# Chronic Hepatitis C in California
# 2016 Technical Notes

## Data Sources & Definitions

The California Department of Public Health (CDPH) received cumulative data on chronic hepatitis C infections from various sources, including case reports and laboratory results submitted by local health jurisdictions (LHJs), laboratories, and health care providers.

Given that multiple case reports regarding the same individual could have been submitted over time, information from multiple data sources was merged and analyzed to identify matched records. Duplicate case reports were removed ("deduplicated") to identify cases newly reported to CDPH each year.

Only newly reported cases with positive test results dated on or before December 31, 2016 were counted in this report. However, data reported to CDPH through June 30, 2017 were included in the analysis to allow for delays in data entry at the local level.

This report presents data for the most recent three-year period (2014-2016) to minimize the chance that an increase in case reports is due to the initiation of statewide electronic laboratory reporting (ELR) and autoprocessing of ELR hepatitis C data of data in October and December, 2013, respectively.

Key information sources and definitions used in this report are explained below.

## Case Definitions

### Chronic Hepatitis C

This report uses the term "chronic hepatitis C infection" to describe cases meeting the Council of State and Territorial Epidemiologists (CSTE) case definition for "hepatitis C, past or present" in 2012-2015 or "hepatitis C, chronic" in 2016. These include some persons with HCV antibody in the blood, which indicates "past infection", and all persons with HCV ribonucleic acid (RNA) or HCV genotype in the blood, which indicates "present infection" or "chronic infection".

To meet the CSTE case definition during 2012-2015, a positive anti-HCV test result and alanine aminotransferase (ALT) test results (not routinely collected by local surveillance programs) were required for a *probable* case classification; either HCV antibody above a certain threshold value established for the specific assay or a positive HCV RNA was considered *confirmed*. CSTE revised the laboratory criteria for chronic hepatitis C diagnosis in 2016. In 2016, a positive anti-HCV result, regardless of test threshold or ALT value, was required for a *probable* case classification; HCV RNA was considered *confirmed*.

LHJs reported cases of chronic hepatitis C infection to CDPH as *confirmed* or *probable* based on the CSTE case definition for "hepatitis C, past or present" or "hepatitis C, chronic" current at the time of the case report. This surveillance report accepted LHJs' case classifications at face value unless laboratory data were available to independently verify whether reported cases met the CSTE case definition.

## OTHER REPORT DEFINITIONS

### Newly Reported Cases

For the purposes of this report, a newly reported case of chronic hepatitis C is defined as a person who is being reported to CDPH for the first time and who meets the U.S. Centers for Disease Control and Prevention (CDC)/CSTE case definition for chronic hepatitis C infection.

### Date of First Report

The report date for each case was defined as the first date the case was submitted to a LHJ or to CDPH as a *confirmed* or a *probable* case. If a confirmatory result for a *probable* case was received within the reporting year, the date of first report reflects the date the case was confirmed.

### Rate of Newly Reported Cases

This report defines the "rate of newly reported cases" as the number of newly reported cases in a defined population, divided by the number of people in the defined population, and multiplied by 100,000 in order to report the rate per 100,000 persons. This method was applied to populations defined by specific demographic groups (e.g., age and gender) to calculate group-specific rates. As described in the Data Limitations section, these rates do not describe incidence of new viral hepatitis infections.

### Local Health Jurisdictions

Individual cases of chronic hepatitis C were attributed to the LHJ in which they resided at the time of their first *probable* or *confirmed* hepatitis C case report. CDPH calculated county-specific rates using data published by the California Department of Finance in December 2016.[1] Data for the three city health jurisdictions (Berkeley, Long Beach, and Pasadena) enclosed in larger counties are included in the county totals and also displayed separately from their respective county totals. These rates exclude individual cases in state prisons, as well as cases whose jurisdiction at the time of contact was outside of California. Rates were not calculated for LHJs with ten or fewer cases. To protect confidentiality, statistical masking was applied

[1] State of California, Department of Finance, *California County Population Estimates and Components of Change by Year, July 1, 2010-2016*. Sacramento, California, December 2016.

where the number of cases is fewer than 11 or the population denominator is less than 20,000. If a cell is suppressed, one or more complementary cells are suppressed to avoid recalculation of the suppressed cell.

