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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, November 4, 2015
9:00 AM



EDMUND G. BROWN JR.
Governor

ATTENDEES:

Convener:

Heather Fukushima, HPS I, Health Information and Research Section

Committee Members:

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

California Department of Public Health (CDPH) Staff:

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

Public Attendees: Phech Colatat, Washington University in St. Louis, Desiree Alderson, Mother and Infant Home Visiting Program Evaluation (MIHOPE)

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, Elaine Bilot, MS, MA, Section Chief, 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

Committee members on the phone included: Jonathan Teague, Manager, Office of Statewide Health Planning and Development, David Grant, PhD, UCLA Center for Health Policy Research, Sun Lee,

MPH, Los Angeles County Department of Public Health, 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.

For the December VSAC meeting, it typically would be held on the second Wednesday, which is December 9. We are hoping to move it to December 16 to provide some time for the applications to be reviewed. The Committee was in agreement to change the date of the December meeting to December 16.

C. APPROVAL OF MINUTES FROM THE PREVIOUS MEETING:

Erlinda Valdez motioned to approve the October 14, 2015 meeting minutes. Sun Lee seconded the motion. Jonathan Teague, Erlinda Valdez, David Grant, 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.

ATTACHMENT 2 – CONSENT CALENDAR: OSHPD DATA REQUESTS

The following three OSHPD projects were placed in the Consent Calendar:

- Project Title: Innovative Approaches for Studying Gestational Weight Gain
Principal Investigator: Barbara Abrams, PhD, University of California, Berkeley
Project Type: New Data Request
Data Requested: 2007-2012 Linked PDD/ED/AS/Birth Cohort File
- Project Title: The Impact of Clinical and Demographic Factors on Risk-Adjusted Outcomes for Urologic Cancer Surgery
Principal Investigator: John Gore, MD, University of Washington

Project Type: New Data Request
Data Requested: 2007-2011 Linked PDD/Death File

- Project Title: Heterogeneity in EMS and Hospital Services Provision:
Impact on Quality and Outcomes
Principal Investigator: Atul Gupta, PhD, Stanford University
Project Type: New Data Request
Data Requested: 1991-2011 Linked PDD/Death File

VSAC Discussion: No Discussion

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, and Sun Lee voted aye unanimously in recommending approval of the data requests. Motion carried. The Committee has voted to recommend that the State Registrar (SR) approve the use of the data as described in the protocol.

Two projects were reviewed. Another project was placed on the agenda for discussion, as it was not approved at the September 9, 2015 VSAC meeting.

The first project reviewed by the Committee was:

Project Title: "Study of Expanded Population of Radiation Workers in Shipyards"

Principal Investigator(s): Genevieve Matanoski, MD, John Hopkins Bloomberg School of Public Health

Project Type: New Project

CPHS Approval: Approved

Project No.: 15-07-2113

Expiration: August 5, 2016

File(s) Requested: 1970-2011 Death Statistical Master Files (select variables), 1970-2010 Multiple Cause of Death (select variables)

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

Personal Contact: No

Identifiers Released: No

History: New Data Request

VSAC Discussion: The Committee said it looks like they addressed the issues of concern. Previously, they were going to sharing de-identified data with other parties but now, they were not specifically named on the request (US Navy). The SA said she reviewed their revision they submitted, and felt it was good to go forward for the Committee to review.

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, 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 (SR) approve the use of the data as described in the protocol.

The second project reviewed by the Committee was:

Project Title: "Social Patterns in Naming Practices in the United States, 1990-2006"

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

Project Type: New Project

CPHS Approval: Pending

Project No.: 12-06-0459

Expiration: Pending

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

Requested Identifiers: BSMF (Name and Mother's Address)

Personal Contact: No

Identifiers Released: No

History: New Data Request

VSAC Discussion: The SA told the Committee that this project was previously considered and the Committee made a recommendation to the SR not to approve these data for release. We had the researcher

on the phone today because he wanted to make a statement to the Committee about this project.

Dr. Colatat said that their project was reviewed at the September meeting but was declined. After reviewing the meeting minutes, they felt they did not do a great job in representing it when the Committee reviewed it for first time.

He wanted to highlight two points. He said that they under-represented the scientific merit towards the field of sociology for this project, the details are outlined in notes in your packet. The second point is that we have some flexibility with respect to the specific variables requested. Certainly some fields are more important than others for their purposes, but they do have flexibility. He would like to submit this for the Committee's consideration again, and he hoped to come away with a better sense of what would constitute a proposal/protocol that would be acceptable to the Committee. The SA asked if there were any comments or questions from the Committee.

