Date of Hearing: July 2, 2024

### ASSEMBLY COMMITTEE ON PRIVACY AND CONSUMER PROTECTION Rebecca Bauer-Kahan, Chair SB 1333 (Eggman) – As Amended June 4, 2024

#### PROPOSED CONSENT

#### **SENATE VOTE**: 37-0

#### SUBJECT: Communicable diseases: HIV reporting

#### **SYNOPSIS**

In 2022, there was a global mpox (formerly monkeypox) outbreak that included a reported 32,603 cases in the U.S, 6,160 of those in California. According to the Centers for Disease Control, "the main transmission route was associated with sexual activity among certain gay, bisexual, and other men who have sex with men."

Since mpox was not included in this list of conditions for which CDPH and LHDs can cross reference HIV data, both local and state public health officials were unable to document and understand whether people with mpox were infected with HIV. This delayed their ability to understand if those infected with HIV were adversely impacted by mpox and subsequently delayed the ability to develop specific guidance and outreach, which would have more promptly enabled local public health and clinical partners to prevent severe mpox disease in this population.

Under existing law, CDPH and LHDs are only authorized to share personally identifying information of a person infected with HIV if they have HIV alone or have a coinfection with one or more of seven reportable diseases: chlamydia, gonorrhea, hepatitis B, hepatitis C, meningococcal infection, syphilis, and tuberculosis.

The purpose of this bill is to allow state and local health departments to react more quickly when there are outbreaks of viruses that may disproportionately impact HIV-positive people by allowing LHDs and CDPH to share the personally identifying information of a person coinfected with HIV and any other reportable conditions.

**SUMMARY:** Expands existing law by removing the limitations on the types of conditions for which the California Department of Public Health (CDPH) and local health departments (LHDs) may disclose personally identifying information of human immunodeficiency virus (HIV) positive individuals in public health records for the coordination of, linkage to, or reengagement in care. Specifically, **this bill**:

- 1) Authorizes CDPH and LHDs to disclose personally identifying information in public health records for the coordination of, linkage to, or reengagement in care, as determined by CDPH or a LHD.
  - a) Removes the limitations on disclosure described in 6) b) through d) of existing law, below.

- b) Removes the requirement that the disclosure is for the purpose of enhancing the completeness of reporting to the Centers for Disease Control and Prevention (CDC) of HIV/acquired immunodeficiency virus (AIDS) and coinfection with certain diseases.
- 2) Authorizes LHD HIV surveillance staff to disclose information to a health care provider who provides care to the HIV-positive person who is the subject of the record for the purpose of facilitating appropriate case management or care coordination or delivery of medical care and treatment.
- 3) Requires CDPH and LHD employees and their contractors to sign confidentiality agreements annually, rather than signing the agreements once, and deletes the requirement that DPH and LHDs review the agreements annually.
- 4) Finds and declares the following:
  - a) According to CDPH, more than 142,700 people in California are living with diagnosed HIV infection.
  - b) Approximately 73.7 % of people living with diagnosed HIV infection in California are in HIV care and 64.7 % have achieved viral suppression.
  - c) The goals of the Ending the HIV Epidemic in the U.S. plan include increasing linkage to care and viral suppression to 95 % by 2025.
  - d) Evidence-based data sharing practices allow state and LHDs to leverage public health and health care systems data to more effectively serve people living with HIV.
  - e) States the intent of the Legislature to enhance data sharing practices concerning people living with HIV, while continuing to prioritize privacy and safety measures to ensure responsible dissemination of sensitive health data and coordination of, linkage to, or reengagement in care.

# **EXISTING LAW:**

- Establishes under federal law, the Health Insurance Portability and Accountability Act of 1996 (HIPAA), which sets standards for the privacy of individually identifiable health information and security standards for the protection of electronic protected health information, including, through regulations, that a HIPAA-covered entity may not condition the provision of treatment, payment, enrollment in a health plan, or eligibility for benefits on the provision of an authorization, except under specified circumstances. Provides that if HIPAA's provisions conflict with state law, the provision that is most protective of patient privacy prevails. (42 U.S.C. § 1320d, et seq.; 45 Code Fed. Regs. Part 164.)
- 2) Establishes the Confidentiality of Medical Information Act, which establishes protections for the use of medical information. (Civ. Code § 56 et seq.)
  - a) Prohibits providers of health care, health care service plans, or contractors, as defined, from sharing medical information without the patient's written authorization, subject to certain exceptions. (Civ. Code § 56.10.)

