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Data: Access, Sources, and Systems

San Francisco, and San Mateo Counties 2017-2021 Integrated HIV Prevention and Care Plan

REGION	West
PLAN TYPE	EMA, Integrated city/county-only prevention and care plan
JURISDICTIONS	San Francisco EMA
HIV PREVALENCE	High

The San Francisco Bay EMA provides detail on their comprehensive use of care, surveillance and risk factor data including the AIDS Regional Information and Evaluation System (ARIES), RSR data, HIV Surveillance data, Medical Monitoring Project (MMP) data, and National HIV Behavioral Surveillance system data. This section also includes information on the qualitative assessments used to inform needs, service gaps, and barriers, as well as descriptions of data policies that facilitated or served as barriers to the Integrated Plan development and data, most notably on the lack of information on use of PrEP, which would have been useful for tracking progress of the Integrated Plan.

SELECTION CRITERIA: DATA: ACCESS, SOURCES, AND SYSTEMS

Exemplary Data: Access, Sources, and Systems sections met the following criteria (based on the Integrated HIV Prevention and Care Plan Guidance):

- Description of the ways data was used to develop needs assessment and HIV Care Continuum, including:
 - ▶ Use of RSR data
 - ▶ Use of Surveillance data
 - ▶ Use of Qualitative data
- Description of data policies that acted as barriers to data access
- Description of data that jurisdictions were unable to access but that would be helpful to access as a way to develop stronger epidemiologic profile and HIV Care Continuum.



Additional exemplary plan sections are available online:
www.targetHIV.org/exemplary-integrated-plans

E. Data: Access, Sources, and Systems

a. Main Data Sources to Assess Needs in the Region

RSR Data: The three counties of the San Francisco jurisdiction participate in the statewide, HIV-specific **AIDS Regional Information and Evaluation System (ARIES)**. ARIES is a custom, web-based, centralized HIV/AIDS client data management system that provides a single point of entry for clients; allows for coordination of client services among providers; meets HRSA and State care and treatment reporting requirements; and provides comprehensive data for program monitoring and scientific evaluations. ARIES enhances services for clients with HIV by helping providers automate, plan, manage, and report client- and service-level data. ARIES incorporates **four** integrated applications that work in conjunction with one another:

- The ARIES **Client Application** is the main application through which staff enters client data and search, edit, and generate reports from records.
- The ARIES **Report Export Application** allows users to define custom reports. Users can also export ARIES data in a variety of formats including XML for inclusion in other applications.
- The ARIES **Import Application** allows users to bring data into ARIES from other sources. ARIES Import accepts XML files, checks them for validity, and then inserts or updates the database with the newly imported data.
- The ARIES **Administration Application** allows users to monitor and control ARIES activity as well as customize ARIES edit screens.

ARIES employs multiple layers of security to protect access to data. Each user has a unique login and password to access ARIES. In addition, each computer must have a separate digital security certificate installed for every user who accesses the system. Not all users have access to all ARIES functions. HHS ARIES administrators have fine-grained control over who has access to which parts of the system. Lastly, the ARIES web servers and databases are protected by firewalls to prevent unauthorized access.

Qualitative Data: Both the San Francisco HIV Community Planning Council and the public entities overseeing HIV data in the three jurisdictional counties rely on numerous qualitative approaches to assess ongoing needs, barriers, conditions, and emerging issues in our region. The Planning Council commissions and conducts ongoing needs assessments as part of its work to prioritize and allocate HIV prevention and care resources. These assessments may be broad-based, covering the full range of needs of local high risk or HIV-infected populations, or topic-specific, exploring needs and preferences related to an emerging issue such as pre-exposure prophylaxis (PrEP) or the needs of persons 65 and older with HIV. Council-generated needs assessments complement ongoing solicitations for public input in regard to HIV prevention and care needs, barriers, and priorities, including town hall meetings; community forums; surveys and questionnaires; and public and consumer input at all Planning Council meetings, including the meetings of Council committees. This input is in addition to the invaluable experiential data provided by persons living with HIV who are members of the new merged Planning Council.

