



RON CHAPMAN, MD, MPH
Director & State Health Officer

Vital Statistics Advisory Committee (VSAC)
Vital Records Protection Advisory Committee (VRPAC)
Joint Meeting
Meeting Minutes for Wednesday October 8, 2014
9:00 A.M.



EDMUND G. BROWN JR.
Governor

ATTENDEES:

Convener:

Terri Mack, MPA, Chief, Health Information and Research Section
(HIRS)

Committee Members:

Absent: Jonathan Teague, MCRP, Office of Statewide Planning and Development, Erlinda Valdez, Board Member, California Funeral Directors Association

Phone: Sun Lee, MPH, Los Angeles County Department of Public Health, David Grant, PhD., UCLA Center for Health Policy Research,
Present: Emily Putnam-Hornstein, PhD, University of Southern California

California Department of Public Health (CDPH) Staff:

Absent: Laura Lund, MA, Science Advisor, Public Health Policy and Research Branch

Present: Terri Mack, HIRS, Henry Montes, Chief, Data Management Unit, Heather Fukushima, HPS I HIRS, Cindy Tanaka-Fong, Research Analyst II, DMU, Colin Chew, Research Analyst I, DMU,

Public Attendees:

CALL TO ORDER: The meeting was called to order at 9:05 A.M.

A/B. WELCOME/INTRODUCTIONS:

Staff and Committee present attending the meeting included Henry Montes, Chief, Data Management Unit, Heather Spencer-Fukushima, Health Program Specialist, Cindy Tanaka-Fong, Research Analyst II, and Colin Chew, Research Analyst I. Our Science Advisor, Laura Lund will not be attending the meeting.

We have researchers attending the meeting, Ann Nakamura and Christine Rinki both from Maternal, Child, and Adolescent Health

(MCAH), and Gary Kean who is working as a CDPH employee and student of UC Davis.

Committee members on the phone included Sun Lee, Department of Public Health, County of Los Angeles and David Grant, Director, California Health Interview Survey, UCLA Center for Health Policy Research, Also in the room was Emily Putnam-Hornstein, PhD., University of Southern California.

Terri informed everyone that the meeting was being recorded to assist with note taking purposes. We have reserved a portion of the meeting for public comment.

An e-mail was sent regarding Form 700. Advisory Committee members are required to sign. Terri said any questions you may have concerning the form, can be referred to her by e-mail, or by phone, or she can refer you to our legal office if you have questions they can help with.

In keeping with the meeting facilitation request from last meeting, discussion of the research projects will be asked prior to asking for the committee's recommendation.

C. APPROVAL OF MINUTES FROM THE PREVIOUS MEETING:

Emily Putnam-Hornstein motioned to approve the September 10, 2014 meeting minutes. Sun Lee seconded the motion. All Committee members voted to approve the minutes. There were no oppositions. Motion carried. The minutes have been 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.

E. NEW BUSINESS:

Eight projects were reviewed.

The first project reviewed by the Committee was:

Project Title: "Decreasing Access to Trial of Labor after Cesarean: What is the Impact on Patients?"

Principal Investigator(s): Melissa Rosenstein, MD, University of California, San Francisco

Project Type: New Project

CPHS Approval: Approved

Project No.: 14-02-1499

Expiration: June 5, 2015

File(s) Requested: 1991-2010 PDD/Linked Birth Cohort File

Requested Identifiers: California identifiers

Personal Contact: No

Identifiers Released: No

History: New Data Request

VSAC Discussion: No Discussion

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

VSAC Vote: The Committee members all voted aye. There were no oppositions. Motion carried. The Committee has voted to recommend that the State Registrar approve the use of the data as described in the protocol.

The second 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: New Project

CPHS Approval: Approved

Project No.: 14-02-1505

Expiration: April 4, 2015

File(s) Requested: 2000-2012 Death Statistical Master File (select variables), 2000-2010 Multiple Cause of Death, 2000-2010 PDD/Linked Death Data

Requested Identifiers: DSMF (Address)

Personal Contact: No

Identifiers Released: No

History: New Data Request

VSAC Discussion: No Discussion

VSAC Motion: David Grant motioned to recommend approval of the data. Emily Putnam- Hornstein seconded the motion.

