

**Planned Parenthood Affiliates of California** 

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## VIA ELECTRONIC TRANSMISSION

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Director
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## RE: PPAC Comments on the Draft Data Exchange Framework (DxF) Documents

## Director Ohanian:

On behalf of California's seven Planned Parenthood Affiliates, who collectively operate more than 100 health centers across the state and conduct more than 1.2 million annual patient visits, Planned Parenthood Affiliates of California (PPAC) respectfully submits the following comments regarding the draft Data Exchange Framework (DxF) Data Sharing Agreement (DSA) and its initial set of Policies and Procedures (P&Ps).

As a member of the CalHHS Data Sharing Subcommittee, PPAC appreciates the time and effort that has gone into drafting the DSA and initial Policies and Procedures. PPAC supports the broad endeavor by CalHHS to improve population health through the facilitation of health information across California's vast and complicated health care landscape. However, as we have voiced throughout the stakeholder process, PPAC remains concerned about the rapid finalization of the DSA without first establishing clear policies and procedures to protect a patient's right to control their sensitive and confidential health information.

**PPAC strongly believes that patients should own their data and have the choice to consent to sharing their personal health information.** If the Data Exchange Framework does not offer patients a choice to opt out of sharing their data without limitation through the DxF, it could weaken or undermine many of California's existing protections for patients who are seeking sensitive services with a provider of their choice, and who may not want their family, Primary Care Physician, or other third party entities to have access to information about the sensitive health care services they received. Patients should be able to declare they are receiving sensitive services and opt out of sharing personally identifiable information at any time to protect their privacy.

**PPAC** believes that broad access to sensitive health information by non-government social services organizations raises serious patient confidentiality and safety concerns. Across the country, state governments and private individuals have taken unprecedented steps to restrict or penalize access to essential health care services – especially contraception, abortion, mental health care, and transgender-affirming services. Any patient, whether a California resident or visiting from another state, has a right to protect their privacy and their safety by choosing who can access their personal health information in California. PPAC does not believe anyone is entitled to personal health information that is not their own, and we are concerned that the DxF could potentially bring harm to patients and force health care providers to breach their legal obligations unless it includes stronger protections for patient confidentiality.

A DxF without exceptions and protections for sensitive services could undermine public trust and Planned Parenthood's ability to improve public health outcomes in our communities. Planned Parenthood is a trusted provider of sensitive health care services for millions of Californians who are disproportionately people with low income, people of color, or living in historically underserved communities. Every year, thousands of Medi-Cal patients exercise their freedom of choice to go out-of-network to a Planned Parenthood health center, not only because they trust Planned Parenthood to provide high-quality health care, but also because they trust Planned Parenthood to protect their privacy and confidentiality. Requiring Planned Parenthood to share personally identifiable information without exception through the DxF could harm the trust and improved health outcomes we have established with Planned Parenthood patients.

PPAC believes the scale and timeline of the DxF will impose an extraordinary burden on Planned Parenthood health centers and other safety-net providers. At this moment, Planned Parenthood is still straining to recover from a multi-year global pandemic, retain adequate staff and operating budgets with record-high inflation, and facing unprecedented national threats to abortion access. While PPAC strongly believes in the importance of using data to improve public health outcomes, we have several outstanding questions about the operation and accessibility of the DxF. PPAC believes requiring safety-net community providers to participate in the DxF when policies and procedures are yet to be finalized will have costly and burdensome and will have serious and deleterious impacts on our ability to continue providing high-quality care, especially in light of these other existing challenges.

For the reasons outlined above, **PPAC respectfully requests a one year implementation delay to the timeline of the DxF and DSA** to allow providers and other stakeholders additional time to work with the DSA Subcommittee and the DxF Stakeholder Advisory Group on clearer policies and procedures.

Thank you in advance for your consideration of our comments. Please feel free to contact me with any questions or concerns.

Sincerely,

Lisa Matsubara

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Vice President of Policy and Government Affairs Planned Parenthood Affiliates of California