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Director & State Health Officer

Vital Statistics Advisory Committee (VSAC)
Vital Records Protection Advisory Committee (VRPAC)
Joint Meeting
Meeting Minutes for Wednesday, October 14, 2015
9:00 AM



EDMUND G. BROWN JR.
Governor

ATTENDEES:

Convener:

Heather Fukushima, HPS I, Health Information and Research Section

Committee Members:

Phone: Jonathan Teague, Manager, Office of Statewide Health Planning and Development, David Grant, PhD, UCLA Center for Health Policy Research, Sun Lee, MPH, Los Angeles County Department of Public Health, Shannon Muir, PhD, Science and Technology Fellow, Senate Health Committee, Erlinda Valdez, Board Member, California Funeral Directors Association

California Department of Public Health (CDPH) Staff:

Present: Cindy Tanaka-Fong, Research Analyst II, Data Management Unit, Colin Chew, Research Analyst I, Health Information and Research Section, Elaine Bilot, MS, MA, Section Chief, Health Information and Research Section, Laura Lund, MA, Science Advisor, Public Health Policy and Research Branch, Heather Fukushima, HPS I, Health Information and Research Section

Public Attendees: No Public Attendees

CALL TO ORDER: The meeting was called to order at 9:00 A.M.

A/B. WELCOME/INTRODUCTIONS:

Staff present attending the meeting included: Cindy Tanaka-Fong, Research Analyst II, Data Management Unit, Elaine Bilot, MS, MA, Section Chief, Health Information and Research Section, Colin Chew, Research Analyst I, Health Information and Research Section, Laura Lund, MA, Science Advisor, Public Health Policy and Research Branch, Heather Fukushima, HPS I, Health Information and Research Section

Committee members on the phone included: Jonathan Teague, Manager, Office of Statewide Health Planning and Development,

David Grant, PhD, UCLA Center for Health Policy Research, Sun Lee, MPH, Los Angeles County Department of Public Health, Shannon Muir, PhD, Science and Technology Fellow, Senate Health Committee, Erlinda Valdez, Board Member, California Funeral Directors Association

Heather informed the Committee that this would be Shannon Muir's last meeting with VSAC. She accepted another position and wanted to congratulate her new successes and thanked her for time and service on this Committee. Shannon told the Committee that her fellowship ends at the end of month.

Heather informed everyone that the meeting was being recorded to assist with note taking purposes. This meeting complies with the Bagley-Keene Open Meeting Act.

We have reserved a portion of the meeting for public comment. We would like to ask our public attendees to reserve comments until we arrive at that portion of the meeting.

The next item of discussion is our VSAC meeting in November. The second Wednesday of November falls on a state holiday. We are trying to look at other dates and wanted to get the Committee's feedback on other alternative dates. The one date in which Laura Lund would be available and able to join is November 4. She is going on vacation thereafter so she would not be able to attend any of these other dates that will be suggested. The other dates that are available are November 10, 12, or 18. Sun wanted to know if we knew how any project/protocols that would have to review. Heather informed the Committee that we have 5 projects and 3 that would be on the consent calendar. Jonathan informed the Committee that the California Health and Human Services Agency Conference Transforming Healthcare is November 9 and 10. Heather informed the Committee if these dates don't work, the meeting can be canceled. The Committee decided that the meeting for November would be held on November 4.

C. APPROVAL OF MINUTES FROM THE PREVIOUS MEETING:

Shannon Muir motioned to approve the September 9, 2015 meeting minutes. Sun Lee seconded the motion. Jonathan Teague, Erlinda Valdez, David Grant, Shannon Muir, and Sun Lee voted aye to unanimously approve the minutes. There were no oppositions. Motion carried. The minutes were approved as distributed.

D. VSAC RECOMMENDATIONS FROM THE PREVIOUS MEETING:

The State Registrar's Responses to VSAC Recommendations are included in your agenda package as Attachment 1.

The first project reviewed by the Committee was:

Project Title: "Prioritizing Cooling Infrastructure Investments for Vulnerable Southwest Populations"

Principal Investigator(s): David Eisenman, MD, University of California, Los Angeles

Project Type: Continuing Project

CPHS Approval: Approved

Project No.: 14-02-1505

Expiration: April 1, 2016

File(s) Requested: 2010-2012 Death Statistical Master File (select variables)

Requested Identifiers: Address and Certificate Number

Personal Contact: No

Identifiers Released: No

History: Previous Data Request

VSAC Discussion: No Discussion

VSAC Motion: Jonathan Teague motioned to recommend approval of the data release. Sun Lee seconded the motion.

