California Health & Human Services Agency
Center for Data Insights and Innovation
Data Exchange Framework Technical Advisory Committee (TAC) Meeting
Transcript (12:00 PM – 1:00 PM PT, July 10, 2025)

The following text is a transcript of the July 10, 2025, meeting of the California Health and Human Services Agency and Center for Data Insights and Innovation Data Exchange Framework TAC. 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 webpage to ensure accuracy.

1

00:00:00.394 --> 00:00:06.854

Andrea - Manatt Events: Hello, and welcome. My name is Andrea, and I'll be in the background answering any zoom technical questions.

2

00:00:07.024 --> 00:00:11.893

Andrea - Manatt Events: If you experience difficulties during the session, please type your question into the Q. And a

3

00:00:12.454 --> 00:00:17.574

Andrea - Manatt Events: individuals in the public audience who have a comment may insert it in the Zoom. Q, and a

4

00:00:18.274 --> 00:00:21.594

Andrea - Manatt Events: public comment will also be taken. Towards the end of the meeting

5

00:00:21.894 --> 00:00:28.363

Andrea - Manatt Events: live closed captioning will be available. Please click on the closed captioning button to enable or disable.

6

00:00:28.724 --> 00:00:31.824

Andrea - Manatt Events: And with that I'd like to introduce rum. Catherine.

7

00:00:32.994 --> 00:00:39.346

Rim Cothren, CalHHS CDII: Great. Thank you and welcome everybody to this, our final meeting of the Consent management

8

00:00:40.314 --> 00:00:58.403

Rim Cothren, CalHHS CDII: Focus group for the tech. I have to say that these are my highlights of my week. Whenever we have these meetings. It is so encouraging to see so many people show up to these meetings. I really appreciate you all. Coming here and sharing your thoughts with us.

9

00:00:58.584 --> 00:01:00.914

Rim Cothren, CalHHS CDII: Let's go on to the next slide, please.

10

00:01:04.254 --> 00:01:13.653

Rim Cothren, CalHHS CDII: so we always share our vision for the exchange framework. I'm not going to read this slide at you, but just suffice it to say, the consent

11

00:01:13.994 --> 00:01:29.524

Rim Cothren, CalHHS CDII: to share information is fundamental to making sure that information gets to all of the places that an individual wants it to get to, to help improve whole person care. Let's move to the next slide, please.

12

00:01:30.104 --> 00:01:57.364

Rim Cothren, CalHHS CDII: Just very briefly our agenda for today. Well, we're in welcome and roll call now. We'll talk a little bit about what we heard in our last meeting. I'll just warn you. I'm hoping to keep that short because I want to leave lots of time for our design discussion today. We'll turn to public comment a little before the top of the hour scheduled for approximately 10 till, and then we'll close out the meeting with a few next steps.

13

00:01:58.174 --> 00:02:00.434

Rim Cothren, CalHHS CDII: Let's go on to the next slide, please.

14

00:02:01.494 --> 00:02:17.524

Rim Cothren, CalHHS CDII: This is just a reminder of everybody that's participating in this group. Thank you all again for coming here and sharing your thoughts with us

today. I don't think we have any new members today, so we'll just let people remind each other of who all is participating.

15

00:02:19.064 --> 00:02:21.574

Rim Cothren, CalHHS CDII: Let's move on to the next slide, please

16

00:02:22.464 --> 00:02:44.123

Rim Cothren, CalHHS CDII: a little bit about those that are attending as members of the public. We currently have 26 members of the public that are listening in on our meetings. I will say that this series has been well attended by the public as well, and thank you all members of the public, for listening in and contributing to our discussions here. We will be taking public comment

17

00:02:44.234 --> 00:03:03.023

Rim Cothren, CalHHS CDII: at the time listed or approximate time listed on the agenda. That's about 10 till the hour we've been getting public comment at these meetings. So I'm going to try to keep us as close to that time as I can today. Members of the public may also use Zoom's Q&A feature to make comments or ask questions.

18

00:03:03.034 --> 00:03:17.363

Rim Cothren, CalHHS CDII: Anything that you type into that can be seen by everyone, including other members of the public members of the panel. Here we've had good, engaging discussions ourselves, and I've always encouraged people not to use the chat.

19

00:03:17.394 --> 00:03:34.043

Rim Cothren, CalHHS CDII: And Q&A can be a distraction. But if you have time to take a look at Q. And A. Sometimes the comments there are useful, and you may want to bring some of those to the forefront for us to discuss the meeting, too, so feel free to monitor what's in Q&A. If you get a chance to.

20

00:03:34.524 --> 00:03:36.424

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

21

00:03:41.304 --> 00:04:07.274

Rim Cothren, CalHHS CDII: Just a reminder. Our objective. This meeting is to develop recommendations for coordinating collection, sharing and use of individuals consent. And today we're really going to try to burn down a little bit further into some of the recommendations we've been hearing with Fo from folks. To give a little bit more detail, we're going to be conducting today's meeting a little differently than we have in the past, and when we get to that point we'll talk a little bit more about how we'll do that.

22

00:04:07.484 --> 00:04:09.583

Rim Cothren, CalHHS CDII: Let's go on to the next slide, please.

23

00:04:09.794 --> 00:04:29.473

Rim Cothren, CalHHS CDII: This is what we heard last meeting, so take a quick look. There was a very vigorous discussion in our last meeting. I'm sure not. Everything is

here, but I am going to pause for a few minutes. If people think that we got anything wrong or we missed something important. Please feel free to bring it to the forefront.

24

00:04:35.174 --> 00:04:36.194

Rim Cothren, CalHHS CDII: Yes, Eric.

25

00:04:36.964 --> 00:04:38.644

Eric Jahn: The on the top.

26

00:04:39.634 --> 00:04:53.743

Eric Jahn: bullet the simple place to view, manage and update or vote consents. I think one of the things that's missing is that it was controllable by the individual. Otherwise this just wasn't that. It's simple, but that

27

00:04:53.924 --> 00:05:01.133

Eric Jahn: that the person offering the consent has control over of their record of consents.

28

00:05:01.134 --> 00:05:09.214

Rim Cothren, CalHHS CDII: Great. Thank you, and we'll be talking a little bit about that point a little bit more about that point later, Eric. So thanks for bringing it up. Now, Robbie.

29

00:05:09.994 --> 00:05:20.153

Robby Franceschini, Blue Shield of California: Yeah, thanks, RAM. I wasn't here last meeting, but wanted to ask it. It is the intention of that 1st bullet to have a single simple place or

30

00:05:20.294 --> 00:05:32.043

Robby Franceschini, Blue Shield of California: simple places to view. Like, I'm thinking, for example, in your health plans. You know, Member Portal in your provider portals. Is that the idea, or a single

31

00:05:32.184 --> 00:05:39.873

Robby Franceschini, Blue Shield of California: repository with a you know individual facing view to to see your consents.

32

00:05:39.874 --> 00:05:50.374

Rim Cothren, CalHHS CDII: So I would say that I did not hear people say a single place, and it doesn't say single here on purpose. But we're gonna pull on that thread a little bit more later on in the meeting. So keep that in mind.

33

00:05:50.374 --> 00:05:51.563

Robby Franceschini, Blue Shield of California: Okay. Thank you.

34

00:05:52.054 --> 00:05:52.594

Rim Cothren, CalHHS CDII: Kate.

35

00:05:52.814 --> 00:06:14.593

Kayte Fisher: Hi, good afternoon. Everyone I did note, and maybe this was sort of unintentional. But in the 4th bullet point, where it says, sensitive information is often embedded in narrative notes. I just want to. Also, maybe it's kind of a sub bullet. Point out that there is some existing State law on

36

00:06:14.724 --> 00:06:28.733

Kayte Fisher: defined sensitive services. And I know this, says sensitive information. But there's, you know, there's a defined term of sensitive services. That is already protected in in from sharing.

37

00:06:29.234 --> 00:06:44.224

Kayte Fisher: depending on the consent of the consumer or the who's the person whose information it is, and we we need make sure that the consent forms are tailored to comply with and and amplify current law.