VSAC Vote: The Committee members all voted in favor of recommending approval of the data request. There were no oppositions. Motion carried. The Committee has voted to recommend that the State Registrar approve the use of the data as described in the protocol.

The third project reviewed by the Committee was:

Project Title: "Vaccine Safety Datalink (VSD)"

Principal Investigator(s): Wansu Chen, Kaiser Permanente

Project Type: Continuing Project

CPHS Approval: Approved

Project No: 12-08-0588

Expiration: October 3, 2014

File(s) Requested: 2011 Multiple Cause of Death, 2013 Death Statistical Master File (select variables),

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

Personal Contact: No

Identifiers Released: No

History: Previous Data Request

VSAC Discussion: The Committee pointed out that on page 11 of the protocol, the PI is asking for social security numbers and thought that

this was removed from the birth data set. Emily thought that they did not update this because they were able to get SSN in the past. Sun commented that since it is a continuing project, it is a good to let them know SSN is unavailable just in case they were not aware of it. We can bring this to the PI's attention and it is the Committee's choice to approve and to make sure we are all clear on what their expectations are. This request is not for birth data but it is still in the protocol. The protocol could be updated to be consistent with the request to not reference birth data and not reference the mother's maiden name and social security numbers for birth data. The Committee did not want to hold the data request but if they could clarify and update that information with the protocol, that should be fine. Emily brought up the point that the Committee talked about this before but was not sure if it has ever been resolved about the outstanding issue of continuing projects which have been going on for some duration of time. Some of the researchers may be in possession of material, social security numbers and mother's maiden name, that were released 7 or 8 years ago, and they have been able to continue working with that data, and Emily doesn't know if there has been any Committee action in terms of whether that is acceptable as long as it has been maintained under CPHS approval. For new releases of birth files, those variables will not be available and that is the reason it is here, that they may possess some of that data from early years.

We can make staff make note of this issue and we can make it an agenda item to discuss this issue.

VSAC Motion: David Grant motioned to recommend approval of the data release contingent upon the removal of the request for mother's maiden name and mother's social security number from the birth master file. Sun Lee seconded the motion.

VSAC Vote: The Committee has voted to recommend that the State Registrar approve the use of the data with the stipulation the protocol be revised to remove the request for mother's maiden name and social security number from the portion of the protocol which refers to birth data. The Committee members all voted aye. There were no oppositions. Motion carried.

The fourth project reviewed by the Committee was:

Project Title: "A Mixed Methods Approach to Evaluating ASD Interventions in KPNC"

Principal Investigator(s): Lisa Croen, PhD, Kaiser Permanente

Project Type: New Project

CPHS Approval: Approved

Project No.: 14-08-1686

Expiration: October 2, 2015

File(s) Requested: 2008-2013 Birth Statistical Master File (select variables), 2008-2013 Birth Cohort Files (select variables)

Requested Identifiers: BSMF (Name, Certificate Number, Address), BC (Name, Certificate Number, Address)

Personal Contact: No

Identifiers Released: No

History: New Data Request

VSAC Discussion: There was confusion with their description, as they said it was a mixed method study and on the other hand, there was no contact with human subjects, yet they are talking about qualitative interviews. They are using multiple sources of Kaiser Records, and administrative data including electronic medical records. The Committee could not understand what they were using the birth files for. Even though they received CPHS approval, there was so much ambiguity about how the files were being used, the Committee was recommending follow-up on better understanding the use of the birth records.

VSAC Motion: Emily Putnam-Hornstein motioned to recommend approval of the data release contingent upon the researcher providing additional details clarifying how the birth records will be used in combination with other data sources. David Grant seconded the motion.

VSAC Vote: The Committee has voted to recommend that the State Registrar approve the use of the data as described in the protocol contingent upon receiving clarification on the use of the birth records in combination with the other data sources mentioned in the protocol. The Committee members all voted aye. There were no oppositions. Motion carried.

The fifth project reviewed by the Committee was:

Project Title: "San Francisco Mammography Registry: A Research Resource"

Principal Investigator(s): Karla Kerlikowske, MD, University of California, San Francisco

Project Type: Continuing Project

CPHS Approval: Approved

Project No.: 12-04-0132

Expiration: June 5, 2015

File(s) Requested: 2011-2013 Death Statistical Master File (select variables)

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

Personal Contact: No

Identifiers Released: No

History: Previous Data Request

VSAC Discussion: No Discussion

VSAC Motions: Emily Putnam-Hornstein motioned to recommend approval of the data release. Sun Lee seconded the motion.