VSAC Vote: Jonathan Teague, Erlinda Valdez, David Grant, Shannon Muir and Sun Lee voted aye unanimously in recommending approval of the data request. Motion carried. The Committee has voted to recommend that the State Registrar (SR) approve the use of the data as described in the protocol.

The second project reviewed by the Committee was:

Project Title: "The Path of Language and Literacy: A Cross Linguistic Longitudinal Approach"

Principal Investigator(s): Margaret Friend, PhD, San Diego State University

Project Type: Continuing Project with No Changes to the Protocol

CPHS Approval: Approved

Project No.: 13-02-1088

Expiration: April 1, 2016

File(s) Requested: 2014 Birth Statistical Master File (select variables), 2014 California Comprehensive Death File (select variables)

Requested Identifiers: BSMF (Name and Address), CCDF (Name, Address, Mother's Maiden Name)

Personal Contact: Yes

Identifiers Released: Yes

History: Previous Data Request

VSAC Discussion: Sun wanted to know if each project was considered as one study. If they have multiple studies in which they are doing using the same data, do they have to submit multiple protocols? The Science Advisor (SA) said yes, they can submit one protocol but they would have to describe each project independently.

Jonathan said that CPHS prefer they submit individual protocols. If they were two projects that were related in some way, on the same topic, it made sense to consider them together, that would be acceptable but CPHS does like to see one at a time as this Committee does as well.

Sun said for this protocol, they do say multiple studies they are doing, and wanted to know if one protocol was okay. The SA said that is up to the Committee. The SA asked Sun if she needed more details on separate protocols on each of the studies. That is something this Committee will need to determine.

VSAC Motion: Sun Lee motioned to recommend approval of the data release. Jonathan Teague seconded the motion.

VSAC Vote: Jonathan Teague, Erlinda Valdez, David Grant, Shannon Muir and Sun Lee voted aye unanimously in recommending approval of the data request. Motion carried. The Committee has voted to recommend that the SR approve the use of the data as described in the protocol.

The third project reviewed by the Committee was:

Project Title: "Mortality Differentials among Native Born, Documented and Undocumented Immigrants from Mexico in California, 1970-2013"

Principal Investigator(s): Ka Yuet Liu, PhD, University of California, Los Angeles

Project Type: New Project

CPHS Approval: Approved

Project No: 15-05-2035

Expiration: August 5, 2016

File(s) Requested: 1970-2013 Death Statistical Master File (select variables)

Requested Identifiers: DSMF (Name, Certificate Number, Address, SSN, and MMN)

Personal Contact: No

Identifiers Released: No

History: New Data Request

VSAC Discussion: As there was some confusion as to what was to be given out to the requestor, the SA clarified that they would only get the data fields that they requested. Unless they requested just a subset of the cases in the file, they would get all the cases and do their own subsetting. If this Committee wants to recommend something differently, they can. If you prefer the SR only release the subset of cases that the requestor will be working with, but this is generally not something we do by default.

The SA told the Committee that she had questions about their original submission. They resubmitted with justifications for all of the fields so unless the Committee has questions about the justifications, she was okay with what they submitted.

VSAC Motion: Jonathan Teague motioned to recommend approval of the data release. Shannon Muir seconded the motion.

VSAC Vote: Jonathan Teague, Erlinda Valdez, David Grant, Shannon Muir, and Sun Lee voted aye unanimously in recommending approval of the data request. Motion carried. The Committee has voted to

recommend that the SR approve the use of the data as described in the protocol.

The fourth project reviewed by the Committee was:

Project Title: "Impact of Economic Factors on Health Outcomes at Birth"

Principal Investigator(s): Margaret Shih, MD, Los Angeles County Department of Public Health

Project Type: Continuing Project

CPHS Approval: Approved

Project No.: 12-08-0619

Expiration: February 5, 2016

File(s) Requested: 1997-2010 Birth Statistical Master Files (select variables), 1997-2010 Death Statistical Master Files (select variable).
Note: PI is requesting to use data files previously obtained.

