

MEETING  
STATE OF CALIFORNIA  
HEALTH AND HUMAN SERVICES AGENCY  
CENTER FOR DATA INSIGHTS AND INNOVATION  
COMMITTEE FOR THE PROTECTION OF HUMAN SUBJECTS

FRIDAY, APRIL 7, 2023

8:30 A.M.

1215 O STREET, 11TH FLOOR  
ALLENBY MEETING ROOM 1181  
SACRAMENTO, CALIFORNIA 95815

AND

WEBEX ONLINE MEETING PLATFORM

Reported by:  
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APPEARANCES

COMMITTEE MEMBERS

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Larry Dickey, MD, MPH, MSW, Vice Chair

Alicia Bazzano, MD, PhD

Maria Dinis, PhD, MSW

Catherine Hess, PhD

Carrie Kurtural, JD

Laura Lund, MA

Philip Palacio, EdD, MS

John Schaeuble, PhD, MS

CPHS STAFF PRESENT

Sussan Atifeh, Staff Services Analyst

Sheryl McCarthy

Karima Muhammad

ALSO PRESENT

CDII

Jennifer Schwartz, Chief Counsel

Ruben Mejia

PRINCIPAL INVESTIGATORS AND ASSOCIATE INVESTIGATORS

Jesse Rothstein, PhD, UCB

Evan White, UCB

Bridgette Lery, PhD, Urban Institute

Katrina Brewsaugh, Urban Institute

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P R O C E E D I N G S

CHAIR RUIZ: My name is Juan Ruiz and I'm the  
Chair of the Committee.

And I would like for Sussan to please do the roll  
call.

MS. ATIFEH: Good morning, everyone. I am going  
to do a roll call to see who's present in this meeting.

So, Dr. Ruiz already introduced himself.

I continue with Dr. Dickey?

VICE CHAIR DICKEY: Present.

MS. ATIFEH: Dr. Bazzano?

She has promised to be present. Okay.

Dr. Dinis?

COMMITTEE MEMBER DINIS: Present.

MS. ATIFEH: Thank you.

Ms. Kurtural?

COMMITTEE MEMBER KURTURAL: Here.

MS. ATIFEH: Thank you.

And Ms. Lund?

COMMITTEE MEMBER LUND: Present.

MS. ATIFEH: Dr. Palacio?

COMMITTEE MEMBER PALACIO: Here.

MS. ATIFEH: And Dr. Schaeuble?

COMMITTEE MEMBER SCHAEUBLE: Yes, I'm here.

MS. ATIFEH: Okay, thank you.

1           With the Committee members present, we have a  
2 quorum established.

3           And, you know, just for the record I want to  
4 inform everyone that today we don't have Dr. Hess. And Dr.  
5 Dinis is present only for the first hour of this meeting.

6           CHAIR RUIZ: Okay, thank you.

7           And I would like to again welcome Peter back to  
8 the group. We're happy to have you back.

9           And this morning the calendar of this meeting has  
10 changed a little bit. And we will start with review of two  
11 projects. The first one is an amendment and the PI is Dr.  
12 Jesse Rothstein. And the reviewer, the reviewers are Dr.  
13 Schaeuble and Dr. Dinis.

14           And I believe that aside from the PI, we also have  
15 Nick Gebbia present.

16           DR. ROTHSTEIN: That's correct.

17           CHAIR RUIZ: Okay. So, Dr. Schaeuble and Dr.  
18 Dinis.

19           COMMITTEE MEMBER SCHAEUBLE: Yes, good morning Dr.  
20 Rothstein and Nick. Good to have you here today.

21           MR. GEBBIA: Thank you. It's good to be here.  
22 Good morning.

23           COMMITTEE MEMBER SCHAEUBLE: And I just wanted to  
24 say at the very beginning to thank you for your thoughtful  
25 additions to the amendment that we recently received at the

1 beginning of this week. And in particular for your efforts  
2 to respond to the obligation for using only the minimum data  
3 necessary for a study. We do appreciate your efforts in all  
4 of these areas. So, I did want to acknowledge that right  
5 away.

6 So, I'd like to divide our discussion of this  
7 proposal into five parts, if we could do that for helping  
8 the Committee to fully understand what's going on here.

9 And, oh, I have to -- my computer is playing games  
10 on me here, I'm sorry. Okay, I think I'm back now.

11 For the first part of this, if you would, Dr.  
12 Rothstein, it would be helpful for the Committee to  
13 understand the current study that is going on, that uses  
14 only the data from the Student Aid Commission. Could you  
15 give everyone a brief overview of those activities, please?

16 DR. ROTHSTEIN: Sure, thanks to everybody for  
17 including me. I'm Professor Jesse Rothstein from UC  
18 Berkeley. I'm the PI for the study and Nick Gebbia is a PhD  
19 student who's working on it.

20 The study is a collaboration with the California  
21 Student Aid Commission to understand how well families  
22 understand the financial system and, in particular, how well  
23 they understand -- how well they're able to use the system  
24 to get themselves the most aid that they can be eligible  
25 for.

1           There's a -- it's a very complex system. Nobody,  
2 or many people have trouble understanding it. There are  
3 lots of resources out there that are available to try to  
4 help families understand it, and then give people sometimes  
5 good advice, sometimes not great advice about what to do.

6           But there's lots of things that you can do to try  
7 to affect how much aid you'll be eligible for. And you get  
8 the advice about changing how many hours you work, or  
9 changing when you get, receive bonuses, or changing your  
10 investment -- changing your allocation of your investments,  
11 all of which can have influence on how much financial aid  
12 you're eligible for.

13           And so, the idea of the study is to use data on  
14 family incomes that is provided through the Free Application  
15 for Federal Student Aid, the FAFSA, to families providing  
16 detailed information about their income and assets to try to  
17 apply for financial aid. And the idea is to use changes in  
18 the information that is -- changes in family's financial  
19 circumstances as reported on the FAFSA, as families move  
20 through the college process and face different incentives in  
21 different years to see whether -- to see whether -- how  
22 families respond to the changing incentives, whether they're  
23 able to adjust their financial information to qualify for  
24 more aid.

25           And the idea, the value of this is that it will



1 help us understand whether families are able to use the  
2 system, help us understand how the costs of the complexity  
3 in the system, and potentially help us adjust the rules so  
4 that there's a better mapping between family need and the  
5 aid that they receive, so that we don't misallocate aid in  
6 ways that we surely do to some extent, now.

7           The study is entirely using de-identified  
8 administrative data that's already collected. There's no  
9 interaction with subjects whatsoever. And the results will  
10 all take the form of regression coefficients or large-scale  
11 summary statistics that would not relate to any individual  
12 family.

13           COMMITTEE MEMBER SCHAEUBLE: Can you cover just a  
14 bit more, perhaps, the process that you're using with regard  
15 to analyzing those data?

16           DR. ROTHSTEIN: Sure. So, the project is being  
17 done through a center at Berkeley, for which I'm the Faculty  
18 Director, called the California Policy Lab, which is running  
19 dozens of studies of similar form, with the Student Aid  
20 Commission, and with other state agencies. I'm sure you all  
21 have seen many of our protocols come through already.

22           The agency de-identifies the data, removes all the  
23 PII, and replaces it with a hashed identifier, so random  
24 strings of digits that can be used to link records together,  
25 but don't tell you anything about who the person is.

1           That data is transferred to the California Policy  
2 Lab's secure data hub, where all the analysis happens. It's  
3 VPN protected, it has state-of-the-art security measures  
4 that we can go into, if you want, about -- to protect the  
5 data. And all of the analysis happens on that server.

6           The kinds of analyses that we're doing are --  
7 well, there are a few different kinds. But mostly it's  
8 looking at the family from one year to the next, where in  
9 those two years they're facing different financial aid  
10 incentives. Sometimes it's because in the first year they  
11 had one child in college and the second year they had two  
12 children in college. That changes their eligibility for  
13 financial aid in important ways.

14           In some other analyses it's because the rule  
15 changed. For those who are familiar with the financial aid  
16 system, there was a change about eight years ago, now, to  
17 what's called the prior-prior. Where instead of asking  
18 about last year's income, they ask about two years' ago  
19 income. And so, that changed the incentives about how you  
20 would want to adjust your financial circumstances.

21           But the idea is to identify fairly large groups of  
22 families. For example, families who go from one kid to two  
23 kids in college in a given year. And look at changes in  
24 their circumstances or changes in their reported income and  
25 reported assets between those two years. And then, compare

1 them to another group of families who we think probably  
2 would have been subject to similar other circumstances, but  
3 who didn't face the change in incentives from financial aid.  
4 That might be families who don't have a second child going  
5 to college or families whose incomes are in a range where  
6 the incentives are different.

7           To implement that sometimes it's just tabulations  
8 of means across, you know, tens of thousands or hundreds of  
9 thousands of families. Sometimes it's regression  
10 coefficients. But the basic idea is that kind of difference  
11 in differences, the change in one year to the next for  
12 families who are affected by some change in effectives  
13 relative to the families that are not changed, not affected  
14 by those effectives.

15           Is that the kind of detail you wanted?

16           COMMITTEE MEMBER SCHAEUBLE: I think that helps  
17 people, yes.

18           DR. ROTHSTEIN: Okay.

19           COMMITTEE MEMBER SCHAEUBLE: So, I think I'll go  
20 on to what I had in mind as part two, and ask you to  
21 similarly describe the proposal in this amendment that would  
22 bring credit data into the picture to the same kind of  
23 overview, and how that would essentially work.

24           DR. ROTHSTEIN: Yes. So, this is an unusual  
25 situation where I think the original study was approved

1 without Committee review, and then the amendment is coming  
2 to the Committee.

3           The amendment would be to bring in another dataset  
4 from something called the University of California Consumer  
5 Credit Panel, which comes from consumer credit records that  
6 are collected by one of the credit bureaus.

7           And that contains data, it has lots of information  
8 about family debt in various categories. An important  
9 category for us is going to be home equity or home mortgage  
10 debt, which I'll talk about why in a minute.

11           But it allows us -- it broadens the study in two  
12 ways. One is it allows us to see something about families'  
13 financial circumstances in years that they didn't submit  
14 FAFSAs describing it, because it was before their child went  
15 to college or after their children were out.

16           And the other is it allows us to see more detail  
17 on the kind of asset and debt side of a family's  
18 circumstances than there is on the FAFSA.

19           The reason that's interesting is because one of  
20 the incentives that families face, and one of the most  
21 widely promulgated pieces of advice that families get is to  
22 pay down their mortgage when they're eligible for aid,  
23 because home equity doesn't -- isn't counted the same way as  
24 other kinds of savings in applying for financial aid. And  
25 so, we'll be able to see mortgage balances and see whether

1 families respond by reducing their mortgage balance, as they  
2 kind of face different incentives.

3           The approach we'll take is that again we'll  
4 receive an extract from the credit panel that is de-  
5 identified. I mentioned that the Student Aid Commission is  
6 hashing all of the identifiers, meaning we get random  
7 strains instead of names, or social security numbers.

8           The credit bureau will hash them the same way.  
9 The two agencies will talk to each other to agree on a  
10 secret phrase. It's called a SALT that both use to hash it.  
11 We don't know what that is and we will never know what that  
12 is. But we will get data from both sides that are hashed in  
13 the same way and then we'll be able to figure out which  
14 records correspond to the same person, even though we won't  
15 know that person's identifying information.

16           And that will allow us to link the credit data to  
17 the Student Aid Commission data to do the analysis.

18           This is the method that we've used in a number of  
19 studies with state-initiated data in California, and the  
20 credit panel in particular.

21           And then, once we have the data linked it will be  
22 the same style of analysis as before, where we'll be looking  
23 at changes in home equity, for example, from year to the  
24 next for families that face incentives to increase their  
25 home equity relative to families that don't.

1 COMMITTEE MEMBER SCHAEUBLE: Okay.

2 DR. ROTHSTEIN: One of -- oh, sorry.

3 COMMITTEE MEMBER SCHAEUBLE: Go ahead.

4 DR. ROTHSTEIN: I was going to say one of the  
5 changes we made to the -- so, one of the complexities of the  
6 credit data is that in the original -- in its kind of  
7 original form it's many, many hundreds of records. It's  
8 kind of transaction -- not quite transaction level data, but  
9 there are detailed records about every financial account  
10 that has a family has, that has information about the  
11 balance, and the origination, and the status at various  
12 times.

13 And to construct the kind of variables we want,  
14 like what is a family's total home mortgage debt, will  
15 require aggregating over a large number of variables.

16 The original proposal was to receive all of those  
17 variables and then do the aggregation. We've worked out a  
18 way of getting the aggregation to be done before the data  
19 come into our study, so that we would only use fairly large-  
20 scale aggregates, like total mortgage debt, rather than all  
21 of the underlying variables. Which I think reduces the  
22 amount of information that would be linked to the Student  
23 Aid Commission and reduces the already, I think, quite small  
24 possibility that if the data were breached somehow that  
25 somebody would be able to re-identify an individual.

1                   COMMITTEE MEMBER SCHAEUBLE:   Okay.  I think I'd  
2 like to go on to part three.  And ask some questions here.  
3 I apologize if some of this will seem painfully obvious to  
4 you, but as reviewers we've not always been sure that we are  
5 exactly clear on the activities and roles of what are at  
6 least four entities involved in this situation, the Student  
7 Aid Commission, the credit bureau, the California Policy  
8 Lab, and the researchers for the particular study.

9                   So, I have a group of questions that are related  
10 to trying to clarify some of that for us.

11                   With regard to the Student Aid data, obviously the  
12 Student Aid Commission has all of the data from applications  
13 there.  Does the California Policy Lab then have a copy of  
14 all of that data by virtue of their agreement with the Aid  
15 Commission, or do they obtain it separately for any  
16 individual research study that is trying to use that data,  
17 or something else that I'm not picking up?

18                   DR. ROTHSTEIN:  There are a number of studies  
19 ongoing with the California -- via the California Policy Lab  
20 with the full data that have been approved under other IRB  
21 protocols.  And so, yes, the other data would be available,  
22 but we wouldn't ever link that to the Student Aid Commission  
23 data for this project.  As we will for this project under  
24 this revised protocol it will become segregated, it will be  
25 in different accounts, on different virtual machines.  But

1 yes, the Policy Lab does have the full data under other  
2 protocols.

3 COMMITTEE MEMBER SCHAEUBLE: Okay. So, the Policy  
4 Lab is storing that data somewhere and is that somewhere at  
5 Berkeley it's being stored?

6 DR. ROTHSTEIN: It's on our secure data hub, which  
7 is physically located at UCLA. But it is, you know, in a  
8 secure data lab there.

9 COMMITTEE MEMBER SCHAEUBLE: Okay. So, it's fair  
10 for me to say, then, the whole dataset for the -- from the  
11 Student Aid Commission really does exist in two places, at  
12 the Commission itself, and at UCLA for the Policy Lab.

13 DR. ROTHSTEIN: Oh, I'm sorry, I thought you were  
14 asking about the credit panel. Maybe I misunderstood. We  
15 have a number of projects also with the Student Aid  
16 Commission, but we've never gotten the full extract of all  
17 of their variables. We've defined a set of variables from  
18 them that we've gotten.

19 It's roughly, you know, similar to the variables  
20 that we're using in this, but it's not every -- it's not  
21 their full dataset.

