

STATE OF HAWAII | KA MOKU'ĀINA 'O HAWAI'I
OFFICE OF THE DIRECTOR
DEPARTMENT OF COMMERCE AND CONSUMER AFFAIRS
KA 'OIHANA PILI KĀLEPA
335 MERCHANT STREET, ROOM 310
P.O. BOX 541
HONOLULU, HAWAII 96809
Phone Number: (808) 586-2850
Fax Number: (808) 586-2856
cca.hawaii.gov

JOSH GREEN, M.D.
GOVERNOR | KE KIA'ĀINA

SYLVIA LUKE
LIEUTENANT GOVERNOR | KA HOPE KIA'ĀINA

NADINE Y. ANDO
DIRECTOR | KA LUNA HO'OKELE

DEAN I HAZAMA
DEPUTY DIRECTOR | KA HOPE LUNA HO'OKELE

Testimony of the Department of Commerce and Consumer Affairs

Office of Consumer Protection

Before the
House Committee on Judiciary & Hawaiian Affairs
and
House Committee on Health & Homelessness

Tuesday, February 6, 2024
2:00 p.m.
Via Videoconference
Conference Room 325

On the following measure:
H.B. 1566, RELATING TO CONSUMER HEALTH DATA

Chair Tarnas, Chair Belatti, and Members of the Committees:

My name is Mana Moriarty, and I am the Executive Director of the Department of Commerce and Consumer Affairs' (Department) Office of Consumer Protection (OCP). The Department supports the intent of this bill and offers comments.

The purposes of this bill are to: 1) Establish requirements, including additional disclosures and consumer consent regarding the collection, sharing, and use of consumer health data information; 2) Establish rights for consumers regarding their health data, including the right to have health data deleted; 3) prohibit the sale of consumer health data without a consumer's signed valid authorization; and 4) prohibit the erection of a geofence around health care centers.

OCP appreciates this measure's attempt to close the gap between HIPAA-protected data and other consumer health data. Health information maintained by hospitals, pharmacies, and health care providers are covered by the Federal Health Insurance Portability and Accountability Act (HIPAA), which requires all individually identifiable health information held or transmitted by the covered entities to be protected. Consumer health data collected by connected devices and health apps, however, are not covered by HIPAA. If this measure passes, Hawaii would join Washington, Nevada, and Connecticut in enacting legislation that specifically protects consumer health data.

H.B. 1566 provides for a private right of action by establishing a violation as an unfair or deceptive act or practice under Section 480-2, Hawaii Revised Statutes. This private right of action applies broadly to any violation of the statute including those relating to consumer rights, notice and consent obligations, and restrictions on selling and sharing of consumer health data. This private right of action does not impose unnecessary barriers on consumer lawsuits, such as having to exceed a minimum harm threshold, or having to give the covered entity an opportunity to cure.

This bill broadly—and appropriately, in our view—defines “consumers” to include either a Hawaii resident or a person whose consumer health data is collected Hawaii. A visitor running the Honolulu Marathon using a smartwatch to collect their heart rate and GPS location or a person anywhere that has their consumer health data processed in Hawaii would fall within the scope of this bill's protections.

While the provisions designating violations as unfair methods of competition and unfair or deceptive acts or practices in trade or commerce create causes of action that could be pursued by the Attorney General or the Office of Consumer Protection (OCP) through a civil enforcement action, the bill does not allocate any additional resources to the State to enforce new violations of law created by the bill. OCP currently lacks technical expertise concerning collection of consumer health data, geofencing, and other aspects of this bill. OCP also has concerns that without additional resources, including technical training and staffing, OCP would be unable to effectively prosecute violations of law created under this bill. OCP notes that existing jurisdictional limitations

Testimony of DCCA

H.B. 1566

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would prevent OCP from prosecuting violations of this act in cases involving business to business transactions, such as a sale of consumer health data from one business to another without valid authorization.

Thank you for the opportunity to testify on this bill.

[Continue text here.]



**STATE HEALTH PLANNING
AND DEVELOPMENT AGENCY**
DEPARTMENT OF HEALTH - KA 'OIHANA OLAKINO

JOSH GREEN, M.D.
GOVERNOR OF HAWAII
KE KIA'ĀINA O KA MOKU'ĀINA 'O HAWAII

KENNETH S. FINK, MD, MGA, MPH
DIRECTOR OF HEALTH
KA LUNA HO'ŌKELE

John C. (Jack) Lewin, M.D.
ADMINISTRATOR

1177 Alakea St., #402, Honolulu, HI 96813 Phone: 587-0788 Fax: 587-0783 www.shpda.org

**House Committee on Judiciary and Hawaiian Affairs and
House Committee on Health and Homelessness**

H.B. 1566 Relating to Consumer Health Data

**Testimony of John C. (Jack) Lewin, M.D.
SHPDA Administrator**

**Tuesday, February 6, 2024
2:00 p.m.**

1 **Agency's Position: SUPPORT**

2 **Fiscal Implications: none**

3 **Purpose and Justification:** SHPDA is the State's oversight body for assuring universal
4 access to high-quality, equitable, and affordable health and long-term care for ALL citizens.
5 We manage Hawai'i's Certificate of Need (CON) program and prepare and update the State of
6 Hawai'i Health Services and Facilities Plan, among other responsibilities. We are also
7 developing, under our legislatively mandated authority, the State's All-Payer Claims Database
8 (APCD), in contractual relationship with the Med-Quest Division of the Department of Human
9 Services and the University of Hawai'i. This data is collected from all Hawai'i health insurers.

10 SHPDA believe this bill addresses important public and privacy protections over our
11 residents' health and personal data, and we strongly support it. We only ask that our
12 responsibilities under HRS 323D-12 that include collection of the privacy-protected and de-
13 identified data for the APCD, which is used for population health status monitoring and public
14 health purposes, be clearly exempted.

15 Thank you for the opportunity to testify.

February 5, 2024

HB 1566 Relating to Consumer Health Data

Committees: House Committees on JUDICIARY & HAWAIIAN AFFAIRS and HEALTH & HOMELESSNESS

Hearing Date/Time: Tuesday, February 6, 2024 at 2:00 PM

Place: Conference Room 325, Hawaii State Capitol, 415 South Beretania Street

Dear Chair Tarnas, Chair Au Belatti, and members of the Committees:

I write in **support** of HB 1566 Relating to Consumer Health Data.

As a privacy expert, I have worked in the field of data privacy for 20 years and was a member of the Hawaii State Legislature's 21st Century Privacy Law Task Force, created in 2019 by HCR 225.

Many of us have at least a passing familiarity with the federal law HIPAA (Health Insurance Portability and Accountability Act). If nothing else, we sometimes sign a form about it at the doctor's office. Fewer people realize the limitations of the law. HIPAA applies only to certain covered health entities, such as hospitals, doctors, and medical insurance companies. It does not apply to internet service providers, mobile health apps, social media companies, online advertisers, data brokers, and many other kinds of companies. These organizations are outside the narrow scope of HIPAA are therefore free to legally gather, buy, package, sell, and share Americans' health-related data with little to no oversight or regulation. And they do all these things. You can buy lists of people online with various characteristics, such as a list of rape survivors, people that take antidepressants, those suffering from cancer, or those that may be pregnant. Often these lists are sold for around 8¢ per name. The companies dealing with this data often say they have consumer's consent, since the sale of data may be buried deep in their Terms of Service and the user pressed the ACCEPT button. But I don't believe anyone would consent to be on a list of people that suffer from erectile dysfunction, if asked about it openly. And, yes, that is one of the lists for sale.

Some people say this bill might hinder medical research. Valid medical research is done through hospitals, doctors and other medical providers. These are all covered by HIPAA and explicitly exempted in Section 10 of the bill. Moreover, medical research is not being done by internet service providers, or even companies like Fitbit, using randomly compiled retail data with no control group. Medical research is certainly not done by people buying a list of 100 people that fit the characteristics previously mentioned.

The only protections that consumers have from companies like this, are in state privacy laws like Washington, California, and Vermont have already passed in varying forms. That's why HB 1566 is so important.

Thank you for your consideration and the opportunity support this legislation.



Kelly McCanlies

Fellow of Information Privacy, CIPP/US, CIPM, CIPT
International Association of Privacy Professionals





To: Hawai'i State House Committees on Judiciary & Hawaiian Affairs Committee/Health & Homelessness
Hearing Date/Time: Tuesday, February 6, 2024 at 2:00 PM
Place: Hawai'i State Capitol, Rm. 325 and videoconference
Re: Testimony of Planned Parenthood Alliance Advocates – Hawai'i in strong support of protecting consumer health data (HB 1566)

Aloha Chairs and members of the Committees,

Planned Parenthood Alliance Advocates **strongly supports HB 1566**. As many states are moving rapidly to criminalize abortion care and gender affirming care, Hawai'i must take steps to bolster data privacy as part of its efforts to support access to all critical health care.

All people deserve to be informed and given the opportunity to consent to the collection and distribution of their personal, private health information. Despite abortion remaining legal in Hawai'i, patients are terrified of being criminally prosecuted for seeking legal health care in our state. Patients are asking questions like “should I delete my period tracking app?” or “is it safe to Google where to find an abortion provider?” Patients are afraid to seek care because of privacy concerns.

