

3/1/06

Region IX IPP Data Procedures

Project Overview

The Region IX Infertility Prevention Program (IPP), sponsored by the Centers for Disease Control and Prevention and the Office of Population Affairs, is part of a national effort supporting chlamydia screening and treatment of women attending family planning, STD and other testing sites. The primary tasks of the project is to collect data and communicate findings and disease trends to participating sites. Data is then sent on to CDC to support a larger national effort. The project is overseen by the Regional Advisory Committee, which is a made up of representatives from State STD, family planning, laboratory and other related health care organizations. It is administered by the Regional Infrastructure agency, The Center for Health Training.

The Regional Advisory Committee's main function is to maintain communication and collaboration among the representatives participating in the project. It convenes twice annually to review and recommend chlamydia test technologies, create screening and treatment guidelines, participate in the development of quality assurance protocols and develop partner and outreach programs. The Data and Analysis Subcommittee of the Regional Advisory Committee oversees and makes recommendations regarding the data collection effort. This procedures manual addresses the data collection aspect of the project.

Sentinel Data Collection Sites in Region IX

Region IX consists of the states of Arizona, California, Hawaii and Nevada. The Pacific Basin Territories and Navajo Nation are included in the region but do not currently submit data to the project. Participating sites are primarily STD and Family Planning clinic sites. Other clinic types also submit data: school-based, teen, prenatal, college student health, primary care, adult and juvenile detention facilities, and alternate test sites such as mobile clinics.

The Region is currently divided into six distinct project areas: Arizona, Hawaii, and Nevada each represent a project area. California is subdivided into three project areas: Los Angeles, San Francisco and the remainder of California (the "California State Project Area").

Administrative Structure

Each data collection site has a local coordinator. The local coordinator collects and submits data to the data manager for that project area (though in larger project areas, there may also be intermediate coordinators). The six project area data managers combine

clinic level data and submit an area data set to the regional data manager who, in turn, combines and creates a regional data set. The data set is archived at the regional level and a copy of it is sent on to CDC.

Timelines and Submission

Quarter	Due to Region
Jan 1 – March 31	June 1
Apr 1- Jun 30	September 1
July 1 – Sept 30	December 1
Oct 1- Dec 31	April 1

Data is submitted quarterly and cumulatively within a calendar year and is due two months after the end of the quarter. The first quarter submission contains data from the first quarter, the second quarter submission contains data from the first and second quarters and so in. In April, a final set is submitted for January through December of the preceding calendar year. There is an extra thirty days added for the year end set to insure that it's complete as possible. The region submits data to CDC thirty days after the internal due dates.

With the data submission the project area data manager should also note any new sites that have been added including their full agency and clinic site names as well as city and zip code; sites that have been dropped; and any known changes in screening criteria or test technologies. It is extremely helpful to also include two or three sample frequencies on core measures to insure no records were dropped at any point in the transfer process.

Data Records

A data record represents a single chlamydia test given to a single patient on a single date. Each record must contain, at minimum, the core data elements as set by the region: a unique site identifier (which is a combination key of elements representing project area, agency identifier and clinic identifier); clinic type; gender; race; Hispanic ethnicity; date of birth; zip code of residence; specimen source; date of specimen collection; type of CT test; and CT test result.

There are also optional data elements a site may choose to collect. These elements include more in-depth information about the testing and treatment, client reason for visit, co-testing for gonorrhea, and patient behavioral factors.

Appendix A is a data dictionary, which details variable names, lengths, data types, permissible responses and a brief description. Appendix B contains a narrative of more detailed variable definitions and explanations, including how the responses are to be determined.

7/1/05

Data Collection Tool

Data is collected from sites one of two ways: as part of a laboratory slip or on a data collection form specifically designed for the purposes of this effort; either is acceptable as long as the collection tool contains the core data elements and is designed so that variables and responses are printed and marked in a clear, unambiguous fashion.

Data Entry

Depending on the arrangement with the project area data manager, data is either entered at the site for electronic transfer or data forms forwarded to the data manager for data entry. Data from the site may be entered as part of a larger information system for managing client visits or the laboratory and then the appropriate measures exported (see *Data File Formats* below).

Data may also be entered in a data management program that has been tailored for the specific purposes of the project. In the past, both Epi-Info and MS Access have been used. Your project area data manager may already have a program available that can be used or tailored for your site, please consult with them.

It is highly recommended that the data entry system have built in system checks that alert the data entry person when incorrect or out-of-range responses are entered.

Data File Formats

Since most data programs can import and export various file formats, the region has no “official” data file format. Common formats currently in use are EpiInfo files (.rec) and Dbase III (.dbf). Common issues that should be considered when testing file transfers are reliable transfer of variable names, variable types (i.e. alpha, numeric, and date), variable length, and preservation of missing values vs. valid zero responses. Project areas may establish what formats are acceptable for transmission and the region may also negotiate acceptable file formats with individual project areas. Contact the regional data manager for more information.

Sentinel Site Requirements and Quality Assurance

Staff at each sentinel site is required to be oriented to the project with specific training on data collection requirements from their area data manager. A local data coordinator (either at the clinic or at the laboratory) should be selected to be responsible for the review of data collection instruments. If data is being entered at the clinic level, data entry staff should be trained to alert the local coordinator if there are significant numbers

of incomplete or erroneous data. Any problems that are identified should be referred back to the site for correction and feedback to staff.

Sentinel site data should be assessed by a review of the first 200 data collection forms/clients. If there are numerous errors in the first 200 forms/clients, then feedback should be given to staff filling out the forms and an additional 100 forms/clients should be reviewed to see if the problems have been resolved. The Region IX standard for quality is 95% accuracy and completeness per variable on the completed forms/clients.

A review of twenty (20) medical records should take place within the first 3 months of the beginning of data collection and annually thereafter to determine if data reported accurately reflects the information in the medical record.

Each project area data manager should review the data for consistency and completeness before submitting it to the region. If there are known issues with missing or incorrect data, those should be reported to region upon submission. Data is reviewed again at regional level and recurring or common data entry and data collection errors are shared with project areas. Problems with the data are resolved by collaboration between infrastructure staff, project area staff and local data managers.

Individual project areas may also have additional QA procedures such as annual file audits that should be described by your project area data manager as part of your orientation.

Data Analyses and Reports

Reports on sentinel site data are generated twice annually to coincide with IPP Advisory Committee meetings (currently in January and July). The midyear set is distributed to the Data Committee members for QA and the year end data is shared with the entire Advisory Committee. Project area managers are responsible for forwarding information back to local clinic coordinators.

Participating agencies are able to request data analysis from the region to answer specific project or clinic level concerns. The regional data set is also made available to interested third parties and there is a process in place to review and approve these requests. (See Appendix C for those instructions).