California Health & Human Services Agency
Center for Data Insights and Innovation
Data Exchange Framework
Digital Identity Consumer Privacy Focus Group Meeting #2
(March 28, 2022, 2:30PM – 4:00PM PST)
Transcript

The following text is a transcript of the California Health & Human Services Agency Data Exchange Framework Digital Identity Consumer Privacy Focus Group Meeting #2. The transcript was produced using Zoom's transcription feature. It should be reviewed concurrently with the recording – which may be foundon the CalHHS Data Exchange Framework website – to ensure accuracy.

00:00:03.600 --> 00:00:13.320
Rim Cothren: Well, thanks everyone for joining this our second meeting of the consumer privacy focus group meeting to discuss the strategy for digital identities, for the data exchange framework.

00:00:14.040 --> 00:00:21.180
Rim Cothren: Again, for those that don't know me i'm Catherine and i'm a consultant to the Center for data insights in innovation within health and human services.

00:00:21.690 --> 00:00:33.630
Rim Cothren: and helping them specifically for with the strategy for digital identities i'd like to just take care of a few housekeeping items before we get started here.

00:00:34.140 --> 00:00:41.220
Rim Cothren: First, our intent is to record today's meeting and you've already heard the announcement of that and we would post that recording.

00:00:41.730 --> 00:00:58.470
Rim Cothren: On the data exchange framework website live notes for members of the public, if you do not wish to be recorded, please keep yourself muted during the public comment period or leave the meeting, are there any objections from our members of the focus group to being recorded today.

00:01:02.160 --> 00:01:02.820
Mark Savage (Savage & Savage LLC): i'm hearing.

00:01:03.240 --> 00:01:05.670
Rim Cothren: Hearing none, thank you very much, I appreciate that.

00:01:07.350 --> 00:01:15.540
Rim Cothren: Live closed captioning is provided for anyone that wishes to use it please click on the CC control at the bottom of your zoom window to turn on closed captioning.

00:01:16.560 --> 00:01:27.630
Rim Cothren: And then today's meeting is being conducted as a public meeting and there will be an opportunity for public comment during today's meeting members of the public have been muted until the agenda item for public comment.

00:01:28.710 --> 00:01:44.940

Rim Cothren: And, like last time my intent is to keep today's meeting informal, but last time we had lots of comments and people chose to raise their hands to be recognized we give everybody a chance to talk so we'll plan on doing that, today, as long as that isn't a barrier for us moving forward.

00:01:46.290 --> 00:01:55.950
Rim Cothren: But all of you have as Co host to the meeting, have the ability to unmute yourselves whenever you want to speak and if I fail to recognize you please interrupt me.

00:01:56.730 --> 00:02:13.470
Rim Cothren: And then, finally I don't plan to call roll today, so if you could just take a minute and adjust your name and zoom window to include your organization, so that people know who law is attending today i'd appreciate that.

00:02:16.080 --> 00:02:19.290
Rim Cothren: Call let's go on to the next slide please.

00:02:23.490 --> 00:02:28.590
Rim Cothren: Just real quickly our agenda for today and Lee I know that you have to.

00:02:29.700 --> 00:02:35.520
Rim Cothren: End early, so we will try to get through the early part of this agenda rapidly.

00:02:36.360 --> 00:02:47.160
Rim Cothren: will go through outcomes and goals of the focus group in this meeting and a review of the requirements for strategy for digital identities that will be incredibly brief.

00:02:47.490 --> 00:02:55.620
Rim Cothren: Will pause for public comment, if there is any public comment, and I have three slides around two primary targets today.

00:02:56.370 --> 00:03:08.220
Rim Cothren: It may look a little like i'm rehashing data from last time, and I do want to acknowledge, but at least I think I heard last time, but I want to make sure that we confirm decisions that I thought I heard last time too.

00:03:08.670 --> 00:03:16.440
Rim Cothren: So we only have three slides to go through for the bulk of this meeting, but I want to touch on the use cases for digital identities.

00:03:16.980 --> 00:03:25.710
Rim Cothren: And i'm interested in feedback on how people feel about those and then we will look at the data elements for digital identities again in light of the use cases.

00:03:26.850 --> 00:03:31.470
Rim Cothren: And then we'll do a few closing remarks and next steps let's go on to the next slide please.

00:03:33.990 --> 00:03:43.590
Rim Cothren: Welcome and goals will be kind of gone through the welcome already The goal is to support our vision for data exchange in California, which is that.

00:03:44.490 --> 00:03:54.240
Rim Cothren: Every California and and the health and human service providers and organizations to care for them have timely and secure access to usable electronic information needed.

00:03:54.570 --> 00:04:01.800
Rim Cothren: To address their health and social needs and enable their effective and equitable delivery of services to improve their lives and well being.

00:04:02.190 --> 00:04:08.670
Rim Cothren: And as we discussed digital identities, today it is in that context of enabling the data exchange framework.

00:04:09.060 --> 00:04:23.430
Rim Cothren: And I see this and i'd like for you to confirm, if that makes sense to you that what we're talking about with digital identities, is to be used solely to meet this goal so we'll talk about use cases as we move forward today let's go on to the next slide please.

00:04:28.830 --> 00:04:35.040
Rim Cothren: And as we've talked before the goal of the focus groups is to gain critical information.

00:04:35.880 --> 00:04:44.460
Rim Cothren: from stakeholders in their specific perspectives and today i'm interested in making sure that we focus on consumer privacy.

00:04:44.790 --> 00:04:57.690
Rim Cothren: Although you are free to talk about any subjects today that you want, that is my goal today is to specifically address address privacy associated with digital identities let's go on to the next slide please.

00:04:59.520 --> 00:05:01.650
Rim Cothren: And then we'll you'll recall that this is the.

00:05:01.650 --> 00:05:03.390
Rim Cothren: Statement yes.

00:05:03.750 --> 00:05:05.580
Lucy Johns: Excuse me, you want to focus on.

00:05:05.580 --> 00:05:13.860
Lucy Johns: Privacy today are you going to focus on the other items in that bullet list at other times.

00:05:14.190 --> 00:05:18.300
Rim Cothren: So we have six separate focus groups that are meeting on different.

00:05:19.980 --> 00:05:20.490
Rim Cothren: topics.

00:05:20.580 --> 00:05:21.120
Lucy Johns: I got it.

00:05:21.450 --> 00:05:32.730
Rim Cothren: And, and the focus of this this group is on privacy, but we're talking about plan perspective healthcare providers perspective, etc across different focus group.

00:05:32.730 --> 00:05:33.510
Lucy Johns: that's coming up.

00:05:33.930 --> 00:05:35.070
Lucy Johns: Other places great.

00:05:35.100 --> 00:05:35.460
Lucy Johns: Thank you.

00:05:35.490 --> 00:05:35.850
Yes.

00:05:37.080 --> 00:05:56.520
Mark Savage (Savage & Savage LLC): A remote i'll tag on to that to say it, the other groups are identified by stakeholder group so plans, you could say consumers not not just

consumer privacy and I think there are other perspectives on happy to focus on privacy, but consumers have a range of perspectives as well.

00:05:57.150 --> 00:06:02.940
Rim Cothren: And I would I would invite you in this meeting, probably to stray beyond just privacy.

00:06:04.920 --> 00:06:17.460
Rim Cothren: This at our at everybody, as we go through the the focus groups everybody wears the consumer hat at some point, I mean that's been my experience in our discussions so.

00:06:18.270 --> 00:06:29.610
Rim Cothren: Despite my admonition and we're really about privacy, today I would I would encourage everybody to think about consumer more broadly than that today as well, thank thanks mark, I appreciate that.

00:06:30.810 --> 00:06:33.390
Pam Dixon - World Privacy Forum: Oh hi this is Pam Dixon can you hear me.

00:06:33.690 --> 00:06:34.830
Pam Dixon - World Privacy Forum: Yes, Oh well.

00:06:34.950 --> 00:06:36.720
Pam Dixon - World Privacy Forum: First off, thank you for the invitation to.

00:06:36.720 --> 00:06:49.350
Pam Dixon - World Privacy Forum: participate in this project, I have a foundational question for you so having been involved in a lot of digital identity ecosystems, I have my fundamental question is is.

00:06:50.220 --> 00:06:59.040
Pam Dixon - World Privacy Forum: You know these ecosystems are very, very complex and there's a lot of depth and nuance to them so i'm just wondering how this.

00:06:59.610 --> 00:07:18.000
Pam Dixon - World Privacy Forum: group is going to begin to address some of those complexities this, these are very, very complex nuanced data ecosystems, with a lot of hawks that move into other ecosystems so it's it's yeah i'm just wondering how that can possibly be addressed, thank you.

00:07:18.240 --> 00:07:29.730
Rim Cothren: And, and I think that's a good question and I would I would welcome your thoughts on how we should do that or, as well as thoughts of other members of the focus group here.

00:07:30.420 --> 00:07:41.430
Rim Cothren: One of the things that we've tried to do in our early meetings and all of the focus groups is define a relatively narrow scope is called out in a B 133 so that we're not trying to boil the ocean here.

00:07:42.090 --> 00:07:48.150
Rim Cothren: However, I think that we should continue to think about what that scope is and how we properly.

00:07:49.980 --> 00:07:54.960
Rim Cothren: limited in in all of our discussions in particular.

00:07:56.130 --> 00:08:06.240

Rim Cothren: What at 133 calls for is that we develop a strategy, not that we develop digital identities were a solution, and so I think that what.
00:08:08.010 --> 00:08:15.780
Rim Cothren: I am trying to collect now are the components that might be a strategy and one of the things that we talked about in our last meeting.
00:08:16.170 --> 00:08:21.840
Rim Cothren: Is that this might be something that develops over time, as we gain maturity in the data exchange framework itself.
00:08:22.440 --> 00:08:34.620
Rim Cothren: and exchanging data and get insight into the data sharing agreement and, as we learn more about what people are and are not comfortable in sharing on the data exchange framework so.
00:08:35.220 --> 00:08:54.030
Rim Cothren: I would, I would suggest that, at least at this point we think relatively narrowly and we'll talk about what that means, but Pam quite frankly I would be interested in your thoughts about how we should go about that as well, either now or during our discussions today.
00:08:54.720 --> 00:09:04.080
Pam Dixon - World Privacy Forum: Okay um it's a so typically when you're talking about first the strategy prior to any implementation or deployment discussions.
00:09:04.590 --> 00:09:15.930
Pam Dixon - World Privacy Forum: Usually the strategic discussions themselves are are greatly constrained show us to avoid any confusion so it's it's a conversation that's too complex for a call this short.
00:09:17.040 --> 00:09:18.750
Pam Dixon - World Privacy Forum: But I will.
00:09:19.890 --> 00:09:30.870
Pam Dixon - World Privacy Forum: I will work to connect with you on this after the call and also there's a lot of documentation that already exists in this area, so I can gather that and also send that along to you.
00:09:31.170 --> 00:09:32.010
Rim Cothren: I appreciate that.
00:09:32.160 --> 00:09:32.970
Rim Cothren: Yes, thank you.
00:09:34.650 --> 00:09:38.280
Lucy Johns: Can I just comment that I have certainly encountered Pam.
00:09:39.960 --> 00:09:51.090
Lucy Johns: and her commitment to privacy in many other settings and I personally would just like to say that we are constrained now.
00:09:51.660 --> 00:10:11.550
Lucy Johns: To provide input to a report required by legislation so uncomfortable as we may be with any number of things that happen or get said, or even written in this report there's a legal requirement here that we need to do our best to.
00:10:15.540 --> 00:10:34.980

Lucy Johns: Implement in a way that we can all live with, and if the report has to be full of caveats and full of cautions and full of we wish we could have done this or talk about that, then I think it has to include that and that's one reason that we're here.

