



### H. 121 Vermont Data Privacy Act

## Senate Economic Development Housing and General Affairs Committee

## Jessica Barquist, Vice President of Public Affairs

# April 10, 2024

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.

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 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.





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.

Personal health information, including consumer's sensitive data related to reproductive health, must be private. Ensuring privacy protections for and control over the collection and use of our own sensitive 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.

### Why these data privacy protections are 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 6% of adults report that they have a strong understanding of what companies do with the data they collect, and the large majority of consumers (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 data, including sensitive 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 sensitive health data is left vulnerable to collection and disclosure without the consumer's knowledge or consent- including by anti-abortion groups, in investigations and prosecutions, or for targeting advertising.

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

• <u>A woman was prosecuted for murder</u> in Mississippi 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 with</u> <u>the FTC</u> over allegations that it shared health information on its 100 million users with third-party data analytics firms.

### Geofencing provision

The term geofencing refers to targeted location-based marketing and advertising, that allows the application of defining a set geographic perimeter around a location-often to send ads to users based on location data signals derived through a mobile phone. This does not address or include location-based check in services for your doctors office or the sharing of information between your health care provider and your insurance company. Geo-fencing restrictions narrowly apply to apps, websites, and devices being 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 has been leveraged by anti-abortion groups to target and bombard people seeking reproductive health care. Digital advertisement agencies use geofences to track and send notifications or ads to any person that brings their cell phone or mobile device across the barrier. This bill will not restrict the practice from any location except for health care providers. Unfortunately there are already examples of this tactic being used against patients seeing reproductive care:

- In 2015, <u>geolocation data was used</u> 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

Geofencing prohibitions are an essential component in protecting the identity and information of those who access sexual and reproductive health care int his state, particularly those coming from states where that health care is criminalized.

## Clarifying the exemption for Protected Health Information

It is important that bills addressing consumer data do not conflate consumer's sensitive health-related data with protected health information ("PHI") subject to HIPAA and related state laws. We have concerns about how cumbersome these laws will be to implement alongside the requirements of HIPPA and are supportive of the suggested language changes from the Vermont Medical Society.





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.