22 But to the extent that we are -- the variables we  
23 are using we do have a copy of on our server.

24 COMMITTEE MEMBER SCHAEUBLE: Okay. So again, I'm  
25 trying to get this clear in my head. The Student Aid



1 Commission has a full set of data. I think you're telling  
2 me that the California Policy Lab has a subset of that full  
3 dataset that they maintain. And from that subset  
4 information can be drawn for individual research studies.

5 DR. ROTHSTEIN: Not -- not quite, I'm sorry.

6 COMMITTEE MEMBER SCHAEUBLE: Okay.

7 DR. ROTHSTEIN: The way it works with the Student  
8 Aid Commission is each project that we've agreed with them  
9 on, there's a data use agreement that covers it. And that  
10 data use agreement specifies the specific variables that we  
11 will use. And then we get those variables from the Student  
12 Aid Commission to use to do that study.

13 And so, we have a number of different studies that  
14 use different combinations of variables.

15 COMMITTEE MEMBER SCHAEUBLE: Okay. So, trying to  
16 revise now what I was saying before.

17 DR. ROTHSTEIN: Sorry.

18 COMMITTEE MEMBER SCHAEUBLE: What I'm hearing now  
19 is that for each individual research study you actually  
20 reach out to the Student Aid Commission for the data that is  
21 needed, and would maintain at the Policy Lab only the  
22 working data for that particular research study. Is that  
23 now correct?

24 DR. ROTHSTEIN: Yes.

25 COMMITTEE MEMBER SCHAEUBLE: Okay.

1 DR. ROTHSTEIN: Apologize for the confusion.

2 COMMITTEE MEMBER SCHAEUBLE: Well, as I said we've  
3 had a hard time wrapping our heads around all of this and  
4 wanted to try to make it clear.

5 So, similarly then, with regard to the credit data  
6 your agreement with the credit agency, does that mean that  
7 the Policy Lab has a copy of the credit data that it is  
8 maintaining?

9 DR. ROTHSTEIN: In that case it's a little bit  
10 more like your original description that there's a set of  
11 information that we've agreed with the credit bureau that we  
12 will have. And we've signed a contract that's been in place  
13 for a number of years. And they provide us those variables  
14 and they don't give us a new extract for every single study.

15 The linking that we would do does involve a new  
16 set of information from them because they give us a new set  
17 of ID variables that allow linkage for every additional  
18 linkage. But the other variables, the ones that aren't used  
19 for identifying observations, those we do have a full set  
20 of.

21 COMMITTEE MEMBER SCHAEUBLE: Okay. And that would  
22 be data that you said was maintained at UCLA.

23 DR. ROTHSTEIN: Yes.

24 COMMITTEE MEMBER SCHAEUBLE: Okay. Let me make  
25 just a couple of notes here before I go ahead, for myself.

1 DR. ROTHSTEIN: Maybe one thing worth clarifying  
2 is that the -- our data hub has separate virtual machines  
3 for every dataset and project. And so, there's a virtual  
4 machine where we store the credit panel data. That is not a  
5 virtual machine that the project researchers will have  
6 access to. We'll create a new virtual machine -- or we have  
7 created a new virtual machine for this project, which is the  
8 one that we'd be using. And that virtual machine would only  
9 get an extract of a subset of information from the credit  
10 panel. And the virtual machines are walled off from each  
11 other, you can't connect from one to the other. So, the  
12 researchers won't have access to the fuller credit panel  
13 data.

14 COMMITTEE MEMBER SCHAEUBLE: Okay. With regard to  
15 the -- what you're describing as the abstract of variables  
16 that would aggregate information about loans, and credit  
17 cards, and mortgages, et cetera, how will those be computed  
18 and who is doing that computation of those aggregated  
19 variables?

20 DR. ROTHSTEIN: It would be research staff at the  
21 California Policy Lab who would make that extract before  
22 it's ever linked to the Student Aid Commission data.

23 COMMITTEE MEMBER SCHAEUBLE: Okay. So, working  
24 with your copy of the credit data, the Policy Lab would  
25 compute these aggregated variables and pass them on to you,

1 as researchers?

2 DR. ROTHSTEIN: Correct. As I understood the  
3 concern about the full set of variables, it was that there  
4 was a risk that if there was a data breach, then somebody  
5 would have access to more information. The full information  
6 from the credit panel and the full information from the  
7 Student Aid Commission.

8 This would ensure that there's no -- there's no  
9 dataset that combines the full information from both sets  
10 that could ever be revealed in a breach.

11 VICE CHAIR DICKEY: Dr. Schaeuble, could I ask a  
12 question?

13 COMMITTEE MEMBER SCHAEUBLE: Sure.

14 VICE CHAIR DICKEY: Just kind of going back to the  
15 original project, you say the data that you get from the  
16 Student Aid Commission is totally de-identified.

17 DR. ROTHSTEIN: Yes.

18 VICE CHAIR DICKEY: If that's the case, then I  
19 wonder why we are even reviewing this. Because the  
20 Information Practices Act only applies to identifiable data.

21 DR. ROTHSTEIN: I guess that's a question for you  
22 all. We understand that any -- that even -- that we have to  
23 come to the IRB with projects that use individual level  
24 administrative data, and so we did that. We were a bit  
25 surprised that this project triggered extra review because

1 we've done other projects of this form that have not.

2 VICE CHAIR DICKEY: Yeah.

3 COMMITTEE MEMBER SCHAEUBLE: Dr. Dickey, I can  
4 give you an answer that I think might be helpful here.

5 VICE CHAIR DICKEY: Okay.

6 COMMITTEE MEMBER SCHAEUBLE: There are three of us  
7 on the Committee who have been already reviewing this  
8 particular proposal and this -- in our view, this is not  
9 data that is totally de-identified. There are HIPAA  
10 identifiers that remain in the data that the researchers  
11 will be working with. And as a matter of face, our legal  
12 staff has also commented that in their view it is not in  
13 fact de-identified data for our purposes.

14 VICE CHAIR DICKEY: Okay. That's all I wanted to  
15 know.

16 CHAIR RUIZ: Anymore comments, Dr. Schaeuble?

17 COMMITTEE MEMBER SCHAEUBLE: Pardon?

18 CHAIR RUIZ: Anymore comments from you?

19 COMMITTEE MEMBER SCHAEUBLE: Oh, yes. Yes, I'm  
20 still trying to continue here.

21 So, the Policy Lab will compute these aggregated  
22 variables. And how is this related, then, to receiving data  
23 with the hashed identifiers?

24 DR. ROTHSTEIN: So, the approach will be that the  
25 -- because the agencies hash the data in the same way to

1 enable a linkage, hash the identifiers in the same way to  
2 enable a linkage, that's not something you can reuse from  
3 project to project because you need to be able to use the  
4 linkage -- to link a particular pair of datasets.

5           And so, we will get a new extract from the  
6 consumer -- from the credit bureau, where they give us a set  
7 of hashed identifiers that allow -- with ID variables that  
8 allow us to identify which other -- to connect to the other  
9 variables that don't include all of the full dataset. And  
10 then, the Student Aid Commission will also give us a set of  
11 -- on the data that they provide will give us a set of  
12 hashed identifiers.

13           So, for example, the first name will be turned  
14 into a random string of 256 digits. So that John would turn  
15 into a different string than Jesse would, but we don't know  
16 -- we don't know the mapping between those. The same with  
17 the last names and with the social security number. Each --

18           COMMITTEE MEMBER SCHAEUBLE: Well, I think what  
19 I'm trying to understand here --

20           DR. ROTHSTEIN: Yeah.

21           COMMITTEE MEMBER SCHAEUBLE: -- is the sequence.  
22 Is it the case, then, that once these hashed identifiers  
23 have been created that the computation, then, of the  
24 aggregated variables is done by the Policy Lab after that?

25           DR. ROTHSTEIN: No, the computation would be done

1 before that, and then would afterward be attached to the  
2 hashed identifiers, after we've done the abstraction into a  
3 smaller number of variables, we then link onto the hashed  
4 identifiers that would allow -- that allow the linkage. And  
5 that's the only version that -- only the abstracted  
6 variables get attached to those hashed identifiers.

7           After we've done the abstraction in to a smaller  
8 number of variables, we then link on the hashed identifiers  
9 that allow the linkage, and that's the only version that --  
10 only the abstracted variables get attached to those hashed  
11 identifiers.

12           COMMITTEE MEMBER SCHAEUBLE: Okay. So, I think I  
13 go on then to a part four of the areas. And I think this  
14 relates to just what we were just talked about. The  
15 hashing, we just clarified, is being done by the Policy Lab.  
16 Not the credit agency itself, correct?

17           DR. ROTHSTEIN: No. No, the hashing is being done  
18 by the credit agency and by the Student Aid Commission. The  
19 Policy Lab never sees the underlying name or social security  
20 number. We only ever see the hashed versions.

21           COMMITTEE MEMBER SCHAEUBLE: Okay. And then the  
22 linking is done by Policy Lab, however. Is that correct?

23           DR. ROTHSTEIN: Correct.

24           COMMITTEE MEMBER SCHAEUBLE: And that means that  
25 the -- so, how is it identified that the people who will

1 need to be linked, the Student Aid Commission and the credit  
2 bureau in order to hash the identifiers don't they have to  
3 know in some way which people are required to be potentially  
4 linked?

5 DR. ROTHSTEIN: No. We get identifiers for  
6 everybody that we then -- only -- only the ones that overlap  
7 match.

8 COMMITTEE MEMBER SCHAEUBLE: Okay. So, the entire  
9 credit data, including many people who would not be in the  
10 Student Aid records, all those people have their identifiers  
11 hashed.

12 DR. ROTHSTEIN: Correct.

13 COMMITTEE MEMBER SCHAEUBLE: Okay. Okay, I think  
14 that deals with the questions in parts three and four.

15 For the next part, this is where I really want to  
16 direct, in the fifth part here, questions to the Committee,  
17 for the Committee to talk about their thinking in this  
18 regard.

19 The big stumbling block for those of us who have  
20 been reviewing this particular applications centers around  
21 the lack of consent from the individuals whose credit  
22 reports are being used. And you did provide information  
23 that's in the amendment about your thoughts on this. And I  
24 think there are some places where reviewers are simply  
25 seeing things from a different perspective that needs to be



1 discussed here.

2           It's clear that the people whose information would  
3 be linked, their credit history is being linked to the  
4 Student Aid Commission data, don't know anything about this  
5 and were never told about such a possibility, were never  
6 given any opportunity to opt out of such a possibility. And  
7 the -- in talking about this, you as researchers have said,  
8 among other things, arguably all users of credit products  
9 implicitly consent to having their information shared in the  
10 credit reporting ecosystem which, in your view, includes a  
11 number of activities beyond uses of credit data simply for  
12 purposes of granting credit.

13           And I have to say, as an individual person, that I  
14 would not think in that way and I don't think I'm very  
15 different from many other people in that respect. If I'm  
16 applying for a credit card or a loan, I think my basic  
17 expectation would be that information that I'm providing for  
18 that purpose will be used for obtaining credit, but not for  
19 something else as distantly related as some future research  
20 project that I will not know anything about.

21           Going on from there, as researchers your  
22 continuation of this was more to the point of the Fair  
23 Credit Reporting Act governs permissible use of credit  
24 reports, it permits the use of de-identified data for  
25 research purposes.

1           And in that respect, I think I would need to say  
2 two things. We've established for our purposes that the  
3 data are not really considered de-identified as we have to  
4 look at the situation. Even though there are identifiers  
5 that are removed or masked, there are still others that  
6 remain.

7           And I think it's also relevant here to look at  
8 what people see about credit reports in the information  
9 that's provided by the credit bureaus themselves. And I  
10 looked back at a credit report I have for the agency that  
11 you're working with and combed through all of the  
12 information that was in it for anything that might have to  
13 do with this kind of situation. I could not find any  
14 disclosure about the agency selling data for commercial and  
15 research purposes, instead of just providing it for credit  
16 granting purposes.

17           And the only kind of opt out that was offered at  
18 all was for marketing purposes for offers of preapproved  
19 credit.

20           There was an attached summary of rights under the  
21 Fair Credit Reporting Act and the relevant part of that  
22 attached page said: Access to your credit file is limited.  
23 A consumer credit reporting agency may provide information  
24 about you only to people with a valid need, usually to  
25 consider an application with a creditor, insurer, employer,

1 landlord, or other business. The Fair Credit Reporting Act  
2 specifies those with a valid need for access.

3 I don't think that kind of information would ever  
4 suggest to individuals the kind of use of credit data that  
5 we are talking about here. And to me, at least, and I think  
6 to other reviewers as well, this seems really pretty  
7 deceptive on the part of the credit agency as far as any  
8 reference to the kind of situation we're discussing here in  
9 the research study.

10 So, this is the ethical dilemma that we as  
11 reviewers have been struggling with and have not been able  
12 to find a way to justify, in our heads. And I know that  
13 Maria, in particular, has had some very specific thoughts on  
14 this and, undoubtedly, would like to add to what I've said.  
15 And as I've said, I'm really wanting the Committee as a  
16 whole to get in on the discussion here, too.

17 So, I'm trying to turn this over to other people,  
18 now, for that to take place.

19 CHAIR RUIZ: Thank you, Dr. Schaeuble. I believe  
20 this is opening up for other members to either opine or  
21 provide any other information, or request any other  
22 information.

23 COMMITTEE MEMBER DINIS: Yeah.

24 CHAIR RUIZ: Maria, are you --

25 COMMITTEE MEMBER DINIS: Yeah. Sorry. Yeah, I

1 have a few things I want to add, too. I want to -- first, I  
2 wanted to ask you to, you know, sort of -- I'm still curious  
3 about -- so, you said that the Experian folks, they hash  
4 tag, you know, their data, and so does the Student Aid  
5 Commission. But then how does it -- you know, do they talk  
6 to each other? How do you know how it matches? I'm  
7 confused about that part, before I go on.

8 DR. ROTHSTEIN: Sure, I can answer that quickly.  
9 I would love to have a chance to respond to some of the  
10 earlier things, but let me --

11 COMMITTEE MEMBER DINIS: Oh, oh, yeah. Okay, I'm  
12 sorry.

13 DR. ROTHSTEIN: -- get through this quick  
14 response.

15 COMMITTEE MEMBER DINIS: Sure. Yeah, I'm sorry.

16 DR. ROTHSTEIN: That's all right. I don't want to  
17 interrupt if that's not the -- if this isn't the time.

18 COMMITTEE MEMBER DINIS: No, no, it's fine.

19 DR. ROTHSTEIN: Let me answer your -- okay, let me  
20 answer your question first, and then I'll go back to the  
21 earlier thing.

22 COMMITTEE MEMBER DINIS: Okay.

23 DR. ROTHSTEIN: So, they do have a conversation  
24 where they agree on what's called the SALT, which is a  
25 secret pass phrase that is used to add to the security of

1 the hashing. They both hash with the same algorithm.

2 COMMITTEE MEMBER DINIS: Ah.

3 DR. ROTHSTEIN: That algorithm, as long as they  
4 use the same algorithm the same name will turn into the same  
5 string for both sides. The value of the SALT is it guards  
6 against some kind of attacks that could be used to de-  
7 encrypt, to basically reverse engineer that algorithm. Like  
8 frequency attacks that take advantage of the fact that John  
9 is a more common name than Jesse, for example. But with the  
10 SALT, even that becomes impossible.

