

## Bonhomme, Penny

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**From:** Susan Israel [REDACTED]  
**Sent:** Wednesday, March 07, 2012 7:50 AM  
**To:** PHC Testimony  
**Subject:** Governor's Bill 5038

Public Testimony to the Committee on Public Health on Governor's Bill No. 5038, March 7, 2012

I appreciate this opportunity to express my views on 5038. I would wish that it not be enacted until regulations and technologies are put in place that would assure patient privacy and control over their medical records.

This may sound extreme, but as I see it, Bill 5038 and others like it, providing for large data bases, are functioning as global search warrants, seizing our medical records without our consent with the assumption that privacy will be maintained. Unfortunately, the public thinks that HIPAA protects them, when in fact, it basically says that hundreds of people can see their records without their consent, as long as they sign privacy agreements. Current governments have the best of intentions for patient care, but we need to make sure that 5038 does not provide a mechanism that would enable future governments and private companies to misuse the data against us, without us even knowing about it.

Dr. Deborah Peel, the founder of the national organization Patient Privacy Rights, said recently (1/ 23/12) in the *Wall Street Journal*, that we need to "implement existing technologies to allow patients to set default rules to govern data exchanges electronically... Consent rules can be changed instantly online, and sensitive information can be selectively withheld at the patient's discretion... Decentralized systems with smaller data sets protect privacy because if any account is broken into, only some information is compromised." And technologies should be implemented to enable patients themselves to track who sees their records.

I will give you some examples of the problems. The HITE-CT (Health Information Exchange) that is now being established defines the unauthorized release of data as a breach, only if it is decided by the processors to be *significant* enough to even notify to the patient. In 5038, how will patients know who will have access to their records, and whether it is the federal government or the private companies that they can sue if there is a breach?

To be more specific, the federal regulations, defining what constitutes the de-identification of patient data, are just not adequate enough to stop the re-identification of the data. The same is true with the proposed use of UPIs, unique patient identifiers, in 5038. There is nothing to stop someone from finding the identity of the patient by cross referencing all the data bases available.

To further quote Dr. Peel, "UPIs would encourage the government and corporations to build massive, centralized databases of health information, rich targets for data theft and abuse. UPIs would become a de facto universal identification system far more harmful than Social Security numbers, enabling millions of government and corporate workers to snoop into

anyone's medical records," ... Claims that UPIs will be kept separate from personal and financial IDs are wishful thinking. All health records have financial records attached," making it easy to re-identify data.

Thank you very much for this opportunity.

Susan Israel, MD

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**From:** Susan Israel [REDACTED]  
**Sent:** Sunday, March 25, 2012 5:31 PM  
**To:** PHC Testimony  
**Subject:** Additoinal Testimony on HB 5038

To the Committee on Public Health

Additional Testimony on HB 5038

March 26, 2012

Submitted by Susan Israel, MD

Is there a contraction between what HB 5038 states and the Commissioner of Public Health's Testimony on 5038? HB 5038, about the All-Payer Claims Database, seems to call for the patient data to be de-identified or transmitted with a unique patient identifier. However, the Commissioner's testimony in support of HB 5038, calls for using the APCD to track patients and combine the APCD data with that taken from hospital discharge data, that is apparently sent to the DPH/OHCA in an *identified* form, as per HB 6652, PA 11-61, Sec. 143 (b). So does Dr. Mullen expect to get the data from the APCD in a de-identified or an identified form? Or will it be de-identified to everyone except the DPH/OHCA? Is the Committee on Public Health comfortable with so much of our medical data going to the DPH without our consent as delineated in her testimony on 5038?

As explained in my previous testimony of March 7, neither the current federal provisions for the de-identification of data, nor the unique patient identifier called for in HB 5038 will assure privacy.

I also would like to make another point about how serious is this issue of patient privacy and right of control over who sees their data. The Health Information Technology Exchange (HITE-CT) will have its patient records available to any provider in the country. I have not yet doubled checked this, but I was told the Epic technology system, that Yale New Haven Hospital plans to use for its patient records, will enable those patient records to be accessed by any provider in the country who is also part of the Epic system. For the HITE-CT and Epic System, we will all be depending on whether or not the audit system catches that person that is not connected with our care.

Thank you very much for this opportunity to express my views.

Susan Israel, MD