38

00:06:45.004 --> 00:06:45.834

Rim Cothren, CalHHS CDII: Thank you.

39

00:06:46.514 --> 00:06:47.414

Rim Cothren, CalHHS CDII: David.

40

00:06:49.504 --> 00:06:53.453

David McCann: Thank you, and I'm going to go back to Eric's comment on the 1st bullet.

41

00:06:53.604 --> 00:06:57.964

David McCann: I think I would replace the word simple with easy to find.

42

00:06:58.304 --> 00:07:17.133

David McCann: and a does mean singular. So I would drop the A, I think we want to have individuals able to have easy to find places plural, because I absolutely don't think there will be one. But I think the important thing we need to think about if you look at what the European Union taught the consumer was

43

00:07:17.234 --> 00:07:19.543

David McCann: Justin. You have the right to be deleted.

CalHHS
California Health & Human Services Agency

CENTER FOR
DATA INSIGHTS
AND INNOVATION
CALIFORNIA HEALTH &
HUMAN SERVICES AGENCY

44

00:07:19.834 --> 00:07:30.114

David McCann: The person engaging with an entity should be able to easily find where to modify consent as long as it's easy to find, and I don't think there'll be one. Thank you.

45

00:07:30.494 --> 00:07:48.104

Rim Cothren, CalHHS CDII: And and thanks for pointing out that putting a on there certainly implied implied something simple was a word that we heard. But again we're going to pull on this more. So that is actually our last question of the day. So we'll make sure what I'm hearing here is reserve some serious time for that. Hans.

46

00:07:48.761 --> 00:08:01.604

Hans Buitendijk: Appreciate that particularly. Get to reserve some time for that, and I respectfully disagree with David on this one. So it will be good discussion that there, that when we talked and when we raised about patient centric.

47

00:08:01.744 --> 00:08:17.663

Hans Buitendijk: that the ability to have the opportunity that there can be one place that can interact with other places to make it simpler should not be precluded where we might disagree of whether everything would be a single place or not.

48

00:08:17.664 --> 00:08:34.054

Hans Buitendijk: but from a patient perspective. I think we need to keep in mind that there are opportunities, abilities, and technologies that could allow for a single place

from where the patient can maintain it, and then share that information with the appropriate data holders and vice versa. That's exactly what

49

00:08:34.054 --> 00:08:49.943

Hans Buitendijk: what the 807 fast project would enable, not that it requires that, but it would enable to have that kind of a federated approach that could yield for a patient a single place where they maintain it, we should not discount that from a patient perspective.

50

00:08:50.474 --> 00:08:52.841

Rim Cothren, CalHHS CDII: I'm going to enjoy today, I can just tell.

51

00:08:54.424 --> 00:08:56.674

Rim Cothren, CalHHS CDII: Thank you, Hans. Jim.

52

00:09:00.994 --> 00:09:25.385

James Shalaby: Can you hear me now? Yeah, you know, I don't think I made this very clear last time, so maybe I'll try to clarify a little bit more, but maybe it's a sub bullet around the 1st bullet. But with respect to individuals should have a simple place to view. I. I felt that it would be important to also capture that

53

00:09:25.814 --> 00:09:46.163

CalHHS
California Health & Human Services Agency

CDII
CENTER FOR
DATA INSIGHTS
AND INNOVATION
CALIFORNIA HEALTH &
HUMAN SERVICES AGENCY

James Shalaby: the dependencies, you know. On consent and revoking consent. So, for example, if a patient has access to both, reviewing what they've consented to and the ability to revoke, they should also be able to view what the implications are. If they revoke consent.

54

00:09:46.474 --> 00:10:00.644

James Shalaby: they may be revoking consent to data for an agency that manages prior authorization for a service. So so having some transparency. Meaningful transparency, I think, is important.

55

00:10:02.244 --> 00:10:02.794

James Shalaby: Thank you.

56

00:10:02.794 --> 00:10:05.844

Rim Cothren, CalHHS CDII: And Robbie. Last comment on this slide.

57

00:10:06.144 --> 00:10:13.634

Robby Franceschini, Blue Shield of California: Yeah, just on the 3rd bullet, is there an underlying assumption that those existing operational consent models

58

00:10:13.694 --> 00:10:37.964

Robby Franceschini, Blue Shield of California: are ones that are here today? Because, the the law mandates, that we collect consent in order to disclose or to share cause. I think that would be something that we would support is to start where the law mandates, that we, you know, collect consent in order to share and and start from there. But, curious if if that is wrapped up in that bullet already. Rem.

59

00:10:39.187 --> 00:10:59.654

Rim Cothren, CalHHS CDII: I think that there is some underlying assign assumptions here. The Dxf does not provide means to share data that does not by Applicable law require consent, there is no free pass there. So yes, there is always going to be the requirement to still apply Applicable law.

60

00:11:00.335 --> 00:11:19.924

Rim Cothren, CalHHS CDII: Thank you for getting us started on our conversation here. I do want to draw people's attention to 2 quick comments in the Q. And a. Lucy points out that there is a difference between consent for care and consent, for sharing information. We are talking about consent to share information today. So I want us to try to focus there

61

00:11:20.044 --> 00:11:44.263

Rim Cothren, CalHHS CDII: and that. Yes, we are also talking about revocation. That one of the options that an individual must have in revising their consent is to revoke all consent, and that is again revoking consent to share. So just want to make sure that people that we're all on the same page here with with the topic today.

62

00:11:44.944 --> 00:11:46.814

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

63

00:11:47.104 --> 00:12:04.443

Rim Cothren, CalHHS CDII: So what we heard if I were going to try to summarize things in a single quick statement that oversimplifies. But give me a break there. From our last meetings has been that Dxf must be able to collect multiple kinds of consent

64

00:12:04.844 --> 00:12:09.633

Rim Cothren, CalHHS CDII: collected in multiple places applied everywhere

65

00:12:09.834 --> 00:12:12.604

Rim Cothren, CalHHS CDII: and managed simply by the consumer.

66

00:12:13.994 --> 00:12:23.444

Rim Cothren, CalHHS CDII: And each of those 4 pieces we want to pull a thread on each one of those today. We're going to do that through starting off with a poll.

67

00:12:23.514 --> 00:12:49.953

Rim Cothren, CalHHS CDII: We're going to ask you to answer a question about each one of those we're going to ask each one of you to choose one of the options. Now there aren't. You may not see a perfect depiction of your option there. But please do the best you can. I want to remind people from Manat and Cdi. We're asking that you not participate in the poll. This is just for our panelists here on the Tac.

68

00:12:50.064 --> 00:13:13.334

Rim Cothren, CalHHS CDII: and then, if you don't all agree on the right approach for any of these we're going to discuss what we need to do about that. I'm gonna time bound all of those because I want to make sure that we have time for all 4 of these. So that means it will spend at most about 5 min talking about these. So if you do have things to discuss. We need to keep them. Keep them short.

69

00:13:13.444 --> 00:13:33.094

Rim Cothren, CalHHS CDII: So let's go on to the next slide and give you a picture of how we're going to end up doing this, so acknowledging that applicable law has different consent requirements for different types of data and or different disclosing entities. How should Dxf approach, collecting multiple types of consent. And there are 3 options here.

70

00:13:33.454 --> 00:13:36.833

Rim Cothren, CalHHS CDII: and you're soon going to see a poll pop up

71

00:13:37.699 --> 00:13:53.313

Rim Cothren, CalHHS CDII: to allow you to choose one of these 3, and we're asking everybody to do a choice real quick. You're going to see this by looking in the chat, and there will be a URL pop up in the chat. Please open that up. It's a Microsoft forms.

72

00:13:53.454 --> 00:13:56.154

Rim Cothren, CalHHS CDII: Choose one and submit the form.

73

00:14:24.974 --> 00:14:30.563

Rim Cothren, CalHHS CDII: So how are we doing on collecting responses? We're looking for about 15 or so.