- 3) Requires CDPH to establish a list of diseases and conditions to be reported by local health officers (LHOs) to CDPH.
  - a) CDPH must specify requirements related to the timeliness of reporting each disease and condition, the mechanisms required for reports, and the content that must be included in the reports.
  - b) Authorizes the list to include both communicable and non-communicable diseases.
  - c) Authorizes the list to be modified at any time by CDPH, after consultation with the California Conference of Local Health Officers. (Health & Saf. Code § 120130.)
- 4) Requires health care providers and laboratories to report cases of HIV infection to the LHO using patient names on a form developed by CDPH.
  - a) CDPH and LHD employees and contractors are required to sign confidentiality agreements, which include information related to the penalties for a breach of confidentiality and the procedures for reporting a breach of confidentiality, prior to accessing confidential HIV-related public health records.
  - b) Those agreements are required to be reviewed annually by either CDPH or the appropriate LHD. (Health & Saf. Code § 121022.)
- 5) Prohibits public health records relating to HIV/AIDS containing personally identifying information that were developed or acquired by CDPH or an LHD, or their agent, from being disclosed, except for public health purposes or pursuant to a written authorization by the person who is the subject of the record or by that person's guardian or conservator. (Health. & Saf. Code §121025(a).)
  - a) Authorizes CDPH or an LHD, or their agent, to disclose personally identifying information in public health records to other local, state, or federal public health agencies or to corroborating medical researchers, when the confidential information is necessary to carry out the duties of the agency or researcher in the investigation, control, or surveillance of disease, as determined by CDPH or an LHD. (Health. & Saf. Code § 121025(b).)
  - b) Any disclosures made are to include only the information necessary for the purpose of the disclosure and only upon agreement that the information will be kept confidential. (*Id.* at (c).)
- 6) Authorizes the following disclosures for the purpose of enhancing the completeness of reporting to the federal Centers for Disease Control and Prevention (CDC) of HIV/AIDS and coinfection with certain diseases:
  - a) Disclosure to the health care provider who provides HIV care to the HIV-positive person who is the subject of the record by LHD HIV surveillance staff.
  - b) Disclosure by LHD tuberculosis control staff to CDPH tuberculosis control staff, who are authorized to further disclose information to the CDC, except for identifying patient

information and only to the extent the information is requested by the CDC for purposes of the investigation, control, or surveillance of HIV and tuberculosis coinfections.

- c) Disclosure by LHD sexually transmitted disease (STD) control staff to CDPH STD control staff, who are authorized to further disclose information to the CDC, except for identifying patient information and only to the extent the information is requested by the CDC for the purposes of the investigation, control, or surveillance of HIV and syphilis, gonorrhea, or chlamydia coinfection.
- d) Disclosure by LHD staff to CDPH staff for purposes of the investigation, control, or surveillance of HIV and its coinfection with hepatitis B, hepatitis C, and meningococcal infection, who are authorized to further disclose information to the CDC, except for identifying patient information and only to the extent the information is requested by the CDC. (Health & Saf. Code § 121025(c)(1).)
- 7) Authorizes specified LHD staff to further disclose information to CDPH or control staff, for the purpose of facilitating appropriate medical care and treatment of persons coinfected with HIV and tuberculosis, syphilis, gonorrhea, chlamydia, hepatitis B, hepatitis C, or meningococcal infection, the HIV-positive person who is the subject of the record or the health care provider who provides their care. (Health & Saf. Code § 121025(c)(3).)

FISCAL EFFECT: As currently in print, this bill is keyed fiscal.