Stigma, fear of prosecution, and harassment from anti-abortion and anti-LGBTQ groups are significant barriers to accessing reproductive and gender affirming health care. Everyone should be able to access the health care they need without their personal health information being collected and shared without their permission or knowledge. Currently, people's health data is left vulnerable to be shared by anti-abortion groups, used in prosecutions, or employed in targeted advertising. HB 1566 would take steps to protect this data and keep it private.

HB 1566 protects personal, private health information not already protected by HIPAA, such as geolocation data and other private information captured by popular health apps.

Data about health care-related search history and website visits are at risk of being bought and sold by data mining companies. For example, in 2021, Flo Health - one of the most popular period tracking apps - settled with the FTC over allegations that it shared health information on its 100 million users with third-party data analytics firms. Health-oriented apps such as period tracking apps collect sensitive health data and should be required to protect the data from being used to harm patients.

Planned Parenthood understands firsthand how data in the wrong hands can lead to violence and harassment of patients and providers. Right now, this data is easily accessible and dangerous. In May 2022, SafeGraph, a location data broker, sold the aggregated location data of people who visited abortion clinics, including more than 600 Planned Parenthoods over a one week period for just \$160. The data showed where patients traveled from, how much time they spent at the health centers, and where they went afterwards. Those who obtain healthcare, including abortions or gender affirming care, should not be subjected to targeted ads about their private health care decisions, and people should not have their locations tracked and shared via geotargeting when seeking health care.

Geofencing tactics have also been launched around health care facilities by anti-abortion and anti-LGBTQ extremists to activate when a person brings their cell phone or mobile device across the barrier. An individual can then be bombarded with text messages and advertisements urging them not to seek care. In 2016, geolocation data was used to target visitors to 140 abortion clinics with ads for anti-abortion pregnancy counseling services displayed on their mobile devices. Geolocation data that identifies personal cell phones and mobile devices can also be used to prosecute out-of-state patients; for example, cell phone information has been used in the prosecution of a woman

who experienced a pregnancy loss after searching online for medication abortion information.

HB 1566 is especially important in protecting already-vulnerable populations like domestic violence survivors, communities of color, the LGBTQ+ community, undocumented immigrants, young people, and people with disabilities. These communities are at an increased risk of surveillance and criminalization and face heightened danger when their health data is leaked and shared by harmful actors.

This bill addresses harms caused by crisis pregnancy centers (CPCs), most of which are not licensed medical providers and do not follow HIPAA or other protections for consumers.

HB 1566 is essential to address profound concerns with crisis pregnancy centers, which threaten the health and privacy of pregnant people. Crisis pregnancy centers, which significantly outnumber licensed health clinics in Hawai'i, often spread misinformation, promote anti-abortion activism, surveil pregnant people, and block access to abortion and contraception. Despite often looking like medical clinics, most crisis pregnancy centers are not licensed health facilities, do not offer health care, and are not required to comply with HIPAA, which puts people's personal health information at risk. This means that crisis pregnancy centers can freely collect and share pregnant people's health information, from ultrasounds to medical histories, in order to advance anti-abortion activism.

HB 1566 would require Hawai'i entities, such as crisis pregnancy centers, to disclose how patient information may be used and disallow collecting, sharing, or selling health data without consumer consent, protecting pregnant people and their health information. No matter who they are or where they come from, everyone deserves to get the health care and information they need without fear of being misled or having their privacy violated.

Patients' data should not be left vulnerable to be shared by anti-abortion and anti-LGBTQ groups, used in prosecutions, or employed for targeted advertising. Thank you for your support of HB 1566 to keep patients and providers safe from harassment, violence, and prosecutions.



Testimony of
Jonathan Ching
Government Relations Director

Before:
House Committee on Judiciary & Hawaiian Affairs
The Honorable David A. Tarnas, Chair
The Honorable Gregg Takayama, Vice Chair

House Committee on Health & Homelessness
The Honorable Della Au Belatti, Chair
The Honorable Jenna Takenouchi, Vice Chair

February 6, 2024
2:00 p.m.
Conference Room 325 & Via Videoconference

Re: HB 1566, Relating to Consumer Health Data.

Chair Tarnas, Chair Belatti, and committee members, thank you for this opportunity to provide testimony on HB 1566, which would extend new protections to consumer health data including prohibitions against: collecting and sharing data without affirmative consent, selling health data without a valid authorization, and use of geofences around health care centers.

Kaiser Permanente Hawai'i provides the following COMMENTS on HB 1566 and requests an AMENDMENT.

Kaiser Permanente supports the intent of HB 1566 to protect consumer health data, however, we are concerned that it could impact our ability to communicate with and care for our members when they are visiting our health care facilities.

Health information maintained by Kaiser Permanente, like other health plans, hospitals, and healthcare providers, is protected by The Health Insurance Portability and Accountability Act of 1996 (HIPAA), which requires national standards to protect patient health information from being disclosed without the patient's consent or knowledge.

We request the following amendment to provide clarification that health data covered by HIPAA, is exempt from this bill:

On § -8 Geofencing Prohibited, Pages 31-32:

§ -8 **Geofencing prohibited.** It shall be unlawful for any person to implement a geofence around an entity that provides in-person health care services where the geofence is used to:

- (1) Identify or track consumers seeking health care services;
- (2) Collect consumer health data from consumers; or
- (3) Send notifications, messages, or advertisements to consumers related to their consumer health data or health care services.

This section shall not apply to a covered entity as defined by The Health Insurance Portability and Accountability Act of 1996, to the extent the covered entity maintains patient information in the same manner as medical information or protected health information as described in this Act.

Mahalo for the opportunity to testify of this measure.

HB-1566

Submitted on: 2/2/2024 11:37:58 PM

Testimony for JHA on 2/6/2024 2:00:00 PM

Submitted By	Organization	Testifier Position	Testify
Michael Golojuch Jr	Stonewall Caucus of the Democratic Party of Hawai‘i	Support	Remotely Via Zoom

Comments:

Aloha Representatives,

The Stonewall Caucus of the Democratic Party of Hawai‘i; Hawai‘i’s oldest and largest policy and political LGBTQIA+ focused organization fully supports HB 1566.

We hope you all will support this important piece of legislation.

Mahalo nui loa,

Michael Golojuch, Jr. (he/him)
Chair and SCC Representative
Stonewall Caucus for the DPH



February 5, 2024

Chair David Tarnas
Vice Chair Gregg Takayama
House Committee on Judiciary & Hawaiian Affairs
Hawaii House of Representatives
Hawaii State Capitol, Room 442
Honolulu, HI 96813

Re: H.B. 1566, Hawaii Health Privacy Legislation — *SUPPORT*

Dear Chair Tarnas and Vice Chair Takayama,

Consumer Reports sincerely thanks you for your work to advance consumer privacy in Hawaii. H.B. 1566 would extend to Hawaii consumers important new protections relating to consumer health data, including prohibitions against collecting such data without affirmative consent, sharing that data without separate and distinct affirmative consent, and selling that data without written authorization, as well as the right to know the consumer health data companies have collected about them and the right to delete that information.

Many companies that collect especially sensitive personal information, including consumer health data, are failing to safeguard it. For example, Consumer Reports recently found that several health-related sites continued to share data with third parties, even after receiving opt-out requests.¹ Similarly, a 2021 Consumer Reports investigation into seven of the leading mental health apps showed that they had significant privacy issues: many shared user and device information with social media companies and all had confusing privacy policies that few consumers would understand.²

Additionally, the Federal Trade Commission has recently enforced against several companies that improperly shared personal health information with third-parties or broke their privacy

¹ Oates et al., Companies Continue to Share Health Data Despite New Privacy Laws, Consumer Reports (January 16, 2024), <https://advocacy.consumerreports.org/wp-content/uploads/2024/01/Companies-Continue-to-Share-Health-Data-1-16-2024-Consumer-Reports.pdf>

² Thomas Germain, Mental Health Apps Aren't All As Private As You May Think, Consumer Reports, (March 2, 2021), <https://www.consumerreports.org/health-privacy/mental-health-apps-and-user-privacy-a7415198244/>

promises to consumers, including fertility tracker apps Flo³ and Premom⁴, online counseling service BetterHelp⁵, and online prescription company GoodRx.⁶

Even when companies do not outright lie about their privacy protections, the hazy bounds of existing privacy law further complicate consumers' ability to understand company data practices. In a 2023 study headed by University of Pennsylvania researchers, 82% of consumers did not realize that HIPAA's privacy protections do not apply to many health-related data in mobile apps.⁷ As a result, many consumers share sensitive health information with businesses under the illusion that it is protected by preexisting legal frameworks, when, in many cases, none exist.

Lawmakers need to remedy this imbalance. At a minimum, businesses should be required to transparently communicate to consumers when they are collecting personal health information. While Consumer Reports would prefer a framework that, by default, prevents the collection *and* secondary use of consumer health information for *any* purposes other than providing the service requested by the consumer, we are glad to see that H.B. 1566 includes strong protections that would improve consumer privacy.

