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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 April 8, 2015
9:00 A.M.



EDMUND G. BROWN JR.
Governor

ATTENDEES:

Convener:

Henry Montes, Chief, Data Management Unit

Committee Members:

Absent: David Grant, PhD., UCLA Center for Health Policy Research,

Phone: Sun Lee, MPH, Los Angeles County Department of Public Health, Emily Putnam-Hornstein, PhD, University of Southern California, Shannon Muir, PhD, Science and Technology Fellow, Senate Health Committee Jonathan Teague, MCRP, Office of Statewide Health Planning and Development, Erlinda Valdez, Board Member, California Funeral Directors Association

California Department of Public Health (CDPH) Staff:

Present: Ellen Badley, MHA, Chief, Public Health Policy and Research Branch, Heather Fukushima, HPS I, Health Information and Research Section, Colin Chew, Research Analyst I, DMU, Laura Lund, MA, Science Advisor, Public Health Policy and Research Branch, Henry Montes, Chief, Data Management Unit

Public Attendees: Gretchen Rothrock, Hallie Randel, Mirasol Apostol, California Emerging Infections Program

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, MHA, Chief, Public Health Policy and Research Branch, Heather Fukushima, HPS I, Health Information and Research Section, Colin Chew, Research Analyst I, Public Health Policy and Research Branch, Laura Lund, MA, Science Advisor, Public Health

Policy and Research Branch, and Henry Montes, Chief, Data Management Unit,

Committee members on the phone included Sun Lee, Department of Public Health, County of Los Angeles, Emily Putnam-Hornstein, PhD, Assistant Professor, University of Southern California, Shannon Muir, Science and Technology Fellow, California Senate Health Committee Jonathan Teague, MCRP, Office of Statewide Health Planning and Development, and Erlinda Valdez, California Funeral Directors Association and public attendees.

Henry informed everyone that the meeting was being recorded to assist with note taking purposes.

Henry reminded everyone of the 3 changes made to Bagley-Keene Opening Meeting Act for 2015.

The three changes are: 1. For all action items at board meetings and meetings of committees of three or more, the law now requires boards to record the vote or abstention of each member present for that action item. This means the board's minutes must include each board member's name under the appropriate vote category (i.e., yes, no abstention). 2. An agency is authorized to provide notice of board/committee meetings by regular mail, email, or both. However, a person requesting notice has the option of choosing by which of the three methods above the person wishes to receive notice and the agency must comply with the option selected by the requestor. 3. If an agency plans to web cast a meeting, then the notice of meeting must include a statement of the intent to web cast the meeting.

This is for the purpose of public attendees. 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.

C. APPROVAL OF MINUTES FROM THE PREVIOUS MEETING:

Jonathan Teague motioned to approve the March 11, 2015 meeting minutes. Sun Lee seconded the motion. Jonathan Teague voted aye, Emily Putnam-Hornstein voted aye, Sun Lee voted aye, Erlinda Valdez voted aye, and Shannon Muir voted aye 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:

Nine projects were reviewed.

The first project reviewed by the Committee was:

Project Title: "Sentinel Headache: Incidence of an ED Visit for Headache Preceding Presentation with Subarachnoid Hemorrhage"

Principal Investigator(s): Anthony Kim, MD, University of California, San Francisco

Project Type: New Project

CPHS Approval: Approved

Project No.: 12-08-0594

Expiration: December 4, 2015

File(s) Requested: 2008-2011 Linked PDD/Death Data

Requested Identifiers: California identifiers only

Personal Contact: No

Identifiers Released: Yes

History: New Data Request

VSAC Discussion: No Discussion

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

VSAC Vote: Jonathan Teague voted aye, Sun Lee voted aye, Erlinda Valdez voted aye, Emily Putnam-Hornstein voted aye, and Shannon Muir voted aye 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.

Due to time constraints, Project # 9 was moved ahead and was discussed.

The second project reviewed by the Committee was:

Project Title: "Cancer Genetics Research Information System (CGRIS)"

Principal Investigator(s): Hoda Anton-Culver, PhD, University of California, Irvine

Project Type: Continuing Project

CPHS Approval: Approved

Project No.: 12-06-0379

Expiration: April 3, 2015

File(s) Requested: 2012-2013 Death Statistical Master File (select variables)

Requested Identifiers: Name, Certificate Number

Personal Contact: No

Identifiers Released: No

History: Previous Data Request

VSAC Discussion: The Science Advisor told the Committee that the original application that was submitted was to create linked data files with the three databases – vital records death data, cancer registry data, and external data files. The original request in the application is to create a linked data file that would be distributed to other researchers. We have had conversations with the PI and the PI understands (please refer to e-mail) stating that they understand that they cannot re-release the linked data files to other investigators. They will be preparing a research application for the use of the linked data files but what they are asking today is for the VSAC Committee to review the request to create the linked data files. Before they use the files, they will submit a research application.

