



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, November 13, 2013
9:00 AM



EDMUND G. BROWN JR.
Governor

ATTENDEES:

Convener: Krista Christian, MBA, Chief, Vital Statistics Unit (VSU)

Committee Members:

Absent: Deborah Williams, California Department of Social Services
Malaika Singleton, PhD, Senate Office of Research; Erlinda Valdez,
California Funeral Directors Association, David Grant, PhD, UCLA
Center for Health Policy Research

Phone: Emily Putnam-Hornstein, PhD., University of Southern
California; Matthew Sundquist, Facebook; Jonathan Teague, MCRP,
Office of Statewide Planning and Development

California Department of Public Health (CDPH) Staff:

Present: Scott Christman, Chief, Public Health Policy and Research
Branch, Laura Lund, MA, Science Advisor, Terri Mack, MPA, Chief,
Health Information and Research Section; Cindy Tanaka-Fong,
Research Analyst II, VSU

Public Attendees: Sun Lee, Los Angeles County Department of
Public Health

Present:

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

A/B. WELCOME/INTRODUCTIONS:

Krista announced that this was a public meeting conforming to the Bagley-Keene Open Meeting Act. Members of the public are allowed to attend and welcome to participate at the end of the meeting.

Attendees present at the meeting and on the phone introduced themselves. Krista welcomed Scott Christman, Branch Chief for the Public Health Policy and Research Branch.

Krista informed everyone that the meeting was being recorded to assist with minute taking.

We anticipate that the 2011 Fetal Death Statistical Master File will be released sometime this week.

The Center for Health Statistics and Informatics has elected to change the VSAC schedule from a two hour meeting every two months to a one hour meeting once a month. The tentative meeting schedule is posted to the SharePoint site. We will reserve discussion of monthly meetings schedule after the projects have been discussed and voted on today.

We are planning to have a discussion of media requests process at a future date.

Research protocols are available for review on our Department's SharePoint site. Protocols are uploaded up to 3 weeks prior to the VSAC meeting. The SharePoint site should be checked frequently as protocols are uploaded when determination has been made that they will be slated for the VSAC meeting.

We are still looking for new members for the VSAC/VRPAC. If any members have recommendations, please contact Krista Christian at (916) 552-9873 or e-mail her at krista.christian@cdph.ca.gov.

C. APPROVAL OF MINUTES FROM THE PREVIOUS MEETING:

Laura mentioned that she was not included as one of the attendees in the meeting minutes. Emily Putnam-Hornstein motioned to approve the September 11, 2013 meeting minutes with the change of adding Laura Lund to the attendees. Jonathan Teague seconded the motion. All Committee members voted to approve the minutes. There were no oppositions. There was one abstention. Motion carried.

D. VSAC RECOMMENDATIONS FROM THE PREVIOUS MEETING:

Attachment 1, the State Registrar's Response to VSAC Recommendations, is a recap of recommendations from the last meeting.

There were 13 projects reviewed during the September 11 meeting. Ten projects received the recommendation of approval. Three projects received recommended approval contingent on the provision of updated CPHS approval notifications to CDPH. All recommendations were adopted by the State Registrar.

E. NEW BUSINESS:

Nine projects were reviewed.

The first project reviewed by the Committee was:

Project Title: "Mortality and Support on Online Social Media"

Principal Investigator(s): James H. Fowler, PhD, UC San Diego

Project Type: New Project

CPHS Approval: Approved

Project No.: 12-11-0930

Expiration: August 1, 2014

File(s) Requested: 2000-2010 Death Statistical Master File (select variables)

Requested Identifiers: Name and Address

Personal Contact: No

Identifiers Released: No

History: New Research Project

VSAC Discussion: The project was reviewed at the January 9th meeting. The Committee has postponed recommendation until CPHS approval. Laura inquired if CPHS approved the protocol exactly as VSAC reviewed it initially or if there were changes. The Committee had concerns with the linkage with Facebook data. Laura wanted to make sure that the Committee was reviewing the application that was finalized by CPHS and not the original version that was reviewed on January 9. Krista stated that her conversations with the requestor or some of the researchers on the project did not revolve around any changes made. A brief overview of the application was provided. The UC researcher had access to the Facebook database, proposing to do a contact study on surviving spouses, look at outcomes of survivors who linked in on online social network compared to those who aren't. The Committee's main concern was the people who were going to be included in the study because they were being identified from death records, didn't have the opportunity to consent to the research which is why the Committee wanted CPHS to take a look at this first before it was reviewed by the Committee. The main point was that the consent issue as it is not clear from enrollment in Facebook than for those who

consent for research purposes and certainly not clear for consent of decedents when named on a death certificate. Another concern was that it was open-ended as to whether there was social network contact with survivors associated with decedents.