VSAC Vote: The Committee members all voted aye. There were no oppositions. Motion carried. The Committee has voted to recommend that the State Registrar approve the use of the data as described in the protocol.

The sixth project reviewed by the Committee was:

Project Title: "Maternal and Infant Health Assessment"

Principal Investigator(s): Michael Curtis, PhD, CDPH, Epidemiology, Assessment, and Program Development Branch

Project Type: New Project

CPHS Approval:

Project No.:

Expiration:

File(s) Requested: Requesting to re-release data previously obtained (2011 BSMF (select variables) to CDC

Requested Identifiers: BSMF (NOPI)

Personal Contact: No

Identifiers Released: No

History: New Data Request

VSAC Discussion: This project was returning to the Committee because there were questions regarding the re-release of data that was discussed in our last meeting. One of the things that the Committee asked for was for the State Registrar to receive a legal opinion on the re-release and additional information from the researchers. Staff did meet with legal. One option was a new data request be submitted by the Centers for Disease Control in which they ask the Department of Public Health for birth data. In the new data request, CDC would be the primary researcher, CDPH Maternal, Child and Adolescent Health would be co-applicant. The work that would be done would be that CDC would receive MIHA data with MCAH working as a consultant to help them produce the data set for their Healthy People Study. The data would be shared as a team. To produce this data set would not be an issue of re-release. It would be a collaborative effort in which the data set would be produced by CDC. That was the option after discussion with legal and staff. This is an option that Terri presented to the Committee per their request that the State Registrar receive a legal option.

One of the issues with the application that was submitted was the re-release of data. Our statutes do not accommodate that kind of re-release of data not to CDC but to any party.

The new application submitted by CDC, would be requesting birth data, MCAH would be the co-applicant, would come before the Committee for review, it would not be an issue of re-release, it would be issue of collaboration.

The options we have is not accept the application as submitted because of the issues of re-release or accept it as that's the recommendation the Committee wants to make to the State Registrar, or the Committee can make a recommendation based on the information that they received regarding the legal opinion that the State Registrar received regarding the re-release issue of the application.

Christine expressed one concern she had was in the process of creating the MIHA analytic file, they link to the BSMF. They would prefer if they could do this themselves, instead of CDC. Christine was told that in the new application environment, MCAH would be doing the work in behalf of CDC.

VSAC Motions: Emily motioned not to act on existing application but to provide feedback to MCAH and CDC that the Committee looks forward to receiving a new application from CDC requesting permission to utilize a subset of variables and fields that has previously been released to MCAH for linkage purposes and we will review that at our next meeting. David wanted to know if it had to be that detailed. It should be the same basic application proposed as a collaborative project between MIHA and CDC. Most of the detail was in the original application except for the re-release of MIHA to CDC. CDC is named as a co-collaborator. We are approving the release of the data from the State Registrar to CDC.

Terri said we would like to clarify that we are not going to act on the proposal as submitted but the Committee looks forward to receiving a new application, CDC is the primary applicant, MCAH is the secondary applicant.

David asked if we needed to take action since we are not going to approve this. Terri said that the motion should not act on the existing project, as the project was carried to this meeting for discussion. We would not act on the application but the Committee looks forward to receiving a new application. CDC is the primary applicant, and MCAH is the secondary applicant. The protocol will identify how they will work together to share the birth and MIHA data to produce the product for Healthy People project. MCAH will be doing the work on behalf of CDC.

Sun Lee seconded the motion.

It was moved and seconded that the State Registrar not act on the existing protocol that has been submitted titled MIHA, but look forward to a new application submitted by CDC. CDC is named as the primary applicant; CDPH MCAH is named as secondary applicant. The protocol will describe how the data files will be shared collaboratively, and describe how MCAH will be doing the linkage work on behalf of CDC.

VSAC Vote: The Committee members all voted aye. There were no oppositions. Motion carried. The Committee has voted to recommend that the State Registrar follow the motion that the Committee has voted on.

