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Senate Committee on Economic Development, Housing, and General Affairs  
State House  
Montpelier, Vermont

Subject: H.639, genetic data privacy, as passed by the House

Dear Committee:

It has been a few sessions since I have testified on personal information and data privacy. I became involved on this topic with the first data broker bill in 2018. My concern at first was that the bill favored data brokers to the detriment of members of the public. By the time the data broker bill came over here to your committee, my concern had spread to the disparate treatment of data elements in the various subchapters of chapter 62 and how the new entity handling personal information (data brokers) would integrate into the universe of regulated entities. Some progress was made then and later to integrate the new with the existing: definitions, groupings of data elements, and regulated entities. There is still work to do.

Unfortunately, H.639 moves in the opposite direction. H.639 separates. It does not integrate the new with the existing. It separates the new by creating a new chapter on data privacy and new definitions of existing data elements.

**Say it once, not twice**

I am a civil engineer with experience in writing and understanding contracts and regulations. One of the lessons taught in preparing contracts is "do not write the same thing twice". If you write it twice and it is not exactly the same in each location, then it must mean something different in each location. That difference leads to confusion and potential conflicts on the job. In H.639 and even within chapter 62, say it twice is too common.

Chapter 62 regulates use and control of personal data elements by multiple entities. Each entity is regulated differently. The categories of regulated entities are: data broker (2430(4)); data collector (2430(6)); business (for protection of social security numbers, 2430(2)); operator (student privacy, 2443(2)); business (for destruction of documents containing personal information, 2445(a)(1)); and covered business (for age-appropriate design, 2449a(10)).

Any entity might be regulated by more than one category. An entity that is a data collector deals only with elements of personally identifiable information. That entity might also deal with brokered personal information, making it also a data broker. Unique biometric data is an element in both personally identifiable information and brokered personal information. Thus it is essential for unique biometric data to be defined identically, so the regulated entity doesn't have to figure out which definition applies to it as a data collector and which applies as a data broker.

H.211 addresses some problems learned from experience since the original data broker bill. H.211 has also been referred to your committee, I believe. I refer to H.211 because it proposes to change the definitions of some terms used by H.639 and in chapter 62.

The definition of "biometric data" is an illustrative example of the problems with defining the same phrase in different locations. Three definitions and no two are the same. Will these differences in definition make a difference in this case? Maybe, maybe not. However, the point is that changes creep in when defining the same term in multiple locations.

Current in chapter 62 Used only in subchapter 6 Vermont Age-Appropriate Design Code Act	Proposed by H.639 in chapter 61A	Proposed by H.211 in chapter 62 Will be used by all of chapter 62, apparently while leaving the definition in subchapter 6
<p>(5)(A) “Biometric data” means data generated from the technological processing of <b>an individual’s</b> unique biological, physical, or physiological characteristics <b>that allow or confirm the unique identification of the consumer</b>, including:</p> <ul style="list-style-type: none"> <li>(i) iris or retina scans;</li> <li>(ii) fingerprints;</li> <li>(iii) facial or hand mapping, geometry, or templates;</li> <li>(iv) vein patterns;</li> <li>(v) voice prints <b>or vocal biomarkers</b>; and</li> <li>(vi) gait or personally identifying physical movement or patterns.</li> </ul> <p>(B) “Biometric data” does not include:</p> <ul style="list-style-type: none"> <li>(i) a digital or physical photograph;</li> <li>(ii) an audio or video recording; or</li> <li>(iii) any data generated from a digital or physical photograph, or an audio or video recording, unless such data is generated to identify a specific individual.</li> </ul>	<p>(3)(A) “Biometric data” means data generated from the technological processing of <b>a consumer’s</b> unique biological, physical, or physiological characteristics <b>that allow or confirm the unique identification of the consumer</b>, including:</p> <ul style="list-style-type: none"> <li>(i) iris or retina scans;</li> <li>(ii) fingerprints;</li> <li>(iii) facial or hand mapping, geometry, or templates;</li> <li>(iv) vein patterns;</li> <li>(v) voice prints <b>or vocal biomarkers</b>; and</li> <li>(vi) gait or personally identifying physical movement or patterns.</li> </ul> <p>(B) “Biometric data” does not include:</p> <ul style="list-style-type: none"> <li>(i) a digital or physical photograph;</li> <li>(ii) an audio or video recording; or</li> <li>(iii) any data generated from a digital or physical photograph, or an audio or video recording, unless such data is generated to identify a specific consumer.</li> </ul>	<p>(2)(A) “Biometric data” means <b>that</b> data generated from the technological processing of <b>an individual’s</b> unique biological, physical, or physiological characteristics <b>can be used to identify an individual</b>, including:</p> <ul style="list-style-type: none"> <li>(i) iris or retina scans;</li> <li>(ii) fingerprints;</li> <li>(iii) facial or hand mapping, geometry, or templates;</li> <li>(iv) vein patterns;</li> <li>(v) voice prints; and</li> <li>(vi) gait or personally identifying physical movement or patterns.</li> </ul> <p>(B) “Biometric data” does not include:</p> <ul style="list-style-type: none"> <li>(i) a digital or physical photograph</li> <li>(ii) an audio or video recording; or</li> <li>(iii) any data generated from a digital or physical photograph, or an audio or video recording, unless such data is generated to identify a specific individual.</li> </ul>

