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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, August 10, 2016  
8:30 a.m.



EDMUND G. BROWN JR.  
Governor

The Vital Statistics Advisory Committee was held on August 10, 2016. The meeting was called to order at 8:30 a.m. The following members were present via telephone:

- Jonathan Teague, Manager, Office of Statewide Health Planning and Development (OSHPD)
- Ninez Ponce, Professor, UCLA Fielding School of Public Health
- Emily Putnam-Hornstein, University of Southern California
- Erlinda Valdez, California Funeral Directors Association

California Department of Public Health staff present:

- Colin Chew, Research Analyst
- Cindy Tanaka-Fong, Research Analyst
- Michelle Miles, Section Chief
- Laura Lund, Acting Science Advisor (SA)
- Henry Montes, Unit Chief

California Department of Public Health staff via telephone:

- Ellen Badley, MPH, Branch Chief

Public Attendees present via telephone:

- Desiree Alderson, MDRC
- Bryan Nguyen, UCLA
- Lauren Wise, Boston University

## **INTRODUCTIONS AND ANNOUNCEMENTS**

Mr. Montes informed those present that the meeting was being recorded to assist with note taking purposes, and that the meeting complied with the Bagley-Keene Open Meeting Act.

Mr. Montes told the Committee that this was his last VSAC meeting he will be attending as he has accepted another position.

Public attendees were asked to reserve any comments until the Public Comments portion of the meeting.

## **APPROVAL OF MINUTES FROM PREVIOUS MEETING**

A **MOTION** was made by Jonathan Teague and **SECONDED** by Ninez Ponce to approve the June 8, 2016 meeting minutes. Jonathan Teague, Ninez Ponce, Emily Putnam-Hornstein, and Erlinda Valdez voted aye to approve the previous meeting's minutes as written.

## **ATTACHMENT 1 – STATE REGISTRAR'S RESPONSE TO VSAC RECOMMENDATIONS**

The State Registrar adopted all thirteen (13) items listed in Attachment 1.

## **ATTACHMENT 2 – CONSENT CALENDAR**

**Discussion:** None

A **MOTION** was made by Jonathan Teague and **SECONDED** by Ninez Ponce to recommend approval of all items. Jonathan Teague, Ninez Ponce, Emily Putnam-Hornstein, and Erlinda Valdez unanimously recommended to approve the following Consent Calendar items:

Project Title: California Cardiac Surgery and Intervention Project  
Principal Investigator: Joseph Carey, MD  
Project Type: Continuing Project  
Data Requested: 2012 PDD/Linked Death

Project Title: California Pediatric Surgery Quality Improvement  
Principal Investigator: Shinjiro Hirose, MD, Jamie Anderson, MD, UCD  
Project Type: New Project  
Data Requested: 1995-2012 PDD/ED/AS Linked Birth Cohort Files,  
1995-2011 PDD/Linked Death Files

### **ATTACHMENT 3 – DISCUSSION ITEMS – NEW BUSINESS**

1. Project Title: Out-of-Hospital Sudden Cardiac Death Records Review

Principal Investigator: Zian Tseng, MD, MAS, UC San Francisco,  
Rana Khan, UC San Francisco,  
Co-Principal Investigator

Project Type: Continuing Project

Data Requested: 2011-2014 Death Files (select variables),  
Quarterly Death Data from 1/1/2016 –  
12/31/2020 (select variables)

**Discussion:** Clarification was provided on the requirements of the Information Privacy and Security Requirements (IPSR). The SA informed the Committee the IPSR is required for any institutional entity where the data would be stored. If the PI and the Co-PI are at separate entities, both would be required to fill out an IPSR. If at the same institution and location, a second IPSR is not necessary as the institution is covered by the original IPSR. An IT officer has the ability to sign the IPSR, rather than the PI, to certify the institution meets the IPSR Requirements.