Qualitative input processes at the Council level are augmented by a range of additional data that feed into the Council's ongoing deliberations regarding HIV prevention and care services. These include reports and presentations by experts in a broad range of fields on emerging HIV prevention and care strategies and findings; circulation to the Council of key new HIV-related reports, articles, and studies; presentation of findings of broad-based client satisfaction surveys and needs assessments conducted by local agencies and programs; and input by the San Francisco HIV/AIDS Provider Network, a group of 43 community-based, non-profit HIV service agencies in the San Francisco region meeting the needs of persons living with HIV and AIDS. In their role as subcontract administrators and monitors, the three local health jurisdictions also collect ongoing qualitative service data from subcontracted HIV prevention and care providers, and report to the Council on issues such as barriers to prevention and care delivery; unanticipated performance issues related to emerging prevention and care issues; and successes in delivering services that either create new models or affirm the quality of new service standards and approaches.

HIV Surveillance Data: As defined by the US Centers for Disease Control and Prevention (CDC), the term 'surveillance' refers to the ongoing, systematic collection, analysis, interpretation, and dissemination of data regarding a health-related event. HIV surveillance entities collect, analyze, and disseminate information about new and existing cases of HIV infection with the ultimate goal of combining information on HIV infection, disease progression, and behaviors and characteristics of people at high risk for HIV on a regional, statewide, or national level. **HIV prevalence data** provides information on all persons or designated sub-groups of persons living with diagnosed HIV infection in a given region as of the end of a given time period, including persons who have ever been classified as having an AIDS diagnosis. **New HIV diagnosis data** reflects persons newly diagnosed with HIV infection in a specific region or sub-population within a given period of time (such as a calendar year). **Mortality data** refers to data on the deaths of overall populations or sub-groups of persons with diagnosed HIV infection in a given region which can either be directly ascribed to HIV-related symptoms or which occurs regardless of cause of death. This latter approach is becoming increasingly common as the population of persons living with HIV continues to age, and as the attribution of a specific cause of death becomes more complex and ambiguous in the face of a multitude of health conditions.

All local health departments collect and report data on new HIV infections in their region following State legislative standards and using State-mandated electronic reporting systems and procedures. This data is in turn aggregated and de-duplicated at the state level to eliminate previously identified cases, then further aggregated at the national level to eliminate cases previously identified in a different state or territory. All 50 states, the District of Columbia, and US territories collect comparable confidential, names-based case reports of persons living with diagnosed HIV infection, based on established case definitions. Medical providers, laboratories, and other organizations providing HIV testing services are required, by law, to report persons diagnosed with HIV to the state or local health department. Meanwhile, the State of California requires automatic reporting of all CD+ T-cell tests to track retention in care and regional viral load levels.

In California and the rest of the United States, HIV infections and AIDS diagnoses are reported through a combination of **passive and active surveillance**. Passive surveillance is conducted through State-required reporting of HIV and AIDS cases by health care providers and reporting of HIV-positive test results from laboratories to Local Health Departments (LHDs). Active surveillance is accomplished through routine visits by LHD staff to hospitals, physician offices, laboratories, counseling and testing clinics, and outpatient clinics to ensure completeness, timeliness, and accuracy of reported data. In California and other states, HIV/AIDS surveillance has historically relied heavily upon local health department staff who perform: a) active case surveillance; b) on-site chart reviews; and c) case report completion. To improve timeliness and completeness of reporting and ensure prompt identification and response to emerging problems in the field, the California Office of AIDS (OA) supports a **decentralized reporting system** where HIV and AIDS case reports are identified through passive and active surveillance efforts coordinated by California's 61 LHDs. HIV/AIDS surveillance case data, reported to local jurisdictions by health care providers and laboratories, is then sent to OA's HIV/AIDS Surveillance Section. The Surveillance Section then submits electronic HIV/AIDS case reports, without personal identifiers, to CDC while providing aggregated data to local health jurisdictions.

Medical Monitoring Project: The Medical Monitoring Project (MMP) is an ongoing CDC-funded national HIV/AIDS supplemental surveillance project. San Francisco is one of **23** project areas currently conducting MMP. Multi-stage probability proportional-to-size sampling is used to recruit HIV-infected adults receiving care at health facilities in San Francisco. Information about care utilization, clinical outcomes, resource needs, and HIV risk behaviors is collected through patient interviews and medical chart review. Data collected through the MMP is intended to provide an enhanced picture of the experience of being a person living with HIV, including information on how many people living with HIV are receiving medical care; how easy or complex it is to access medical care, prevention, and support services; what the met and unmet needs of persons living with HIV are; and how HIV treatment is affecting persons living with HIV. Ongoing MMP data and findings are continually shared with the San Francisco Planning Council and incorporated into prevention and care planning in all three county health departments.

