



Letter in Support of SB 703

February 18, 2019

Dear Chairman Prozanski and Members of the Oregon Legislature:

WEGO Health is pleased to support SB 703, which provides needed updates to the privacy provisions of HIPAA by making it explicit that an individual's personal health data ought to be considered personal property, subject to the same protections afforded other personal property owned by the citizens of Oregon.

WEGO Health exists to support engaged and empowered health consumers who are passionate advocates of a consumer-driven and patient-centered healthcare system. Our network includes more than 100,000 patient advocates across hundreds of chronic, complex and rare diseases. A critical and growing area of concern for our members is their ability to control who within the healthcare system has access to their personal health data, how that data is used and who profits from their data.

Patients like those in our network, who interact with the healthcare system frequently and who have therefore amassed a significant amount of personal health information (PHI), have benefited greatly from the privacy guidelines promulgated by the Healthcare Insurance Portability and Accountability Act (HIPAA). However, in recent years, it has become clear that HIPAA alone is not sufficient to offset the combined power of algorithms and data mining to identify individuals using anonymized data. In short, the lawmakers who had the wisdom to pass this legislation could not readily foresee how quickly its utility would be eclipsed by new technologies in the hands of data brokers who purchase personal health data from a broad cross section of healthcare providers and insurers.

Recent surveys by our company and others clearly show that healthcare consumers are increasingly alarmed by revelations of the size and scope of this issue. The majority are adamant that no company should have the right to profit from their health data without their expressed consent. The majority believe that they alone should own their data. They also believe they alone should be afforded the right to determine with whom their data are shared and on what terms.

For many individuals in our network who cope with complex health conditions, research into new cures and treatments is literally a matter of life and death. For them and countless others, a law like SB 703 makes it possible, for the first time, to build relationships with research foundations and other entities that are based on transparency and trust. Relationships that can open up new pathways for research and new hope for medical breakthroughs within their lifetime.

For these reasons, and many others that will come to light as debate on this bill unfolds, WEGO Health strongly encourages the Oregon legislature to vote yes on Senate Bill 703.

Jack Barrette  
Founder and Chief Executive Officer