Vital Statistics Advisory Committee (VSAC)
Vital Records Protection Advisory Committee (VRPAC)
Joint Meeting
Meeting Minutes for Wednesday, September 9, 2015
9:00 AM

ATTENDEES:

Convener:
Heather Fukushima, HPS I, Health Information and Research Section

Committee Members:

Phone: David Grant, PhD, UCLA Center for Health Policy Research, Sun Lee, MPH, Los Angeles County Department of Public Health, Jonathan Teague, Manager, Office of Statewide Health Planning and Development, Shannon Muir, PhD, Science and Technology Fellow, Senate Health Committee, Erlinda Valdez, Board Member, California Funeral Directors Association

California Department of Public Health (CDPH) Staff:

Present: Cindy Tanaka-Fong, Research Analyst II, Data Management Unit, Tori Pena, Administrative Assistant, Public Policy and Research Branch, Elaine Bilot, MS, MA, Section Chief, Health Information and Research Section, Colin Chew, Research Analyst I, Health Information and Research Section, Laura Lund, MA, Science Advisor, Public Health Policy and Research Branch, Heather Fukushima, HPS I, Health Information and Research Section

Public Attendees: No Public Attendees

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

A/B. WELCOME/INTRODUCTIONS:

Staff present attending the meeting included: Cindy Tanaka-Fong, Research Analyst II, Data Management Unit, Tori Pena, Administrative Assistant, Public Policy and Research Branch, Elaine Bilot, MS, MA, Section Chief, Health Information and Research Section, Colin Chew, Research Analyst I, Health Information and Research Section, Laura Lund, MA, Science Advisor, Public Health Policy and Research Branch, Heather Fukushima, HPS I, Health Information and Research Section

DRAFT

Committee members on the phone included: Jonathan Teague, Manager, Office of Statewide Health Planning and Development, Sun Lee, MPH, Los Angeles County Department of Public Health, David Grant, PhD, UCLA Center for Health Policy Research, Shannon Muir, PhD, Science and Technology Fellow, Senate Health Committee, Erlinda Valdez, Board Member, California Funeral Directors Association

Heather informed everyone that the meeting was being recorded to assist with note taking purposes. This meeting complies with the Bagley-Keene Open Meeting Act.

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:
Sun Lee motioned to approve the August 12, 2015 meeting minutes. Jonathan Teague seconded the motion. Jonathan Teague, Erlinda Valdez, David Grant, Shannon Muir, and Sun Lee voted aye to unanimously approve the minutes. There were no oppositions. Motion carried. The minutes were 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.

The first project reviewed by the Committee was:

Project Title: "Improving the Reporting of Race, Ethnicity, and Language in California"

Principal Investigator(s): David Zingmond, MD, University of California, Los Angeles

Project Type: Continuing Project

CPHS Approval: Approved

Project No.: 12-04-0127

Expiration: June 3, 2016

File(s) Requested: 2012 PDD Linked Birth File, 2010-2012 PDD Linked Death Files

Requested Identifiers: OSHPD files with identifiers

Personal Contact: Yes

Identifiers Released: Yes`

History: Previous Data Request

VSAC Discussion: The Committee wanted to know if the comment made from the Science Advisor (SA) stating only the requested data fields should be released should be included in the motion. The SA said you can if you want but you don't have to. The data file we would create would be a custom file with what they asked for.

There was confusion on the first and second project as these were approved by OSHPD. They thought these would be included on the Consent Calendar and wasn't sure if one of the Committee members had some concerns and wanted to discuss these projects. It was explained by Cindy that because we did not get the reviewed projects in time to send to the Committee, it was not put on the Consent Calendar and was put on the agenda.

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

VSAC Vote: Jonathan Teague, Erlinda Valdez, David Grant, Shannon Muir and Sun Lee voted aye unanimously in recommending approval of the data request. 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: "Early Liver Transplantation for Acute Alcoholic Hepatitis"

Principal Investigator(s): Eitan Neidich, MD Candidate, University of California, San Francisco

Project Type: New Project

CPHS Approval: Approved

Project No.: 14-09-1707

Expiration: June 3, 2016

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

Requested Identifiers: OSHPD files with identifiers

Personal Contact: No

Identifiers Released: Yes

History: New Data Request

VSAC Discussion: No Discussion

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

VSAC Vote: Jonathan Teague, Erlinda Valdez, David Grant, Shannon Muir and Sun Lee voted aye unanimously in recommending approval of the data request. 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: "Callbacks and Names"
Principal Investigator(s): Melissa Tartari, University of Chicago