**Age and Gender**

For this report, age is defined as the age of the person at the time that a LHJ or CDPH received the first *probable* or *confirmed* chronic hepatitis C case report for that individual. The actual time of infection is not possible to approximate without continuous testing because people may have been infected with hepatitis C for many years prior to their first case report. Rates of newly reported cases by age and gender were calculated using data published by the California Department of Finance in February 2017.[2] Rates by gender are presented for females and males only. Although LHJs began reporting transgender as a separate gender category in 2011, data on transgender identity are inconsistently reported, and California population denominator data for transgender persons are uncertain. Rates were thus not calculated for transgender persons.

**Race/Ethnicity**

Race/ethnicity was categorized as American Indian/Alaska Native, Asian/Pacific Islander (API), African American/Black, Hispanic/Latino, White, and Multi-race/Other Race. For the purposes of this report, Hispanic/Latino encompasses patients of Hispanic or Latino ethnicity, regardless of reported race; all other race categories presented do not include persons of Hispanic or Latino ethnicity. Starting in 2010, information regarding identification of API individuals within specific API groups (e.g., Chinese, Hmong, Vietnamese, Native Hawaiians) was collected but was only available for less than 1 percent of hepatitis C cases reported as API; thus the specific API groups are not used in this analysis.

The race/ethnicity data in this report should be interpreted with caution because 66 percent of chronic hepatitis C cases were missing race/ethnicity information during 2014-2016. For this reason, percentages, rather than rates, were used to describe newly reported cases for which race/ethnicity is known. Rates of newly reported cases were not calculated for “Other Race” and “Multi-race” groups because current California population denominator data do not allow for differentiating between Other Race, Multi-race, and racial categories that are not specified.

**Incarcerated Persons with Chronic Hepatitis C**

For the purposes of this report, individuals with chronic hepatitis C infection who were incarcerated in state prisons at the time of their first *probable* or *confirmed* hepatitis C case report were not attributed to the LHJ in which they were incarcerated. This is because people are often incarcerated in a different county than the one in which they would reside were they

[2] State of California, Department of Finance, Report P-3: State and County Population Projections by Race/Ethnicity, Detailed Age, and Gender, 2010-2060. Sacramento, California, February 2017.

not incarcerated. In order to avoid overestimating the burden of disease in (often rural) counties with state prisons, chronic hepatitis C cases reported from state prisons were attributed to the state prison system at large. However, persons incarcerated in local county jails at the time of their first case report were attributed to the LHJ in which they were incarcerated. This is because people are more likely to reside in the jurisdiction in which they are incarcerated in a local county jail, and because the length of stay in a county jail is often shorter than the length of stay in a state prison. Accordingly, the data highlighted in this report are presented in two separate sections—the first for the entire state (which includes cases in state prisons), and the second for hepatitis C cases in state prisons only.

Rates of newly reported chronic hepatitis C cases among persons incarcerated in the overall state prison system were calculated using aggregate population data from the California Department of Corrections and Rehabilitation (CDCR).[3] Prison census data were stratified by specific demographic groups (e.g., age, gender, and race/ethnicity) for persons incarcerated in state prison institutions, camps, and state hospitals. Data do not include cases reported in federal prisons or immigration detention centers.

## DATA LIMITATIONS

For a number of reasons, chronic hepatitis C surveillance data do not represent the true prevalence of chronic hepatitis C infections in California. First, surveillance data only include those persons reported to CDPH. Cases not reported to CDPH include: (1) persons unaware of their infection (i.e., those who have not been tested, including due to lack of access to care), (2) persons who were tested before the state required that providers and laboratories report cases to the LHJ, (3) individuals whose provider or testing laboratory did not report the results to the LHJ, and (4) individuals residing in LHJs where some cases are not reported.

Second, the migration of individuals with hepatitis C infection, either between counties within or outside of California, might limit the accuracy of case counts for the state, as well as by LHJ.

Third, these data include both living and deceased persons with chronic hepatitis C infection in California. In order to determine prevalence, only currently living cases should be counted, a task that requires a match to state and national death records and which was beyond the scope of this surveillance report.