74

00:14:30.774 --> 00:14:35.324

Emma - Manatt Events: Yeah, last couple just trickling in. We're at 17. I'll go ahead and share those results with you. Now.

75

00:14:35.324 --> 00:14:36.394

Rim Cothren, CalHHS CDII: Yeah, please.

76

00:14:41.034 --> 00:14:43.284

Rim Cothren, CalHHS CDII: So this is what people chose.

77

00:14:44.094 --> 00:14:48.913

Rim Cothren, CalHHS CDII: Luckily something else didn't get very many choices here, but we're very

78

00:14:49.384 --> 00:14:54.343

Rim Cothren, CalHHS CDII: split on. Everybody uses their own consent, form with their own language.

79

00:14:54.534 --> 00:15:09.733

Rim Cothren, CalHHS CDII: and everybody uses the same unified consent form. I'm going to start with the 1st one. Does somebody that chose everyone is free to use their own consent. Form. Want to explain why you chose that one, and why you think that's important.

80

00:15:12.354 --> 00:15:13.474

Rim Cothren, CalHHS CDII: Yes, Eric.

81

00:15:16.514 --> 00:15:41.484

Eric Nielson: Sure. I mean, I'm just thinking of operationalizing this in terms of you know, county interactions with folks. I mean, we're going to partner with individuals that are, you know, in data exchange and want to be able to manage, consent to share electronic data. But we're also managing, you know, social workers, eligibility workers, you know, folks in counties that are serving individuals managing services with other folks that may not be on a digital platform. And so.

82

00:15:41.484 --> 00:15:54.544

Eric Nielson: you know, looking at consent, we need to have the flexibility of providing some way to streamline, you know, gathering consent for for workers to to reduce the administrative burden. But but recognize we're never going to have

83

00:15:54.544 --> 00:16:12.814

Eric Nielson: ever right, you know, for the foreseeable future, a model that that encompasses all of the use cases, and so really need to think about a way to do this flexibly to leverage automation where we can to facilitate the sharing of information where it's available electronically. But this is going to coexist with

84

00:16:12.813 --> 00:16:25.074

Eric Nielson: with, you know, ongoing kind of analog paper processes. And so just thinking about we're gonna we are going to have, regardless of of, you know, perfect work here multiple consents.

85

00:16:25.194 --> 00:16:37.454

Eric Nielson: And it's going to exist with paper consent. So I think we need to be realistic about thinking about. How can we make that administratively less burdensome to facilitate it for both our consumers and the folks that are administering it? Thanks.

86

00:16:37.454 --> 00:16:39.683

Rim Cothren, CalHHS CDII: Sure. Thank you, Eric. David.

87

00:16:41.555 --> 00:16:48.944

David McCann: I I would aspire that in 3 years we might evolve to a common digital form.

88

00:16:49.154 --> 00:17:03.584

David McCann: But I think we need to acknowledge we're going to start with innovation. And so I would allow innovation to be done by the county in a county for the program with a set of orgs and let innovation flourish. But I think we create a forum

89

00:17:03.804 --> 00:17:14.683

David McCann: over time to try and standardize. So I vote for innovation at the front. But I aspire for your number 3. I just wouldn't vote for 3. I think we journey to 3.

90

00:17:14.684 --> 00:17:16.383

Rim Cothren, CalHHS CDII: Thank you. David Jessica.

91

00:17:19.874 --> 00:17:31.264

Jessica Rougeux: Thank you. I I think one of the things I'd also like to point out, and I think in a similar vein to what Eric is sharing is that there are different contexts in which we engage with consumers, and

92

00:17:32.014 --> 00:17:46.954

Jessica Rougeux: in particular child welfare. We have a very sensitive relationship with families where they may have just had a child removed or an out of home care. It's complex. It's a very difficult time gaining shared agreement

93

00:17:47.064 --> 00:18:09.374

Jessica Rougeux: for giving that consent is a very sensitive engagement. Right? You're not just talking about offering them services. Sometimes the court is intervened where they do not want engagement right? And so getting consent in that space, it's very specific to child welfare and those services. And I think that in particular there may be some context in which

94

00:18:09.394 --> 00:18:23.544

Jessica Rougeux: a generic or or universal form does not necessarily meet the engagement needs of the social worker and the family of the clinician and the family of the eligibility, worker and family. And so in those specific contexts.

95

00:18:23.774 --> 00:18:34.304

Jessica Rougeux: having the ability to use that form that maps back to like a universal set of rules and consents that we can track to ship to support our goals administratively.

96

00:18:34.344 --> 00:18:57.023

Jessica Rougeux: but really still allows it to feel like a tailored experience for the family, I think, removes barriers to families, feeling engaged and like, they understand the context in which they are giving consent. I do agree that they need to have control over provoking consent or changing consent at any time, but it needs to feel specific and tailored to to that engagement. In my opinion.

CalHHS

CENTER FOR
DATA INSIGHTS
AND INNOVATION
CALIFORNIA HEALTH &
HUMAN SERVICES AGENCY

97

00:18:57.294 --> 00:19:03.164

Rim Cothren, CalHHS CDII: Thank you, Jessica. We're over halfway through our time on this topic. So, Robbie, I'm gonna ask you to be quick.

98

00:19:04.464 --> 00:19:27.754

Robby Franceschini, Blue Shield of California: Yeah, just really quickly, I think, just to to support what Jessica noted that we heard much the same thing internally from our folks working with social services agencies, and would just add, you know, especially for payers, right like for Medicaid versus medicare advantage, right? The types of social services. Agencies we may working be working with are different. The needs for consent are much different.

99

00:19:27.754 --> 00:19:51.243

Robby Franceschini, Blue Shield of California: and I think to even just thinking about the laws that apply in different to different lines of business, to different providers across the State. So I'll just say I. And I see this in the Q, and a. Too. That is there a way to think about not just computable standards, but also maybe templates that organizations could leverage that we could start discussing before we get to maybe an ultimate goal of universal forms.

100

00:19:51.454 --> 00:20:03.133

Rim Cothren, CalHHS CDII: I saw some heads nodding on the idea of templates. So thank you for that. How about somebody that said no, there needs to be a universal consent that everybody uses. Why did you choose that? Why do you think that's important?

101

00:20:07.594 --> 00:20:08.514

Rim Cothren, CalHHS CDII: Yes, Kate.

102

00:20:08.764 --> 00:20:21.564

Kayte Fisher: I can talk, I mean, I sort of took seriously. And I now I don't see it anymore. But where? When? It said that there could be several primary, or I don't want to use the word master, but several primary forms

103

00:20:23.774 --> 00:20:31.974

Kayte Fisher: such that. So I wasn't thinking there would be just one. I definitely don't think that's I don't even think that's good policy. I think there should be

104

00:20:32.614 --> 00:20:52.524

Kayte Fisher: a wide range and a wide variety specific. I was just typing out a response to what Jessica was saying. I was sort of envisioning, like a primary form for all, for for families and children who are in the system, with some variations among the counties, but that it should look

105

00:20:52.524 --> 00:21:06.234

Kayte Fisher: basically the same from county to county. Not that not that that should be the exact same form as what I'm looking at in a doctor's office, or you know that it should be that, and we it could be up to, you know.

106

00:21:06.484 --> 00:21:26.324

Kayte Fisher: 1015, possibly more, depending on, you know, people who are going out and engaging directly in unhoused populations, or people who are getting consent pre-surgery, or you know all those different. There's a huge array, and I do agree that you're never going to get to to sort of

107

00:21:26.464 --> 00:21:36.393

Kayte Fisher: uniformity, and I do agree that this is a process. So I'm not opposed to allowing entities to kind of do their own thing with a with a

108

00:21:36.584 --> 00:21:45.894

Kayte Fisher: set of values for the 1st couple of years. But putting a cap on that, and we've seen at the Department over the years. Just our specific situation with

109

00:21:46.054 --> 00:22:07.203

Kayte Fisher: like, well, prior authorizations is a great example where you know, the big companies just came out and sort of said, we're going to voluntarily create a standardized PA document, because this is driving everyone insane providers, insurers facilities. It is truly blocking up the system. So I think

110

00:22:07.524 --> 00:22:13.323

Kayte Fisher: the a variety but standardized. If that makes any sense.