Sun Lee wanted to know what he meant by having flexibility with respect to the specific variables requested. In their protocol they submitted for September 9, they requested variables from the birth data, names, and year of birth. From the minutes, there was concern over health-related variables; for instance, birth weight, and number of months upon gestation. What we have done across the spectrum of variables in their data request, Dr. Colatat stated that their research can carry on without some of the variables. He thinks it makes it stronger to have those in, but he believes the project can move forward, dropping some variables from their data request. In the Data Request and Flexibility Section, it basically maps out the fields they had requested in their original data request and lays out the level of importance for carrying out their research. There is some potential they can scale back on the variables that they request. They feel that it distracts a little from the research but they can carry on and be productive by dropping some of these variables.

The researcher was told we aren't in the business to obstruct research however, we do have a responsibility to think about patient privacy when we review applications and try to decide what to approve. In this particular request, there was some concern about the list of variables and also concerns with the linkages that were proposed as well, which were tying things down to a fairly specific and identifiable geographical level. Jonathan told Dr. Colatat that we are not interested in trying to compromise the research, but there was some

concern with what people would think, whose data this is, and if they knew we were offering it up for the study. That is kind of internal question we are asking ourselves as we review these kinds of project protocols.

David Grant commented that we have very little information about the scientific contribution of the study in the original application other than some statement about innovation theory or diffusion theory, something he felt he was not familiar with. It was hard to reconcile the level of data that was requested and the identifiable nature of the data requested including mother's first and last name, address, father's first and last name, address. He said that some of the linkages, for example, the parcel data, to get the information on the exact household of the mother, without understanding what this would contribute to would seem like a lot of identifiable data for an unclear purpose.

Jonathan said one way around it is to figure out a way to meet the study objectives without either surrendering custody of the sensitive records. If there is analysis that needs to be done with those working files that would be created, the confidential data itself can be stripped so we would not have exposure. That might be one approach. He said he has seen this with some of the data requests they have processed. In these requests, it is clear, there is a sensitive linkage that requires various elements. There is no reason to have that material remain in the file, once the linkage is executed. There is a way to think about how to design the project in that mode. That might allay some of the Committee's concern.

Dr. Colatat said that sounds like a technical question, and he asked where does the data reside when the fields are stripped off? If they come up with something satisfactory, where the linked data are not residing on a computer that could be breached in some way; that would allay some of the concerns. David Grant felt this would make him feel more comfortable and thought it was good suggestion.

The SA added that there were concerns about the very specific request for detailed confidential medical information, and that some of our most sensitive information in the department on the confidential portion of the birth certificate. The Committee was not clear how all of that private medical information that would contribute to the body of knowledge. The SA clarified it was all the confidential medical information – plurality of pregnancy.

As far as the scientific merit, they did pitch it as something about diffusion of innovation. For the field of sociology, there is a lot to be learned in terms of social status affects people's decision making and believe that the address data are important to the research. We can resolve some puzzles in the literature by using basically this better measure. For us, some fields are more important. The address is very important to them, but birth weight or gestation period, we can carry on without.

Jonathan said we understand the utility of geographical data as a proxy for social economic status and was not sure any way around that.

David said that census tract is used as a proxy for socio economic status or race ethnic composition or nature born, foreign born status. David wanted to know if that was sufficient level of detail for their needs. Dr. Cololat said that geographic area or census tract would be helpful to them. The things this project brings to the table, is precision around some measure of socio economic status. He has seen measures based on census tract where census data has been used as a measure of economic status. Sun felt uncomfortable in releasing mother's residential address.
Sun felt uncomfortable in releasing mother's residential address.

The SA said what she is hearing from the Committee is that there is a lot of discomfort with the very individual level identifiable information of tying full names, mother and father with an actual specific address. The SA asked if it is possible for you in your study to have the address, but only a first name associated and would that alleviates some of the Committee's concern?

Dr. Cololat said that their research could carry on with the first name, last name would help them. If they had to prioritize, first name and address are at the top of their priority list of variables.

David asked if Dr. Cololat could explain the value of the address. It appears that census tract is being used for a lot of the measurement, and wanted to know the additional value the address adds above and beyond the information available at the census tract level. Dr. Cololat said that the address would help them with the linkage to the county parcel data, which would give them some measure of socio-economic status based on the estimated property values of the structure in which the folks reside at the time of birth. They can normalize this by the type (i.e., a building, single family home) and they can normalize

that by square footage. The address will give them an individual level or mother's level measure of socio-economic status at the time of birth.

The Committee noticed that the property data is considered public information.

The SA said the next steps here would be based on any recommendations the Committee would like to provide. Dr. Cololat is welcome to submit a revised application, which would come before VSAC again for review and discussion and will include any changes to the protocol.