Requested Identifiers: BSMF (Name and Address), DSMF (Address)

Personal Contact: No

Identifiers Released: No

History: Previous Data Request

VSAC Discussion: David said on Page 5 of the Vital Statistics application, under Security, interim files would be created. They describe how Dr. Simeonova will de-identify the data and create de-identified data that would be stored at John Hopkins. On Page 7, Access to Data, they state all personally identifiable information except for FIPS codes would be removed from the data before transferred to John Hopkins. Only the de-identified data will be accessible to Dr. Basurto-Davila and Dr. Simeonova which seems inconsistent with the previous statement that states that Dr. Simeonova will create the de-identified data. David said he does not have a problem with the project but does have a problem with the inconsistency and how the personally identifiable data is handled.

Dr. Basurto-Davila will have the raw data and send it to John Hopkins. Dr. Simeonova would create a de-identified data set. In order to complete the linkages, they would need sensitive variables. Once they prepared their research files with the actual variables, they were going

to strip the rest of the sensitive data. They are trying to provide an additional measure of security. They do not have to retain sensitive data once they've done their data. We have to depend on their good faith when they say they are going to do something.

Sun pointed out that on Page 7, Yeabin Moon is listed as having access to the data but not listed in detail. The SA told Sun we do not require that of any other researchers who provide name of people who will access to the data. The SA asked Sun if there was a particular reason she wanted this. We just require them to list who is going to have access and they do not have access how.

Sun points out that on No. 3, Research Personnel with Access to Protected Personal Information, she said maybe this person does not access to it to it, that's fine but everyone here is listed on the access to data on the Vital Statistics application.

The SA said that the only thing we formally require here at CDPH is that they identify on page 7 who is going to have access to the file. They do not have to describe their nature of their access as long as they tell us who they are. We have not required this on any other application so she asked Sun if she wants this application to provide that additional information from this person.

VSAC Motion: Jonathan Teague motioned to recommend approval of the data release. Sun Lee seconded the motion.

VSAC Vote: Jonathan Teague, Erlinda Valdez, David Grant, Shannon Muir, and Sun Lee voted aye unanimously in favor of recommending approval of the data request. Motion carried. The Committee has voted to recommend that the SR approve the use of the data as described in the protocol.

The fifth project reviewed by the Committee was:

Project Title: "Autism Metabolomics and Environment (AIME)"

Principal Investigator(s): Beate Ritz, MD, PhD, University of California, Los Angeles

Project Type: New Project

CPHS Approval: Approved

Project No.: 15-07-2135

Expiration: August 5, 2016

File(s) Requested: 2000-2013 Birth Statistical Master Files (select variables)

Note: PI is requesting to use data files previously obtained.

Requested Identifiers: Name, Certificate Number, and Address

Personal Contact: No

Identifiers Released: No

History: New Data Request

VSAC Discussion: Sun wanted to know if they talked about the cell size suppression rule. Jonathan said that CPHS has a requirement for cell size suppression. The SA said she did not get the impression that they would release their data in tabular format. It looks like a fairly sophisticated analysis. They are doing a variation of regression analysis based on their description, so cell size suppression would not apply.

One of the things we are now requiring for everyone who receives any file other than our Public Use File, they have to complete and sign an Information Privacy and Security Requirement (IPSR) document. This is prepared by our CDPH Privacy Officer and the Information Security Office. Any contractors that are involved if the data goes offsite to a contractor, the IPSR has to cover the contractor as well as the original requestor.

Sun wanted to know if contractors have to sign an IPSR. The SA said if we are releasing the data to a requestor who is then going to provide the data to a contractor, yes, they would need to fill out an IPSR. If the contractor works on site with the data requestor, for example at CDPH, we have contractors that are embedded. The contracting agency does not have sign the IPSR because the staff is working inside our firewalls on our system. If the data are going outside of the requestor to an external entity for use, like the John Hopkins University application, then that entity would have to sign an IPSR.

David asked if they could get a copy of this.

VSAC Motion: Jonathan Teague motioned to recommend approval of the data release. Sun Lee seconded the motion.

VSAC Vote: Jonathan Teague, Erlinda Valdez, David Grant, Shannon Muir, and Sun Lee voted aye unanimously in favor of recommending approval of the data request. Motion carried. The Committee has voted to recommend that the State Registrar approve the use of the data as described in the protocol.

F. ITEMS FOR DISCUSSION: Heather asked the Committee to refer to Attachment 3, Recap of Data Requests Approved in the Vital Statistics Unit.

G and H. PUBLIC COMMENTS and DISCUSSION TOPICS:

There was no public comment.

