

S. 173 Vermont My Health My Data Act

Senate Health and Welfare Committee

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Planned Parenthood of Northern New England provides comprehensive reproductive and sexual health care to more than 16,000 people in Vermont at seven health centers located in Burlington, Williston, St. Johnsbury, Barre, White River Junction, Rutland, and Brattleboro and virtually through our telehealth program. People turn to us for affordable, high-quality care including wellness exams, birth control, sexually transmitted infections testing and treatment, cancer screenings, abortion care, as well as a variety of limited primary care services. We see everyone who comes to us regardless of their ability to pay, and 54% of our patients have low incomes (defined as less than twice the Federal Poverty level). Last fiscal year, we provided \$802,000 in free and discounted care to our communities in Vermont.

As a mission driven health care provider, we fundamentally believe everyone should be able to access affordable, high quality sexual and reproductive health care in their communities, no matter where they live or how much money they make, and we advocate for policies that help make this vision a reality. All people deserve to access comprehensive reproductive health care, including abortion and gender-affirming care, free from shame, stigma, and intimidation. Stigma, fear of prosecution, and harassment from anti-abortion and anti-LGBTQIA+ 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 Vermont 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 that care and jeopardize access to 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 LGBTQIA+ 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 these essential health care without fearing for our safety and our privacy- and protections



for all of our personal health and health-related information is an increasingly important component of that access.

Personal health information, including consumer data related to reproductive health, must be private. Ensuring privacy protections for and control over the collection and use of our own health data is even more important as the breadth of information collected and inferred from our personal data grows. No one should fear that their personal data will be compromised or used against them, and people seeking care in our state should not be subjected to targeted ads about their private health care decisions or have their locations tracked and shared via geotargeting when seeking health care.

Sadly, this information is already being weaponized to surveil and prosecute pregnant people, including those seeking abortions, and Black communities and people with low incomes are disproportionately targeted.

Why S. 173 is needed:

Currently people have little insight into, and even less control over how their information is collected, used, shared and sold. Despite the widespread use and disclosure of personal data, just <u>6% of adults</u> report that they have a strong understanding of what companies do with the data they collect, and the <u>large</u> <u>majority of consumers</u> (nearly 68%) are somewhat or very concerned about their online privacy.

While the federal Health Information Portability and Accountability Act (HIPAA) law provides protections for data collected by health care entities, a growing amount of personal health and health-related information is held by non-health care providers and collected through website and app data, among others, and is not protected by HIPAA. As a result, a growing amount of personal health data is left vulnerable to collection and disclosure without the comsumer's knowledge or consent- including by anti-abortion groups, in investigations and prosecutions, or for targeting advertising.

Period tracking apps collect sensitive information about a person's menstrual cycle and fertility, including information about a late period or miscarriage. This sensitive information can then be disclosed and sold by companies and data brokers.



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 could then 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. 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, and can bombard users with text messages and advertisements urging them not to seek reproductive or gender-affirming care.

These are not just hypothetical concerns but real tactics being used to target pregnant people in this country. Some examples include:

- In 2016, geolocation data was used to identify visitors to 140 abortion clinics in order to send those individuals ads for anti-abortion pregnancy counseling;
- In 2022, a local data broker sold <u>aggregated location data</u> of people who visited abortion clinics, including more than 600 Planned Parenthoods over a one-week period, for just \$160;
- A woman was prosecuted for murder after experiencing a pregnancy loss based on cell phone information that she searched online for medication abortion information. In our new reality, where abortion is criminalized, cell phone data is being used to identify, threaten, and prosecute those seeking health care;
- In 2021, Flo Health, one of the most popular period tracking apps, <u>settled</u> with the FTC over allegations that it shared health information on its 100 million users with third-party data analytics firms.

What S. 173 does:

S. 173 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 express consent.
- Requiring entities that collect people's personal health data to maintain and publish a privacy policy for consumers' health data.
- Establishing consumer rights
- Prohibiting "geofences" from being used at facilities that provide health care.
- Empowering the Attorney General to enforce the bill under the state Consumer Protection Act

Planned Parenthood supports policies that protect individuals' right to privacy and control over their personal health-related information. As states across the country ban access to abortion and gender-affirming care, Vermont plays a critical role as a safe harbor for patients and their loved ones from throughout the country. Improving privacy protections for personal health data is essential in safeguarding health care access.

To strengthen the intent and protections found in this bill, we would recommend the following revisions:

Section 1896: Clarify consumer rights under the bill

As written, the bill establishes the consumer rights, including the right to confirm whether the entity is collecting, sharing, or selling their consumer health data and the right to withdraw consent to the collection and sharing of their consumer health data. Subsections (a) and (b) of this section should be amended to better align with the rest of the bill and clarify consumer rights:

(a) A consumer has the right to confirm whether a regulated entity or a small business is collecting, sharing, using, or selling consumer health data regarding the consumer and to access that data, including a list of all third parties and affiliates with whom the regulated entity or small business has shared or sold the consumer's health data and an active e-mail address or



other online mechanism that the consumer may use to contact these third parties.

(b) A consumer has the right to withdraw consent from a regulated entity's or small business's collection and sharing, and selling of consumer health data regarding the consumer.

Thank you for your efforts to protect Vermonter's privacy and better ensure that no one fears harassment, investigation, or prosecution for seeking, providing, or assisting another in accessing essential health care.