In particular, we appreciate that H.B. 1566 includes:

- *A strong definition of consumer health information.* The definition of “consumer health information” included in this legislation covers key categories of personal information consumers may share with businesses that deserve additional protection, including any inferences that companies make that relate to consumers physical or mental health.
- *A private right of action.* Given the AG's limited resources, a private right of action is key to incentivizing companies to comply and we appreciate that one is included in the bill. Under an AG-only enforcement framework, businesses that recognize that the AG is

³ Federal Trade Commission, FTC Finalizes Order with Flo Health, a Fertility-Tracking App that Shared Sensitive Health Data with Facebook, Google, and Others, (June 22, 2021), <https://www.ftc.gov/news-events/news/press-releases/2021/06/ftc-finalizes-order-flo-health-fertility-tracking-app-shared-sensitive-health-data-facebook-google>

⁴ Federal Trade Commission, Ovulation Tracking App Premom Will be Barred from Sharing Health Data for Advertising Under Proposed FTC Order, (May 17, 2023), <https://www.ftc.gov/news-events/news/press-releases/2023/05/ovulation-tracking-app-premom-will-be-barred-sharing-health-data-advertising-under-proposed-ftc>

⁵ Federal Trade Commission, FTC to Ban BetterHelp from Revealing Consumers' Data, Including Sensitive Mental Health Information, to Facebook and Others for Targeted Advertising, (March 2, 2023), <https://www.ftc.gov/news-events/news/press-releases/2023/03/ftc-ban-betterhelp-revealing-consumers-data-including-sensitive-mental-health-information-facebook>

⁶ Federal Trade Commission, FTC Enforcement Action to Bar GoodRx from Sharing Consumers' Sensitive Health Info for Advertising, (February 1, 2023), <https://www.ftc.gov/news-events/news/press-releases/2023/02/ftc-enforcement-action-bar-goodrx-sharing-consumers-sensitive-health-info-advertising>

⁷ Turow, J., Lelkes, Y., Draper, N. A., & Waldman, A. E, Americans Can't Consent To Companies' Use Of Their Data, (February 20, 2023), https://repository.upenn.edu/asc_papers/830/

only capable of bringing a handful of enforcement actions each year might simply ignore the law and take their chances in evading detection. Further, it's appropriate that consumers are able to hold companies accountable in some way for violating their rights. We strongly encourage legislators to retain this provision going forward.

- *Restrictions on collection without consent, opt-in for sharing, and written authorization for sales.* H.B. 1566 requires that regulated entities obtain affirmative consent to collect consumer health information unless such collection is necessary to provide a product or service requested by the individual. Importantly, the bill also requires businesses to receive separate, specific opt-in consent to share consumer health data and written authorization to sell consumer health data, which will ensure that consent for such unanticipated secondary uses of information cannot be bundled into a general terms of service or blanket privacy policy and instead must be presented to consumers in a standalone format.
- *Meaningful non-discrimination provisions.* We appreciate that the bill prohibits regulated entities from discriminating against consumers that exercise their rights under this act, including by charging different prices or rates for products or services or by providing a different level of service or quality. Importantly, the bill also provides that consumers can reject processing of regulated health information not strictly necessary to provide the service and still use the service.

For these reasons, we strongly urge passage of H.B. 1566. We look forward to working with you to ensure that Hawaii consumers have the strongest possible privacy protections.

Sincerely,

Matt Schwartz
Policy Analyst



**TESTIMONY OF TINA YAMAKI, PRESIDENT
RETAIL MERCHANTS OF HAWAII
February 6, 2024**

Re: HB 1566 RELATING TO CONSUMER HEALTH DATA

Good afternoon, Chair Tarnas and Chair Belatti and members of the House Committee on Judiciary and Hawaiian Affairs and the House Committee on Health and Homelessness. I am Tina Yamaki, President of the Retail Merchants of Hawaii and I appreciate this opportunity to testify.

The Retail Merchants of Hawaii was founded in 1901 and is a statewide, not for profit trade organization committed to supporting the growth and development of the retail industry in Hawaii. Our membership includes small mom & pop stores, large box stores, resellers, luxury retail, department stores, shopping malls, on-line sellers, local, national, and international retailers, chains, and everyone in between.

We understand the intent to ensure that consumers have important protections on the use of their data, and that they continue to be able to access healthcare, including reproductive healthcare or gender-affirming care. However, as it is currently written we are respectfully opposing this measure as we have concerns.

This bill establishes requirements, including additional disclosures and consumer consent regarding the collection, sharing, and use of consumer health data information; establishes rights for consumers regarding their health data, including the right to have health data deleted; prohibits the sale of consumer health data without a consumer's signed valid authorization; and prohibits the erection of a geofence around health care centers.

As drafted, the overly broad definitions that would negatively alter the consumer experience and fail to accomplish the legislative intent of this bill.

The key definitions in the law are exceptionally vague and expansive. (For example, the definition of physical or mental health status includes basically anything that involves having a human body, and the data is not limited to data that a company is actually using to diagnose or treat an actual medical condition.) Without changes to these key definitions, virtually all data could be included, including the purchase of everyday products like toilet paper, deodorant, shampoo, and shoes, because information about any of those purchases might disclose information about a consumer's "past, present, or future physical or mental health status." This means that the reach of the law could be exceptionally broad – at a minimum to all stores that collect information about an individual's physical attributes or shopping patterns, including any store that sells clothes, toiletries, or food products and wants to send e-mails to customers. More precise definitions focused on individuals accessing reproductive or gender-affirming care services would better accomplish the intended goals of this legislation.

The definitions are so broad—and the obligations of the bill are so burdensome—that the bill could have the unintended consequences of limiting consumer access to the same reproductive and sexual health services the authors seek to maintain. For example, the definitions mean that a bookstore might need to take extra precautions before, e.g., selling a book like "What to Expect When You're Expecting" (which might arguably disclose that the reader is pregnant) or allowing customers to create a baby registry.

Faced with these extra compliance obligations, businesses may choose not to sell these items or offer these features, which would not be the intended consequence. Further, the current draft takes away a consumer's ability to decide if they want marketing communications, which may make it harder for Hawaii businesses to reach their customers.

In the absence of narrowing the definition to capture only health data, the bill essentially becomes omnibus privacy legislation that is entirely unaligned with other states' privacy laws (many of which include careful provisions designed to help businesses protect privacy while coping with the burden of compliance), fails to include a small business exemption, lacks many key definitions, and requires opt-in consent notices for consumers making normal, everyday purchases.

We also have serious concerns with enforcement being conducted via a private right of action (PRA). A PRA in this legislation will not provide consumer protections but will encourage unnecessary litigation (often focused on technicalities) that could lead to negative, unintended consequences for Hawaii businesses of all sizes. The penalties imposed under this bill would enable class action firms to wield this statute as a cudgel against well-meaning businesses with little or actual value delivered to the consumer.

The only privacy statute in effect that allows a PRA is the Illinois Biometric Information Act (BIPA), which has seen flagrant abuse of class action litigation, with over 1,000 class action lawsuits filed in the past five years. The end result of BIPA's PRA is that legislators have expressed bipartisan support for reforms of its remedies

Mahalo again for this opportunity to testify.



1003 Bishop Street
Honolulu, Hawaii 96813
Telephone (808) 525-5877

Alison H. Ueoka
President

TESTIMONY OF ALISON UEOKA

COMMITTEE ON JUDICIARY & HAWAIIAN AFFAIRS
Representative David A. Tarnas, Chair
Representative Gregg Takayama, Vice Chair

COMMITTEE ON HEALTH & HOMELESSNESS
Representative Della Au Belatti, Chair
Representative Jenna Takenouchi, Vice Chair

Tuesday, February 6, 2024
2:00 p.m.

HB 1566

Chair Tarnas, Vice Chair Takayama, and members of the Committee on Judiciary & Hawaiian Affairs, and Chair Belatti, Vice Chair Takenouchi, and members of the Committee on Health & Homelessness, my name is Alison Ueoka, President for Hawaii Insurers Council. The Hawaii Insurers Council is a non-profit trade association of property and casualty insurance companies licensed to do business in Hawaii. Member companies underwrite approximately forty percent of all property and casualty insurance premiums in the state.

Hawaii Insurers Council submits comments and requests one amendment to this bill. This bill creates a new Chapter on Consumer Health Data Protection. While we commend your Committees' effort to protect the privacy of consumer health data, property and casualty insurers in Hawaii are already subject to its own Data Security Model Law as enacted by Hawaii in 2021 and codified as Article 3B, Chapter 431, Hawaii Revised Statutes. This National Association of Insurance Commissioners (NAIC) model law was specifically drafted for the insurance industry to properly manage and secure personal information, including health information.

Accordingly, we respectfully request an addition to the definition of “regulated entity” to add a fourth item under subsection (2) exemptions to read:

“(4) Licensed insurers, producers, or any other persons licensed or required to be licensed, authorized or required to be authorized, or registered or required to be registered, under chapter 431.”

Thank you for the opportunity to testify.