00:10:36.630 --> 00:10:37.320
Rim Cothren: Thanks Lucy.

00:10:41.070 --> 00:10:41.430
Rim Cothren: i'm.

00:10:42.540 --> 00:10:52.920
Rim Cothren: on the screen now you see what the language is in at 133 associated with digital identities and this is the the full content ID language in.

00:10:53.700 --> 00:11:03.030
Rim Cothren: The legislation and as Lucy said it requires that by July 31 that cal hhs and consult consultation with the.

00:11:03.330 --> 00:11:13.830
Rim Cothren: stakeholder advisory group develop a strategy for unique secure digital identities capable of supporting master patient indices, to be implemented by both private and public organizations.

00:11:14.970 --> 00:11:27.030
Rim Cothren: And so, through the focus groups, we have talked about the focus for these activities and today we'll discuss some of the potential use cases of a little bit more detail.

00:11:29.130 --> 00:11:48.660
Rim Cothren: The one thing that I would say here is through our discussions, both in this focus group and in others, digital identities, often comes to meet mean identity proofing consumers and issuing them credentials, and that is not what we're talking about today in order to support.

00:11:49.800 --> 00:12:09.960
Rim Cothren: Data exchange framework, the goal that we have here that we've I think agreed to is that the focus is to link health and human services data to a real person, so that you have assurance that you're that you're properly identifying a person associated with their data.

00:12:11.700 --> 00:12:13.710
Rim Cothren: let's go on to the next slide please.

00:12:13.830 --> 00:12:14.640
Lucy Johns: So room.

00:12:14.850 --> 00:12:15.750
Rim Cothren: Yes, Lucy.

00:12:15.780 --> 00:12:22.260
Lucy Johns: Did you did you just say there were we're really doing is patient matching secure digital identities.

00:12:22.890 --> 00:12:24.690
Rim Cothren: So the.

00:12:25.740 --> 00:12:34.110
Rim Cothren: There are a couple of ways to think about the term but yes patient matching is often the way that it is described, if you are searching for.

00:12:34.650 --> 00:12:41.970

Rim Cothren: A common patient with an organization that would be patient matching the way some organizations, think about it, is a.

00:12:42.270 --> 00:12:57.990
Rim Cothren: person resolution or record linking where you're linking my health data with a common understanding of an identity, I would say both of those areas are describing the use case in broad terms, to use case we're talking about here today.

00:12:58.890 --> 00:13:11.520
Lucy Johns: Is that the understanding of everyone working on this project, because that the previous slide said, if you go back to the previous slide secure digital identities.

00:13:13.440 --> 00:13:17.700
Rim Cothren: So that is the focus that we've talked about.

00:13:18.870 --> 00:13:34.800
Rim Cothren: At least, that I meant to describe at our last focus group meeting and I believe that we landed on, and it is also the focus that we discussed with the invite stakeholder advisory group that are less stakeholder advisory group meeting.

00:13:37.770 --> 00:13:46.530
Mark Savage (Savage & Savage LLC): I would guess that if it said, a strategy for patient matching we'd be having a much broader conversation, because the wording would not have been as targeted.

00:13:47.820 --> 00:13:58.560
Pam Dixon - World Privacy Forum: So i'm I i'm really have a question here, so do identification and de duplication, which is broadly being called patient matching her.

00:14:00.180 --> 00:14:09.840
Pam Dixon - World Privacy Forum: is really different than secure digital identities, there are not even in playing in the same ballpark you know a lot of very meaningful ways so which are we actually doing.

00:14:12.000 --> 00:14:14.700
Rim Cothren: So the way that we have.

00:14:17.400 --> 00:14:26.640
Rim Cothren: The way that I have tried to consistently define digital identities here is the collection of.

00:14:27.660 --> 00:14:29.040
Rim Cothren: Data elements that.

00:14:30.390 --> 00:14:51.060
Rim Cothren: identify an individual that might be demographic information might be other information and not identity proofing and credentialing and information and individual, which is often also referred to is digital identities, so an example of my digital identity within.

00:14:52.170 --> 00:15:02.370
Rim Cothren: The context of my work at cal hhs is my first name my last name and my email address, which I used.

00:15:03.060 --> 00:15:18.840
Rim Cothren: to identify myself i'm in it i'm ambiguously there, but it does not include any work that has been done to identity proof me so that you know that I actually am Robert cause rent or to issue me login credentials against any system.

00:15:20.220 --> 00:15:27.180
Pam Dixon - World Privacy Forum: Okay that's better um I, I do have a quick recommendation to make, which is, I would really consider.

00:15:28.080 --> 00:15:38.550
Pam Dixon - World Privacy Forum: kind of moving to the industry standard terms, so that would be the the attributes, and I think it'll keep us out of a lot of hot water i'm.

00:15:39.000 --> 00:15:57.390
Pam Dixon - World Privacy Forum: Going forward, because those terms, have you know really steady defined applications in the in the standards world, and I would be much more comfortable if we're using words that have standardization behind them, so that everyone is very clear with with what we're doing.

00:15:57.780 --> 00:15:59.700
Rim Cothren: I think that's an excellent idea and.

00:15:59.760 --> 00:16:10.560
Rim Cothren: One of the things that I find myself doing and I hope you'll just forgive me for this is, I often pulled the language in the legislation, which does not necessarily Member Member.

00:16:10.950 --> 00:16:29.490
Rim Cothren: mirror industry standards and so early in the report associated with this will make sure that we define the terms that we're going to use and align with industry standards in that way as a description of how we're meeting the goals, the legislation does that make sense to you Pam.

00:16:30.990 --> 00:16:31.680
Pam Dixon - World Privacy Forum: Yes, it does.

00:16:31.710 --> 00:16:32.400
Rim Cothren: Thank you, thank you.

00:16:32.820 --> 00:16:33.300
Rim Cothren: Thank you.

00:16:37.110 --> 00:16:41.850
Rim Cothren: let's go on to the next slide and if, and thank you Lucy for your thumbs up as well.

00:16:43.500 --> 00:16:50.370
Rim Cothren: And we'll pause here a minute for public comment if you're interested in making a comment.

00:16:51.300 --> 00:17:02.010
Rim Cothren: As a member of the public, if you would please raise your hand using the dune the zoom teleconferencing options and you'll be called upon in the order that your hand is raised at that time.

00:17:02.580 --> 00:17:13.890
Rim Cothren: You can unmute yourself state your name your organizational affiliation, and we ask that you keep your comments respectful and brief do we have any comments from the public.

00:17:24.480 --> 00:17:29.490
Rim Cothren: see no public comments, I think we can go ahead and move on call.

00:17:32.610 --> 00:17:45.420

Rim Cothren: So, as I said before, the questions that I have for you on the strategy for digital identity today fall into broadly into two different areas let's go on to the next slide and the first I.

00:17:45.990 --> 00:17:52.050
Rim Cothren: will start off by recapping fun at least I thought I heard at our last meeting.

00:17:52.740 --> 00:18:08.760
Rim Cothren: And I had four people that joined us early today I had already mentioned that it may seem that I am being repetitive, and some of the later materials today, but I want to reaffirm what I thought I heard so we may be, we may appear to be a little bit redundant.

00:18:10.320 --> 00:18:28.380
Rim Cothren: First we identified that it was difficult to assess privacy needs without use cases so we'll talk about use cases a little bit today that some diff demographics may be of concern to some populations, and I do want to talk again about different attributes associated with digital identities.

00:18:29.460 --> 00:18:44.700
Rim Cothren: and ensure that I hear properly those that may be of concern for populations, so that they are flagged that we only use demographics, necessary to link data similar to a minimum necessary type of rule.

00:18:45.450 --> 00:18:57.870
Rim Cothren: But that means that we're not going to include the attributes or data elements simply that describe an individual, but wouldn't be used to match patients are linked data.

00:18:58.710 --> 00:19:17.610
Rim Cothren: That we focus on health related local identifiers as an example that we might use an insurance number assurance Member ID, but we would not use your driver's license that has utility beyond health care, even if it is useful.

00:19:18.570 --> 00:19:39.900
Rim Cothren: Potentially for identifying individuals and that we would prefer a statewide mpi if one is created a statewide index to be operated, not by a government organization by but by some other organization, because some of the consumers may.

00:19:41.310 --> 00:19:52.230
Rim Cothren: be uncomfortable with sharing information, like a demographics, with a government organization i'll pause there for just a second and for those that were at the last meeting.

00:19:53.340 --> 00:20:07.500
Rim Cothren: Make sure that I at least roughly heard things correctly because there's going to be lots of opportunity to add detail or reaffirm that or for anyone that wasn't present at our last meeting to ask questions about that.

00:20:11.280 --> 00:20:12.690
Pam Dixon - World Privacy Forum: oh dear it's Pam again.

00:20:13.320 --> 00:20:14.130
Rim Cothren: that's fine.

00:20:14.580 --> 00:20:17.100
Rim Cothren: you're raising good issues here and that's fine.

00:20:17.220 --> 00:20:23.730
Pam Dixon - World Privacy Forum: yeah i'm so sorry I couldn't make that first meeting I had a conflicting appointment, but um, I just wanted to.

00:20:24.990 --> 00:20:25.800
Pam Dixon - World Privacy Forum: Talk about.

00:20:26.820 --> 00:20:35.220
Pam Dixon - World Privacy Forum: Number four well, actually, let me, let me affirm one, two and three, I agree with those very, very much.

00:20:35.760 --> 00:20:53.910
Pam Dixon - World Privacy Forum: Number four I think could be problematic in the medium and long term so number four is us health related local identifier, for example, insurance Member ids not driver's license I agree that a driver's license is inappropriate to be used in this circumstance, but insurance.

00:20:55.050 --> 00:21:16.110
Pam Dixon - World Privacy Forum: Insurance numbers are really challenging I would have to look at the recent iteration of where the data breach statute is but insurance numbers are considered to be formal government ID numbers at this point, subject to breach notification requirements, there are.

00:21:17.400 --> 00:21:27.060
Pam Dixon - World Privacy Forum: As such, they are a sensitive piece of information there as sensitive and, in some respects, as drivers ids and for medical forms of identity theft they're very important.

00:21:27.510 --> 00:21:40.740
Pam Dixon - World Privacy Forum: And can be very problematic so that's the first real problem, there are challenge, I would say the second thing is is for a for an identity or D duplication system, what you really want are.

