



CRISP

SB984: Health Data Utility

Position

CRISP supports Senate Bill 984, with amendments as discussed with stakeholders.

Explanation

Craig Behm, as the Executive Director for CRISP, the State-Designated Health Information Exchange (HIE), supports this bill. Nearly 15 years ago, the Maryland General Assembly laid the foundation for our HIE. Through a focus on connecting health care providers, we now share information at the point of care over 200,000 times per week, with much of the data flowing seamlessly into electronic health records. We provide analytics to hospitals and the Health Services Cost Review Commission to support population health. More recently, we have been working hand in glove with the Maryland Department of Health and local health departments on public health issues ranging from the opioid epidemic to Covid-19. This has been a natural evolution in the right direction. I am proud of what we have collectively accomplished and am optimistic for what will come next.

Senate Bill 984 will enable the advancement of the HIE in three ways. First, it formalizes the HIE's position as a Health Data Utility, which means we have a long-term role in sharing data for public health and may continue to supplement the State's public health IT infrastructure. It does not force the Department to use the HIE, but helps create expectations if they do. Second, it expands the data available for providers and health departments by mandating the sharing of medications. Finally, it ensures the HIE will continue well into the future by requiring a financial sustainability report and additional consumer protections.

I'd like to share a brief example as to why SB 984 is critical. When the pandemic first happened, state and local health departments wanted to understand whether Covid testing was accessible to all Marylanders; later, they wanted to ensure vaccines were broadly available. CRISP generated reports that included race, ethnicity, and geography so public health officials could reach out to underserved communities and improve equity. When it comes to new Covid antiviral drugs, however, we do not have dispensed medication data so we cannot know today whether they are being distributed equitably. This bill would fix that.

Of course the uses for medications certainly expand well beyond a pandemic and health equity. Providers need comprehensive data to avoid medication interactions when prescribing. Epidemiologists could use the data to support antibiotic stewardship programs in nursing homes. The list goes on.

Importantly, the HIE follows State and Federal laws, industry best practices, and engages with governing committees to ensure privacy and security. Patient-level data is only shared for specific, allowable purposes while summary reports are created for public health use cases.



CRISP

I assure you, we worked extensively with industry partners and consumer advocates to ensure this bill works for everyone. We support the amendments to reduce burden on data submitters and that establish privacy protections for consumers. It is clear to me that as the State-Designated HIE enables new interventions, we need even more meaningful input from patients.

CRISP is ready to assist our health care leaders as they confront challenges that extend beyond direct patient care and into social determinants of health, health equity, access, and community support. A comprehensive, safe, and thoughtful approach with the HIE operating as a Health Data Utility will give Maryland significant advantages, just as it has in our fight against Covid-19. I urge a favorable report with amendments and am available to answer any questions. Thank you for your consideration.

Amendments

Many groups reviewed the language and intent of this bill. While there is broad support for the concept, there are some recommended language changes which would clarify the data use and further protect consumers. We support the changes (included on the following page), and the House adopted the amendments.



Draft modifications to SB984 based on stakeholder input.

Page 2, line 5: Correct typo by removing “the” at the end of the line

(C) THE PURPOSES OF THE HEALTH DATA UTILITY INCLUDE ~~THE~~:

Page 2, line 8 / Page 2, line 10 / Page 2, line 29 / Page 3, line 20 / Page 3, line 26: Specify that the public health data is to be shared with the Maryland Department of Health and Local Health Departments

~~PUBLIC HEALTH OFFICIALS~~ **THE MARYLAND DEPARTMENT OF HEALTH AND LOCAL HEALTH DEPARTMENTS**

Page 2, line 10: Clarify that data is bi-directional between public health and health care providers

(2) THE COMMUNICATION OF DATA ~~FROM~~ **BETWEEN** PUBLIC HEALTH OFFICIALS AND HEALTH CARE PROVIDERS TO ADVANCE DISEASE CONTROL AND HEALTH EQUITY; AND

Page 2, line 15: Simplify language and remove references to the Department, nursing homes, and EHNs because it is redundant with existing law

(D) ~~THE FOLLOWING ENTITIES~~ **DISPENSERS** SHALL PROVIDE DATA TO THE STATE DESIGNATED EXCHANGE.

