

## California Vectorborne Disease Surveillance Data Policy

May 19, 2010

### Introduction

**What follows is a policy statement that outlines permission to use electronically-stored vectorborne disease surveillance data for multiple uses and by various organizations. The proceeding guidelines are intended for agencies that participate in the California Vectorborne Disease Surveillance Program (CalSurv), a joint activity of the Mosquito and Vector Control Association of California (MVCAC), the California Department of Public Health (CDPH), and the University of California (UC). This policy is administered by the CalSurv Steering Committee, comprised of members from the three agencies listed above.**

### Preamble

Over the past decade, the migration from locally-maintained paper surveillance data records to centrally-stored electronic records has raised questions concerning the ownership, use, release, and publication of data. Ownership issues were clearer in the past because data were generated by relatively few individuals and organizations and they were retained in formats that were not easily shareable. However, as the goal of centrally-coordinated collection and testing of surveillance specimens has come closer to realization, it has also become apparent that a set of guidelines is required to address questions of stewardship of the data, availability of the data for analysis and publication, acknowledgement of data origination, and permission for use of the data.

### Guiding principles

1. Data generated as a result of publicly supported programs are public property and will ultimately become part of the public record. However, unrestricted, immediate availability of all data is not guaranteed and should not be expected.
2. Permission is required before surveillance data may be used for any purpose. Uses for which permission is required include, but are not limited to: publication or presentation in any written, oral, or electronic format; collation, summarization, or analysis; redistribution to secondary parties.
3. In the interest of fairness and protection of individual privacy, availability of these data is subject to restrictions, including but not limited to the release of names, addresses, phone numbers or other contact information, and other personal identifiers associated with disease cases and related surveillance. Where there are privacy concerns, certain private information may be redacted, when present, from the original records before they are provided to a requestor.
4. Persons intending to aggregate, analyze, or publish these data are required to credit in the form of a citation acknowledging those individuals and organizations most responsible

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for the creation and collection of said data and, in the case of ongoing data programs, those individuals and organizations most responsible for organizing and maintaining the mechanisms by which data are assembled.

Example: Data obtained through CalSurv Data Request #00001 on 1 January 2008: California Vectorborne Diseases Surveillance System.

5. Because of the impracticality of publicly acknowledging individual agencies and their employees in wide-ranging studies, a blanket permission request may be made in these cases and submitted to CalSurv. The guiding principles listed here must be acknowledged and accepted by the inquiring party.
6. Any individual (“requestor”), regardless of parent agency affiliation, must obtain permission to use surveillance data prior to any intention for presentation, publication or redistribution. However, exceptions exist for the following situations (all exceptions terminate upon the individual’s separation from their parent agency):
  - a. An individual need not request permission to use data generated solely by his or her parent agency. (Permissions for access still may be needed within the individual’s agency, but are beyond the purview of CalSurv and not addressed in this document.)
  - b. An individual appointed by CalSurv as the Data Steward. This appointment is automatically granted to the server administrator overseeing all pertinent datasets and is limited in scope to only the distribution of requested datasets approved by the CalSurv Steering Committee.
7. Requestors must be directed to the CalSurv Data Steward for procedures to formally request use of such data.
8. Requests for use of CalSurv data will be considered by the CalSurv Steering Committee. Individual agencies whose data may be part of the request may provide opinions to be considered by the CalSurv Steering Committee. A request requires two-thirds of the committee to vote for approval. Written request approvals will be forwarded to the Data Steward for fulfillment. Once the Data Steward compiles the requested dataset, the steering committee will inspect the data before delivery to the requestor.
9. The intellectual property rights to the surveillance data belong to the originating agencies participating in the California Vectorborne Disease Surveillance System. Any decisions made by the CalSurv Steering Committee do not transfer, release or grant any intellectual property rights to the requestor. The only permitted exception is if the transfer, release or granting of rights is explicitly written in the request approval.

**Limits of the Data Policy**

1. This policy applies only to those datasets managed by CalSurv. These datasets are:
  - a. Arboviral surveillance and infections among sentinel animals, dead birds and mosquitoes.
2. Datasets exempt from this policy are:
  - a. Summaries of surveillance measures needed by agencies such as CDPH to satisfy statutory requirements for agency reports.
3. Permission to use data from surveillance datasets not stated in this policy must be sought from the agencies possessing the data.

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## Data request form

If the spaces provided are insufficient, please use addition sheets of paper. Please be as descriptive as possible.

Request date:
Project name:
Requestor/investigator  Name: _____  Title: _____  Organization: _____  City: _____ State: _____  Phone: _____ Email: _____
Brief description of project:
Data requested:
How will the data be used/ project outcome (e.g., funding proposal, scientific manuscript, news article)?:
By what date do you need the data?:
When do you anticipate completing the project?:

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### Data use agreement

In accepting data from CalSurv, I agree to the following:

1. I acknowledge and accept the terms of the CalSurv Data Policy and in good faith will uphold the terms of the policy regarding this request.
2. I accept that only with the express written consent of the CalSurv Steering Committee for this request will any data be released.
3. I accept that permission to any released data is granted solely for the purpose expressed in this request and that any modification of the intended use will require submitting a revised written request to the CalSurv Steering Committee.
4. I accept that access to any released data is limited to the "Requestor" named on the form and will not be released to other persons.
5. I accept that any data released from this request will not transfer, release or grant any intellectual property rights to me or my parent organization unless expressly written in the request approval.
6. I accept that the California Vectorborne Diseases Surveillance System (CalSurv) and its constituent agencies are not liable or responsible for any released data or their use; or for any loss, damage, claim, cost or expense that arise from use of any released data.
7. I agree to appropriately reference the California Vectorborne Diseases Surveillance System in any publications or presentations deriving from any released data. A final copy of the publications or presentations resulting from any released data will be provided to the California Vectorborne Diseases Surveillance System.

I have read and understand the limitations of CalSurv data as presented above. I will consider these limitations in any analysis and interpretation of the data, and will include an explanation of these limitations in any resulting presentations or publications. If I have any questions regarding CalSurv data, the limitations of CalSurv data, or the data use agreement or policies, I will contact the Data Steward at CalSurv.

Name: \_\_\_\_\_

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

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**Please return your completed form and agreement to:**

Bborie Park, Data Steward  
California Vectorborne Diseases Surveillance System (CalSurv)  
C/O Center for Vectorborne Diseases, UC Davis  
Old Davis Road  
One Shields Ave  
Davis, CA 95616  
bkpark@ucdavis.edu  
Phone: 530-752-8380  
Fax: 530-754-6360