



Planned Parenthood Federation of America, Inc.

April 15th, 2024

## VIA ELECTRONIC TRANSMISSION

**Micky Tripathi, Ph.D., M.P.P.**

Office of the National Coordinator for Health Information Technology  
U.S. Department of Health and Human Services  
330 C St SW Floor 7  
Washington, DC 20201

**RE: In Support of the University of California, San Francisco (UCSF) Person-Centered Reproductive Health Program's Submission to Add the Self-Identified Need for Contraception (SINC) Data Element to the US Core Data for Interoperability (USCDI)**

Dear National Coordinator Tripathi:

Planned Parenthood Federation of America (PPFA) is pleased to submit this letter expressing its support for the University of California, San Francisco (UCSF) Person Centered Reproductive Health Program's submission to add the Self-Identified Need for Contraception (SINC) data element into the US Core Data for Interoperability (USCDI) set. As a trusted advocate for sexual and reproductive health (SRH) and national representative of Planned Parenthood health centers, PPFA appreciates the opportunity to weigh in on policy proposals that impact the communities we serve across the country. PPFA is also deeply concerned about issues impacting people's privacy, such as interoperability.

PPFA is a 501(c)(3) charitable organization that supports the independently incorporated Planned Parenthood affiliate health centers across the United States. Planned Parenthood health centers<sup>1</sup> are the nation's most trusted, nonprofit source of primary and preventive care for people of all genders, and they are also the nation's largest sex educator and provider of information on healthy relationships. PPFA and its affiliated health center providers are experts on meeting people where they are through innovative apps, chat programs, and culturally responsive care for young people, LGBTQ+ patients, and patients of color.

Each year, Planned Parenthood health centers provide affordable birth control, lifesaving cancer screenings, testing and treatment for sexually transmitted infections (STIs), abortion, and other essential care to 2.1 million patients annually, and ensure that all people have accurate information about sexual and reproductive health. Notably, one in three women in the United States has visited a Planned Parenthood health center. The majority (nearly 70%) of Planned Parenthood patients have incomes at or below 150 percent of the Federal Poverty Level (FPL).

Planned Parenthood health centers utilize electronic medical records, billing systems, and interact with Electronic Health Records (EHRs) as a critical part of health care infrastructure. Therefore, our health centers play a vital role in health data collection. At the same time,

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<sup>1</sup> Planned Parenthood health centers are 501(c)(3) charitable organizations that provide health care and basic reproductive health services across the United States, and also work to protect and promote health care through education and advocacy programs.

Planned Parenthood health centers recognize the trust that our patients place in us to keep their health information safe, secure, and private. Furthermore, because Planned Parenthood health centers provide health care, education and information for lesbian, gay, bisexual, transgender, queer and gender-nonconforming people, women, communities of color, immigrants, people with chronic illnesses and disabilities, and others who frequently experience systemic oppression and barriers to care, we are acutely aware of the racism, homophobia, xenophobia, transphobia, and sexism that is rooted in our society, and how these systems of oppression impact people's health. Thus, we are providing feedback to the USCDI+ datasets released by ONC because we recognize the need for a balance between equitable collection of health information, the necessity to report cases to public health agencies and protecting individual patients' privacy.

Moreover, PPFA is aware that sharing the health information related to a patient's sexual and reproductive health care could lead to substantial harm, including criminalization. If patients do not trust that providers will respect and protect the integrity of their health information, there cannot be an interoperable, reliable health care system.

**I. The USCF proposed inclusion of the SINC data element into USCDI centers patient autonomy in the sexual and reproductive health care setting.**

Effectively providing contraceptive services to those who may be most likely to experience unintended pregnancy is crucial for a comprehensive health care system that advances sexual and reproductive health. Given the long history of reproductive coercion and oppression in the United States, centering patient autonomy is critical to the reproductive health needs assessment. Research has shown that patients prefer a service-needs approach when asked about their reproductive health needs, as this area of health care can be sensitive and highly stigmatized, especially within certain communities. SINC is a standardized screening tool which can help providers center their patients' reproductive health preferences and needs, using a service-needs screening question. SINC is unique in its approach, as other recognized contraceptive care screening questions counsel patients through a pregnancy-intention frame, which makes assumptions about a patient's desire for contraceptive use based on their feelings around becoming pregnant within a calendar year.

SINC's design allows for integration into a range of patient-centered clinical workflows, which enables use by all members of the health care team and during any visit, whether in person or virtual. This comprehensive approach to implementation means broader and more consistent uptake of the reproductive needs assessment, which ensures contraceptive goals are addressed for more patients.

By integrating the SINC data element into the USCDI — which defines what data elements are available for interoperable health information exchange through certified electronic health records (EHRs) — and systemizing how patients' desire for contraceptive services is captured in clinical settings, the United States can make a significant step in advancing health equity by enhancing the delivery of contraceptive care and other reproductive needs for everyone who needs it.

**II. People who obtain, provide, or facilitate sexual and reproductive health services are under increasing threat and ONC should ensure the patients have the ability to protect their data**

Generally, PPFA supports expanding health data collection and exchanges for the benefit of patients, its communities, and for public health. However, we are always careful in considering interoperability expansions, since the current hostile political and legal landscape for reproductive care represents a data privacy risk to our patients' safety, as well as the safety of their families and providers. People seeking sensitive services like those that Planned Parenthood health centers provide, such as SRH care or behavioral health care, have a heightened need for confidentiality. It is imperative that patients and providers have the ability to protect health care data related to these services and protect patients from harms caused by state or individual actors.