A **MOTION** was made by Jonathan Teague and **SECONDED** by Ninez Ponce to recommend approval. Jonathan Teague, Ninez Ponce, Emily Putnam-Hornstein, and Erlinda Valdez voted aye to unanimously recommend to the State Registrar to approve the use of the data as described in the protocol.

2. Project Title: Mother and Infant Home Visiting Program Evaluation - Strong Start

Principal Investigator: Charles Michalopoulos, Ph.D., MDRC,  
Virginia Knox, Ph.D., MDRC, Co-Principal Investigator

Project Type: Continuing Project with Changes to the Protocol

Data Requested: 2014-2015 Birth Files (select variables),  
2014-2015 Fetal Death Files (select variables)

**Discussion:** None

A **MOTION** was made by Ninez Ponce and **SECONDED** by Jonathan Teague to recommend approval. Jonathan Teague, Ninez Ponce, Emily Putnam-Hornstein, and Erlinda Valdez voted aye to unanimously recommend to the State Registrar to approve the use of the data as described in the protocol.

3. Project Title: Kaiser Permanente Inter-Regional Behavioral Health  
Suicide Metric for Quality Improvement  
Benchmarking

Principal Investigator: Sumita Bhatia, Kaiser Permanente

Project Type: Continuing Project

Data Requested: 2014 Death File (select variables)

**Discussion:** The SA provided clarification to the Committee that this was a research project. Their approval letter dated June 2, 2016 approved their project in accordance with 45 Code of Federal Regulations, which is the Federal code that governs human subjects.

A **MOTION** was made by Jonathan Teague and **SECONDED** by Erlinda Valdez to recommend approval. Jonathan Teague, Ninez Ponce, Emily Putnam-Hornstein, and Erlinda Valdez voted aye to unanimously recommend to the State Registrar to approve the use of the data as described in the protocol.

4. Project Title: Infant Social and Emotional Development

Principal Investigator: Eric Walle, Ph.D., UC Merced

Project Type: Continuing Project

Data Requested: 2015 Birth Data, 2015 Infant Death Records

**Discussion:** None

A **MOTION** was made by Ninez Ponce and **SECONDED** by Jonathan Teague to recommend approval. Jonathan Teague, Ninez Ponce, Emily Putnam-Hornstein, and Erlinda Valdez voted aye to unanimously recommend to the State Registrar to approve the use of the data as described in the protocol.

5. Project Title: Tracking the Well-Being of Children in California

Principal Investigator: Mark Mather, Ph.D., Population Reference  
Bureau

Project Type: New Project

Data Requested: 2014 Birth File (select variables), 2014 Death File,  
(select variables)

**Discussion:** It was clarified this was a new project, not a continuing project.

A **MOTION** was made by Ninez Ponce and **SECONDED** by Jonathan Teague to recommend approval. Jonathan Teague, Ninez Ponce, Emily

Putnam-Hornstein, and Erlinda Valdez voted aye to unanimously recommend to the State Registrar to approve the use of the data as described in the protocol.

6. Project Title: Adverse Birth Outcomes Associated with Ambient Temperatures and Air Pollutants in California  
Principal Investigator: Rupa Basu, Ph.D., Cal EPA/OEHHA  
Project Type: Continuing Project  
Data Requested: 2010-2013 Birth Files (select variables),  
2010-2012 Fetal Death Files (select variables)

**Discussion:** It was clarified this was a continuing project, not a new project. As the project will expire on August 5, 2016, this is pending CPHS approval. Data would not be released without CPHS approval.

A **MOTION** was made by Jonathan Teague to approve conditionally upon receiving the extension from CPHS and **SECONDED** by Emily Putnam-Hornstein. Jonathan Teague, Ninez Ponce, Emily Putnam-Hornstein, and Erlinda Valdez voted aye to unanimously recommend to the State Registrar to approve the use of the data as described in the protocol conditionally upon receiving the extension from CPHS.