11 And so, they do have a conversation to agree on  
12 that SALT and then they encrypt it.

13 Let me just go -- I won't give a long argument,  
14 but I want to just make a quick framing point about the --  
15 about the concerns about consent that were raised.

16 The Common Rule specifies that if a study is a  
17 minimal risk that you don't -- that that qualifies you for a  
18 waiver from this kind of consent rules. Under the Common  
19 Rule, it recognizes that there are some people who would be  
20 included, who wouldn't consent if they could be asked. But  
21 in a minimal risk setting that is okay.

22 This study was already ruled minimal risk with the  
23 Student Aid Commission data. The addition of the credit  
24 panel data doesn't add to the risk. We've talked about  
25 extensive protocols that will ensure that the data can't be

1 breached, and that even if they could be breached that they  
2 wouldn't -- they wouldn't be re-identifiable.

3           So, I think that this -- in my judgment, obviously  
4 you all are the Committee, but in my judgment this qualifies  
5 as minimal risk. Even if it doesn't quality as minimal  
6 risk, the Common Rule also specifies approved safe projects  
7 that are being done on behalf of a state agency with -- for  
8 evaluation of a public benefit program. And I think that  
9 that qualifies -- this qualifies under that rule as well.

10           And it really wouldn't be practicable to carry  
11 this out if you would require consent, because you would  
12 need millions of people's consent to be able to do it. And  
13 of course, even approaching them for consent would require  
14 access to identifiers that we will never have.

15           So, okay, but I'll stop there and --

16           COMMITTEE MEMBER DINIS: Yeah. So, I mean taking  
17 from that point, you know, I also went into the Student Aid  
18 Commission privacy laws, and whatever that they give to  
19 their folks, on their website. And, you know, what's hard  
20 here for me in a way there's -- well, many things. But one  
21 is even in the Student Aid Commission and they tell, you  
22 know, the people who are applying for aid that they're not  
23 going to divulge their private information, blah, blah,  
24 blah, to this agency or to that one, whatever. You know,  
25 I'm just sort of summarizing. They're not going to do that,

1 per se.

2           And, you know, but they can't. And they can't do  
3 this with their private information and they can't collect  
4 this with their private information. So, they have this  
5 whole page that everybody's welcome to go and check it out  
6 and I'm not -- I'm a bit tired, so I'm not even able to  
7 articulate their policy altogether.

8           But what came up for me was, certainly, in nowhere  
9 there says, oh, we're going to at some point, you know, for  
10 research purposes match your information that you have just  
11 submitted to us, your 1040, and whatever your parents stuff,  
12 and we're going to do for research purposes. We're going to  
13 also get your credit data that goes back 20 years, or your  
14 parents, and for research purposes to find out how you  
15 applied for aid, you know, how did you get in. You know,  
16 what ways were you able to figure the system out.

17           And there's just something about that just doesn't  
18 set -- settle well with me. Because I kept thinking being  
19 one of those students that benefitted from the Pell Grant,  
20 et cetera, I'm thinking, you know, if you are a rich person  
21 in this country I don't think you need to go to the Student  
22 Aid Commission. You're going to be able to afford to put  
23 your kid through college just fine.

24           So, the idea that now, you know, we're going to  
25 have researchers go in and figure, you know, who in the

1 middle class folks, or the poor people are figuring out the  
2 system, my view was if they figure out the system good for  
3 them. I never did. Yay. Wonderful.

4           So, they figure out the system, they get these  
5 loopholes into their heads and they go, great, I'm going to  
6 pay down my mortgage, I'm going to do this, I'm going to do  
7 that so I can get aid.

8           I guess my person here is if the person has a lot  
9 of resource they're not going to bother to do all of this.  
10 And I have a real, really big problem blocking people from  
11 accessing education that is already very expensive for most  
12 people. That's one thing. So, you know, you can comment on  
13 that in a second.

14           And I have never in my time -- well, you know,  
15 I've been sitting here in this Committee a long time and,  
16 you know, it's this idea that this research project is more  
17 like, you know, trying to find some harm of sorts. It's  
18 just a weird way that maybe you phrased the project, I'm not  
19 sure, but I have trouble with that.

20           I have more to say, but you can respond to me on  
21 these things and then I'll go on to the other point I want  
22 to make.

23           COMMITTEE MEMBER KURTURAL: Can I ask something?  
24 This is Carrie Kurtural. So, we mentioned about the  
25 disclosure in the Student Aid Commission and, admittedly, I



1 haven't looked at that. And it sounds that that disclosure  
2 that popped up, I kind of view that as being akin to I'm  
3 going to a doctor's office and I have to sign off on the  
4 notice of privacy practices. And, you know, in that notice  
5 of privacy practices I'm given a heads up that, hey, this  
6 particular provider might use my health information for  
7 research purposes, or operational purposes, and there's  
8 usually something in there.

9           And is that what I'm hearing from you, Dr. Dinis,  
10 is that the disclosure doesn't have that little heads up?

11           COMMITTEE MEMBER DINIS: Yes.

12           COMMITTEE MEMBER KURTURAL: Okay, if it has that,  
13 I mean this might not be a popular view to the Committee,  
14 but in my view from, you know, we have to think of what our  
15 role is as a Committee. Is our role to say do I like the  
16 substance of this project or not.

17           Because the way I see it is that my concern, and  
18 maybe I'm more legal focused, but my concern is were they  
19 somehow given that heads up to put it in the category of it  
20 being a minimal risk. And if they were, you know, that's  
21 just my two cents. So, thank you.

22           COMMITTEE MEMBER DINIS: Well, yeah, I can always

23 --

24           CHAIR RUIZ: Maria, are you done? Laura?

25           COMMITTEE MEMBER LUND: Yeah, I just wanted to

1 ask, because now I might be confused, I thought when Dr.  
2 Dinis was speaking that she said there was not a mention of  
3 research. There's not that little, oh, we might use this  
4 for research someday. That there are other things that are  
5 mentioned, but research was not one of them. Was that  
6 correct?

7 COMMITTEE MEMBER DINIS: Well, it may say  
8 research, may be used for research purposes. But what it  
9 doesn't say is how. A number of things. They go into great  
10 length and I -- I guess we could pull it up and see. But  
11 they kind of go into great length saying something to the  
12 effect of, you know, your data is not going to be shared.  
13 There's no staff member here that will be sharing any of  
14 your private information, financial information with other  
15 entities, on and on.

16 And I'm thinking, well, what the hell, you know,  
17 all of the sudden you are, actually. Not only are you  
18 sharing it, you are now having hired, or something, you  
19 know, researchers that will go and get their credit report  
20 going back 20 years, and figuring out all these details.

21 And if they can do that, that should be on the top  
22 of the application saying this is what we're going to do.  
23 So, basically, watch out, you know. This is what we're  
24 going to do.

25 Because the idea here to me, and here's what I'm

1 having trouble is if you're going to apply for services in  
2 the State of California, you know, that you need the  
3 services, whether they're WIC, or this, or something else,  
4 you're subject to more scrutiny, more, I don't know what you  
5 want to call it here, but something. You're subject to  
6 something that others would never ordinarily go through.  
7 And I have a big problem with that. It's -- and it goes on.

8 I mean this is just, you know, thinking about the  
9 purpose of this research and the idea that, yes, they have a  
10 database, but we all know now you tie that database to  
11 another database and you cross, you have an interaction.  
12 It's like medicine. Take one medication, it doesn't harm  
13 you. Take another separately, doesn't harm you. But now  
14 you interact them, oh, yes, it's going to harm you quite a  
15 bit.

16 That's how I feel about this particular  
17 interaction of these two databases. And if they are -- and  
18 I don't even know the state agencies are aware that they can  
19 do this sort of thing, that they can -- you know, that they  
20 can loan these databases out, which is in the IPA. But does  
21 the IPA say that now they can cross them with other  
22 databases? And are they fully aware of the consequences of  
23 what that could be for people?

24 I mean that's -- I don't know, I'm just like  
25 flabbergasted on that.

1 COMMITTEE MEMBER LUND: I have a couple of  
2 comments.

3 CHAIR RUIZ: Okay, I just want -- can I say  
4 something. That I would like to remind you that this is an  
5 amendment. So, please keep your comments in regards to the  
6 amendment, because I don't think we are reviewing the whole  
7 study, but I may be wrong. So, let's maintain to the key  
8 issue.

9 So, Laura.

10 COMMITTEE MEMBER LUND: Yeah, thank you. I have  
11 just a couple of comments and perhaps a question. So, when  
12 I was reading the reviewer's comments about the amendment, I  
13 believe that both reviewers were concerned that the version  
14 of the amendment that I read was greater than minimal risk  
15 because of the addition of these large numbers of possibly  
16 identifying variables from this second database.

17 And I just wanted to ask both Dr. Schaeuble and  
18 Dr. Dinis, given the changes that were made in regard to the  
19 data do you still consider this to be greater than minimal  
20 risk at this point?

21 COMMITTEE MEMBER DINIS: I do.

22 COMMITTEE MEMBER SCHAEUBLE: My response would be  
23 that the changes in the variable -- the credit variables  
24 being requested are certainly helpful, very helpful. But I  
25 do have to keep in mind that the credit data is being linked

1 to Student Aid data that contains more than 450 variables.  
2 So, the final working data file that would be a composite  
3 from these two sources still has, I think, the risk of  
4 people being re-identified if there ever were a data breach.

5 Now, I understand that the researchers think that  
6 is really not a possibility. But in our view, as reviewers,  
7 from what we've seen of other situations where data has been  
8 re-identified, I would say that that is still a risk. And  
9 more than -- it's one of these situations where we're  
10 talking about a potentially very unlikely event, but  
11 potentially harmful if it does happen. And then that, that  
12 makes me say that this looks like more than minimal risk to  
13 us.

14 COMMITTEE MEMBER LUND: Thank you. When I read  
15 through this I tended to agree with that. And the reason  
16 for my question then becomes that the federal regulations  
17 really don't allow us to grant a waiver of informed consent  
18 for greater than minimal risk studies. That's my  
19 understanding of the federal regulation. So, that becomes a  
20 concern here when we're talking about the waiver of informed  
21 consent.

22 My other comment is that I wanted to reinforce  
23 what Dr. Dinis was saying. One of the reasons that SB 13  
24 exists and one of the reasons that this Committee exists is  
25 that very private data is coerced from individuals in order

1 to provide them with government services, right. You guys  
2 have heard me on this one before about birth certificates.  
3 The Cancer Registry data, which contains a huge amount of  
4 very private medical information.

5           And ethically, I think one of the things that I  
6 know I consider as a reviewer, and I would perhaps urge the  
7 Committee to consider, is that in giving the waiver of  
8 informed consent we are really standing in as advocates. We  
9 are the Committee for the Protection of Human Subjects, so  
10 it's our job to consider what are those protections that are  
11 in place or should be in place.

12           And one of the things that I consider is whether  
13 when we grant such a waiver the class of people whose data  
14 are being used would benefit from the study. So, when we  
15 grant a waiver of informed consent for a Cancer Registry  
16 study, say for outcomes for individuals with cervical  
17 cancer, the studies that we see, that we give that waiver  
18 for are generally advancing a body of knowledge that will  
19 improve outcomes for cervical cancer survivors.

20           In this case I don't see an advantage for the  
21 people whose data are being used here, right. They had to  
22 give their data in order -- they had to disclose all of this  
23 information in order to apply for both the Student Aid  
24 Program and for the credit bureau, they don't even have a  
25 choice about that one, and not only is the data not being

1 used in the study to their direct or indirect benefit, but  
2 it may even be potentially used against them or the class of  
3 people to which they belong to sort of close these  
4 loopholes.

5 I think, I agree with Maria, Dr. Dinis on this  
6 one, good for them if they've figured out how to exploit  
7 loopholes in the system in order to get their kids educated.  
8 And I don't think it's appropriate for this Committee to  
9 allow a research study that uses their data against them or  
10 others in their class. So, that's my two cents and thank  
11 you.

12 CHAIR RUIZ: Thank you, Laura. Anybody else?

13 VICE CHAIR DICKEY: This is Dr. Dickey.

14 CHAIR RUIZ: Yes, Dr. Dickey.

15 VICE CHAIR DICKEY: I'm glad that we are having  
16 this discussion. I know there was a desire not to have this  
17 discussion in full Committee. But I guess one of my  
18 messages to when we have subcommittees doing expedited  
19 review, do not try to resolve everything on your own and  
20 bring it to the full Committee, so that we can all discuss  
21 it.

22 And let me remind you, expedited review  
23 subcommittees cannot deny a project, it has to be done by  
24 the full Committee.

25 I also want to say that I don't know that we can

1 make judgments about whether we approve a project because  
2 we're afraid that it's going to come to some conclusion that  
3 we don't want. I think we have to look at are we protecting  
4 human subjects, but not the issue of we really don't want  
5 this study.

6 So, but I can understand the concern about  
7 combining databases. And we might come up with something  
8 that can harm individuals. And that that is a legitimate  
9 concern.

10 I don't know, how does one -- how does one  
11 quantify risk? I know in the HIPAA rules there is a section  
12 that says, you know, things have to be, I think a very small  
13 chance somebody can be identified. And, you know, either  
14 you use the 16 safe harbor identifiers in HIPAA or you  
15 basically have a statistician determine that the risk meets  
16 some standard that things are very -- I forget the exact  
17 terminology, I think it's very low or minimal.

18 And I wonder if there is any way of quantifying  
19 the risk in this case and whether the researchers have  
20 considered looking at statistical issues, maybe getting a  
21 statistician involved in this.

22 DR. ROTHSTEIN: I haven't wanted to jump in until  
23 it was appropriate. Is now a good time for me to respond to  
24 some of these?

25 VICE CHAIR DICKEY: Yeah, I'm through with my



1 thoughts.

2 DR. ROTHSTEIN: Okay. So, we haven't considered  
3 engaging a statistician on this. I think our view of the  
4 minimal risk is largely about the near impossibility of a  
5 data breach given the security setting that we're in. And  
6 then on top of that if you had, if somehow the data were  
7 breached, to re-identify somebody you could only do that if  
8 you could match to some other data that had all this  
9 information, that had this information to begin with. And  
10 if you had that, then you don't need -- then you're not  
11 learning anything from having re-identified our data. It  
12 does not -- this isn't -- this isn't -- there's no public --  
13 there's not enough public information here that you could  
14 identify somebody, even if you had the data out there,  
15 without -- if you didn't already have access to the private  
16 information.

17 I also wanted to address some of the discussions  
18 about loopholes and kind of benefits to the class. This  
19 study is not about identifying loopholes and going after  
20 people who figure them out. We're not going after anybody.  
21 We don't -- we're only analyzing at the aggregate level.

22 The study is about improving policy. It's about  
23 helping us better educate families about how to use the  
24 financial aid system. These incentives are there because  
25 they're intended incentives in some cases, and we want

1 families to use them. And if the families don't know about  
2 them, then that's a failure of the system that can be  
3 improved.

4           In other cases there are situations where people  
5 may be responding in ways that weren't intended. But what  
6 that means is that the limited money that the state has  
7 available for financial aid is not going to -- is going to  
8 families who don't need it as much as some other families  
9 that do. And I think that's improving the allocation to  
10 reach families who need it, which are part of the class of  
11 families who we're studying here. I think that's a very  
12 legitimate state purpose and that's the reason that the  
13 Student Aid Commission thinks this is a valuable study to  
14 perform.