111

00:22:13.324 --> 00:22:16.623

Rim Cothren, CalHHS CDII: Thank you. Thank you, Kate. Jim, can you bring us home?

112

00:22:17.414 --> 00:22:40.694

James Shalaby: Sure. Sure. So the way I view it from a standards perspective is that I I see option one and option 3 possibly. Being able to work together. In other words, we start with option one where you're allowing, you know, a lot of flexibility. You can identify over time common themes

113

00:22:40.694 --> 00:22:51.394

James Shalaby: which can actually lead to convergence, to potentially universal consent forms and standards. But but I don't necessarily see them, as

114

00:22:51.644 --> 00:23:21.094

James Shalaby: you know, as as very, you know, as completely different unrelated options. I I feel that option. One can lead over time to option. 3 once we identify common consent, you know, templates and platforms patterns that can be applied hopefully in the future. It's basically a learning system. And I'll and you know standards have grown that way over time for for decades. So it's just my my perspective on that.

115

CalHHS
California Health & Human Services Agency

CENTER FOR
DATA INSIGHTS
AND INNOVATION
CALIFORNIA HEALTH &
HUMAN SERVICES AGENCY

00:23:21.254 --> 00:23:22.394

Rim Cothren, CalHHS CDII: Thank you, Jim

116

00:23:22.524 --> 00:23:34.103

Rim Cothren, CalHHS CDII: Irene. Our timer has gone off, and I'm gonna move us on. I'm sorry about that. If you and Eric want to drop something in the chat. If we have time today we'll come back. Let's go on to our next question, please.

117

00:23:36.454 --> 00:24:00.463

Rim Cothren, CalHHS CDII: So the next thing we said is a consent should be collected in multiple places by multiple entities. I wanna see. Do you agree with that statement? Do you believe the consent may be collected anywhere. Care is being delivered, or must it be collected in one place by one authority, perhaps. Through, you know, a technical system or something else.

118

00:24:00.694 --> 00:24:17.774

Rim Cothren, CalHHS CDII: Or is there another option that it can be collected anywhere as long as it follows approved processes? And so there's a certification or something like that process. Here, let's bring up the poll. There you see the link again in the chat. Please.

119

00:24:37.414 --> 00:24:38.834

Kayte Fisher: Can I ask a quick question.

120

00:24:38.834 --> 00:24:39.374

Rim Cothren, CalHHS CDII: Sure.

121

00:24:39.714 --> 00:24:53.304

Kayte Fisher: So this is just kind of a maybe it's semantics, but it feels a little important, you know, for these examples consent may be collected consent may be collected. So what we're really talking about is the consent form, because

122

00:24:53.484 --> 00:25:02.303

Kayte Fisher: it might be consent right so and so every time I see it says consent may be collected. What I'm what I'm the information I'm getting is

123

00:25:02.574 --> 00:25:10.724

Kayte Fisher: we're only accepting consent, not if you're not consenting, you go away like we won't give you your services. That.

124

00:25:10.724 --> 00:25:18.923

Rim Cothren, CalHHS CDII: Now, now we're talking about consent to share information, not consent for services here. So this is this is a dxf con conversation.

125

00:25:18.924 --> 00:25:25.453

Kayte Fisher: But it's a but it's a question of. If you don't consent for me to share your information. I will not give you services.

126

00:25:25.454 --> 00:25:29.303

Rim Cothren, CalHHS CDII: That is, that is not an assumption you should be making.

127

00:25:29.304 --> 00:25:39.134

Kayte Fisher: Okay. But but that is what I get from this. So what I'm suggesting is, maybe we should say the consent form may be collected, it may have a non consent on it.

128

00:25:39.134 --> 00:25:39.734

Rim Cothren, CalHHS CDII: Okay.

129

00:25:42.944 --> 00:25:48.327

Rim Cothren, CalHHS CDII: do we have answers on this poll that we can bring up? Yeah, thank you. So

130

00:25:49.364 --> 00:26:13.444

Rim Cothren, CalHHS CDII: one place, certainly not the winner here a slight majority for maybe collected anywhere as long as it follows approved processes, maybe twice as many on that one. Not quite twice as many on that one is the 1st choice. So tell me about collecting anywhere as long as it follows processes. Do you have a thought about what those processes should be, or why did you choose that?

131

00:26:16.404 --> 00:26:17.614

Rim Cothren, CalHHS CDII: Yes, Selena.

132

00:26:17.984 --> 00:26:22.764

Alana Kalinowski, she/they, CIE/211 SD: Yeah. And this also is potentially part of my interpretation. So who knows? But I think part of it is.

133

00:26:22.764 --> 00:26:23.894

Rim Cothren, CalHHS CDII: What I want to hear.

134

00:26:23.894 --> 00:26:48.343

Alana Kalinowski, she/they, CIE/211 SD: You know, you know, like even like what constitutes informed consent? Is it a part of a conversation where people feel equipped and are able to ask questions and those kinds of things. So I think when I'm thinking process, it's also whoever is able to collect that consent form feels equipped to also educate someone and answer questions, and it be a truly informed consent process. And and

135

00:26:48.774 --> 00:26:56.013

Alana Kalinowski, she/they, CIE/211 SD: you know that that is not just like here, sign and go along through, because I think that is part of that. Like ethical responsibility.

136

00:26:56.274 --> 00:26:57.513

Rim Cothren, CalHHS CDII: Thank you. Thank you.

137

00:26:58.024 --> 00:27:05.323

Rim Cothren, CalHHS CDII: David. I see your hand up next. But I'm gonna let Eric talk. Since Eric has, as Derek has not yet talked today. So Derek, to you.

138

00:27:06.224 --> 00:27:26.623

Derek Plansky: Thank you, hey? So with regards to consent, I think there needs to be some level of standardization of what we're consenting around. So that's why there needs to be some structure of doing this, because, having someone write something on a piece of paper and sign it, saying, I share my data for X,

139

00:27:26.624 --> 00:27:39.394

Derek Plansky: and that's not even anything that we've agreed upon. As the you know, the widgets or switches that we have in the system is is effectively useless. It's capturing the patient's intent, but

140

00:27:39.684 --> 00:27:55.063

Derek Plansky: it might be moot. So there there needs to be some agreed upon structure, or else this won't work. I agree with flexibility up to a point, but I think we need to figure out some collective guidance that we can offer the process.

141

00:27:55.524 --> 00:27:58.584

Rim Cothren, CalHHS CDII: Great. Thank you, Derek. Well, we still have time, David.

142

00:27:59.644 --> 00:28:07.264

David McCann: So I'd love to illustrate a use case to reinforce the discussion. 1st of all on the notion of form.

143

00:28:07.394 --> 00:28:12.674

David McCann: Let's discuss a real world. In 2. On one we encounter people on the phone.

144

00:28:12.944 --> 00:28:18.633

David McCann: We read them a legally approved script. We record the conversation.

145

00:28:19.064 --> 00:28:26.673

David McCann: The conversation becomes a digital object. We've actually got room consenting to what was read.

146

00:28:26.964 --> 00:28:32.874

David McCann: It's time stamped. It's secure, it's encrypted. It's not a form notes.

147

00:28:33.264 --> 00:28:34.784

David McCann: There is no signature.

148

00:28:35.134 --> 00:28:54.554

David McCann: We might choose to. Then add SMS validation, text confirmation. It's a second factor. So I think we need to get off the notion of paper and forms and go digital and assume that we're living in a world of digital voice and voice can also grant consent. So there's a use case that is not assigned form.

149

00:28:54.754 --> 00:29:03.963

Rim Cothren, CalHHS CDII: Thank you, David. I think it's important for us to to not get stuck in the past and think about other options here, as we have these discussions. How about somebody that chose

150

00:29:04.224 --> 00:29:06.134

Rim Cothren, CalHHS CDII: any place? Care is delivered?

