



**California Health & Human Services Agency
Center for Data Insights and Innovation
Data Exchange Framework
Digital Identity Consumer Privacy Focus Group Meeting #1
(March 14, 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 #1. The transcript was produced using Zoom's transcription feature. It should be reviewed concurrently with the recording – which may be found on the CalHHS Data Exchange Framework [website](#) – to ensure accuracy.

00:00:03.750 --> 00:00:14.580

Rim Cothren: And mark, yes, all of the members of the focus group are listed as Co hosts that allows you to make sure that you can mute and unmute yourself whenever you like to.

00:00:17.279 --> 00:00:28.440

Rim Cothren: So I want to welcome people to the first consumer privacy focus group meeting on the strategy for digital identities, for the data exchange framework, I know some of you here, but I don't know everyone.

00:00:30.330 --> 00:00:45.720

Rim Cothren: So I will introduce myself i'm rim Catherine and i'm consultant to the Center for data insights and innovation within health and human Services Agency and i'm working with the CDI to aid in developing.

00:00:47.730 --> 00:00:57.120

Rim Cothren: The data exchange framework and specifically on the strategy for digital identities we'll start off with just a few housekeeping.

00:00:57.600 --> 00:01:06.510

Rim Cothren: Items here our intent is to record today's meeting and post the recording to the data exchange frame work website in lieu of notes.

00:01:06.870 --> 00:01:21.060

Rim Cothren: So for the members of the public, if you do not wish to be recorded keep yourself muted during the public comment period or leave the meeting, are there any Members of the focus group that have an objection to being recorded today.

00:01:26.220 --> 00:01:35.100

Rim Cothren: Seeing none, thank you very much for that that allows us to do a better job of capturing your thoughts, rather than trying to do it through your notes.

00:01:35.760 --> 00:01:48.090

Rim Cothren: We have enabled live closed captioning for anyone you permission to use it to turn on live closed captioning click on the CC control at the bottom of your zoom window.

00:01:49.350 --> 00:01:55.710

Rim Cothren: today's meeting is being conducted as a public meeting there will be an

opportunity for public comment during today's meeting.

00:01:56.130 --> 00:02:09.990

Rim Cothren: members of the public have been muted until the agenda item for public comment my intent for everyone else, though, is to keep today's meeting informal to encourage discussion so that means that members of the focus group.

00:02:11.310 --> 00:02:17.220

Rim Cothren: Can unmute themselves whenever they like, I would encourage you to turn your cameras on if you feel comfortable doing that.

00:02:18.030 --> 00:02:21.600

Rim Cothren: So that we can get to know each other, a little better and.

00:02:22.260 --> 00:02:32.220

Rim Cothren: I would suggest that people raise their hand using the raise hand feature just because that makes it really clear to me that you have something that you want to say.

00:02:32.520 --> 00:02:43.050

Rim Cothren: And it allows me to give everybody an opportunity to participate in the meeting, however, if I drone on or you feel like I have missed you feel free to just.

00:02:43.470 --> 00:03:04.680

Rim Cothren: jump in with a comment that you have again, you can unmute yourself, I also don't plan on calling roll today, so if everyone would just take a minute and make sure that you have set your name and potentially your organization in the zoom window that helps us all get to know who is speaking.

00:03:07.050 --> 00:03:11.460

Rim Cothren: Before we get started quiet don't see anybody that's just on the phone is that right.

00:03:13.890 --> 00:03:14.490

Khoua Vang: yeah No one on.

00:03:15.300 --> 00:03:15.960

Okay.

00:03:19.440 --> 00:03:24.420

Rim Cothren: Thanks leave for joining us, I was just kicking this off with some.

00:03:25.500 --> 00:03:41.220

Rim Cothren: housekeeping items, the one thing that I would mention to you is you can unmute yourself anytime you like, and we are recording today's meeting and plan to post the recording in lieu of notes on the website, you have any problem with being recorded today.

00:03:51.240 --> 00:03:52.890

Rim Cothren: that's fine and thanks.

00:03:54.120 --> 00:04:03.870

Rim Cothren: So please, if you did have an objection we didn't hear it, maybe you didn't get yourself off mute, but let me know if you object to being recorded today and will turn off the recording.

00:04:05.670 --> 00:04:07.470

Rim Cothren: let's go on to the next slide please call.

00:04:10.740 --> 00:04:13.860

Rim Cothren: And I start all of the focus group meetings with this slide.

00:04:16.320 --> 00:04:28.470

Rim Cothren: I just get pause here to give everybody a chance to consider any potential conflict that you may have with participating with today's meeting, please take a minute to read the notice i'm not going to bother to read it.

00:04:31.020 --> 00:04:38.100

Rim Cothren: I can't say whether procurement result from this strategy for digital identities that we will be discussing today.

00:04:38.460 --> 00:04:47.700

Rim Cothren: However, I would expect the input from these focus group discussions will include recommendations on the need work involved or the strategy.

00:04:48.030 --> 00:04:54.750

Rim Cothren: So attendees who might intend to bid or be part of a team that bids on a new procurement that might result.

00:04:55.230 --> 00:05:04.920

Rim Cothren: should not participate in the focus group and should leave today's meeting you're still welcome to attend and listen to today's and future meetings, as a member of the public.

00:05:05.370 --> 00:05:12.660

Rim Cothren: But I want to make sure that you have an opportunity to leave the meeting to avoid creating a conflict of interest for you.

00:05:17.130 --> 00:05:19.170

Rim Cothren: Well, why don't we go on to the next slide please.

00:05:21.510 --> 00:05:32.430

Rim Cothren: So here's today's agenda we're going to start off with talking a little bit about the requirements for strategy for digital identities, so that we have a common place to.

00:05:33.480 --> 00:05:42.570

Rim Cothren: To come there with will pause then for public comment and then, I have two main areas where I want to discuss and get input from you.

00:05:43.440 --> 00:06:00.750

Rim Cothren: The first is on the types of components that might be included in a digital identity strategy and the second we'll talk a little bit about some of the specific data elements that might be in a digital identity and privacy concerns your priorities associated with them.

00:06:02.610 --> 00:06:04.470

Rim Cothren: let's go on to the next slide please.

00:06:05.730 --> 00:06:06.810

Rim Cothren: Welcome and goals.

00:06:08.280 --> 00:06:12.090

Rim Cothren: we've done our welcome already, but the goal of these stakeholder.

00:06:13.200 --> 00:06:27.060

Rim Cothren: Focus groups is to gain input from specific perspectives on a strategy for digital identities, for the data exchange framework so it's very specific to that i'm asking you all to really think in terms of privacy here.

00:06:27.780 --> 00:06:38.310

Rim Cothren: Both as advocates for consumers, but as individuals yourself that might

be looking to benefit from the data exchange framework.

00:06:38.730 --> 00:06:50.640

Rim Cothren: we're asking for input from a number of different stakeholder perspectives that include health information exchanges healthcare providers health plans and social service organizations, as well as.

00:06:51.030 --> 00:07:07.710

Rim Cothren: State health and human service departments within a state government today we're really focusing on consumer privacy, but as I said before, this is your meeting, this is my opportunity to get input, so you can take this discussion wherever you want to.

00:07:08.730 --> 00:07:10.260

Rim Cothren: let's go on to the next slide please.

00:07:11.820 --> 00:07:21.630

Rim Cothren: And let's talk just very briefly about the requirements for digital identity strategy as they're called out in the legislation it's gone to the next slide please.

00:07:22.350 --> 00:07:31.560

Rim Cothren: ab 133 requires us to develop a strategy for unique secure digital identities capable of supporting master patient indices.

00:07:31.920 --> 00:07:42.060

Rim Cothren: To be implemented by both private and public organizations, this is the only language within a be 133 associated with digital identities at all.

00:07:42.570 --> 00:07:51.240

Rim Cothren: And there are a few things in this that I want to touch on just very briefly, so that we are all again approaching this from a common standpoint.

00:07:51.720 --> 00:08:03.030

Rim Cothren: it's gone to the next slide please, first of all, it calls for us to develop a strategy that strategy is to be published, no later than July 31 of this year.

00:08:03.780 --> 00:08:16.590

Rim Cothren: That means that we are not required to actually stand up digital identities in that timeframe, but we should be talking about where our priorities are selections that we're recommending that.

00:08:18.870 --> 00:08:28.500

Rim Cothren: Health and Human Services Agency follow, and perhaps a roadmap for how we would develop a strategy for digital identities over time.

00:08:29.970 --> 00:08:31.650

Rim Cothren: it's gone to the next slide please.

00:08:33.510 --> 00:08:38.550

Rim Cothren: And it calls for digital identities, in particular, it doesn't call for a digital identifier.

00:08:39.810 --> 00:08:59.460

Rim Cothren: And the way that we are interpreting digital identities here is to establish an identity through a collection of data that can be associated with a real person in a particular context and for our purposes that context is to.

00:09:00.900 --> 00:09:19.680

Rim Cothren: is associated with their health and human services information so again, it is not a call for us to establish a digital identifier unless our focus group input says

that we need to do that as part of our strategy, but a collection of data that helps the site identify a real person.

00:09:21.030 --> 00:09:34.170

Rim Cothren: it's gone to the next slide please, it needs to be unique, which means that we need to ensure that we can establish an unique linkage between an individual and their data and it needs to be secure.

00:09:35.490 --> 00:09:50.820

Rim Cothren: And really that is a what what is called foreign, security is that we can protect it against unauthorized disclosures access or use, but also against unintended modification, corruption or loss.

00:09:52.320 --> 00:09:53.460

Rim Cothren: in particular.

00:09:54.720 --> 00:10:00.090

Rim Cothren: The legislation does not call out the need for digital identities, to be private.

00:10:00.630 --> 00:10:08.100

Rim Cothren: But I want to make sure we discussed that today, and I would ask that people specifically think about privacy, not just security.

00:10:08.400 --> 00:10:19.140

Rim Cothren: And thinking about digital identities today i've asked that at the other focus groups as well, so that's not special here, but I want to make sure that we keep that in mind let's go on to the next slide please.

00:10:21.750 --> 00:10:32.460

Rim Cothren: We need to be thinking about this in terms of things that can be implemented by both private and public sector organizations, so not only by state government, but by the providers plans.