National HIV Behavioral Surveillance (NHBS): First initiated by the CDC in 2003, the NHBS system tracks risk behaviors, HIV prevalence, and HIV incidence among populations at high risk for HIV infection in **22** high prevalence areas, including San Francisco. The NHBS uses state of the art sampling methods to reach members of high risk populations for standardized behavioral surveys and HIV testing. The NHBS samples **three** populations at highest risk for HIV in alternate cycles: men who have sex with men (MSM), people who inject drugs (PWID), and heterosexuals living in high risk areas. The NHBS survey instrument collects demographic, social experience, sexual behavior, alcohol and substance use, drug treatment, HIV testing, prevention activity, and health data. HIV testing is conducted using validated HIV testing kits and standardized laboratory methods for confirmation of HIV-positive cases. NHBS findings cited in this plan summarize data from the first **nine years** of the NHBS and comprise **three data collection cycles** for each high-risk population.

Estimate of ART Use: Information on ART use is generally obtained from **medical chart review**, since the use of surveillance data alone to estimate ART use tends to result in an underestimation of overall ART utilization rates. This underestimation occurs because ART data is collected at the time a person with HIV infection is first reported, which is often very close to the time of first diagnosis; this is often a time when newly diagnosed persons have not yet been linked to treatment. The SFDPH collects follow-up information from selected health care facilities in an attempt to more fully track current ART use. For persons who receive care at selected sites, treatment data are likely to be more complete because ART use is captured at a later date following initial diagnosis. ART follow-up information is not available for persons who have moved away from San Francisco or who receive ongoing care outside of the city, and ART data gathered through surveillance also does not include information on ART adherence. Because of the limitations of ART use data, the category is generally **not** included in HIV Care Continuum charts produced in the three-county region.

San Mateo and Marin County HIV Data: In Marin and San Mateo Counties, HIV cases are reported to local health departments using the California Department of Public Health Office of AIDS HIV/AIDS confidential case report form. The case report form collects demographic information, patient risk history, laboratory data to confirm and stage diagnosis, opportunistic and HIV-associated malignancy diagnoses, and treatment and service referrals. Cross-jurisdictional HIV data generally utilizes the electronic HIV/AIDS Reporting System (eHARS) for San Mateo and Marin County, which includes persons who reside in San Mateo County and Marin County at the time of diagnosis.

b. Facilitating or Inhibiting Data Policies

The City and County of San Francisco are fortunate to be able to draw on a wealth of HIV-related data when making decisions regarding resource allocation and program development. The region's largest data challenge continues to involve how to coordinate, streamline, and leverage data in real time (or as close as possible to real time) to allow for impactful public health consideration and action. In addition, fragmented data systems at times create missed opportunities for intervention. For example, in San Francisco, if a patient who has fallen out of care accesses sexually transmitted infection (STI) testing in the community, the STI provider does not currently have the ability to find out the patient's known HIV status or that she or he was out of care, resulting in a missed opportunity to re-link the patient to care. Although San Francisco has made significant strides in recent years to make better use of available data, including developing collaborations across departmental sections and divisions, work remains to be done to fully integrate all data systems within and across the health department.

As noted above, a broader challenge involves the varied levels of data and data systems available across counties within our region. San Francisco has a nationally recognized surveillance system that allows for highly sophisticated and precise data analysis for not only tracking the epidemic, but for isolating small pockets of persistent infection and revealing hidden disparities across the continuum of care. But because of resource disparities, these

capacities currently do not exist in the other two counties of our region. The just-completed integrated planning process re-emphasized not only the scale of these disparities, but the degree to which they inhibit the collection and reporting of accurate data and the development of optimal systems to maximize prevention and care resources across the three counties. Applying San Francisco's resources and expertise to enhancing the data collection and reporting capacity of Marin and San Mateo Counties is a key goal of the new five-year Plan.

c. Missing or Unavailable Data

The advent of Pre-Exposure Prophylaxis (PrEP) has transformed the HIV prevention landscape and has the potential to significantly reduce new HIV infections. However, while much progress has been made, there remains little actual data on how PrEP is being used, such as adherence and disparities in access across different sub-populations and regions. While some data can be pieced together to reveal a somewhat fragmented picture of the impact of PrEP on risk behaviors, there is, as yet, no comprehensive source of data currently available. The San Francisco Department of Public Health continues to work closely with and through the SF Getting to Zero initiative to develop new strategies for tracking PrEP use and adherence in our region, and for potentially incorporating this data into the HIV Care Continuum and ongoing HIV data reports.