15           And I guess the last thing I'll say is my  
16 understanding of the Common Rule is that even if you do  
17 judge this to be more than minimal risk, there's still a  
18 waiver of the consent rules for projects that are approved  
19 state projects that are for evaluation of public benefit  
20 programs, and I think this would qualify under that rule.

21           We could kind of go down the road of trying to  
22 engage a statistician. I'm not as familiar with that part  
23 of the HIPAA rules. But since this isn't actually a project  
24 that's covered by HIPAA, I'm not sure how that would apply.

25           VICE CHAIR DICKEY: Yeah, you're right because

1 it's not health data, it's financial data.

2 DR. ROTHSTEIN: Right.

3 VICE CHAIR DICKEY: But that is one -- that's how  
4 it is in HIPAA. But since it is financial data, we actually  
5 do not have to stick to the, you know, necessarily the same  
6 rules.

7 I just want to point out that this may not  
8 actually be covered under the Common Rule at all because  
9 it's -- really because the federal government has said that  
10 releasing data for research is not being engaged in research  
11 and -- but it is covered under the Information Practices  
12 Act, which is basically silent about these issues of  
13 consent, et cetera.

14 All the Information Practices Act says is that  
15 there has to be a legitimate use for the data, it has to be  
16 the minimum necessary, and there has to be security measures  
17 in place that will protect the data.

18 So, I think that it's -- actually, in some ways,  
19 the Information Practices Act is a pretty low bar. But the  
20 Committee can, you know, and has interpreted the Information  
21 Practices Act, you know, on a different basis.

22 COMMITTEE MEMBER SCHAEUBLE: If I could add a few  
23 thoughts here, in much of the discussion we're hearing  
24 various aspects of what laws might apply to the situation,  
25 but I think the dilemma for us, as reviewers, has been

1 whether at -- whether we can believe that it is ethically  
2 justified to do this kind of linkage in this particular  
3 study. Which is really a different question from whether it  
4 is legally possible to do it, as has been pointed out in  
5 some of the communications from both legal staff, and  
6 various people who have commented on this along the way of  
7 some things that may be possible legally might not be  
8 considered the best practice from an ethical point of view.  
9 And that, I think, is the real dilemma that we have been  
10 trying to resolve and have not been able to justify in our  
11 heads.

12 VICE CHAIR DICKEY: And John, this is Dr. Dickey  
13 again. You're correct, we do have on our website, when it  
14 talks about the purpose of the Committee. And it says that  
15 we -- one of the first issues is ethics and that the  
16 Committee operates according to the Belmont Report in terms  
17 of ethics.

18 So, I agree with you that some things may be  
19 legal, but not ethical. And that's probably the reason IRBs  
20 were set up to start with, to try to make those hard ethical  
21 decisions.

22 DR. ROTHSTEIN: Maybe, let me jump in with two  
23 thoughts. One is that this is a project that if I were  
24 doing it -- if I were doing -- I do projects along these  
25 lines all the time, and if they don't involve state

1 administrative data that's covered by the IPA, it wouldn't  
2 come to this Committee at all. I think it's the IPA that  
3 brings it to this Committee.

4 Typically, at Berkeley this would be considered  
5 de-identified data and probably would be exempt to begin  
6 with. So, it's a tricky question about how the different  
7 intersecting rules that bring things to you can be applied  
8 here.

9 I did want to address one thing that was mentioned  
10 earlier about what information is given to people when they  
11 fill out the FAFSA. The FAFSA has an extensive kind of  
12 disclosure and one of the things that it discloses is your  
13 data may be linked to data from a number of other agencies.

14 To be fair, you know, to be totally transparent  
15 it's not saying that it would be linked for research, it  
16 would be linked for enforcement purposes.

17 But I don't think that anybody who filled out the  
18 FAFSA and looked at the disclosure could be surprised at the  
19 kind of linkage that we're doing here. I think it's fully  
20 disclosed that that is a routine aspect of the FAFSA  
21 process. So, I'll stop there.

22 COMMITTEE MEMBER DINIS: But does it say that the  
23 -- you know, that we're going to compare it with your credit  
24 report? That, I did not get. Is that in there?

25 DR. ROTHSTEIN: I don't have it in front of me. I

1 don't know if it says that. It probably doesn't  
2 specifically say the credit report.

3 COMMITTEE MEMBER DINIS: Yeah, I mean --

4 DR. ROTHSTEIN: I don't think it's that specific.

5 COMMITTEE MEMBER DINIS: -- in fact I saw --

6 DR. ROTHSTEIN: It says it can be linked to a  
7 range of other datasets.

8 COMMITTEE MEMBER DINIS: Yeah. In fact I saw some  
9 language kind of the opposite. Because, you know, I'm  
10 thinking along the ways, I'm thinking, you know, if they're  
11 really interested in this kind of research why don't they  
12 ask the students, the applicants to submit the credit report  
13 at the same time. And my read of their website was it  
14 wasn't legal for them to do it, that's why they didn't do  
15 it.

16 And to me, this seems like a backdoor way of  
17 getting to the -- of getting to that in-depth without having  
18 to actually go again -- you know, they probably would have  
19 to go to the Legislature and ask to have that right to have  
20 the parents or the child, or the student, application submit  
21 the credit report along when they filed this application.

22 And I mean from my read of their website, and then from  
23 details, I did a lot of research for this, it was it wasn't  
24 there. And in fact they kind of went far into saying how  
25 they wouldn't be disclosing, and wouldn't be doing this and

1 that and, you know, including some stuff about the credit,  
2 their credit.

3           So, that's why for me it brings -- you know, it  
4 kind of raises red flags. And when you go -- when you say,  
5 you know, yes, I'm a professor at Sac State, at Sac State  
6 the same thing, all this data is de-identified.

7           But keep in mind, too, that, you know, we have  
8 IPA. I mean we have the SB 13 because of Berkeley. You  
9 know, because they compromised the data of a lot of  
10 students, including me when I was at Berkeley. One of a  
11 hundred thousand students whose social security and  
12 everything else was out there. And I have been fighting all  
13 this stuff for years. So, I'm a -- you know, excuse me if  
14 I'm a little sensitive, but it has affected my life  
15 profoundly. And their two years of offering credit  
16 monitoring services does not go very far when your identity  
17 is stolen and you have to deal with a lot of crap trying to  
18 fix that, you know.

19           So, Berkeley is not a model here, in my view, of  
20 how they handle the students' data. And we used to have  
21 social security numbers as the IDs back in the day, I was  
22 the same. And then when I got hacked and I've been -- I  
23 mean and that has followed me through my lifetime, including  
24 last week I got hacked again.

25           So, I'm just saying that this is something kind of

1 close and personal because it's happened to me. And I think  
2 that -- I think it's the responsibility of the state, and  
3 maybe legally we don't have it because maybe there isn't  
4 those laws in place, I recognize that, but it is the  
5 responsibility of somebody. It should be the state and  
6 maybe this Committee, I don't know, to recognize the dangers  
7 within something like this and what does it bring up for --  
8 what are the possibilities. Not just data breaches but, you  
9 know, what are we trying to do.

10 I mean are you going to be the person that  
11 determines, oh, this person makes 20,000, maybe 15,000 more,  
12 this family, so they shouldn't get any aid for their kid to  
13 go to college, but this other person does.

14 I mean this is a -- I don't know, it's just a  
15 really -- I don't know, it's kind of beyond for me to think  
16 that this is ethical to do to families, I guess.

17 COMMITTEE MEMBER SCHAEUBLE: If I could jump in  
18 here just a bit, I'd sort of like to pull our thoughts back  
19 to what is likely communicated to families when they apply  
20 for student aid. And I will admit that I haven't combed  
21 through all of the documents that the Student Aid Commission  
22 may provide.

23 But I have to assume that the situation is very  
24 likely similar to others that people deal with. That in  
25 given the materials to apply for student aid, the focus is



1 on what information do you need to provide for you to be  
2 considered, and any discussion of other possible uses of  
3 that information is almost surely buried in fine print  
4 somewhere that we have to assume is rarely read or processed  
5 by the people involved.

6 And furthermore, that that fine print is certainly  
7 vague about anything beyond some general statement to the  
8 effect that your information might be used for some other  
9 purpose than to provide student aid.

10 So, we have a situation where it seems the people  
11 are really not being informed in the first place, and any  
12 information, even if they make the effort to look at the  
13 fine print is not going to suggest the possibility of  
14 something like linkage to their credit history. But at the  
15 most might suggest something like information we already  
16 have about you may be used for program evaluation purposes.

17 And it's that respect in which I am seeing an  
18 ethical dilemma here in supposing that after the fact it's  
19 fair to do this kind of linkage is something that we should  
20 consider fair for the families involved.

21 DR. ROTHSTEIN: Let me just clarify one thing  
22 because I think it was really incorrect, and then I -- an  
23 that is this idea that we would be telling somebody that  
24 they don't get aid because their income is some range.  
25 There is no individual level analysis. We will never have

1 individual identifiers and nothing will feed back from our  
2 analysis to any individual respondent here.

3           What we will -- at most, the kind of responses  
4 that would happen to this is that we would understand better  
5 how the -- how our system is working and we would make  
6 tweaks to the system that might -- that would enable it to  
7 function better. And I think this is a -- that's a totally  
8 normal part of the evaluation of public benefit programs.  
9 And sometimes those kinds of changes lead to some families  
10 benefitting and other families not benefitting, but the goal  
11 is to make the program achieve its intended purposes better.

12           I also wanted to -- we have on the call Evan  
13 White, who's the Executive Director of the Policy Lab and  
14 has forgotten more than I'll ever know about the Fair Credit  
15 Reporting Act, another aspect of this. And I wanted to, if  
16 it's all right, pull him in to address some of the things  
17 that have been raised about that.

18           CHAIR RUIZ: Please do.

19           MR. WHITE: Hi everybody. Thanks for giving me  
20 the opportunity to say something.

21           I just -- I guess there's a point I want to make  
22 about -- there's been a lot of speculation about the various  
23 laws that apply to these different datasets, as well as the  
24 language that's provided to individuals when they initially  
25 provide their data.

1           And I think we have to -- I think this body has to  
2 defer to those agencies on their own laws. Right. Like I  
3 don't think we can review the credit bureau's determination  
4 that they make about the Fair Credit Reporting Act, because  
5 that's a statute that they have to deal with everybody. And  
6 the same thing with the Student Aid Commission, which has to  
7 deal with their own statutes everyday about what is a  
8 permissible use of their data and what isn't a permissible  
9 use of their data.

10           For both of those agencies, and for both of those  
11 data types, if you go on to Google Scholar you will see  
12 thousands of studies using those datasets, because both of  
13 those agencies has made the determination that research  
14 purposes with those data is absolutely allowable.

15           In addition, if you will see several dozens, if  
16 not hundreds of studies that link those datasets to other  
17 datasets as well. Because again, there's nothing in the  
18 statutes that apply to those datasets that would prohibit  
19 that.

20           I think in reviewing this amendment, you know, the  
21 questions I think that are really most relevant is, you  
22 know, if we have a line from the original -- for the  
23 original study, which was the FAFSA data, we're able to see  
24 what's in the FAFSA. We're then adding to that some  
25 information, for example on, you know, original mortgage or

1 total mortgage balance, right.

2           And I think the question is if you're adding that  
3 type of information to the FAFSA data, which already has a  
4 lot of information on a family's assets and income, is that  
5 increasing the re-identification risk of the FAFSA data? I  
6 would argue that it is not.

7           There's -- you know, there's no social security  
8 numbers on this. I really respect the -- as somebody whose  
9 social security number was also shared in that breach, Dr.  
10 Dinis, I am furious at Berkeley for not keeping that data  
11 safe.

12           And in our study there are no social security  
13 numbers. There are no names. There are no I would say  
14 traditional PII. There are HIPAA identifiers in the form  
15 of, for example, a data of origination for a particular  
16 loan, but we're not -- in the amendments we made at the  
17 request of Dr. Schaeuble, we're not bringing that loan level  
18 information up, we are aggregating it. So, it's total  
19 mortgage balances. We can't see the date of origination of  
20 the mortgage anymore. Right.

21           So, and I would argue that date of origination of  
22 a mortgage is a much, much, much less identifiable thing  
23 than something like the name, or social security number or  
24 something like that.

25           I wanted to bring us back to that because I think,

1 you know, at the end of the day this study is trying to  
2 improve public policy, right. We've done this exact set up,  
3 where we're linking two datasets, two large administrative  
4 datasets. This Committee reviewed an application in which  
5 we linked the state tax data with the state's social  
6 services data. We linked it at the individual level. And  
7 the purpose was to try and figure out how many people who  
8 were on the SNAP program were also taking advantage of the  
9 Earned Income Tax Credit. We were trying to improve a  
10 public benefit program.

11 That is indeed what we're trying to do here as  
12 well. We're trying to improve a public benefit program,  
13 which is a financial aid program. And we're doing that at a  
14 very aggregated level. None of this feeds back into  
15 individual level determinations. There's no piece of this  
16 study that is going to affect one individual in these data.  
17 And I just think that that's really important. Right.

18 I think, you know, as Dr. Dickey said, the  
19 origination of the IRBs was for these human subjects things,  
20 like the Stanford Prison Experiment, where you're dealing  
21 with individuals.

22 In this study, we do have to link data at the  
23 individual level, but the purpose of the study is really to  
24 look more broadly at the impact of the financial aid  
25 program. And there's nothing about the purpose of the study

1 that's going to pertain to the individual.

2           And, you know, I could go into the -- I helped to  
3 build our secure data hub, and which was then modeled to  
4 create the other UC secure data hubs. And I just want to  
5 say like the security precautions are incredibly robust.  
6 Once you are on the data hub there is no outbound internet  
7 access whatsoever. There's no way to send the data off the  
8 data hub. Every virtual machine is locked down so that only  
9 users for that particular project can access it.

10           It is the equivalent of the Census Research Data  
11 Centers, but in a more virtualized format.

12           And so, I think even if -- I think the likelihood  
13 that these data every leave that hub is incredibly low. And  
14 even if they did, I think that we would not have a situation  
15 like what Dr. Dinis described. We would have a situation in  
16 which people's FAFSA records, that have no PII on them, but  
17 do have like a total mortgage balance attached to them are  
18 then revealed. And that I think it would be very hard -- I  
19 think that perhaps I could find my own record, but I think  
20 it would be very difficult for me to find anybody else's  
21 record, right. I would have to have information that only I  
22 have about my own financial situation to identify those  
23 records.

24           So, I just wanted to offer those thoughts because  
25 it felt like the conversation was going in a lot of

1 different ways that was sort of talking about the laws that  
2 pertain to these other datasets and not, in my mind, seeing  
3 the place that this Committee is meant to review projects.  
4 Thanks for giving me the opportunity to talk.

5 VICE CHAIR DICKEY: This is Dr. Dickey --

6 COMMITTEE MEMBER SCHAEUBLE: If I could jump back  
7 in for just a moment here. It's good, of course, to have  
8 these additional comments and the information in them. But  
9 much of that information is, again, focused on what may be  
10 considered a legal activity. And I keep coming back here to  
11 wanting the Committee to look specifically at do we think  
12 it is ethically justifiable in this particular circumstance  
13 to link credit data to the Student Aid data, given the kind  
14 of information, or I might say the lack of information  
15 provided to the families when they apply for student aid,  
16 and when they deal with their credit reports.

17 That, I think, is the concern that is different  
18 from the kinds of arguments that we've just been hearing,  
19 again.

