for is, is your thoughts on on this topic, Lisa,

I guess, you know, think something just to consider as we're kind of drilling down on some of these definitions and is to just consider not creating too many like different definitions so like the same terms that things that mean different things, and consider you know guidance or or sort of examples kind of like in how the register Federal Register does it sometimes where they provide sort of various cases and fit them into different pieces of the definition rather than having really specific definitions that may or may not match up with other legal requirements.

That's a really great point.

Stephen.
Yeah. Somebody mentioned prior off as a treatment related use case and you know prior authors is clearly an important use case and need to support the all sorts of care, and it's one that you know is going on today.

You know, in a often inefficient way, and there's all kinds of work being done to make that more efficient it's a major focus of the work that the da Vinci project is doing on fire.

So it's a gap that's being addressed there's lots of federal policy work going on around supporting prior off. So again it's one of those things I'm not sure we need to try to jump into that fray and fix it for California and not sure that we have sort of you know this brilliant answer to a problem that other people are still in the process of solving. So again I'm not I'm not averse to us focusing on opportunities to improve health related data exchange to support treatment use cases I just, I just don't see the need, at this point.

Let me just see if there any other hands up, Stephen you still have your hand up, Louis. Yeah, I think the world of payments and social services as.

It's very complicated environment with payments being made to, you know, foster parents or for other goods and services. And, and in addition through, you know, services that were authorized and rendered by behavioral health and physical health providers that are paying you know pretty much through, through medical or you know through standard HIPAA health care payment processes so I don't know, I'm trying to assess whether or not we have any go here and social services but I think it's a bridge too far for what we're asked to do, but if we have a framework for exchanging that might be adapted some time in the future that, you know, for any of those payment types made that are not the type that were otherwise speaking about, then the framework and the data sharing agreement will be available, but I.

It's such a complicated area in social services, because they're making payments through their counties.

General Ledger systems for different services for children or families. And so I don't know that we should get into it, but I wanted to make the group aware of that, you know, in case it is relevant to to this great.
Patrick.
Hello, Jennifer so from a healthcare payer perspective.
I've seen where giving access for payment healthcare operations and I could see public health is a net good thing that we should consider. I've seen in our operations that not having this data has slowed things down.
I haven't seen a change the outcome. But what I have seen it without having data, it slows things down and having more data could speed things up, make things more efficient, and ultimately help our providers, and our, and our members together so I'm a supporter of keeping a broad perspective on allowing data exchange for payment and healthcare operations from my perspective.
and I am coming from a little bit of a pie in the sky, a little bit of an altruistic perspective.
I believe Carrie was next.
Thank you. And just one thing to think about. I think there's a lot of great comments on his definition of GPO, and whether you know it's appropriate to expand that are not in particular with regard to social services and other things I just wanted to say that the 58 counties. You know they they most every county is different but many portions of social services functions are not under the covered component where arguably HIPAA would apply.
You know in our perspective when it comes to development services. We do believe that Developmental Services.
You know would fall under the umbrella of treatment because we believe that HIPAA applies to us and and we have a business associate agreement and all of that.
So this is sort of I think the difficulty here it's really going to be with social services.
See, and then it looks like. Those are all the hands.
Oh, Stephen. Go ahead. Sorry, I was just going back through the chat and I saw a she, she asking where would sth fall in these categories. I think Truly Social determines fall into all the categories.
You know that there's, there's all kinds of different data that would support these various purposes but clearly social determinants impact treatment payment operations and public health, just to respond to that.
01:09:26.000 --> 01:09:28.000
Thank you.
01:09:28.000 --> 01:09:41.000
See, it looks like we don't have any other hands. So why don't we go ahead and go to the next element on this slide which is healthcare operations. So again this afternoon.
01:09:41.000 --> 01:09:59.000
Again, go ahead. Sorry Jennifer, I came in very late, but you know the thing that struck me is that everything in these slides, is about HIPAA, and I'm was wondering if you, there was anything that we should be aware of.
01:09:59.000 --> 01:10:11.000
Generally in terms of HIPAA CMI a gaps that are quote differences that are going to affect the way we think about this. Thank you.
01:10:11.000 --> 01:10:29.000
That is a really good point because they are not perfectly aligned. And so clearly will need to, you know, consider California law, not just HIPAA and you're right these are somewhat focusing at the beginning of our conversations on kind of unknown quantity because a lot of the existing agreements talk very much in that way but I want to share folks that you know the data sharing agreement will be taking in California law, not ignoring it.
01:10:44.000 --> 01:10:48.000
Um, so let me just make sure. okay.
01:10:48.000 --> 01:10:53.000
So let's talk a little bit about healthcare operations.
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Again this is super broad, it can be a lot of possibilities here.
01:10:57.000 --> 01:11:12.000
And it's also challenging because of some of the sort of abilities to do healthcare operations and yes this is coming sort of from HIPAA requires kind of a direct relationship with the patients and that's really hard to track.
01:11:12.000 --> 01:11:32.000
So, similar to payment Tucker has some sort of narrowed focus on business planning and development quality assessment and improvement. So I'd like to hear your thoughts on we'd like to sort of hear what you have to think about how this term should be defined.
01:11:32.000 --> 01:11:33.000
Should it be limited. Should it stay abroad. What are your thoughts on that.
01:11:33.000 --> 01:11:41.000
Devon.
01:11:41.000 --> 01:11:56.000
Yeah, I don't, I'm the definition of healthcare operations has a lot in it, I think, more than what people realize, I wanted to sort of cut and paste something in the chat from online and it wasn't working very well for me.
Quality Assessment and improvement population based activities care management care coordination I think folks are familiar with and acknowledge those but it also includes reviewing qualifications of healthcare professionals, evaluating provider and plan performance training accreditation certification licensing or credentialing underwriting and other activities related to the, to the creation of contracts of insurance, conducting arranging for medical review legal and auditing services including fraud and abuse detection and compliance programs business planning and development including cost management and planning analysis related to managing and operating the entity and business management in general administrative activities, just for a catch all at the bottom, including customer service resolution of internal grievances sale or transfer of assets, creating de identified data or limited data sets and fundraising for the benefit of a HIPAA covered entity.