The revised research plan mentioned a survey of approximately 100,000 users would be used. There was concern as to how these people would be selected or if families involved in some type of tragedy would be targeted. Committee members discussed possible questions for a survey that was administered to Facebook users via the social network site. One of the Committee members commented that Facebook users or members of the public affected by trauma who received letters asking to complete a survey might be upset. Researchers mentioned death records are not being used to contact subjects, but ultimately, subjects are contacted. One member interpreted the study as the use of the death file to determine deceased users within a repository Facebook data. The Committee asked if CPHS has approved the survey as it was not forwarded with the materials received. Krista said she can follow-up with CPHS. Page 4 describes an existing data study that will not involve any contact with subjects. Clearly the survey involves outreach and this would seem to involve contact with subjects. Krista stated that researchers say there is no actual contact with subjects as the subjects they are studying are dead.

After the discussion, there were several questions:

- 1) Whether CPHS approval was obtained for the survey in attachment A.
- 2) Is the CPHS approved protocol the original protocol reviewed by VSAC in January versus a revised protocol that the requestor was required to submit. Terri asked the Committee if those were the issues to address before recommending the state registrar approve the use of the vital records for this study.
- 3) The possibility that the Committee was not reviewing the most current documents.

VSAC Recommendation(s): The Committee has voted to delay recommendation to the December meeting pursuant to the receipt of Attachment 2 (Survey) and the correct protocol associated with Attachment 2. In addition, they would like to obtain information on contacting individuals.

VSAC Motions: Jonathan Teague motioned to delay recommendation until additional information is provided regarding any protocol revision and the survey mentioned in Attachment 2.

VSAC Vote: Committee members voted to delay recommendation to the December meeting pursuant to receipt of the correct protocol that associated with Attachment 2 (Survey) and obtaining information on contacting individuals.

There were no oppositions. Motion carried.

The second project reviewed by the Committee was:

Project Title: "Multiethnic/Minority Cohort Study of Diet and Cancer"

Principal Investigator(s): Kristine Monroe, PhD., University of Southern California

Project Type: New Project

CPHS Approval: Approved

Project No.: 12-07-0550

Expiration: October 4, 2013

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

Requested Identifiers: Name, Certificate Number, Address, SSN

Personal Contact: No

Identifiers Released: No

History: New Research Project

VSAC Discussion: No Discussion

VSAC Recommendation(s): Approve the data request.

VSAC Motions: Jonathan Teague motioned to recommend approval of the data release. 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 third project reviewed by the Committee was:

Project Title: "Effect of Material Education on Adverse Birth Outcomes"

Principal Investigator(s): Lela Bachrach, MD, MS, University of California, Berkeley

Project Type: New Project

CPHS Approval: Requested

Project No: 12-12-0963

Expiration: June 6, 2014

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

Requested Identifiers: No Personal Identifiers

Personal Contact: No

Identifiers Released: No

History: New Research Project

VSAC Discussion: No discussion

VSAC Recommendation(s): Approve the data request.

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

VSAC Vote: The Committee members voted in favor of recommending approval of the data request. There were no oppositions. Motion carried.

The fourth project reviewed by the Committee was:

Project Title: "Portrait of California 2014"

Principal Investigator(s): Patrick Guyer, Measure of America, Social Science Research Council

Project Type: Continuing Project

CPHS Approval: Pending

File(s) Requested: 2009-2012 Death Statistical Master File (select variables)

Requested Identifiers: No Personal Identifiers

Personal Contact: No

Identifiers Released: No

History: Previous Data Request

VSAC Discussion: The Committee brought up that the requestor indicated that this was not subject to CPHS approval. The project was presented to the committee since the requester was asking for addresses. Laura felt that this would fall under statute that would require VSAC approval. It does not fall under any statutes that would authorize release without VSAC approval. Records with address information would have to go for CPHS approval. Krista reminded the Committee that death data requests that are not being reviewed in tandem by CPHS and VSAC are generally reviewed by VSAC first and then by CPHS. The Committee had concerns on data security. They were explicit on using file encryption on their computers.