00:10:32.970 --> 00:10:40.050

Rim Cothren: Long term care facilities labs other signatories to the data exchange frameworks data sharing agreement.

00:10:40.470 --> 00:10:51.120

Rim Cothren: So it is potentially a large number of organizations, some of those organizations might include health information exchange organizations or human service organizations.

00:10:51.450 --> 00:11:04.020

Rim Cothren: Although they're not called out specifically in the legislation signatories they might be participating in the data exchange framework as well, so think about this in terms of a very large potential group of stakeholders.

00:11:05.670 --> 00:11:07.020

Rim Cothren: Next slide please call.

00:11:09.060 --> 00:11:19.890

Rim Cothren: And the legislation says that we need to establish digital identities capable of supporting master patient indices, so it doesn't call for a statewide.

00:11:20.250 --> 00:11:29.280

Rim Cothren: master person index, but we might again indicate that that is useful or desirable to meet the goals of a digital identity.

00:11:29.640 --> 00:11:39.060

Rim Cothren: But we should be thinking about how organizations might use digital identities, or whether i'm master person index as a as a potential portion part of that.

00:11:39.990 --> 00:11:47.430

Rim Cothren: The legislation says master patient index, I will just note here that we may not only be talking about patients.

00:11:47.880 --> 00:12:06.390

Rim Cothren: But people in other contexts as well, I tried to adjust my own language to refer to them as master person index if I fail to do that just please read in in your head that rim is talking about people in any context associated with the data exchange framework, not necessarily just patients.

00:12:08.490 --> 00:12:24.540

Rim Cothren: let's go on to the next slide before we turn to public comment, I want to pause here for a second and see if there are any questions or comments about the A, B 133 language or anything about kind of the charge, as I put it in front of you.

00:12:25.650 --> 00:12:26.760

Rim Cothren: Mark yes please.

00:12:28.770 --> 00:12:30.480

Mark Savage: couple of questions, one is.

00:12:32.130 --> 00:12:35.130

Mark Savage: The john or your last point would.

00:12:36.150 --> 00:12:44.940

Mark Savage: Family caregivers Personal Representatives, etc, also be considered the PR as one of the persons people that would be covered by this.

00:12:46.530 --> 00:12:48.540

Mark Savage: Not just the individual herself or himself.

00:12:49.470 --> 00:13:04.410

Rim Cothren: I think that that's a good question and one of the first things that I want to talk about here is the scope of the individuals that are involved here so i'm going to be really i'm going to turn the question back over to you in a few minutes and get your input from that.

00:13:07.440 --> 00:13:14.850

Rim Cothren: Because one of the questions that i've asked to the other focus group members has been what should be the focus of our purpose.

00:13:15.390 --> 00:13:21.720

Rim Cothren: At the focus of our purpose is consumer access to their data I would answer your question potentially yes.

00:13:22.110 --> 00:13:34.470

Rim Cothren: If the focus of our purpose is to make sure that rim conference health information at three providers one plan and some social services, the answer might be no, but I think that we need to discuss that.

00:13:37.860 --> 00:13:39.450

Rim Cothren: Lee I see that you have your hand up.

00:13:40.260 --> 00:14:09.540

tien@eff.org: yeah I just had a very quick question about in this identity digital identity matrix are we also going to be identifying individuals who are working for or Member or

part of the organizations that are part of that is it's not just me a patient or you were patient but also say.

00:14:10.560 --> 00:14:13.230

tien@eff.org: You, a member of the.

00:14:14.610 --> 00:14:31.260

tien@eff.org: Of the organization that is a stakeholder in it, and so is there going to be some sort of generic it is it going to be like everyone who touches the system has an identifier, including the say the bureaucrats in a county.

00:14:32.310 --> 00:14:35.190

tien@eff.org: Or is it just individuals who are like.

00:14:37.020 --> 00:14:38.700

tien@eff.org: You know clients I guess.

00:14:40.080 --> 00:14:49.800

Rim Cothren: I think that's an excellent question and nobody's asked that question yet so I don't have a good answer for you so let's let's think about that and see if we can wrap our own heads, as a group.

00:14:50.220 --> 00:14:59.340

Rim Cothren: Around how we might approach that today we can touch it again in our second meeting in a couple of weeks if we don't get a good feeling for that today.

00:14:59.640 --> 00:15:14.430

tien@eff.org: From my perspective, the reason, one reason would be to have audit trails right, so that everyone who accesses the system is known as well, so it seems like at least has a segue into the goal of security that's part of it.

00:15:14.760 --> 00:15:19.740

Rim Cothren: And, and I hear you there and I think that that's an excellent point.

00:15:20.430 --> 00:15:31.050

Rim Cothren: I will just note for people that are on the call here that one of the other components that people have been suggesting needs to be part of the data exchange framework.

00:15:31.470 --> 00:15:40.140

Rim Cothren: Is a provider directory that gets some quietly to your thoughts about other individuals that are test touching the system.

00:15:41.130 --> 00:15:50.280

Rim Cothren: The legislation doesn't call for that, and it may not be part of the framework as it's initially described, but it is one of the conversations.

00:15:50.640 --> 00:15:59.130

Rim Cothren: Going forward, and if the recommendations of these focus groups is that we prioritize that from a security standpoint that I'll make sure that I know that.

00:16:00.300 --> 00:16:01.830

Rim Cothren: back, I see that you have your hand up.

00:16:02.340 --> 00:16:13.470

Becca Cramer-Mowder ACLU (she/her): yeah I have a clarifying question which is we are just talking about how to identify a person and not, and that is being separate from.

00:16:13.890 --> 00:16:28.770

Becca Cramer-Mowder ACLU (she/her): Who has access to the records correct so it's like how to identify in the records who back a Kramer matter is not who which records, I

have access to, or who has access to my records.

00:16:28.980 --> 00:16:39.450

Rim Cothren: Show yes and no and I answer it both of those ways is that, yes, our primary task here is to identify who becca is.

00:16:40.530 --> 00:16:49.710

Rim Cothren: and information that is associated with becca and perhaps that becca can access her own information will come back to that.

00:16:51.150 --> 00:17:02.820

Rim Cothren: But is is not associated with the purpose for use of the health information its associated with you, that is being deliberated in the data.

00:17:03.390 --> 00:17:12.540

Rim Cothren: sharing agreement subcommittee another set of public meetings that if people are interested in participating in those I would certainly welcome you to do that.

00:17:14.190 --> 00:17:21.300

Rim Cothren: The the exception to that is I do want us to think about access to the digital identity.

00:17:23.340 --> 00:17:25.860

Rim Cothren: example the digital identity, I.

00:17:26.970 --> 00:17:37.020

Rim Cothren: aim, maybe my at my date of birth, perhaps a phone number associated with me, because those are all useful in identifying me.

00:17:37.710 --> 00:17:54.120

Rim Cothren: But I do want us to touch on what are the acceptable purposes of that demographic information, for example, and we'll come back to this later, but, for example, are you allowed to use the phone number associated with my digital identity to contact me.

00:17:55.320 --> 00:18:10.560

Rim Cothren: Or can you only use it to link my data or if we were to include addresses, could you use the address information to stratify a public health study.

00:18:11.310 --> 00:18:32.340

Rim Cothren: So that it was a demographically separated, or can you only use that to identify me so that is some of the discussion, I want to make sure that we specifically talk about today, and in that case, yes, it is completely within our scope to talk about how digital identity data can be used.

00:18:33.960 --> 00:18:36.420

Rim Cothren: How I completely confused you back or did that help.

00:18:37.980 --> 00:18:53.550

Becca Cramer-Mowder ACLU (she/her): helped, I just want to clarify that this is entirely separate even from like how I might access my own record so it's completely separate from any sort of verification of identity, other than.

00:18:54.210 --> 00:19:07.350

Becca Cramer-Mowder ACLU (she/her): Once you're already in the system, making sure all of becca's records match up with the correct becca but not even making verifying that becca is who she says she is in order to access around records.

00:19:07.530 --> 00:19:10.320

Rim Cothren: That that's right, at least at this time.

00:19:11.520 --> 00:19:22.170

Rim Cothren: I think that we've if you've been for people that have been participating in or been listening to the advisory group meetings, you know that the advisory group is prioritized.

00:19:22.770 --> 00:19:32.670

Rim Cothren: Consumers accessing their own health information, but the legislation does not call for that so that will be developed over time and for today's discussion.

00:19:33.090 --> 00:19:42.900

Rim Cothren: I don't believe we will be talking about how you access your own information and how your identity proof, although we will discuss that again as well, so we'll come back to that.

00:19:44.850 --> 00:19:45.840

Rim Cothren: Mark yes.

00:19:47.340 --> 00:19:55.470

Mark Savage: So it sounds like there are instances where the same piece of information that's been used for digital identity like name or date of birth.

00:19:56.820 --> 00:19:57.600

Mark Savage: could be.

00:20:00.600 --> 00:20:07.740

Mark Savage: We could just focus group we could recommend not disclose for that purpose, and yet it would be disclosed for another purpose.

00:20:09.120 --> 00:20:15.090

Mark Savage: They for purposes of treatment and i'm just mentioning that, because unless one is tracking.

00:20:16.170 --> 00:20:29.700

Mark Savage: That, along with the is not going to tackle that one thinks that may think that just the identifier is being treated in a singular way and we'd be surprised.

00:20:31.110 --> 00:20:33.750

Mark Savage: If you got access to it in another way, and it was disclosed.

00:20:35.670 --> 00:20:49.740

Rim Cothren: Well, and I say that because that's the way I think about things in my own mind mark, but if you think that that is a distinction that is unnecessary or problematic, please let us know.

00:20:50.700 --> 00:21:02.820

Mark Savage: No instead I think it's I think it's something to be clear about at the beginning, so that there are no surprises no misunderstanding, but I think I think that's necessary.

00:21:04.500 --> 00:21:13.080

Mark Savage: Here, given that these are letter being considered at least initially, as identifiers or basic pieces of information and one health record.

00:21:13.530 --> 00:21:28.230

Rim Cothren: Yes, and and Lee in particular i'll just call out for you, since you're a member of the DS the data sharing agreement subcommittee this exact topic is going to come up with the next subcommittee meeting as well, so.