CHSI DATA RELEASE PROCEDURES

Over the last 6 months, the Center for Health Statistics and Informatics has been reviewing our data release policy. It came to our attention that we had been releasing data in violation of statute. Once we realized that, we stopped all of our data deliveries while we reviewed everyone who was receiving data from Vital Records. We reviewed them in regard to what they are allowed to receive in statute, what they were receiving, whether they were receiving data via a contract or some other arrangement, and we have overhauled all of our data release procedures.

We have several standard data products. We have a Public Use File, defined in statute Health & Safety (H&S) Code Section 102330. It contains data for birth and death, limited number of fields but is available to anyone who wants to request as long as they follow the procedures that are required in statute. They have to submit a notarized request and describe how they are going to use the data, they can't use it for fraudulent purposes and there are some other stipulations in statute. We can deliver a Public Use File for birth or death, weekly, monthly, quarterly, or an annual file. We can deliver it in near real time. Monthly files are generally prepared on the 15th of the month following the month the event was registered.

We also have an Anti-Fraud File. The context of this file is specified in statute. It contains everything in the Public Use File plus a couple of additional fields, Social Security Number (SSN) and Mother's Maiden Name (MMN). It is still a very limited file. This file is available to legitimate entities who need it for fraud prevention purposes and that is defined in statute. For example, insurance companies want to make sure they know who is deceased so they are not continuing to pay out any claims of any kind. It is also available to law enforcement

agencies for law enforcement purposes. There is a special procedure and they have their own special application form. The stipulations who can receive it and what they have to do to receive it are specified in statute. Because they are receiving information that is identifiable, SSN and MMN, we require anyone who is receiving that file to sign the IPSR before they receive the file. They can get that file weekly, monthly, quarterly, or on an annual basis.

We have requests from researchers. Researchers can come from a number of different kinds of organizations. We do not distinguish among type of organizations. Researchers who are working for government agencies or UC's, or other kind of academic institutions all go through the same process. The research process involves being reviewed by VSAC. Based on VSAC's review, there is a SR review. Based on the SR's decision, the data is either released or not released to the requestor. This is the piece the Committee is familiar with because that is generally what you participate in.

We also have a separate application for request from government agencies. Under statute, H&S Code 102230, the SR has brought discretion in regard to providing data to government agencies. The SR can provide any data from the death file and most data from the birth file to government agencies on request. We have a special review process for those requests. They can have near real time data, weekly, monthly, quarter or an annual data file. Generally, they have to enter into a contract with us. The IPSR is part of that contract.

The SA told Sun that she would need to fill this application out in order to request data from us. She also told Sun she did not have to request Death Data, only Birth and Fetal Death until we have those files available on VRBIS and then she would not have to make any requests to us at all. The SA said that an IPSR will need to be submitted us; it is the same IPSR that the County signed for VRBIS. If you have a signed VRBIS IPSR, you can attach with the application. The IPSR covers you for 3 years, part of the contract.

We have a separate application for CDPH programs. The SR has broad latitude to what can be provided to them. Because they are internal to the Department, they don't have to sign an IPSR. It is assumed that they play by the Information Security Officer and Privacy Officer rules that we adhere, following the same requirements.

Jonathan wanted to know when the contracts will be available for government agencies. OSHPD has a pending data request but will be

asking for more data and wanted to show the contract to OSHPD's legal department. The SA referred him to Michelle Miles and asked him to send her an e-mail, which she would forward to her. We have a mechanism until the contract is in place, we do have a mechanism to do data delivery through a signed application process. If you want your data sooner, she told Jonathan to send her an e-mail because we are trying to move the contracts through quickly as possible but because we changed over and we have a lot of contracts, we were delivering data outside contracts, which was not a good idea so that is why all these people are having contracts, so it has created a huge workload.

If want data that is not just a one-time delivery, you would have to have a contract. This is one of the reasons that we are moving towards VRBIS as our data delivery mechanism because once you are trained on VRBIS, you can access and download your own data. You don't have to apply for the death data. Once we have the birth and fetal death functionality fully implemented, you won't ever have to apply to us for birth or fetal death either.

I. MEETING ADJOURNMENT: Jonathan Teague motioned to adjourn the meeting. Jonathan Teague, Erlinda Valdez, David Grant, Shannon Muir and Sun Lee voted aye unanimously in favor of adjourning the meeting. Motion carried.