7. Project Title: County Health Ranking Sub-County Level Measures for California  
Principal Investigator: Dulce Bustamante-Zamora, Ph.D.,  
CDPH/Office of Health Equity  
Project Type: New Project  
Data Requested: 2009-2014 Birth Files (select variables)

**Discussion:** The SA told the Committee that this project is not "research" but comes to the Committee because under the requirements of Health and Safety Code (H&SC) Section 102430, VSAC has to review all requests for the data from the confidential portion of the birth certificate if it is being used for scientific purposes as this is a CDPH program and is bound by the department's requirements, an IPSR is not necessary.

A **MOTION** was made by Jonathan Teague and **SECONDED** by Erlinda Valdez to recommend approval. Jonathan Teague, Ninez Ponce, Emily Putnam-Hornstein, and Erlinda Valdez voted aye to unanimously recommend to the State Registrar to approve the use of the data as described in the protocol.

8. Project Title: Life Course Social Context and Disparities in Birth Outcomes

Principal Investigator: Michelle Pearl, Ph.D., CDPH/Sequoia Foundation

Project Type: Continuing Project

Data Requested: The use the files in their possession  
(1982-2011 Birth Files (select variables)  
1982-2011 Fetal Death Files (select variables),  
2000-2011 Linked PDD/Birth Cohort Files,  
2005-2010 Linked PDD/EDD/AS/Birth Cohort Files

**Discussion:** None

A **MOTION** was made by Ninez Ponce and **SECONDED** by Jonathan Teague to recommend approval. Jonathan Teague, Ninez Ponce, Emily Putnam-Hornstein, and Erlinda Valdez voted aye to unanimously recommend to the State Registrar to approve the use of the data as described in the protocol.

9. Project Title: Brain Mechanisms of Visual Development

Principal Investigator: Scott Johnson, Ph.D., UCLA

Project Type: Continuing Project

Data Requested: 2016 Monthly Birth Data (select variables)  
2016 Monthly Death Data (select variables)

**Discussion:** Bryan Nguyen commented that they had modified their request to obtain data through 2021. SA stated she did not know of the additional data being requested and did not review the application in that context but did not have any concerns with the initial request. This would set a precedence for the Committee as that is a lot of years in the future to approve without coming back to the Committee for subsequent review of the study or the data being requested. There is no requirement under the law for the researcher to come back to VSAC unless VSAC requests it. It would be at this Committee's discretion to approve any or all of the years of data that has been requested.

A **MOTION** was made by Ninez Ponce to recommend approval subject to review if there are any changes or amendments in the CPHS protocol. Emily Putnam-Hornstein **SECONDED** to recommend approval. Jonathan Teague, Ninez Ponce, Emily Putnam-Hornstein, and Erlinda Valdez voted aye to unanimously recommend to the State Registrar to approve the use of the data as described in the protocol subject to review if there are any changes or amendments in the CPHS protocol.

10. Project Title: Visual Development in Infants  
Principal Investigator: Karen Dobkins, Ph.D., UC San Diego  
Project Type: Continuing Project  
Data Requested: 2016 Birth Files (select variables)

**Discussion:** None

A **MOTION** was made by Jonathan Teague and **SECONDED** by Emily Putnam-Hornstein to recommend approval. Jonathan Teague, Ninez Ponce, Emily Putnam-Hornstein, and Erlinda Valdez voted aye to unanimously recommend to the State Registrar to approve the use of the data as described in the protocol.

11. Project Title: Sickle Cell Disease Longitudinal Data Collection  
Principal Investigator: Susan Paulukonis, CDPH/Environmental Health Investigations Branch  
Project Type: New Project  
Data Requested: 2004-2014 Death Data (selected variables),  
2004-2018 OSHPD Non-Public PDD,  
2005-2018 Non-Public EDD

**Discussion:** None

A **MOTION** was made by Ninez Ponce and **SECONDED** by Jonathan Teague to recommend approval. Jonathan Teague, Ninez Ponce, Emily Putnam-Hornstein, and Erlinda Valdez voted aye to unanimously recommend to the State Registrar to approve the use of the data as described in the protocol.