00:21:41.610 --> 00:22:00.120
Pam Dixon - World Privacy Forum: You know, for example, a 12 string or more unique number that is not related to any other provision of service, and that makes it much more resilient to cyber attacks and it makes people much safer from any kind of cyber attacks, should this particular.

00:22:01.170 --> 00:22:04.140
Pam Dixon - World Privacy Forum: De duplication, you know system.

00:22:05.370 --> 00:22:15.930
Pam Dixon - World Privacy Forum: You know, get into the wrong hands, so I would just be very cautious about the use of insurance ids and that that's my main comment, thank you.

00:22:16.620 --> 00:22:25.890
Rim Cothren: Thanks Pam and I appreciate that, and it is one of the things that we've talked about at a number of the focus groups, and I think that we need to remember here is that by.

00:22:26.340 --> 00:22:36.120
Rim Cothren: including information like insurance ids That means that we are including very sensitive information, we do need to be concerned concerned about.

00:22:37.050 --> 00:22:48.030
Rim Cothren: A compromise and medical identity theft, on the other hand, we also need to make sure that we have sufficient information to properly identify people.

00:22:49.800 --> 00:23:01.560
Rim Cothren: To link their records as well, and so there is a consideration there part of the discussion we've had with the data sharing agreement subcommittee is what.

00:23:02.760 --> 00:23:08.520
Rim Cothren: Use constraints and what security constraints needs needs to be put around.

00:23:09.960 --> 00:23:20.850
Rim Cothren: Digital identities, especially if they include local health identifiers, and that is an ongoing discussion there, so I think you raise a really good question a really good point Pam.

00:23:24.870 --> 00:23:32.820
Mark Savage (Savage & Savage LLC): Remind i'd like to have a little something on one I sure, I think, in some ways, one is self sufficient but.

00:23:33.930 --> 00:23:35.340
Mark Savage (Savage & Savage LLC): I find that it's.

00:23:36.360 --> 00:23:41.460
Mark Savage (Savage & Savage LLC): Even more important than the use case is to have a map of the data flow.

00:23:42.480 --> 00:23:53.940
Mark Savage (Savage & Savage LLC): So, for example, knowing if the disclosure is going from an individual to a provider or the other way around from provider to an individual changes the privacy assessment.

00:23:55.140 --> 00:24:02.910
Mark Savage (Savage & Savage LLC): So when I sit down to to answer questions that I usually sketch out where the data is originating where it's flowing.

00:24:04.230 --> 00:24:11.100
Mark Savage (Savage & Savage LLC): To help me think through what the issues might be there that might, you could say the use case captures all of that.

00:24:12.180 --> 00:24:19.110
Mark Savage (Savage & Savage LLC): But I find it that in particular across every problem i've ever assessed has been important, so I just wanted to mention at least for purposes of conversation.

00:24:19.530 --> 00:24:25.920
Rim Cothren: Great thanks mark and let's make sure that we tried to touch on that again when we put the use case slide up.

00:24:27.150 --> 00:24:29.490
Rim Cothren: Make make sure that we talked about the data flow there.

00:24:30.690 --> 00:24:32.220
Rim Cothren: Lee I see you have your hand up.

00:24:32.460 --> 00:24:42.120
Lee Tien, Electronic Frontier Foundation (he/him): yeah, I just wanted to sort of amplify mark's point because the you know what we have seen this in numerous.

00:24:42.690 --> 00:24:53.430
Lee Tien, Electronic Frontier Foundation (he/him): State privacy laws, where people talk about a, for instance, a consumers right to know about what information is being held about them.

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AND INNOVATION
CALIFORNIA HEALTH & HUMAN
SERVICES AGENCY

00:24:53.700 --> 00:25:05.190
Lee Tien, Electronic Frontier Foundation (he/him): Where it's come from where it's gone and then repeatedly one we will save that and then somehow it gets lost in translation and then at the end of the day, it's like Oh well.

00:25:05.670 --> 00:25:17.100
Lee Tien, Electronic Frontier Foundation (he/him): we'll tell you what categories of information or about you, or will tell you what categories of entities your information was transferred to, but they will not tell you.

00:25:17.370 --> 00:25:22.980
Lee Tien, Electronic Frontier Foundation (he/him): Oh, it went to this company he went to this university he went to and it's.

00:25:23.520 --> 00:25:34.290
Lee Tien, Electronic Frontier Foundation (he/him): And so, this was, I mean mark's point about data flows here is is spectacularly right on because you might think like Oh, the use case is research.

00:25:34.830 --> 00:25:51.270
Lee Tien, Electronic Frontier Foundation (he/him): But it's you don't know who is doing that research and I myself don't have this bias, but someone might be biased in favor of Johns Hopkins and against say our hospital system and.

00:25:52.320 --> 00:26:05.010
Lee Tien, Electronic Frontier Foundation (he/him): So it really does actually matter in terms of assessing the use cases in assessing an individual's comfort level with what.

00:26:05.700 --> 00:26:11.550
Lee Tien, Electronic Frontier Foundation (he/him): Their date of being in a system actually means to actually have a good picture of.

00:26:12.210 --> 00:26:22.020
Lee Tien, Electronic Frontier Foundation (he/him): What entities would be getting their information or would would be likely to have access to it under some circumstances and.

00:26:22.560 --> 00:26:34.260
Lee Tien, Electronic Frontier Foundation (he/him): To put them put it the other way is, if you don't tell them and then they find out later oh it went to X and they're gone, I had no idea, it would go to X.

00:26:34.620 --> 00:26:49.740
Lee Tien, Electronic Frontier Foundation (he/him): that's a failure right that's a failure of the system, and we will have basically violated, you know the the understandings that this to have done that, and so, so I just want I think mark's point about data flows is incredibly important.

00:26:50.850 --> 00:26:51.810
thanks for that Lee.

00:26:53.850 --> 00:26:55.230
Rim Cothren: Yes, Pam I see your hand up.

00:26:56.070 --> 00:27:10.770
Pam Dixon - World Privacy Forum: Yes, um so in terms of the mark any point in regards to data flows, I could not agree more with that assessment, I would like to add on a little bit to that which is.

00:27:11.580 --> 00:27:23.280
Pam Dixon - World Privacy Forum: One of the very significant areas of consumer confusion has been the very silent operate a silent kind of behind the scenes operation of the interoperability role.

00:27:23.940 --> 00:27:34.740
Pam Dixon - World Privacy Forum: For hipaa and because of the the way the interoperability rule is working for most platforms, where records of patient records are being shared.

00:27:35.610 --> 00:27:48.180
Pam Dixon - World Privacy Forum: Those patient records, as all of us on this call know can be shared readily with third parties outside of the pipa coverage, you know hipaa entity coverage, so any.

00:27:50.160 --> 00:28:04.350
Pam Dixon - World Privacy Forum: You know any identifiers need to be really viewed in that light as well, and we need to ensure that, as part of our data flow and use case tracking that we're tracking what identifiers would or could escape.

00:28:04.800 --> 00:28:09.570
Pam Dixon - World Privacy Forum: The hipaa ecosystem, where they would be treated very differently by third parties, thank you.

00:28:10.230 --> 00:28:10.920
Rim Cothren: Thanks Pam.

00:28:12.450 --> 00:28:28.110
Rim Cothren: Call why don't you move us on to the slide that has the the titles to use cases, because I do want to talk about those very briefly, and then it that may end up adding some additional context here Lucy I see you have your hand up.

00:28:29.040 --> 00:28:37.890
Lucy Johns: yeah I was just gonna say that, from my point of view, once use cases are specified flow charts are a logical consequence.

00:28:38.250 --> 00:28:50.610
Lucy Johns: So I would hope that our ultimate report to the legislature talks about use cases and specifies each one in terms of the kind of flow chart that mark and we were just talking about.

00:28:52.440 --> 00:29:02.250
Rim Cothren: Great Thank you Lucy so what I have gathered together here is information that has been specified in at 133.

00:29:04.560 --> 00:29:08.850
Rim Cothren: scenarios that have been discussed with the stakeholder advisory group.

00:29:10.110 --> 00:29:20.940
Rim Cothren: And initial discussions about a data sharing agreement that I can update people on a little bit, and these are not use cases, but this starts to get to some.

00:29:21.480 --> 00:29:32.850
Rim Cothren: of what might enter into a use case and in this case it is not the purposes or use cases for the flow of digital identity information, but the flow of.

00:29:33.210 --> 00:29:48.090

Rim Cothren: health information it's defined in a B 133 at 133 states that the only the allowed purposes on the data exchange framework our treatment payment healthcare operations and doesn't define it any further than that.

00:29:48.930 --> 00:29:58.050

Rim Cothren: But it does call for the exchange of certain information by healthcare providers that's electronic health information is defined.

00:29:59.760 --> 00:30:10.890

Rim Cothren: In federal regulation and for health plans its claims encounters and US CDI version one clinical data effectively to align.

00:30:11.460 --> 00:30:19.650

Rim Cothren: With the cms rule for patient access and peer to peer exchange at 133 goes on, so.

00:30:20.250 --> 00:30:36.300

Rim Cothren: The the actors, which I did not write down in here, but if you recall the actors that are called upon to sign the data sharing agreement are required to exchange are covered entities it's hospitals its ambulatory care providers, including.

00:30:38.130 --> 00:30:51.840

Rim Cothren: Mental health and behavioral health labs and plans, but the legislation also encourages cali chicest to work with county health, public health and social services organizations.

00:30:52.260 --> 00:31:07.470

Rim Cothren: And Pam to your point about getting outside of covered entities, there is a potential there, although it is not in the legislation today and discussions with the stakeholder advisory group and mark you're a member of the group here.

00:31:08.760 --> 00:31:22.230

Rim Cothren: You may recall these discussions happen early in the meeting so last calendar year there were a number of scenarios that were discussed at that time care coordination.

00:31:22.680 --> 00:31:39.390

Rim Cothren: Population health emergency response, public health, response and transitions from incarceration and those were the primary scenarios that were discussed with the stakeholder advisory group some of those are treated are covered under treatment.

00:31:40.530 --> 00:31:43.800

Rim Cothren: and potentially health care operations.

00:31:45.390 --> 00:31:46.410

Rim Cothren: Public health.

00:31:47.430 --> 00:31:54.960

Rim Cothren: is absent from being specifically called out in a be 133 other than a work to encourage.

00:31:55.530 --> 00:32:04.380

Rim Cothren: And population health in particular might end up with being a different use than we've talked about for digital identities.

00:32:04.830 --> 00:32:12.930

Rim Cothren: Where digital identities are used to link records, but not to stratify a population so that's at least something to consider.

00:32:13.650 --> 00:32:25.020
Rim Cothren: And then, finally, in the data sharing agreement, some of the discussions with that subcommittee have been purpose purposes, for us it would add benefits determination and public health.

00:32:27.150 --> 00:32:27.570
Lucy Johns: But.

00:32:28.530 --> 00:32:39.630
Rim Cothren: I believe that the data sharing agreement is likely to align with law for covered entities, rather than calling out purposes for use explicitly.

00:32:40.020 --> 00:32:47.430
Rim Cothren: And Lee you'll be in those discussions as we continue to have them with the dsa and so there's an opportunity to to talk about those.

