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Testimony in SUPPORT for House Bill 5857

**AN ACT RELATING TO HEALTH AND SAFETY -- REPRODUCTIVE FREEDOM AND GENDER AFFIRMING CARE
HEALTH DATA PRIVACY ACT
House Committee on Health and Human Services
April 23, 2025**

Chair Donovan and honorable members of the House Committee on Health Human Services, my name is Gretchen Raffa, Chief Policy and Advocacy Officer at Planned Parenthood of Southern New England (PPSNE) testifying in **support of House Bill 5857 (Rep. Knight)**. PPSNE provided sexual and reproductive health care to nearly 8,000 Rhode Island patients last year and believes all people should have access to quality, affordable, and compassionate health care as a basic human right — regardless of who you are, where you live, your income, if you have health insurance or your immigration status.

There is an urgent need for lawmakers to protect sensitive consumer health data related to reproductive and gender-affirming health care following the overturning of *Roe v Wade* in the U.S. Supreme Court decision *Dobbs v. Jackson Women’s Health Organization*, changing the privacy landscape on a national scale and an increase in attacks on access to reproductive and gender-affirming health care across the country.

Currently, consumers including Rhode Island residents would expect sensitive health information and data to remain confidential. Unfortunately, the Health Insurance Portability and Accountability Act (HIPAA) only protects personally identifiable health information collected by health care providers, and non-HIPAA entities, are not required to keep people’s medical information confidential. In reality, health-related data held by fitness apps or period trackers, websites, retailers, employers and non-HIPAA covered entities can lawfully collect, share, and sell sensitive medical information in the same manner as all other data, including data connected to their medical history, diagnoses, and treatments. Without increased health data privacy protection, consumer health data is left vulnerable.

We are grateful for the Rhode Island General Assembly’s ongoing commitment and action to protect and expand reproductive freedom. While abortion and gender-affirming health care are legal in Rhode Island, we are not immune to the efforts of the global anti-abortion movement’s attempts to restrict or deny access to pregnancy-related care. House Bill 5857 will ensure Rhode Island follows through on its promise to be a safe harbor for our residents and those who seek legal health care within our state’s boundaries. This bill is an essential next step after passing the Healthcare Provider Shield Act last session. Privacy is non-negotiable and is an essential component of exercising bodily autonomy and reproductive freedom.

In our post-*Roe* world, the serious threat and harm caused by data privacy violations are significantly heightened. The reality is, data collection, surveillance, and privacy abuses already disproportionately target and harm populations including undocumented people, Black, brown, and Indigenous people, and low-income communities. With bans or severe restrictions on abortion care in 19 states and 25 states that have banned gender-affirming care since the *Dobbs* decision data shared between companies, private parties, and the government are already being utilized to surveil, penalize, target and harass individuals accessing health care and their support networks.

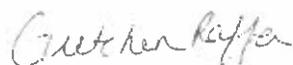
Laws that criminalize reproductive health are already being used by police and prosecutors to surveil, penalize, and control people who are disproportionately Black and Brown.

Conversations that are believed to be private via social media, text messaging, and other digital communication platforms have already been weaponized to criminalize and harm abortion-seekers and their support networks including examples such as in 2017, when an online search for misoprostol, one of two medications most commonly used for medication abortion was used to charge one woman with second-degree murderⁱ, in 2022, when a Nebraskan woman and her teenage daughter were prosecuted for seeking abortion care when Facebook handed over their direct messages to the policeⁱⁱ and in 2023 a Texas man filed a wrongful death lawsuit against three women for allegedly helping his ex-wife obtain medication abortion pills and included screenshots of the women's private messages in the lawsuit.ⁱⁱⁱ

There are serious concerns that with the absence of specific protection for consumer health data not otherwise protected under HIPAA, ongoing practices by anti-abortion limited-service pregnancy centers will continue to put pregnant people in harm. These centers, also referred to as "crisis pregnancy centers" and "CPCs," typically present as medical providers, but are not licensed medical providers— thus, are not held to the same level of oversight and regulation set forth by state and federal regulations. Pregnant individuals sometimes contact or visit a CPC looking for reproductive health care services, only to find that they cannot receive an abortion at that facility. But while they are there, the CPC can collect and share the person's sensitive data with anti-abortion groups who can then target the person with anti-abortion messaging and political ads.

In recent years, the anti-abortion movement has expanded and elevated the role of CPCs within the broader movement, in part by facilitating the coordination of sophisticated data collection and exploitation systems through their national and/or international affiliate networks, including Heartbeat International, the country's largest network of CPCs, according to a report by Privacy International, a UK-based organization that defends and promotes the right to privacy across the world.^{iv} Evidence has surfaced that CPCs are, in fact, widely sharing visitor data with their many thousands of volunteers and, in at least one case, the general public. *Abortion, Every Day* revealed that Heartbeat International has been collecting and sharing CPC visitors' health data with corporate employees, thousands of center trainees and, in one instance, publicly on the internet.^v Ensuring the privacy of sensitive health information and data should be the guaranteed reality for every single individual seeking comprehensive reproductive health or gender-affirming health care, and a standard practice for an industry left unregulated far too long.

All people, no matter where they live, should be able to make personal health care decisions and access their care with privacy, safety, and security. In a post-*Roe* landscape, strengthening privacy and confidentiality protections for reproductive health and gender-affirming health care is urgent. The *Dobbs* decision changed the privacy landscape- and it is our responsibility to further protect patients seeking legally protected health care in Rhode Island which is why we strongly support H 5857 with suggested amended language based on feedback from stakeholders. Thank you for your time and consideration.



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ⁱ <https://www.fastcompany.com/90468030/how-an-online-search-for-abortion-pills-landed-this-woman-in-jail>

ⁱⁱ <https://www.npr.org/2022/08/12/1117092169/nebraska-cops-used-facebook-messages-to-investigate-an-alleged-illegal-abortion>

ⁱⁱⁱ <https://www.npr.org/2023/03/11/1162805773/texas-man-sues-abortion-pills>

^{iv} <https://privacyinternational.org/long-read/3669/documentation-data-exploitation-sexual-and-reproductive-rights>

^v [EXCLUSIVE: Health Data Breach at America's Largest Crisis Pregnancy Org](#)