20 VICE CHAIR DICKEY: This is Dr. Dickey. Can I  
21 make a comment. Thanks John.

22 I think part of it, part of the ethical issue,  
23 though, is do we believe that this is -- that this research  
24 will -- is justified in terms of what issues it may be  
25 addressing.

1           And I do agree with -- you know, I hate that there  
2 has to be a Student Aid Program. I personally believe that  
3 education, like health, should be a right. But,  
4 unfortunately, it isn't.

5           And just like with healthcare and the Medicaid  
6 Program, we have to assess that program. And so, that we  
7 have all sorts of studies of Medicaid, trying to determine  
8 whether the right people who, you know, who need it most  
9 should be getting it. And I don't see any difference in  
10 this in terms of assessing student aid, to make sure that  
11 the program is being administered in the most efficient  
12 manner, and those in the most need are getting the  
13 resources.

14           So, ethically, I don't have any problem with this  
15 study from that perspective.

16           I think the issue that we as a Committee, under  
17 the Information Practices Act, have to assure ourselves of  
18 is that there's proper security, and that -- and that's the  
19 -- if you look at the Information Practices Act that's two-  
20 thirds of it, or three-fourths of it, is the proper security  
21 in place.

22           And I don't know if it would do anything for those  
23 who object to this to have more information, or similar  
24 about the security and what, you know, Dr. White has been  
25 addressing in terms of the security measures that are in



1 place, and what is the actual, possible risk.

2 CHAIR RUIZ: Uh-hum. Thank you, Dr. Dickey.

3 Do we have any other comments from any of the  
4 other members?

5 COMMITTEE MEMBER DINIS: Yes. So, let me see if I  
6 can put this in the chat and see if people can quickly see  
7 it and wonder. Because in this -- I don't know, let me see.  
8 Am I allowed to put anything in the chat? Let me see. I'm  
9 going to try. Can you see it on your end?

10 CHAIR RUIZ: I can see the link.

11 COMMITTEE MEMBER DINIS: Yeah, data sharing, a  
12 white paper on, and it talks about the federal -- it talks  
13 about the federal, let's see, student aid. Let's see, and  
14 if we go to -- it's about the applicable laws, I believe,  
15 from the Federal Student Aid Programs. When you read  
16 through it, and the Privacy Act, and HE, and FERPA, and the  
17 Privacy Act, and all these things. It almost -- you know,  
18 I'm having trouble, I'm trying to digest it all.

19 But it kind of -- to me this suggests that what  
20 we're doing -- this kind of research cannot be done,  
21 basically, from the federal perspective because these are  
22 federal loans. And it's more than just, you know, that this  
23 is a Student Aid Commission, and whatever happens in the  
24 data of California, de-identified and whatever, anything can  
25 go.

1           But from this document here, it doesn't appear  
2 that this research could be done. So, I'll give you guys a  
3 minute to digest, like me.

4           COMMITTEE MEMBER KURTURAL: For myself, I think  
5 that in order to make a kind of thoughtful decision to  
6 oppose or grant is to get some clarity. I mean not only  
7 these laws, thank you for pointing these out, and FERPA is  
8 quite strict, I will say it's more strict than HIPAA.

9           But I think the crux of, you know, a lot of the  
10 privacy laws is that notice ahead of time. And I think what  
11 kind of the issue is, is what that notice says. Right.  
12 Because if it talks about combining with other datasets,  
13 like the credit report, like what's before us now, you know,  
14 that's one thing.

15           But I was going to get some -- I don't have clear  
16 information to digest, you know, what was provided in that  
17 notice to see if it even fits that balancing factor of  
18 minimal risk.

19           I think most of the privacy laws are going to have  
20 a research exception, but the saying is research exceptions  
21 are, in my view, not enough if you want to avoid, you know,  
22 getting consent. And that the crux of where this falls with  
23 me is what that disclosure says.

24           And so, I don't want to make a motion for John,  
25 but I almost want to table it and see -- you know, take a

1 look at that.

2 CHAIR RUIZ: Okay. Anybody else?

3 DR. ROTHSTEIN: Let me just add, I haven't  
4 reviewed, obviously, every word of the document that Dr.  
5 Dinis just sent out. In looking through it, I see a few  
6 clauses that sure look like they do specifically enable this  
7 study.

8 But I wonder if it would be -- if a useful move  
9 would be for us to provide a legal analysis of the rules  
10 under this. Again, I'm not -- I'm a little surprise that  
11 that is the Committee's, or at least some of the -- much of  
12 the focus of this discussion, because I think that's the  
13 purview of the Student Aid Commission to make that, and  
14 their legal staff to make that determination. But we can  
15 provide that, if that would be helpful. I just don't want  
16 to do it in real time.

17 COMMITTEE MEMBER KURTURAL: I don't --

18 CHAIR RUIZ: Anybody --

19 COMMITTEE MEMBER KURTURAL: Sorry. I don't think  
20 providing -- we're asking for a legal analysis. But we're  
21 asking, okay, we have to have information to show that this  
22 is a minimal risk. And so, I need information on what is  
23 the -- that's not a legal opinion. I need information on  
24 what type of notice was provided at the time when a  
25 particular student or prospective student would have applied

1 for funding.

2 COMMITTEE MEMBER LUND: And, Dr. Ruiz, this is  
3 Laura.

4 CHAIR RUIZ: Laura.

5 COMMITTEE MEMBER LUND: I just wanted to respond  
6 to the last comment. This Committee is absolutely concerned  
7 with making sure that data are released in compliance with  
8 all laws. And sometimes we have found that state agencies  
9 are not always as diligent about releasing data under the  
10 laws, which is why we have now required letters of support  
11 that specifically say the data will be released in  
12 compliance with all laws.

13 So, I don't think it is outside of our purview or  
14 inappropriate for us to be concerned that we understand the  
15 laws under which these data would be released.

16 CHAIR RUIZ: Okay.

17 VICE CHAIR DICKEY: And so we have such a letter  
18 from Student Aid Commission?

19 COMMITTEE MEMBER SCHAEUBLE: Yes, we do.

20 CHAIR RUIZ: Okay, I believe, Dr. Schaeuble, I'm  
21 going to ask you come up with a motion.

22 COMMITTEE MEMBER SCHAEUBLE: I'm not sure where we  
23 stand. But I'm thinking that what I've heard most recently  
24 is a suggestion to --

25 CHAIR RUIZ: Table it.

1 COMMITTEE MEMBER SCHAEUBLE: -- table this until  
2 the next meeting.

3 CHAIR RUIZ: Okay. Dr. Dickey and others, do you  
4 agree with that?

5 VICE CHAIR DICKEY: Yeah, but the question is  
6 what's going to happen between now and the next meeting.

7 CHAIR RUIZ: Right.

8 VICE CHAIR DICKEY: That might help move this  
9 along.

10 COMMITTEE MEMBER DINIS: Well, it seems like we do  
11 need clarification on the federal law, legal clarification.  
12 And I believe, you know -- I mean I believe the -- I don't  
13 know who was talking earlier that said, you know, needed  
14 time to digest, because I was looking at something here,  
15 too. Needed time to digest this and actually interpret  
16 information and that's -- we haven't done that part, yet.  
17 So, we need to know if this -- what the Student Aid  
18 Commission is doing and if this is violating the federal  
19 policy. That's what it seems to me like it is.

20 COMMITTEE MEMBER LUND: So, I think I heard a  
21 couple of things. I think I heard that we need to actually  
22 see the language that the people see when they sign off on  
23 their FAFSA forms, so that we have an understanding of what  
24 people's understanding might be about how their data will be  
25 used.

1 COMMITTEE MEMBER DINIS: Yeah.

2 COMMITTEE MEMBER LUND: I personally would  
3 recommend that we ask our legal staff to take a review -- to  
4 review and provide us input on the federal law in regard to  
5 the release of these particular data.

6 In particular, I was reading through the document  
7 that Maria shared, and a lot of this hinges on what de-  
8 identification means.

9 CHAIR RUIZ: Uh-hum.

10 COMMITTEE MEMBER LUND: And I believe that it's  
11 the position of our researchers that the data are de-  
12 identified. But in fact what I heard from Dr. Schaeuble,  
13 when he gave his presentation in consult with our legal  
14 folks, is that the data may not be considered de-identified  
15 for our purposes. So, I think that we need to get some  
16 clarify around that in order to be able to make a decision.

17 CHAIR RUIZ: Okay. Any other comments.

18 COMMITTEE MEMBER SCHAEUBLE: I think I would add,  
19 it seems to me it's relevant to look at not only what is  
20 disclosed to families applying for student aid, but also  
21 what is disclosed to families with regard to their credit  
22 reports. Because there are, I think, the two ways that  
23 people might be apprised of the possibility of their credit  
24 information being used for something other than the purposes  
25 they might otherwise expect.

1 CHAIR RUIZ: Okay.

2 MR. WHITE: Can I ask one thing, just so that we  
3 provide you with the right information in following up on  
4 that?

5 CHAIR RUIZ: Sure.

6 MR. WHITE: In terms of the language that is given  
7 to folks when they apply for student aid, for example, can  
8 you help us understand what portion of the Committee's  
9 analysis, like where -- I'm a little lost as to where we're  
10 -- like what framework we're using to review this project.  
11 Like is it under Common Rule, is it under IPA, is it some  
12 third and overarching ethical review that I'm not familiar  
13 with?

14 That would be helpful just because I think we  
15 would want to be able to sort of say, okay, here's what the  
16 language is and try and make our best case for why we think  
17 that the project is justified. And right now, I'm very  
18 confused as to what framework is being used. Thanks.

19 VICE CHAIR DICKEY: This is Dr. Dickey. And I  
20 would maintain it's the IPA.

21 COMMITTEE MEMBER DINIS: Yeah. Yeah, it is.

22 CHAIR RUIZ: Agree.

23 VICE CHAIR DICKEY: So, the IPA is rather short.  
24 You just look at the IPA.

25 COMMITTEE MEMBER SCHAEUBLE: Well, I think I would

1 add to that, though, beyond any specifics in the Information  
2 Practices Act is our obligation as a Committee to make  
3 decisions that we consider ethically responsible. And in  
4 that regard, the question for me at least keeps coming back  
5 to what have people been told that would in any way make  
6 them think that their credit reports could possibly be used  
7 for this kind of purpose.

8           And I'm wondering if several of you who have  
9 talked agree with what I've just said?

10           COMMITTEE MEMBER DINIS: Yeah, absolutely.

11           MR. WHITE: And can you point me to that framework  
12 because I'm just not familiar with it, and so it gives us  
13 very little to help give you the information that you would  
14 need. Like what, where is that authority?

15           COMMITTEE MEMBER SCHAEUBLE: Under the Belmont  
16 Report.

17           COMMITTEE MEMBER DINIS: Yeah. Simple, yeah.

18           COMMITTEE MEMBER LUND: I believe there's a link  
19 to the Belmont Report on our CPHS website.

20           DR. ROTHSTEIN: Originally, with the Belmont  
21 Report, right.

22           MR. WHITE: Thank you.

23           CHAIR RUIZ: Okay. Dr. Schaeuble, do you want to  
24 restate the motion, because the only thing I'm seeing here  
25 is table discussion until next meeting, but then there were



1 other things that were requested that I'm not -- so, can you  
2 summarize what the motion is?

3 COMMITTEE MEMBER SCHAEUBLE: Okay, I'm looking at  
4 what has been copied on the screen here from what we've --  
5 what has just been discussed in the past few minutes.

6 Table -- so, let's say table discussion of the  
7 amendment until the next meeting, at which time the  
8 Committee will consider the applicable requirements under  
9 FERPA, the Information Practices Act, and what disclosures  
10 and consent have been provided by families when applying for  
11 student aid, and when receiving their credit reports.

12 COMMITTEE MEMBER LUND: Dr. Schaeuble, could we  
13 ask the researchers to provide those two things to us?

14 COMMITTEE MEMBER SCHAEUBLE: Yes. So, I guess I  
15 could -- oh, here, I guess I can scroll up. Well, I can't  
16 scroll up.

17 Okay, so the beginning of the motion said --

18 VICE CHAIR DICKEY: How about this?

19 COMMITTEE MEMBER SCHAEUBLE: This doesn't work.

20 VICE CHAIR DICKEY: The Committee will consider  
21 evidence provided by the researchers for those issues.

22 CHAIR RUIZ: Uh-hum.

23 COMMITTEE MEMBER SCHAEUBLE: Okay, thank you.

24 MS. MCCARTHY: Would you like me to type over the  
25 existing text?

1 CHAIR RUIZ: Yes.

2 COMMITTEE MEMBER SCHAEUBLE: The Committee will  
3 consider --

4 VICE CHAIR DICKEY: You can just add another  
5 sentence.

6 MS. MCCARTHY: Okay, I'm ready.

7 COMMITTEE MEMBER SCHAEUBLE: At the beginning  
8 there, where it says the Committee will consider evidence,  
9 add the words evidence, information provided by the  
10 researchers about, and then go on with the rest of the  
11 sentence that says the applicable requirements under FERBA,  
12 Information Practices Act, and disclosures and consents  
13 provided to families.

14 Does that make sense to everyone now?

15 VICE CHAIR DICKEY: Does it make sense to the  
16 researchers?

17 DR. ROTHSTEIN: Yes. I think there's a -- I mean  
18 we can interpret it this way, but the disclosure isn't about  
19 when people receive their credit report, it's when people  
20 apply for credit I would think, because that's when the data  
21 gets provided, but --

22 VICE CHAIR DICKEY: Right, when applying for  
23 credit.

24 DR. ROTHSTEIN: Then it's more interacting with  
25 financial institutions.

1 MR. WHITE: But I think you get the gist. It's  
2 more than just FERBA, also, in terms of federal education  
3 laws. But I think we get the idea of what you're looking  
4 for. That's what's important.

5 CHAIR RUIZ: Okay. So, we have a motion. Is  
6 there anyone to second that motion, please?

7 COMMITTEE MEMBER DINIS: I'll second.

8 COMMITTEE MEMBER SCHAEUBLE: And I'm assuming in  
9 making this kind of motion that in working with the  
10 researchers here Committee members can also seek out any  
11 information about these topics, in addition to what the  
12 researchers can provide. Is that a fair statement?

13 VICE CHAIR DICKEY: I think that's implied.

14 COMMITTEE MEMBER SCHAEUBLE: Okay, just wanted to  
15 clarify.

16 COMMITTEE MEMBER LUND: Is there a subcommittee?

17 COMMITTEE MEMBER SCHAEUBLE: The assigned  
18 reviewers have been myself and Dr. Dinis.

19 CHAIR RUIZ: Do we need another person?

20 COMMITTEE MEMBER SCHAEUBLE: Pardon?

21 COMMITTEE MEMBER DINIS: Can we get another  
22 person? Is that possible?

23 COMMITTEE MEMBER LUND: Not unless you want to  
24 have a public meeting.

25 COMMITTEE MEMBER DINIS: Oh, then we can't.

1 CHAIR RUIZ: Oh, that's right. So, can we then  
2 have one of the two reviewers, and then maybe have Dr.  
3 Dickey. Dr. Dickey, would you like to be part of that  
4 subcommittee?

5 VICE CHAIR DICKEY: Wouldn't that make it three?

6 CHAIR RUIZ: No, no, I was saying in case we can  
7 have one of the two reviewers, either Dr. Schaeuble or Dr.  
8 Dinis.