00:21:29.610 --> 00:21:47.550

Rim Cothren: You have another chance to to weigh in on a pair Lucy i'm sorry I did see

your note to me, and I see that you found your hands up and if people are having trouble finding their hands up feel free to just jump in and interrupt me as well, but yes Lucy Please go ahead.

00:21:48.690 --> 00:22:07.470

Lucy Johns: yeah i'm from my point of view, it would be helpful if it's within the scope that you envision for this group and with your assistance to perhaps enumerate some use cases for which.

00:22:08.460 --> 00:22:18.030

Lucy Johns: Our digital identities might be used because the elements of digital identity that you would like us to consider.

00:22:18.450 --> 00:22:28.110

Lucy Johns: It seems to me do reflect the use cases that we anticipate are additional identities might be used for you know the words.

00:22:28.800 --> 00:22:45.390

Lucy Johns: Talking about elements of digital identity, independent of how our digital identity might be used, even if not specified in legislation, it seems to me that might be something that a focus group, like this.

00:22:46.560 --> 00:23:02.700

Lucy Johns: should be envisioning and specifying so that it's clear when we're finished the elements of our digital identity is the outcome of this process so.

00:23:04.290 --> 00:23:16.860

Lucy Johns: For me, logically, thinking about how the digital identity associated with this legislation is intended to be used should be specified and use cases.

00:23:17.430 --> 00:23:24.570

Rim Cothren: Great that's a very good point let's touch on that as part of the first discussion after public comment.

00:23:25.200 --> 00:23:38.910

Rim Cothren: And maybe we can co design some of that those use cases and I can talk about the assumed use case, I think, from some of the other focus group meetings will do that there great Thank you.

00:23:41.070 --> 00:23:46.080

Rim Cothren: Since I don't see any other hands raised i'm going to turn us to public comment period.

00:23:48.060 --> 00:23:57.150

Rim Cothren: If you are interested in making a comment, please raise your hand in the zoom telecom teleconferencing options and you will be called on in the order that your hand is raised.

00:23:58.350 --> 00:24:05.970

Rim Cothren: Then you can unmute yourself and state your name organizational affiliation, and we ask that you keep your comments respectful and brief.

00:24:07.140 --> 00:24:13.260

Rim Cothren: If anyone from the public is interested in making a public comment, please raise your hand now.

00:24:28.890 --> 00:24:34.020

Rim Cothren: I don't see any hands raised quiet haven't missed anyone have I then we'll move on, please.

00:24:36.960 --> 00:24:44.670

Rim Cothren: So there are really some threshold questions that I want to start to discuss today, I have a few questions that I would like, for you to just to consider.

00:24:45.210 --> 00:25:03.120

Rim Cothren: For most of the focus groups i've moved forward with just a blank slate I haven't done that, today, I thought I would expose you a little bit to some of the discussions that have been going on already as a starting point, because i'm really interested in getting folks thoughts about.

00:25:04.560 --> 00:25:17.520

Rim Cothren: privacy concerns considerations and concerns about any of that data or any of those potential uses let's go on to the next slide please we'll talk really in two main areas and.

00:25:18.000 --> 00:25:25.110

Rim Cothren: These are not hard boundaries, we can move between them and we've talked about a little bit on both of these already.

00:25:25.680 --> 00:25:36.750

Rim Cothren: Today that's fine we'll take today's discussion wherever you want to take today's discussion, however we'll start off talking a little bit about potential components of a strategy for digital identities.

00:25:37.620 --> 00:25:48.240

Rim Cothren: that'll also touch just very briefly, I would say, on what potential use cases might be so i'll at least give you some of my thoughts there but i'm really interested in your thoughts.

00:25:48.690 --> 00:25:55.620

Rim Cothren: And then under privacy priorities for digital identities, I want to start talking about data that might be associated with the digital identity.

00:25:56.760 --> 00:26:12.150

Rim Cothren: And some of the suggestions that have been made in some of the other focus groups and get your thoughts about those and any other data that should or should not be included and again this is primarily from the standpoint of privacy.

00:26:13.170 --> 00:26:29.100

Rim Cothren: And we all have to weigh that against safety and in properly identifying individuals and their health information but i'm really looking for you folks to help us as we go down that path scantron the next slide please.

00:26:30.150 --> 00:26:38.430

Rim Cothren: My first question is, how should digital identities, be used in California and Lucy I think that this starts to touch an incredibly high level.

00:26:38.880 --> 00:26:51.690

Rim Cothren: On what the different use cases might be and I guess, I would say that they kind of fall into three different areas, the first is, are we really talking about what traditionally is often referred to as patient matching sometimes.

00:26:52.080 --> 00:26:58.410

Rim Cothren: person resolution sometimes data linking but, in any case, that the sole purpose here.

00:26:58.920 --> 00:27:05.430

Rim Cothren: is to match health records or human service records for rim cothran at

one organization.

00:27:05.760 --> 00:27:18.990

Rim Cothren: With records at another organization, so that when I collectively look at that body of data, I know that they're all associated with rem kathryn and I know that they belong to the same person and they belong to rim.

00:27:20.160 --> 00:27:30.720

Rim Cothren: The second potential use case, that is not exclusive from that would be what's often referred to as master data management when you're talking to geeks like me.

00:27:31.110 --> 00:27:48.510

Rim Cothren: But is really associated with identifying a golden record for the consensus view of key demographic information about me so now you want to make sure that you establish what is rim catherine's real name which it's not Ram that is not my legal name.

00:27:49.710 --> 00:28:03.510

Rim Cothren: What is my current address the only address it should be used for me, what are valid phone numbers and, potentially, what is even a concern a consensus view of my race, ethnicity, etc.

00:28:04.530 --> 00:28:13.680

Rim Cothren: Are we really talking about just linking records or do we want to know the correct information about Ram is it important to know his current address as opposed to.

00:28:14.190 --> 00:28:19.020

Rim Cothren: All of the addresses that may have been recorded for Ramadan various institutions.

00:28:19.950 --> 00:28:36.030

Rim Cothren: And then, finally, we touched on this just a little bit is a third use case might be to actually identity proof and credential Ram Conference, so that I have login credentials and a very established proof identity to access my own records.

00:28:38.160 --> 00:28:40.410

Rim Cothren: And what I will what I will say.

00:28:41.430 --> 00:28:48.240

Rim Cothren: Just to put in front of you here, I would say that number one, at least, is what is called for in the legislation.

00:28:48.900 --> 00:29:02.970

Rim Cothren: And from a treatment purpose standpoint seems to be of most interest of the focus group members that i've talked to so far is that our purpose should be in linking data and not establishing a golden record.

00:29:04.740 --> 00:29:10.800

Rim Cothren: i'm going to shut up now because i'm more interested in your folks and what you have to say so Lee you had your hand up.

00:29:13.050 --> 00:29:15.570

tien@eff.org: yeah thanks, so I mean I certainly.

00:29:16.860 --> 00:29:24.570

tien@eff.org: You know I wanted to express the the opinion that the primary use case here is patient matching.

00:29:26.190 --> 00:29:46.860

tien@eff.org: I think and but then the, the question I am we we talked about this in I think I asked the same question in one of our earlier stakeholder groups but we're not talking about in patient natural we're not actually trying to.

00:29:48.930 --> 00:30:06.630

tien@eff.org: cope correct or make or like verify the information that is associated with the identity, that is, for instance I you know when I applied for the bar.

00:30:07.530 --> 00:30:23.580

tien@eff.org: To take the state bar I had to list, like all of my former previous residence addresses you know I think they were all correct, but you know i'm not sure I might have entered an incorrect, you know.

00:30:24.870 --> 00:30:29.370

tien@eff.org: house number somewhere, but we are not talking about.

00:30:30.510 --> 00:30:45.090

tien@eff.org: Any attempt to verify the accuracy of this information right written this situation and patient matching for number one, we are simply talking about the data, as is right.

00:30:46.080 --> 00:30:57.540

Rim Cothren: Well, so that that is the question that i'm asking you, I am number one on this list would say that, yes, that is correct number two would say no it's not that it is important.

00:30:58.110 --> 00:31:12.840

Rim Cothren: To understand the correct piece of information and so that's part of the question that i'm posing to folks here Lee I saw that you raised, your hand again if you'd like to follow up on that before we move on to someone else feel free.

00:31:13.590 --> 00:31:15.090

tien@eff.org: No, I was trying to lower it.

00:31:15.420 --> 00:31:16.350

Rim Cothren: Okay, good.

00:31:18.300 --> 00:31:18.870

Rim Cothren: Lucy.

00:31:22.170 --> 00:31:23.100

Lucy Johns: Is Thank you.

00:31:24.210 --> 00:31:42.510

Lucy Johns: Could you elaborate on master data management, which I don't think is mentioned in the legislation, where would a golden record reside that's my first question and, secondly, what does consensus view.

00:31:43.590 --> 00:31:47.130

Lucy Johns: mean who who's the consensus here.

00:31:47.640 --> 00:31:57.450

Rim Cothren: So I don't know the answer to either of your questions, but let's let's talk a little bit about what the intent of a golden record is.

00:31:59.010 --> 00:32:10.020

Rim Cothren: So I depending on context go by Robert cothran or rim cothran or Robert m Catherine Robert MAC coffin is my legal name.

00:32:10.560 --> 00:32:29.820

Rim Cothren: And part of a golden record would establish what my legal name is I currently reside in walnut creek but i've had addresses that in the past have been valid in several other towns golden record would focus on ensuring that my address is correct and ballad.

00:32:30.930 --> 00:32:49.230

Rim Cothren: A golden record would also establish that of the three phone numbers, I give out which one is my work which one is my home and which one is my mobile number and make that very clear and that there aren't any errors in those now, as you can imagine that the heavy left.

00:32:50.550 --> 00:33:00.900

Rim Cothren: Where it resides is an excellent question that would require piece of infrastructure that's and, as you note this isn't called out in the legislation so that would be a heavy lift for us to take on.

00:33:01.320 --> 00:33:10.260

Rim Cothren: And so that's why i'm asking whether it's necessary and you have to identify in some way what the right information is.

00:33:10.650 --> 00:33:23.130

Rim Cothren: And so you either validate that with the patient or you validated through some other means, and without specifying what that is that's what I meant by consensus view, that is, those are my words, you should read that much into it.

00:33:23.580 --> 00:33:31.110

Rim Cothren: But that there is some agreed to buy some method, what is the correct information associated with me.

