



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 August 13, 2014
9:00 A.M.



EDMUND G. BROWN JR.
Governor

ATTENDEES:

Convener: Henry Montes, Chief, Data Management Unit

Committee Members:

Absent: Deborah Williams, California Department of Social Services, Matthew Sundquist, Emily Putnam-Hornstein, PhD, University of Southern California

Phone: Sun Lee, MPH, Los Angeles County Department of Public Health, Jonathan Teague, MCRP, Office of Statewide Planning and Development, David Grant, PhD., UCLA Center for Health Policy Research, Erlinda Valdez, Chief, California Funeral Directors Association

California Department of Public Health (CDPH) Staff:

Absent: Terri Mack, MPA, Chief, Health Information and Research Section

Present: Ellen Badley, MHA, Chief, Public Health Policy and Research Branch, Cindy Tanaka-Fong, Research Analyst II, DMU, Colin Chew, Research Analyst I, DMU, Heather Fukushima, RPS I, Laura Lund, MA, Science Advisor

Public Attendees: Elizabeth Anderson, University of California, Berkeley

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

A/B. WELCOME/INTRODUCTIONS:

Staff and Committee present attending the meeting included Ellen Badley, Chief, Public Health Policy and Research Branch, Laura Lund, Science Advisor, Cindy Tanaka-Fong, Research Analyst II, Colin Chew, Research Analyst I, and Heather Spencer-Fukushima, Health Program Specialist.

Committee members on the phone included, Sun Lee, Department of Public Health, County of Los Angeles, Jonathan Teague, Manager, Office of Statewide Planning and Development, David Grant, Director, California Health Interview Survey, UCLA Center for Health Policy Research, Erlinda Valdez, Board Member, California Funeral Directors Association, and Elizabeth Anderson, Public Attendee .

Henry 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. We sent a reminder e-mail for this meeting as the previous meeting was postponed due to a lack of a quorum.

C. APPROVAL OF MINUTES FROM THE PREVIOUS MEETING:

Jonathan Teague motioned to approve the June 11, 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:

Twelve projects were reviewed.

The first project reviewed by the Committee was:

Project Title: "Visual Processing and Later Cognitive Effects in Infants with FXS"

Principal Investigator(s): Susan Rivera, PhD., University of California, Davis

Project Type: Continuing Project with changes to the protocol

CPHS Approval: Approved

Project No.: 12-04-0103

Expiration: June 5, 2015

File(s) Requested: 2008-2014 Birth Records (select variables), 2008-2014 Infant Death Records (select variables) Principal Investigator is requesting to use files that were obtained by Lisa Oakes.

Requested Identifiers: Birth Records (Name and Address), Infant Death Records (Name and Address)

Personal Contact: Yes

Identifiers Released: No

History: Previous Data Request

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

VSAC Discussion: No Discussion

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: "Factors Associated with the Closure of Emergency Services & Impact on Patient Outcomes: Effect of Unemployment on Emergency Department Utilization"

Principal Investigator(s): Renee Hsia, MD, University of California, San Francisco

Project Type: Continuing Project

CPHS Approval: Approved

Project No.: 12-04-0073

Expiration: June 6, 2015

File(s) Requested: 2010 PDD/linked Death Data

Requested Identifiers: California identifiers

Personal Contact: No

Identifiers Released: No

History: Previous Data Request

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

VSAC Discussion: As there was a concern regarding data linkage, Jonathan provided an explanation. He said that they would be doing

internal linkage within the file using the record linkage numbers. If you have a particular episode of care, the record linkage number would be used to associate the individual encounter associated with that. This is something that happens in the linked file itself. This is patient specific linkage but not combining other data sets from the outside. The other data sets they are going to use "combining" with the data are categorical data sets, things like county level employment data or census level files, generally applied on a categorical basis.

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: "The California Maternal Data Center: Establishing a Statewide Data Center for use in Rapid-Cycle Maternity Care Improvement Projects"

Principal Investigator(s): Jeffrey Gould, MD, MPH, Stanford University

Project Type: Continuing Project

CPHS Approval: Approved

Project No: 12-04-0157

Expiration: June 5, 2015

File(s) Requested: 2014-2015 Birth Statistical Master File (select variables)

Requested Identifiers: California Identifiers

Personal Contact: No

Identifiers Released: No

History: Previous Data Request

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

VSAC Discussion: No Discussion

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 fourth project reviewed by the Committee was:

Project Title: "Regional Opportunity Index"

Principal Investigator(s): Chris Benner, PhD., University of California, Davis

Project Type: Continuing Project with changes to the protocol

CPHS Approval: Approved

Project No.: 13-07-1287

Expiration: August 7, 2015

File(s) Requested: 2012 Birth Statistical Master File (select variables), 2012 Death Statistical Master File (select variables)

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

Personal Contact: No

Identifiers Released: No

History: Previous Data Request

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

VSAC Discussion: Comments from the Science Advisor included that this is not a research application for surveillance use of the data.

