



Patient Consent and Privacy Rights Act

Summary:

This bill guarantees patient ownership and control of their medical records by requiring informed, voluntary consent for any disclosure or sharing of protected health information. It establishes that a provider or facility acts as the custodian of the patient's medical record but may not disclose information in the record without written consent from the patient, unless specifically permitted by state law. **Notably, the federal HIPAA privacy rule does not protect privacy rights. It is considered a permissive data-sharing rule.**

The bill also prohibits conditioning medical treatment on a patient's consent to share information, closes loopholes related to de-identified data and limited data sets, and requires explicit patient consent for any research use. It includes strong enforcement mechanisms, allowing patients to bring legal action and recover damages for unauthorized disclosures.

Section 1 – Short Title

Section 2 – Purpose

Section 3 – Definitions

Section 4 – Ownership and Control of Health Records

Section 5 – Consent Required for Disclosure

Section 6 – Consent for Research Use

Section 7 – Enforcement and Remedies

Section 8 – Effective Date.

Reasons to support:

1. This bill restores patient ownership and control over their personal medical data, ensuring that individuals—not institutions—decide how data is shared and used.
2. This bill requires informed consent before any disclosure or use of data in medical records, ensuring transparency and respect for patient rights.
3. Appropriate exceptions to consent requirements are available such as when a patient is incapacitated and unable to give consent for access to medical records.
4. This bill protects patients from coercion or unauthorized data sharing by prohibiting clinics from conditioning treatment based on consent decisions.
5. This bill provides a private right of action, allowing patients to seek justice and compensation for violations of their privacy and consent rights.
6. This bill reaffirms the ethical foundation of medicine by upholding confidentiality and patient privacy rights as a fundamental aspect of patient care.