The *Dobbs v. Jackson Women's Health Organization*<sup>2</sup> Supreme Court decision led to numerous states prohibiting or severely restricting access to abortion. The abortion bans that have been enacted have caused access to contraceptive care to become increasingly threatened. The consequences of criminalizing sexual and reproductive health care can include investigations, arrests, civil penalties, loss of children and reputational harm. In particular, individuals' access to contraceptive options like intrauterine devices (IUDs) and emergency contraceptive pills are often mistakenly alleged to cause abortions.<sup>3</sup> This misconception, along with the definitions utilized in abortion bans enacted by certain states, could potentially serve as means to restrict access to contraception.<sup>4</sup> For example, definitions in abortion bans that establish the existence of a pregnancy from the moment of fertilization could be construed to mean that preventing the implantation of a fertilized egg equals terminating a pregnancy – therefore potentially banning certain types of contraception.<sup>5</sup>

While interoperability facilitates record sharing for patient-centered care, it also increases opportunities for utilizing a patient's pregnancy data against them, including a patient's contraceptive data. Since SINC collects data of the type of contraception a patient currently has or wants, the out-of-state sharing of SINC health information to an abortion-restricted state could potentially allow a patient or a provider to unjustly suffer criminalization for seeking essential health care where it was lawful to do so. To mitigate this harm, ONC should make sure that the patient has the ability to request a restriction on sharing their SINC data.

### **III. If integrated in the USCDI, the collected and exchanged SINC information must comply with HIPAA privacy rule.**

Patients seeking lawful sexual and reproductive health care, including contraception and abortion services, should not fear legal repercussions for accessing that care. Therefore, collected SINC data must allow the patient to restrict its sharing as well as comply with the HIPAA privacy rule. Currently, under the HIPAA privacy rule<sup>6</sup> individuals have the right to request restrictions on how a covered entity will use and disclose their PHI; although, in most cases, covered entities are not required to agree with the requested restrictions.

Following the *Dobbs* decision, President Biden directed HHS through Executive Order 14076,<sup>7</sup>

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<sup>2</sup> Mabel Felix, Laurie Sobel, and Alina Salganicoff. *The Right to Contraception: State and Federal Actions, Misinformation, and the Courts*. KFF (October 26, 2023). <https://www.kff.org/womens-health-policy/issue-brief/the-right-to-contraception-state-and-federal-actions-misinformation-and-the-courts/>

<sup>3</sup> Id.

<sup>4</sup> Id.

<sup>5</sup> Id.

<sup>6</sup> 45 CFR Part 160 and Subparts A and E of Part 164.

<sup>7</sup> President Joe Biden. *Protecting Access to Reproductive Healthcare Services*. Executive Order 14076, 87 FR 42053 (July 8, 2022). <https://www.govinfo.gov/content/pkg/FR-2022-07-13/pdf/2022-15138.pdf>.

to “consider ways to strengthen the protection of sensitive information related to reproductive health care services and bolster patient-provider confidentiality.”<sup>8</sup> Therefore, the request to ONC for making sure that collected SINC data complies with the HIPAA privacy rule is consistent with the actions of the Biden-Harris administration seeking to bolster the privacy of patients’ reproductive health data in response to the post-*Dobbs* increasing hostile sexual and reproductive health landscape.<sup>9</sup>

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The hostile sexual and reproductive landscape and the ongoing changes in health information sharing necessitate both improving patients’ access to quality SRH care and protect their privacy. PPFA urges ONC to include SINC data element in the USCDI system for bolstering patient-centered care while ensuring the information can be protected through a patient restricted request as well as being accessed in compliance with the HIPAA privacy rule.

PPFA is grateful for the opportunity to share its perspective on SINC data element inclusion in the USCDI system as a provider of sensitive health care services. We are available to support this initiative as needed as ONC moves toward finalizing this and other system innovations. Please do not hesitate to reach out to Frances Collazo, Director, Legal Policy Strategy and Research, at [frances.collazo@ppfa.org](mailto:frances.collazo@ppfa.org) or 929-388-9448 for additional information.

Respectfully,



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<sup>8</sup> Department of Health and Human Services. *HHS Proposes Measures to Bolster Patient-Provider Confidentiality Around Reproductive Health Care*. HHS Press Statement (April 12, 2023). <https://www.hhs.gov/about/news/2023/04/12/hhs-proposes-measures-bolster-patient-provider-confidentiality-around-reproductive-health-care.html#:~:text=The%20HIPAA%20Privacy%20Rule%20supports,care%2C%20will%20be%20kept%20private>.

<sup>9</sup> HIPAA Privacy Rule To Support Reproductive Health Care Privacy, 88 FR 23506 (April 17, 2023).; Department of Health and Human Services. *HHS Proposes Measures to Bolster Patient-Provider Confidentiality Around Reproductive Health Care*. HHS Press Statement (April 12, 2023). <https://www.hhs.gov/about/news/2023/04/12/hhs-proposes-measures-bolster-patient-provider-confidentiality-around-reproductive-health-care.html#:~:text=The%20HIPAA%20Privacy%20Rule%20supports,care%2C%20will%20be%20kept%20private>. (Although not yet finalized, on April 17, 2023, the HHS Office for Civil Rights (OCR) published a proposed HIPAA Privacy Rule to Support Reproductive Health Care Privacy (proposed HIPAA reproductive privacy rule) in an effort to strengthen privacy protections by prohibiting the use or disclosure of protected health information (PHI) by a HIPAA regulated entity. The proposed HIPAA reproductive privacy rule would modify existing standards by prohibiting uses and disclosures of PHI for the purpose of criminal, civil, or administrative investigations or proceedings against individuals, covered entities or their business associates, or other persons for seeking, obtaining, providing, or facilitating reproductive health care that is lawful under the circumstances in which it is provided).