HB-1566

Submitted on: 2/3/2024 9:16:05 AM

Testimony for JHA on 2/6/2024 2:00:00 PM

Submitted By	Organization	Testifier Position	Testify
Doris Matsunaga	Save Medicaid Hawaii	Support	Written Testimony Only

Comments:

Save Medicaid Hawaii supports HB 1566



Judiciary & Hawaiian Affairs and Health and Homeless Committees

Hearing Date/Time: February 6, 2024/2:00 PM

Place: Hawaii State Capitol, Room 325

Re: Testimony in **STRONG SUPPORT** of **H.B. No. 1566, RELATING TO CONSUMER HEALTH DATA.**

Dear David A. Tarnas, Chair, Gregg Takayama, Vice Chair, Della Au Belatti and Vice-Chair Jenna Takenouchi and Members of the Judiciary & Hawaiian Affairs and Health and Homeless Committees:

Members of AAUW of Hawaii thank you for this opportunity to testify in strong support of H.B. No. 1966 to **prohibit the erection of a geofence around health care centers.**

Everyone should be able to access the health care they need without their personal health information being collected and shared without their permission or knowledge. States like Hawai'i that protect abortion and gender affirming care access will now play an even more critical role in providing care to people from states that criminalize abortion and jeopardize access to needed health care services. Providing privacy protections is a crucial step to safeguarding health care access.

HB 1566/SB 2696 Protects personal, private health information not already protected by HIPAA, such as geolocation data and other private information captured by popular health apps.

- Health-oriented apps such as period tracking apps collect sensitive health data that could be used to prosecute people seeking abortion care in Hawai'i from states with restrictions and bans.

- In 2021, Flo Health, one of the most popular period tracking apps, settled with the FTC over allegations that it shared health information on its 100 million users with third-party data analytics firms.

- Geolocation data that identifies personal cell phones and mobile devices can be used to prosecute out of state patients. HB 1566 shields the privacy of individuals accessing vital and protected health care by prohibiting use of this data.

- In May 2022 a location data broker sold the aggregated location data of people who visited abortion clinics, including more than 600 Planned Parenthoods over a one week period for just \$160. The data showed where patients traveled from, how much time they spent at the health centers, and where they went afterwards. The data collected by the company includes an

analysis of where people appear to live, based on where their cell phones are commonly located overnight.

- Cell phone information was also critical in the prosecution of a woman who experienced a pregnancy loss after searching online for medication abortion information.

- Geofencing tactics have been launched around health care facilities by anti-abortion extremists and activate when a person brings their cell phone or mobile device across the barrier. An individual can then be bombarded with text messages and advertisements urging them not to seek reproductive or gender-affirming care.
 - In 2016, geolocation data was used to target visitors to 140 abortion clinics with ads for anti-abortion pregnancy counseling services displayed on their mobile devices.

- This bill is especially important in protecting already-vulnerable populations like domestic violence survivors, communities of color, the LGBTQ+ community, undocumented immigrants, young people, and people with disabilities.

Addresses harm caused by Crisis Pregnancy Centers (CPCs), most of which are not licensed medical providers and do not follow HIPAA or other protections for consumers.

- Despite often looking like medical clinics, most crisis pregnancy centers are not licensed health facilities, do not offer health care, and are not required to comply with HIPAA, which puts people's personal health information at risk. This means that crisis pregnancy centers can freely collect and share pregnant people's health information, from ultrasounds to medical histories, in order to advance anti-abortion activism.

- HB 1566/SB 2696 would require Hawai'i entities, such as crisis pregnancy centers, to disclose how patient information may be used and disallow collecting, sharing, or selling health data without consumer consent, protecting pregnant people and their health information.

Sincerely,
Elizabeth Jubin Fujiwara, Esq.
Public Policy Committee, AAUW of Hawaii
publicpolicy-hi@aauw.net

The American Association of University Women (AAUW) of Hawaii is an all-volunteer, statewide chapter of a national organization and is made up of six branches: Hilo, Honolulu, Kaua'i, Kona, Maui, and Windward Oahu. UH Hilo, UH Manoa, UH Maui College, and Windward Community College are also AAUW partners. AAUW's mission is to advance gender equity for equal opportunities in education, at workplace and for economic security, and in leadership.



February 5, 2024

Hon. Della Au Belatti
Chair, House Committee on Health & Homelessness
House District 26
Hawai'i State Capitol, Room 420
Honolulu, HI 96813
repbelatti@capitol.hawaii.gov

Hon. David A. Tarnas
Chair, Committee on Judiciary & Hawaiian Affairs
House District 8
Hawai'i State Capitol, Room 442
Honolulu, HI 96813
reptarnas@capitol.hawaii.gov

RE: ATA ACTION COMMENTS IN OPPOSITION TO HOUSE BILL 1566 “RELATING TO CONSUMER HEALTH DATA”

Good afternoon Chair Belatti, Chair Tarnas and members of the Health & Homelessness and Judiciary & Hawaiian Affairs Committees,

On behalf of the ATA Action, I am submitting the following comments opposing House Bill 1566 along with the following recommendations to improve the legislation.

ATA Action, the American Telemedicine Association's affiliated trade association focused on advocacy, advances policy to ensure all individuals have permanent access to telehealth services across the care continuum. ATA Action recognizes that telehealth and virtual care have the potential to truly transform the health care delivery system – by improving patient outcomes, enhancing safety and effectiveness of care, addressing health disparities, and reducing costs – if only allowed to flourish.

Telehealth is and will remain an important way Americans access the healthcare they need. As more providers come online – figuratively and literally – ATA Action urges increased vigilance by the healthcare community to ensure these practices meet standards for patient safety, data privacy, and information security. Indeed, patient privacy and the protection of patient data are prerequisites for connected care and core principles for our organization. State and federal regulatory schemes should allow for innovation and support the advancement of technology-assisted care; however, telehealth and virtual care platforms, systems, and devices should be required to mitigate cybersecurity risks and provide for patient safety and confidentiality.

In light of the advancement of privacy legislation in many states across the country to address such concerns, the American Telemedicine Association has published [Health Data Privacy Principles](#) (also attached) to aid legislators in crafting legislation that supports both secure data practices and patient access to care. ATA Action hopes these policy principles are helpful in crafting forward-thinking privacy legislation in Hawaii.

ATA ACTION

901 N. Glebe Road, Ste 850 | Arlington, VA 22203
Info@ataaction.org



ATA Action has several concerns that HB1566 (“the Act”) runs counter to sound data privacy policy and puts undue burdens on telehealth providers due to its complexity and undefined breadth. Specifically, ATA Action makes the following recommendations:

Legislators should seek uniform privacy laws consistent across states and industries: As states adopt privacy laws across the nation, efforts to establish uniformity with existing federal and other state standards would reduce both complexity and costs regarding compliance, as well as confusion for consumers. Unfortunately, the Act at hand is both specific only to healthcare data and creates uneven burdens on providers relative to federal laws (discussed below). Instead, ATA Action encourages legislators to take an approach that mirrors Virginia (see the Virginia Consumer Data Protection Act¹) and Connecticut (see the Connecticut Consumer Data Privacy and Online Monitoring Act²). As HB1566 continues to work through the legislative process, we hope this Committee and the Hawaii legislature will strive for uniformity with these existing state regulatory frameworks and avoid burdensome requirements that would be specific only to Hawaii.

Make clear that HIPAA-covered entities are exempt from this Act: ATA Action believes the current HIPAA rules provide detailed and appropriate protections for the confidentiality of protected health information, as they have been a fixture in our healthcare system for more than two decades. Imposing additional, duplicative and potentially inconsistent regulation on HIPAA covered-entities would create unnecessary and inappropriate burdens and cost. ATA Action recommends HB1566 be revised to clearly exempt HIPAA-covered entities and business associates from the provisions of this Act.

Restrictions on collection and use of data are inconsistent with and exceed HIPAA, setting up an unequal framework for Hawaii providers and consumers: The intent and preamble of HB1566 states Hawaii residents have the misimpression that HIPAA protects them anytime they share health information and that this legislation intends to “close the gap” to afford privacy protections where HIPAA would not apply. ATA Action supports this intent and believes state consumer privacy laws should be consistent with and not exceed HIPAA’s standards to the greatest extent possible.

However, we are concerned that HB1566 imposes obligations and requirements that exceed HIPAA and other existing state and federal regulatory frameworks, creating significant uncertainty about compliance. The lack of clarity is particularly troubling as our organization represents both HIPAA and non-HIPAA covered entities, who nonetheless share a commitment to protect the confidentiality of patient’s personal information.

Under HB 1566, for example, a regulated entity would need a specific consent to both collect and use a consumer’s data for any purpose other than to provide the product or service that the consumer requested. This would, for example, prohibit a regulated entity from sending communications about its own products or services to the consumer. However, a HIPAA-covered entity – and in some situations their contracted third-party business associates – could engage in that same activity with the consumer’s HIPAA protected health information without any need for specific consent from the consumer under the HIPAA Privacy

¹ Virginia Consumer Data Protection Act, VA Code Ann. § 59.1-575 *et seq.*, <https://law.lis.virginia.gov/vacodefull/title59.1/chapter53/>.

² Connecticut Consumer Data Privacy and Online Monitoring Act, Conn. Gen. Stat. § 42-515 *et seq.*, https://www.cga.ct.gov/current/pub/chap_743jj.htm.