00:33:32.850 --> 00:33:36.300

Lucy Johns: So that's why ends there are vendors out there now.

00:33:37.530 --> 00:33:55.440

Lucy Johns: doing what you just said, namely they get a record don't ask me how but then they verify the information in it don't ask me how but I guess what i'm getting at is that consensus view.

00:33:57.330 --> 00:34:14.430

Lucy Johns: From my point of view, not knowing very much about this, but knowing that there are vendors out there is already becoming a commercial idea I don't know whether it can be monetized or not I don't know what their business plans are but.

00:34:15.570 --> 00:34:37.380

Lucy Johns: The commerce in this idea is already out there, so if we are going to talk about that, then one element of our conversation might be whether we want to see a golden record, be a market product or, if not.

00:34:38.490 --> 00:34:49.500

Lucy Johns: something about state policy and how we would like to see that come about and how it would be handled and manage.

00:34:50.220 --> 00:34:51.390

Rim Cothren: Great thanks Lucy.

00:34:53.850 --> 00:34:55.170

Rim Cothren: Back I see your hand up.

00:34:55.830 --> 00:35:01.140

Becca Cramer-Mowder ACLU (she/her): yeah Thank you so much for starting here with a potential use cases.

00:35:02.280 --> 00:35:19.890

Becca Cramer-Mowder ACLU (she/her): Because I think, from my perspective, there's no way to analyze the privacy implications of any of the other pieces without knowing what they use is because, depending on the use it's going to have different privacy risks.

00:35:21.180 --> 00:35:35.550

Becca Cramer-Mowder ACLU (she/her): Likewise, I would say that, who has access to the information also is an essential component of looking at the privacy implications for potential ways of doing digital identities.

00:35:37.320 --> 00:35:38.010

Becca Cramer-Mowder ACLU (she/her): and

00:35:40.800 --> 00:35:42.480

Becca Cramer-Mowder ACLU (she/her): and part of that is knowing.

00:35:43.830 --> 00:36:00.990

Becca Cramer-Mowder ACLU (she/her): Who has access and what other laws and regulations guide them and restrict how they can use the information so, for example, seeing that this is going to be recognized this is going to be health records, but this is going to be something that's held on by the state.

00:36:03.480 --> 00:36:11.610

Becca Cramer-Mowder ACLU (she/her): Are cma and hipaa protection is going to be extended to this so that this will all the information in here will be treated as though.

00:36:12.150 --> 00:36:25.860

Becca Cramer-Mowder ACLU (she/her): It was housed by a covered entity for covered health purposes, or is it going to be subject to information practices act or to some other privacy regime is essential in order to analyze.

00:36:26.400 --> 00:36:44.670

Becca Cramer-Mowder ACLU (she/her): What components might make sense from a privacy perspective and which feel off the table for determine for consideration for digital identities and I will just say as kind of like a without knowing all of those contacts.

00:36:46.380 --> 00:36:52.620

Becca Cramer-Mowder ACLU (she/her): All of these raise my blood pressure, a little bit from a privacy perspective, but as we go down the list it is.

00:36:54.450 --> 00:37:12.060

Becca Cramer-Mowder ACLU (she/her): quite expensive actually raises my blood pressure, in terms of privacy concerns, but just wanting to flag that I appreciate were starting here and I hope that we get more information, because I don't know that we can do an informed privacy analysis without those other pieces of information.

00:37:12.450 --> 00:37:21.420

Rim Cothren: Okay well let's make sure that we at least get to some of those other pieces of information and I appreciate that back, I even knowing that as we go down this list.

00:37:21.810 --> 00:37:28.740

Rim Cothren: Your blood pressure exponentially increases, because that is a useful

piece of information, for me, so I appreciate you sharing that.

00:37:30.150 --> 00:37:41.820

Rim Cothren: And I will repeat something that I kind of started off with when I talked to health information exchanges and providers, which is the only two focus groups that i've actually had meetings with so far.

00:37:42.270 --> 00:37:59.550

Rim Cothren: They are focusing on number one so part of the question, so I think what is probably best for today's conversation is for us to focus on on number one as the use case unless you as a focus group think we need to go lower on this list.

00:37:59.820 --> 00:38:09.660

Becca Cramer-Mowder ACLU (she/her): And i'm i'm happy to start there, but I would go back to lucy's question about who is going to host this because that also is going to affect my blood pressure if it's.

00:38:09.690 --> 00:38:12.720

Becca Cramer-Mowder ACLU (she/her): Okay, to be housed by someone who.

00:38:14.070 --> 00:38:23.580

Becca Cramer-Mowder ACLU (she/her): is considered a covered entity for all of our work that's a different conversation than if it's going to be housed by an entity that's not.

00:38:24.270 --> 00:38:35.580

Becca Cramer-Mowder ACLU (she/her): Under the medical privacy laws and as under some other sort of privacy scheme but as providing this service that may or may not fall under cma, for example.

00:38:35.970 --> 00:38:47.370

Rim Cothren: Okay, I think that's on the next slide and if you don't think that we get to that topic, then please raise your hand or speak up again mark, I see you've been very patient with your hand up for a while, thank you mark.

00:38:50.460 --> 00:38:51.660

Rim Cothren: you're still muted, though.

00:38:51.930 --> 00:38:57.870

Mark Savage: That I am yeah Thank you so i'm i've been thinking about the different.

00:38:59.040 --> 00:39:01.290

Mark Savage: elements used for patient matching.

00:39:02.490 --> 00:39:11.790

Mark Savage: I pretty quickly go to what's the right value, and I think I slip over to the golden record questions because so many of the.

00:39:13.170 --> 00:39:23.670

Mark Savage: Different data elements might change I I sit on the interoperability standards work group we're talking about address right now address is not static it changes over time.

00:39:24.780 --> 00:39:39.540

Mark Savage: we're trying to prevent a patient matching system that might use address standardized address that doesn't consider whether it's an unstable address or a homeless person we don't want to build an algorithm that has.

00:39:40.560 --> 00:39:52.860

Mark Savage: Some bias in it so we're having conversations about whether you actually need to have access to address plus some other element that says, this is a

temporary address or person actually doesn't have an address.

00:39:54.270 --> 00:39:55.830

Mark Savage: As an as an example.

00:39:57.810 --> 00:39:59.970

Mark Savage: If gender were used as an element.

00:40:01.200 --> 00:40:13.620

Mark Savage: distinct from gender identity, if there were some clarity about what that meant it might be a stable identifier, but I think more likely it's not going to be a stable identifier.

00:40:14.730 --> 00:40:31.980

Mark Savage: And then we're looking at race and ethnicity, we find instances where while there's a preference for self reporting somebody may self report, it might be overwritten by clinical observation and, in turn, both might be overwritten by a batch file from from an employer.

00:40:33.840 --> 00:40:46.230

Mark Savage: All of that gets me to thinking that there's probably if we're going to use this for patient matching and to be sure that we are even just linking the right thing, there is some degree to which we're looking at whether the one of the.

00:40:47.610 --> 00:40:50.730

Mark Savage: values that fill the identifier are correct.

00:40:51.840 --> 00:40:53.370

Mark Savage: This and, to some degree.

00:40:55.410 --> 00:41:01.350

Mark Savage: And so i'm sort of thinking that there's there's some overlap that raises, for me, then, are we looking at actually identities.

00:41:02.400 --> 00:41:09.150

Mark Savage: With a timestamp on them some sort of provenance, so that we know what we're what we're identifying.

00:41:10.410 --> 00:41:13.470

Mark Savage: Grand so that's one set of initial.

00:41:14.670 --> 00:41:23.580

Mark Savage: thoughts, based on the three use cases that that i'm that i'm seeing here the other thought is we're talking about this as patient matching, but it does this really.

00:41:24.420 --> 00:41:34.290

Mark Savage: An example of a of a larger question about matching generally, so I come back to my question about care TEAM members, I think about how patient matching might work in a shared care planning.

00:41:35.130 --> 00:41:48.990

Mark Savage: Use case where you have you have the individual, but you have family care members, maybe you have a clinical provider, but also somebody at a Social Services Agency that's providing providing social services.

00:41:50.310 --> 00:42:04.410

Mark Savage: Are those are we trying to match identity that some way across the that set I don't know the answer, but I but i'm wondering if this is actually a patient matching of the subset of a larger consideration thanks.

00:42:05.400 --> 00:42:08.490

Rim Cothren: Thanks mark Lucy you have your hand up.

00:42:10.560 --> 00:42:27.270

Lucy Johns: yeah um This may sound a little arbitrary, but I personally am most interested in the patient matching and identity proofing use cases and the master data management i'm going to adopt.

00:42:28.260 --> 00:42:37.290

Lucy Johns: becca's metaphor here really raises my blood pressure and we don't have a lot of time we only have three meetings.

00:42:37.890 --> 00:42:59.250

Lucy Johns: And so i'm just going to say personally that the concept of a golden record which is not mentioned in the legislation to me raises so many privacy and, as I suggested before commercial issues that.

00:43:00.750 --> 00:43:15.000

Lucy Johns: Maybe we could say we don't want to see this, or if anybody wants to think about this, this is a matter for future state policy discussion so i'm just going to say that, in terms of.

00:43:15.870 --> 00:43:25.770

Lucy Johns: What I would hope to bring to these meetings patient matching and identity proofing for where I would like to see us focus, thank you.

00:43:26.160 --> 00:43:28.080

Rim Cothren: Thanks Lucy appreciate that.

00:43:29.430 --> 00:43:30.990

Rim Cothren: let's go on to the next slide.

00:43:32.520 --> 00:43:35.250

Rim Cothren: I will say already that I am.

00:43:38.100 --> 00:43:46.860

Rim Cothren: i'm tempted to talk about this one for a minute and talk about the next slide for a minute and then come back to this one, because i'm already feeling that.

00:43:47.850 --> 00:43:57.240

Rim Cothren: By taking these topics in order i'm holding back information that might be useful to you in talking about these so give me a minute let's talk about this slide.

00:43:57.720 --> 00:44:05.130

Rim Cothren: we'll talk about the next slide and then we'll come back to this one here, I want to start to get to rebecca's question about Where does this information reside.