00:32:48.090 --> 00:32:58.260
Rim Cothren: And I see a couple of hands up but give me one more second mark to your point about data flow here, then this means that we are really talking about information.

00:32:58.590 --> 00:33:09.180
Rim Cothren: That is passing from one actor on the data exchange framework to another actor on the data exchange framework all of those being covered entities, so they would either be.

00:33:10.140 --> 00:33:24.060
Rim Cothren: Hospitals ambulatory care providers plans or labs until such time as we expand into public health or social services organizations.

00:33:24.510 --> 00:33:33.480
Rim Cothren: But are not you know the the date that digital identities, at least the way i'm looking at them right now.

00:33:34.080 --> 00:33:43.740
Rim Cothren: are not part of a disclosure that an individual does, for instance, with their health care provider, they can choose to share with them, whatever they want a digital identities within defined.

00:33:44.130 --> 00:33:52.620
Rim Cothren: Between that health care provider trying to link records with another health care providers example, so the data is moving between organizations.

00:33:54.030 --> 00:33:54.870
Mark Savage (Savage & Savage LLC): So real to.

00:33:55.830 --> 00:34:03.960
Mark Savage (Savage & Savage LLC): flag that for the appropriate time, it seems a little more complicated than what you just said and i'm happy to unpack that a little bit okay well let's.

00:34:04.590 --> 00:34:11.280
Rim Cothren: let's make sure, well, I think the appropriate time to start unpacking that is going to be as soon as Pam and Lucy.

00:34:13.770 --> 00:34:17.040
Rim Cothren: make their comments and then let's let's do that Pam Please go ahead.

00:34:17.670 --> 00:34:21.570
Pam Dixon - World Privacy Forum: yeah actually I was going to encourage us to unpack that a bit.

00:34:22.980 --> 00:34:30.690
Pam Dixon - World Privacy Forum: I know the legislator could be very tempted to quote unquote encourage county health, public health and social services.

00:34:31.290 --> 00:34:42.750
Pam Dixon - World Privacy Forum: But I think we have to be very cautious here about legal frameworks so as, as you well know, hipaa is a profoundly different legal framework, then, for example, public health.

00:34:43.320 --> 00:35:02.460
Pam Dixon - World Privacy Forum: And I think we have to be very, very cautious about an identity ecosystem that crosses legal frameworks in my experience, this is very tricky business, and I think we have to be very cautious here, because the minute you use, for example, an insurance identifier for de duplication.

00:35:03.570 --> 00:35:15.240
Pam Dixon - World Privacy Forum: And then you're you're using this across county health, public health and social services it gets very complicated and it becomes an issue so that's just just worth thinking about at the stage, thank you.

00:35:15.720 --> 00:35:26.820
Rim Cothren: So Pam before you before you go on mute there, I have some questions, because this is, this is the discussion, I want to have today it on on this slide so is your suggestion.

00:35:28.140 --> 00:35:44.100
Rim Cothren: BAT digital identities be confined to just signatories to the data sharing agreement, which establishes a legal framework, or is it that it be limited to covered entities that fall under.

00:35:45.150 --> 00:35:52.080
Rim Cothren: federal and state regulation, the same state and federal regulation or is it something else.

00:35:53.250 --> 00:36:04.140
Pam Dixon - World Privacy Forum: um Okay, so if they do it, I believe they do need to be signatories to be able to use the the the identifier, given the way.

00:36:05.010 --> 00:36:15.840
Pam Dixon - World Privacy Forum: This has been written that's my current view with more information that may shift, but I think that you know thinking about especially public health.

00:36:16.380 --> 00:36:26.340
Pam Dixon - World Privacy Forum: Where you're going to have data crossing state lines and even international lines those those identifiers can go places, no one ever suspected, they would go.

00:36:26.670 --> 00:36:36.720
Pam Dixon - World Privacy Forum: I say this because I coach our World Health Organization global data governance committee and I know what's going on with this data and it gets very, very sticky.

00:36:37.410 --> 00:36:55.860
Pam Dixon - World Privacy Forum: With some of these data fields that are end up getting really stuck to the patient information it's very, very challenging to get them out on a scale, so I would just I feel very leery about the you know the service provision aspect that goes beyond.

00:36:57.060 --> 00:37:15.510
Pam Dixon - World Privacy Forum: Treatment payment operations at this point, unless there's a way of definitively constraining it to a unique number that is not possible to utilize in in in any kind of fraudulent way if that's if that's useful I yeah.

00:37:16.200 --> 00:37:19.530
Rim Cothren: Great Thank you and so i'm going to ask you one more question.

00:37:21.840 --> 00:37:34.470
Rim Cothren: What what I heard you say is that they should be signatories is that sufficient so if the state public health department was a signatory to the dsa and the dsa called out limitations and how digital entities.

00:37:34.920 --> 00:37:50.880
Rim Cothren: would be or even more if it is a social services organization that is very clearly not falling under the same regulatory environment but signed the dsa and that called out limitations, would you feel that that is sufficient or do they need to be bound by law.

00:37:51.930 --> 00:37:56.910
Pam Dixon - World Privacy Forum: there's going to have to be some ability to have a very robust.

00:37:58.830 --> 00:38:02.250
Pam Dixon - World Privacy Forum: ability to audit and and trace and track that data.

00:38:03.480 --> 00:38:05.910
Pam Dixon - World Privacy Forum: in some way, shape or form so.

00:38:07.560 --> 00:38:12.270
Pam Dixon - World Privacy Forum: Until until we have more details on the table it's really difficult to make the determination.

00:38:13.380 --> 00:38:31.350
Pam Dixon - World Privacy Forum: But I think that what you've laid out is correct, I mean that is definitely Those are the questions that that laid before us right now, and so much say that the the state, you know the state public health authority has you know, signed a document well.

00:38:32.430 --> 00:38:41.970
Pam Dixon - World Privacy Forum: What are the are there, broad guidelines that will become part of a state level framework would it be possible for example to.

00:38:42.960 --> 00:38:53.610
Pam Dixon - World Privacy Forum: determine that the identifier would never be sent out of the State boundary that sort of thing would really make a difference, because if the identifier.

00:38:54.270 --> 00:39:09.000
Pam Dixon - World Privacy Forum: is curtailed in us and there's additional ways of curtailing not protecting it, including encryption at rest, etc, but if that identifier is less exposed and is less circulated that that improves.

00:39:09.720 --> 00:39:21.270
Pam Dixon - World Privacy Forum: The data flow risk, but if you add a lot of untethered services, you really you, you really exponentially increase the risk.

00:39:21.720 --> 00:39:30.720

Pam Dixon - World Privacy Forum: that's just those are very broad statements like I said they're always have to be specific, that you apply these these broad ideas to you, but that's that's the general place i'm coming from breaking.

00:39:31.080 --> 00:39:34.290
Rim Cothren: Thanks Pam Lucy thanks for your patience.

00:39:35.040 --> 00:39:54.150
Lucy Johns: yeah, this is a very nitpicking question in the the second box emergency response, could you clarify rim, is that someone responding to me as a patient when i'm having an emergency, or is this about how we find people after an earthquake.

00:39:54.870 --> 00:39:58.080
Rim Cothren: It is the former in the way that that was described to the.

00:40:00.660 --> 00:40:13.590
Rim Cothren: stakeholder advisory group, it would cover either Disaster Response or emergency response to a medical emergency by that subset of the provider community.

00:40:14.550 --> 00:40:26.430
Lucy Johns: So you said disaster response if there's a you know after Katrina the pharmaceutical sector or the pharmacy sector.

00:40:27.330 --> 00:40:50.760
Lucy Johns: worked 24 seven for about a week to enable prescription refills across state boundaries, because people were fleeing New Orleans and they had to renew their their prescriptions so i'm trying to understand the scope of the concept emergency response in this box.

00:40:52.380 --> 00:41:02.760
Rim Cothren: To be honest with you, I would have to go back to better understand the end and review again the scenario is it was laid out to the advisory group.

00:41:04.200 --> 00:41:04.410
Rim Cothren: I.

00:41:04.440 --> 00:41:13.320
Rim Cothren: don't believe that it's talking about something that's that is necessarily beyond state lines, but the the exact.

00:41:14.460 --> 00:41:16.710
Rim Cothren: Language in that scenario I haven't have to read you.

00:41:17.220 --> 00:41:18.210
Lucy Johns: Okay, thank you.

00:41:18.510 --> 00:41:21.060
Rim Cothren: Thanks mark I said he's for.

00:41:21.240 --> 00:41:22.680
Rim Cothren: sharing everything, sir.

00:41:22.890 --> 00:41:36.480
Lucy Johns: Sure i've heard him several times now refer to a number and it's my understanding that such a number is actually forbidden under federal law.

00:41:36.930 --> 00:41:52.350
Lucy Johns: And if California wants to do something like that I hope that we talk about that a lot more and don't just keep using the idea of unique number for each person in the state without talking about a lot more.

00:41:52.680 --> 00:42:01.350
Rim Cothren: Okay, well, I am certainly not a lawyer, my understanding is what is prohibited is from the Federal Government and spending any money to create.

00:42:01.920 --> 00:42:12.240
Rim Cothren: A health identifier, but there is no prohibition from California doing one for state purposes, but that is certainly something that i'll make sure that we follow up on.

00:42:13.080 --> 00:42:15.900
Lucy Johns: We need to talk about in this committee, thank you.

00:42:18.690 --> 00:42:19.950
Rim Cothren: mark, I said that I.

00:42:21.240 --> 00:42:26.280
Rim Cothren: unbundle things a little bit as the talk I didn't know if.

00:42:28.290 --> 00:42:30.390
Rim Cothren: Here, before I turn the floor over totally.

00:42:32.640 --> 00:42:35.400
Mark Savage (Savage & Savage LLC): You know me i'm happy to happy to jump in.

00:42:37.860 --> 00:42:44.250
Rim Cothren: Well, I saw Lee take his hand down i'm gonna let leech choose, because I know that you have time constraints as well lead to you.

00:42:44.700 --> 00:42:45.240
Rim Cothren: I just.

00:42:45.540 --> 00:42:47.490
Lee Tien, Electronic Frontier Foundation (he/him): wanted to make a really super quick point we didn't.

00:42:47.490 --> 00:42:48.030
Rim Cothren: Please do.

00:42:48.300 --> 00:42:57.840
Lee Tien, Electronic Frontier Foundation (he/him): same old same old legal arbitrage point that I always make we can't forget that some entities in the state are not simply not bound.

00:42:58.230 --> 00:43:10.770
Lee Tien, Electronic Frontier Foundation (he/him): By a statewide information practices act and, therefore, even if they have good privacy rules we don't know what they are and we'd have to like nail them down at the level of granularity of.

00:43:11.070 --> 00:43:17.280
Lee Tien, Electronic Frontier Foundation (he/him): Every county public health pro, and this is especially difficult on the public out there and I know we have others like the.

00:43:18.240 --> 00:43:27.240
Lee Tien, Electronic Frontier Foundation (he/him): wi fi program or all these other social services programs that are very, very interested in getting into this and that's why I think.