So, I'm just, I just offer that, because to suggest that if we were to broadly require that information be shared for healthcare operations with that big definition we're including a lot.

That, that goes beyond I think what, maybe some people may have realized. So, what do you think fun should be sort of minimum pieces for what it should be. Yeah well i think i mean i think the Tesco went in and a healthy direction which is to sort of recognize there are at least for entities covered by HIPAA some limitations on their ability to share data with one another to only sort of the, you know, top two categories of of healthcare operations versus being you know being able to share for another entities, you know, review of the physicians credentials for example, that doesn't mean that that sharing couldn't or shouldn't occur it's permitted but whether that gets pre op prioritized as a required sharing of the network is another is another issue altogether and especially if there’s sort of an effort to sort of limited it to just the statutory purposes we've essentially told patients, your data, your ability to access this information from the network is not prioritized, but we're going to allow entities to, we're going to require entities to share for each other’s Business and Management priorities. I just don't think that's a good message.
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We want to go narrower than the full healthcare operations, I think that's okay i think it still has to be broader than tough because though it we have to at least capture even what Stephen was talking about earlier where care coordination when provided
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by, nurse practitioner operating under the umbrella of a hospital system that is treatment but if the exact same person happens to be operating under the umbrella of a health plan, then it becomes healthcare operations and we want that covered in both
01:14:55.000 --> 01:14:59.000
of those scenarios I would expect.
01:14:59.000 --> 01:15:12.000
So I think we still we need to go broader than half cup but if we want to get down into where exactly that ends I think that's a valid question,
01:15:12.000 --> 01:15:15.000
carry
01:15:15.000 --> 01:15:33.000
things in thinking, especially lately with this definition of healthcare operations is where do you draw the line with this quality assurance stuck in a situation where we have too many cooks in the kitchen where we have to get like exemptions from our
01:15:33.000 --> 01:15:56.000
IRB boards, and all of that, to be able to do healthcare operations so I think it would be advantageous to actually have some specific points on, on what exactly are operations than having this such a broad, I mean that's so broad quality assurance, but
01:15:56.000 --> 01:16:03.000
just my two cents.
01:16:03.000 --> 01:16:09.000
Then I'm not seeing hand so let's go to the chat.
01:16:09.000 --> 01:16:12.000
I'm a little slow on this sorry.
01:16:12.000 --> 01:16:16.000
Um, let's see.
01:16:16.000 --> 01:16:30.000
So, uh bill Do you want to kind of expand a little bit we have plenty of time we're actually ahead of time, on, on this costs of sharing concern that you raised.
01:16:30.000 --> 01:16:40.000
I'm having trouble getting my head around it is very very broad and developing that kind of, you know, if you're a delegate capitated delegated position group.
01:16:40.000 --> 01:16:53.000
You could be swept under these requirements quite easily and and man it could just be so costly so I'm going to have to pull more information from my membership.
01:16:53.000 --> 01:17:03.000
And so off the top my head I would support more limited use cases.
01:17:03.000 --> 01:17:10.000
And then, let's see.
01:17:10.000 --> 01:17:17.000
So shall we do you want to expand a little bit on your support of limited use cases as well.

Well it seems to me that healthcare operations really is an internally focused, exercise, and that the data that would be used on HIPAA allows you know disclosure data for certain purposes right outside of the treatment arena.

So, the information that would be relevant to an organization for, for, you know, you, and it gets fraud detection or, or you know it's operational uses would really only be relevant from its own internal sources right, it should not be looking at other organizations to, To determine how it's doing.

So I support a limited use case for health care operations.

Lisa.

I think somebody mentioned in the chat before to I think it's also really important to think about the fact that I'm treatment payment health care operations is always been a permitted use as opposed to mandated use.

So, like the frameworks a little bit different. And I think that's really important to think about as we're moving forward in this space about what we're going to require versus what's permitted.

Excellent point.

So, to that point, at least for those who are actors covered by the information sharing requirements under the ONC rule, if it's permitted. And it's requested, it's required.

So it's, it's important that the the rules of the game are changing depending on what kind of an actor you are.

will note that we've seen permitted been required in all the national networks, and what has resulted in is nobody responding to anything that's not required, right.

So, it is Stephen is Greg, that it is what is required as expanding beyond just the definitions and the networks give it for a small subset of players but it's not everybody, but it is.

You don't see voluntary exchange on the national networks who have a permission system permitted this, but I think we should keep that, you know, a dynamic compression, for example, right now we are moving towards requiring responding to requests for
individual access on as part of the Care Quality Framework Hopper, you know, documents, so. So I think, you know, we want to keep our eyes looking forward and not backwards in that, in that regard.

But, and I just want to point out to that. I think this area is a little bit evolving, I think everybody understands that there’s some sort of conflicts in the way the framework set up between the RNC the Cures Act and, and HIPAA, as it exists, is that in addition to CMIA, which is mostly set up as a framework based on the old HIPAA rules so I know there’s a new proposed rule coming out and hit but I think, you know, we just need to keep that in mind that we need to be flexible because I think that this area is going to be changing as we move forward.

Okay.

And it doesn't look like there any other hands up.

So, sorry.

Again, little slow. So let's also finish this slide with talking about public health. So, public health is is also somewhat broad.

It doesn't appear that there have been limit added to that in the Tesco.

We've heard from stakeholders that they want public health information, particularly from state and local public health authorities.

We've heard that there may be some concerns over the broad nature of public health activities.

There may be concerns over, or that public health activity should not include enforcement or oversight by government entities because of the need to create a trust environment, and bring people into that trust environment.

So we would like to hear your thoughts and concerns with respect to what public health means leave.

So, um, hi Jennifer, I want I'm not. I think public health clearly includes a lot of the stuff that we're talking about right now in the contact racing and vaccine area.
And that's the reason that I'm concerned because I feel as though currently in California we don't have a great, a great framework or even a greatly transparent framework that promotes citizen or patient trust in where the data moves.

Once it is collected for public health purposes so that's my primary concern is, is that whatever the definition of public health HIPAA seems to be terribly permissive about allowing the data to move from protected from covered entities into public health authorities, but then the, the controls on public health authorities or public health agencies becomes very.

