

Principles for Protecting and Supporting Consumer Privacy in Health Information Systems

House Bill 1486/SB 752 - Non-Controlled Substance Prescription Record System Program

Support with Amendment

House Bill 1486/Senate Bill 752 proposes to create a state-designated database that would contain all prescriptions dispensed by Maryland providers. The goal of the bill is to give practitioners an additional tool in care coordination. As advocates for consumers, we encourage innovation in health information technology (IT) to meet consumers' health care needs. **The ability of consumers to control their own health data should be front and center of the development of any new technology.**

Principles Supporting Consumer Decision Making in the Sharing of their Data

As the Committee is considering HB 1486/SB 752, we wanted to offer these consumer privacy principles that are also relevant to other issues involving data-sharing.

- **Consumer Decision-Making in Health Data Sharing:** Consumers should have control over if and how their health data is shared. With developments in health IT, it is now possible for consumers to work with providers to customize which data is shared. Consumers should be able to choose to share all prescription drug information, only certain types of prescription drug information, or no prescription drug information.
- **Protecting Against Unintended Public Health Outcomes:** While there are significant benefits to health care providers having access to a patient's health care data, there could also be some unintended consequences to initiatives such as HB 1486/SB 752. Consumers with an increased need for confidentiality may forgo care rather than risk increased access to their private information. These consumers include those seeking the following types of services: reproductive health including treatment of sexually transmitted infections, LGBTQ, PreP and HIV care, behavioral health, and services to support survivors of domestic violence and sexual assault.

Implementation Issues

As the Committee moves forward in working on this legislation, we would like to suggest the following issues be examined for possible amendments:

- **Opt-In vs Opt-Out:** The bill contemplates that consumers would be able to opt-out of having *all* of their prescription drug information shared. Technology advances make it possible for consumers to customize which health data, including prescription drug data, can be shared. We suggest that the bill be revised to require a more customized approach where consumers can choose to share all, only some, or none of their prescription drug data. Consumers should be able to make those decisions independently or work with their providers if they choose;

- **Clear Protections When There is a Heightened Need for Confidentiality:** We believe that it is the underlying intent of the bill to suppress the sharing of prescription drug information when there is a heightened need for confidentiality. For example, there may be a need to discuss suppressing HIV prevention medication, e.g. PrEP, because of privacy concerns. We recommend more explicit statutory provisions that protect this type of information. The language should also address the additional safeguards required by federal law for substance use disorder treatment;
- **Consumer Input in Implementation:** We think there is a room to increase consumer involvement in decision-making through the advisory committee delineated in the bill. We believe that consumers should have the majority of the input since the initiative is about sharing their data; and
- **Limit Data Collected to Pharmacy Data:** As drafted, the bill would require reporting by pharmacies and any providers, including physicians and nurses, that dispense medication. We would note that this would include providers, such as local health departments, that dispense medication for family planning and treatment of sexually transmitted infections. These dispensing providers are often safety net providers to whom consumers turn when they want to protect their privacy. We therefore recommend that the bill limit the data collected to only pharmacies. This would also assist providers, as it will be expensive and cumbersome for these safety net providers to set up systems to report dispensing data.

Thank you for the opportunity to submit feedback on this legislation. Our organizations are represented by many individuals, but communications may be coordinated through Robyn Elliott at relliott@policypartners.net or (443) 926-3443.

Advocates for Children & Youth

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Trans Recognition Maryland

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