

SUPPORT SB 93 (HA 1)

PROTECT HEALTH DATA PRIVACY ACT

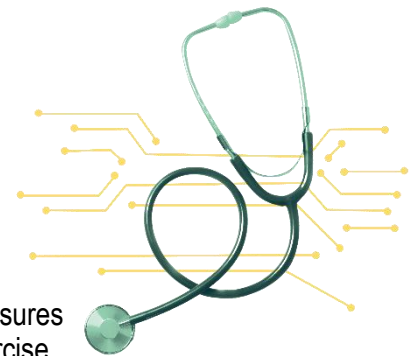
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The Protect Health Data Privacy Act ("PHDPA") will help safeguard the privacy of every Illinoisans' sensitive health information by implementing new privacy protections that will significantly reduce the likelihood that any Illinoisan's health information will end up in the wrong hands.

The PHDPA requires companies that collect health data and/or offer health services ("regulated entities") to offer greater privacy protections to all Illinoisans over their health data. The PHDPA is built on three pillars: (1) transparency, (2) consent, and (3) rights. Under the PHDPA, regulated entities must:

1. be more **transparent** about the details of their health data collection practices,
2. obtain a person's **consent** prior to collecting, sharing, selling or storing that person's health data, and
3. provide people with **rights** to control their health data, such as the ability to request that health data be deleted from a regulated entity's systems.



In addition, the PHDPA requires regulated entities to implement reasonable security measures to protect health data, prohibits such entities from discriminating against people who exercise their privacy rights under the law, and also authorizes those whose rights have been violated to seek damages in court.

Greater Transparency About How Companies Handle Your Health Data

The PHDPA will require regulated entities to adopt and publish a Health Data Privacy Policy. This policy must be written using plain language, and must disclose: (a) the specific types of health data being collected and why it is being collected, (b) where the health data originated from, (c) third parties with whom the health data may have been shared, (d) information about how you can assert your rights under the PHDPA, and (e) other categories of information that provide greater transparency into how companies collect and use health data.

Your Consent is Key

Companies in the United States today share most people's personal information without their consent. The PHDPA makes consent an essential prerequisite to the collection, sharing, sale or storing of any health data. Under the PHDPA, consent is defined as "a clear affirmative act by a consumer that unambiguously communicates the consumer's express, freely given, informed, opt-in, voluntary, specific, and unambiguous written agreement."

- + Under the PHDPA, regulated entities will not be allowed to collect, share, sell or store your health data without your consent (or unless strictly necessary to provide you with any health services or products you requested).
- + The PHDPA also prohibits regulated entities from selling your health data unless you provide written consent in a separate agreement specifically authorizing the sale of your health data.

Real Rights to Privacy

The PHDPA establishes new privacy rights to empower Illinoisans to protect their health data.

These rights include: (a) the right to confirm whether a regulated entity is collecting, selling, sharing, or storing any of the consumer's health data, (b) the right to request that a regulated entity delete health data, and (c) the right to bring a lawsuit against any regulated entity that violates the law.

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ACLU Illinois

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