

WA My Health, My Data

Support SHB 1155 & SB 5351



Everyone should be able to access the health care they need without their personal health information being collected and shared without their permission or knowledge. Stigma, fear of prosecution, and harassment from anti-abortion and anti-LGBTQIA2S+ groups are significant barriers to accessing reproductive and gender affirming health care, and therefore, providing privacy protections is a crucial step to safeguarding health care access.

States like Washington that protect abortion and gender affirming care access will now play an even more critical role in providing care to people from states that criminalize abortion and jeopardize access to needed health care services. The fall of Roe has had devastating and far-reaching impacts that land disproportionately on the people who have always faced systemic barriers to care — communities of color, the LGBTQIA2S+ community, undocumented immigrants, young people, those living in rural communities, people with disabilities, and people with low incomes. These individuals, and all of us, need to be able to access health care without the added barrier of fearing for our safety, and our privacy.

Why SHB 1155 & SB 5351 Are Needed

- Currently, people have little insight into, and even less control over how their information is collected, used, shared and sold. While many think that the federal Health Information Portability and Accountability Act (HIPAA) law protects all of their private health data, HIPAA actually only covers data collected by specific health care entities, including most health care providers. Website and app data, among others, is not protected by HIPAA. As a result, people's health data is left vulnerable to be shared by anti-choice groups, used in prosecutions, or employed for targeted advertising. Period tracking apps can sell sensitive information about a person's late period or miscarriage to data brokers, who can link that information to a profile for sale on the open market. Law enforcement from states with strict anti-abortion laws or anti-abortion advocacy groups can purchase that data profile and use that information to prosecute people who had an abortion or miscarriage in another state.
- Pregnant individuals sometimes contact or visit crisis pregnancy centers looking for reproductive health care services, only to find that they cannot receive an abortion at that facility. But while they are there, the crisis pregnancy center 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.
- Digital advertising firms can set up geofencing around health care facilities that activate when a person brings their cell phone or mobile device across the barrier. The individual can be bombarded with text messages and advertisements urging them not to seek reproductive or gender-affirming care.
- For more examples, see the ACLU-WA harms of health care data abuse handout.

What SHB 1155 & SB 5351 Do:

The Washington My Health, My Data Act protects access to health care and reduces barriers to access by:

- Preventing apps and websites — like health tracking apps, search engines and advertisers, and many other entities— from selling, collecting, and sharing people's health data without their opt-in consent.
- Prohibiting “geofences” from being used up to 2,000 feet from the perimeter of the physical location of facilities that provide health care. Geofences are a virtual perimeter drawn on a map around a physical location. Apps, websites, and devices can be programmed to send advertisements and/or messages to individuals when they enter a specific location. This is a tactic frequently used by digital advertisers.
- Requiring entities that collect people's personal health data to maintain and publish a privacy policy for consumers' health data.
- Violations of the law would be a violation of the Consumer Protection Act.