151

00:29:07.124 --> 00:29:08.903

Rim Cothren, CalHHS CDII: Why did you make that choice?

152

00:29:17.554 --> 00:29:18.714

Rim Cothren, CalHHS CDII: Yes, Linda.

153

00:29:19.694 --> 00:29:34.804

Linda Deaktor: It was really a choice that I made just based on the fact that some of these members do not go to all these different locations. So if they are in a location where this is available, then we might as well use that opportunity to ask them if they'd like to sign the form.

154

00:29:35.034 --> 00:29:35.614

Rim Cothren, CalHHS CDII: Right?

155

00:29:35.724 --> 00:29:55.613

Rim Cothren, CalHHS CDII: Thank you. I think we do need to. You know, it's it's interesting. This is a technical group. We have a tendency to to think about technology. And we continue to talk about technology. But I'm also looking for people to think about how we operationalize this. And I think, Linda, that's part of what you're speaking to here. So I think that's helpful.

156

00:29:56.894 --> 00:30:04.153

Rim Cothren, CalHHS CDII: There have been a couple of comments here in the chat. Does anybody want to bring them to the forefront. We got about another minute on this question.

157

00:30:09.694 --> 00:30:10.854

Rim Cothren, CalHHS CDII: Yes, Eric.

158

00:30:11.294 --> 00:30:17.323

Eric Jahn: Well, in addition to, you know, standardizing the consent types, the grants that can be. You know that

159

00:30:17.444 --> 00:30:30.804

Eric Jahn: the grants of consent that a that a client could make. There's also just standardization we can embark upon to a make, a specification that can be used across the many retrieval points of

160

00:30:30.894 --> 00:30:50.702

Eric Jahn: of consent, if it's, you know, since it won't be central centralized. As this group is kind of leaning towards. So we can talk about. You know what is the common metadata not enforced, or anything. But you know what common metadata is involved,

what common archetypal workflows are involved. You know, revocation, you know, acquiring, requesting,

161

00:30:51.634 --> 00:31:08.484

Eric Jahn: retrieving, you know, the consent document. So I think a lot of that could go a long way to supporting, you know, app developers in in kind of a decentralized way, where there's many points of collection, and then, you know, it'll support it'll support standardization over time as well.

162

00:31:08.974 --> 00:31:09.983

Rim Cothren, CalHHS CDII: Thank you, Eric.

163

00:31:10.414 --> 00:31:12.524

Rim Cothren, CalHHS CDII: Why don't we bring up the next question?

164

00:31:16.584 --> 00:31:18.903

Rim Cothren, CalHHS CDII: So consent needs to be

165

00:31:19.673 --> 00:31:42.744

Rim Cothren, CalHHS CDII: applied everywhere. So how? How is it shared or otherwise communicated, so that it can be applied everywhere, and we came up with 4 choices.

Here there may be choices that you don't see. Please choose what is closest to what you would suggest. But I'll point out of a few things. Is that

166

00:31:43.769 --> 00:31:49.394

Rim Cothren, CalHHS CDII: the ask me, project is focusing on a single repository for at least that consent.

167

00:31:49.744 --> 00:31:58.584

Rim Cothren, CalHHS CDII: But Dxf. Might have multiple repositories for different types. You talked about different templates, etc, perhaps go that path.

168

00:31:59.034 --> 00:32:08.253

Rim Cothren, CalHHS CDII: passing consent to the requesting party is something the nationwide networks have played with, so that with a request a consent is set sent along

169

00:32:08.976 --> 00:32:29.223

Rim Cothren, CalHHS CDII: and the way most nationwide networks work today is, I must have authorization to collect this information, to request this information, and it is implied in the request. So those are kind of the the things that we saw there today. There's a link in the chat. Please vote for your favorite choice.

170

00:32:53.114 --> 00:32:55.973

Emma - Manatt Events: Give it another few seconds. Here rem.

171

00:33:14.134 --> 00:33:24.236

Rim Cothren, CalHHS CDII: If you've already voted, want to take a look, there's been quite a bit of chat, and the QA. From our public members to take a look at the answered questions I've been

172

00:33:24.754 --> 00:33:27.444

Rim Cothren, CalHHS CDII: trying to read through them and acknowledge them there.

173

00:33:29.214 --> 00:33:33.333

Rim Cothren, CalHHS CDII: so all consents are stored in a single repository, was

174

00:33:34.994 --> 00:33:41.800

Rim Cothren, CalHHS CDII: the most chosen but we're a little bit all over the board here, so

175

00:33:42.794 --> 00:33:50.243

Rim Cothren, CalHHS CDII: I'd like to touch on each one of these. So somebody that voted for single repository. Why do you think that is necessary?

176

00:33:56.754 --> 00:33:57.904

Rim Cothren, CalHHS CDII: Yes, Elena.

177

00:33:58.274 --> 00:34:02.934

Alana Kalinowski, she/they, CIE/211 SD: I'm this is my my aunt that I'm least married to, just as a note.

178

00:34:02.934 --> 00:34:03.284

Rim Cothren, CalHHS CDII: Okay.

179

00:34:04.078 --> 00:34:07.653

Alana Kalinowski, she/they, CIE/211 SD: But I think like from a I think Kelly.

180

00:34:08.314 --> 00:34:13.764

Alana Kalinowski, she/they, CIE/211 SD: who's able to see who's accessing services, who's enrolled like the lack of

181

00:34:14.414 --> 00:34:27.803

Alana Kalinowski, she/they, CIE/211 SD: visibility for coordinating parties who are trying to get people connected to these valuable services to me illustrates why line of sight is necessary of what someone has already consented to share or access.

182

00:34:28.034 --> 00:34:47.634

Alana Kalinowski, she/they, CIE/211 SD: particularly because, like, if there might be consent on file for something, and it's a meaningful step for care, coordination, and if you're only say, between a plan and Mcp and a contracted service provider or something like that. To me it's the exact same problems we're facing with Kaleem from

183

00:34:47.694 --> 00:35:08.773

Alana Kalinowski, she/they, CIE/211 SD: anyone else. That person is interacting with within the community and trying to get support and help from has no line of sight. And so to me, it's a. It's a similar type of unnecessary barrier, especially if that consent is, is providing specific types of access and sharing with all the other kind of things we've talked about.

184

00:35:09.044 --> 00:35:09.644

Debbie Spray - Alameda Alliance for Health: Great.

185

00:35:09.644 --> 00:35:10.424

Rim Cothren, CalHHS CDII: Thank you.

186

00:35:11.004 --> 00:35:36.093

Rim Cothren, CalHHS CDII: A lot of you chose repositories, either a single repository or multiple repositories. Hans. I didn't see your hand go up. Let me finish my thought. Here, then we'll go to you. I'm really interested in someone that chose passing consent along with the request. And in particular, how would something like that work. If you are making a request for information.

187

00:35:36.504 --> 00:35:51.723

Rim Cothren, CalHHS CDII: perhaps like prior to an admission, and therefore you haven't yet seen the individual to obtain that consent. There are use cases that have proven to be difficult for that, Hans. I did see your hand pop up, and I do want to give you a chance? Did you have something you wanted to say before.

188

00:35:52.014 --> 00:35:56.643

Hans Buitendijk: No, not from this one. I accidentally hit it too too quickly.

189

00:35:56.794 --> 00:35:58.634

Rim Cothren, CalHHS CDII: Okay. Eric.

190

00:36:00.284 --> 00:36:14.634

Eric Nielson: Room thinks I wish there were an option between 2 and 3. I'm really sensitive, I think, to what a lot of shared around Calaim. But but I would propose like that if we have initiatives like that where we've got a shared set of partners and a shared set of data

191

00:36:14.634 --> 00:36:15.073

Eric Nielson: same kind of

192

00:36:15.074 --> 00:36:36.223

Eric Nielson: some common themes. We have a repository around that. So I like the idea of 2 of having repositories that may be built around particular populations or constellations of services that work for an initiative. But you know, at the end of the day I did select Number 3, because, given, I think, the sensitivity of some of the programs that we're involved in.