The same thing happens more significantly with the definition of "Genetic data". When a data collector acquires genetic data, the definition of genetic data governing reporting requirements for a data breach in chapter 62 is different than for protecting privacy under H.639 I don't see that there should be a difference. Placing H.639 into a new subchapter in chapter 62, with a common set of definitions applying to all of chapter 62, will alleviate that confusion. This is why I urge you to place H.639 into a new subchapter of chapter 62.

Current in chapter 62 Used only in subchapter 6 Vermont Age-Appropriate Design Code Act	Proposed by H.639 in chapter 61A
<p>(16) “Genetic data” means any data, regardless of its format, that results from the analysis of a biological sample of an individual, or from another source enabling equivalent information to be obtained, and concerns genetic material, <b>including</b> deoxyribonucleic acids (DNA), ribonucleic acids (RNA), genes, chromosomes, alleles, genomes, alterations or modifications to DNA or RNA, single nucleotide polymorphisms (SNPs), epigenetic markers, uninterpreted data that results from analysis of the biological sample or other source, and any information extrapolated, derived, or inferred therefrom.</p>	<p>(9)(A) “Genetic data” means any data, regardless of its format, that results from the analysis of a biological sample from a consumer, or from another element enabling equivalent information to be obtained, and concerns genetic material. <b>Genetic material includes</b> deoxyribonucleic acids (DNA), ribonucleic acids (RNA), genes, chromosomes, alleles, genomes, alterations or modifications to DNA or RNA, single nucleotide polymorphisms (SNPs), uninterpreted data that results from the analysis of the biological sample, and any information extrapolated, derived, or inferred therefrom.</p> <p><b>(B) “Genetic data” does not include deidentified data . . .</b></p> <p><b>(C) “Genetic data” does not include . . . [data or samples used for research] . . .</b></p> <p>(B) and (C) together take 1 1/2 pages.</p>

Under H.639, one of the exclusions of the definition is deidentified data. So it appears that a direct-to-consumer genetic testing company can transfer deidentified data to another entity without consent of the individual. I fail to see why deidentified data are not genetic data in one set of circumstances and are genetic data in a separate set of circumstances.

Recommendations:

- Place the content of H.639 into a new subchapter in chapter 62. Place all the definitions in H.639 (or at least the definitions of terms already used in chapter 62) into the main definitions section (2430) of chapter 62. And resolve any differences between definitions of the same term in chapter 62 and H.639, considering how they will affect use of those terms in all of chapter 62.
- Change the term "genetic information" in the definition of personally identifiable information to "genetic data" (9 V.S.A. §2430 (10)(A)(vi)).

**Privacy notices and clear language**

H.639 requires that certain information be clear or in plain language. What does this really mean?

I understand plain language from insurance policies. That use of plain language seems to work OK.

Privacy statements are another issue. Even the few written in plain language are opaque. A paraphrase of my bank's privacy policy is that it shares my personal information only to trusted parties or affiliates. That's plain enough. The opacity is that the bank does not identify the trusted parties by name. It does not state what data are provided to each trusted party. [NOTE: I use data as a plural collective noun, thus "data are".] It does not state what each trusted party does with the data. Thus I can not understand what the privacy policy really does.

My questions are then:

- What will a clear, meaningful, and prominent notice look like? (p. 3/9)
- What will clear and complete information regarding the company's policies and procedures look like? (p. 7/14)
- What will a privacy policy written in plain language look like? What will it contain? (p. 7/18)

Recommendation: Provide additional information on what is needed in those notices, information, and policies in order to achieve the requirements of clear and plain.

I have provided recommendations in each of the two sections of these comments. I ask that you find that these recommendations have merit and that you incorporate them into H.639.

Sincerely,  
Thomas Weiss