I don't know I'll use the non technical word very squeaky, because, you know, we know that public health authorities can be designated companies private entities there's all sorts of entities that can be public health authorities pursuant to the HIPAA rags, and I don't really understand how whether California law is more restrictive about that. And then, as I've mentioned before, many public health authority entities in this state are not even regulated by the IPA because they are county or city level and in our work with County Public Health Executives on stuff like contact tracing legislation. They freely admitted to me that there was no standard sort of way across the you know the Counties of California the public health data is treated, or exchanged or what the protocols are and so that feels like a very very messy thing to try to drop into an exchange system that is, you know, that has its goal of accelerating and increasing the velocity of exchange when we are not clear.

And we cannot assure the public, where their data is going so that that's my very generic general things actually see no other hands, a Morgan.

Yeah, just the way he doesn't that doesn't. What you describe, perhaps make it more important that this framework address that, that it could provide to provide the framework for more consistency for for the local public health agencies to, to, to advance their practices to I or level like that. Take your time. I know you're completely right. That practices very, you know we got 58 counties and 75 ways of doing things.
I think that might make it make this work more important that we carve it in, not that we leave them out, or we're making them easier for them to move ahead.

Definitely, yeah, my point is similar to Morgan's. I think, which is and I just raised it in the chat which is the actually the agreement might give us an opportunity to play some expectations around data recipients who may not be subject to sort of robust legal requirements regarding how they handle or protect data once they've received it.

Really good point.

And then I believe Lewis here next.

Thank you. And I would agree that it's very diverse. It's also structured differently and counties where I've seen behavioral health and the public health department, and its own agency in some counties. But it runs the gamut, for me, from speaking from a county perspective from where we set up something with an exchange NHL seven with the immunization registry. Or if we're looking for something in social services from vital stats or, or the death registration system, but I've seen it in the county where you know animal control and public health, work with communicable diseases and they have a genealogist, and I don't, not all of these are like electronic data exchanges. So I think it would be bent, this is the way I entered this conversation, or this subcommittee was thinking that would be beneficial should public health agency as a local level want to exchange or automate some of the processes that may not be automated now to have the framework to use.

And all of the privacy and data sharing agreement of protections that come along with it. So I think that's consistent with, with some of the way, lead or comments that I just heard, and the social services agent, you know agencies in the county will work. Along with health children's disability and prevention programs and making referrals back and forth so I think having framework would be an advantage.
Just to add to that, I was going to say you know a lot can happen with the social service grant agreements that are provided at the state and trickled down to the counties. And because right from my recollection from when I used to be in county council, none of those social service comp, you know grant agreements have a business associate agreement in there. So if there’s certain programs that we want social services to touch as part of this exchange. I think it’s messy I know it’s so messy but it may be that we need to look at the programs at a high level like IHSS and some of those other programs to say okay we just need to put a business associate agreement. And this grant agreement that you know is renewed so often, and then you know each county board of supervisors is going to have to adopt that and then they’ll have the framework. It’s not an easy path, but I would kind of make the county’s put social services or the portion we want as part of this exchange into their health care component so they’re, they’re complying with the same, you know, have a roles, where they can have adequate framework at the same level. So, Thank you. So, Look at the chat, really quickly. Great point Stephen. So it looks like this, some of your comments might be about infrastructure. And so, and some of it might be sort of about the DSA, can you kind of expand a little bit on raising the floor. Well, you know, the point I was just trying to make is you know that we we providers have found the the counties are all over the map, in terms of their capabilities and their desires and therefore requirements for data exchange and and it just makes a total mess. In so far as those of us who operate across multiple counties have to deal with with them and so the bigger and more spread out you are the more of a cluster it is to try to keep up with with what each of the counties wants.
So if we're trying to do something innovative, you know to benefit, California. One of the first things we should do, I believe, is, you know, in this space of public health data exchange is to raise the floor for our public health jurisdictions and to provide you know both guidance and support to get them, you know on the same page in terms of what what data they want for what purposes, and what situations, you know in what formats and by what transport means they are you know going to be able to accept that, you know, in the same way that we've talked about supporting small, you know office practices that are not very technologically, you know, competent or savvy or or enabled, you know we should we should think about the public health agencies in the same way, and identify those those that are struggling and take the opportunity of this effort to bring them up to be able to exchange.

Thank you.

I just want to comment that my recollection I've been out of the county for about six years now. But the public health agency was always fiscally constrained compared to other agencies they had the most difficulty in funding, some of their programs and so when you say assistance I hope it includes, you know, the financial ability for them to adopt as well, because they always seem to be the, you know, in more need than other agencies.

Thank you.

Okay. Let me just make sure there aren't any other hands, and there are not so why don't we go ahead and move on to the next slide please.

Okay, so let's move from the legislative required purposes for exchange and discuss other possible reasons for exchange. So for example, typical is benefits determination as an exchange purpose.

Tough good benefits determination definition is limited to the use of health data by a state or federal agency to determine whether an individual qualifies for public benefits for purpose other than health care.
So for example, Social Security, Social Security disability benefits.

But this definition is limited to state and federal government entities, it does not include the local governments, nor does it include organizations to contract with local governments to, to perform eligibility determinations.

Moreover existing agreements like their care quality tough to focus on health industry and not on human services, necessarily, whereas our charge and a B 133 is to do this work while considering how to include and incorporate Human Services.

We've heard from folks about permitting exchange for research pursuant to an authorization to give individuals access to their own information and potentially any other legally permitted purpose.

so we would actually like your thoughts on several questions.

First should any additional purposes be required by this data sharing agreement so additional require purposes outside of what the legislation says. So for example, additional purposes to align with Tesco such as individual access and benefits determination.

Second, should have particular permitted to use be limited in scope or broad in scope, technical limited benefits determination, but many of California is counties actually do eligibility determinations, and many counties contract with nonprofits to perform that work.

So, should this data sharing agreement broaden the benefits determination definition to allow or require exchange for eligibility determinations for public benefits by counties and non government organizations that have contracts with government entities.

So we’d like your thoughts on what additional uses should be required. What uses should be permitted. And what particular uses should be limited or expanded in scope.

I'm going to open it up, and I know that's really broad we can take those one at a time, if you like, but we have lots of time so feel free to jump in.