Project Type: New Project

CPHS Approval: Approved

Project No: 14-10-1751

Expiration: December 4, 2015

File(s) Requested: 1986 Birth Statistical Master File (select variables)

Requested Identifiers: BSMF (Name)

Personal Contact: No

Identifiers Released: No

History: New Data Request

VSAC Discussion: Sun wanted to know if they were requesting the entire 1986 data file or a subset of that because the categories are black and white population only. She also brought up that the data would be stored at someone's residential home. The Science Advisor (SA) said that we told them no. They revised their application since then. The original application came from two graduate students. CPHS protocol had been issued to their advisor. We asked them to resubmit their vital statistics application in the name of the person who received the CPHS approval. In the revised application, they are storing their data on site on the University of Chicago and not the graduate student's apartment. On page 4 of the revised application, it

states the computer will be used in a private office on the University of Chicago premises.

David responded to Sun's first concern saying it was not clear as to the categories as he did not see any racial groups mentioned. The SA said that in their original application on page 3, it says they are looking at what names are stereotypically "black" or "white" as well as stereotypically "poor and rich".

Sun referenced page 4 of the CPHS protocol as it stated each name will receive a race score and an income score, which will sort names into one of four categories: rich white, poor white, rich black, and poor black. The SA told Sun we do not have a data field that is black and white, and that we would provide them with the race information in the categories in which it is collected, or in which it is coded in multi-race field, and they would have to subset on their own. They will not be getting the whole data file, they will be receiving minimum data necessary.

The Committee seemed to be still puzzled by deception as they are going to send these bogus applications to people to see if they would get call backs. David said this has been done in other studies to detect differences in race ethnicity and it is a moot policy, these are increasingly diverse populations, and that these were interesting questions. He felt that this was an innovative use of birth data and that it was a well-designed use of the data.

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

VSAC Vote: Jonathan Teague, Erlinda Valdez, David Grant, Shannon Muir, and Sun Lee voted aye unanimously in recommending approval of the data request. 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: "Using CalEnviroScreen to Evaluate the Relationship between Perchlorate and Thyroid Function in California Newborns"

Principal Investigator(s): Martin Kharrazi, PhD, CDPH, Environmental Health Investigations Branch

Project Type: New Project

CPHS Approval: Approved

Project No.: 15-05-2043

Expiration: August 5, 2016

File(s) Requested: Requesting to use data they previously obtained: 2000-2003 Birth Statistical Master File (select variables), 2009-2011 Birth Statistical Master File (select variables), 2009-2011 Fetal Death Statistical Master File (select variables), 2009-2011 Death Statistical Master Files (select variables)

Requested Identifiers: BSMF (Certificate Number and Address), FDSMF (Certificate Number), DSMF (Certificate Number and Address)

Personal Contact: No

Identifiers Released: No

History: Previous 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: Jonathan Teague, Erlinda Valdez, David Grant, Shannon Muir, and Sun Lee voted aye unanimously in favor of recommending approval of the data request. 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: "Vaccine Safety Datalink (VSD)"

Principal Investigator(s): Steven Jacobsen, MD, Kaiser Permanente

Project Type: Continuing Project with No Changes to the Protocol

CPHS Approval: Approved

Project No.: 12-02-15

Expiration: October 2, 2015

File(s) Requested: 2012 Fetal Death Statistical Master Files (select variables)

Requested Identifiers: Name and Certificate Number

Personal Contact: No

Identifiers Released: No

History: Previous Data Request

VSAC Discussion: It was noted that on the application that they only requested the Fetal Death Statistical Master File; but reading the application, it is clear they have a broader need for other data files that they have mentioned. Colin told the Committee that in the past, they have purchased other files for this continuing project. The SA said that there has been a special situation with Kaiser South but that would be changing as from now on. When you see future applications from them, you should see all the data files they are requesting.

Sun commented they are supplying data to CDC and wanted to know if they were Co-Principal Investigators. Jonathan noted also as they said they would only provide summary data to them. There may be an ambiguity with the word "data" as they were not providing any record level data. The SA said that was correct as they did provide a response that they would not share the study results in forms of tables and figures.

