

Bonhomme, Penny

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To: PHC Testimony
Subject: HB 5514 resubmission

To the Committee on Public Health

March 21, 2012

Testimony on H.B. 5514, Sec. 5, Subsection (b)

Submitted by Susan Israel, MD

I am Susan Israel, a physician. It is my hope that Sec. 5, Subsection (b) of HB 5514 will specifically state that only *unidentifiable* patient data, as it is being taken without consent, will be sent to the Dept. of Public Health, by the hospitals, labs and providers, and that no DNA testing be done on the tissue without patient consent. And only aggregated data be released to the public, to further protect patient privacy.

Subsection (b) mandates that tissue of tumors may be sent to the DPH, along with demographic and treatment information, and the "Commissioner of Public Health shall promulgate a list of required data items." So the Commissioner has open ended authority to delve into your medical record without your consent. It seems that the intention must be to have the name of the patients, as per the testimony of the Commissioner of Public Health on HB 5038, the All-Payer Claims Database, CT Tumor Registry (CTR). And to quote: "The CTR conducts follow-up on all cancer patients for vital status. The CTR uses data sources such as *driver's license* renewal date or hospital discharge date and ... status to ascertain that a patient was alive at a certain date. An all-payer claims database, extending to *outpatient care and prescriptions*, would improve the completeness of the follow-up...". So this seems to mean that the CTR will receive our cancer information and our hospital information *with* our identities attached.

So let's say a woman has cervical cancer. The state may wish to know her history of sexually transmitted infections because HPV may cause cervical cancer. But please let us have laws that would avoid a patient having an invasive tumor and an invasive state.

Thank you very much for this opportunity.