And it looks like Shelly has a comment in the chat.

Yes. So it sounds like you support broadening determination of eligibility. Do you want to expand a little bit on that. Well I think you brought you brought up a good point.
And do you see that as something that should be under the permitted category or under the required category.

01:35:30.000 --> 01:35:34.000
I think it should be.

01:35:34.000 --> 01:35:44.000
Well I'm, you know I'm, I don't think we'd have to go back to the farmer side I think it should sit, definitely set up there with the state and federal use cases.

01:35:44.000 --> 01:35:53.000
I think more happens in the count at the county level. Then, at the state or federal level.

01:35:53.000 --> 01:36:13.000
Now, we recognize obviously that some uses may be permitted, and also require an authorization so I'm, I'm, I want to be clear that you know, just because the data sharing agreement might say you can do this activity that activity may also require, you

01:36:13.000 --> 01:36:23.000
know, a consent. So I want to make sure that you are recognized that we see that but we wanted to have this conversation kind of around scope so we could get a sense from you.

01:36:23.000 --> 01:36:35.000
You know what, what we should do with this. Belinda I believe your next right yes I was going to mention this on the previous slide, and I think it's a really important thing to call out as a separate purpose if it is in scope and I'll share that in LA,

01:36:35.000 --> 01:36:48.000
we have a large advocates benefits advocacy program is through contracted agencies, and our county council when they were creating both data sharing agreements and the client level release of information for whole person care, really had to treat that

01:36:48.000 --> 01:37:00.000
use case and purpose separately for their analysis, because that team is not only getting medical records and lots of other data that they're getting things like IPS that may be subject to special regulations.

01:37:00.000 --> 01:37:13.000
So, I would advocate for this being in scope if others agree and then I think we need to really specify what's what's permissible.

01:37:13.000 --> 01:37:26.000
And I'm going to pose the question to you again. And do you feel like that should be a required purpose or permitted purpose.

01:37:26.000 --> 01:37:40.000
Great question. Um, I think it depends how far we want to push the envelope I'm sure our benefits advocacy partners would would love it to be required but I think if it is at least permitted, that would be extremely helpful.

01:37:40.000 --> 01:37:42.000
I believe we are next.

01:37:42.000 --> 01:38:00.000
Hi. Yeah, thanks. But so one of the examples that I was thinking with about the benefits termination is probably like the wick stuff right i think we could go through there, but I think there's a lot of of as others have mentioned county and local sort
of non state involvement in the whip process it's.

We had someone ask us about how, how we thought that should be handled, and so it's a very attractive use case right especially given that, you know, we already have other federal and state benefits.

So, and this is one that particularly, you know near and dear to my heart, but at the same time. I'm also a little concerned that the scope is too large for the way that this system has been stood up, that it may, I just don't know how, whether the added complexity to do the system is, is the thing that we should be doing some to we're trying to stand, something up that is pretty big in new and that's not really my expertise.

You know I just post that for others whether or not it will distract us from the core things that that we're supposed to be doing, and then the only other point is, because the local city and county and again I am a broken record are not covered by the Information Practices Act. Then there are significant questions about standardizing the privacy and security stuff for all of those things when they hit a network where they presumably will have the data will be much more easily available too many more entities. So thanks very fair point.

Yeah, I know we're, you know, we're in the process of implementing, you know, Cal says which will be used by all the counties for determining eligibility pretty complicated so I'm not sure what we exactly mean by delegating benefits determination, because I think that would still need to be done through Cal saws. It's extremely regulated and very complex so I, I'm trying to get to understand the scope.

You know, of that of that statement with respect to determining you know CalFresh or, or medical benefits.

You know through that program and all of the information that they need to collect and store to determine whether eligible for a particular program.

So, I don't know that it's an area that I'm not sure what the agreements are, you know, with the CEOs that are doing it all, in part, but they have to be using the county consortia system or Cal saws, in my opinion, to be doing that so I don't know what
those agreements are that are in place now. But I would just say that it is pretty complicated application. And then I don't know what the exposure is if, if you will, to if if that opens up the, you know, the scrutiny of a HIPAA process on a non HIPAA entity and I don't know all the ramifications of, you know, I'm not in a subject matter expertise on that but I would imagine that there would be some so it sounds like my colleagues in LA, have already entered into their frameworks I may have to defer to them on what the scope is, but I know how complex that system is so I'm not sure what we mean by delegating benefits determination. And if that would mean healthcare providers would be using that system to try and determine benefits for patients. And that's that's because that's the case as and I assume it's all done under this Agreement and would be permitted, not mandated. I would think. I would thank my I hope I'm tracking with the conversation because sometimes I know too much detail and adjust my clothes my thought process but if that will be my opinion as if it was somebody, for example at a facility that was able to determine eligibility eligibility there on the spot using those systems, then I think that certainly should be permitted. That's that's what we're referring to. Yes, thank you. And so there's a myriad of services that are sort of eligibility terminations made at the county level and there are a lot of counties that choose to sort of contract with a particular CEOs or nonprofits around providing that kind of service their community based and so for example CalFresh a sisters would assist with doing applications and helping with some work on eligibility determinations of just as examples of things not necessarily needing health information but rather just an example of how this would work. So, what could be another one that's the woman infants and children supplemental nutrition. And so, there's, there are some. That's why we wanted to have this conversation around benefits determination because the tough code definition is really quite limited and in California, the counties do most of this work rather than the state, and so that would make it very difficult for us to do, to use this use case for example.
So I did see some chat conversation around research, and the thought was that research should be a permitted use, not a required use so can we have a conversation on research.

Now, research, I defined research as being essentially the same as kind of the common rule where we’re talking about advancing the generalized knowledge of, you know, of science essentially and so, and it would go through an IRB and all that.

So why don't we talk in terms of what you think research means, because it could mean many things. And, and kind of narrow that down a little bit in terms of what your thoughts are on research.

Does anybody want to weigh in on that.

I mean, I'll just say that if you if you're limiting the definition of research to sort of common role defined, you know IRB approved or way of research, I am super in support of that.

But of course research takes all sorts of forms as I, as I commented in the chat and we just need to be be cautious.

And so in that case, if research would be a permanent purpose.