The seventh project reviewed by the Committee was:

Project Title: "Using the Donut Method and Census Block Demographics to Protect the Anonymity of Persons Included in Data Releases"

Principal Investigator(s): Gary Kean, Graduate Student, University of California, Davis

Project Type: New Project

CPHS Approval:

Project No.:

Expiration:

File(s) Requested: 2009-2011 Death Statistical Master File (select variables)

Requested Identifiers: DSMF (Address)

Personal Contact:

Identifiers Released:

History: New Data Request

VSAC Discussion: Discussion revolved on the request for the special medical indicator. The special medical indicator has the specific causes of death and has any special circumstances, and may include homelessness. The reason he is asking for this is that the idea of the project is to anatomize the data and be able to use it for research purposes. In order for him to test prior to his process and after his process, he wanted to have that piece of data to determine whether he can use it for research purposes. He will determine if the data is recognizable but not identifiable to the person related to.

The special medical indicator is a function of the Multiple Cause of Death from the transax file. The file is searched for ICD-10 codes indicating conditions such as HIV, certain respiratory conditions and cancers. Once it is mentioned in the special medical indicator, it would be flagged. Ann did not recall it including demographic information like homelessness. It is scanning of the transax records for specific cause codes.

The Committee felt that there was not enough information as the application was unclear. After the project was completed, there was no publication or no work on the releases. Gary explained this was the basis of his Master's Thesis at UC Davis, Health Informatics Department. It would be technically published as the school's process. If it works, they will publish the process.

From the Committee's perspective, it would be helpful having that information understanding the intent but also how the results will be released and the release of the method and not the confidential information released from the State Registrar's office.

The Science Advisor had similar concerns that were already discussed.

VSAC Motions: David motioned to recommend approval contingent upon release of information regarding the methods used for de-identification clarified or added to the application. Emily Putnam-Hornstein seconded the motion.

VSAC Vote: The Committee has voted to recommend that the State Registrar approve the use of the data as described in the protocol with the stipulation that the application be revised to clarify the release of the methodology and publication or however it will be released. The Committee members all voted aye. There were no oppositions. Motion carried.

The eighth project reviewed by the Committee was:

Project Title: "Children's Data Network/CA Children's Services Archive/ Child Welfare Indicators Project/CA California's Services Archive"

Principal Investigator(s): Emily Putnam-Hornstein, PhD, University of Southern California **Project Type:** Continuing Project

CPHS Approval: Approved

Project No.: 13-10-1366

Expiration: June 5, 2015

File(s) Requested: 2011-2012 Birth Statistical Master File (select variables), 2010-2011 Birth Cohort File (select variables), 2008-2013 Death Statistical Master File (select variables)

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

Personal Contact: No

Identifiers Released: No

History: Previous Data Request

VSAC Discussion: The VSAC cover letter was cut off in the PDF version which was sent to Colin last night. There is nothing new that is not in the CPHS protocol or VSAC application. Comments from the Science Advisor said that this project is open ended and very broad in scope. If the Committee approves the release of the data, they may want to consider asking to review again every 2 years or so, to make sure the project is on track and stay completely within scope.

Emily clarified that the data partners would not have access to the data. Their plan is to better understand the trajectories of children of California through their different services systems. If they have a new data partner who is willing to share data with them in which they can link that with birth records so they can have one more event on that trajectory, they would want to do that. They would first go to the state agency to receive CPHS approval. If there are any new data sources that would be linked to existing birth records that they were working with in the context of the larger project, they would come back to VSAC to request permission to link another data source to the records.

The Committee stated as long as any future data acquisition or merging would be put before for the Committee, there was no concern about additional requirements on Committee review. The project was approved as is.

VSAC Motions: Sun Lee motioned to recommend approval of the data release. David Grant seconded the motion.

VSAC Vote: The Committee members all voted aye. There were no oppositions. 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: Terri asked the Committee to refer to Attachment 3, Recap of Data Requests Approved in the Vital Statistics Unit.

G and H. Public Comments and AGENDA ITEMS:

Discussion topics will include the request from the Committee to make an agenda item of one of the points of discussion; this will be brought to the additional business portion of the agenda for future meeting.

We are working with ITSD as there have been problems with our SharePoint site.

I. MEETING ADJOURNMENT: Sun Lee made a motion to adjourn the meeting. David Grant seconded the motion. The meeting was adjourned at 10:20 A.M.

DRAFT