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 fifth project reviewed by the Committee was:

Project Title: "Predicators of Recurrent Breast Tumors in Women with DCIS"

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

Project Type: Continuing Project

CPHS Approval:

Project No.:

Expiration:

File(s) Requested: 2011-2012 Death Statistical Master File (select variables)

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

Personal Contact: No

Identifiers Released: No

History: Previous Data Request

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

VSAC Discussion: Since we did not receive all the documents for review, the Committee recommended that the project be approved contingent upon receiving a new approval from CPHS.

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 contingent on receiving a more recent CPHS approval.

The sixth project reviewed by the Committee was:

Project Title: "Impact of New Medicare Readmission Policy on Hospital Readmissions for All Patients"

Principal Investigator(s): David Zingmond, MD, PhD, Jose Scarce, MD, PhD, UCLA School of Medicine

Project Type: New Project

CPHS Approval: Approved

Project No.: 13-11-1414

Expiration: May 1, 2015

File(s) Requested: 2011PDD/Linked Death Data (select variables)

Requested Identifiers: California Identifiers

Personal Contact: No

Identifiers Released: No

History: New Data Request

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

VSAC Discussion: No Discussion

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 seventh project reviewed by the Committee was:

Project Title: "Gestational Vitamin D and Its Relationship with Autism Spectrum Disorder"

Principal Investigator(s): Jaime Sconberg, Graduate Student, University of California, Davis

Project Type: New Project

CPHS Approval: Approved

Project No.: 14-01-1472

Expiration: June 5, 2015

File(s) Requested: 1998-2008 Birth Statistical Master File (select variables), 1998-2008 Death Statistical Master File (select variables)
PI is requesting to use data previously obtained by Dr. Irva Hertz-Picciotto

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

Personal Contact: No

Identifiers Released: No

History: New Data Request

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

VSAC Discussion: No Discussion

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 contingent on receiving a new approval from CPHS.

The eighth project reviewed by the Committee was:

Project Title: "Trends in Regional Specialty Care Hospitalization for Children in California"

Principal Investigator(s): Paul Wise, MD, Stanford University

Project Type: Continuing Project

CPHS Approval: Approved

Project No.: 12-07-0488

Expiration: October 3, 2014

File(s) Requested: 2010-2011 PDD/linked Death Data

Requested Identifiers: California Identifiers

Personal Contact: No

Identifiers Released: No

History: Previous Data Request

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

VSAC Discussion: No Discussion

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 ninth project reviewed by the Committee was:

Project Title: "California, Maternal, Child, and Adolescent Health Report"

Principal Investigator(s): Dr. Lisa Nicholas, University of California, Los Angeles

Project Type: Continuing Project with changes to the protocol

CPHS Approval: Approved

Project No.: 12-08-0596

Expiration: February 7, 2015

File(s) Requested: 2007-2010 PDD/linked Birth Cohort File

Requested Identifiers: California Identifiers

Personal Contact: No

Identifiers Released: No

History: Previous Data Request

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

VSAC Discussion: The previous Principal Investigator for this project is Angela Chen. It was noted that Angela Chen's name is mentioned in the protocol, if the State can make sure that this is deleted or omitted. Henry stated we would do that.

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 tenth project reviewed by the Committee was:

Project Title: "Study of Project Use for Relatives and their Family Health (SPUR)"

Principal Investigator(s): Jacqueline Barkoski, MPH, University of California, Davis

Project Type: New Project

CPHS Approval: Approved

Project No.: 13-10-1362

Expiration: February 6, 2015

File(s) Requested: 1993-2012 Birth Statistical Master File (select variables), 1993-2012 Death Statistical Master File (select variables)

Requested Identifiers: BSMF (Name, Certificate Number, Address), DSMF (Name and Certificate Number) The PI is requesting to use data previously obtained by Dr. Irva Hertz-Picciotto

Personal Contact: No

Identifiers Released: No

History: New Data Request

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

VSAC Discussion: The Science Advisor had concerns that under statute, one Principal Investigator cannot transfer the data to another Principal Investigator. If the PI on this project were the original person who obtained the data, that would be fine but in this case, this person is asking to use someone else's data without obtaining it directly from the State. This is a rerelease of data. A suggestion was made that the Committee could decline the request as specified but suggest that the PI reapply and ask to obtain the data directly instead of from the other PI. Jonathan said we move to recommend to them the current PI submit a direct application for the data. Irva Hertz-Picciotto was named as a co-PI but not included on the VSAC application. Paperwork may have to be resubmitted to get it straight so it is very clear.

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 with the stipulation that the original owner be clearly described as the Principal Investigator on the VSAC application.