It was clarified that any specific research project would have to come back to Committee for approval and that they understand they need to do this.

The Science Advisor made it clear that we do not allow Principal Investigators to share their data; as it is in statute that the data files or any part of the data file cannot be re-released. What the Committee has done in the past, is suggesting that the new requestor

add the original Principal Investigator as a co-PI on the application. There would be no sharing of data beyond the original PI and they understand they would not be able to release to other researchers.

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

VSAC Vote: Jonathan Teague voted aye, Sun Lee voted aye, Erlinda Valdez voted aye, Emily Putnam-Hornstein voted aye and Shannon Muir voted aye to recommend that the State Registrar approve the use of the data. There were no oppositions. Motion carried.

The third project reviewed by the Committee was:

Project Title: "Comparing Heart Failure Care Transition Intervention Effects"

Principal Investigator(s): Michael Ong, MD, PhD, University of California, Los Angeles

Project Type: New Project

CPHS Approval: Approved

Project No: 13-10-1373

Expiration: September 4, 2015

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

Requested Identifiers: California identifiers only

Personal Contact: Yes

Identifiers Released: No

History: New Data Request

VSAC Discussion: No Discussion

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

VSAC Vote: Jonathan Teague voted aye, Sun Lee voted aye, Erlinda Valdez voted aye, Emily Putnam-Hornstein voted aye and Shannon Muir voted aye to recommend 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 fourth project reviewed by the Committee was:

Project Title: "Hospital Variation in Obstetric Care"

Principal Investigator(s): Xiao Xu, PhD, Yale University

Project Type: Continuing Project with Changes to the Protocol

CPHS Approval: Approved

Project No.: 13-05-1227

Expiration: November 6, 2015

File(s) Requested: 2007-2011 Linked PDD/Birth Data

Requested Identifiers: California identifiers only

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. Emily Putnam-Hornstein seconded the motion.

VSAC Vote: Jonathan Teague voted aye, Sun Lee voted aye, Erlinda Valdez voted aye, Emily Putnam-Hornstein voted aye and Shannon Muir voted aye 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 fifth project reviewed by the Committee was:

Project Title: "Health Insurance and Financial Protection"

Principal Investigator(s): Carlos Dobkin, PhD, University of California, Santa Cruz

Project Type: Continuing Project with No Changes to the Protocol

CPHS Approval: Approved

Project No.: 12-10-0849

Expiration: December 4, 2015

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

Requested Identifiers: California identifiers

Personal Contact: No

Identifiers Released: No

History: Previous Data Request

VSAC Discussion: One of the Committee members had a question about the protocol, as it stated that they were re-requesting data. The Committee member wanted to know if CDPH provided the incomplete file. It was clarified that they wanted to add the vital statistics death file and had neglected to do that on their initial project.

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

VSAC Vote: Jonathan Teague voted aye, Sun Lee voted aye, Erlinda Valdez voted aye, Emily Putnam-Hornstein voted aye and Shannon Muir voted aye 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 sixth project reviewed by the Committee was:

Project Title: "The Impact of Restricting Balance Billing on Quantity and Quality of Emergency Care"

Principal Investigator(s): Yaa Akosa Antwi, Indiana University-Purdue University

Project Type: Continuing Project with No Changes to the Protocol

CPHS Approval: Approved

Project No.: 12-05-0196

Expiration: February 5, 2015

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

Requested Identifiers: California identifiers

Personal Contact: No

Identifiers Released: Yes

History: Previous Data Request

VSAC Discussion: No Discussion

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

VSAC Vote: Jonathan Teague voted aye, Sun Lee voted aye, Erlinda Valdez voted aye, Emily Putnam-Hornstein voted aye and Shannon Muir voted aye 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 seventh project reviewed by the Committee was:

Project Title: "Investigations of Language Learning and Social Cognition in Infants and Children"

Principal Investigator(s): Michael Frank, PhD, Stanford University

Project Type: Continuing Project with Changes to the Protocol

CPHS Approval: Approved

Project No.: 12--10-0815

Expiration: December 4, 2015

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

Requested Identifiers: Name and Address

Personal Contact: Yes

Identifiers Released: No

History: Previous Data Request

VSAC Discussion: It was not clear if the requestor was acquiring the Death Statistical Master File to avoid contact with grieving families.

In the CPHS protocol, it does state they would delete deceased infants. The State will need to follow up with them in order to make sure they would be consistent with what they described in the protocol.

Staff asked if we couldn't provide them with the Cross match File for the birth to give them the decedent babies? The Science Advisor stated that they typically order the Birth Statistical Master File (BSMF), as it has information the cohort doesn't have. We would have to ask the requestor if this would be a sufficient replacement. It would be their decision which file they want, as it would not be the same. Usually the Committee has asked if folks are requesting the BSMF, that they also request the DSMF.