~~(1) THE DEPARTMENT;~~

~~(2) NURSING HOMES REQUIRED TO PROVIDE DATA UNDER § 4-302.3 OF THIS ARTICLE;~~

~~(3) ELECTRONIC HEALTH NETWORKS REQUIRED TO PROVIDE DATA UNDER § 4-302.3 OF THIS ARTICLE; AND~~

~~(4) DISPENSERS.~~

Page 3, line 7: Add text in bold

(III) IN A MANNER **THAT MINIMIZES BURDEN AND DUPLICATION BY BEING AS COMPATIBLE AS POSSIBLE WITH EXISTING DATA SUBMISSION PRACTICES, INCLUDING TECHNOLOGY SOFTWARE OF DISPENSERS;** AND

Page 3, line 18: Add text in bold

(F) THE STATE DESIGNATED EXCHANGE SHALL PROVIDE DATA, AS ALLOWED BY LAW, TO INDIVIDUALS AND ORGANIZATIONS INVOLVED IN THE TREATMENT AND CARE COORDINATION OF PATIENTS AND TO PUBLIC HEALTH OFFICIALS **INCLUDING THE MARYLAND HEALTH CARE COMMISSION AND HEALTH SERVICES COST REVIEW COMMISSION** TO SUPPORT PUBLIC HEALTH GOALS, THAT MAY INCLUDE:

Page 3, line 18: Clarify that the HIE is not conducting direct provider outreach or advocating for specific interventions



(F) THE STATE DESIGNATED EXCHANGE SHALL ~~MAY~~ PROVIDE DATA, AS ALLOWED BY LAW, TO INDIVIDUALS AND ORGANIZATIONS INVOLVED IN THE TREATMENT AND CARE COORDINATION OF PATIENTS AND TO PUBLIC HEALTH OFFICIALS TO SUPPORT PUBLIC HEALTH GOALS, **FOR PUBLIC HEALTH PURPOSES** THAT MAY INCLUDE:

- ~~(1) IMPROVING HEALTH EQUITY THROUGH ACCESS TO UNDERSTANDING AND PROMOTING THE EQUITABLE AVAILABILITY TO PATIENTS OF PRESCRIPTION MEDICATIONS, INCLUDING FOR THE TREATMENT OF INFECTIOUS DISEASE;~~
- ~~(2) ASSISTING **PROGRAMS LED BY** HEALTH CARE PROVIDERS, CARE MANAGERS, AND PUBLIC HEALTH OFFICIALS ~~TO IN~~ IDENTIFYING OPPORTUNITIES TO USE TREATMENTS MORE EFFECTIVELY **FOR QUALITY IMPROVEMENT**, INCLUDING FOR STEWARDSHIP OF ANTIBIOTIC MEDICATIONS; AND~~
- ~~(3) **CONDUCTING CASE INVESTIGATIONS AND RELATED ACTIVITES** ~~ANY~~ ADDITIONAL PATIENT INTERVENTIONS AND ACTIVITIES, INCLUDING CASE INVESTIGATION.~~

Page 3, line 18: Add new language to create a Consumer Advocacy Committee

(E) (1) THE STATE-DESIGNATED HEALTH INFORMATION EXCHANGE SHALL ESTABLISH A CONSUMER ADVISORY COUNCIL TO BRING THE PERSPECTIVES OF INDIVIDUALS AND ORGANIZATIONS WITH AN INTEREST IN PROTECTING CONSUMERS INTO THE DELIVERY OF SERVICES PROVIDED BY THE HEALTH INFORMATION EXCHANGE.

(2) THE CONSUMER ADVISORY COUNCIL ESTABLISHED BY THE HEALTH INFORMATION EXCHANGE SHALL:

- (I) CONSIST OF A MINIMUM OF SIX MEMBERS, INCLUDING AT LEAST FOUR CONSUMER REPRESENTATIVES AND TWO STAFF REPRESENTATIVES, WHILE MAINTAINING A RATIO OF CONSUMER REPRESENTATIVES TO NON-CONSUMER REPRESENTATIVES OF AT LEAST TWO TO ONE;
- (II) CONSIDER DIVERSITY OF EXPERIENCE WHEN SELECTING MEMBERS;
- (III) IDENTIFY AND REPORT CONSUMER PRIVACY CONCERNS TO SENIOR LEADERSHIP OF THE HEALTH INFORMATION EXCHANGE;
- (IV) ADVISE ON EFFORTS TO EDUCATE CONSUMERS ON DATA EXCHANGE POLICIES, INCLUDING OPTIONS FOR CONSUMERS TO OPT-OUT OF DISCLOSURE OF PROTECTED HEALTH INFORMATION;
- (V) CONVENE NO FEWER THAN THREE TIMES EACH YEAR; AND
- (VI) ADOPT AND MAINTAIN A CHARTER TO BE POSTED ONLINE THAT STATES THE PURPOSE, MEMBERS, AND MEETING SCHEDULE OF THE COUNCIL.

Page 4, line 3: Add bold language and a new item to establish appropriate consumer protections

(2) THE REGULATIONS SHALL **TAKE INTO ACCOUNT CONSUMER PERSPECTIVE AND** INCLUDE:

- (VI) IDENTIFICATION AND NECESSARY SUPPRESSION OF INFORMATION RELATED TO PROVIDERS OR MEDICATIONS THAT ARE DETERMINED TO HAVE SIGNIFICANT POTENTIAL TO CAUSE HARM.**