12. Project Title: Premature Mortality Among Individuals with Substance Use Disorders  
Principal Investigator: Tina Kim, Ph.D., Los Angeles County  
Project Type: New Project  
Data Requested: 2004-2014 Death Files (select variables),  
2004-2014 Multiple Cause of Death Files

**Discussion:** None

A **MOTION** was made by Jonathan Teague and **SECONDED** by Erlinda Valdez to recommend approval. Jonathan Teague, Ninez Ponce, Emily Putnam-Hornstein, and Erlinda Valdez voted aye to unanimously recommend to the State Registrar to approve the use of the data as described in the protocol.

13. Project Title: Early Language and Social Cognition

Principal Investigator: Rose Scott, Ph.D., MA, UC Merced  
Project Type: Continuing Project  
Data Requested: 2013-2014 Birth Files (select variables)

**Discussion:** None

A **MOTION** was made by Ninez Ponce and **SECONDED** by Jonathan Teague to recommend approval. Jonathan Teague, Ninez Ponce, Emily Putnam-Hornstein, and Erlinda Valdez voted aye to unanimously recommend to the State Registrar to approve the use of the data as described in the protocol.

14. Project Title: Boston University Pregnancy Study Online (PRESTO)  
Principal Investigator: Lauren Wise, Sc.D., Boston University School of Public Health  
Project Type: New Project  
Data Requested: 2014-2018 Birth Files (select variables)

**Discussion:** None

A **MOTION** was made by Jonathan Teague and **SECONDED** by Ninez Ponce to recommend approval. Jonathan Teague, Ninez Ponce, Emily Putnam-Hornstein, and Erlinda Valdez voted aye to unanimously recommend to the State Registrar to approve the use of the data as described in the protocol.

15. Project Title: Understanding Social Factors That Influence Risk of Involvement with the Criminal Justice System  
Principal Investigator: Justin Erlich, California Department of Justice  
Project Type: New Project  
Data Requested: 2005-2014 Birth Files (select variables)

**Discussion:** The SA had a concern with the birth data dictionary that was submitted, as the requestor was asking for all of the data fields. The justification provided was contextual data for social factors that influence risk of involvement with the criminal justice system. In review of the request, SA could not understand how each particular data field or data fields would fit with that justification. For example, the requestor has requested the name of both parents, first, middle, and last. SA was uncertain how a name could provide contextual data to understand a social problem. There is no mention of data linkage in

the request which would be a specific reason to request these fields. The justification should be explicit to the description of the project.

The second concern is this data application is requesting confidential birth and medical information including the mother's history (cigarette smoking, pre and post pregnancy weight). SA indicated the project description should include some context for requesting this type of confidential medical information. In addition, confidential birth data is governed by H&SC 102430 which limits its release and requires the project be related to health. The SA was unable to tie the requested data fields to any health aspect.

The final concern was that the application reads like a research project and not a surveillance analysis, yet requests birth weight, gestational age, etc. Requesting those types of data variables and connects them to later life interaction with the criminal justice system is a research project and not a surveillance project.

A **MOTION** was made by Ninez Ponce to recommend to the State Registrar that the requestor resubmit an application making changes to the data dictionary by clearly justifying how each of the data fields will be used. Also, explain in the description of the study how it ties in with the health requirements in H&SC 102430 pending approval of CPHS. The motion was **SECONDED** by Jonathan Teague. Jonathan Teague, Ninez Ponce, Emily Putnam-Hornstein, and Erlinda Valdez voted aye to unanimously recommend to the State Registrar not approve the application in its current format but recommend the requestor resubmit an application making changes to the data dictionary by clearly justifying how each of the data fields will be used, and explain in the description of the study how it ties in with the health requirements in H&S Code 102430 pending approval of CPHS.