00:43:27.540 --> 00:43:35.610
Lee Tien, Electronic Frontier Foundation (he/him): The point about we can't let anybody in unless we have them and I I, my answer to your question room is they've got to be bound.

00:43:35.970 --> 00:43:52.680
Lee Tien, Electronic Frontier Foundation (he/him): they've got to be bound by law now a contract can bind i'm not saying that a contract camp, but it's got to be it's got to actually

be something that someone could enforce in court if it's merely hortatory merely a guideline, then it will not be compliant so.

00:43:53.160 --> 00:43:54.360
Rim Cothren: i'll start right Nice.

00:43:54.720 --> 00:43:55.650
Rim Cothren: Great Thank you.

00:43:56.640 --> 00:43:57.780
Rim Cothren: Mark I think it's your turn.

00:43:59.310 --> 00:44:02.910
Mark Savage (Savage & Savage LLC): Those the way I read the Statute, I think the.

00:44:04.230 --> 00:44:08.550
Mark Savage (Savage & Savage LLC): I think things are are broader than at least your introductory remarks, I think.

00:44:10.080 --> 00:44:26.070
Mark Savage (Savage & Savage LLC): Yes, there's a distinction in terms of actors there's a distinction between who must sign and who is encouraged to sign if you consider that encouraged group let's say they all sign they don't have to, but they do, they become a part of the players and they're not all covered entities.

00:44:27.420 --> 00:44:30.570
Mark Savage (Savage & Savage LLC): Likewise, the purposes, I think there's a reason that Tesco.

00:44:31.710 --> 00:44:39.630
Mark Savage (Savage & Savage LLC): has turned to the six permitted purposes as a as a framing to help people understand and they include public health.

00:44:40.260 --> 00:44:46.770
Mark Savage (Savage & Savage LLC): And right right of act patients the individuals right of access as two of those permitted purposes.

00:44:47.610 --> 00:44:59.310
Mark Savage (Savage & Savage LLC): Because, although they're not they don't fit within the TPA or the treatment payment healthcare operations rubric that's frequently used with hipaa they still are covered under the hipaa privacy rule.

00:45:00.390 --> 00:45:03.270
Mark Savage (Savage & Savage LLC): And I did me one of the things that's.

00:45:05.640 --> 00:45:11.490
Mark Savage (Savage & Savage LLC): Right good about at 133 is broadening the ecosystem, to think about that public health use case.

00:45:12.240 --> 00:45:34.080
Mark Savage (Savage & Savage LLC): and making sure that that we can can meet those needs, especially as we're trying to work through coven right now, so I think I think the Statute envisions this is being rotter also the social service organizations that can are encouraged, but not required to sign the process there.

00:45:35.370 --> 00:45:44.430
Mark Savage (Savage & Savage LLC): They they can there can be according to the author civil right there can be disclosures by providers to those social service organizations.

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00:45:45.000 --> 00:45:59.550
Mark Savage (Savage & Savage LLC): for purposes of treatment payers can make disclosures to social service organizations for purposes and healthcare operations, I think those things are an ad, but that does not, in turn, make them covered entities, or even business associates.

00:46:00.870 --> 00:46:05.100
Mark Savage (Savage & Savage LLC): So that's why I use the word unpack I think it's a little more little more complicated.

00:46:06.330 --> 00:46:09.870
Mark Savage (Savage & Savage LLC): and happy to to discuss that further as.

00:46:11.280 --> 00:46:12.930
Mark Savage (Savage & Savage LLC): As you see it fitting in here.

00:46:13.350 --> 00:46:24.690
Rim Cothren: Well, and and thanks mark, I appreciate you calling beyond things that I say that that may not be properly reflected in the legislation, so I I.

00:46:25.980 --> 00:46:27.450
Rim Cothren: If if.

00:46:29.010 --> 00:46:38.340
Rim Cothren: If a social services organization signs the dsa becomes a signatory to the data sharing agreement and exchanges data.

00:46:39.480 --> 00:46:59.700
Rim Cothren: What needs to be done for you to feel comfortable that digital identities are protected there and I come back to since it's not a covered entity, it does not make them a business associate necessarily our is good, control language in the dsa sufficient.

00:47:01.980 --> 00:47:07.200
Mark Savage (Savage & Savage LLC): And i'll harking back to what we were saying I think you can have an agreement that.

00:47:09.240 --> 00:47:16.620
Mark Savage (Savage & Savage LLC): that binds and is enforceable if it's written properly the one difference i'll note though is.

00:47:19.860 --> 00:47:23.010
Mark Savage (Savage & Savage LLC): People when people hear about that they're going to hear that it's not hipaa.

00:47:24.150 --> 00:47:28.140
Mark Savage (Savage & Savage LLC): you're getting here there's something different, and so there you will miss.

00:47:29.430 --> 00:47:38.220
Mark Savage (Savage & Savage LLC): The trust the familiarity that go along with people saying oh I, this is a this is, this is the kind of hip arrangement that.

00:47:38.730 --> 00:47:46.170
Mark Savage (Savage & Savage LLC): Our organizations have been working with for the past 20 years we know how to do this, or we know how to game, the system with it, but.

00:47:46.680 --> 00:47:53.160
Mark Savage (Savage & Savage LLC): least we know what we're we're talking about and patients are our, to the extent they understand it tended to be to be.

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CALIFORNIA HEALTH & HUMAN
SERVICES AGENCY

00:47:54.060 --> 00:48:06.870
Mark Savage (Savage & Savage LLC): Maybe they don't call it hipaa but they tend to be comfortable with their doctors, making the call to make sure that their information is waiting at their specialist before they get there for the for the referral we're not going to have that piece.

00:48:07.920 --> 00:48:18.990
Mark Savage (Savage & Savage LLC): When we say we're Now this is now being covered by the California digital exchange framework, we would, I would recommend that we think carefully about how to do some messaging.

00:48:20.010 --> 00:48:20.550
Mark Savage (Savage & Savage LLC): and get.

00:48:22.530 --> 00:48:32.370
Mark Savage (Savage & Savage LLC): To try to encourage and build that trust before before we launch if, for example, the contract said we're going to we're going to apply all the hipaa rules.

00:48:32.850 --> 00:48:41.340
Mark Savage (Savage & Savage LLC): As if, as if you were governed by hipaa That would be a pretty you know, there would still be some uncertainty, but it would it would go a long way.

00:48:42.570 --> 00:48:44.820
Mark Savage (Savage & Savage LLC): that's an example of how you can try to bridge that gap.

00:48:46.140 --> 00:49:00.960
Rim Cothren: And mark i'll just say for everybody's benefit that that is part of the discussion that has happened that the dsa subcommittee is specifically saying that all signatories are bound to the hipaa privacy rule to.

00:49:01.860 --> 00:49:08.880
Rim Cothren: To follow the requirements that hipaa privacy will whether or not they are bound to it as a covered entity or a BA.

00:49:09.480 --> 00:49:17.070
Rim Cothren: So that and I don't know where that's going to go but that's been part of the conversation there and it might be something as an advisory.

00:49:17.670 --> 00:49:26.190
Rim Cothren: group member for you to pay attention to when the dsa comes around and whether you believe that that is the right thing, or the wrong thing to be including.

00:49:28.230 --> 00:49:28.950
Rim Cothren: Pam you've had.

00:49:29.430 --> 00:49:32.610
Mark Savage (Savage & Savage LLC): One why don't think then remy, to the extent it.

00:49:34.620 --> 00:49:41.430
Mark Savage (Savage & Savage LLC): Apps are being used as a as a as a way to provide information for digital identities.

00:49:42.450 --> 00:49:49.290
Mark Savage (Savage & Savage LLC): And to just be mindful about whether the APP vendors are also signatories.

00:49:50.490 --> 00:49:58.770
Mark Savage (Savage & Savage LLC): The agreement and does bound bound by it and not not solely by whatever their respective notices and privacy practices might be.

00:49:59.220 --> 00:50:10.290
Rim Cothren: And I think that's a very good point, and although we have often reaffirmed at the Advisory Group, the need for access.

00:50:11.310 --> 00:50:19.290
Rim Cothren: Individual access to their health information, some of the details that you're talking about is how do we deal with vendors and Apps etc.

00:50:20.910 --> 00:50:22.050
Rim Cothren: Maybe a.

00:50:23.490 --> 00:50:31.110
Rim Cothren: There hasn't been a great deal of detail in that discussion, yet and and so we'll we'll have to see where that where that goes.

00:50:31.530 --> 00:50:48.240
Rim Cothren: But i'd like to continue to think about that in terms that that may be an eventuality here as well, and therefore we need to be considering that, if they have access to that information given this in a consumers hands does that make a difference, what does that mean so.

00:50:49.320 --> 00:50:52.320
Rim Cothren: Bam you've been very patient with your hand up Thank you.

00:50:53.640 --> 00:51:01.020
Pam Dixon - World Privacy Forum: Yes, thank you so a couple of comments just following along the conversation, so a couple of things.

00:51:02.940 --> 00:51:19.110
Pam Dixon - World Privacy Forum: I agree that we will lose trust of patients, and I think rightfully so, and let me explain a little bit more about why so um if we continue with the use of the insurance information that the.

00:51:20.220 --> 00:51:29.370
Pam Dixon - World Privacy Forum: The moment you leave the hipaa ecosystem, the insurance information itself becomes a really difficult thing, because in public health.

00:51:29.760 --> 00:51:39.780
Pam Dixon - World Privacy Forum: you're not necessarily going to request require or have insurance information for every patient or individual who's involved with the public health ecosystem.

00:51:40.350 --> 00:51:58.530
Pam Dixon - World Privacy Forum: So then it becomes having have nots and then you end up with a variety of identifying you know systems, so I think that if this number is viewed as it appears to be viewed as something that will become more widely used you've got to go with a more.

00:52:00.090 --> 00:52:03.780
Pam Dixon - World Privacy Forum: neutral and universal number.

00:52:04.920 --> 00:52:12.600
Pam Dixon - World Privacy Forum: Instead of an insurance number, there will be a lot of complications with that if it stays with a broader ecosystem.

00:52:13.500 --> 00:52:28.470
Pam Dixon - World Privacy Forum: In terms of the trust you know hipaa has seven broad rights for patients, including the right to be notified of subpoenas and all in quash subpoenas etc they're they're very important rights.

00:52:28.860 --> 00:52:38.400
Pam Dixon - World Privacy Forum: These rights are not granted under any privacy law in in California include you know cow lead in the very newest California law, this hipaa.

00:52:38.880 --> 00:52:52.740
Pam Dixon - World Privacy Forum: is its own you know sectoral laws, we all know, so, for example, where this really gets I think very tricky so are the pay out of pocket provisions that came in in 2013.

00:52:53.730 --> 00:53:01.260
Pam Dixon - World Privacy Forum: Along with obamacare where, if you are a patient, you can pay out of pocket to ensure that your.

00:53:02.010 --> 00:53:08.190
Pam Dixon - World Privacy Forum: insurance company does not ever get the information and the information doesn't go to your insurance company.