00:44:05.910 --> 00:44:21.330

Rim Cothren: And there are at least three different ways, and there are many more, but three different categories, I might say and how digital identities might be used, especially for linking data or poor patient matching.

00:44:22.020 --> 00:44:34.050

Rim Cothren: One of them is for organizations that hold my data to use those digital identities to query each other that's typically how the see 10 works how national networks work.

00:44:34.950 --> 00:44:47.340

Rim Cothren: it's how tough CA envisions working and becca to your point, that means that the data ends up residing in covered entities that hold health information.

00:44:47.910 --> 00:45:06.030

Rim Cothren: Unless social services organizations are part of the data exchange framework yet to be determined, in which case they would also be parties and therefore outside of cmi or outside of hipaa unless the data sharing agreements bind them to those same requirements.

00:45:07.320 --> 00:45:20.460

Rim Cothren: i'll just say for the record that that is one of the discussions it's continuing to be ongoing with the data sharing agreement discussions, the one in the middle, is a good example of.

00:45:21.600 --> 00:45:30.930

Rim Cothren: A commercial service like what Lucy alluded to earlier, is that there are services that will help identify rim cothran.

00:45:31.320 --> 00:45:43.860

Rim Cothren: Based on public information about me, such as in credit reports or other things where my previous addresses, for instance, are known because they're part of public records someplace.

00:45:44.490 --> 00:45:51.570

Rim Cothren: My other phone numbers are known because they're part of records some place and therefore can be identified with me.

00:45:52.650 --> 00:46:01.140

Rim Cothren: And so there is a sharing in that case of some of the information between covered entities and probably some commercial service.

00:46:01.620 --> 00:46:12.810

Rim Cothren: And then the third would be that the state or some other organization working on behalf the state would stand up an index that would hold all of these identifiers.

00:46:13.230 --> 00:46:25.170

Rim Cothren: And everyone would have access to that means that the data might be held by the state, but access would still be granted to the data sharing agreement and signatories to it.

00:46:25.530 --> 00:46:42.240

Rim Cothren: And therefore, are covered entities with the potential again addition of social service organizations if they sign the data sharing agreement so that's perhaps where things would be held, especially if we're talking about.

00:46:43.830 --> 00:46:45.210

Rim Cothren: Use case number one.

00:46:46.470 --> 00:46:53.520

Rim Cothren: i'm going to go down to the next slide for just a minute, because it talks about the potential data.

00:46:53.880 --> 00:47:03.390

Rim Cothren: That might be in a record that might be housed in one of these places so cough we can go on to the next slide very quickly and then we'll come back to that last one.

00:47:03.810 --> 00:47:22.830

Rim Cothren: And this is to think about start to think about what data should be included in a digital identity Now I will note that at 133 requires signatories to exchange

elements in the US CDI the US, the US.

00:47:23.970 --> 00:47:41.040

Rim Cothren: clinical data for interoperability version one and it includes specification of a large amount of data, but if we look specifically at the demographics data it requires the exchange of name previous name, date of birth, as a.

00:47:42.420 --> 00:47:52.890

Rim Cothren: race and ethnicity sex assigned at birth preferred language Kurt address previous address phone number and email address.

00:47:53.760 --> 00:48:00.930

Rim Cothren: So organizations that sign on to the data sharing agreement will be required to exchange that information.

00:48:01.890 --> 00:48:15.180

Rim Cothren: Those items in general, do not uniquely identify an individual taken separately, my father and I have exactly the same name, we have exactly the same sex assigned at birth.

00:48:15.630 --> 00:48:24.000

Rim Cothren: But taken along with other information I can be distinguished from my father in some probabilistic way you can do matching there.

00:48:24.810 --> 00:48:47.760

Rim Cothren: What we've also started to discuss is that there's a potential for unique identifiers that might be added to this, but are not called for us CDI, for example, sharing my Meta cow identifier would uniquely identify me and pick an all on its own, makes it a better piece of data for matching.

00:48:49.440 --> 00:48:56.820

Rim Cothren: There are also medical record identifiers that are used by providers that uniquely identifying me within their systems.

00:48:57.360 --> 00:49:10.500

Rim Cothren: I also have a health insurance identifier, I have a driver's license if I were a veteran I would have an identifier associated with that, so there are unique identifiers without creating a new one.

00:49:10.800 --> 00:49:17.040

Rim Cothren: That might also be used, so I want to make sure we reserve some time to talk about the different.

00:49:18.390 --> 00:49:32.880

Rim Cothren: elements here again what i've been hearing from previous conversations is the type of data in the US CDI that might be useful in linking would be named previous name, date of birth.

00:49:34.410 --> 00:49:47.100

Rim Cothren: Gender current previous address phone number and email address, and specifically does not include race and ethnicity or preferred language is not found to be terribly useful and linking individuals.

00:49:47.940 --> 00:50:09.480

Rim Cothren: And a strong preference for including existing identifiers, especially if they are issued by the State, such as a driver's license number state ID card number or medical ID or by the Federal Government, such as a medicare ID or a veterans ID.

00:50:10.800 --> 00:50:31.530

Rim Cothren: And so, think on that because I really want to come back to that and see where people's blood pressure is there, but if we can first go back to the last slide and talk a little bit if you thinking about that body of data, where does it reside, and do you have concerns about where it resides.

00:50:34.740 --> 00:50:38.610

Rim Cothren: So I will finally shut up and i'm really interested in your thoughts.

00:50:43.830 --> 00:50:53.970

Rim Cothren: And if you pause for very long and really want to talk about the data will talk about the data I did this is your time again, I want to talk about whatever you think is important mark yes please.

00:50:55.230 --> 00:51:04.020

Mark Savage: Just for clarification you did mention us CDI be one of the body of information, but that's up to October or November.

00:51:05.070 --> 00:51:06.420

Rim Cothren: October of next year, I.

00:51:06.420 --> 00:51:07.380

Rim Cothren: Believe yes.

00:51:08.610 --> 00:51:09.600

Mark Savage: I think it's this year.

00:51:09.690 --> 00:51:10.410

Rim Cothren: Is it this year.

00:51:11.430 --> 00:51:11.700

Rim Cothren: Right.

00:51:12.780 --> 00:51:17.280

Mark Savage: And then the wind is electric electronic health information which is a much broader set.

00:51:18.270 --> 00:51:22.650

Mark Savage: of data that may be neither here nor there if we're just thinking really about.

00:51:23.940 --> 00:51:27.810

Mark Savage: Data elements that may be identifiers that I just wanted to check.

00:51:29.190 --> 00:51:43.500

Mark Savage: If that broader set of information is exchanged does that change your question to us, as it is to how the identifier data of being kept separately, so that we would just consider this the assignment as you've got it in front of us.

00:51:44.670 --> 00:52:04.080

Rim Cothren: So I would say that, at least, my question is around the idea that, yes, identities would be separate and at least potentially treated separately and, therefore, that an identity might not include some of the data elements that we would be exchanging.

00:52:06.210 --> 00:52:12.480

Rim Cothren: Again i'm interested in your thoughts on that, but that's that's at least the way that my head has been approaching this.

00:52:13.380 --> 00:52:21.240

Mark Savage: Well, I think, both from a broad consumer perspective and particular

consumer privacy perspective to focus on the small set is.

00:52:22.470 --> 00:52:24.240

Mark Savage: is much easier and more reassuring.

00:52:26.010 --> 00:52:36.960

Mark Savage: That, if the identity, the identity data is kept separate and it's just the the element that you identify and that's not walled off a whole range of issues that might otherwise be president.

00:52:39.060 --> 00:52:42.840

Rim Cothren: I think that it might be especially important also.

00:52:44.040 --> 00:52:52.830

Rim Cothren: So I want us to think in these terms is that, although the mandatory signatories called out in the legislation are all covered entities.

00:52:53.550 --> 00:53:10.410

Rim Cothren: health information exchanges may be signatories social service organizations may be signatories, and therefore aren't bound by that very broad definition of data and so also limiting digital identities might be useful in that case, if that makes sense to you mark.

00:53:11.490 --> 00:53:12.210

Mark Savage: make sense to me.

00:53:12.750 --> 00:53:14.670

Rim Cothren: Okay becca you have your hand up.

00:53:15.750 --> 00:53:26.190

Becca Cramer-Mowder ACLU (she/her): I would just start with saying that it also makes sense to me, in addition to wearing privacy, I also Bobby on LGBT Q I rights, and so, including.

00:53:26.610 --> 00:53:47.130

Becca Cramer-Mowder ACLU (she/her): Sex assigned at birth and previous name as part of the digital identifiers raises concerns about both detonating dead naming transcripts and also outing trans folks, and so the more of those could be walled off and the better.

00:53:48.150 --> 00:53:49.530

Becca Cramer-Mowder ACLU (she/her): Particularly if.

00:53:50.640 --> 00:53:58.590

Becca Cramer-Mowder ACLU (she/her): The information is going to people who are not providing health care services that require that knowledge.

00:54:00.480 --> 00:54:06.240

Becca Cramer-Mowder ACLU (she/her): The other piece that I would raise is on this current slide on the common matching service that.

00:54:06.870 --> 00:54:21.210

Becca Cramer-Mowder ACLU (she/her): Also, going back to my previous metaphor raises my blood pressure as well oftentimes these types of services are actually data brokers that rely on really egregious practices from a privacy standpoint, they are.

00:54:21.870 --> 00:54:28.590

Becca Cramer-Mowder ACLU (she/her): One of our big big boogey man and really problematic, I would also add that they are not.

00:54:29.880 --> 00:54:38.100

Becca Cramer-Mowder ACLU (she/her): it's a double edged sword, where they are both not super accurate, they often have a lot of issues in their data set so like looking at my.

00:54:38.610 --> 00:54:50.310

Becca Cramer-Mowder ACLU (she/her): Life, for example, they frequently mismatch me as being my father, who I have not I don't share a name with except for part of my last name and have not shared an address with.

00:54:50.880 --> 00:54:59.340

Becca Cramer-Mowder ACLU (she/her): In a decade and a half, and yet, because of data brokers and frequently getting things directed to me that are actually for him, but they also.

00:55:01.230 --> 00:55:09.810

Becca Cramer-Mowder ACLU (she/her): Are not great at necessarily identifying folks if it was, for example, going to be as as an identity proofing thing.