Rule.³ This inconsistency would afford differing rights to Hawaii consumers and unequal burdens on entities based solely on being subject to HIPAA. We suggest aligning the permitted uses and disclosures of the Act, at a minimum, with the HIPAA Privacy Rule, including that consumer health data may be used for purposes of treatment, payment, and health care operations.

State attorneys general should have sole enforcement authority when privacy laws are violated:
HB1566 cites the Hawaii Trade Regulation and Practice laws (chapter 480) for the Act's enforcement component when violations occur. Chapter 480 includes both personal and class rights of action, in addition to actions available to the Attorney General or Office of Consumer Protection against violators.

ATA Action believes that state attorneys general should have sole, appropriate authority to investigate possible violations of privacy laws and determine when it is appropriate to pursue sanctions against bad actors. ATA Action also recommends that legislators avoid including private rights of action as a method of enforcing privacy laws, which are prone to a lack of clarity, result in frivolous lawsuits and out-of-court settlements that exacerbate legal uncertainty. ATA Action hopes that the Committee will embrace these changes so as to simultaneously ensure patient data is effectively protected while not placing undue burdens on providers. We believe that this strikes a fair balance between these two significant public policy goals.

Thank you for your support of telehealth. We encourage you and your colleagues to consider amendments to HB1566 to ensure easy and efficient access to high-quality health care services in Hawaii. Please do not hesitate to let us know how we can be helpful to your efforts to advance common-sense telemedicine policy. If you have any questions or would like to discuss the telemedicine industry's perspective further, please contact me at kzebley@ataaction.org.

Kind regards,

A handwritten signature in black ink, appearing to read "Kyle Zebley", written in a cursive style.

Kyle Zebley
Executive Director
ATA Action

³ *Marketing*, U.S. Dept. of Health and Human Servs. (July 26, 2013), <https://www.hhs.gov/hipaa/for-professionals/privacy/guidance/marketing/index.html>.

STATE PRIVACY & SECURITY COALITION

February 5, 2024

Representative David A. Tarnas
Chair, Committee on Judiciary and Hawaiian Affairs
Hawai'i State Capitol, Room 442
Honolulu, HI 96813

Representative Della Au Belatti
Chair, Committee on Health & Homelessness
Hawai'i State Capitol, Room 420
Honolulu, HI 96813

Re: Consumer Health Data Protection (HB 1566)

Dear Chair Tarnas, Chair Belatti, and Members of the Respective Committees,

The State Privacy & Security Coalition (SPSC), a coalition of over 30 companies and six trade associations in the retail, telecom, technology, automobile, health care, and payment card sectors, writes in opposition to HB 1566. While we do not oppose the intent of the legislation, the bill needs significant modification before being ready for enactment.

Unfortunately, the bill as drafted suffers from overbroad definitions – namely that of “Consumer Health Data” – that cover far more than the bill likely intends. In fact, because the outer boundary of the definition would require opt-in consent to collect or process *any* linkable personal data “that identifies...bodily functions” or “products that...affirm an individual’s gender identity,” the actual scope of the bill as drafted could effectively be read to cover *virtually all data* that an individual generates – including purchases of deodorant, food, makeup, and clothing.

The definitions in this bill are so broad—and the obligations of the bill are so burdensome—that the bill could have the unintended consequences of limiting consumer access to the same reproductive and sexual health services the authors seek to maintain. For example, the definitions mean that a bookstore might need to take extra precautions before, e.g., selling a book like “What to Expect When You’re Expecting” (which might arguably disclose that the reader is pregnant) or allowing customers to create a baby registry.

This expansive scope, when combined with opt-in requirements, will not just be disruptive to the consumer experience, resulting in unintended consequences (such as collecting more data than necessary to demonstrate that it is not Consumer Health Data) – but it also threatens to obscure the use of opt-in consent for the truly sensitive uses of data regarding reproductive care and gender-affirming care. If consumers get used to clicking through opt-in mechanisms routinely, the mechanisms will cease to be a signal that there is truly sensitive information being collected or shared. This is known as “consent fatigue,” and occurs around, for example,

STATE PRIVACY & SECURITY COALITION

the GDPR cookie banners that consumers regularly click through just to access the services and information they seek.

We do not believe this is the intent of the legislation, and it is this scope that we believe can be fixed by tightening the definitions and including language found in other state privacy laws that have been vetted by legislatures such as Connecticut and Nevada.

Lastly, the bill does not make it clear that enforcement is exclusive to the Attorney General's office. This will create a flood of litigation for good-faith actors who are unsuspecting due to the overbroad definitions.

1. "Consumer Health Data Definition"

While we appreciate the modest narrowing of this definition by adding a "linked or reasonably linkable" standard, there is another critical change necessary – language ensuring that for the data covered, the Regulated Entity **actually be using it as health data**. Because the list of data covered goes far beyond actual health-related data and covers data that **could** be used to create inferences around health, our request is for language as follows:

"Consumer health data" means personal information that is linked or reasonably linkable to an identified or identifiable consumer and that a Regulated Entity uses to identify a consumer's past, present, or future physical or mental health."

SPSC recommends these changes because this statute's stated intent is to fill the sectoral gaps in regulating health data, impose heightened protections for this sensitive data, and empower consumers with significant rights to control their health data.

We support this laudable goal. But the key to achieving it is to ensure that the bill's scope and definitions are not ambiguously overbroad and focused on encompassing data that is not clearly identifiable to either a Regulated Entity or a consumer as health data; we believe that the appropriate boundary for this type of ambiguous data – which again, may well **not** be used as health data – is when the Regulated Entity actually begins using it in a health-related context.

This is our highest priority request, because it affects the entire scope of the bill. As presently drafted, the data does not have to be health-related in order for opt-in consent to apply for its collection and processing.

This overbreadth **will result in a deluge of opt-in consent notifications for consumers** as they attempt to access services that are not related to reproductive or other health-care uses of the data, because businesses will need to provide these in order to comply with the law. This will lead to consent fatigue, desensitizing consumers to opt-in notifications similar to the way many consumers do not read GDPR cookie banners on websites now.

STATE PRIVACY & SECURITY COALITION

While this outcome creates difficulties for businesses, it is, more importantly, confusing for consumers. Consumers benefit from clear privacy standards in order to navigate the complex digital landscape. If a bill requires, or highly incentivizes, business to treat all data as potentially health data, it will be difficult for consumers to make informed choices about when to consent to data uses and when to exercise their rights over such sensitive data.

SPSC wants to ensure that when a consumer receives an opt-in notification, they notice and understand its implications. As drafted, the scope of the bill will prevent this from happening.

2. Other Key Definitional Amendments

a. “Collect”

We also appreciate why the bill as drafted seeks to establish opt-in consent for sensitive data collection and sharing. But because the definition of “collect” also includes the phrases “infer, derive, or otherwise process” consumer health data, the bill would require opt-in consent for not only the collection and sharing of data, but also for *any processing after collection*. This means that, again, consumers will receive multiple opt-in notices for the same data points. For example, a consumer that provides opt-in consent for the collection of data related to their purchase of ibuprofen will have to provide an additional opt-in consent choice for that data to be used as part of a coupon program, *even as the individual was given such information at the point of collection*. We do not believe this is the intent of the law.

Again, because this law as drafted will be enforced not by individuals or offices with expertise in data privacy, but by class action lawyers with expertise in frivolous litigation, the confusion created by including one set of data processing activities that are not commonly understood to be “collection” will be exploited and used against regulated entities and processors who are attempting in good faith to comply.

We urge this committee to amend this definition so as to eliminate this confusion and align the definition of “collect” with what is commonly understood as such.

b. “Deceptive Design”

SPSC believes that this definition should align with other state law definitions, such that it reads as follows:

“Deceptive Design” means a user interface designed or manipulated with the substantial effect of subverting user autonomy, decision making, or choice.”

As drafted, this definition would encompass virtually any user design, because it is not tied to any recognizable legal standard. Other states have adopted a definition that require a “substantial effect” because they have recognized that in order to be enforceable, the outcome of a deceptive design must be to **actually deceive**. Again, the private right of action further

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complicates this, as nearly every website and consent mechanism will be subject to a lawsuit under this provision.

c. “Sale”

As drafted, the terms “sale” and “sharing” have distinct uses and meanings in the legislation. Regulated entities are required to obtain opt-in consent for collection and “sharing” of consumer health data, but a much more extensive process for obtaining permission to sell consumer health data.

Unfortunately, the definition of “sale” currently *fails to exempt transfers to processors*. Every privacy framework in the country recognizes that a transfer of data to a processor – an entity contractually bound to process data only on behalf of a controller – should not qualify as a sale. The definition as drafted means that a business which obtained consent to collect consumer health data would then need to obtain a written authorization simply to store that data in a cloud storage provider. We do not believe this is the intent of the law and would encourage the committee to adopt a more conventional definition of “sale” as found in other comprehensive privacy laws.

3. Operational Provisions

There are several critical changes that still need to be made before this bill is ready to be implemented.

a. **Separate Privacy Policy**

SPSC supports the requirement to have a separate section in its privacy policy for Consumer Health Data, but does not believe that it will be effective to have a separate privacy policy altogether, for several reasons.