00:53:09.000 --> 00:53:22.350
Pam Dixon - World Privacy Forum: If you're patient record is still attached to an inch an insurance identifier, I wonder about this, it makes me, it gives me a lot of questions about that so that's one thing, but in terms of saying.

00:53:22.830 --> 00:53:31.800
Pam Dixon - World Privacy Forum: And then that's just one segregated point but moving on to another point I I really, really are.

00:53:33.690 --> 00:53:43.290
Pam Dixon - World Privacy Forum: That we not go down what I call the hipaa compliant road, so all sorts of Apps and non hipaa covered entities today.

00:53:43.830 --> 00:53:49.980
Pam Dixon - World Privacy Forum: And i'm not talking about business associates i'm talking about like you know Apps that say we're hipaa compliant.

00:53:50.970 --> 00:54:03.120
Pam Dixon - World Privacy Forum: Patients really don't know what that means and it's very, very, very confusing to patients patients believe that these entities are actually covered under hipaa so unless California.

00:54:03.660 --> 00:54:16.620
Pam Dixon - World Privacy Forum: finds a way of bringing this language under actual hipaa compliance I think it's really problematic and it, it is very fair to argue that it's actually an unfair and deceptive business practice.

00:54:16.950 --> 00:54:30.300
Pam Dixon - World Privacy Forum: Because you're kind of adding hipaa to a place that it doesn't actually give provision or evacuation of all of those rights of hipaa so that's it's just really problematic, so I think that.

00:54:31.620 --> 00:54:40.950
Pam Dixon - World Privacy Forum: I think it's better to solve this problem in a very transparent and very straightforward way and if we think that the public won't like it well.

00:54:41.700 --> 00:54:50.430
Pam Dixon - World Privacy Forum: let's get some feedback let's let's find out, but we shouldn't cover it over with the hipaa compliant language we're going to need a framework that covers us.

00:54:51.510 --> 00:55:08.940
Pam Dixon - World Privacy Forum: It would be great if you know I can definitely see that certain certain entities could be Brighton under a BA kind of a situation, but I think to just say you have to be hipaa compliant it's not enough it's not enough, not with this breath.

00:55:10.770 --> 00:55:15.360
Pam Dixon - World Privacy Forum: So I just Those are just some things to really be thinking about Thank you.

00:55:15.720 --> 00:55:19.620
Rim Cothren: Great thanks Pam and one of the things that.

00:55:22.440 --> 00:55:24.210
Rim Cothren: i'd like to clarify.

00:55:25.470 --> 00:55:31.260
Rim Cothren: Is that I would expect that your comments are.

00:55:33.150 --> 00:55:47.760
Rim Cothren: Broadly, about the sharing of information on the data exchange framework, not just about digital identities, but do apply specifically to digital identities, the way we've been talking about them today, as well as that right.

00:55:48.240 --> 00:55:58.470
Pam Dixon - World Privacy Forum: that's correct i'm really thinking of the Ai the digital identity framework and how how digital identity works through the ecosystem, I do think that having.

00:55:59.250 --> 00:56:09.780
Pam Dixon - World Privacy Forum: A de duplication identity, you know, identifying factor, whatever that ends up being within the hipaa ecosystem has far fewer risks, then that same.

00:56:11.190 --> 00:56:16.920
Pam Dixon - World Privacy Forum: You know identifier being used outside of the ecosystem for what it's worth.

00:56:17.130 --> 00:56:21.000
Rim Cothren: So, so I want to, I want to follow up a little bit on on.

00:56:22.560 --> 00:56:37.860
Rim Cothren: In many ways, i'm glad that I chose what I thought would be probably the least controversial of local identifiers and saying Member ID and it's turned out to a way not be the case, because you pointed out, a gap in my own thinking which is good.

00:56:39.420 --> 00:56:39.960
Rim Cothren: If.

00:56:44.490 --> 00:56:49.080
Rim Cothren: What I want to make sure that I understand I mean if I already know.

00:56:50.220 --> 00:57:01.650
Rim Cothren: The Member ID because i'm a provider and my patient gave me their ID card, and I use it against a de duplication service to identify rim cost friend.

00:57:02.430 --> 00:57:11.550
Rim Cothren: Is your concern that if I don't have it, but you also identify rim cothran that that Member ID should not be shared back with me.

00:57:12.330 --> 00:57:31.320
Rim Cothren: Is that you would perhaps give back a fictitious identifier that's associated with rim cothran, but it should not be linkable to a Member ID or any other local identifier, is that what you're saying.

00:57:32.250 --> 00:57:41.580
Pam Dixon - World Privacy Forum: That that's one small part of what i'm saying there, there is a very significant fraud risk with using that identifier now within the.

00:57:41.940 --> 00:57:51.810
Pam Dixon - World Privacy Forum: ecosystem it's not nearly the same kind of risk that we're talking about when it's used outside of the hipaa ecosystem, even though the hipaa ecosystem is not perfect.

00:57:52.680 --> 00:58:03.030
Pam Dixon - World Privacy Forum: it's well constructed at this point and people know how to get around it, but the moment you start talking about social services, public health and county health.

00:58:03.360 --> 00:58:13.050
Pam Dixon - World Privacy Forum: you're dealing with a completely different ecosystem and legal framework and so all of a sudden and and also you're talking about a breadth of information so.

00:58:13.800 --> 00:58:23.310
Pam Dixon - World Privacy Forum: All of a sudden, the the rights of hipaa for patients do not apply the cyber security aspects and and the.

00:58:24.270 --> 00:58:29.490
Pam Dixon - World Privacy Forum: The various an analytical aspects of hipaa in terms of risk assessments.

00:58:30.120 --> 00:58:39.480
Pam Dixon - World Privacy Forum: Also don't apply, I mean so much stops applying and so you allow that information to enter a little more of a Wild West scenario.

00:58:39.780 --> 00:58:50.430
Pam Dixon - World Privacy Forum: In comparison with the more structured environment of hipaa that's a big concern but there's an additional concern which is if you're talking about public health and and.

00:58:50.880 --> 00:59:02.550
Pam Dixon - World Privacy Forum: county health and social services you'll be dealing with a much broader population that may not necessarily have insurance and this This puts a real kink in the number.

00:59:03.090 --> 00:59:24.150
Pam Dixon - World Privacy Forum: let's just, for example, say there's not an insurance linked number, I think that helps because that in itself does not provide an additional data point about patients just by virtue of its existence or non existence, it would also not require workarounds and it would also create.

00:59:25.170 --> 00:59:27.870
Pam Dixon - World Privacy Forum: More robustness in the actual.

00:59:28.890 --> 00:59:39.870
Pam Dixon - World Privacy Forum: Identity ecosystem and how it would operate there's just there's there's different techniques that could be applied to a more neutral number that didn't have to be.

00:59:41.460 --> 00:59:49.050
Pam Dixon - World Privacy Forum: authenticated itself by a third party if that makes sense, so those are Those are some of the things that i'm thinking about with this.

00:59:51.060 --> 01:00:03.780
Pam Dixon - World Privacy Forum: And just in general, I think that wherever we can you know, this is really conceived of is you know, for the purposes, primarily have to so if that's the case.

01:00:05.520 --> 01:00:09.990
Pam Dixon - World Privacy Forum: i'd love to see it stay within the hipaa ecosystem and if it's if that's not the case.

01:00:11.310 --> 01:00:21.540
Pam Dixon - World Privacy Forum: It has to be conceived of as a much, much broader program with different kinds of legal and physical and security controls so.

01:00:21.810 --> 01:00:34.890
Pam Dixon - World Privacy Forum: Basically, you have to if it if the if the system is conceived of as being used more broadly, then you have to actually conceive of a broader identity ecosystem for the purposes of duplication.

01:00:35.250 --> 01:00:42.840
Pam Dixon - World Privacy Forum: duplication gets really rough in the public health contexts, and I think everyone knows that it's a really hard.

01:00:43.800 --> 01:00:55.800
Pam Dixon - World Privacy Forum: So you have to take it has to be a slightly different approach for that, as opposed to something that would work within it, a hipaa ecosystem, where there's already a lot of data in a lot of cases I hope that's helpful.

01:00:56.310 --> 01:00:58.500
Rim Cothren: Yes, yes it is Thank you.

01:01:00.030 --> 01:01:18.690
Rim Cothren: And, and the only thing that I would add to that is just as mark was pointing out, as long as the language in the regulation includes encourage social services that we are likely to get out of the hipaa ecosystem, at some point, and so I think we need to prepare for that.

01:01:21.270 --> 01:01:24.000
Lucy Johns: When, could you define de duplication.

01:01:27.090 --> 01:01:35.430
Rim Cothren: Well, I glommed on to that term because that was one that Pam used it means something to me that may not mean to Pam.

01:01:37.590 --> 01:01:46.650
Rim Cothren: It least in my case i'm thinking about a service that unambiguously determines.

01:01:49.260 --> 01:02:04.560

Rim Cothren: The identity, the single real person associated with a digital identity at two different organizations, so that, if I have seen two providers that they can appropriately associate.

01:02:05.010 --> 01:02:16.800
Rim Cothren: My health information at both of those institutions Pam if I have really messed up how you're thinking about that the use of that word, please fix it for me.

01:02:18.150 --> 01:02:24.120
Pam Dixon - World Privacy Forum: Okay, so the best way of fixing this so de duplication, is an ISO defined term.

01:02:25.410 --> 01:02:37.980
Pam Dixon - World Privacy Forum: So it's authentication and all of these things that we've been talking about today are already ISO defined very extensively defined so do you duplication, is where you work to basically.

01:02:40.050 --> 01:02:45.900
Pam Dixon - World Privacy Forum: You you take a database and you ensure that let's say you have 18.

01:02:47.100 --> 01:02:51.180
Pam Dixon - World Privacy Forum: john and Jane smith's in that in that database.

01:02:52.800 --> 01:03:08.190
Pam Dixon - World Privacy Forum: duplication means that each one of those entries are a separate identifiable unique person and you need to make sure that all the john and Jane Smith are just one person and.

01:03:09.450 --> 01:03:20.430
Pam Dixon - World Privacy Forum: Depending on what jurisdiction you're talking about I mean there are some jurisdictions in the world where many people have the same exact last name duplication, is very, very important process.

01:03:20.940 --> 01:03:28.380
Pam Dixon - World Privacy Forum: It can also mean within the broader data flows and broader data ecosystem what you were saying, which is.

01:03:28.950 --> 01:03:42.210
Pam Dixon - World Privacy Forum: Okay, you know you D duplicate you know that same data that's coming in and you make sure that you know the providers are talking the same language, it can be roughly this it's not quite that but it's close.

01:03:42.360 --> 01:03:44.580
Rim Cothren: But then, and the reason that I strayed.

01:03:44.580 --> 01:03:54.150
Rim Cothren: From the definition that you are giving is that we don't have a commitment to a single statewide database that would be duplicated.

01:03:55.170 --> 01:04:11.640
Rim Cothren: At this point that there isn't funding and at 133 for that it may be something that we recommend that the State do as part of our deliberations here, but there is a commitment for that So yes, there, there needs to be some.

01:04:12.150 --> 01:04:18.270
Rim Cothren: broader sense of how we match patients outside of just simply duplicating the database, but.