00:55:10.980 --> 00:55:24.330

Becca Cramer-Mowder ACLU (she/her): A lot of times the information contained by these data brokers or also contained on that first list on the next slide are things that other people might know about someone, including.

00:55:24.690 --> 00:55:44.910

Becca Cramer-Mowder ACLU (she/her): Current and former partners, sometimes former landlords will collect a lot of that type of information, and so they are not privacy standpoint secure or ideal and can be used in a lot of other contexts, and so a breach of them can be really problematic great.

00:55:45.180 --> 00:55:56.340

Rim Cothren: Thank you, I want to come back to your first comment for a minute, if I can because I want to understand how we should treat it, so I heard at least.

00:55:57.030 --> 00:56:11.640

Rim Cothren: That we should be concerned about prior names and sex at birth, are you thinking that they should come off the list in total, as opposed to individuals being allowed to not.

00:56:12.780 --> 00:56:23.160

Rim Cothren: disclose that information, so the past history is not part of the I want to make sure that I understand your recommendation and it kind of sounded like they should not be part of the set.

00:56:24.120 --> 00:56:36.690

Becca Cramer-Mowder ACLU (she/her): It again goes back to this question of who is going to have access and what the purpose is going to be as far so if, for example, it is going into a database that somehow is.

00:56:37.260 --> 00:56:47.130

Becca Cramer-Mowder ACLU (she/her): programmed to connect all of the people with a certain name and then look at some of these other features and match them but it's not necessarily.

00:56:47.580 --> 00:56:56.700

Becca Cramer-Mowder ACLU (she/her): A person who's going to know oh this person's current name and is different in a way that might tell me something.

00:56:57.150 --> 00:57:05.910

Becca Cramer-Mowder ACLU (she/her): About that person that's a little less troublesome if it's going to just be used on the back end to make sure that the records are all matching.

00:57:06.630 --> 00:57:12.660

Becca Cramer-Mowder ACLU (she/her): that's that's a little, and I could see that being less problematic if, for example, though.

00:57:13.140 --> 00:57:26.760

Becca Cramer-Mowder ACLU (she/her): When someone is accessing the database they're going to have access to this information that's when it starts to raise problems and then would need to be tied to certain use cases.

00:57:27.270 --> 00:57:37.740

Becca Cramer-Mowder ACLU (she/her): Where, for example, if it's a physician, who is providing direct medical care to someone and may need to have this information in order.

00:57:38.190 --> 00:57:51.030

Becca Cramer-Mowder ACLU (she/her): To fully understand someone's medical or to understand more of someone's medical history that's less concerning than if it is someone else accessing this database for some other purpose.

00:57:52.650 --> 00:58:08.610

Becca Cramer-Mowder ACLU (she/her): And so, going back to you can't it's impossible to break out the question of privacy and what is appropriate to be included in a digital identity, without first having nailed down what is the digital identity being used for and who has access.

00:58:10.110 --> 00:58:11.880

Rim Cothren: that's really that's helpful.

00:58:14.850 --> 00:58:19.350

Rim Cothren: I will say that, at least for myself i'm having trouble.

00:58:21.690 --> 00:58:30.330

Rim Cothren: Knowing how we address that, given that the data exchange framework might be used for many potential purposes.

00:58:32.040 --> 00:58:47.070

Rim Cothren: At least any that are allowed by hipaa for covered entities, but and i'm just i'm trying to figure out how we meet the requirements that you're i'm hearing requirements here that don't seem unreasonable.

00:58:47.850 --> 00:58:54.990

Rim Cothren: i'm just in my head trying to figure out how do we implement something like that, and so i'm really glad that you're bringing up those distinctions.

00:58:55.200 --> 00:59:18.090

Becca Cramer-Mowder ACLU (she/her): And my suggestion is to the extent that it's impossible at this time to know these answers the two paths forward I see are to wait on figuring out this piece and tell those other pieces are known or to assume the most expansive use of this information and then.

00:59:19.380 --> 00:59:30.180

Becca Cramer-Mowder ACLU (she/her): Look at what is the most privacy protective, even if it means that the data set might not be as useful for the purposes that it was

originally intended for.

00:59:31.620 --> 00:59:40.290

Rim Cothren: Great Thank you mark before we turn to your question I wanted to touch just very briefly Lucy dropped a couple of comments in the chat.

00:59:42.210 --> 00:59:57.510

Rim Cothren: I wanted to clarify that we're still having discussions about whether social service organizations would be business associates, or would have to fall under that category, I am not a lawyer, we do have at least one lawyer on the phone here.

00:59:58.560 --> 01:00:04.560

Rim Cothren: But that is not a given that they would be BA and, therefore, that hip a might not apply to them.

01:00:05.640 --> 01:00:16.770

Rim Cothren: So we shouldn't assume that social service organizations that are participating on the data exchange framework or necessarily acting as business associates.

01:00:17.640 --> 01:00:20.520

Lucy Johns: So it's really important for what becca just said.

01:00:20.640 --> 01:00:21.540

Rim Cothren: It are you.

01:00:21.600 --> 01:00:25.350

Lucy Johns: If we assume the most expensive case.

01:00:27.030 --> 01:00:38.850

Lucy Johns: Implicit is that is the most expensive set of users, some of whom may be very virtuous and really contribute to.

01:00:39.930 --> 01:00:46.170

Lucy Johns: Addressing social determinants and improving population health but are not covered by hipaa.

01:00:46.920 --> 01:00:54.360

Lucy Johns: And I don't know what they are covered by I think there are some agencies, like the aging agencies apparently.

01:00:54.870 --> 01:01:14.670

Lucy Johns: Have pretty strict privacy rules correct me if i'm wrong mark, but the food pantries don't they're not covered by anything so it's very important what you just said that we cannot assume that all users will be covered by hipaa right.

01:01:15.180 --> 01:01:21.720

Rim Cothren: And, and that is a discussion that's continuing in the data sharing agreement discussions this month and next month.

01:01:21.960 --> 01:01:44.310

Lucy Johns: So maybe you could convey to them that it's really hard to address consumer patient identity, without the privacy, the minimal privacy assurance that hipaa provides, and if that isn't going to be required, then that really changes our conversation.

01:01:44.760 --> 01:01:47.100

Rim Cothren: Great Thank you mark.

01:01:49.380 --> 01:01:53.430

Mark Savage: That last point, the Office for civil rights released.

01:01:55.290 --> 01:02:05.970

Mark Savage: think it was an notes of public rulemaking or request for information in January of 2021 covering the situation where either a provider or a payer would be.

01:02:06.450 --> 01:02:17.550

Mark Savage: Sending information to a Social Services Agency for in the case of the provider purposes of treatment and the case of the payer for purposes of operation health operations.

01:02:18.240 --> 01:02:24.450

Mark Savage: Both would be allowed under hipaa according to ups for civil rights without any further amendment of the the rules.

01:02:25.260 --> 01:02:38.010

Mark Savage: Both would not require a business associate agreement before making that permissive permitted disclosure by the provider or painter and then but acknowledging that they're not covered entities or business associates, so I think.

01:02:39.150 --> 01:02:47.880

Mark Savage: Just to say, that is, that is out there hhs is that it doesn't resolve the question but i'm just a perfect point.

01:02:49.620 --> 01:03:03.960

Mark Savage: For you, the discussion about the number two the common matching service reminds me of work that I did on the consumer work group under I went to high tech where we were trying to.

01:03:04.980 --> 01:03:21.330

Mark Savage: develop a notice of privacy policies for healthcare applications and the kinds of questions that we came up with we thought any APP should disclose in order for an individual to decide whether or not they wanted to use it so.

01:03:22.380 --> 01:03:27.000

Mark Savage: that some of the things that might not be in our minds today so i'm going to mention them.

01:03:29.070 --> 01:03:38.430

Mark Savage: How might the here common matching service use that data down the road so secondary use that kind of thing permitted.

01:03:39.600 --> 01:03:43.530

Mark Savage: Do they if there is some sort of a termination of an account.

01:03:44.640 --> 01:03:52.590

Mark Savage: Do they destroy the data or do they keep the data is the data stored in the United States is the data stored outside of the United States.

01:03:53.160 --> 01:04:02.430

Mark Savage: Is it encrypted at rest is it only encrypted in transit, those are kinds of questions when you when you're saying how should digital identity be used in California.

01:04:03.210 --> 01:04:14.070

Mark Savage: And I think it, it may become a question set of questions to go beyond the common matching service but, at least for that, and because I just flag those as as other considerations that we should be talking about.

01:04:15.990 --> 01:04:16.260

Rim Cothren: Thanks.

01:04:18.120 --> 01:04:18.540

Rim Cothren: Lee.

01:04:19.470 --> 01:04:28.680

tien@eff.org: yeah, I just wanted to really quick quickly amplify with some other folks have been saying, but you know, in addition to you know the other thing that the common matching service.

01:04:29.550 --> 01:04:52.020

tien@eff.org: reminds me of is what you know what we do when, in terms of flying you know the tsa has been like first, starting with caps to, and since then, with like Secure Flight there has been a tremendous amount of use of like commercial firms for vetting identity and none of those things.

01:04:53.280 --> 01:05:02.550

tien@eff.org: Have have been very secure with respect to the data that is that is sloshed back and forth, my understanding is that data is.

01:05:02.910 --> 01:05:15.090

tien@eff.org: It gets used by the by the recipient the folks who are vetting then get to use the data at least to augment and correct their own systems, if not to further.

01:05:15.600 --> 01:05:29.880

tien@eff.org: disseminated and those are all those are all things that those kinds of practices, I don't think should be part of the default assumption that we have here I mean it seems to me that.

01:05:30.420 --> 01:05:41.880

tien@eff.org: That whether you use a commercial service or do it yourself, you should be doing it for this purpose, and this purpose only and the idea that we would be.

01:05:42.420 --> 01:05:55.050

tien@eff.org: Using some other service and then not a lot not actually binding them to the kind of confidentiality and security that we expect throughout this system that would be.

01:05:56.010 --> 01:06:15.570

tien@eff.org: That would that would not that's not what patients and or people would expect so i'd be very, very concerned about that the other half the other half of my comment is them there is experience you know in these other contexts, with the use of with.

01:06:16.650 --> 01:06:27.000

tien@eff.org: Matching with trying to figure out who people are for purposes of travel, and so I wanted to make sure that we weren't.