First, it will be confusing for residents of Hawai'i to be covered by two separate privacy policies – one for Consumer Health Data, and one for general data. Again, because the definition of Consumer Health Data is so broad and covers lots of data that would normally be in a general privacy policy, it will be difficult to discern exactly what data is covered outside of a general data set, and what is not.

Second, it sets a precedent that will lead to more confusion as other states pass privacy laws. SPSC does not believe that having separate privacy policies for only part of a general data set is a helpful precedent for consumers. It would be better to be able to include this information in a general privacy policy, with the disclosures being directly linked to by whatever consent mechanisms a regulated entity deploys.

b. **Archived/Backup Data**

As drafted, the legislation ignores norms that other states such as California and Colorado have recognized around retrieving data from backup or archived systems. These states recognize

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that when responding to a consumer deletion request, businesses should not face a requirement to open up their archived and backup systems – which often contain unstructured data that is no longer being used – in responding to such requests, but instead require deletion **only when such data is retrieved or activated again**. We have suggested the same language here; particularly with the broad definition of “consumer health data,” this requirement will allow companies to focus on deleting information that is meaningfully accessible.

Again, the private right of action looms over the compliance requirements here, threatening to overwhelm even good-faith errors and omissions that could otherwise be easily corrected. The numerous avenues for frivolous lawsuits in this legislation could make Hawai’i the new home for class action lawsuits.

4. Operational Exemptions

SPSC suggests standard operational exemptions that have not been controversial in other states that have adopted privacy laws; these exemptions preserve the ability of the regulated entities to fix internal errors, make everyday services better, and preserve the safety of consumers when health emergencies arise. We believe that consumers should not have to wade through opt-in consent notifications or mechanisms when these types of everyday interactions are at issue. Furthermore, we support adding additional language that ensures regulated entities cannot use the data for these reasons as a pretext for avoiding the consent requirements.

5. Private Right of Action

It is critical that this legislation make explicit that there is no private right of action associated with a violation of this act.

As discussed throughout this testimony, we strongly believe that a private right of action **will not help consumers or regulated entities**. It will not help regulated entities because the compliance lens will not be focused on the consumer, but rather on avoiding litigation; this is likely to lead to an amplification of opt-out mechanisms and notifications in order to “play it safe;” it is likely to further desensitize consumers to these notifications; and trial lawyers will be enriched while consumers, as usual, recover minimal compensation for many technical, not material, errors by the regulated entities.

We have seen what happens when a private right of action is deployed. In Illinois, **consumers are less safe than in any other state**, because companies that use biometrics to prevent fraud and identity theft turn down their services in order to avoid certain litigation; startups do not offer services to residents because they know they will be sued.

SPSC wants consumers to have increased control over the data and increased transparency as to how their data can be used. We want consumers to know that when they receive an opt-in

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consent mechanism flagging that a company is about to collect or share consumer health data, it is something to seriously consider.

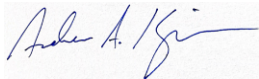
A private right of action jeopardizes all of this; it will result in an overload of opt-in consent requests, and consumers will lose the context of why carefully considering the use of their data is important' instead, requests will blur together in consumers' minds with no particular importance attached to providing consent in order to simply to access everyday services and products that have nothing to do with their consumer health data.

On the flip side, Hawai'i will become the new home of class action litigation. A regulated entity that provided only opt-in consent for the sharing of its data will be sued for not realizing that transferring data to a vendor is in fact part of "sale," which requires a different permission structure entirely. Businesses that offer any consumer choice at all on a website will be vulnerable to lawsuits claiming that their choice architecture has the "potential" to be deceptive – **and no proof will be required that it is in fact deceptive**. A regulated entity that provides opt-in consent at the point of collection but neglects to obtain consent for that same storage of data will be sued because it did not realize that "collect" actually means "any and all types of processing."

SPSC does not oppose the intent of this law, but instead wants to ensure that it is actually possible to comply with; that it meaningfully benefits consumers; and that the focus be on compliance, not litigation defense.

We would be happy to discuss this legislation further at your convenience.

Respectfully submitted,



Andrew A. Kingman
Counsel, State Privacy & Security Coalition

TESTIMONY OF THE AMERICAN COUNCIL OF LIFE INSURERS
COMMENTING ON HB 1566, RELATING TO
CONSUMER HEALTH DATA

February 6, 2024

Honorable Rep. David A. Tarnas, Chair
Honorable Rep. Gregg Takayama, Vice -Chair
Committee on Judiciary and Hawaiian Affairs
Honorable Rep. Della Au Belatti, Chair
Honorable Rep, Jenna Takenouchi, Vice Chair
Committee on Health and Homeless
Hawaii State Capitol, Room 325 and Videoconference
415 South Beretania Street
Honolulu, Hawaii 96813

Dear Chairs Tarnas and Belatti; Vice-Chairs Takayama and Takenouchi; and Members of the Committees:

Our firm represents the American Council of Life Insurers (“ACLI”). The American Council of Life Insurers (ACLI) is the leading trade association driving public policy and advocacy on behalf of the life insurance industry. 90 million American families rely on the life insurance industry for financial protection and retirement security. ACLI’s member companies are dedicated to protecting consumers’ financial wellbeing through life insurance, annuities, retirement plans, long-term care insurance, disability income insurance, reinsurance, and dental, vision and other supplemental benefits. ACLI’s 275 member companies represent 93 percent of industry assets in the United States.

Two hundred sixteen (216) ACLI member companies currently do business in the State of Hawaii; and they represent 95% of the life insurance premiums and 99% of the annuity considerations in this State.

Thank you for the opportunity to submit comments on HB 1566, Relating to Consumer Health Data.

The insurance industry is a consumer privacy leader in support of clear obligations in the appropriate collection, use and sharing of personal information. ACLI has long advocated for common-sense, consumer-oriented policy proposals. For over 175 years, life insurers have ably managed consumers’ sensitive medical and financial data and as an industry, we advocate for sound public policy.

Insurers must collect and use personal information for risk management, to comply with a complex array of federal, state, and sector-specific laws and regulations, and to perform essential business functions to provide the innovative insurance and financial products that consumers seek to meet their needs and our customer’s demand. Insurers use personal information for a host of business purposes, such as to underwrite applications for new insurance policies, to pay claims

submitted under these policies, to provide customer service, to combat fraud and to offer investment and retirement products.

Our policyholders are protected by a wide range of state and federal laws safeguarding their information from unauthorized use, and they can expect life insurers to make smart and responsible decisions to keep personal information secure. A major component of the existing framework is the federal Gramm Leach Bliley Act:

Gramm Leach Bliley

The federal Gramm Leach Bliley Act (“GLBA”) imposes transparency, confidentiality, and security obligations on all financial institutions, including life insurers, with respect to nonpublic personal information obtained and used by these institutions. The GLBA imposes safeguards regarding the collection, disclosure, and protection of consumers' nonpublic personal information and personally identifiable information.

The GLBA establishes that each financial institution, including each insurer, has an affirmative and continuing obligation to respect the privacy of its customers and to protect the security and confidentiality of those customers' nonpublic personal information.

Under the GLBA, insurers must:

- Provide customers with a clear and conspicuous initial and annual privacy notice describing their data collecting and handling practices and the conditions under which information may be disclosed to non-affiliated third parties. ;
- Secure data through administrative, technical, and physical safeguards;
- Provide consumers with rights to, and limit certain disclosures of their non-public personal information;
- Implement a proactive compliance program; and
- Limit the reuse and marketing of a consumer's information.

The proposed bill would add complexities, expenses of implementation and even potentially inconsistencies to existing comprehensive privacy laws that govern insurers and will inevitably result in conflicting scopes, definitions, notice requirements and consumer rights.

Many other states, including Connecticut, Colorado, Delaware, Virginia, and Utah, recognize how a comprehensive state privacy law would adversely impact the financial services industry by including an exemption from their laws for entities that are otherwise regulated by GLBA or state privacy laws. We strongly recommend adoption of a similar entity-level exemption, which would exempt financial services entities and their affiliates that are regulated by the GLBA. Without an entity level exemption, consumers and insurers alike face the uncertainty created by duplicative and even conflicting rules.

Accordingly, ACLI requests that the exception set forth in Section 10(a)(5) of the proposed chapter of the Hawaii Revised Statutes be amended as follows:

- (5) Personal information that is governed by and collected, used, or disclosed pursuant to the following federal laws and regulations:
 - (A) The Gramm-Leach-Bliley Act (32 U.S.C. 6801 et 12 seq.) and implementing regulations;
 - (B) Part C of title XI of the Social Security Act (42 14 U.S.C. 1320d et seq.);
 - (C) The Fair Credit Reporting Act (15 U.S.C. 1681, et 16 seq.)and implementing regulations; and
 - (D) The Family Educational Rights and Privacy Act (20 18 U.S.C. 1232g) and implementing regulations;
- (6) Entities and their affiliates that are governed by and collect, use or disclose personal information pursuant to the Gramm-Leach-Bliley Act (32 U.S.C. 6801 et 12 seq.) and implementing regulations;

Consumers and companies need privacy requirements that are consistent and equivalent across state borders, provide equal protections to all consumers regardless of where they are located, support growth and innovation, and which provide legal transparency. Differing privacy standards will lead to consumer confusion, differing consumer rights and protections, obstruct the flow of information, and impede interstate commerce. Differing state privacy approaches are confusing and frustrating to consumers facing divergent rights to control over their personal information based upon where they live or with whom they are doing business. These conflicts must be taken into consideration as you work to develop comprehensive obligations regarding the use of personal information which applies equally and uniformly to all industries.

