

**Illinois Health Information Exchange Authority  
Patient Health Data Privacy & Security Policies  
July 17, 2012**

**Written Testimony of Pamela A. Sutherland  
Vice President of Public Policy  
Planned Parenthood of Illinois**

I am Pamela Sutherland, Vice President of Public Policy of Planned Parenthood of Illinois (PPIL). PPIL provides reproductive health care services at seventeen health centers throughout Illinois. Last year we provided 163,261 patient visits. Because of the sensitive nature of many of the health care services we provide, we welcome the opportunity to comment on policies related to data privacy and security for the Illinois Health Information Exchange.

Panel 1: Patient Choice: Options and Permitted Uses for patient Data

Patients need to feel empowered when it comes to accessing health care. If they are denied choices when it comes to controlling their health information, their relationships with medical staff can be diminished. In certain circumstances involving deeply private and personal issues, patients may avoid seeking care if they fear they cannot control who has access to sensitive information as well as how they have access to it. Therefore, patients should be given a choice whether their electronic patient data is transmitted through an HIE. Moreover, they should be afforded choices when it comes to the use of data by clinical treatment professionals. To make it easiest for both patient and provider, the option of opting out (affirmatively declining) of participation in the HIE must be afforded to all patients.

Panel 2: Granularity of Patient Data

On occasion, some patients have met with judgment and even outright disapproval from health care professionals when they have revealed drug use, unconventional sexual behavior, or having had an abortion. These patients have often felt that the treatment they received would have been different and possibly of a higher quality if certain information were not revealed to the provider. Therefore, while we understand that it is best when a provider has all of the information, there may be times when a patient does not want certain health information released. Therefore, patients should have the right to sequester specific elements of their patient record from all or certain providers. In addition, the patient can be given the option of sequestering certain health information or allowing the entire medical record to be accessed in the case of emergency treatment. The decision to sequester certain information must not exclude the patient from participation in the HIE because the benefit of having quick electronic access to most of a patient's record is better than have no access at all. Finally, a patient's data should only be available to medical professionals providing health care to that patient. The patient data should not be open to access by public health authorities. Opening the HIE to access by public health authorities would foster mistrust and unease in many patients.

### Panel 3: Sensitivity of Patient Data: Safeguards for Certain Personal Health Information

As stated above, patients often have to reveal highly personal and private information when receiving medical care. The purpose of having special consent procedures for certain health services is to ensure a heightened security for that information and to assure patients that they are “safe” in revealing sensitive information to health care professionals. If patients do not feel “safe” some of them will decline health care putting themselves and possibly others at risk. Therefore, special opt out procedures should be extended to the inclusion of personal health information related to services such as behavioral health and substance abuse. When these health services are involved, the patient should be given the opportunity to opt out of entering that health information into the HIE or sequestering it from certain providers.

Another issue which is pertinent here is the issue of minors who consent to health care services. In Illinois, minors are guaranteed confidential care without parental consent for certain health services. These services include mental health, substance abuse, testing and treatment for sexually transmitted infections, family planning services, abortion, and pregnancy care. One of the main reasons that the law allows for minors to receive these kinds of health care without parental involvement is because there is a risk that some minors will forgo care and put themselves and possibly others at risk if parents are involved. Because minors are allowed to give consent for certain confidential health services but not all health services, the HIE must have a system set up to allow minor patients to sequester certain personal health information from both specific providers and from their parents or guardians. The minor must be able to sequester information from providers who they do not trust to keep such information confidential. For example, a teen might be concerned that a primary care physician may intentionally or even inadvertently reveal information about birth control use to a parent. Moreover, if the HIE allows parents to access the confidential personal health information of a minor, it would be in violation of numerous Illinois laws which guarantee confidentiality for certain health services.

### Panel 5: Patient Choice and Consent: Operational Protocols

We suggest that a good way to inform patients of the risks and benefits of the HIE is provide an informational brochure or pamphlet to patients when they are given the option to completely opt out or sequester data and each time they consent to care for sensitive issues such as substance abuse. The brochure should be easily understandable to someone at a sixth grade reading level. The brochure should include an explanation of a minor’s right to privacy for certain types of health care. Providers should designate a staff person who can provide additional explanation if a patient has questions. This person does not have to be the health professional that is directly providing care. Consent can be provided orally as this information sharing is similar to when patients are orally asked if test results or reports should be sent to primary care providers. Consent to participation in the HIE should continue until a patient revokes the consent. It does not need to be renewed.

### Panel 6: Patient Choice: Current and Future Technologies

Patients should be given a unique identifier. They should also have access to their own medical records. If they believe there is an inaccuracy, they should not be allowed to unilaterally change the data. Instead, a system should be in place for the patient to contact the provider to correct the data. This will ensure that if a patient does not understand a particular test or report, they will not change something they do not understand.

### Panel 7: Protecting Patient Data: Security Compliance Standards for Health Information Exchanges

As stated above, patients should be assured the utmost privacy and security, particularly when it comes to sensitive health information and minors' access to confidential care. Access to data stored in the HIE should be limited to patients and the health care professionals providing them with health care. If personal patient information is accessible to public health authorities, governmental bodies, or others, patients will not have confidence in the security and privacy of the HIE. Security and privacy standards should be consistent across all HIEs in Illinois to ensure that all patients are provided the same standards and to avoid patient confusion. In order for the HIE to be successful, patients must be willing to participate. If patients do feel that the system is secure and the information they want to be private will be kept private, they will not participate.

Thank you for the opportunity to provide comments on behalf of Planned Parenthood of Illinois. If you have any questions or need additional information, please feel free to contact me:

Pamela A. Sutherland  
Vice President of Public Policy  
Planned Parenthood of Illinois  
1000 East Washington Street  
Springfield, IL 62703  
217-522-6776 ext. 6001  
pams@ppil.org