9 VICE CHAIR DICKEY: Yeah, I'm willing to. But,  
10 you know, I think these materials, et cetera, are going to  
11 need to be provided to the whole Committee.

12 CHAIR RUIZ: Uh-huh, okay.

13 VICE CHAIR DICKEY: Because we're going to have to  
14 reconsider this. The whole Committee's going to have to  
15 reconsider it.

16 CHAIR RUIZ: All right. So, we leave the  
17 subcommittee as Schaeuble and Dinis.

18 VICE CHAIR DICKEY: Yeah.

19 COMMITTEE MEMBER DINIS: I'm happy to step out and  
20 have somebody else do it.

21 VICE CHAIR DICKEY: The question is what the  
22 function of the subcommittee is going to be.

23 COMMITTEE MEMBER DINIS: Because I'm not sure it's  
24 required. Since it's going to be tabled and people coming  
25 to the next meeting, I'm not sure that the subcommittee is

1 required.

2 VICE CHAIR DICKEY: Right.

3 CHAIR RUIZ: Right. Okay, shall we do not have a  
4 subcommittee and we just have the original two reviewers.

5 Okay.

6 COMMITTEE MEMBER DINIS: Okay.

7 CHAIR RUIZ: So, we're ready for a roll call.

8 COMMITTEE MEMBER LUND: I think we need a -- was  
9 there a second?

10 COMMITTEE MEMBER DINIS: I was the second, yeah.

11 CHAIR RUIZ: Sorry, second.

12 COMMITTEE MEMBER DINIS: That's already.

13 MS. ATIFEH: Dr. Dinis second.

14 Okay, so Dr. Dickey?

15 VICE CHAIR DICKEY: Approve.

16 MS. ATIFEH: Dr. Bazzano?

17 COMMITTEE MEMBER BAZZANO: Approve.

18 MS. ATIFEH: Ms. Kurtural?

19 COMMITTEE MEMBER KURTURAL: Approve.

20 MS. ATIFEH: Thank you.

21 Ms. Lund?

22 COMMITTEE MEMBER LUND: Approve.

23 MS. ATIFEH: And Dr. Palacio?

24 COMMITTEE MEMBER PALACIO: Approve.

25 MS. ATIFEH: Thank you.

1           Okay, the motion passed.

2           CHAIR RUIZ:   Okay.   Thank you very much Dr.  
3 Rothstein for joining us this morning, and we look forward  
4 to receiving the information for the following meeting.

5           DR. ROTHSTEIN:   Thank you all for your time.

6           CHAIR RUIZ:   And thank you, Dr. Dickey -- I mean  
7 Dr. Schaeuble, Dr. Dinis, and Dr. Dickey for reviewing this  
8 project.

9           CHAIR RUIZ:   All right, we would like to move to  
10 the next project.   Do we have Dr. Lery on?

11          DR. LERY:   Yes, hello.

12          CHAIR RUIZ:   Hello.   Okay, and this project was  
13 reviewed by Dr. Palacio.   Dr. Palacio, you can proceed with  
14 the review.

15          COMMITTEE MEMBER PALACIO:   Yes.   Welcome Dr. Lery.  
16 Would you go ahead and introduce yourself and your team.

17          DR. LERY:   Sure thing, I will.   My name's  
18 Bridgette Lery, I'm a Senior Fellow at the Urban Institute,  
19 based in Washington, D.C., but I'm based in California.   And  
20 I am the principal investigator, or co-principal  
21 investigator of the California Guaranteed Income Pilot  
22 Program evaluation.

23                 And I'd also like to introduce my colleague,  
24 Katrina Brewsaugh, who's the Project Director.

25          COMMITTEE MEMBER PALACIO:   Very well.   Please go

1 ahead and give us a summary of this project and the impact  
2 it will have on the populations being surveyed, the human  
3 beings.

4 DR. LERY: Great. Great, I hope it does have an  
5 impact.

6 COMMITTEE MEMBER PALACIO: Yes.

7 DR. LERY: That's the idea, right.

8 COMMITTEE MEMBER PALACIO: Yes.

9 DR. LERY: So, the project is that California  
10 funder, under SB 739, a Guaranteed Income Program for two  
11 populations. Youth aging out of foster care, transitioning  
12 to adulthood, and low-income pregnant individuals.

13 And under this legislation they are -- the state  
14 is funding a series of pilots taking place throughout the  
15 state, operating by California Department of Social  
16 Services, which went through a process to decide who those  
17 pilot organizations would be. They landed on seven  
18 different pilot sites.

19 And the intervention is a 12- to 18-month cash  
20 payment to those two priority populations I mentioned, youth  
21 aging out of foster care and low-income, pregnant  
22 individuals. And benefits counseling is offered, as well as  
23 potentially other services, but all of that is voluntary.

24 And in five of the sites, five of the seven sites  
25 there are not enough resources to serve everyone who might

1 be eligible, and so the state has decided to randomize or to  
2 do a lottery to determine who will get those limited  
3 resources.

4 In two of the seven sites, they do have enough  
5 resources to serve their entire population.

6 CDSS has contracted with Urban Institute, and UC  
7 Berkeley as a partner, to evaluate what it takes to  
8 implement the GI, this Guaranteed Income Program, as well as  
9 whether or not it has an impact on a variety of outcomes.

10 Today we're here to request approval to conduct  
11 our baseline survey, which will allow us to understand the  
12 baseline for which we want to then later measure outcomes  
13 regarding health, well being, financial well being, housing  
14 and food, security, quality of life, all of those  
15 categories.

16 And so, there's both an implementation study and  
17 impact study, and we're here today to request approval for  
18 the baseline survey.

19 Everyone who participates in the program is just  
20 completely on a voluntary basis. They're invited to  
21 participate through a referral organization in each site, or  
22 through the ether, if they hear about the program. And the  
23 application for the program, as well as an invitation to  
24 participate in the survey is all going to be done through  
25 AidKit, which is a software platform that operates in many



1 other locations to administer their Guaranteed Income  
2 Programs.

3 And finally, I'll say that we are not asking for  
4 any PII as part of the application for the survey. That  
5 AidKit will -- is the contractor that will do the software  
6 platform for application, and it will administer the survey.  
7 And it will not collect any -- not send us any PII, as far  
8 as who's randomized to treatment and control.

9 And I'll just -- I think that's enough for an  
10 intro.

11 COMMITTEE MEMBER PALACIO: Yes, thank you very  
12 much for that. I responded to your email and I just want  
13 you to comment on my responses, whether you agree with them.

14 DR. LERY: Yes, that is all good. Let me pull up  
15 that email. That made sense.

16 So, with respect to translating materials into  
17 other languages, we are -- we've currently got a draft of it  
18 in Spanish. I understand that we need to come back for an  
19 amendment to get that approved.

20 COMMITTEE MEMBER PALACIO: That is correct.

21 DR. LERY: Okay, happy to do that.

22 And then, the second question is, yes, everyone  
23 will be an adult or an emancipated minor. I anticipate  
24 hardly any, if any, emancipated minors. But all the  
25 pregnant people will be adults or emancipated minors. And

1 all the youth aging out of foster care by definition will be  
2 21 or older.

3           The third one is we are happy to provide that  
4 table of the amount of the disbursement by site, because  
5 each site is providing a slightly different disbursement  
6 amount depending on their geographic location.

7           I'm sorry, am I speaking too fast? I see you're  
8 taking notes, sorry.

9           COMMITTEE MEMBER PALACIO: No, no, no, go ahead.

10          DR. LERY: Okay.

11          COMMITTEE MEMBER PALACIO: It is fine.

12          DR. LERY: Okay. The fourth question is, is  
13 AidKit managed through CDSS or Urban Institute? It is  
14 managed through CDSS.

15                 We are currently working on a data sharing  
16 agreement so that AidKit can send Urban Institute  
17 information, non-PII, about who is participating.

18                 And the last question is around compensation. And  
19 so, we will ensure to make that consistent throughout the --  
20 there's a \$25 incentive for completing this baseline survey,  
21 if they elect to do so. And we can make that clear, if we  
22 haven't.

23                 COMMITTEE MEMBER PALACIO: Okay, wonderful. I'd  
24 like to now at this time, having had my questions  
25 satisfactorily met, open it to the Committee for questions,

1 queries, concerns.

2 CHAIR RUIZ: Any comments?

3 VICE CHAIR DICKEY: I think we're all exhausted  
4 from the last discussion.

5 (Laughter)

6 COMMITTEE MEMBER KURTURAL: Absolutely.

7 COMMITTEE MEMBER LUND: I think that that is true.

8 COMMITTEE MEMBER SCHAEUBLE: We probably are but,  
9 unfortunately, I have a couple of questions.

10 CHAIR RUIZ: Please go ahead.

11 COMMITTEE MEMBER PALACIO: Go for it, Dr.  
12 Schaeuble. I was waiting for you. I always love your  
13 questions, your input.

14 COMMITTEE MEMBER SCHAEUBLE: And these are small  
15 things, fortunately, so I don't think it will tax our brains  
16 too much.

17 It seemed to me, in reading the documents, that  
18 the text of the separate survey consent form was different  
19 in a few respects from what was shown as a block of  
20 information about consent at the beginning of the survey. I  
21 assume they should be the same, whatever differences  
22 currently exist there.

23 In particular, I noticed that the survey describes  
24 a later invitation for focus groups and mentions a larger  
25 incentive amount in that situation, that did not appear in

1 the other document. And I don't know whether it belongs at  
2 this point, in any case. But I'd ask you to work that out  
3 with Dr. Palacio.

4 There was also a noticeable change in the size of  
5 the type near the end of the consent information in the  
6 survey. I'm not sure why there was a difference in the two  
7 places there.

8 DR. LERY: Sorry, probably an error. Thank you.

9 COMMITTEE MEMBER SCHAEUBLE: And I wasn't quite  
10 clear about one comment in the protocol which said: If any  
11 personal information is collected, it will be hosted on an  
12 encrypted server that requires internet WiFi access. Why  
13 would it be on a server that was open to the internet?  
14 Or did you even mean to say that?

15 DR. LERY: Let's see, Katrina, do you have a  
16 thought there? I'm trying -- I need to find where it's  
17 written to follow.

18 MS. BREWSAUGH: You're talking specifically about  
19 on the consent form or in the protocol?

20 COMMITTEE MEMBER SCHAEUBLE: This was in the  
21 protocol.

22 MS. BREWSAUGH: Can you clarify?

23 COMMITTEE MEMBER SCHAEUBLE: And I will search  
24 here and try to see if I can find where in the protocol,  
25 again, but you'll have to give me a moment to scroll down to

1 that.

2 MS. BREWSAUGH: I'm wondering if it was in the  
3 sense of I know we had some data security questions that had  
4 to be answered.

5 COMMITTEE MEMBER SCHAEUBLE: Likely, it was in  
6 that part.

7 MS. BREWSAUGH: And so, we probably took it from  
8 other, similar protocols. I'm trying to find data storage.

9 COMMITTEE MEMBER SCHAEUBLE: Ah, yes. Near the  
10 end, the sections that says internet accessibility. It  
11 says: We will not be collecting any personal information.  
12 If it is collected, it will be hosted on an encrypted server  
13 that requires internet WiFi access. And I couldn't quite  
14 process what all that was trying to tell me.

15 MS. BREWSAUGH: Basically, I think like you said,  
16 we're not planning on collecting the PID, so if we just  
17 deleted everything after that semicolon would that suffice?

18 COMMITTEE MEMBER PALACIO: That sounds acceptable  
19 to me.

20 COMMITTEE MEMBER SCHAEUBLE: Yeah. So, you could  
21 literally say we will not be collecting any PID, so nothing  
22 will be accessible to the internet.

23 MS. BREWSAUGH: Okay, we can make that change.

24 COMMITTEE MEMBER SCHAEUBLE: That's all I had.  
25 See, I'm not even going to talk a lot today.

1 MS. BREWSAUGH: Can I just ask a clarifying  
2 question? I was trying to follow, you were talking about  
3 that the consent language is -- describes some of our future  
4 planned activities that are not in another document. Are  
5 you saying that are not described in the protocol currently,  
6 is that what you mean by other document?

7 COMMITTEE MEMBER SCHAEUBLE: No, you had two  
8 attachments. You had one copy that supposedly was the  
9 consent form by itself, and other document that was the  
10 survey, which had supposedly the same consent text at the  
11 very beginning of it, in what you called a consent block.  
12 And those two didn't seem to match entirely.

13 DR. LERY: Okay. Yeah, we will make sure that  
14 they are matching with our revisions.

15 COMMITTEE MEMBER LUND: Thank you.

16 CHAIR RUIZ: Great, any other comments?

17 COMMITTEE MEMBER LUND: I just had two, a couple  
18 minor things.

19 CHAIR RUIZ: Sure.

20 COMMITTEE MEMBER LUND: You ask for their consent  
21 for text messaging. Would you just please let them know  
22 that their carrier rates may apply to text messaging. Not  
23 all text messaging services are free.

24 And the only other comment I had was that you are  
25 asking some -- even though you're not asking for PII, you're

1 asking for some -- you ask questions that are potentially  
2 sensitive. Could you please include that in your consent  
3 form under risks, that the questions might be sensitive.

4 DR. LERY: Okay.

5 CHAIR RUIZ: Thank you. Any other comments?

6 Okay, Dr. Palacio, I think we're ready for a  
7 motion.

8 DR. LERY: I do have a question, if I could?

9 CHAIR RUIZ: Oh, yes.

10 DR. LERY: We had submitted a request for  
11 reciprocity of IRBs, and we got very confused about like  
12 when that's appropriate, when we can do it, and we didn't  
13 hear back, so -- well, I mean we heard back in the sense  
14 that we are here today, so we assume we were not granted  
15 reciprocity. Could you say a little bit about when -- how  
16 and when we would do that, because we were -- see, we have  
17 our IRB approval from Urban Institute, of course. But just  
18 curious about what -- and our IRB -- and we were requesting,  
19 correct me if I'm wrong, Katrina, we were requesting  
20 reciprocity in the direction of allowing Urban's IRB to  
21 stand as the IRB of record.

22 MS. BREWSAUGH: Correct, that's what we put in our  
23 request.

24 VICE CHAIR DICKEY: I guess I could say something  
25 about this.

1 CHAIR RUIZ: Yes, please.

2 VICE CHAIR DICKEY: And I -- maybe we should  
3 specify this better on our website. In general, our  
4 Committee does not delegate reviews to other IRBs, except  
5 for federal IRBs.

6 CHAIR RUIZ: Uh-hum.

7 VICE CHAIR DICKEY: Like CDC, NIH, et cetera. Or  
8 where we're required to because the feds have designated a  
9 central IRB. So, that's -- but maybe we should make that  
10 more explicit on our website.

11 CHAIR RUIZ: Okay.

12 DR. LERY: I'm aware of a project at UC Berkeley  
13 where they do have the reciprocity with the state in that  
14 direction. So, I think that's why we thought it would be  
15 possible.

16 VICE CHAIR DICKEY: I'm not aware of any that was  
17 --

18 CHAIR RUIZ: Neither am I.

19 VICE CHAIR DICKEY: We -- they have delegated to  
20 us.

21 DR. LERY: Uh-hum.

22 VICE CHAIR DICKEY: But we've never delegated to  
23 them.

24 DR. LERY: Okay.

25 VICE CHAIR DICKEY: The -- and it's just sort of a



1 principle. The reason the Information Practices Act was  
2 created was because of something that happened at Berkeley  
3 University many years ago.