ACLI is proud of our member companies' longstanding role as conscientious and responsible guardians of customers' vulnerable personal information. We remain strongly committed to the proper use and protection of consumer data.

Again, thank you for the opportunity to comment on HB 1566, relating to Consumer Health Data.

LAW OFFICES OF
OREN T. CHIKAMOTO
A Limited Liability Law Company

Oren T. Chikamoto
P. O. Box 4277
Honolulu, Hawaii 96812
Telephone: (808) 531-1500
E mail: otc@chikamotolaw.com



TECHNET
THE VOICE OF THE
INNOVATION ECONOMY

TechNet Southwest | Telephone 505.402.5738
915 L Street, Suite 1270, Sacramento, CA 95814
www.technet.org | @TechNetSW

February 5, 2024

Representative David A. Tarnas
Chair, Committee on Judiciary and Hawaiian Affairs
Hawai'i State Capitol, Room 442
Honolulu, HI

Representative Della Au Belatti
Chair, Committee on Health & Homelessness
Hawai'i State Capitol, Room 420
Honolulu, HI

Re: HB 1566 (Tarnas) – Relating to Consumer Health Data - OPPOSE

Dear Chair Tarnas, Vice Chair Belatti, and Members of the Committee,

TechNet respectfully submits this letter in opposition to HB 1566, regarding consumer health data.

TechNet is the national, bipartisan network of technology CEOs and senior executives that promotes the growth of the innovation economy by advocating a targeted policy agenda at the federal and 50-state level. TechNet's diverse membership includes dynamic American businesses ranging from startups to the most iconic companies on the planet and represents over five million employees and countless customers in the fields of information technology, e-commerce, the sharing and gig economies, advanced energy, cybersecurity, venture capital, and finance.

The protection of consumer health data is of critical importance and TechNet supports the intent of the underlying legislation. TechNet's members place a high priority on consumer privacy and the technology industry is committed to securing privacy and security protections, including for sensitive personal information such as health and reproductive data. We are respectfully opposed to the bill as drafted, however, due to its overly broad definitions. We look forward to working with the author to amend the bill to address these issues.

Under the current definition of "consumer health data" in HB 1566, virtually all data would be captured because data collection and processing are not limited to health data. Given such an overly broad universe of covered data, everyday activities, including the purchase of everyday products such as ibuprofen, makeup, and deodorant, as well as following a fitness influencer on a social media platform, would invoke opt-in consent. In the absence of narrowing the definition to capture only health data, the bill essentially becomes omnibus privacy legislation that is

entirely unaligned with other states' privacy laws and requires opt-in consent notices for consumers making normal, everyday purchases.

The bill's scope is likely to have two unintended consequences. First, companies may limit access to the reproductive or health services to avoid inadvertently violating the bill's requirements. Second, the scope is also likely to result in consumers being presented with numerous opt-in mechanisms for purchases and data that isn't within the intent of this bill. In this instance, consumers will start to ignore these notices, potentially endangering their sensitive information.

We also believe the bill should explicitly preclude enforcement via a private right of action (PRA), which will not help consumers access their rights or ensure compliance from regulated entities. A PRA in this legislation will not provide consumer protections but will encourage unnecessary litigation that could lead to negative, unintended consequences for businesses of all sizes. The penalties imposed under this bill would enable class action firms to wield this statute as a cudgel against well-meaning businesses with little or no actual value delivered to the consumer. The only privacy statute that allows a PRA is the Illinois Biometric Information Act (BIPA), which has seen flagrant abuse of class action litigation, with over 1,000 class action lawsuits filed in the past five years. Since its passage, no other state has enacted BIPA legislation and Illinois legislators have expressed bipartisan support for reforming its remedies.

Residents of Hawaii and employers deserve privacy protections that safeguard their sensitive data while also promoting innovation, security, and job creation. TechNet welcomes the opportunity to work with your office to address issues of privacy protection without unintended consequences.

Thank you for your consideration. If you have any questions regarding TechNet's position on this bill, please contact Dylan Hoffman at dhoffman@technet.org or 505-402-5738.

Sincerely,

A handwritten signature in black ink, appearing to read 'Dylan Hoffman', with a stylized flourish at the end.

Dylan Hoffman
Executive Director for California and the Southwest
TechNet



ACOG

The American College of
Obstetricians and Gynecologists

*The American College of Obstetricians and Gynecologists
District VIII, Hawai'i, Guam & American Samoa Section*

TO: House Committee on Judiciary & Hawaiian Affairs
Representative David A. Tarnas, Chair
Representative Gregg Takayama, Vice Chair

Senate Committee on Health & Homelessness
Representative Della Au Belatti, Chair
Representative Jenna Takenouchi, Vice Chair

Date: Tuesday February 6, 2024

Place: Hawaii State Capitol, House Conference Room 325 and Video Conference

From: Hawai'i Section, ACOG
Angel Willey, MD, FACOG, Chair
Reni Soon, MD, MPH, FACOG, Legislative Chair

Re: HB1566 - Relating to Consumer Health Data
Position: STRONG SUPPORT

As a section of the nation's leading group of physicians dedicated to improving women's health and the health of our families, the Hawai'i Section of the American College of Obstetricians and Gynecologists (HI ACOG) **strongly supports HB1566**, which provides additional protection to personal private health information. Simply put, privacy is a fundamental right to freedom.

First and foremost, while all patients' health information and data is protected to some degree by the Health Insurance Portability and Accountability Act (HIPAA), patients seeking abortion, patients identifying as LGBTQIA+, patients seeking gender affirming care, patients who experience domestic violence, minors, and other such patient groups are especially vulnerable because their health information being shared could cause them harm.

Since *Roe v Wade* was overturned, officials in some states have threatened legislation restricting the ability of their residents to get abortions or other types of healthcare in other states by targeting and collecting consumer health care data. For example, many of our reproductive age patients use apps to track their monthly period – apps that alert them when they miss their period. This health data could be known, shared and geolocation data could be used to track the patient. In this "Post Roe" era, the sensitive health data in these apps could be used to prosecute individuals who seek abortion care in Hawaii. Increasingly, states (like Idaho, Tennessee, Oklahoma, and most recently Mississippi) are enacting legislation to restrict care or punish patients who desire abortions. Other tactics by anti-abortion extremists include enacting a "geofence" that activates when a person brings their mobile device into a particular location, usually surrounding a healthcare center. That patient can then be bombarded with text messages and advertisements urging them not to seek reproductive or gender-affirming care.

With many patients having a smartphone, with sensitive health information and geolocation tracking, these patients can easily be monitored by restrictive states or anti-abortion groups. As one of the first states in the nation to allow for abortion, we are a safe harbor for patients who make the decision to come to Hawai'i for their healthcare. We need them to continue to feel comfortable and confident that they can receive the best healthcare from us, and this includes feeling safe that their health information will be confidential and private.

Hawaii ACOG is dedicated to serving our patients first and above anything else, to provide them with the health care they deserve and have the right to obtain, without fear of persecution. Thus it is critical for us here in Hawai'i to protect consumer health data by passing **HB1566**.

Mahalo for the opportunity to testify.

HB-1566

Submitted on: 2/2/2024 5:59:25 PM

Testimony for JHA on 2/6/2024 2:00:00 PM

Submitted By	Organization	Testifier Position	Testify
Kimi Murphy Ide-Foster	Individual	Support	Written Testimony Only

Comments:

Thank you for this opportunity to provide testimony on HB1566. I am writing in strong support of this bill.

Technology is becoming an increasingly integrated part of our lives, and this bill includes provisions that are critical to protect personal, private health information not already protected by HIPAA, such as geolocation data and other private information captured by popular health apps.

Geofencing tactics have been launched around health care facilities by the anti-choice movement. They activate when a person brings their cell phone or mobile device across the barrier and can cause an individual to be bombarded with text messages and advertisements urging them not to seek reproductive or gender-affirming care. Everybody should be able to access the care they want and need without fear of assault in any form. This bill is especially important in protecting vulnerable and marginalized populations like domestic violence survivors, communities of color, the LGBTQ+ community, undocumented immigrants, young people, and people with disabilities.

This bill will also go a long way towards addressing the serious harms caused by crisis pregnancy centers or "fake" pregnancy centers. Under this bill, they will be required to disclose how patient information may be used and disallow collecting, sharing, or selling health data without consumer consent, protecting pregnant people and their health information - as it should have been all along.

Thank you for your time and consideration in evaluating this important bill.