The eleventh project reviewed by the Committee was:

Project Title: "Evaluating the Effects of Exposure to Air Pollution on Adverse Birth Outcomes in Southern California"

Principal Investigator(s): Dr. Beate Ritz, University of California, Los Angeles

Project Type: Continuing Project with changes to the protocol

CPHS Approval: Approved

Project No.: 12-10-0861

Expiration: December 6, 2014

File(s) Requested: 1995-2012 Birth Statistical Master File (select variables)

Requested Identifiers: BSMF (Name, Certificate Number, Address)
The Principal Investigator is requesting to use data they previously obtained

Personal Contact: No

Identifiers Released: No

History: Previous Data Request

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

VSAC Discussion: The Science Advisor had some concerns. The Committee asked if the project could be approved with the stipulation on how the data will be used and not to be distributed. Laura pointed out that on Page 10 of the CPHS protocol, the applicant discusses a possible collaboration with another researcher, John Molita, who will be provided with geo-coded information from this study. Researchers may not provide data they create to other researchers. A separate application would be needed for the Molita study. They have a couple of choices, they need to expand their study to encompass this other work or if they are characterizing this as a separate study, they need to submit a separate application. The Committee recommended approval with stipulation that the researcher be instructed not to re-release the data as described to Dr. Molita unless there is an additional application submitted to the Committee describing that particular research study.

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 with stipulation that the researcher be instructed not to re-release the data as described to Dr. Molita unless there is an additional application submitted to the Committee describing that particular research study.

The twelfth project reviewed by the Committee was:

Project Title: "A Rigorous System to Determine the Health Impacts of Policies & Programs"

Principal Investigator(s): Jennifer Ahern, PhD, MPH, University of California, Berkeley

Project Type: New Project

CPHS Approval: Approved

Project No.: 13-10-1382

Expiration: May 1, 2015

File(s) Requested: 2005-2012 Death Statistical Master File (select variables), 2005-2011 Birth Cohort File (select variables)

Requested Identifiers: DSMF (Address), Birth Cohort (Address)

Personal Contact: No

Identifiers Released: No

History: New Data Request

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

VSAC Discussion: The concern of the Science Advisor was that the requestor appears to be asking to create a VR database that would exist in perpetuity and would be used for multiple research purposes, generally and broadly falling into evaluation/research related to health policies and programs. It appears that others might access the created database, although that is not clearly described in the protocol. Release of the data for the purposes described here would seem to be inconsistent with statute and would raise concerns about uses of the data in the future without VSAC review and State Registrar approval. The Committee commented that in the last couple of years, we have seen research projects that require construction of a database which could be applied to other research. The Committee has handled these types of requests previously but have made it clear that, that if the requestors would use the data, they have to come back for approval on a project specific basis. The Science Advisor thought that this project was so open-ended and broad. The Committee can give them permission to create the database as they discussed but stipulate to use it, they would have to come back for each project they want to use it for.

Beth Anderson told the Committee, Jennifer Ahern had sent follow-up attachments addressing the Science Advisor's concerns and that they agreed that they would limit it to the violence initiative. Their plan is to use it for the violence project and come back when they have their next idea of a project or a type of health outcome they want to look at. There has been a lot of confusion including MIH when the grant was proposed about the simulator. It seems like they are going to be putting data out there. There are two separate things. The point of the simulator is to come up with the best way to evaluate a project. The data used for that is not real data. They have restricted for this time with the idea that in the future, that they may do something else.

Laura had asked to submit a revision of your VSAC application to reflect that change. Two amendments were sent within the last month. This has also been done with Jonathan's group and has been working since September doing multiple revisions to figure out how to do this within the scope of what is allowed with the State.

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 with the attachments as described for the project.

F. ITEMS FOR DISCUSSION: Henry 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:

Elizabeth wanted to know if she needed to get the applications notarized as she has had previous protocols notarized. It could be that different staff and managers interpreted statutes differently over the years. In statute, it states there has to be a notarized signature. They may be interpreting that as a new notarized signature each time or in the past, they interpreted that as an older notarized signature to be sufficient.

Jonathan inquired about the release of the 2013 Birth Statistical Master File, 2013 Death Statistical Master File and the 2012 Fetal Death Statistical Master File. Henry stated that we have a problem with the 2012 Fetal Death Statistical Master File because the Fetal Death Registration System was established last year and the certificates for the Fetal Death but do not have the electronic data to process the Fetal Death Master File. We should be finalizing the 2013 Birth Statistical Master File and the 2013 Death Statistical Master File by the end of this month, probably early next month we will be releasing the file. The files can be requested when the file will be released as the application is not updated until that time.

Elizabeth had a question on applications submitted by students and felt that this is where some of the problems come in for as a co-Principal Investigator. If you are a student, you are in charge of the project but in reality you are under the supervision of a professor, not necessarily the same as being a co-PI. Although many students are not working on a grant, technically the professor can be considered a co-PI. As students can't afford to spend \$\$ or have a budget, how does a student go about it, do they use the professor they are working

with under the supervision as a co-PI or how do they apply to use the data? [They_Students](#) would be in the same situation that anybody else applying for the data, the statute does not differentiate between student researchers or researchers not affiliated with academic institution. Section 102230 and 102231 are very clear about not being able to obtain the data and share it with someone else. If you are a Principal Investigator and obtained the data, you can apply to use the data but you can't share the data. The statute is in place to ensure there is a responsible party in control of the data. The person, who is requesting the data, is legally responsible for the data. In the student's situation, if they want to have a professor as a co-PI, that satisfies the requirements as both people are Principal Investigator and legally responsible.

I. MEETING ADJOURNMENT: The meeting was adjourned.