One of the members pointed out for their previous projects, have they been asking for the death files at all? Have they been contacting grieving parents?

VSAC Motion: Jonathan Teague made motion to recommend to the State Registrar to release the data to the researcher contingent upon the inclusion in their data order, the appropriate Death Statistical Master File to allow them to avoid contacting parents of a decedent child and to receive clarification as they did that for earlier years or not. Sun Lee seconded the motion.

VSAC Vote: Jonathan Teague voted aye, Sun Lee voted aye, Erlinda Valdez voted aye, Emily Putnam-Hornstein voted aye and Shannon Muir voted aye to recommend that the State Registrar approve the use of the data contingent upon the inclusion in their data order, the appropriate Death Statistical Master File to allow them to avoid contacting parents of a decedent child and to receive clarification as they did that for earlier years or not. There were no oppositions. Motion carried.

The eighth project reviewed by the Committee was:

Project Title: "Evaluating the Effectiveness of a 13-Valent Pneumococcal Vaccine among Children"

Principal Investigator(s): Mirasol Apostol-Largeteau, Co-PI: Pamala Kirley

Project Type: Continuing Project with Changes to the Protocol

CPHS Approval: Approved

Project No.: 12-09-0705

Expiration: December 4, 2015

File(s) Requested: PI is requesting to use the 2014 Preliminary Birth Data (Name, Certificate Number), 2014 Infant Death (Name, DOB, MMN) as previously purchased by Pamala Kirley

Requested Identifiers: Birth Data (Name, Certificate Number), Infant Death (Name, DOB, MMN)

Personal Contact: Yes

Identifiers Released: No

History: Previous Data Request

VSAC Discussion: On page 7 of the Vital Statistics application, it states that they would be posting on a monthly basis, without any personal identifier variables, export and post on the CDC secure website. Is it necessary to have people on that end accessing the data even though the data is de-identified or is unnecessary as they cannot identify or define a person? They said that they are going to report aggregate results without identifiers.

The Science Advisor (SA) stated if they are posting aggregate findings; that's fine. If they are posting individual records, it is not an allowable release. If it is de-identifiable, it is not an allowable release at the individual record level. If there is any confusion about that in the application, we may want to ask the applicant to clarify.

The researcher replied that as of right now, it is not aggregate data. If you would like us to change, they said they can add CDC as a Co-PI or they can do aggregate the data there before they sent it to CDC.

The SA said either of those options would be fine as it would put us in compliance with statute; the State Registrar cannot release the data files to you and have you re-release as an individual data file.

The SA suggested that the Committee may want to recommend approval of the application with stipulation that only aggregate data be shared and in the future, the applicant wants to share individual record level data; they would need to submit a new application. The application can be an amended version of the current application; you would be changing the PI.

VSAC Motion: Sun Lee made motion to recommend to the State Registrar to release the data to the researcher with stipulation the data would be transferred in aggregate form only and the applicant would reapply with a modified application to release individual level data. Jonathan Teague seconded the motion.

VSAC Vote: Jonathan Teague voted aye, Sun Lee voted aye, Erlinda Valdez voted aye, Emily Putnam-Hornstein voted aye and Shannon Muir voted aye in favor of recommending approval of the data request with the stipulation that the data would be transferred in aggregate form only and the applicant would reapply with a modified application to release individual level data. There were no oppositions. Motion carried.

The ninth project reviewed by the Committee was:

Project Title: "FoodNet Non-0157 Shiga Toxin Producing E.coli Study"

Principal Investigator(s): Katie Wymore, Co-PI: Pamala Kirley

Project Type: Continuing Project with Changes to the Protocol

CPHS Approval: Approved

Project No.: 12-06-0460

Expiration: August 7, 2015

File(s) Requested: PI is requesting to use the 2014 Preliminary Birth Data (Name, Certificate Number, Address), 2014 Infant Death (Name, DOB, MMN) as previously purchased by Pamala Kirley

Requested Identifiers: Birth Data (Name, Certificate Number, Address), Infant Death (Name, Certificate Number, Address, MMN)

Personal Contact: Yes

Identifiers Released: No

History: Previous Data Request

VSAC Discussion: No Discussion.

VSAC Motion: Shannon Muir motioned to recommend approval of the data. Sun Lee seconded the motion.

VSAC Vote: Jonathan Teague voted aye, Sun Lee voted aye, Erlinda Valdez voted aye, Emily Putnam-Hornstein voted aye and Shannon Muir voted aye 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.

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: There were no additional questions or comments from the public attendees.

I. MEETING ADJOURNMENT: Jonathan Teague motioned to adjourn the meeting. The meeting was adjourned at 9:50 A.M.

DRAFT