What you would you support them limiting it to sort of that common rule approach.

Certainly if we're saying permitted, as opposed to required yes i think you know if we wanted to switch that to required, then you know that that's a whole big step that California could take, you know. it's not not something to be taken lightly.

I mean that would be like a major initiative and you know groundbreaking on the world stage but I'm not averse to it, but but we have to be prepared, you know, and go into that with full information from the research community of California.

And then, let's see.

So, Elizabeth brings up a really great point.

So, what about some of these other things on the list, we've focused on benefits determination, or eligibility determination. We've talked about research.

But what about in response to an authorization. Or what about other permitted by law purposes as permitted purposes.

What does that look like to folks.
Devon yeah I'm, I think I'm in agreement with Elizabeth, that we, we should not sort of create a network that's a little too heavy with even a lot of permitted you.

Well, I mean, for permitted use cases I mean, frankly, because it's it's permitted, which one would assume would still allow for some discretion on the part of the data and points to decide whether or not they're exchanging or not I'm not sure.

Maybe there's something that I'm missing here but I'm not sure us coming up with a list of permitted use cases really advances the ball very much beyond you know any other sort of, you know, authorized, some any other sharing that's authorized by law in some degree or another. So that's what I'll say initially about permitted use cases but we we have had some good discussion in the chat and it's certainly something that I bring up a lot admittedly I wanted to see see if someone else brought it up but I do want to have a discussion about individual access because while it's not a statutory designated purpose. It is one of the few purposes for which the law actually does require at least some entities to directly respond and it's a major priority of national data sharing initiatives and in my view it's subsumed in the vision statement around every California, being able to access their information and I think we've we were doing a lot we're, we're doing a lot to make sure that sharing can happen for the benefit of the patient for lots of other purposes, but I don't think that we should leave out that patients should be in there and their proxies should be able to, to have that same data access and decide what uses that they want to put it to as opposed to kind of a more caretaking approach, well we're doing this all for you right I just I just, especially since I presume a lot of the sharing per law will take place without necessarily the patient consenting to it first, or in some cases even necessarily being able to object to it so at a minimum, we should be creating a network that empowers patients in their proxies to get copies of data, under the nothing about me without me theme that I so often hear from patient advocates.

Elizabeth.

I don't object to the Devon's point on an individual access but I guess what I was really trying to get at is what is our baseline here because it looks like what we're trying to discuss here is a piecemeal should this be permitted to this be permitted should this be permitted I think we can skip past that we can say, Once we set this up. You are permitted, but not required to exchange information for any legally permissible purpose, under the various regs what that will look like may vary a bit by
entity, it may vary a bit right so there are things you can exchange for but only to certain entities I understand that. And then from there, what we're really talking about where the concerns are is what's required.

What do you have to say as to what you really have to respond to. And to me that makes it so much cleaner baseline as opposed to listing out 400 permitted purposes individually, trying to make sure that we capture everything but we exclude three tiny things for no discernible reason.

And then we're required but what we're really requiring is still the same court eight purposes or whatever it may be.

I don't want us to have 50 100, specifically enumerated permitted purposes, if what we're really trying to get out is we want to network that functions that people can use to exchange data you can use it to exchange data for any legally permitted purpose, you're not required to change the data, except for in X y&z circumstances.

So what I'm trying to sort out is whether there is an objection to that baseline approach if there is a anybody in the group that truly believes we need to enumerate each individual permitted purpose.

And that is a fantastic question. So I think it would be really helpful if we heard from you on that would that have an impact on trust or would it just be too messy and convoluted to try and figure out whether or not your purpose is listed in that list of purposes, even if it's a lawful purpose of Lewis.

Well, I like that approach. But I have to say when whenever I think about research data. It's always de identified.

So federal federal agencies will require data for outcome measurements to ensure that treatment is, you know, as effective, but it's de identified data, one way you provide data from social services systems like child welfare to University in St identify this for the you know the purpose of advancing our programs through the use of data. So, the.

For me that's a key protection of privacy that we, you know, should be baked in, and I do, don't think we need to identify every specific permitted type I liked your, your suggestion.

In terms of keeping you know at that at that level you specify.
Thank you.
01:51:59.000 --> 01:52:03.000
Okay, so there's Morgan, go ahead.
01:52:03.000 --> 01:52:16.000
Thanks, Jen. I think this issue in some respects raises a question I commented on some, some time back and and that I think Devin raise just a moment ago.
01:52:16.000 --> 01:52:30.000
And that is about what kind of control do we want individuals to have, what kind of participation in these processes and hip opposes the question perfectly.
01:52:30.000 --> 01:52:46.000
And I want us to be constrained just to that but but but sets up the question nicely, because most almost all other than individual access to their own records HIPAA permits, many disclosures.
01:52:46.000 --> 01:52:54.000
Some with and without authorization of the, of the patient, but it doesn't require any of them.
01:52:54.000 --> 01:53:08.000
And so it raises a question here about for for disclosures, which could be made without the patient's consent.
01:53:08.000 --> 01:53:17.000
Are we going to articulate the extent to which we think patients should be involved in that, in those choices.
01:53:17.000 --> 01:53:38.000
In this framework. At a minimum, we, I think we will have to, if we don't kick that place on that issue will have to accommodate that. That all the participants participants will do so that some provider networks will say we have, we don't do this without our patients consent. Others may say, Well, the law allows us to move this data without the patient's consent. We're happy to move it will at least have to accommodate those differences.
01:53:38.000 --> 01:53:49.000
If we don't pick a place and say this is where we think this should land.
01:53:49.000 --> 01:54:00.000
That's a really great point.
01:54:00.000 --> 01:54:06.000
And then it looks like from the actually I'll just wait lead Go ahead.
01:54:06.000 --> 01:54:27.000
Yeah, sure. I just wanted to say that I I view the sort of the expansion all expansions beyond what is you know what we're, we're tied to by the by the law with a great deal of trepidation, I understand that, that there are a lot of things that are permitted disclosures under existing law but I also think that those, the, the universe of permissions.
01:54:27.000 --> 01:54:36.000
01:54:36.000 --> 01:54:59.000
While it has changed over time and, you know, people have revisited the rags. It still is sort of based in an much older vision of how data moves and isn't wasn't calibrated from either a privacy, security, or patient.