28

01:04:19.320 --> 01:04:21.390
Rim Cothren: A point well taken, thank you for that Pam.

01:04:22.890 --> 01:04:24.240
Lucy Johns: So thank you for that.

01:04:26.310 --> 01:04:36.750
Lucy Johns: Beginning of an explanation if there's not going to be a statewide database that accomplishes uniquely identifying each Jane Smith in it.

01:04:38.160 --> 01:04:40.080
Lucy Johns: To me, that implies.

01:04:41.640 --> 01:04:46.410
Lucy Johns: That every silo in the state is going to do this for itself.

01:04:47.760 --> 01:05:09.780
Lucy Johns: And i'm curious about and maybe this is out of scope for us, but what is the technology that is going to do that and how intrusive is it going to be and how will a patient who would like to be trusting but is skeptical understand what's going on there.

01:05:10.710 --> 01:05:18.090
Rim Cothren: Well, and I think that that's very good question and I do not have an answer for you, I think that the recommendation that i'm hearing.

01:05:18.630 --> 01:05:38.220
Rim Cothren: from many of our stakeholders, as we have these discussions, is that we do have a statewide index that that would do this, however, as I say, there is not funding for it at this point so we can't assume it, we can only recommend it this time.

01:05:40.380 --> 01:05:59.910
Rim Cothren: And so I don't have a good answer for you today individual organizations do that D duplication and are forced to do patient matching by exchanging demographic information and the best that we can do at this point is to put boundaries around that demographic information.

01:06:01.290 --> 01:06:04.020
Rim Cothren: to standardize it as best we can perhaps.

01:06:05.700 --> 01:06:08.040
Lucy Johns: And how about consumer patients.

01:06:08.100 --> 01:06:09.510
Lucy Johns: opting out of that.

01:06:11.250 --> 01:06:22.710
Lucy Johns: Is that a protection for consumers, since we don't have and the legislation does not provide for some entity having.

01:06:24.390 --> 01:06:39.060
Lucy Johns: jurisdiction and accountability for doing this right, as long as we don't have that can a patient can a consumer patient opt out of whatever a silo might decide to do.

01:06:39.840 --> 01:06:55.380
Rim Cothren: And that is a question that I have at least put to the data sharing agreement subcommittee to talk about patient consent for being both in the data exchange framework and in.

01:06:56.730 --> 01:06:58.560
Rim Cothren: The digital identities.

01:07:00.120 --> 01:07:03.270
Rim Cothren: So perhaps out of.

01:07:05.100 --> 01:07:09.750
Rim Cothren: Perhaps out of scope for our deliberations here, but is a very legitimate question.

01:07:10.830 --> 01:07:12.840
Lucy Johns: Thank you, I hope you will pursue that.

01:07:13.800 --> 01:07:15.150
Rim Cothren: And, and I want to.

01:07:16.830 --> 01:07:23.310
Rim Cothren: And and Lucy to be clear, I said that I have i'm not the only person that has put that question so that that.

01:07:24.930 --> 01:07:32.850
Rim Cothren: That little piece of brilliance isn't on me, that is something that a lot of people have identified I did want to call attention to.

01:07:33.420 --> 01:07:50.430
Rim Cothren: marks note in the chat here that at 133 seems to place jurisdiction and accountability, with CAA hhs I think that that's going to be some of the discussion as we continue to discuss governance and I believe governance is on the next ag meeting agenda but.

01:07:51.780 --> 01:07:55.650
Rim Cothren: that's a good point, and thank you for that mark Pam I see your hand up again.

01:07:56.640 --> 01:08:05.700
Rim Cothren: I did not mean to sound that way, I appreciate your hand and for you, seeing your thoughts, so do not take it that way.

01:08:06.180 --> 01:08:21.660
Pam Dixon - World Privacy Forum: No worries at all, so I just wanted to respond to some of lucy's questions so i'm having a centralized index is considered to be very, very old fashioned way of doing duplication.

01:08:22.470 --> 01:08:30.990
Pam Dixon - World Privacy Forum: There are a lot better ways and more modern ways of doing that now now we're in the dregs of identity ecosystem management, there are a lot of.

01:08:32.880 --> 01:08:43.770
Pam Dixon - World Privacy Forum: I would say procedures of art involved in this and they're well understood at this point there's a lot of data and a lot of resources, about this, but I would.

01:08:45.150 --> 01:08:54.090
Pam Dixon - World Privacy Forum: You also don't necessarily need to build silos you also don't have to necessarily do that anymore there's some really good real time ephemeral.

01:08:54.780 --> 01:09:05.190
Pam Dixon - World Privacy Forum: De duplication techniques that are possible I just think we just have to think in terms of a little bit more of a modern architecture and we'll be fine, but I would really.

01:09:06.060 --> 01:09:20.130
Pam Dixon - World Privacy Forum: Encourage very strongly to not go to a centralized index that's like that's like building a really beautiful Fort Knox of data and proclaiming it to the world, it would be such a such a difficult.

01:09:21.000 --> 01:09:28.830
Pam Dixon - World Privacy Forum: thing to maintain free of attacks, it would be much better to use a more more modern system thanks.

01:09:29.070 --> 01:09:29.730
Rim Cothren: Thanks Pam.

01:09:30.480 --> 01:09:32.010
Rim Cothren: Mark do you have your hand up.

01:09:33.270 --> 01:09:34.470
Mark Savage (Savage & Savage LLC): yeah so i'm.

01:09:36.330 --> 01:09:43.110
Mark Savage (Savage & Savage LLC): not sure where there's going to be room for this point and we've got one more meeting, so I just wanted to say it in case useful for now are useful in the future, and that is.

01:09:44.160 --> 01:09:46.770
Mark Savage (Savage & Savage LLC): If you're looking at patient matching as a use case.

01:09:47.940 --> 01:09:54.180
Mark Savage (Savage & Savage LLC): We talked about what what data elements or demographic characteristics, we will be looking at.

01:09:55.020 --> 01:10:08.160
Mark Savage (Savage & Savage LLC): There is a there's a point of also looking at what's missing and trying to avoid building in any structural bias and an example of this from work I do I know and sees interoperability standards work group is they.

01:10:09.390 --> 01:10:18.630
Mark Savage (Savage & Savage LLC): asked us to look at the address standardization of address we raised the point about people who don't have an address.

01:10:19.650 --> 01:10:30.690
Mark Savage (Savage & Savage LLC): and making sure that we don't build a page and they don't build a patient matching system that actually has a bias against homeless or housing unstable people.

01:10:32.040 --> 01:10:49.080
Mark Savage (Savage & Savage LLC): that's a that's an example of the broad concept, how to apply it really depends on when we start looking at particular demographics, we might use to to establish digital identities, but I just wanted to get it out there and something to protect against this.

01:10:50.340 --> 01:10:50.730
Mark Savage (Savage & Savage LLC): happen.

01:10:51.750 --> 01:11:07.440
Rim Cothren: Well, with with that call why don't we go on to the next slide because I said that one of the things that I wanted to talk about was specific attributes that might be associated and so mark that this is one of the items that comes up.

01:11:08.970 --> 01:11:31.170
Rim Cothren: quite a bit 133 calls for is the exchange of US CDI V one through October, and thank you mark, it is October of this year, as you had said in our last meeting and not next year, as I had remembered and all electronic health information for providers beyond that point.

01:11:32.610 --> 01:11:45.270
Rim Cothren: And so what is in US CIV one is a mean minimum for of demographic information that at least healthcare providers will be required takes change.

01:11:46.800 --> 01:12:03.660
Rim Cothren: part of my questions here were what might be associated with digital identities, we talked just very quickly, we talked last time about previous name and sex assigned at birth will be sensitive to some populations.

01:12:04.680 --> 01:12:06.150
Rim Cothren: As you say here mark.

01:12:07.500 --> 01:12:10.710
Rim Cothren: current or previous address may be sensitive.

01:12:11.850 --> 01:12:20.490
Rim Cothren: We have also heard from some of the other groups that race and ethnicity and preferred language are not good.

01:12:21.960 --> 01:12:37.560
Rim Cothren: Demographics to do matching against because they're inconsistent reported and maybe sensitive to some groups, I would like to at least take a few minutes to identify and and and Pam I didn't mean to skip over this, but.

01:12:38.940 --> 01:12:47.940
Rim Cothren: Health plan ID number is clearly another one, a local identifier, but there may be other local identifiers, it should be avoided.

01:12:48.930 --> 01:13:05.730
Rim Cothren: I do want to take it at least a couple of minutes here to collect up i'm your thoughts on attributes and identity and data elements that should not be included here and why so Pam you had your hand up first.

01:13:07.950 --> 01:13:30.570
Pam Dixon - World Privacy Forum: Okay, so yeah, this is a great slide actually it really lays it out, so a couple of things here and I just want to be as helpful as possible, so in terms of data attributes in the digital ID space, so the demographic data utilized for any kind of ID.

01:13:33.540 --> 01:13:36.360
Pam Dixon - World Privacy Forum: It can be really problematic I think there's some mean.

01:13:37.890 --> 01:13:46.650
Pam Dixon - World Privacy Forum: race and ethnicity sex assigned at birth preferred language some of some of these also contain you know.

01:13:48.270 --> 01:14:06.000
Pam Dixon - World Privacy Forum: You know native language native spoken language country birth that kind of thing current address previous address all of these things can be really, really dicey but the thing the thing I do not see here is, for example, the attributes that could be token.

01:14:07.080 --> 01:14:18.750
Pam Dixon - World Privacy Forum: For the last mile so, for example, let's take a driver's license or passport number just just by way of example, you can token is that number and have.

01:14:19.320 --> 01:14:28.950
Pam Dixon - World Privacy Forum: A token ization that's mediated through an APP or even you can get a token ID just in an online patient portal.

01:14:29.610 --> 01:14:39.180
Pam Dixon - World Privacy Forum: And then the token ization can be utilized at the last mile so that this information is shielded and you get enough, yes, no response is this patient.

01:14:39.990 --> 01:14:53.790
Pam Dixon - World Privacy Forum: can do we do you know, is this patient do you duplicate it yes know if it's no well, then you have to get more data attributes if it's yes, then you can stop there, but I, I do think that.

01:14:54.960 --> 01:15:03.180
Pam Dixon - World Privacy Forum: If you're going to include some of these really risky data elements, or even consider them you've got to consider also to organization.

01:15:05.730 --> 01:15:16.080
Pam Dixon - World Privacy Forum: Yes, for sure and and I would also say that there's there's a lot of additional types of attributes, that would be.

01:15:18.120 --> 01:15:20.580
Pam Dixon - World Privacy Forum: I think less objectionable Thank you.

01:15:21.090 --> 01:15:23.610
Rim Cothren: Great thanks Pam Lucy I see your hand up.

01:15:29.880 --> 01:15:31.770
Rim Cothren: Lucy you're still on mute if you're talking.

01:15:34.110 --> 01:15:47.130
Lucy Johns: Sorry it's my understanding mark correct me if i'm wrong that usc di V one becomes mandatory for Certifiable hrs as of October 1 Is that correct.