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

VSAC Vote: Jonathan Teague, Erlinda Valdez, David Grant, Shannon Muir, and Sun Lee voted aye unanimously in favor of recommending approval of the data request. 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: "Cost Containment in WIC: Lessons from the California WIC Vendor Market"

Principal Investigator(s): Maya Rossin-Slater, PhD, University of California, Santa Barbara

Project Type: New Project

CPHS Approval: Approved

Project No.: 15-02-1875

Expiration: April 1, 2016

File(s) Requested: 2010-2013 Birth Statistical Master File (select variables)

Requested Identifiers: No Personal Identifiers

Personal Contact: No

Identifiers Released: No

History: New Data Request

VSAC Discussion: No Discussion

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

VSAC Vote: Jonathan Teague, Erlinda Valdez, David Grant, Shannon Muir, and Sun Lee voted aye unanimously in favor of recommending approval of the data request. 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: "Cancer Genetics Research Information System (CGRIS)"

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

Project Type: Continuing Project with Changes to the Protocol

CPHS Approval: Approved

Project No.: 12-06-0379

Expiration: April 1, 2016

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

Requested Identifiers: Name, Certificate Number, and Social Security Number. PI is requesting to use files previously obtained.

Personal Contact: No

Identifiers Released: No

History: Previous Data Request

VSAC Discussion: Sun brought up that in the protocol, study procedures, they are sending data electronically to CCR. Is CCR part

of the study? The SA told Sun that CCR is acting as their contractor as they are doing the work for them. Sun asked if they should be listed as their contractor. The SA said they don't specifically name them as a contractor. We can ask them to make that explicit in their application so that we will have a chain of possession for the data, if the Committee would like to make the recommendation. They would not have to come back to VSAC, if the Committee are comfortable in resubmitting and including CCR as their contractor doing the work.

It was pointed out the on page 7 of the protocol, it states that the CDPH, Cancer Surveillance and Research Branch, California Cancer Registry will perform data linkage on all three databases. It also states it is a fee-for-service so they are clearly the contractor.

The SA said that the Committee can ask to make that clear in the VSAC application as well but it would not have to come back to the Committee, it would not hold up their data release, but it would have to be put in the motion.

VSAC Motion: Jonathan Teague motioned to recommend approval of the data release with the stipulation the applicant clarify CCR is the contractor doing the work within the VSAC application. Sun Lee seconded the motion.

VSAC Vote: Jonathan Teague, Erlinda Valdez, David Grant, Shannon Muir, and Sun Lee voted aye unanimously in recommending approval of the data request with stipulation the applicant clarify CCR is the contractor doing the work within the VSAC application. Motion carried. The Committee has voted to recommend that the State Registrar approve the use of the data as stated above in the motion.

The eighth project reviewed by the Committee was:

Project Title: "Social Patterns in Naming Practices"

Principal Investigator(s): Phech Colatat, PhD, Washington University in St. Louis

Project Type: New Project

CPHS Approval: Approved

Project No.: 12-06-0458

Expiration: Pending

File(s) Requested: 1990-2006 Birth Statistical Master File (select variables)

Requested Identifiers: Name and Address

Personal Contact: No

Identifiers Released: No

History: New Data Request

VSAC Discussion: The comments made by the SA included to release only the data fields requested. They are requesting extremely detailed geographic information and personal health information. The SA wanted to know if the study has enough scientific merit to justify release of these data fields. Sun wanted to know if this was because they were requesting census tract information. The SA said no, they were requesting the actual address.

The SA told the Committee that CPHS had contacted her a few of months ago. The reviewer was concerned about the personal health information detail that was being requested given the nature of the application. CPHS went ahead and approved it, but they did have some concerns about it. The SA asked them to justify the reason for all of the fields they were requesting. They have a reason for all the information they are requesting, but it is up to the Committee whether or not this level of detail and this particular study has a level scientific merit that warrants it.

The SA was concerned with confidential medical information from the birth certificate. Another concern was that they were going to link residential address to county records and will have a lot of linked information on each of these individuals.

David commented that he shared the concerns on the scientific validity and was surprised that there was this much research and literature on diffusion of innovations business. There was no hypothesis that they were testing.

The SA told the Committee that the statute does not say legitimacy, the study can be a legitimate study, statute said scientific merit.

David said that he would be less concerned if they asked for less data and less detailed information with all the ability to link. Jonathan asked if we could edit their request, we would approve this but not that? The SA said the Committee does have the ability to recommend

to the State Registrar to release the data on a limited basis, release some fields and not others. The Committee can certainly make that recommendation; it is completely up to them on how much of this gets released.

Concern was raised with the data elements they were requesting: birthweight, birth type, and month prenatal began. How is this related to naming? They are asking for way too many fields. It then becomes identifiable, especially when you will be following up with residential address and match it with county record for sale of property.