4 DR. LERY: Uh-huh.

5 VICE CHAIR DICKEY: So, in general we just don't  
6 delegate to others, other than federal.

7 DR. LERY: Okay.

8 CHAIR RUIZ: All right. So, Dr. Palacio, I think  
9 we would be ready for a motion.

10 COMMITTEE MEMBER PALACIO: Yes. I move deferred  
11 approval, minimal risk, for one year subject to the minor  
12 additions that have been discussed, to be reviewed by a  
13 committee of myself.

14 CHAIR RUIZ: All right. So, we have a motion. Is  
15 there anyone to second that motion?

16 VICE CHAIR DICKEY: I'll second.

17 CHAIR RUIZ: Okay, thank you, Dr. Dickey.

18 And Sussan, I think we're ready for roll call.

19 MS. ATIFEH: Okay, thank you.

20 I start with Dr. Bazzano?

21 COMMITTEE MEMBER BAZZANO: Approve.

22 MS. ATIFEH: Dr. Dinis? I think Dr. Dinis left  
23 the meeting, I think.

24 CHAIR RUIZ: Correct.

25 MS. ATIFEH: Ms. Kurtural?

1 COMMITTEE MEMBER KURTURAL: Approve.

2 MS. ATIFEH: Ms. Lund?

3 COMMITTEE MEMBER LUND: Approve.

4 MS. ATIFEH: Dr. Schaeuble?

5 COMMITTEE MEMBER SCHAEUBLE: Approve.

6 MS. ATIFEH: Okay, the motion passed.

7 CHAIR RUIZ: All right, thank you very much --

8 COMMITTEE MEMBER PALACIO: Thank you.

9 CHAIR RUIZ: -- for coming to the board this

10 morning.

11 DR. LERY: Thank you very much.

12 MS. BREWSAUGH: Thank you.

13 DR. LERY: Hope you all have a restful rest of

14 your day.

15 COMMITTEE MEMBER PALACIO: You too, and a happy

16 Good Friday.

17 DR. LERY: Thank you. You, too.

18 MS. BREWSAUGH: Thank you.

19 DR. LERY: Take care, bye.

20 COMMITTEE MEMBER PALACIO: Bye.

21 CHAIR RUIZ: All right. Thank you. That's the

22 two projects that came to us for review. And I think now

23 we're ready to go back to some of the updates.

24 And Dr. Dickey, can you give us a brief update

25 with the newly created documents?

1           VICE CHAIR DICKEY: Yeah, we circulated them  
2 around, I believe.

3           CHAIR RUIZ: Uh-hum.

4           VICE CHAIR DICKEY: There's something called a --

5           CHAIR RUIZ: CPHS Basics.

6           VICE CHAIR DICKEY: -- CPHS Basics, which is  
7 intended to make it clearer to researchers how they go about  
8 approaching the Committee. Just some of the basic  
9 principles so that they don't have to read our policies and  
10 procedures, which actually haven't been revised since 2014,  
11 which is the next thing that needs to happen.

12           Anyway, those are circulated around. Dr.  
13 Schaeuble submitted some comments, which we've accepted.  
14 Thank you, Dr. Schaeuble.

15           So, if there aren't any other comments, I think we  
16 can see about posting them on our website.

17           CHAIR RUIZ: Yeah. And then the other two  
18 documents was a not research application and the accept  
19 research application.

20           VICE CHAIR DICKEY: Yeah.

21           CHAIR RUIZ: Which is great, this is very much  
22 needed. Thank you.

23           VICE CHAIR DICKEY: Sure. And, you know, those  
24 forms, only you and I really see them because we're the ones  
25 that make the determinations of whether something is --

1 CHAIR RUIZ: Correct.

2 VICE CHAIR DICKEY: -- research or not, or whether  
3 it's exempt.

4 CHAIR RUIZ: Correct.

5 VICE CHAIR DICKEY: But we did circulate them to  
6 the Committee and I think there were no concerns.

7 CHAIR RUIZ: Yeah.

8 VICE CHAIR DICKEY: You and I had talked about  
9 perhaps we need to have something where maybe entities can  
10 apply to us to determine that they're not under our purview.

11 CHAIR RUIZ: Correct.

12 VICE CHAIR DICKEY: Because that's the other issue  
13 that we commonly run into. So, if it's okay, Dr. Ruiz, I'll  
14 work on a form for that.

15 CHAIR RUIZ: Great. Thank you.

16 All right, then if we can jump to another update,  
17 it's the Los Angeles Mom and Baby Project adverse event, and  
18 Ms. Lund or Dr. Dickey.

19 COMMITTEE MEMBER LUND: My personal favorite, huh.

20 CHAIR RUIZ: Yes. I was tempted for saying that.

21 COMMITTEE MEMBER LUND: So, the update is that  
22 since the last meeting there were a couple of requirements  
23 associated with the adverse event. Some were for the  
24 researchers and some were for this Committee.

25 So, for this Committee we were to provide CDPH

1 with the protocols for all of these inappropriately released  
2 research studies that we had approved. And thanks to staff,  
3 especially Sussan, she was able to locate almost all of  
4 them. There are two that we can't find, or they, thank you,  
5 can't find anywhere. And she even went and looked in the  
6 hardcopy archives and they're just missing. So, we were  
7 only able to provide CDPH with I think it's 11 of the 13  
8 studies.

9 L.A. has the contact information, the name and  
10 contact information for the PIs for those studies, and has  
11 provided that to CDPH to see if they can follow up with  
12 them. But we have done the best that we can in terms of  
13 providing them with assistance in what they need to do to  
14 mitigate the damage on their side from this adverse event.

15 We also, as a committee voted to develop language  
16 for researchers. And I don't know if that's a separate  
17 agenda item or if you just want me to talk about that now?

18 CHAIR RUIZ: Go ahead, yeah, and you can talk  
19 about that, please.

20 COMMITTEE MEMBER LUND: Okay, I'll go ahead and  
21 talk about that now. So, we drafted information for  
22 researchers who want to use data that was originally sourced  
23 from either birth certificates or death certificates.  
24 Because that's where the problem came in with this adverse  
25 event and with the inappropriately released data is that

1 information as shared from one researcher to other  
2 researchers without going through the procedures that are  
3 required in law.

4           So, you should all have gotten a copy of this  
5 document. It touches on the three main errors that we  
6 commonly see when people are inappropriately requesting  
7 Vital Records data for their studies.

8           Oh, thank you so much. Okay, so on your screen,  
9 so the first thing that researchers need to know is that  
10 only the State Registrar, housed at CDPH, can legally  
11 provide Vital Records data. So, if they're getting data  
12 from someone other than that, they're not following the  
13 procedures that are required in the law. And if they are  
14 getting data from someone else, we need to know that CDPH is  
15 aware that they're doing that, and that CDPH will provide us  
16 with information in a letter of support saying that this is  
17 okay with them.

18           The second thing is that the -- any data, birth or  
19 death data, has to be -- the research study must be reviewed  
20 and approved by the Vital Statistics Advisory Committee.  
21 So, researchers are being requested to attach their VSAC  
22 application to their research protocol when we review it, to  
23 ensure that they have done that.

24           This also will help with the problem of getting  
25 data from other researchers, instead of directly from CDPH,

1 because CDPH will not allow them to do that through the VSAC  
2 process. So, having that VSAC application is evidence that  
3 CDPH is being made aware of the data strategies of the  
4 researcher.

5 And then, finally, the third thing, again coming  
6 out of the Lamb Study, is that researchers are linking Vital  
7 Records data to data from other sources. In the case of the  
8 Lamb Project, it was the Lamb Survey data.

9 But this comes across my desk all the time when I  
10 have expedited reviews from like Kaiser. People want to  
11 develop linked data files, and they want to develop  
12 registries, and then they want to share that information  
13 with other researchers.

14 And this third bullet tells researchers that  
15 because this is not consistent with what's allowed under  
16 state law, CPHS will not be able to approve studies that  
17 propose to use -- to develop registries or create linked  
18 data files that will be shared with other researchers. And  
19 we direct them to CDPH to review their proposed plan. But  
20 we can't, under the law, approve those studies.

21 This informational document has been reviewed by  
22 CDPH and they're okay with it. They're actually very happy  
23 that we're going to be telling people this. And it has also  
24 been reviewed by our legal folks, who made some wording  
25 changes, but nothing substantive, and all of our legal --

1 all of the changes made by our legal folks have been  
2 incorporated. So, what you're seeing here is the proposed  
3 final version of the document.

4 In the adverse event stipulation we had voted on  
5 adding this to our website, so that researchers would be  
6 able to see this. And also adding it into IRBManager, so  
7 that when they -- we'll have to figure out where the best  
8 place is. But when they are requesting data, they need to  
9 see that this -- these are the rules around Vital Records  
10 data.

11 Our attorney also suggested that we include this  
12 language in our boilerplate when we approve a Vital Records  
13 related data study. And that's okay with me. This is a lot  
14 to include, but that was a really nasty adverse event. And  
15 so, if we can avoid that in the future, and if the Committee  
16 thinks that that would be a good idea, we should do it.

17 Our attorney also suggested that CDPH might want  
18 to include this information when they release data. And I  
19 reviewed their materials and all of this is really clearly  
20 stated in the materials that they provide to the researchers  
21 at the time they get the data. Which is again why it's  
22 really so disappointing that we had this adverse event.

23 So, I don't think that we need to ask CDPH -- my  
24 opinion is that we don't need to ask CDPH to do anything  
25 above and beyond what they're currently doing to inform



1 people that these are the rules. But if the Committee  
2 thinks otherwise, we can certainly reach out and ask them to  
3 include some or all of this.

4 So, those are the two -- so, those are the two  
5 things that were required for the Committee in regard to the  
6 adverse event. And I'm going to pend discussion of this  
7 document for just a minute, while I tell you about the Los  
8 Angeles follow up side.

9 So, Los Angeles Department of Public Health has  
10 been attempting to reach out to the researchers, who  
11 received the data. They still haven't been able to contact  
12 all of them. I think that they still have two outstanding.

13 They will be coming back to us at the June meeting  
14 to give an update on where they are. And they have provided  
15 all of the requested information to CDPH regarding the  
16 adverse event. That is the PI information and the contact  
17 information for PIs for that study.

18 So, before I go on to talk specifically about it,  
19 because I think I'll ask for a motion to adopt this  
20 document. Before I go on to that, are there any questions  
21 about the adverse event and follow up to that adverse event.

22 MS. ATIFEH: Ms. Lund, can I say something.

23 COMMITTEE MEMBER LUND: Yes.

24 MS. ATIFEH: This is Sussan. I just wanted for  
25 the record to ensure we captured everything correctly. I

1 just wanted to clarify there were not 13 projects. There  
2 were just 11 and we found 9 of them. Two of them are  
3 missing.

4 COMMITTEE MEMBER LUND: Great. Thank you for that  
5 clarification. I'm sorry, my notes were wrong. I  
6 appreciate that.

7 MS. ATIFEH: No problem.

8 COMMITTEE MEMBER LUND: Okay.

9 COMMITTEE MEMBER SCHAEUBLE: Laura, just one  
10 question.

11 COMMITTEE MEMBER LUND: Yes.

12 COMMITTEE MEMBER SCHAEUBLE: Very glad to see the  
13 information put together here on this. It seems so  
14 important considering what we've experienced.

15 With regard to the last part of this, there's a  
16 phrase in there that says: Without prior CDPH approval in  
17 discussing the possibility of linked data files or  
18 registries. Are we supposed to interpret from this a  
19 conclusion that researchers can ask for CDPH approval, but  
20 they're not going to get it?

21 COMMITTEE MEMBER LUND: So, that's a great  
22 question. And these Vital Records laws are so darn  
23 complicated. So, the reason that that wording is there is  
24 that one of the things that the VSAC Science Advisor does is  
25 -- it's a he now -- he, when people propose to do this data

1 file linkage and sharing, or to develop a registry, he very  
2 specifically works with them to ensure that if they want to  
3 share the Vital Records data those data fields are  
4 transformed sufficiently to make all of the legal people at  
5 CDPH happy that they are different than information that was  
6 originally on either the birth or death certificate.

7           So, for example, if it is complications of  
8 pregnancy, instead of the actual code or the complication of  
9 pregnancy that's listed in the data file, the researcher  
10 might group those under, you know, things that are related  
11 to hypertension, or things that are related to blood  
12 disorders, or whatever the grouping is.

13           So, you would not, from the transformed variable,  
14 be able to understand or identify what the data field was on  
15 the actual certificate itself.

16           And so, if that's what they're proposing to do,  
17 because I recently referred one from -- reviewed one from  
18 North Carolina who had done this, and I'm like, wait, you  
19 can't do this. And I talked to CDPH about it and as long as  
20 they have been through that process and gotten CDPH approval  
21 for the transformation, they can link those transformed data  
22 fields because they're no longer considered to be CDPH data  
23 once they've been changed, and then they can do it. That's  
24 why we need this letter of support.

25           COMMITTEE MEMBER SCHAEUBLE: Okay.

1 COMMITTEE MEMBER LUND: So, that was a long  
2 explanation. Did that answer your question?

3 COMMITTEE MEMBER SCHAEUBLE: Yes, thank you.

4 CHAIR RUIZ: Good.

5 COMMITTEE MEMBER LUND: Anybody else?

6 CHAIR RUIZ: Nope. Thank you, Laura.

7 COMMITTEE MEMBER LUND: So, let me just go back to  
8 this, is I just want to make sure if everyone is okay with  
9 this document. Do we need a motion to move forward to put  
10 it on the website, or since that was part of the motion for  
11 the adverse event can we just go ahead and do that, if  
12 everyone is okay with the document? What are the thoughts  
13 here procedurally?

14 CHAIR RUIZ: I'm fine with the documents. I think  
15 we probably would like to have a motion. And I don't know  
16 whether everybody has read the documents and agree or  
17 whether somebody may need more time. But yeah, I agree with  
18 a motion.

19 Dr. Dickey, would you agree with that?

20 VICE CHAIR DICKEY: Well, we didn't make a motion  
21 for my documents.

22 CHAIR RUIZ: Oh, well, we can include a motion --  
23 in the motion we can include yours and Laura's.

24 VICE CHAIR DICKEY: I don't want a motion.

25 CHAIR RUIZ: Okay. All right, so if we don't need

1 a motion that's okay, too.

2 VICE CHAIR DICKEY: My feeling on documents is  
3 unless there are no objections --

4 CHAIR RUIZ: Okay.

5 VICE CHAIR DICKEY: -- then we go ahead and post  
6 them. If we had to have a motion on every document we post  
7 --

8 CHAIR RUIZ: All right. Well, I guess it's in the  
9 whatever information for this meeting it will be stated that  
10 we reviewed and we agree with the documents. So, thank you,  
11 Laura. And thank you, Dr. Dickey.

12 COMMITTEE MEMBER LUND: And if you just bear with  
13 me, I have one more comment.

14 CHAIR RUIZ: Yes.

15 COMMITTEE MEMBER LUND: So, this was quite a  
16 learning experience. And I have a concern I want to raise  
17 to the Committee that we may want to be more sensitive about  
18 all of -- because it's not just Vital Records data that  
19 these issues come up. And the laws are different for  
20 different data sources.