### **COMMENTS**:

1) Author's statement. According to the author:

California law only allows state and local public health personnel to communicate with each other or with health care providers about a person's HIV status to facilitate medical care and treatment if the person has HIV alone or has HIV coinfection with specific diseases (tuberculosis, hepatitis B, hepatitis C, meningococcal infection, chlamydia, gonorrhea, syphilis, or meningococcal infection). Sharing of information for other reportable communicable disease, such as hepatitis A, mpox, or Shigella, is not allowed. During the 2022 mpox outbreak, CDPH could not disclose a patient's HIV status to an LHD or health care provider even when responding to an urgent request for clinical consultation on a complex mpox case, potentially resulting in more fragmented patient care and delaying appropriate treatment risking more severe infections. Not being able to record an mpox case's HIV status in the secure and confidential data systems for mpox investigations meant that LHDs were also unable to determine whether people diagnosed with mpox needed linkages to HIV care or prevention services, resulting in missed opportunities to prevent HIV transmission. California laws limiting the sharing of HIV data has seriously hindered the ability of LHDs and health care providers to triage mpox cases and delivery of timely, clientcentered mpox services for the people at highest risk of mpox complications. This bill will improve California's ability to ensure timely, quality health care for people with HIV and other reportable communicable diseases.

2) **Purpose of this bill.** In 2022, there was a global mpox (formerly monkeypox) outbreak that included a reported 32,603 cases in the U.S, 6,160 of those in California.<sup>1</sup> Mpox is a viral illness caused by the monkeypox virus. Symptoms include a skin rash or mucosal lesions which can last 2–4 weeks accompanied by fever, headache, muscle aches, back pain, low energy, and swollen lymph nodes. The virus can be transmitted to humans through physical contact with someone who is infectious, with contaminated materials, or with infected animals. The World Health Organization data shows that 110 countries reported about 87 thousand cases and 112 deaths.<sup>2</sup> According to the Centers for Disease Control, "the main transmission route was associated with sexual activity among certain gay, bisexual, and other men who have sex with men."<sup>3</sup>

Since mpox was not included in this list of conditions for which CDPH and LHDs can cross reference HIV data, both local and state public health officials were unable to document and understand whether people with mpox were infected with HIV. This delayed their ability to understand if those infected with HIV were adversely impacted by mpox and subsequently delayed the ability to develop specific guidance and outreach, which would have more promptly enabled local public health and clinical partners to prevent severe mpox disease in this population.

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The purpose of this bill is to allow state and local health departments to react more quickly when there are outbreaks of viruses that may disproportionately impact HIV-positive people by allowing LHDs and CDPH to share the personally identifying information of a person coinfected with HIV and any other reportable conditions. This ensures that the delays associated with the mbox outbreak will not be repeated as a result of not being able to access HIV cross reference data. The author does not propose waiving any additional privacy protections that have not already been waived in the current law.

3) **Related legislation.** SB 249 (Leno, Ch. 445, Stats. 2013), among other things, authorized CDPH and LHD to access reports of HIV infection that are electronically submitted by laboratories, and authorized LHD staff to further disclose information to the HIV- positive person or the health care provider.

# **REGISTERED SUPPORT / OPPOSITION:**

# Support

APLA Health (co-sponsor) Equality California (co-sponsor) San Francisco Aids Foundation (co-sponsor)

<sup>&</sup>lt;sup>1</sup> Data from the Centers for Disease Control. <u>https://www.cdc.gov/poxvirus/mpox/response/2022/us-map.html</u>

<sup>&</sup>lt;sup>2</sup> World Health Organization. *Mbox Fact Sheet* (Apr. 18, 2023), <u>https://www.who.int/news-room/fact-sheets/detail/monkeypox</u>.

<sup>&</sup>lt;sup>3</sup> Centers for Disease Control. *Risk of Clade 1 Mpox Outbreaks Among Gay, Bisexual, and Other Men Who Have Sex With Men in the United States* (Jun. 4, 2024), <u>https://www.cdc.gov/forecast-outbreak-analytics/about/modeling-forecasting/mpox-gbmsm-technical-brief.html</u>.

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### **Opposition**

None on file.

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