VSAC Recommendation(s): The Committee recommended that the data only be released if stored in an encrypted format. Not only is this a recommendation for the researcher but to the State Registrar for the conditions of which the data would be released.

VSAC Motions: Jonathan Teague motioned to recommend to the State Registrar approval of the data request contingent upon encryption being used for the data. Emily Putnam-Hornstein seconded the motion.

VSAC Vote: Committee members all voted in favor of recommending approval of the data request. There were no oppositions. Motion carried.

The fifth project reviewed by the Committee was:

Project Title: "Infant Social and Emotional Development"

Principal Investigator(s): Eric A. Walle, Ph.D., University of California, Merced **Project Type:** New Project

CPHS Approval: Approved

Project No.: 13-08-1316

Expiration: October 3, 2014

File(s) Requested: 2012-current Birth Statistical Master Files-monthly files (select variables)

Requested Identifiers: Name, Address

Personal Contact: Yes

Identifiers Released: No

History: New Research Project.

VSAC Discussion: The Committee expressed concern regarding contacting families that may have suffered a loss of a child. There was no reference to that in the documentation. In the past, we have asked that they need to request the death file so they could do a crosswalk to make sure they are not contacting families of deceased children.

VSAC Recommendation(s): The Committee has recommended approval with stipulation that death data be purchased to remove decedents from the cohort of study.

VSAC Motions: Jonathan Teague motioned to recommend approval of the data request. Matthew Sundquist seconded the motion.

VSAC Vote: Committee members all voted in favor of recommending approval of the data request. There were no oppositions. Motion carried.

The sixth project reviewed by the Committee was:

Project Title: "Cancer Disparities in California"

Principal Investigator(s): Ulrike Boehmer, Boston University School of Public Health

Project Type: New Project

CPHS Approval: Exempt –Federal Common Rule

Project No.: N/A

Expiration: N/A

File(s) Requested: 2000-2009 Merged Death (select variables)

Requested Identifiers: California identifiers

Personal Contact: No

Identifiers Released: No

History: New Research Project

VSAC Discussion: The Committee wanted clarity as they made reference to the California Cancer Registry and to the California Health Interview Survey. It seems they were merging data with one or another, possibly both and it was not clear what they were doing. They also wanted clarification if the project had CPHS approval. The application did not indicate any encryption. Laura stated that it is not possible to link CHIS data on an individual level; it is a geography based association. They are looking at proportion of the population at some local level that is gay, lesbian or bisexual. Krista informed the Committee that CPHS deemed the project as exempt from approval based on Federal Common Rule. There were no individual identifying records because of the ecological nature of the analysis.

VSAC Recommendation(s): Approve the data request.

VSAC Motions: Jonathan Teague motioned to recommend approval of the data request. Emily Putnam-Hornstein seconded the motion.

VSAC Vote: Committee members all voted in favor of recommending approval of the data request. There were no oppositions. Motion carried.

The seventh project reviewed by the Committee was:

Project Title: "Pesticides and Child Development Outcomes"

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

Project Type: New Project

CPHS Approval: Approved

Project No.: 13-07-1301

Expiration: Pending

File(s) Requested: 1994-2014 Birth Statistical Master File (select variables), 1994-2014 Death Statistical Master File (select variables)

Requested Identifiers: BSMF – Name, Certificate Number, Address; DSMF – Name, Certificate Number, SSN, MMN

Personal Contact: No

Identifiers Released: No

History: New Research Project

VSAC Discussion: The Committee wanted clarification on Hilary Aralis and who she was is. Krista said she can verify that.

VSAC Recommendation(s): Approve the data request

VSAC Motions: Emily Putnam-Hornstein motioned to recommend approval of the data request. Matthew Sundquist seconded the motion.

VSAC Vote: Committee members all voted in favor of recommending approval of the. There were no oppositions. Motion carried.