16. Project Title: UCLA Health System: Obtaining Death Data in Order to Update Deceased Status in UCLA's Electronic Health Record System (Epic "CareConnect") for Matching Patients  
Principal Investigator: Sean O'Connell, UCLA Faculty Practice Group  
Project Type: Continuing Project  
Data Requested: 2013-2015 Death Files (select variables)

**Discussion:** None

A **MOTION** was made by Emily Putnam-Hornstein and **SECONDED** by Jonathan Teague to recommend approval. Jonathan Teague, Ninez Ponce, Emily Putnam-Hornstein, and Erlinda Valdez voted aye to unanimously recommend to the State Registrar to approve the use of the data as described in the protocol.

17. Project Title: Clinical Profile and Treatment Utilization Patterns Associated with Suicide Among Youth in Medicaid in the U.S.

Principal Investigator: Cynthia Fontanella, Ph.D., Ohio State University, Danielle Steelesmith, Ohio State University, Co-Principal Investigator

Project Type: New Project

Data Requested: 2009-2013 Death Files (select variables)

**Discussion:** Project removed from the agenda as all documentation was not received prior to meeting date.

18. Project Title: Residential Proximity to Pesticide Use and Birth Outcomes in California

Principal Investigator: Paul English, Ph.D., CDPH/Environmental Health Investigations Branch, Brenda Eskenaki, Ph.D., U.C. Berkeley, Co-Principal Investigator

Project Type: New Project

Data Requested: 2007-2014 Birth Files (select variables),  
2007-2014 Birth Cohort Files (select variables)

**Discussion:** None

A **MOTION** was made by Emily Putnam-Hornstein and **SECONDED** by Erlinda Valdez to recommend approval. Jonathan Teague, Ninez Ponce, Emily Putnam-Hornstein, and Erlinda Valdez voted aye to unanimously recommend to the State Registrar to approve the use of the data as described in the protocol.

19. Project Title: California Environmental Health Tracking Program

Principal Investigator: Eric Roberts, MD., Ph.D., CDPH/  
Environmental Health Investigations  
Branch

Project Type: Continuing Surveillance Project(s)  
Data Requested: 2013 Birth Cohort Files (select variables)

**Discussion:** None

A **MOTION** was made by Jonathan Teague and **SECONDED** by Erlinda Valdez to recommend approval. Jonathan Teague, Ninez Ponce, Emily Putnam-Hornstein, and Erlinda Valdez voted aye to unanimously recommend to the State Registrar to approve the use of the data as described in the protocol.

### **ADDITIONAL DISCUSSION TOPICS – RECORD RETENTION**

A sub-committee of the CAL-IVRS Steering Committee will be looking into data retention strategies, data achieving, and all the various issues associated with record retention. The first meeting is scheduled for this week, and would be ongoing as this will probably be a year-long project to resolve all the issues. SA indicated CDPH will keep the Committee apprised of policy recommendations as developed. SA will provide a briefing at the next meeting so the Committee can advise on how they might want to be involved.

The CAL-IVRS Steering Committee is comprised of CDPH staff with representation within the Center for Health Statistics and Informatics, Dr. Jim Greene and the SA are co-chairs, in addition to having representation from ITSD staff. Ellen Badley is heading an external stakeholders group to keep people apprised of changes in registration that will become effective January 2018. If the Committee is participating in the external stakeholders group, advise CDPH staff.

Jonathan brought up membership issues and informed the Committee that he was retiring at the end of the year. Mr. Teague felt that it was helpful to OSHPD have involvement on the Committee. Ms. Badley said there is no application process; it is by appointment. It has been brought up to Dr. Greene to add additional members, possibly broadening the membership.

### **MEETING ADJOURNMENT:**

A **MOTION** was made by Jonathan Teague and **SECONDED** by Ninez Ponce to adjourn the meeting. Jonathan Teague, Ninez Ponce, Emily Putnam-Hornstein, and Erlinda Valdez voted aye to unanimously recommend to approve adjourning the meeting.

The meeting was adjourned at 9:46 a.m.