Trust the standpoint, to the situation that we're contemplating of all of the have so much patient data including data that hasn't traditionally been attached to a patient record being available at this level of scale so I'm just very concerned that we you know we see so much of this in the, you know, as a result of the changes in technology, the internet the rule that applied before. It's the same rule, but the implications and consequences are so different, because of how many entities are moving the data around are able to do things with it. And so I just I'm just very very concerned that the mere fact that something is permitted now does shouldn't automatically mean that it should be permitted when we're essentially to me like piloting and building something you know at level one.

So so that that's all I say thanks.

Okay, so, um, thank you all. And let me just double check and see if there are any other hands raised.

Okay, so let's talk very quickly and we're, we're now starting to go through our time. So, because we had a fantastic conversation so that's good. Let's talk about the entities that are signing on to the data sharing agreement.

So, as mentioned there are a list of entities that are required to sign it, but there are a lot of entities that are not required to sign it, health information organizations and networks community information exchanges community based organizations technology vendors human services organizations, emergency medical services,
local governments, state departments, and many others who are all critical Partners in Health Care, and Human Services, they’re critical from the Integrated Health and Human Services or whole person care standpoint as well.

So our approach because of the very tight timeframe to move this forward from the legislation, we’re focusing on the required entities, but we still want to establish a trust framework for other entities to sign on to.

So we would like your thoughts on who other than the required entities should sign the agreement.

And why to help us understand various perspectives business processes, and how we can help move integrated healthcare and social services forward.

So I'm going to go ahead and open it up to folks to jump in.

Let's see.

I'm not seeing. Oh, there we go, Elizabeth takes a second to get the hand up. I know, sorry.

I think that the answer to this depends a little bit on how we're going to structure, all of the required signatories participation right so if we are going to set up a system where we deem 15 entity us all to be acceptable intermediaries.

Are they going to sign the same agreement, or they should there be an agreement that is part of the process of getting that validation from the state.

If we're not going to take that approach and they're just going to be kind of grouped in with the rest, then yes they absolutely should be designing this because we have to take that into consideration.

But so it depends a lot on how we end up structuring. How would these people can comply the mandatory signatories how they can comply there several different structures that could work.

And that means several different groups of people who could sign this for something else first nothing at all.

Shelley.

I'm very much important, allowing additional entities that are not covered entities to sign on to the agreement.
That's how we're going to achieve more health equity and, you know, address the social services needs so we need to allow for that to happen.

And I think some of the concerns might be, you know, security, and that can be addressed procedure on context so I think we need to allow this to happen.

Thank you.

Let's see. So,

That's a great question from Stephen.

How are we going to advance reciprocal exchange, if the entities who are not part of the legislation, are not required to participate. So let's talk about that.

What if they were required to participate.

What if there were a list of uses that were required for everyone to participate and a list of uses that are not required to participate. And let's put a pin in the thought in terms of technology or readiness or business readiness for a moment.

And let's assume that authorizations that are necessary, are there. What are your thoughts around that.

Let me just look and see.

Shelly Did you still have something you wanted to address that I think that we can't require CTOs to participate. I think a lot of a lot of situations, they're not going to have the technology to do that, but I certainly think that there might be some,

some form of evaluating their readiness and then allowing them to access data.

Thank you. And Devin I think you were next yeah i mean i i am I sort of I put it put this in the chat, I, and I think this is what you were getting at Jennifer but I wasn't entirely sure like if you're not a required signatory under the statute, but you want to participate, you want to be able to at least be able to get data from this new network, then you have to be willing to contribute back, and that might be the way to sort of without a separate legal requirement past to get people to sign.

It's like we're creating this wonderful sandbox. Ideally, and if you want to play in it, here's, here's the, here are the rules and sign on and then you and then you sign on to a set of obligations that are associated with with that agreement.
If the end, in addition to any legal obligations that apply and subject any legal obligations that apply on your part.

Yes, that's you, you summarized what I was saying well Thank you, Bill.

wasn't fast enough on the draw there, I agree with Devon's point, I mean I don't see how we do Kalyan without at least establishing a floor permitting Cabos to be reciprocal users.

If they're going to participate in these networks, many of them are going to be delegated down to buy plans for example.

So I think we have to create a pathway for them to do it but when they do it. I think they need to be part of this.

Lewis.

Well, there's there's such an overlap that I'm having some difficulties but we were already already traveling down this road in some ways, we, as part of our state child welfare system to be seamless compliant we have to be able to have a two way exchange

with our child welfare community.

Child Welfare contributing agencies. We also do you know make referrals out to Cabos for services that they can provide a certain steps of a process.

You know, and we're looking at more and more, you know, prevention programs. So, I think having the framework for folks to opt in opt into is very beneficial, I think, where I'm looking at it, you know, is there a specified technology that they, when we establish this on a path that we may already be on you know we're already intending to exchange data with many agencies. So is there a, you know, an agreement that we can use a technology with us over what we're planning to do.