21 I went back and reviewed, and I know the Vital  
22 Records statutes. I am not as familiar with the statutes  
23 for some of the other CDPH data sources and some of the  
24 other data sources we deal with. And I went back and I  
25 reviewed the CCR statutes. And it seems to me that we might

1 have this problem with the CCR data as well, because there  
2 is something very specifically about not sharing the CCR  
3 data from one researcher to another.

4           And I'm wondering if we should ask CDPH if we  
5 should have similar advisories for CCR data. I know that  
6 this same language would apply to the Immunization Branch  
7 data. And it even says that in the ICB data use agreement  
8 that they give to researchers, very specifically.

9           We had someone come to our October meeting who had  
10 been working on a long-standing project that linked CCR data  
11 with I think Medical Records data, and there were a lot of  
12 offspring projects. And his argument was that we didn't  
13 want to see all of those and that they were really all part  
14 of the same approved research because they were all on the  
15 same topic.

16           And I know at least in regards to the Vital  
17 Records data that CDPH has a very narrow interpretation of  
18 what they mean by sharing and reuse. And that is that it  
19 can't be -- no individual data field or combination of data  
20 fields can be shared beyond the originally approved data  
21 protocol, including the principal investigator approved for  
22 that protocol, and all of the research staff approved.

23           So, researcher number two over here can't come and  
24 say, oh, you're doing research on, you know, morbidity among  
25 women in L.A. County. I'm doing that research, too, so your

1 data approval covers my research project. CDPH says no,  
2 that is actually not what the law says.

3 And I'm wondering if we should get a read, at  
4 least, from CCR on how tightly they're interpreting their  
5 data laws, because this comes up a lot. And I know the  
6 person who came and spoke to us in October wanted to reshare  
7 CCR data to other researchers working on similar studies.

8 So, thank you for letting me put in my two --

9 CHAIR RUIZ: I think that's a very good question.  
10 And we're still waiting for CCR. We had requested a meeting  
11 with them. And that meeting was never agreed upon. So,  
12 maybe we can go back and request a meeting and include this  
13 as part of the conversation.

14 Unless, Dr. Dickey, you may have another option.

15 VICE CHAIR DICKEY: I sort of think we've kind of  
16 posed this to them as part of it. And the fact that they  
17 haven't come back to us -- but, yeah, I think it's good to  
18 try to get another meeting with CCR.

19 CHAIR RUIZ: Okay. And Laura, if we have that  
20 meeting, would you like to be invited to that meeting?

21 COMMITTEE MEMBER LUND: Yeah, actually I would.  
22 Thank you.

23 CHAIR RUIZ: All right, great.

24 All right, any questions regarding any of the  
25 documents? If not, then Sussan, is Elaine part of this

1 meeting today, or do we have any reports or updates from the  
2 Administrator?

3 MS. ATIFEH: No, but I think I can provide a quick  
4 update on Agenda Item B.

5 CHAIR RUIZ: Okay.

6 MS. ATIFEH: You know, Agenda Item B is about the  
7 instructions that we received from the legal team to  
8 simplify the process of posting agenda and meeting materials  
9 for our full meetings on the website, on the CPHS website.

10 Actually, the very first thing that legal team  
11 clarified for us was the fact that agenda can only include a  
12 very general description of the project that will be  
13 discussed. And it doesn't have to include the various  
14 specific information of the project, like their title, their  
15 numbers, the name of PI.

16 And it means we can separate the very long list of  
17 projects that usually comes at the continuation of agenda  
18 and post it as a separate document.

19 And you know, if I share my -- do I have time to  
20 share my screen?

21 CHAIR RUIZ: Sure.

22 MS. ATIFEH: Yeah, you know, so we used to post  
23 everything as one single document. For example, in  
24 December, last December 18, 2022, as you see there is just  
25 one link in our website. When you click on it, it opens a



1 kind of very long document with 90 pages that has the -- 90  
2 pages. But actually, based on what I heard from legal team,  
3 the first three pages or sometimes four pages are actual  
4 agenda, with very general description for the items that we  
5 plan to discuss.

6 For example, I can -- agenda item -- agenda item,  
7 for example Agenda Item F. It says: Projects with reported  
8 adverse events. It's enough. It's enough to ensure  
9 compliance with the requirements of that.

10 CHAIR RUIZ: Okay.

11 MS. ATIFEH: Of the Bagley-Keene Open Meeting Act.  
12 Because as you know, we are under the Act and we have to  
13 post the agenda 10 days before the meeting. And after  
14 posting this, we cannot change it.

15 But we used to post the long list of projects as a  
16 continuation of this document. And, you know, IRBManager,  
17 the program is designed in a way to grab and select some  
18 words, but they are not necessarily the best words.

19 So, legal team wanted us to change some words.  
20 For example, deleting this agenda and changing attachment to  
21 meeting materials. They said, when you say attachment it  
22 means it should be attached to the actual agenda and comes  
23 as the continuation of it.

24 And in some situation, for example when after  
25 posting agenda we receive a very important project with new

1 adverse event, and the Chair and Vice Chair really want that  
2 report to be discussed, so it's hard -- it's actually  
3 impossible to incorporate that project to update this list,  
4 because after posting it we cannot change it.

5           But as soon as you change the attachment to  
6 meeting materials, you can separate it. And, you know,  
7 after applying those changes, for example you can see April  
8 2023 meeting, we have two links. One is agenda, which is  
9 just a very brief document with 3 pages. It's a very  
10 general description for the projects.

11           And then, when you click on the second attachment  
12 it opens the list of projects. As you see, we removed the  
13 word "agenda" and we changed the attachment to meeting  
14 materials.

15           So, I posted this one actually at the same time of  
16 agenda, but because it was after posting agenda we went  
17 through a lot of changes. Like two PIs decided to withdraw  
18 their application, we received a new one. So, actually I  
19 update this one and I reposted this document because its  
20 name is meeting material, it's not agenda. It's not subject  
21 to the requirement of the Act. And after posting it we can  
22 edit it, we can repost it.

23           So, to ensure people, the public, the researchers  
24 during the meeting they not only have access to the agenda  
25 that has been posted 10 business days before the meeting,

1 but also they have access to the meeting materials that have  
2 been updated adequately to reflect the important  
3 information about all the projects that have been planned to  
4 be discussed in the meeting. And no project is missing.

5 So, that's what I wanted to inform Committee  
6 members about it.

7 CHAIR RUIZ: Wonderful.

8 MS. ATIFEH: And actually, there is a very  
9 important point. The intention behind these instructions  
10 was just simplifying posting agenda for us and giving more  
11 flexibility to our Committee members to --

12 CHAIR RUIZ: To make changes, yeah.

13 MS. ATIFEH: Yes, yes. But they didn't want us to  
14 announce it to researchers to change our submission  
15 deadline. They really wanted our researchers to take the  
16 submission deadlines very seriously and to prepare the  
17 projects based on those deadlines, especially if it's a  
18 subject involved with human subject contacts. Because we  
19 really want our Committee members have enough time, like at  
20 least two weekends, two weeks to vote on those projects.

21 So, it doesn't mean changing our policy,  
22 procedures, and those submission deadlines.

23 CHAIR RUIZ: Great, thank you.

24 VICE CHAIR DICKEY: But it does --

25 CHAIR RUIZ: Yes?

1           VICE CHAIR DICKEY: This change does give us  
2 flexibility.

3           MS. ATIFEH: Flexibility, exactly.

4           VICE CHAIR DICKEY: So, for example, this project  
5 that Dr. Palacio reviewed --

6           MS. ATIFEH: Yes.

7           VICE CHAIR DICKEY: -- came in after our  
8 traditional deadline.

9           MS. ATIFEH: Yes, yes.

10          VICE CHAIR DICKEY: And if we hadn't changed  
11 things, we wouldn't have been able to discuss that at this  
12 meeting.

13          CHAIR RUIZ: Correct.

14          MS. ATIFEH: You know, we might be able to discuss  
15 it because as the legal team explained to me the general  
16 description's there.

17          VICE CHAIR DICKEY: I understand.

18          MS. ATIFEH: Yes. But the problem is they really  
19 want people, the public, the researchers during the meeting  
20 have access to what we discuss. They really want when they  
21 open the -- you know, let me show you. When they come to  
22 our website, when they open the page of the current meeting  
23 and they see the links, and open the meeting materials they  
24 see exactly what we plan to discuss. Not something that  
25 should be deleted. Not something that has not been added.

1 The very updated, adequately updated meeting materials.

2 CHAIR RUIZ: Right. Well, thank you for the  
3 update, Sussan.

4 And I would like to also take a look at the -- for  
5 us to take a look at the minutes. As you remember in  
6 February we had a couple of meetings.

7 MS. ATIFEH: Yes.

8 CHAIR RUIZ: One was on February the 3rd and the  
9 other one was on February the 27th.

10 MS. ATIFEH: Yes.

11 CHAIR RUIZ: So, may I ask you please, if you have  
12 any comments or revisions for either one of the two sets of  
13 minutes?

14 Having none, can I ask someone to come up with a  
15 motion to approve both sets of minutes?

16 VICE CHAIR DICKEY: I move that we approve both  
17 sets of minutes.

18 CHAIR RUIZ: Thank you.

19 MS. ATIFEH: Both of them? Both minutes?

20 CHAIR RUIZ: Yeah, February the 3rd and February  
21 27th.

22 MS. ATIFEH: Got it. Okay, thank you so much.

23 COMMITTEE MEMBER LUND: I second. This is Laura.

24 CHAIR RUIZ: Okay.

25 MS. ATIFEH: Okay, thank you, Laura.

1 VICE CHAIR DICKEY: I just want to say, actually,  
2 maybe we should separate them because there may be people  
3 who were at one meeting, but not at the other.

4 CHAIR RUIZ: Well, true.

5 MS. ATIFEH: Oh, okay.

6 CHAIR RUIZ: Okay. All right, so let's go with  
7 February the 3rd.

8 MS. ATIFEH: So, Dr. Dickey made the motion and  
9 the Ms. Lund approved it.

10 And I'm going to start with Dr. Bazzano? Oh, Dr.  
11 Bazzano is not present.

12 Okay, and Dr. Dinis is not here.

13 Okay, Ms. Kurtural?

14 COMMITTEE MEMBER KURTURAL: Approve.

15 MS. ATIFEH: Okay. And Dr. Palacio.

16 COMMITTEE MEMBER PALACIO: Approve.

17 MS. ATIFEH: Thank you.

18 Dr. Schaeuble? Oh, Dr. Schaeuble was present?

19 Yes, yes, yes, okay.

20 COMMITTEE MEMBER SCHAEUBLE: I would have to  
21 abstain since I couldn't be present for the meeting.

22 MS. ATIFEH: Oh, okay. So, I'm going to ask Dr.  
23 Ruiz to break the tie.

24 CHAIR RUIZ: Approve.

25 MS. ATIFEH: Did you approve?

1 CHAIR RUIZ: Yes.

2 MS. ATIFEH: Okay, thank you.

3 Yes, the motion passed.

4 CHAIR RUIZ: Okay. All right. So, what about now

5 the February 27th minutes.

6 MS. ATIFEH: Okay, I think that's Dr. Dickey made

7 the motion.

8 CHAIR RUIZ: Uh-hum.

9 VICE CHAIR DICKEY: I make the motion that we

10 approved February 27th.

11 MS. ATIFEH: Okay. And Ms. Lund approved it.

12 Okay, so I again start with Dr. Bazzano. Oh,

13 actually, again, Dr. Bazzano -- sorry, Dr. Bazzano is not

14 present.

15 Oh, Ms. Kurtural?

16 COMMITTEE MEMBER KURTURAL: Approve.

17 MS. ATIFEH: Thank you.

18 Dr. Palacio?

19 COMMITTEE MEMBER PALACIO: Approve.

20 MS. ATIFEH: Dr. Schaeuble? Dr. Schaeuble?

21 COMMITTEE MEMBER SCHAEUBLE: Can you hear me?

22 MS. ATIFEH: Yes.

23 COMMITTEE MEMBER SCHAEUBLE: Yes, I approve.

24 MS. ATIFEH: Approve. Okay, thank you.

25 So, the motion passed.

1 CHAIR RUIZ: Thank you. Well, thank you so much  
2 for joining us today. The next meeting is scheduled for  
3 June 2nd.

4 VICE CHAIR DICKEY: Dr. Ruiz?

5 CHAIR RUIZ: Yes.

6 VICE CHAIR DICKEY: Don't we have a personnel  
7 issue? Maybe have more staff by then?

8 CHAIR RUIZ: Oh, yeah, I think I mentioned it at  
9 the beginning that Lucila Martinez will be joining us as a  
10 retired annuitant, as of next Monday.

11 MS. ATIFEH: Yes.

12 CHAIR RUIZ: And so, I'm glad because Sussan and  
13 Karima have had a lot of work on their plate. So, I'm glad  
14 that Lucila is coming back.

15 MS. ATIFEH: Yes. And, you know, I think it's a  
16 good opportunity. I inform everyone that Ruben Mejia was  
17 helping us a lot with the, you know --

18 CHAIR RUIZ: Yes. Oh, yes.

19 MS. ATIFEH: -- reviewing. Yes. The continuing  
20 review application for the data only projects.

21 CHAIR RUIZ: Uh-huh.

22 MS. ATIFEH: And always we had Sheryl McCarthy,  
23 and hopefully we continue to have her, as the primary note  
24 taker.

25 CHAIR RUIZ: Great. And thank you, Ruben. I'm



1 sorry for not mentioning your name. And thank you.

2 So, yeah, so --

3 COMMITTEE MEMBER PALACIO: But I really think that  
4 Sussan, and Karima, and the team need to be commended for  
5 doing such a wonderful job.

6 CHAIR RUIZ: Agreed.

7 MS. ATIFEH: Thank you so much, thank you.

8 COMMITTEE MEMBER LUND: Absolutely, yes.

9 MS. ATIFEH: Thank you so much for all the  
10 guidance that when I needed, I received from you very  
11 quickly. Especially I know I sent a lot of email to Dr.  
12 Dickey, Dr. Ruiz and Ms. Lund. So, I really appreciate you  
13 responded to my questions. Thank you.

14 CHAIR RUIZ: All right.

15 MS. ATIFEH: Thank you every, all Committee  
16 members.

17 CHAIR RUIZ: Thank you all. We'll see you in  
18 June, hopefully.

19 MS. ATIFEH: Thank you.

20 (Thereupon, the meeting was adjourned at  
21 11:10 a.m.)

22 --oOo--

23

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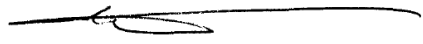
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I do hereby certify that the testimony in the foregoing hearing was taken at the time and place therein stated; that the testimony of said witnesses were reported by me, a certified electronic court reporter and a disinterested person, and was under my supervision thereafter transcribed into typewriting.

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IN WITNESS WHEREOF, I have hereunto set my hand this 16th day of May, 2023.



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PETER PETTY  
CER\*\*D-493  
Notary Public

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I do hereby certify that the testimony in the foregoing hearing was taken at the time and place therein stated; that the testimony of said witnesses were transcribed by me, a certified transcriber.

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IN WITNESS WHEREOF, I have hereunto set my hand this 16th day of May, 2023.

A handwritten signature in black ink, appearing to read "Barbara Little", is written over a horizontal line. The signature is stylized and cursive.

Barbara Little  
Certified Transcriber  
AAERT No. CET\*\*D-520