01:06:27.840 --> 01:06:36.630

tien@eff.org: That we're not just talking about this in an empirical Void or vacuum right where there's actually research about what.

01:06:37.530 --> 01:06:56.610

tien@eff.org: Elements give you I didn't give allow you to drill down to Oh, this is this is Lee versus oh that's that's not useful for resolving it so do we have within this focus group framework any kind of sort of like.

01:06:57.750 --> 01:07:04.290

tien@eff.org: fact common fact basis about the utility of the different.

01:07:05.610 --> 01:07:09.210

tien@eff.org: elements in terms of being useful for.

01:07:10.770 --> 01:07:12.330

tien@eff.org: Patient matching um.

01:07:13.590 --> 01:07:23.490

tien@eff.org: yeah that that's basically my basic question is, do we have anything that we can rely on other than our intuitions thanks.

01:07:24.300 --> 01:07:24.810

tien@eff.org: sure.

01:07:24.930 --> 01:07:35.610

Rim Cothren: And so, Paul why don't we go on and move on to the next slide because I think that this is in in kind of response to lee's question, maybe this is a good place for us to talk.

01:07:36.570 --> 01:07:57.570

Rim Cothren: i'd say that a shortcoming of what we know is that most of it is based on matching for the purposes of linking health information and so anything that skews the population that we're talking about or the ultimate goals and.

01:07:59.490 --> 01:08:06.750

Rim Cothren: tolerance of false negatives or false positives is colored by that I will also would also say that.

01:08:07.650 --> 01:08:27.660

Rim Cothren: It is very difficult to conduct studies of matching accuracy, because it is usually very dependent upon the population characteristics of the population and, therefore, your test data and in a real situation you simply don't have much way of discovering.

01:08:29.400 --> 01:08:54.420

Rim Cothren: failures to match most, most notably false negatives, are often not discovered so Lee the The thing that i'd say is we do have experience, it is not rigorously upheld by studies, because those studies are seldom run or sell them for terribly reliable that sad when we talk about.

01:08:55.500 --> 01:09:16.230

Rim Cothren: The problem within our Community, we are told that the useful pieces of information demographic information for linking records our name, interestingly, not previous names so becca it doesn't give me much heartburn to take that one off the list a date of birth.

01:09:18.240 --> 01:09:21.030

Rim Cothren: A current or previous address.

01:09:22.410 --> 01:09:37.350

Rim Cothren: phone number, especially mobile phone number, because it has a tendency to be less volatile and email address, and so, in particular, sex assigned at birth is not particularly useful because there is.

01:09:38.820 --> 01:09:53.280

Rim Cothren: The way it is defined in US CDI it has one of two values it's male or female there's so there just isn't much differentiating power their preferred language race and ethnicity, have not been found to be terribly useful.

01:09:54.870 --> 01:09:56.580

Rim Cothren: determining factors.

01:09:57.900 --> 01:10:04.140

Rim Cothren: And, as I said, mobile phone number is one of the big determining factor so.

01:10:05.160 --> 01:10:18.540

Rim Cothren: that's what I would say about us CDI and then depending on whether you're talking to providers or health information exchanges both believed that there is value in unique elements.

01:10:20.010 --> 01:10:42.090

Rim Cothren: providers have a tendency to favor state or federally issued numbers for as the health information exchanges would also like to know, local identifiers, such as your identifier in your health systems ehr or the Member ID for your insurance provider.

01:10:43.650 --> 01:10:50.610

Rim Cothren: So everybody is really favoring the addition of unique elements that you see on the right hand side.

01:10:51.660 --> 01:11:01.080

Rim Cothren: In addition to the demographics, that are traditionally used so my question to you and back i'm going to use I like your.

01:11:01.710 --> 01:11:20.370

Rim Cothren: Your metaphor here what on this list elevate your blood pressure, what would you prefer not be included, given that we're probably talking primarily but not exclusively by covered entities having access to this information so back to you had your hand up first.

01:11:21.510 --> 01:11:21.930

Becca Cramer-Mowder ACLU (she/her): And I.

01:11:23.220 --> 01:11:36.780

Becca Cramer-Mowder ACLU (she/her): hate to sound like a broken record, but it again goes back to who has access and what the uses are for because these unique elements can still tell a lot about a person so.

01:11:36.810 --> 01:11:45.930

Becca Cramer-Mowder ACLU (she/her): Try social security number can tell whether you your citizenship, if you are undocumented that can be a particularly vulnerable.

01:11:47.460 --> 01:12:01.080

Becca Cramer-Mowder ACLU (she/her): piece of information to be asking for that can have other implications, whether what type of health insurance, you are on can indicate either your age or your income.

01:12:01.800 --> 01:12:22.740

Becca Cramer-Mowder ACLU (she/her): would also could be quite telling and quite sensitive and so just recognizing that while these unique elements might bring added value they are not risk free and so again any analysis it's it's gonna be hard and this abstract but.

01:12:24.870 --> 01:12:31.140

Becca Cramer-Mowder ACLU (she/her): But, to the extent that they are unique to a particular person, if there are not very strict.

01:12:34.530 --> 01:12:38.370

Becca Cramer-Mowder ACLU (she/her): laws or regulations about who has access and under what.

01:12:39.450 --> 01:12:49.620

Becca Cramer-Mowder ACLU (she/her): For what uses the information can be used and when it can be accessed as well as transparency and accountability pieces, to make sure that that's.

01:12:50.010 --> 01:13:01.980

Becca Cramer-Mowder ACLU (she/her): being followed and enforcement mechanisms to make sure that that's being followed, then, including these unique elements does in fact raise my blood pressure, regardless of which unique element, it is.

01:13:02.580 --> 01:13:05.340

Rim Cothren: So i'd like to follow up on that a little bit.

01:13:05.370 --> 01:13:15.480

Rim Cothren: yeah and it's so let's turn the question around what would need to happen to lower your blood pressure if we said that we are going to use.

01:13:17.040 --> 01:13:27.570

Rim Cothren: Medical a medical identifier, which could help in properly identifying a large number of patients on an unambiguous large number of people and ambiguously.

01:13:28.350 --> 01:13:36.450

Rim Cothren: What controls would need to be put around that for you to feel that that was safe, does that mean it's only communicated to covered entities.

01:13:36.780 --> 01:13:50.190

Rim Cothren: Does that mean it's covered its communicated to covered entities and other organizations that are bound under the data sharing agreement, a contract not law to behave with the same requirements.

01:13:51.660 --> 01:13:53.550

Rim Cothren: What What would you need to see.

01:13:54.180 --> 01:14:04.740

Becca Cramer-Mowder ACLU (she/her): And I would need to see the data sharing agreement before I could answer, whether that would be enough to kind of lower some of my blood pressure and I realized that that's still being hammered out in a different.

01:14:06.090 --> 01:14:23.670

Becca Cramer-Mowder ACLU (she/her): subcommittee and so it would depend, but the more that it would be kind of limited to covered entities and that there would be some sort of audit trail showing that it was only accessed by covered entities for.

01:14:25.050 --> 01:14:26.640

Becca Cramer-Mowder ACLU (she/her): purposes authorized.

01:14:27.960 --> 01:14:30.870

Becca Cramer-Mowder ACLU (she/her): and that there be some sort of repercussion if they are.

01:14:32.340 --> 01:14:43.560

Becca Cramer-Mowder ACLU (she/her): Not following those, whether it's a law of regulation, a contract that does lower my blood pressure, but again, it depends on you know, for example, what the contents of these.

01:14:43.950 --> 01:14:54.780

Becca Cramer-Mowder ACLU (she/her): Data sharing agreements are because there can be really wonderful data sharing agreements that are incredibly tight with really strict provisions and there are others that can say.

01:14:55.230 --> 01:15:06.510

Becca Cramer-Mowder ACLU (she/her): Have at it do whatever you want with the data, and so I hate to be a broken record, but in the abstract it's just really hard to say but I'm surely also has thoughts on that as well.

01:15:06.780 --> 01:15:25.020

Rim Cothren: So I went to before I turned to Lee I'd like to make sure that I understood what you said so, independent of the unique data element, you would feel more comfortable if it were only disclose to covered entities, therefore, bound under federal and California privacy law.

01:15:26.070 --> 01:15:33.480

Rim Cothren: That it might be okay under a very strictly and appropriately worded data sharing agreement.

01:15:34.350 --> 01:15:45.540

Rim Cothren: But might be and I'm not a lawyer, either, so I don't know what that means, but I'm going to look at people like Lee who's on that subcommittee and I can pass on to the subcommittee that that is a recommendation to this group, and I will.

01:15:48.420 --> 01:15:53.400

Rim Cothren: But under those circumstances unique unique identifiers.

01:15:55.350 --> 01:15:56.400

Rim Cothren: are probably okay.

01:15:58.320 --> 01:15:58.950

Becca Cramer-Mowder ACLU (she/her): I think so.

01:15:59.280 --> 01:16:09.390

Rim Cothren: Okay, and that it doesn't make any difference, do you do you consider a difference between a social security number, which you mentioned, and a medical number, which I mentioned.

01:16:11.130 --> 01:16:13.500

Becca Cramer-Mowder ACLU (she/her): I think there can be differences.

01:16:16.410 --> 01:16:32.730

Becca Cramer-Mowder ACLU (she/her): And someone else who knows more about kind of the layout of each of these when we need to say share, but I think it my recommendation would be that they're not be like one, this is what we're going to use for people who don't have one or the other type of member.

01:16:33.360 --> 01:16:36.180

Becca Cramer-Mowder ACLU (she/her): Yet, but that it would be a set of them and.

01:16:37.770 --> 01:16:39.510

Becca Cramer-Mowder ACLU (she/her): And that potentially even.

01:16:40.680 --> 01:16:49.140

Becca Cramer-Mowder ACLU (she/her): Even to covered entity that might make sense to block some of those these identifiers from being shown to them.

01:16:49.470 --> 01:16:59.850

Rim Cothren: Okay, and and I didn't mean to suggest that we would choose one and

that's what we use that that was not my intention and that's not the recommendation i'm hearing from others.

01:17:00.240 --> 01:17:18.210

Rim Cothren: I will say for the record that I believe the DHS Department of Health care services considers disclosure of medical with personally identifier file information to be pH I therefore so that would really raised the bar here so.