But I certainly think

that in most areas, we're already sharing, if not electronically and other ways information between the agents in between agencies. And so using this framework should be, you know, easy to adopt and and expect to what I said initially we already have regulatory requirements for Julian that exchange and and specific transactions that we know we need to engage or we need to be exchanged. In some cases, either by business need or by regulation.
So I think this is necessary, I think, to be able to have the ability to adopt this, you know and and then I think though.
There'll be some details by each agency on whether they can and what the you know what the issues may be to why they can't.
And that's what concerns me, the most because the details are, you know, are just not physical right now to me and.
Let me just check and see. Morgan, it looks like you also have your hand raised.
Yeah, I think, I think mostly mostly piling on about about wanting to be open to to their signatories that we need to have this product, be inviting to them, I think, you know, obviously, unless there's, you know subsequent legislation that forces some players in caps and that we need something that will encourage them as Bill pointed out.
my department will have difficulty implementing its major initiatives, without the participation of of systems that go well beyond traditional health care.
So we really need to make it inviting to them. And I'll go back to one point just very briefly to that, even within traditional healthcare. The are the legislation allows small providers to not be required to participate in this and I assume that that's a sort of money question.
In some respects, but if we really want to advance equity.
We need to make it inviting to those providers also to rural practices, rural hospitals, and those that serve disadvantaged communities that may not be as connected to the rest of the big network is most to what we see.
Okay so, um, as we can all understand as we've actually talked about there'll be some entities that are simply that are technologically ready to exchange information they have the infrastructure they have staff who are trained they have business processes established, but there are going to be many entities who will be required or encouraged to sign the data sharing agreement that are not technologically ready to exchange information, and they don't have that infrastructure or that staff experience at 133 requires exchange of health information by January 31 2024. So, how do we recognize this technological and business process readiness difference, and the data sharing agreement so that entities can participate in a meaningful way. But not allow organizations to hide behind a lack of technology or readiness, when they could otherwise meaningfully participate. Should the DSA allow for various levels of participation, essentially based on technologically readiness, should the DSA require entities to obtain a method that allows them to exchange, if they're currently unable to. We'd like your thoughts on this, Stephen. Yeah, so I've been putting a couple of sort of smarmy notes into the chat and I apologize, but, you know, technological readiness in 2022 means a very different thing than it meant in the 1990s, or even in the arts. You know, all you need is an app. You know the end we all download apps, all the time that allow you to collect and exchange data and all sorts of ways. I mean, this can be done mobile it can be done on a laptop, I mean this notion that just because you're low budget community based organization means that you can't exchange data I just think is is crazy. And, and we should we should really stop saying that because I think we insult the people you know in our communities who are doing this this hard work you know they've all got mobile phones they've all got laptops they they have internet, you know connectivity. I, you know, there are vendors out there who are offering all sorts of super low cost access to standardized exchange. You know which which leverages direct messaging query based document exchange the Care Quality Framework.
So I just don't think that the barrier is what we're making it out to be. And that we should be focusing on, you know, collaborating with, you know, some developers or vendors to you know to get solutions out there that will allow these folks to come on board rather than lamenting their inability to do so.

Thank you.

I'm Kelly, you have a really great comment about ci ease. Do you want to expand a little bit on that.

Yeah, sure. So, um, you know do work in San Diego and I do work with San Diego help connect and two in one community information exchange.

So I'm very aware of how we're sharing data between healthcare and CTOs, and you know the way we're implementing this is to allow CVS access to information you know of course all based on patient consent client consent.

But a number of them cannot exchange data is just simply the way it is at the moment.

So, you know, by allowing access we were able to put the information in the hands of people who are actually you know boots on the ground working with the underserved.

They need the information and that information is also available to you know the clinics and in health care providers so I don't think it helps us to require studios or, or, you know, these other types of entities to sign on.

but I think we should, you know, rather encourage them and provide perhaps financial incentives to help them do so, just like a lot of covered entities were financially incentivize and rewarded under meaningful use.

So, that's kind of where I'm at, I think again cis, I don't think we should require them but I think they will join and help them fill that gap between the more sophisticated EHR, and, you know, community based organizations data repositories.

That's what I mean.

Thank you.

Does anybody else have a thought around technology and readiness and potentially a tiered approach or, or an approach where you either have the technology or you go out and you obtain the technology to do it.

Any last thoughts on that.
It's okay if you don't have any. I'll give it one second.

Okay.

Alright, so. Next slide please.

So let's talk a little bit about the sort of developing the various documents that might be associated with the data sharing agreement.

There was a lot of conversation earlier and and sort of question around governance, you know, specifications, implementation, having more detailed policies and procedures what all that looks like.

So, we'd like to show you a visual here about how these different documents might work together so that we have a data exchange framework, which establishes a high level policy framework, including the principles that John presented earlier that supports Health and Human Services data exchange California to improve the health and well being of all Californians. Then we have the data sharing agreement which is a high level legal agreement that allows many various health and human services organizations to exchange Health and Human Services data.

And then we have something that's a little bit more detailed and we're kind of the meat is policies and procedures that accompany the framework and the data sharing agreement will be the details, provide standards specifications guidance around implementing the framework, and the data sharing agreement. So in other words how to do the exchange. Next slide please.

So, again, to sort of provide a little bit more detail around what this looks like. Our approach is to do what other data exchange groups have done, and have one high level legal agreement that defined certain terms like what information can be exchanged participants that must comply with the law, and with the rules outlined in policies and procedures that participants. Excuse me, I'm trying to get over something, but our participants must cooperate and exchange information in a way that is non discriminatory.

I know your typical legal terms, some rules around these things. The exchange uses what's required.
You know, some of the things we’ve already talked about today’s meeting the framework will be a high level, that's also intended to be high level and discuss governance at a high level, such as management and oversight of the data sharing agreement, how
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participants can benefit from being part of the efforts, the principles that guide the framework and the exchange of data framework could be modifiable according to a process that's established in the policies and procedures.
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And so that gives you a sense of maybe how that might work. Lastly, policies and procedures will have details around implementation specifics technical standards and technical specifications appropriate security standards dispute resolution procedures, 02:15:54.000 --> 02:16:00.000
the policies and procedures would be incorporated into the data sharing agreement by reference.
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Since the policies and procedures have to change with time, a standard change business processes change needs change since they have to change these would be modifiable by process that's outlined in the policies and procedures, without having to update
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or we execute the data sharing agreement.
02:16:18.000 --> 02:16:35.000
So, are there any thoughts on this approach on this kind of structure and, or, you know, any concerns or questions, or even thoughts around what should be in the policies and procedures, versus what should be in the data sharing agreement.
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Devon.
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I mean I think in general this is the right way to go, something very lightweight around the data sharing agreement itself. I mean as lightweight as, as, as we can get it given that there are some things we probably need to have in it and then peace and
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peace to handle some of the more details. I think the only thing that I'm worried about is again.
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If we envision that people in the technology. Going back to the technology agnostic decision discussion and how we know that people will be participating in an established networks that already have agreements are we want to encourage them to participate
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in networks where they might sign agreements and get almost like Diem status if we've got it might make it a little harder to do that in this kind of P and P plus data sharing agreement environment where we want to essentially give people credit for having
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signed something that's otherwise in compliance with our expectations but maybe it's not I'm just, I have that as I have that in mind is sort of something that again would allow us to leverage what's already out there, without necessarily, but, but that have some consistency across the board in some way shape or form and without making people sign like multiple agreements to accomplish the same thing.