193

00:36:36.404 --> 00:36:43.824

Eric Nielson: I know if I were thinking as a social worker, let's say I wouldn't necessarily trust that that you know the consent that was obtained

194

00:36:43.844 --> 00:37:05.143

Eric Nielson: by, let's say, a primary care physician with someone in a clinical setting would necessarily address maybe some of the kinds of information that they're collecting, let's say, from a child welfare social worker, and so would want to ensure that we're have a chance to review the consent, review the language, and maybe potentially an ability to follow up with the consumer to ensure that

195

00:37:05.144 --> 00:37:20.514

Eric Nielson: it was informed there's an understanding of what's being disclosed, and that it complies with the rules that govern. You know the information that's being requested to be disclosed. And so I think that there is. There's really is a need to allow and recognize that there are many different

196

00:37:20.784 --> 00:37:47.904

Eric Nielson: policies and laws that govern information that we hold, and there may need to be a circumstance where we need to review that consent to ensure that it meets. You know both those law and policy standards as well as truly being, you know, informed by the consumer and and meeting the consumer's wishes. And so I definitely like the very last option of an implied consent, with a request. I think that would absolutely be a no-go for social data, at least from you know, county side things.

197

00:37:47.904 --> 00:38:05.124

Rim Cothren, CalHHS CDII: Thank you, Eric. One of the things that we need to bear in mind that you know, being able to review the consent may stand in the face of real time exchange. So we need to figure out how we operationalize that. And I see a lot of heads nodding. There have been cases where that's failed in the past. I will quit.

198

00:38:05.254 --> 00:38:09.363

Rim Cothren, CalHHS CDII: Try to quit my own commentary, Derek. You've had your hand up for a while.

199

00:38:12.444 --> 00:38:13.604

Rim Cothren, CalHHS CDII: You're muted, Derek.

CalHHS

CENTER FOR
DATA INSIGHTS
AND INNOVATION
CALIFORNIA HEALTH &
HUMAN SERVICES AGENCY

200

00:38:15.044 --> 00:38:19.913

Derek Plansky: Sorry I'm arguing on this one, because it led me to the conclusion to pick number 2.

201

00:38:20.204 --> 00:38:20.904

Rim Cothren, CalHHS CDII: Fine.

202

00:38:20.904 --> 00:38:33.184

Derek Plansky: If you need to have the information, you need to have it from somewhere, because you might not have it yourself from the patient which led me to the conclusion that you know we need some sort of, and I generally prefer federated architectures just because

203

00:38:33.724 --> 00:39:01.044

Derek Plansky: centralized is overly simplified, and we need to live in a trusted sort of multipolar kind of environment. One last thing on the real time validation, the arguments that were just presented about needing to validate the data are exactly arguments I heard previously, for reasons why people didn't want to share data. In the 1st place. So we have to get to a point where we trust that the data, the consent data that's captured

204

00:39:01.224 --> 00:39:21.033

Derek Plansky: can be used in a real time, computable way, because otherwise the we're back to square one where people are saying we should share. But I don't

necessarily trust that I understand. The the intention is seems to be pure. I'm not, Eric. I'm not trying to say. You know you're you're doubting, Thomas, or anything like that. But

205

00:39:21.144 --> 00:39:29.433

Derek Plansky: the the it's just. It impedes free flow of information. And the we have to figure out how to do this in a trustworthy way.

206

00:39:29.954 --> 00:39:30.404

Rim Cothren, CalHHS CDII: Okay.

207

00:39:31.364 --> 00:39:40.644

Rim Cothren, CalHHS CDII: thank you. I'm gonna try to hold us to just another minute on this topic, because people wanted to talk about the last one. So, Eric, if you can keep us quick.

208

00:39:41.004 --> 00:39:58.093

Eric Jahn: Okay. I just wanted to say that we don't necessarily have to sync the whole consent. We could sync the record locators to a smaller set of centralized aggregators, and then you could store them, and you know you have to have permission to be able to retrieve it from the the request, or have permission to retrieve it from the owner of the consent. Doc. Over.

209

Rim Cothren, CalHHS CDII: Okay. Thanks. Eric. Hans.

210

00:40:00.524 --> 00:40:13.663

Hans Buitendijk: Yeah, I'm I was going towards number 2 consensus share in multiple repositories, but not necessarily for the same reasons as others might have raised. I'm not convinced that it's necessarily going to be based on groupings or settings, or otherwise

211

00:40:13.674 --> 00:40:40.914

Hans Buitendijk: much more based on that. There are going to be places, either because there are patients that have choose a different place to manage their consent, because they trust their provider or somebody else better to keep it there, as well as the reality, is that there will be places where the consent is still going to be kept with the setting, and therefore I do need to reach out, and it's going to be between 2 and 3 a little bit on how it's going to play out.

212

00:40:40.914 --> 00:40:44.114

Hans Buitendijk: But to get to that computable approach.

213

00:40:44.134 --> 00:41:05.154

Hans Buitendijk: and not have a dependency on individuals to have to review that every time a query is made or an interaction is made that does mean that federated approach that Derek is talking about of multiple repositories is really where we need to end up, where we can differ, perhaps in opinion about whether those repositories are

214

00:41:05.224 --> 00:41:15.383

Hans Buitendijk: different, because every patient has the choice of their own, and therefore I need for each patient to go to the one that they use. But then I only need to maintain it in one place.

215

00:41:15.384 --> 00:41:39.044

Hans Buitendijk: but everybody needs to have access to it. So I need to federate that, or that I have to maintain it in many different places, which is more inconvenient, but I still, as the disclosing party, I still have to interrogate all of them in order to determine whether for this patient I can share that. So I think it's going to gravitate towards Number 2 in some fashion.

216

00:41:39.344 --> 00:41:41.334

Rim Cothren, CalHHS CDII: Thank you, Hans, David.

217

00:41:41.444 --> 00:41:43.144

Rim Cothren, CalHHS CDII: Please try to keep it quick.

218

00:41:43.994 --> 00:41:45.234

David McCann: Very quick.

219

00:41:45.964 --> 00:41:50.444

David McCann: We've previously agreed that there's probably 4 or 5 sent pipes.

220

00:41:50.694 --> 00:42:12.704

David McCann: so I think what we need to make easy is the changing of the person with the consent types. And I would encourage us to think program in county, because we've also discussed that really, Dx talks about innovating at the county level, which is why I advocate, for there will be a county level 1st before you need to go to state.

221

00:42:13.694 --> 00:42:15.943

Rim Cothren, CalHHS CDII: Thank you and, Ria, you want to bring us home.

222

00:42:16.614 --> 00:42:43.184

Rita Torkzadeh: I will try. I just want to challenge the. What I heard was an assumption I made earlier about consents, whether they're they're like informed, based on whether it's the requesting party or the party sharing, because I don't necessarily think it's 1 way or another, like I don't think that necessarily because it's a requesting consent that that's going to be known necessarily or explicit, to a person.

223

00:42:43.264 --> 00:43:00.614

Rita Torkzadeh: And so I would say, it's also between 2 and 3, but more likely to, because ultimately, like, we also need to know the entity. Need we need to know that

that they, what data is authorized for sharing whether it's particularly if it's like in a clinical environment or or elsewhere. So that's that's what I'll end at.

224

00:43:00.864 --> 00:43:08.524

Rim Cothren, CalHHS CDII: Thank you, Rita. Let's bring up our last question. This one. I don't think I have to read it PE to people, because you are already talking about this one

225

00:43:08.724 --> 00:43:19.763

Rim Cothren, CalHHS CDII: on our very 1st slide for today. But I want to start. Get at to. How do you operationalize simple management of consent. I heard some of these

226

00:43:19.884 --> 00:43:27.334

Rim Cothren, CalHHS CDII: potentially as solutions already, so try to choose something that you think is closest to what you would envision.