The eighth project reviewed by the Committee was:

Project Title: "Mortality Among Released Juvenile Offenders in California"

Principal Investigator(s): Hans Steiner, MD/Arash Anoshiravani, MD, Stanford School of Medicine

Project Type: Continuing Project with Protocol Revisions

CPHS Approval: Approved

Project No.: 13-05-1213

Expiration: August 1, 2014

File(s) Requested: 2007-2009 Death Statistical Master File (select variables). 2007-2009 Multiple Cause of Death Files (select variables)

Requested Identifiers: MCOD (California identifiers), DSMF (Name, Certificate Number Address, SSN/MMN)

Personal Contact: No

Identifiers Released: No

History: Previous Data Request

VSAC Discussion: Concern was expressed regarding the researcher obtaining data and immediately handing it over to someone at a completely different facility to do the work of the linkage and return the finished data. This is an ongoing relationship they have had and not the first time they have done this. The people they are subcontracting with at Corrections are not part of the application but subcontractors. They are identifying the juveniles and linking the two data files. Emily worked with them before, and said they would not release the data, they will typically structure it and link data the

researcher is able to access from other sources and provide to them, that is the only way the linkage can take place. The Committee asked if there was an agreement between CDCR and the requestor we could see. Laura stated that we require substantial documentation from our applicants on how they are going to house the data, we require them agree to destroy it or return it, and yet this person is going to turn it over to someone else without those same protocols in place with the person they are turning over to. Jonathan noticed that the application was not signed. Krista said she contacted the requestor regarding the unsigned application.

VSAC Recommendation(s): The Committee recommended approval of data pending additional documentation regarding the handling, storage, and disposal of data will of by CDCR.

VSAC Motions: Emily Putnam-Hornstein motioned to recommend approval of the data request pending additional documentation on the agreement on the use, storage, and disposal of the data. Jonathan Teague seconded the motion.

VSAC Vote: Committee members all voted in favor of recommending approval of the data request. There were no oppositions. Motion carried.

The ninth project reviewed by the Committee was:

Project Title: "Study to Explore Early Development (SEED)"

Principal Investigator(s): Gayle C. Windham, PhD, CDPH
Environmental Health

Project Type: Continuing Project (revisions to the protocol)

CPHS Approval: Approved

Project No.: 12-07-0484

Expiration: October 4, 2013

File(s) Requested: 2003-2007 Birth Statistical Master File (select variables)

Requested Identifiers: Name, Certificate Numbers, and Address

Personal Contact: Yes

Identifiers Released: No

History: Previous Data Request

VSAC Discussion: No discussion

VSAC Recommendation(s): Approve the data request.

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

VSAC Vote: Committee members all voted in favor of recommending approval of the data release. There were no oppositions. Motion carried.

F. ITEMS FOR DISCUSSION: Krista asked the Committee to refer to Item F, Recap of Data Requests Approved in the Vital Statistics Unit, Attachment 3. There were forty-nine data requests that did not require VSAC/VRPAC review were reviewed and approved by the Health Information and Research Section.

The VSAC meetings will occur on the second Wednesday of every month from 9:00 AM – 10:00 AM. The purposed schedule is on the SharePoint site.

G. PUBLIC COMMENT: There was one member, Sun Lee, Los Angeles County of the public attending the meeting.

Sun wanted to know what happens when the projects, specifically Project #3 and #7, request data we do not have, (2013 and 2014). Once the projects are approved, do they have to come back on an annual basis to submit this application or do they say we are still waiting for the data or inform us they are doing the study for additional years? If they need additional years and we don't have the information available, we will send them what we have and they can apply for the data at a later date. If we already approved the project, or VSAC has recommended approval of the project and the State Registrar approves it, we would honor the CPHS approval. Typically, with the project they would get an annual review by CPHS. The VSAC review is always synchronized with the CPHS review. They don't have to be reviewed again by VSAC unless there are changes to the protocol. They do have to submit the protocol annually to CPHS.

A committee member asked if they have to submit payment in advance if they ordered data in the future. When we get an application we sent an invoice, we would tell them we don't have that information available and will send the invoice for the

information that we have and they can apply for the additional years at a later date. They would give us their CPHS approval number and expiration date and we will review the history of the project. As long as the CPHS approved protocol has not expired, we can release the data and they would not have to go through the VSAC review process.

Sun Lee wanted to know the review process Project #4 as it was a continuing project. This was a new project. If this were a continuing project, we have documentation of the history of the project we can go back to.

H. AGENDA ITEMS: No agenda items

I. MEETING ADJOURNMENT: Jonathan Teague motioned to adjourn the meeting. Emily Putnam-Hornstein seconded the motion. Committee members all voted in favor of adjourning the meeting at 10:25 A.M.