HB-1566

Submitted on: 2/3/2024 6:29:51 AM

Testimony for JHA on 2/6/2024 2:00:00 PM

Submitted By	Organization	Testifier Position	Testify
Younghee Overly	Individual	Support	Written Testimony Only

Comments:

Mahalo for hearing HB1566 which would protect individuals' health data. Everyone should be able to access the healthcare they need without their personal health information being collected and shared without their permission nor knowledge. States like Hawaii that protect abortion and gender affirming care access will now play an even more critical role in providing care to people from states that criminalize abortion and gender affirming care. Please pass this measure.

HB-1566

Submitted on: 2/3/2024 9:10:07 AM

Testimony for JHA on 2/6/2024 2:00:00 PM

Submitted By	Organization	Testifier Position	Testify
Doris Segal Matsunaga	Individual	Support	Written Testimony Only

Comments:

I support HB 1566 to assist with health care privacy and access on Neighbor Islands from Waimea, Hawaii Island.

HB-1566

Submitted on: 2/3/2024 11:46:37 AM

Testimony for JHA on 2/6/2024 2:00:00 PM

Submitted By	Organization	Testifier Position	Testify
Deb Nehmad	Individual	Support	Written Testimony Only

Comments:

Everyone should be able to access the health care they need without their personal health information being collected and shared without their permission or knowledge. States like Hawaii that protect abortion and gender affirming care access will now play an even more critical role in providing care to people from states that criminalize abortion and jeopardize access to needed health care services. Providing privacy protections is a crucial step to safeguarding health care access.

HB 1566/SB 2696 Protects personal, private health information not already protected by HIPAA, such as geolocation data and other private information captured by popular health apps.

Please support

Deborah Nehmad

Hawaii Kai

HB-1566

Submitted on: 2/3/2024 2:12:56 PM

Testimony for JHA on 2/6/2024 2:00:00 PM

Submitted By	Organization	Testifier Position	Testify
Elizabeth Bush, APRN	Individual	Support	Written Testimony Only

Comments:

Please protect what little remains of medical privacy.

Elizabeth Bush, MSN, APRN, CARN-AP, CSAC, CCDP-D
Board Certified Psychiatric Advanced Practice Nurse (NP and CNS)
Certified Addiction Registered Nurse, Advanced Practice
Certified Substance Abuse Counselor
Certified Co-Occurring Disorder Professional-Diplomate (retired)

February 4, 2024

Aloha Representative Tarnas, Representative Belatti, and members of the Committee on Judiciary & Hawaiian Affairs and the Committee on Health & Homelessness,

My name is Abigail Naaykens and I reside in Kapa‘a on Kaua‘i. I write to you as an advocate for victims of violence and a full-time grad student at the University of Hawai‘i Myron B. Thompson School of Social Work. As a student, an advocate, and a person with a uterus, I **testify my support for House Bill 1566 relating to consumer health data.**

Since the overturn of Roe V. Wade, approximately 22 million people with biological child-bearing ability live in U.S. states where abortion is either heavily restricted or completely inaccessible ([Human Rights Watch, 2023](#)). As medication and procedural abortion access continues to be threatened in many Continental U.S. states, vulnerable populations may seek out care in places like Hawai‘i that have robust legal protections for abortion care. However, unrestricted use of consumer data can lead to the criminalization of individuals seeking or providing abortion care in Hawai‘i, highlighting the need to restrict the use of consumer data.

Additionally, Hawai‘i’s own residents may be at risk of unethical use of their data. In victim advocacy, we see how reproductive coercion can be inextricably intertwined with interpersonal violence ([National Network to End Domestic Violence, 2022](#)). Women victims of domestic violence, young victims of interfamilial child sexual abuse, and gender minority victims of hate-based sexual assault are just a few examples of populations that are susceptible to coercive control.

Although abortion is a legal medical practice in Hawai‘i, crisis pregnancy centers in Hawai‘i pose a threat for the spread of scientifically inaccurate misinformation. Given the chance to steal consumer data, these centers can coerce victims into making decisions based on faulty evidence, effectively perpetuating the cycle of violence and robbing them of their autonomy.

HB1566 is crucial for protecting both residents from other states who seek abortion care in Hawai‘i, abortion providers in Hawai‘i, and Hawai‘i residents who have a legal right to make informed decisions on their bodies. I am confident that this bill will provide the protections needed to best serve Hawai‘i residents and visitors alike.

I extend my heartfelt mahalo to the Committee on Judiciary & Hawaiian Affairs and the Committee on Health & Homelessness for considering my testimony.

Sincerely,



Abigail Naaykens

HB-1566

Submitted on: 2/5/2024 12:12:13 PM

Testimony for JHA on 2/6/2024 2:00:00 PM

Submitted By	Organization	Testifier Position	Testify
Natalie Kahn	Individual	Support	Written Testimony Only

Comments:

Everyone should have a right to privacy, especially when it comes to their health.

HB-1566

Submitted on: 2/5/2024 12:20:34 PM

Testimony for JHA on 2/6/2024 2:00:00 PM

Submitted By	Organization	Testifier Position	Testify
Shandhini Raidoo	Individual	Support	Written Testimony Only

Comments:

Aloha,

I am an obstetrician-gynecologist and I strongly support this bill. Protecting the privacy and confidentiality of people seeking healthcare, particularly healthcare services that are highly stigmatized such as abortion or gender-affirming care, is extremely important as consumer data is easily accessed and manipulated in ways that can endanger people's safety.

Mahalo,

Shandhini Raidoo, MD, MPH

HB-1566

Submitted on: 2/5/2024 12:57:12 PM

Testimony for JHA on 2/6/2024 2:00:00 PM

Submitted By	Organization	Testifier Position	Testify
Bo Breda	Individual	Support	Written Testimony Only

Comments:

HB 1566 will put in place those health data protections by doing the following:

- Making it illegal to sell health data without affirmative consent
- Preventing apps and websites from collecting and sharing health data without users' consent
- Banning location-based data collection and advertising at health care facilities

HB-1566

Submitted on: 2/5/2024 12:55:36 PM

Testimony for JHA on 2/6/2024 2:00:00 PM

Submitted By	Organization	Testifier Position	Testify
Peter Wilson	Individual	Support	Written Testimony Only

Comments:

HB 1566 will put in place those health data protections by doing the following:

- Making it illegal to sell health data without affirmative consent
- Preventing apps and websites from collecting and sharing health data without users' consent
- Banning location-based data collection and advertising at health care facilities

I fully support this legislation.

HB-1566

Submitted on: 2/5/2024 2:16:59 PM

Testimony for JHA on 2/6/2024 2:00:00 PM

Submitted By	Organization	Testifier Position	Testify
Kathy Kosec	Individual	Support	Written Testimony Only

Comments:

Please approve this bill that protects the privacy of all health information. Women need to have the option to keep ALL of their health information private AND protected.

Kathy Kosec, Hawaii resident and retired RN.

HB-1566

Submitted on: 2/5/2024 4:47:03 PM

Testimony for JHA on 2/6/2024 2:00:00 PM

Submitted By	Organization	Testifier Position	Testify
Jeanne Ohta	Individual	Support	Written Testimony Only

Comments:

I am writing in support of HB1566 which would protect individuals' health data. Everyone should be able to access needed healthcare without their personal health information being collected and shared without their permission or knowledge. This measure would prevent apps and websites from collecting and sharing health data without users' consent and would ban location-based data collection and advertising at health care facilities. Banning geofencing is critical in preventing unwanted text messages just because an individual sought care at a clinic or health facility. I respectfully ask that the committee pass HB 1566. Thank you for this opportunity to provide my support of HB 1566.

HB-1566

Submitted on: 2/5/2024 5:46:04 PM

Testimony for JHA on 2/6/2024 2:00:00 PM

Submitted By	Organization	Testifier Position	Testify
Amanda Waltz	Individual	Support	Written Testimony Only

Comments:

No one should be able to share or collect my health information or geolocation data without first getting my active consent, on a case by case basis. This law is important for protecting personal privacy.

HB-1566

Submitted on: 2/5/2024 9:12:30 PM

Testimony for JHA on 2/6/2024 2:00:00 PM

Submitted By	Organization	Testifier Position	Testify
Linda C. Middleton	Individual	Support	Written Testimony Only

Comments:

People needing health care should be able to get it without having their personal health information documented and shared without their knowing of, or agreeing to, such sensitive disclosure. In states like Hawai'i that protect abortion and gender affirming care, privacy of access is now an even more critical aspect of obtaining needed care for people who live in the islands, and those from states that criminalize abortion and complicate or forbid its access. This is also true of gender affirming care.

HB 1566/SB 2696 Protects private health information not already protected by HIPAA, including geolocation data and other private information captured by popular health apps such as period tracking apps that collect sensitive health data and could be used to prosecute people seeking abortion care in Hawai'i from states with restrictions and bans. Two examples of what can happen without the protection of HB1566 follow:

- In 2021, *Flo Health*, one of the most popular period tracking apps shared health information on its 100 million users with third-party data analytics firms.**
- Geolocation data can identify personal cell phones, and mobile devices can be used to prosecute out of state patients.**

HB 1566 shields the privacy of individuals accessing vital and protected health care by prohibiting use of this data. I support its passage as consistent with Hawai'i's existing legalization of abortion and its allowance of gender affirming care.