01:15:48.870 --> 01:15:49.650
Mark Savage (Savage & Savage LLC): I think it's all right.

01:15:51.540 --> 01:15:51.990
Lucy Johns: Yes.

01:15:52.050 --> 01:15:53.400
Mark Savage (Savage & Savage LLC): I think it was already being used.

01:15:54.510 --> 01:16:06.450
Lucy Johns: Okay, well, so what I what i'm thinking is that whatever we may think about the validity or desirability of these bulleted items, they are going to be.

01:16:06.930 --> 01:16:22.860
Lucy Johns: What hrs are designed to collect so if we're not happy with one or another, I just want to be sure that we all understand that we can't change that for the hrs, at least where the certified ehr is so new paragraph.

01:16:23.670 --> 01:16:36.750
Lucy Johns: for local identifiers is a too crazy to imagine that consumer patients can be asked by somebody which of these they would prefer.

01:16:39.750 --> 01:16:48.270
Pam Dixon - World Privacy Forum: I think it's totally normal to ask which attributes, you want to use as an identifier, as long as it's on the official identifier list, and I think.

01:16:48.480 --> 01:16:49.560
Lucy Johns: We could we.

01:16:49.920 --> 01:17:04.110
Lucy Johns: Could we actually instead of really out any of these or maybe we'd like to one or another, but as a general proposition, could we take the position.

01:17:05.400 --> 01:17:15.450
Lucy Johns: With respect to this project and the scope of this law that consumer patients will be presented by somebody somehow.

01:17:15.990 --> 01:17:35.160
Lucy Johns: With a list of identifiers that could be token eyes, I think that's a wonderful idea, but in any case, the consumer patient chooses or is allowed to choose, if they want to which of these identifiers they're not they they would like to.

01:17:36.990 --> 01:17:41.010
Lucy Johns: They would like to have in the system to be sure that they can be followed around.

01:17:42.270 --> 01:17:43.710
Pam Dixon - World Privacy Forum: I think that's reasonable.

01:17:44.820 --> 01:17:59.580
Pam Dixon - World Privacy Forum: In terms of US us C D one V one or within the hip ecosystem, I think those identifiers are fine because there's the hipaa you know guardrails it's when they go outside of the hipaa ecosystem that's really problematic.

01:17:59.640 --> 01:18:03.660
Pam Dixon - World Privacy Forum: But yeah I couldn't agree more with that going outside of hipaa.

01:18:04.080 --> 01:18:20.640
Lucy Johns: i've had to get used to that idea over the last three years and i'm still not really used to it so anything that you or others or this whole project can identify to protect people's confidentiality and privacy outside of hipaa boundaries.

01:18:21.810 --> 01:18:23.760
Lucy Johns: The more the better, thank you.

01:18:24.540 --> 01:18:25.410
Rim Cothren: Thanks Lucy.

01:18:26.040 --> 01:18:28.350
Rim Cothren: mark, thank you for your patience you've had your hand up.

01:18:29.400 --> 01:18:34.590
Mark Savage (Savage & Savage LLC): Sure couple things one is it with patient matching as a use case.

01:18:35.940 --> 01:18:40.320
Mark Savage (Savage & Savage LLC): My understanding is that different combinations of demographic factors.

01:18:41.400 --> 01:18:48.180
Mark Savage (Savage & Savage LLC): have more or less likelihood of matching the individual correctly and therefore.

01:18:49.860 --> 01:19:04.320
Mark Savage (Savage & Savage LLC): fitting into the middle of that a patient or an individual's choice of what factors are going to be used will change the likelihood of matching for that individual and frankly may change it for the system, overall I don't know.

01:19:04.950 --> 01:19:09.630
Lucy Johns: I was just talking about actual local identifiers mark, not the demographics.

01:19:10.800 --> 01:19:14.730
Mark Savage (Savage & Savage LLC): Thank you, I missed that that can second thing is.

01:19:17.220 --> 01:19:27.060
Mark Savage (Savage & Savage LLC): Just to note that the US CDI V1 some of the discussions that are happening are not to change the name of the data element, but to change the standard being used.

01:19:27.780 --> 01:19:41.040
Mark Savage (Savage & Savage LLC): The coding system, the value set so when I was talking about address yes current address previous address are listed his UFC the IV one but we we the interrupt really sound is workgroup are preparing a recommendation to say.

01:19:42.090 --> 01:19:46.740
Mark Savage (Savage & Savage LLC): Which over to this standardization process used by project USA.

01:19:47.790 --> 01:19:56.340
Mark Savage (Savage & Savage LLC): But include that project metadata element which will, which will identify whether the person is homeless or as housing instability.

01:19:57.600 --> 01:20:08.100
Mark Savage (Savage & Savage LLC): So that in some ways, there are things that we might be thinking of is sort of adequate established are also changing hopefully for the better, but.

01:20:09.420 --> 01:20:22.950
Mark Savage (Savage & Savage LLC): But still changing and I don't and i'm guessing it's not my area of expertise, but i'm guessing that introduces some complexity for patient matching if you have a if you have an evolving set of standards over.

01:20:24.000 --> 01:20:37.200
Mark Savage (Savage & Savage LLC): Over time, some of the things, for example, in the two there's also gender identity we're working on some significant changes there, which would go back in effect sex assigned at birth under US CDI V1.

01:20:38.400 --> 01:20:43.770
Mark Savage (Savage & Savage LLC): and so forth, so the general point being that that some of the standards within the data element.

01:20:44.940 --> 01:20:52.530
Mark Savage (Savage & Savage LLC): are changing, hopefully, for the better, but that may hopefully that makes patient matching better but it's still a change.

01:20:53.670 --> 01:21:01.830
Pam Dixon - World Privacy Forum: that's interesting so there's a lot of federal language around homeless systems and homeless information systems hmm is so.

01:21:02.640 --> 01:21:19.830
Pam Dixon - World Privacy Forum: there's actually a lot of standards around that as well, so identity ecosystems in general are one of the most complex ecosystems on the planet

and then, when you add the complexity of healthy ecosystems on top of that, you get a really, really complicated set of things, but.

01:21:20.910 --> 01:21:23.040
Pam Dixon - World Privacy Forum: I do think that.

01:21:24.630 --> 01:21:39.120
Pam Dixon - World Privacy Forum: Even if let's let's say that we, you know this was able to be maintained within the ecosystem if if the various attributes in the US CD one view one.

01:21:39.570 --> 01:21:50.310
Pam Dixon - World Privacy Forum: or di you want our are you know if there are token, it would really help a lot, and it would it would prevent, for example, so things such.

01:21:50.820 --> 01:22:03.750
Pam Dixon - World Privacy Forum: date of birth, which is very risky factor, along with legal name it we prevent that from just you know being shared out in the open all over the place, which is really the kind of risk, you want to avoid.

01:22:06.780 --> 01:22:07.410
Rim Cothren: Thanks Pam.

01:22:08.940 --> 01:22:25.920
Rim Cothren: Well, we are reaching the end of our time today, this has been a great discussion and I really appreciate your time quad why don't we we can skip over the next slide and go to next steps here.

01:22:27.750 --> 01:22:42.180
Rim Cothren: What we've been what we're working towards is completing a first draft to the strategy and April and April is just around the corner here refining that strategy with the advisory group.

01:22:43.350 --> 01:23:02.100
Rim Cothren: In May, and ensuring that we align with any potential requirements, either with the data exchange framework or the data sharing agreement and finalized strategy in June and July, that is a short timeframe, with a lot of lot of work still to be done on a lot of different fronts.

01:23:03.750 --> 01:23:04.260
Rim Cothren: The.

01:23:06.900 --> 01:23:14.010
Rim Cothren: Upcoming ag meeting has a significant discussion of digital identities at that meeting so.

01:23:14.700 --> 01:23:22.320
Rim Cothren: you're certainly welcome to attend that meeting, as a member of the public or mark you're going to hear about digital identities get at that meeting.

01:23:22.680 --> 01:23:33.000
Rim Cothren: in some detail and there'll be some discussion then with the ag police that's that's my hope to go on to the next slide we've had two meetings of this advice this.

01:23:33.990 --> 01:23:41.340
Rim Cothren: focus group so far, the other meeting that you'll find, I believe, on your calendars is Monday April 25th.

01:23:42.000 --> 01:23:58.860

Rim Cothren: Just to note as mark had mentioned last time, the executive order that does not require these meetings to be public meetings to be held in person expires at the end of this month, that means it will be moving to in person meetings in April.
01:23:59.970 --> 01:24:16.380
Rim Cothren: And as so the advisory group meeting on April 7 will be an in person meeting, and we will be reaching out to you soon about how we will make adjustments, if there are adjustments to these meetings to.
01:24:18.030 --> 01:24:27.450
Rim Cothren: take advantage of or address the need to move to in person meetings in April so we're going to leave.
01:24:28.560 --> 01:24:28.980
Lucy Johns: From.
01:24:29.070 --> 01:24:32.220
Lucy Johns: Did you just say April 25 is going to be in person.
01:24:32.820 --> 01:24:40.290
Rim Cothren: That all public meetings, after a march 31 have to be in person means.
01:24:41.730 --> 01:24:46.140
Lucy Johns: Yes, that means we all have to be driving to sacramento or flying or something.
01:24:47.790 --> 01:24:55.830
Rim Cothren: That is the requirement of the Bagley keen act is that public meetings are held in person.
01:24:56.970 --> 01:25:07.590
Lucy Johns: But we can call and if we're not up to if we're not if for some of our own personal reasons we don't want to be in groups at that point.
01:25:08.760 --> 01:25:10.140
Lucy Johns: We can call in right.
01:25:10.590 --> 01:25:22.380
Rim Cothren: So what we are doing for the advisory group meeting on the Seventh and there'll be more details about what we're going to do with these focus group meetings forthcoming but what we're doing with that one is.
01:25:23.760 --> 01:25:36.960
Rim Cothren: A holding a hybrid meeting where at least a majority of the meeting attendees must be in person at the meeting in order to actually convene a meeting.
01:25:37.680 --> 01:25:58.140
Rim Cothren: And so, there are some members of the Advisory Group that are attending remotely but a majority must be present in order to hold the meeting and so that that's what we're going to have to work out with a group as small as this one, where a majority is relatively difficult to.
01:26:00.330 --> 01:26:03.450
Rim Cothren: to convene how we're going to deal with our own meetings.
01:26:07.380 --> 01:26:17.220
Rim Cothren: And I understand the potential hardship there it's a State law it's not a it's it's not a policy of CDI it is State law.
01:26:18.600 --> 01:26:19.980
Pam Dixon - World Privacy Forum: says all State law.

01:26:24.630 --> 01:26:25.170
Mark Savage (Savage & Savage LLC): Probably.

01:26:25.530 --> 01:26:27.450
Rim Cothren: At least at least pre coven.

01:26:30.840 --> 01:26:41.010
Rim Cothren: Thank you very much, we are in time now I do appreciate everybody's participation today and the good discussion, thank you all for attending and for your time and we will be in touch Thank you.

01:26:41.790 --> 01:26:42.180
Pam Dixon - World Privacy Forum: Thank you.