227

00:43:27.514 --> 00:43:29.343

Rim Cothren, CalHHS CDII: and then we'll talk about this one.

228

00:43:30.284 --> 00:43:42.683

Rim Cothren, CalHHS CDII: I'm gonna ask everybody to take a quick look at the time we're supposed to be at public comment about 6 min. So I've tried to reserve some time. Let's not bleed over into public comment. Comment. Time too much, if we can.

229

00:44:06.494 --> 00:44:08.173

Rim Cothren, CalHHS CDII: How are we doing on answers.

230

00:44:08.494 --> 00:44:11.004

Emma - Manatt Events: Coming in slowly but surely.

231

00:44:11.004 --> 00:44:15.361

Rim Cothren, CalHHS CDII: Yeah, I thought this was gonna be the hard one. Maybe we should have started here today. But

232

00:44:19.534 --> 00:44:22.723

Emma - Manatt Events: Let's give it just another 20 seconds or so.

233

00:44:44.054 --> 00:44:51.054

Rim Cothren, CalHHS CDII: So I'm not surprised that we're a little bit varied in our responses here. I'm not going to call out any particular, answers.

234

00:44:51.608 --> 00:44:56.733

Rim Cothren, CalHHS CDII: Who who wants to support a particular approach, and why they chose that.

235

00:44:59.574 --> 00:45:03.738

Rim Cothren, CalHHS CDII: Oh, come on, you guys all wanted to talk about this, Hans. We'll get started with you.

236

00:45:04.324 --> 00:45:22.023

Hans Buitendijk: You push me into it? I I choose number 3 based on the prior discussions, and the comments made is that it seems to have to come down to multiple registries for one reason or another, which we can debate otherwise

237

00:45:22.024 --> 00:45:43.403

Hans Buitendijk: is that there are multiple repositories in play, and what that means, that for systems to automatically and quickly understand whether they can release the data for a particular patient to another party, they need to have access to that variety of locations to either aggregate it, or there is a place where it is being aggregated. But that might be different places.

238

00:45:43.474 --> 00:45:56.284

Hans Buitendijk: That means is that to me? 3, is the most logical answer that you have to be able to do, that they have to be in constant communication within their authorities to to be able to understand. What can I share or not?

239

00:45:57.074 --> 00:45:59.973

Rim Cothren, CalHHS CDII: Thanks, Hans, David, what did you choose? And why?

240

00:46:00.844 --> 00:46:16.314

David McCann: If you go back to your choice list. I went with Number 4 for the following use case. It's our data that when 2, 1, 1 encounters a person. Ultimately that person's engaging with at least 4 entities a hospital.

241

00:46:16.514 --> 00:46:22.653

David McCann: possibly a mental health clinic cbo doing housing, support, 2 on one on an ongoing basis.

242

00:46:23.054 --> 00:46:25.304

David McCann: And in my view, the person

243

00:46:25.454 --> 00:46:28.044

David McCann: has that relationship with 4 orgs.

244

00:46:28.214 --> 00:46:48.944

David McCann: and they're never gonna remember some other central place. So I think we rely on the human engaging with the org where they grant they engage the consent and the consent they grant to a Uc. Hospital is different than the consent they grant to 2 on one. So I think we have to have a few places for the population of focus.

245

00:46:49.634 --> 00:46:52.523

Rim Cothren, CalHHS CDII: Thanks, Derek, what did you choose? And why?

246

00:46:55.334 --> 00:47:08.054

Derek Plansky: Chose the the 3rd one. It was the closest to what I was thinking, but I don't. I think there's an assumption in there that you have to replicate the data to the other ones, and I want to make sure that isn't explicitly the case.

247

00:47:08.164 --> 00:47:28.994

Derek Plansky: You should be able to go to one place, and that can be where you keep your consent. But there could be multiple, you know, whether it's at the county level or a regional level or whatever grouping. But it doesn't have to be copied everywhere, because that's basically virtual centralization. Again, it should be federated. So if I change it in one of the approved places. That's just

248

00:47:29.134 --> 00:47:38.204

Derek Plansky: where it lives. And I can remember that one place I don't have to worry about the other ones and the people that are enforcing the consent, go and retrieve the information from that.

249

00:47:38.924 --> 00:47:46.933

Rim Cothren, CalHHS CDII: So I wanna make sure that I'm I'm clear here, Derek, so that I, as an individual, would have one place where I kept my consent.

250

00:47:47.934 --> 00:47:50.363

Derek Plansky: As opposed to multiple places.

251

00:47:50.364 --> 00:48:08.574

Derek Plansky: Yes, that the system should support that. You can make those consents in one place if you want to have it in multiple places and split the difference. But there's I don't see a reason why there couldn't be one place, even if there were multiple of those repositories throughout the State.

252

00:48:08.574 --> 00:48:16.563

Rim Cothren, CalHHS CDII: So one of the things that I'm struggling with, and I'm just gonna raise the question here is, if we're collecting consent in multiple places.

253

00:48:16.844 --> 00:48:27.224

Rim Cothren, CalHHS CDII: How do I manage it in in one place, and that is, that's the the dichotomy that I'm struggling with here in this model, Eric. I saw you pop a hand up.

254

00:48:27.224 --> 00:48:35.964

Eric Jahn: Yeah, I was, you know, trying to address that exactly. I think there needs to be. And this gets to the the personally controllable data store, where they just have

255

00:48:36.544 --> 00:48:51.453

Eric Jahn: pointers to all the consents they've made all over the place, and from this, maybe an app could manage to this some 3rd party app, and from that they're linking out, spidering out to the various consents and the various consent repositories out there, many of them, and from there they can revoke

256

00:48:51.504 --> 00:49:09.863

Eric Jahn: or you know, just download them to have a copy of what they've they've done. And so there is technology for this, like solid pods out there, you know, Tim Berners-lee Solid project could store this for a person. It's a personally controllable data store, but the consents are all out there, you know, in many organizations.

257

00:49:11.014 --> 00:49:12.683

Rim Cothren, CalHHS CDII: Thank you. Jessica.

258

00:49:14.304 --> 00:49:20.923

Jessica Rougeux: I think I just add that, similar to the conversation we were having before about the context. Sensitive.

259

00:49:20.984 --> 00:49:46.724

Jessica Rougeux: One of the concerns that's out there is, if you're managing it from a centralized location, if you have a consumer who's not clear on what consent ties, to what program or what entity one of the risks of that centralized control is that they could inadvertently remove consent from something they need as a part of, let me say, a court ordered case that might be really different than something with with a medical provider in another space. And so

260

00:49:46.724 --> 00:50:11.173

Jessica Rougeux: one of the concerns is that when when you separate that out. You create this risk, that that could be happening because this population is not trained to work with consent documents, and they may not see or make the correlations in what those impacts are. And so I would say, it's 1 of the risks in in that centralized model that we'd really have to think through. How do you mitigate that so that you don't have

261

00:50:11.304 --> 00:50:26.983

Jessica Rougeux: a revoke of consent that could then impact other elements of a case. It's 1 thing when it's about eligibility, it's another. When it's about healthcare, it's another when it involves a court ordered set of services or requirements that may be there. So I just want to throw that out there.

262

00:50:27.274 --> 00:50:31.324

Jessica Rougeux: There's some kind of complicating factors in those specific scenarios.

263

00:50:31.564 --> 00:50:32.591

Rim Cothren, CalHHS CDII: Thank you, Jessica.

264

00:50:33.084 --> 00:50:39.487

Rim Cothren, CalHHS CDII: Well, we're at time for public comment. So I'm gonna move this to public comment. Now, if

265

00:50:40.394 --> 00:50:42.654

Rim Cothren, CalHHS CDII: if events you want to take us home there.

266

00:50:44.254 --> 00:51:00.713

Andrea - Manatt Events: Thanks. Rim. Participants may submit written comments and questions through the Zoom, Q&A. Box. All comments will be recorded and reviewed by staff to make a verbal comment. Members of the public must raise their hand for zoom facilitators to unmute them. You can click, raise hand at the bottom of your screen.