VSAC Motion: No Motion

VSAC Vote: No Vote

The third project reviewed by the Committee was:

Project Title: "Mother and Infant Home Visiting Program Evaluation (MIHOPE)"

Principal Investigator(s): Virginia Knox, PhD, MDRC

Project Type: Continuing Project

CPHS Approval: Approved

Project No: 13-02-1114

Expiration: June 3, 2016

File(s) Requested: 2012-2015 Birth Statistical Master Files (select variables), 2012-2015 Fetal Death Statistical Master Files (select variables)

Requested Identifiers: BSMF (Name, Certificate Number, Address), FDSMF (Name, Certificate Number)

Personal Contact: No

Identifiers Released: No

History: Previous Data Request

VSAC Discussion:

The SA told the Committee that the application being reviewed was for MIHOPE. The SA said there are some issues with this application. She wasn't sure if the current version of the application clarified

everything and would be interested in hearing the Committee member's comments.

On the previous application, the Committee was concerned with the re-release of confidential data elements. The SA told the Committee they have been informed that they cannot create that file and re-release the data elements. We have asked for a revision to the application to address some of the questions and that a revision needs to be made before we could release the data.

The Committee commented that some of these answers are contained in VSAC responses to questions about MIHOPE. The roles of the contractors have been clarified.

The requestor was notified that we do not have the staffing or resources to do the matching. If the Committee approves the release of the data and the State Registrar chooses to release the data for this study, we would be able to provide them with the data file but we would not be able to do any of the. They have asked for Social Security Numbers and we have also told them we cannot provide that.

David asked if we are waiting for a revised application for the original request.

There was confusion on the revised application as the SA had an application dated July 8, 2015 and it appeared that the Committee had a MIHOPE edited application dated October 14, 2015.

Based on the MIHOPE October 14 revision, the SA asked the Committee if they have any comments or questions or if they need clarification. The last version she had, she had asked Colin to ask the requestor to revise and submit a clear application because a lot of the answers were contained in e-mails strings. We really need those formally documented in the application. The SA said she did not have a copy, and do not have access to the October 14 version so she did not know how much of the clarity was achieved in that version.

Sun pointed out that on page 22 of the October 14 application, they mention SSN as one of the variables they would be using to linking other data sources. The SA said that they will need to submit a revised application as they cannot have SSN. The revised application will need to have the specific data fields that we would be able to release and we will not release SSN.

The SA said the only other thing was the re-release of the data as they want to create a de-identified data file for re-release. We have told them they cannot do this and we will not release the data until we have a revised application stipulating that there will be no re-release.

Desiree said we were not asking for SSN but were expecting the agency would do the match. The SA said that is against Federal law. Federal law allows SSN from the birth certificate to be used only for child support services and follow-up. It can't be used for anything else. It is not a matter of releasing it, it is a matter of how it can be used. The SA said it is the Privacy Act of 1974, TITLE 42 > CHAPTER 7 > SUBCHAPTER II > § 405 (3) (C) (ii).

Desiree said all the vital agencies seem to be okay to do this linking. The SA told Desiree if they can provide her with the federal law that trumps that particular section, please provide it to us because we have many people who ask for Social Security Numbers and we would like to be able to release it.

The Public Use File would contain name, date of birth, and some other variables. It would depend on what you would need to do the linkage. We can't give you mother's marital status or social security number. We do not have the Medicaid number, which is on your list. Address is not public. For purposes of research, we can provide address based on this Committee's review and approval of the request. The SA told Desiree that she would need to provide the list of data fields that you would need for linkage. This Committee would review those and recommend to the State Registrar to approve or not approve.

Without the SSN or Medicaid ID, Desiree said they would definitely request the address and add this to the list.

The SA clarified that John Hopkins was not accessing the vital records data.

The SA said that the Committee has a choice here. The Committee can either recommend approval of the application with the stipulation these issues be addressed in a revised application prior to data release or not approve and ask for the revised application to be resubmitted for VSAC review.

VSAC Motion: Jonathan Teague motioned to recommend approval of the data release for this project with the stipulation that the applicant submit a revised application with Social Security Number be removed

from the list of variables to be released and from the text of the study description. The applicant will remove the description that the data will be re-released as part of a restricted access data file and a description of the variables being requested for data linkage. David Grant seconded the motion.

VSAC Vote: Jonathan Teague, Erlinda Valdez, David Grant, and Sun Lee voted aye unanimously in recommending approval of the data request stipulation that the applicant submit a revised application with Social Security Number removed from the list of variables to be released and from the text of the study description. The applicant will remove the description that the data will be re-released as part of a restricted access data file and will provide a description of the variables being requested for data linkage. Motion carried. The Committee has voted to recommend that the State Registrar approve the use of the data as stated above in the motion.

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 DISCUSSION TOPICS:
There was no other discussion from the public.

I. MEETING ADJOURNMENT: David Grant motioned to adjourn the meeting. Jonathan Teague seconded the motion. Jonathan Teague, Erlinda Valdez, David Grant, and Sun Lee voted aye unanimously in favor of adjourning the meeting. Motion carried.