That's the only thing I'm worried about but I think as we continue to sort of flesh out with the elements of this would be it might be a little bit more clear how that's going to work. And then, let's see. Okay.

So, looks like Stephen has a comment in the chat that it's sort of consistent with how things are addressed in care quality and Tucker. And, yes, this structure is kind of intended to mirror that and to allow folks to have something that they're familiar with.

Bill, great question about governance. And so, governance is a conversation that the advisor group hasn't quite gotten ahold of yet and that's because we're still working on what the framework is. And so we are going to have to talk about some things like we have so far, a little bit in a vague way, only because the framework itself hasn't been built.

And so, that's an excellent question about governance and what that looks like. And so right now we're considering placeholders about what that would look like, but we will be having a conversation about that in the future. And then of course, there is a real place for having the data sharing agreement referred to governance or a steering committee or you know whatever kind of structure that looks like governing body whatever that looks like, and then have the policies and procedures flesh that out a little bit more, so that they could be changed and updated with time as appropriate. So I hope that kind of addresses that question.

If not, can you jump in bill and let me know if you have some additional things you want to discuss around that.

No it does Jennifer i mean i ha for example Integrated Health Care Association has done this for 15 years where they've got two technical subcommittees that look at performance metrics on an annual basis, and modify them based on changing needs or objectives.
or goals.

So I think it's a good approach. I just don't want to be cited as somebody recommending more stakeholder meetings.

Understand.

All right, and then.

Yes, I understood Stephen said because of the detail nature of policies and procedures, they would need to be something that is very flexible in terms of changing legal requirements changing standards changing technology all of that.

And that's one of the reasons why it's pushed into the policies and procedures which is far more flexible than re doing a legal agreement for example.

So thank you for that.

So let's go ahead.

Oh yeah, there's a question for Patrick.

Excellent question. So, uh, oversight over the agreement or I'm calling a governance, if you will.

That's something that again will have to be discussed a little bit in the future by the advisory group. And so what that looks like, who's managing it, who's overseeing it all of that kind of high level governance piece should be flushed out in the future.

And then of course we would add a lot of that to the DSA at a high level and then more detailed in the policies and procedures, and this this subcommittee will not be drafting the policies and procedures but.

So I hope that that goes to your concern bill. So, I don't think that there are any more hands raised. Nope. Okay.

Then if that is all of the sort of desire to talk through this piece, we can move on to the next slide.

Thank you.

So I have no doubt that everyone is just breathless with anticipation wondering when they can see a draft of the data sharing agreement.
And I want to reassure you that you are absolutely going to.

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And, and it's in the future. So because of the need of this stakeholder engagement, and the simultaneous work that's being done, establishing the data exchange framework, which again is the basis for the data sharing agreement.

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We have to have a little bit of a different approach. So we will be sending out draft language before our subcommittee meetings, we will ask that to provide your feedback within 10 days of getting the draft language so you will have an opportunity to

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provide written feedback on draft language draft language will be portions or topics of the data sharing agreement, so that we can focus on certain areas and then move on to other areas, feedback and the reason why we need to do this is because of the nature of how we're, we're creating the framework simultaneously.

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And then we will be providing regular updates on what we're doing in this subcommittee to the advisory group, and we will be asking for their input as well.

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You will have an opportunity to review the entire draft in April or May, which will also be shared with the advisory group and the public for feedback, you'll actually have opportunities to review the full draft and provide comments more than once.

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So at first it will be pieces, and then we'll do these things on a rolling basis because the timelines for this are so tight. We have no choice but to get feedback.

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Continue to revise get feedback continue to revise and so but you will have opportunities to read the whole thing, and to provide feedback more than once on that.

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Are there any questions or concerns on this. So when should we expect the first pieces are our next meeting. We will be looking at draft language, and it'll be a few days before the meeting, but you'll have 10 days after the meeting once we have conversations to, to provide feedback so you'll have some time.

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Also you'll always have time because of course we accept public comments throughout this process, to answer your question.

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Excellent question from Lee who asks who can enforce the data sharing agreement, great question.

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And that is, that's part of that governance conversation that oversight conversation that'll happen by the Advisory Group, a little bit later on in the next year.

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And so that will come, and then we’ll have a better understanding of what that looks like, so that it could be discussed in our group as well.

So are there any other questions or concerns about this piece. If not, I'm going to move on to the next slide, and hand it on over to the month.

Thank you. So, this is for folks that are visually oriented want to calibrate their calendars. It rolls out on the top you can see in blue, what are the legislative requirements as Jen indicated that we’re going to roll through on a rolling basis, various components. The data sharing agreement and present that to you and ask for feedback. And then we’re going to huddle after the last meeting in April, to help develop the final version, which again everyone will have another opportunity and bite of the apple to provide comments. So what you see in the orange box underneath the line is the cadence of meetings, and we’ve sent you invitations to those so we’re hoping you would get those on the calendar.

And as Jennifer indicated is that there’s going to be a ritualized cadence of little bit before get some materials help you prepare for the meeting, also provide feedback and intuitively we’re going to incrementally build the data sharing agreement.

So Jen I hope that gave you a chance to get a sip of water and bring us to the conclusion.

So I believe this next piece if we could go to the next one. JOHN. Are you available, or would you like to say thank you.

So big shout out to Jen, for her leadership and all of this. We are so fortunate to have someone like Jennifer on our team who can put such incredible technical projects such a technical project into such clear words, especially for me and help facilitate this group. So I’ve just been in are watching her facilitate this and now I have to take over and you’re stuck with me for the last minute.

But I just wanted to let you all know that we are going to be summarizing all the meetings and getting the notes out to all of you.

We are going to continue drafting the data sharing agreement language in advance of next meeting. And all of you hopefully will be giving us as you do much of the time.

Give us notes and feedback, and we will get in materials out to you in advance for you to take a look at before the next, next slide,
how our next meeting is on January, 18, and then you can see the series of meetings through April, as, as always, if you have any questions you know how to contact us just want to take a moment to thank all of you for your continued participation wish