Planned Parenthood® of Northern New England

Senator Carney, Representative Moonen, and members of the Joint Standing Committee on the Judiciary, my name is Lisa Margulies, I serve as Vice President of Public Affairs, Maine, for Planned Parenthood of Northern New England, and I am pleased to submit testimony in support of LD 1902 and express my strong support for increased data privacy protections in this state.

Planned Parenthood of Northern New England provides comprehensive reproductive and sexual health care to more than 14,000 people in Maine at four health centers located in Biddeford, Portland, Sanford and Topsham. People turn to us for affordable, high-quality care including wellness exams, birth control, disease testing and treatment, cancer screenings, abortion care as well as a variety of primary care services. We see everyone who comes to us regardless of ability to pay, and in a typical year, we provide more than \$4 million in free and discounted care to our communities in Maine.

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.

Personal health information, including consumer data related to reproductive health, must be private. Ensuring privacy protections for and personal 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. Examples pre-date the repeal of *Roe* and include:

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- <u>Use of geolocation data</u> to identify visitors to 140 abortion clinics in order to send those individuals ads for anti-abortion pregnancy counseling;
- <u>The sale of aggregated location data</u> of people who visited abortion clinics, including more than 600 Planned Parenthoods over a one-week period for just \$160;
- <u>The prosecution of a woman</u> who experienced a pregnancy loss based on cell phone information after she searched online for medication abortion information. In our new reality, where abortion is criminalized, cell phone data could be used to identify, threaten, and prosecute those seeking health care;
- Allegations that one of the most popular period tracking apps <u>shared health</u> <u>information</u> on its 100 million users with third-party data analytics firms, resulting in an FTC settlement.

Despite the widespread use 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.

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, Maine 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.

In light of this, Planned Parenthood supports the legislature's interest in increasing data protections in the state, including through LD 1902.

However, to best ensure workable protections, we would recommend the following revisions:

1. Clarify the exemption of Protected Health Information held by HIPAA covered entities or businesses

It is important that bills addressing consumer data do not conflate consumer's sensitive health-related data with patient information protected under HIPAA and related state laws. We would ask you to amend the scope of LD 1902 to exclude

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Protected Health Information held by HIPAA covered entities or business associates to ensure that these important consumer protections do not create confusion or compliance concerns for health care providers, who already must comply with a broad range of privacy protections and limitations on disclosures.

Although there are notable gaps in HIPAA protections, attempting to address these gaps by subjecting HIPAA covered entities to two different, and sometimes conflicting, data maintenance regimes can create significant compliance concerns for health care providers and entities covered by HIPAA. We welcome the opportunity to work with legislators to address these gaps through more workable means, including by increasing state level protections for patient's reproductive health-related protected health information.

To clarify that LD 1902 is intended to protect consumer health data not otherwise protected under HIPAA and related state law, Section 1350-X should be amended to more clearly state that the chapter does not apply to Protected Health Information held by HIPAA covered entities and business associates.

2. Clarify the ability to withdraw consent to use data

As written, the bill establishes the consumer rights to withdraw consent to collection and sharing of their consumer health data but does not clearly establish a right to similarly withdraw consent to the *use* of such data. To clarify this consumer right, Section 1350-R(1)(C) should be amended to clearly allow a consumer to withdraw consent for the collection, sharing, and *use* of their data.

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