

Dear Chair Donovan and honorable members of the House Committee on Health and Human Services:

My name is Karin Ulanovsky, I am a medical student at the Warren Alpert Medical School of Brown University. I'm writing to you to testify in strong support of House Bill 5857 (Rep Knight).

This bill is an important step to protect sensitive consumer health data related to reproductive and gender-affirming health care.

As a medical student, I've been living with trepidation for the health outcomes of birthing people and transgender individuals in our country. Following the overturning of *Roe v Wade* in the Supreme Court, I've watched states criminalize abortion care, jeopardize access to gender-affirming care, and crucially, use data sharing between companies to surveil, persecute and penalize individuals trying to access the health care that they need.

I've had the privilege of shadowing an OB/GYN here in Rhode Island. Despite current reproductive protections in Rhode Island, some patients still arrive feeling afraid, uncertain, that their personal health data may be used against them, threatening the trust between provider and patient.

In the clinic, HIPPA protects the personally identifiable health information my mentor and I collect. However, outside the clinic, health related data from fitness apps, period trackers, retailers and employers has no such protections. When my mentor sends a patient out to continue to care for themselves, by having them track their period for instance, she cannot reassure them that their information is safe.

With legislative attacks on gender-affirming care, some of my closest friends have new fears around data privacy, and what the future holds for them with the current administration. As a future physician, I want to be able to encourage them to seek the health care they need always, without any caveats about what they can do with their personal phones.

Our federal administration and Congress are growing more hostile toward reproductive health care, as well gender-affirming care, so the need for stronger data privacy law is more crucial for patients than ever. Patients must know their privacy is protected, it is critical for their ability to exercise bodily autonomy and reproductive freedom.

With House Bill 5857, patients can gain more control over their personal data, so that future physicians like me can continue to practice ethical, evidence-based reproductive and gender-affirming care, without fear of retribution for my patients and their loved ones.

It is our responsibility to protect the privacy and therefore bodily autonomy of our patients. Rhode Island cannot call ourselves a safe haven for this care until patients are safe in all aspects of their lives, most crucially their personal data. This bill is the essential next step after passing the Healthcare Provider Shield Act last session

Thank you for all your time and consideration

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Use the talking points in italics below to explain why legislators should support the bill and what the bill seeks to accomplish. Please make sure to write comments in your own words in paragraph form - it's the personal touches that make the testimony more compelling!

*In the wake of the Supreme Court's decision in Dobbs v. Jackson Women's Health Organization, which overturned Roe v. Wade, states have increasingly targeted health care providers and others who offer or facilitate reproductive or gender-affirming healthcare.*

*In this post-Roe landscape where states are rapidly moving to criminalize abortion care and jeopardize access, 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.*

*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 who have long been subject to criminalization related to pregnancy.*

*Since the Dobbs decision, concerns and confusion about data privacy and safeguarding personal information from potential weaponization against patients, their loved ones, and our health care providers have intensified. Now with a federal administration and Congress that is hostile towards sexual and reproductive health care and access to gender-affirming care, the need for stronger data privacy laws is more urgent for patients. Privacy is non-negotiable, and is an essential component of exercising bodily autonomy and reproductive freedom.*

*The Health Insurance Portability and Accountability Act (HIPAA) only protects personally identifiable health information collected by healthcare providers.*

*Health-related data held by fitness apps, period trackers, retailers, and employers may not be subject to HIPAA, which is limited to traditional health care providers and related entities.*

*House Bill 5857 will give consumers more control over their personal data that is generated through various means, including period trackers, fitness apps, location-based services, and even at brick-and-mortar establishments, all of which may demonstrate or provide a means of identifying or predicting someone's pregnancy status or other identifying information about their identity including gender identity.*

*Federal and state governments, as well as the private sector, have an important role to play in strengthening privacy protections and mitigating the threat of surveillance and criminalization for those seeking reproductive and gender-affirming health care.*

Lastly, add a concluding statement and thank them. Here's an example:

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's our responsibility to further protect patients seeking legally protected health care in Rhode Island which is why I strongly support H 5857. 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.

Thank you for your time and consideration.

Your Name  
Address