**These data describe the number of *newly reported cases* per year; they do not measure the actual rate of new infections in the population per year (incidence).** Incidence is the measure of new infections in a defined, at-risk population during a specified time period, usually a year. These data represent cases that LHJs newly reported to CDPH each year. Although the date that LHJs report a case to CDPH is used to measure newly reported infections, it does not necessarily reflect the actual date a person was initially infected or diagnosed with hepatitis C. Due to the

[3] State of California, Department Corrections and Rehabilitation, Offender Information Services Branch, County-Level Population Data Stratified by Age, Sex, and Race/Ethnicity for Institutions, Camps, and State Hospitals as of June 30th of each Year. Sacramento, California, 1994 - 2016.

asymptomatic nature of chronic viral hepatitis infection, individuals may have been infected many years ago, but only tested and diagnosed when they began to experience symptoms of viral hepatitis. Individuals may have also been tested—even if they lacked symptoms—due to implementation of 2012 CDC screening guidelines for persons at risk for hepatitis C infection, and for all persons born during 1945-1965.

**These data are more complete for HCV-related tests reported by selected labs.** Prior to the implementation of electronic laboratory reporting (ELR) in the California Reportable Disease Information Exchange (CalREDIE) in October 2013, CDPH received line-listed laboratory data from only two laboratories, Quest and Foundation, and not from other laboratory sources. Quest and Foundation laboratories served the state prison system for some or all of the years between 2007 and 2016. Thus the data presented in this report provide a more complete picture of hepatitis C cases reported by Quest and Foundation laboratories than by other laboratories and a more complete picture of chronic hepatitis C cases in state prisons than in the state overall.

**Information is missing from these data.** Despite state regulations (California Code of Regulations, Title 17, Section 2500 and Section 2505) requiring providers and laboratories, respectively, to provide race/ethnicity information in case reports, this information is often missing from provider reports and is almost always missing from laboratory reports. Since the majority of viral hepatitis cases in California are reported by laboratories, and not health care providers, 61 percent of chronic hepatitis C cases were missing race/ethnicity information in 2016. Patients' addresses are also often missing in case report forms and laboratory reports. LHJs typically do not have sufficient resources to obtain information missing for reported cases due to the high volume of HCV-related laboratory reports. As a result, CDPH is currently unable to provide a complete description of the demographic characteristics of chronic hepatitis C infections in California.

**These data may differ from local public health estimates.** Due to CDPH's ability to match and deduplicate cases across time and LHJs, case counts provided in local health jurisdiction data summaries and/or California chronic viral hepatitis data summaries will often differ from local public health estimates. The extent to which state and local case counts may differ is influenced by a number of factors, including access to legacy data sources, use of methods to match and deduplicate cases, and methods for counting cases (e.g. definition of first report date).

**These data may contain errors in matching and deduplication.** A probabilistic record linkage algorithm was used to determine which records from multiple data sources refer to the same individual. The algorithm uses a set of demographic variables to calculate scores for each pair of records. Pairs of records with a score above a certain threshold are considered a match. It is possible that records for the same person were incorrectly matched (e.g., due to slight variations in name spelling), and thus two cases were counted instead of one. The opposite may also be true; it is possible that records for two separate persons were determined to be a match and were thus inappropriately counted as a single case. Although the matching algorithm was checked for accuracy, the large volume of records made it impossible to verify all matches and non-matches determined by the algorithm were correct prior to deduplication. In addition, our

use of probabilistic determination methods to ascertain the most likely value for demographic variables might not accurately determine correct values for age, race, sex, and other variables in all instances. However, the record linkage methodology applied here is robust and has been used for previous CDPH human immunodeficiency virus (HIV), sexually transmitted disease (STD), and viral hepatitis surveillance reports.

**Rates for small populations are unstable. They could be either inflated or deflated.** Caution should be used when interpreting county-specific rates of newly reported cases for counties of population size fewer than 100,000; rates fluctuate widely due to their small population size. The same caution applies when interpreting rate changes over time in small subpopulations, such as females in state prisons.

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