

Vectorborne Disease Surveillance Data Policy

Approved by CalSurv Steering Committee November 1, 2007

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. These 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, the California Department of Public Health, and the University of California. This policy is administered by a CalSurv steering committee, comprised of members from the three agencies listed above.

Preamble. 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 these 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. All surveillance data are subject to the regulations of the Health Insurance Portability and Accountability Act (HIPAA) of 1996. As such, 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 acknowledgment or authorship those individuals and organizations most responsible 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.

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 or publication. However, exceptions exist for the following situations (all exceptions terminate upon the individual’s separation from their parent agency):

- An individual need not request permission to use data generated or held in sole custody 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.)
- An individual appointed by CalSurv as a data steward. This appointment is automatically granted to the server administrator overseeing all pertinent datasets.

7. Requests for use of CalSurv data will be considered for approval by the CalSurv Steering Committee. Approved requests 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.

Limits of the Data Policy

1. This policy applies only to those datasets managed by CalSurv. Datasets exempt from this policy are:

- Non-CalSurv databases, such as the CDPH Dead Bird database (dhs_deadbird).
- Summaries of surveillance datasets needed by agencies such as CDPH to satisfy statutory requirements for agency reports.

2. Permission to use data from surveillance datasets not covered by this policy must be sought from the agencies possessing the data.

Suggested permission form

The form to be submitted by individuals or organizations wishing to use surveillance data other than datasets belonging strictly to the requestor should include the following:

1. Requestor name and contact information
2. Parent organization of requestor.
3. Indication of whether requestor is applying for permission as an individual or as a representative of an organization.

4. Intended use of data (analysis, publication, commercial, etc.) and intended time frame.
5. Statement of acknowledgement and acceptance of guiding principles listed above, and detailed explanation of measures the requestor intends to implement to ensure that the principles are upheld in the context of the specific request.
6. Agreement that data be released only with express permission from the agency responsible for said data.
7. Acknowledgment that permission is granted solely for the purpose expressed in the request and that any modifications of the intended use protocol will require resubmission of an appropriately revised request.
8. Requests for use of electronic CalSurv data should be sent to:

Bborie K. Park, Data Steward,
California Vectorborne Diseases Surveillance System (CalSurv)
C/O Center for Vectorborne Diseases
University of California
Old Davis Road
Davis, CA 95616