

The Washington My Health, My Data Act

SB 5351 HB 1155



What does this bill matter?

There is an urgent need for lawmakers to protect private health-related data following the U.S. Supreme Court decision overturning **Roe v. Wade**. In July 2022, a Nebraskan woman and her teenage daughter were prosecuted for seeking abortion care when Facebook handed over their direct messages to the police. Conversations believed to be private are being used to criminalize and harm abortion-seekers, particularly Black women, women of color, and LGBTQIA+ patients, for their private healthcare decisions.

We expect our sensitive health information to be kept confidential. Unfortunately, the Health Insurance Portability and Accountability Act (**HIPAA**) only protects personally identifiable health information collected by health care providers. Non-HIPAA entities, like fake pregnancy clinics known as Crisis Pregnancy Centers (**CPCs**), are not required to keep people's medical information confidential.

In fact, apps, websites, and non-HIPAA covered medical facilities 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. Increased health data privacy protections are long overdue. Without them, consumer health data is left vulnerable:

- **Period tracking apps** can sell a user's data about their late period or miscarriage to data brokers. Data brokers can link that information to the user's data profile, which is essentially for sale on the open market. Law enforcement from states with strict anti-abortion laws can purchase that data profile and use the information to prosecute the user for an abortion or miscarriage even in another state.
- **CPCs** intentionally mislead patients about the services they offer, so pregnant patients often contact or visit CPCs looking for abortion care. By the time they realize, the CPC can collect and share their information with anti-abortion groups who can then target them with harmful anti-abortion messaging or harassment.
- **Geofencing** by digital advertisers around healthcare facilities are triggered when a person brings their mobile device across the geofencing barrier. The individual can then be bombarded by anti-abortion and anti-trans text messages and advertisements.

How does this bill help?

The Washington My Health, My Data Act will protect people's personal health information by preventing it from being shared without their consent, including by CPCs or with law enforcement in states that criminalize abortion and gender-affirming care.

Specifically, the Washington My Health, My Data Act will close the gap on health data privacy protections and provide Washingtonians more control of their data by:

- Requiring entities that collect Washingtonians personal health data to maintain and publish a privacy policy for consumers health data.
- Blocking entities from collecting and sharing Washingtonians' health data without their consent.
- Protecting Washingtonians' health data from being sold to third parties.
- Guaranteeing Washingtonians the right to withdraw consent and request their data be deleted.
- Stopping geo-fencing around health care facilities.