The SA told the Committee they provided justification on the variables in Table 4 Data Transformation. It tells you what they plan to do with it. Sun felt she did not have a good understanding of what they trying to do. The SA referred the Committee to Table 3 – Key variables and data sources for each research question. Under the control variables, they talk about health characteristics of child. Their explanation is health characteristics may be related to a given name. Birth complications may indicate the quality of prenatal care (a measure of SES) and may affect parents' decision to have future children. Expected future children may be an important factor as parents may have long term plans to use a set of names for the set of future children. Parents are known to have such expectations about the sex of their children. Given names may therefore be affected by the child's health characteristics. The SA said that's their explanation why they need birth weight, gestational age, and month prenatal care began, also, birth order and type of child.

These individuals represented in these data were not consented. One of the questions the SA had was would this be a study that these people would want their information used for. Some of the health studies people ask confidential information from the birth certificate, the SA could see where people who were not consented would not mind, but not sure about not consented would agree that this was appropriate use of their confidential health information.

Shannon wanted to know if we could bring in a sociologist on call for their expertise as it seems pretty far out of area of their expertise. She felt that it did not have the merit that we are striving in the studies that we approve.

David said that he is a sociologist, but studies like this are one of the reasons he does not actively practice. Potential suggestion is to

identify the variables we are least comfortable with. The variable he struggles with is mother's residential address and the birth weight. He felt they can get by with the use of zip code for SES of parent, and reduce the identifiability of variables, provide month and year of birth instead of date of birth.

Jonathan said they probably want some of the things in order to execute the linkage. If we dilute the variables in order to protect privacy, we also avoid the potential to link the other data sets. The SA agreed that one of the reasons they want all this identifiable information is identify the individuals and be able to link them.

The SA said one of the things they want to do with the mother's residential address is they want to match it a census tract.
As there was concern about the match to property data, the SA said it was on page 2, Table 3. The mother's address will be geocoded and matched with public records from county property assessor's offices. The assessor's offices, we will obtain the square footage and property value, and calculate a price per square foot. The assessor's office data will also indicate the type of property, e.g., single family home, condominium, apartment building, etc.

Jonathan made a motion to recommend to the State Registrar that the requestor be contacted with the concerns of the Committee about the depth and the identifiability of the information requested and to see if they would be willing to resubmit a less intrusive proposal. The SA said we will have to contact the requestor, we will need to know the Committee's concern – identifiability, confidential health information, what is it you would like them to not have in their next revision? The Committee replied detailed level of personal information including health information as well as the association with other data sets that would make the aggregate more indentifiable. Shannon asked would it be possible to also address the hypothetical consent of the people involved. The SA said that the problem is that vital records are exempt from consent. The fact that they are asking for vital records gets them off the consent hook. The SA's concern was if you are going to enroll these people in a study, and ask for this information, they would have to be consented, and they did not have the opportunity to do that for the use of this data.

The SA said what she heard from the Committee is that they recommend that the State Registrar not approve the application as submitted and the State Registrar ask the requestor to resubmit an application that is less individually identifiable and does not have

confidential health information included. Sun Lee seconded the motion.

VSAC Motion: Jonathan Teague motioned to recommend that the State Registrar not approve the application as submitted, and that the State Registrar ask the requestor to resubmit an application that is less individually identifiable and does not have confidential health information included. Sun Lee seconded the motion.

VSAC Vote: Jonathan Teague, Erlinda Valdez, David Grant, Shannon Muir and Sun Lee voted aye unanimously recommending that the State Registrar not approve the application as submitted and the State Registrar ask the requestor to resubmit an application that is less individually identifiable and does not have confidential health information included. Motion carried. The Committee has voted to recommend that the State Registrar approve the use of the data as stated above in the motion.

The ninth project reviewed by the Committee was:

Project Title: "Cancer Mortality by Asian and Hispanic Subgroup in California"

Principal Investigator(s): Paulo Pinheiro, PhD, University of Nevada, Las Vegas

Project Type: New Project

CPHS Approval: Approved

Project No.: 15-08-2161

Expiration: Pending

File(s) Requested: 2008-2012 Death Statistical Master Files (select variables)

Requested Identifiers: No Personal Identifiers

Personal Contact: No

Identifiers Released: No

History: New Data Request

VSAC Discussion: No Discussion

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

VSAC Vote: Jonathan Teague, Erlinda Valdez, David Grant, Shannon Muir, and Sun Lee voted aye unanimously in favor of recommending approval of the data request. 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: Heather 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 was no Public Comment.

It was noted as Shannon made the comment about the OSHPD requests, as two months ago, they were placed on a consent calendar but realizes that it may be difficult in the timing process of getting the requests reviewed, but wanted to mention keeping it as it does save a lot of time.

I. MEETING ADJOURNMENT: The meeting was adjourned at 10:20 A.M.