01:17:18.510 --> 01:17:23.760

Becca Cramer-Mowder ACLU (she/her): And I would just go back to them, it also depends on the use, so, for example, if this is going to be used.

01:17:23.970 --> 01:17:26.040

Becca Cramer-Mowder ACLU (she/her): As identity proofing.

01:17:29.160 --> 01:17:31.440

Becca Cramer-Mowder ACLU (she/her): I know my wife's social security number I.

01:17:31.440 --> 01:17:32.520

Becca Cramer-Mowder ACLU (she/her): Have her.

01:17:32.970 --> 01:17:48.840

Becca Cramer-Mowder ACLU (she/her): Kaiser card number, etc, and so be thinking about what who has access to these numbers, other than the person whose identity might be, we might be trying to prove if that is, unfortunately, going to be one of the uses of the data.

01:17:49.440 --> 01:17:52.770

Rim Cothren: Great Thank you Lee you've been very patient Thank you.

01:17:53.910 --> 01:17:57.300

tien@eff.org: yeah, I just wanted to do say that.

01:18:00.180 --> 01:18:12.480

tien@eff.org: agreeing with with all of becca's concerns, I still think there is a difference between certain of the between government issued numbers and privately issued numbers.

01:18:13.650 --> 01:18:33.450

tien@eff.org: I think that there is a I think there is a greater risk with either state or federally issued numbers in terms of people's privacy and the use of the use of an identify your as an organizing tool, then, if it is using.

01:18:35.160 --> 01:18:46.470

tien@eff.org: privately generated numbers, such as my Kaiser patient ID which I don't which may receive quite a bit of of.

01:18:46.920 --> 01:18:57.450

tien@eff.org: Maybe disseminated throughout you know the health care system that is not something that is, that is, that is part of sort of the general information.

01:18:58.050 --> 01:19:13.770

tien@eff.org: ecosystem so to that some extent that is purely empirical in contingent, I mean we know how government ID numbers like SS sounds and deals have become critical to you know.

01:19:14.730 --> 01:19:26.580

tien@eff.org: indexing everything and part of what i'm saying is like let's stay away from using those but the same time I I do worry just because.

01:19:27.120 --> 01:19:42.720

tien@eff.org: It always comes up that the soon as you move away from from any of those and we start to to talk about biometrics, which we have not talked about, yet I just want to put in that that's something that we're really meanie meanie meanie really.

01:19:44.280 --> 01:19:55.920

tien@eff.org: very, very hostile to in terms of of what it what kinds of safeguards are are needed in a system to make any of these unique elements.

01:19:56.910 --> 01:20:04.320

tien@eff.org: more palatable on less blood pressure, raising I mean, I think the fundamental thing is that we are do is to design.

01:20:04.800 --> 01:20:13.500

tien@eff.org: The system so that the incentives faced by the entities, who have access to this information are strongly towards.

01:20:14.310 --> 01:20:24.150

tien@eff.org: clients with every privacy and security and confidentiality value that we have if the incentive structure does is not set up that way.

01:20:24.600 --> 01:20:42.630

tien@eff.org: Then this inform them this information will be weaponized against the interests of patients and in order to have the incentives aligned at some point, because some of these entities are likely to remain for profit.

01:20:44.940 --> 01:21:07.350

tien@eff.org: or be allied with for profit entities, then there has to be a possibility as a significant realistic possibility of some kind of legal liability or other kind of penalty or punishment or fine for breaching these rules in the system has to maintain enough resources.

01:21:08.580 --> 01:21:26.400

tien@eff.org: and protocols, so that it can actually engage in some level of policing or self policing, because we do this without thinking about the Horsemen the secondary costs of maintaining privacy and security, then we will simply not have that's all I needed right.

01:21:26.460 --> 01:21:39.900

Rim Cothren: tanksley one real quick question for you and just so that everybody knows we're six minutes before the end of the meeting, and as a public meeting, we need to end this on time so i'm going to try to be brief and I see that.

01:21:40.290 --> 01:21:55.890

Rim Cothren: Lucy and becca you both have your hands up so i'm not going to try to steal your time, but I do have one quick question for you Lee, you said that you would stay away from state or federal issued identifiers, and I want to make sure that I understand what you meant there.

01:21:57.090 --> 01:22:13.440

Rim Cothren: As a medical and medicare ids or state and federal identifiers, do you mean to stay away from non health identifiers and therefore not driver's license or social security number or all state or federal issued issued identifiers.

01:22:13.830 --> 01:22:30.450

tien@eff.org: Well, you know I had I had not really thought about the the health issued identifier, so my own personal experience of hostility is cord for ones that I know are

currently very, very much used by law enforcement I don't actually know how.

01:22:30.780 --> 01:22:50.580

tien@eff.org: know enough about how medicare calor medicare ids are either used or disseminated throughout the ecosystem so that's that's I have my default concern with with government issuance, but it may not be as a cute or the magnitude of that cancer may not be as great.

01:22:52.290 --> 01:22:53.700

Rim Cothren: Thanks Lee Lucy.

01:22:57.810 --> 01:22:59.160

Rim Cothren: Lucy you're still on mute.

01:23:02.340 --> 01:23:21.060

Lucy Johns: Sorry, I wanted to plus one everything that becca said and i've been very interested in leaves comments, because my instinct would have been the opposite of what he said, but now cogitating about what he did say in terms of social security or driver's license.

01:23:22.710 --> 01:23:37.500

Lucy Johns: I did want to comment, maybe off the wall about race and ethnicity and just remind everybody that coven has revealed such stupefying disparities in terms of.

01:23:38.070 --> 01:23:51.210

Lucy Johns: outcome measures of coven and the reasons that people get coven, I just wanted to say that, coming out against race and ethnicity data and.

01:23:52.170 --> 01:24:01.560

Lucy Johns: On us CDI version, one I don't even know if that would have any impact anywhere, since all electronic health records have to have all this.

01:24:02.130 --> 01:24:15.930

Lucy Johns: I think we should revisit this rim if there's time we need if anything more race and ethnicity data with for health.

01:24:16.890 --> 01:24:38.670

Lucy Johns: Care purposes, then we now have, and we should recognize that the literature now is fulminating on this issue, so we want to be careful about saying we really don't think race and ethnicity is important, even if people who've been using it for patient matching say that Thank you.

01:24:39.000 --> 01:24:40.710

Rim Cothren: Thank you Lucy becca.

01:24:42.120 --> 01:24:52.350

Becca Cramer-Mowder ACLU (she/her): I just wanted to plus one to lee's strong hostility towards any use of biometrics, I would say that.

01:24:52.950 --> 01:25:12.900

Becca Cramer-Mowder ACLU (she/her): Based on my conversations with people at various privacy organizations, I think that the privacy Community generally would view use of biometrics either in a digital identity or in an identity proofing system as a non starter, and so just wanted to.

01:25:14.040 --> 01:25:17.100

Becca Cramer-Mowder ACLU (she/her): put that on record and plus one leave with lead for that.

01:25:17.910 --> 01:25:23.910

Rim Cothren: Great Thank you I see Lucy added genetic identifiers to that.

01:25:25.110 --> 01:25:26.820

Rim Cothren: And, in general I would.

01:25:28.440 --> 01:25:36.870

Rim Cothren: But I will bring before you is intended to not include my own bias, but always will because I can't not do that.

01:25:37.500 --> 01:25:49.950

Rim Cothren: And my personal bias is also against biometrics, so please make sure that you mentioned things, even if they seem to be assumed here, because your opinion is more important than mine.

01:25:50.490 --> 01:26:02.100

Rim Cothren: And so don't don't just assume because it's missing on these we're not considering it I think it's important to to bring those out, so I really appreciate that we're really about at the top of the hour.

01:26:03.510 --> 01:26:14.580

Rim Cothren: I really appreciate people's conversation today, this is really been useful let's go on to the next slide and we'll close this out here, real quickly as we move forward with.

01:26:16.950 --> 01:26:26.430

Rim Cothren: The strategy for digital identities, our goal here in March is to refine the strategy and, especially, consider privacy and security.

01:26:26.820 --> 01:26:32.160

Rim Cothren: The intention is to complete an initial draft in April, that will be presented to the.

01:26:32.640 --> 01:26:45.300

Rim Cothren: advisory group meeting at that time and be released for public comment, and then I will come back to you folks to look at that again so that will be the purpose of our third meeting in the series.

01:26:45.720 --> 01:26:56.040

Rim Cothren: And then, our our target is to finalize the digital identity strategy in June and July we own to publish it at the end of.

01:26:58.080 --> 01:26:59.370

Rim Cothren: slide please.

01:27:00.390 --> 01:27:16.650

Rim Cothren: Do upcoming meetings that should be on your schedule the first is two weeks from today, at the same time and then that the third one again is in April to discuss.

01:27:17.850 --> 01:27:24.750

Rim Cothren: The findings in the final strategy before it is finalized i'm sorry to draft strategy before it's finalized.

01:27:25.200 --> 01:27:31.320

Rim Cothren: I would encourage anybody that has specific topics, you want to discuss at our last meeting to let me know.

01:27:32.130 --> 01:27:47.400

Rim Cothren: in advance, or at the meeting again this is your meeting to tell me what



you're thinking so I really appreciate you bringing those topics with you, I want to say again, I really appreciate the discussion today and everybody's participation, this is really been useful, thank you very much.

01:27:48.150 --> 01:27:52.830

Mark Savage: Random quick quick question the one in April is in person in sacramento correct.

01:27:53.370 --> 01:28:06.210

Rim Cothren: Up likely is and we are working with agency now to understand how best to conduct our meetings in April and you should all see.

01:28:06.600 --> 01:28:18.840

Rim Cothren: Information, the next few days finalizing what we do about that meeting, we might combine it with the other focus groups rather than holding separate meetings but that'll will detail about one in the next few days.

01:28:19.740 --> 01:28:20.070

Mark Savage: Thank you.

01:28:21.240 --> 01:28:24.330

Lucy Johns: Thank you everyone thanks for him good meeting.

01:28:25.380 --> 01:28:26.970

Becca Cramer-Mowder ACLU (she/her): bye bye.

01:28:27.300 --> 01:28:28.200

tien@eff.org: Thanks bye.