267

00:51:00.914 --> 00:51:06.754

Andrea - Manatt Events: all individuals will be given 2 min. Please state your name and organizational affiliation. When you begin

268

00:51:07.114 --> 00:51:09.524

Andrea - Manatt Events: 1st up we have Marquita Graves.

269

00:51:10.344 --> 00:51:13.243

Andrea - Manatt Events: Marquita. You should be able to unmute yourself. Now.

270

00:51:23.774 --> 00:51:30.914

Andrea - Manatt Events: Okay, we'll move on to next hand. Brian. Hands picker. Brian, you're able to unmute.

271

00:51:39.474 --> 00:51:44.064

Brian Handspicker: This is Brian Hans Picker. Sorts of Change Institute. Can you hear me? Okay.

272

00:51:44.434 --> 00:51:45.253

Rim Cothren, CalHHS CDII: We can.

273

00:51:45.874 --> 00:51:48.878

Brian Handspicker: Great I'd like to point out that

274

00:51:49.474 --> 00:51:54.724

Brian Handspicker: focusing on whether a repository of data storage is central or not is.

275

00:51:55.024 --> 00:52:14.093

Brian Handspicker: I think, a challenging problem, because even if you are able to assert within the bounds of a certain group of organizations that everything shall be centralized into this one repository. There are always going to be organizations that come along that either aren't part of the the

276

00:52:14.304 --> 00:52:21.713

Brian Handspicker: the group in your State, or are associated with somebody who's moved in from another State.

277

00:52:21.864 --> 00:52:37.464

Brian Handspicker: or are associated with an application that isn't isn't registered with that central repository. So there are always going to be consents and other kinds of data that are scattered all over the place. It's better to take a federated approach in general

278

00:52:37.644 --> 00:52:42.743

Brian Handspicker: and say, Okay, now, how do we solve the problem of centralized access to distributed information?

279

00:52:42.884 --> 00:52:48.184

Brian Handspicker: And that's where the San Diego leap Cds implementation kind of but

280

00:52:48.284 --> 00:52:52.784

Brian Handspicker: rises to the top here because they had built into it

281

00:52:53.114 --> 00:53:01.333

Brian Handspicker: a consent discovery service, whose sole job it was to keep track of where in that local community were various.

282

00:53:02.296 --> 00:53:12.433

Brian Handspicker: consents stored really, where our various sensitive records likely to be stored, and therefore consents associated with those those records storing, and by.

283

00:53:12.434 --> 00:53:12.944

Rim Cothren, CalHHS CDII: For.

284

00:53:13.144 --> 00:53:15.464

Brian Handspicker: You go to one place, you solve the problem.

285

00:53:15.774 --> 00:53:16.963

Rim Cothren, CalHHS CDII: Thank you, Brian.

286

00:53:17.694 --> 00:53:19.214

Rim Cothren, CalHHS CDII: Are there other hands.

287

00:53:19.784 --> 00:53:21.964

Andrea - Manatt Events: We have no hands raised at this time.

288

00:53:21.964 --> 00:53:28.143

Rim Cothren, CalHHS CDII: Let's give people just a half a minute to see if anybody has another public comment to make.

289

00:53:31.114 --> 00:53:33.524

Andrea - Manatt Events: Next we have Lucy Johns.

290

00:53:33.724 --> 00:53:36.203

Andrea - Manatt Events: Lucy, you should be able to unmute yourself. Now.

291

00:53:37.754 --> 00:53:39.294

Lucy Johns: Thank you. Can you hear me?

292

00:53:39.294 --> 00:53:40.194

Rim Cothren, CalHHS CDII: We can.

293

00:53:40.684 --> 00:54:07.223

Lucy Johns: Thank you. I'm not going to comment on the options. I just want to compliment Rim and the staff for capturing so much complexity in just 3 or 4 questions, with 3 or 4 options under each one. This has been a really valuable discussion. I think it will be a miracle if it comes to closure. But it certainly is a case study in how to talk about

294

00:54:07.224 --> 00:54:12.303

Lucy Johns: really complicated problems. So as a member of the public, I want to thank you.

295

00:54:12.704 --> 00:54:26.294

Rim Cothren, CalHHS CDII: Thank you, Lucy. I have to pass the credit on to both my team. But our excellent panelists that are really continuing to to raise the issues and talk very frankly about them.

296

00:54:27.514 --> 00:54:28.914

Rim Cothren, CalHHS CDII: Any other hands.

297

00:54:30.334 --> 00:54:35.723

Andrea - Manatt Events: We have Carol Robinson, Carol Robinson, you should be able to unmute yourself. Now.

298

00:54:37.164 --> 00:54:40.874

Carol Robinson: Hi, thanks for taking my question.

299

00:54:41.997 --> 00:54:51.393

Carol Robinson: I am curious. I haven't heard the group discuss resolution of conflicting

300

00:54:51.494 --> 00:55:04.343

Carol Robinson: consent information when perhaps, you know a person has given consent. Multiple times, and those are stored in in various

301

00:55:04.834 --> 00:55:12.054

Carol Robinson: registries or repositories of consent documents. What's the source of truth? How do you resolve

302

00:55:12.334 --> 00:55:18.363

Carol Robinson: those questions around conflicting data, sharing instructions.

303

00:55:18.774 --> 00:55:31.110

Rim Cothren, CalHHS CDII: Thanks for raising that carol that's we. We did touch in one of our prior meetings a little bit on resolving conflicts, but didn't bring it to the front in this meeting, and perhaps should have

304

00:55:31.936 --> 00:55:35.103

Rim Cothren, CalHHS CDII: so I think that that is a good question.

305

00:55:37.674 --> 00:55:39.934

Andrea - Manatt Events: We have no more hands raised at this time.

306

00:55:40.464 --> 00:55:41.484

Rim Cothren, CalHHS CDII: All right.

307

00:55:42.454 --> 00:55:52.903

Rim Cothren, CalHHS CDII: Well, I'm going to move us forward to closing things out a little bit here. This was our final meeting. As always, we're going to post materials. From this meeting the slides.

308

00:55:52.934 --> 00:56:01.653

Rim Cothren, CalHHS CDII: the poll results still anonymized will get posted along with that, so that members of the public and others can reference what those are.

309

00:56:01.664 --> 00:56:26.044

Rim Cothren, CalHHS CDII: what we have not done in the past. We've been summarizing recommendations internally, but we're going to start posting the recommendations as we heard them coming out of these meetings, and so you should see that coming out here shortly for those that attend our lac meetings, we'll be talking about the recommendations from the Social Services Focus group at our lac meeting coming up in a week.

310

00:56:26.530 --> 00:56:55.793

Rim Cothren, CalHHS CDII: I'm going to call an audible here, and one of the things that I'd be interested in is for everybody that attended today's meeting. If today's discussion changed your mind about any of the choices you made. So if I can talk, talk to Staff here, watch your inboxes. You may see a survey coming to you by email to answer

these 4 questions again, and I'll just be interested to see if anybody's responses changed as a result of today.

311

00:56:56.526 --> 00:57:10.033

Rim Cothren, CalHHS CDII: I really want to thank people for participating very vigorously in 4 meetings on a really difficult con concept. I think that we learned a lot and really appreciate everybody's participation.

312

00:57:10.034 --> 00:57:27.614

Rim Cothren, CalHHS CDII: Some of you will see again starting in August to talk about event notification for those of you that aren't members of that focus group. Please tune in as members of the public. If you're interested in that topic. We'll also be talking about identity management later on in the year.

313

00:57:28.011 --> 00:57:31.884

Rim Cothren, CalHHS CDII: But our our next meeting series is on event notification.

314

00:57:31.994 --> 00:57:46.884

Rim Cothren, CalHHS CDII: Thank you again for your wonderful attendance to these 4 meetings and never never hearing silence out of you when we were asking for input really appreciate everybody's participation. Thank you very much.