



Testimony of

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AMERICAN COLLEGE OF OBSTETRICIANS AND GYNECOLOGISTS

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Subcommittee on Privacy and Confidentiality

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Thank you for inviting testimony from the American College of Obstetricians and Gynecologists (ACOG), representing our 51,000 physicians and partners in women's health, on individuals' rights to control the content of and access to their health records on the Nationwide Health Information Network (NHIN).

This subject is of serious and growing importance as medical information moves from paper charts to electronic record systems and raises many technical questions about the ability to protect the sensitive records of millions of Americans and ethical dilemmas involving patient autonomy. Given the importance of these issues and the preliminary development of the NHIN architecture, ACOG has not yet fully settled on answers to the questions posed by Recommendations 6 & 7, but we hope to offer constructive comments as this Subcommittee and others navigate through these difficult issues. We will continue to monitor this as the NHIN takes shape and as we learn lessons from other early adopters of health information technology.

General Concerns Regarding Health Information Technology

The United States health system is at a crossroads in the development of health information technology (HIT). Movement from paper to electronic health records has the potential to improve patient safety, to increase efficiency in services delivered by minimizing duplication between providers, and to reduce paperwork in medical offices. The need for electronic health records is exacerbated by the staggering fragmentation of the health care system. Americans utilize an increasing number of screenings, tests, and procedures from multiple health care providers, but care provided in each health care setting is often siloed, inhibiting care coordination.

Despite some obvious advantages, many physicians are unwilling or unable to invest in HIT. Practices transitioning to an HIT system often encounter months of reduced productivity as physicians and staff face a steep learning curve in adjusting to the new office workflow. Once a practice completes the transition, HIT acquisition rarely translates into an increased number of patients or increased revenue. Most private insurers, Medicare and Medicaid fail to offer financial incentives for the adoption of information technology. Given up-front and ongoing costs of HIT adoption, uncertainty about interoperability and little financial incentive, many offices have difficulty making the business case for investing in HIT.

Partly as a result, the United States has not yet achieved the tipping point in the adoption of electronic health records. The establishment of the NHIN, and the promise of secure, seamless transfer of information between connected providers, could offer one more incentive to make this investment.

ACOG holds patient privacy and the confidentiality of a patient's medical records in very high regard and respects the fundamental right of an individual patient to make her own choices about her health care. As such, we believe the protection of a patient's health information is of paramount importance. The vast scale of the proposed NHIN multiplies the potential for misuse of information. While the architecture of the NHIN is still under development, it is difficult to know if adequate patient protection can be achieved.

Previous Work of the Subcommittee

ACOG supports the prior recommendation of the Subcommittee to allow health care providers to continue to store information according to a method of their choice (R-1). Patients rarely, if ever, are given the option of opting out of electronic recordkeeping. Giving patients that option would lead to costly administrative complications for practices and diminishes the value of the record system. On the whole, patients like seeing their physicians use modern technology to track their health information and many practices believe it puts them at a competitive advantage in their area.

Patient approval of electronic recordkeeping within the confines of a physician's office should not necessarily imply that patients would be as agreeable to other information-sharing, such as availability of information through the NHIN. Accordingly, ACOG also strongly supports the NCVHS recommendations that individuals should have a choice about whether to participate in the NHIN (R-2) and that providers should not be able to condition treatment on an individual's agreement to have his or her health records accessible via the NHIN (R-3). Given the reasonable privacy and data security concerns inherent in such a new system, it is understandable that not everyone will choose to participate. Recommending immediate mandatory participation would surely hurt public support for such a project. Keeping participation in the NHIN voluntary also will minimize any public health concerns regarding patients' refusal to seek treatment for a condition because of fear that records will become public.

ACOG supports the ongoing evaluation of opt-in and opt-out approaches to consent to participate in the system (R-4), given the concerns that may be raised by the public and providers and the glitches that will inevitably occur with NHIN's initial implementation. Regardless of the method of consent, HHS should ensure that patients are presented with clear, understandable and

unbiased information to ensure that patients understand the implications of their decisions on participation in the NHIN (R-5).

Individual Control of Information

The degree to which patients can have control over the information in their records that is accessible by the NHIN is central to the operation and usefulness of the system. Patients have both rights and responsibilities regarding the sharing of their health information, and both have implications for the NHIN. Although we outline these in the following sections, it is difficult to express opinions with certainty without a firmer grasp of the architecture of the NHIN, an assessment of the feasibility of hiding certain elements of patient records, and the overall security of such a large system.

The Value of a Complete Health Record

One of the prime advantages of the NHIN is the ability to have a complete health record that all treating physicians can access. Currently, health records are often limited to a single practice in a single specialty, providing only a slice of a patient's medical history and potentially missing information from other treating physicians that may be relevant to the diagnostic or treatment process (e.g., medication allergies, noting when a particular therapy failed.)

In lieu of shared medical data, the physician relies on the recollection of each patient, which is known to be less than exact. While patients have an ethical obligation to provide accurate information about their lifestyle, health habits, sexual practices, and religious and cultural beliefs when these may affect medical judgment, this disclosure is sometimes incomplete, often from unintentional omissions. A patient may be uncertain about the name or dosage of a medication, fail to remember the date of a particular screening exam, or not have information regarding the results of lab tests done by another physician. The value of the NHIN would be in its ability to fill these holes. This is particularly relevant for patients who have inconsistent contact with health care providers. For instance, a patient who frequently cycles between Medicaid and being uninsured will likely see multiple providers in various settings – physician offices, community clinics, the emergency department, etc. Since, statistically, Medicaid and uninsured patients have greater instances of chronic diseases, these patients may most benefit from sharing medical information, while today, they are least likely to have complete and accurate medical records. The potential consequences of incomplete information are duplication in testing, delays in diagnosis, less accuracy in diagnosis and less effective—or even harmful—treatment.

In other cases, a patient may intentionally hide information from her physician. A recent study by Dr. Nancy Jasper, an assistant clinical professor of obstetrics and gynecology at Columbia University's College of Physicians and Surgeons, found that more than half of women admitted to having told their physician a "little, white lie." The majority (64%) said they did this because they didn't want a lecture and 38% said they did not want to be judged. A common example is whether a patient smokes and how much. Patients not wanting to be counseled on tobacco use may not disclose that they smoke, but it's an important consideration in the prescription of hormonal contraception.

Of course, the most serious omissions are not the little white lies, but serious medical events that carry stigma or embarrassment. Medical care can be compromised if physicians are unaware of

a patient's alcohol or drug abuse and miss related diagnoses or medication interactions with alcohol or illegal substances. If the problem is not identified, major health risks, such as human immunodeficiency virus (HIV) exposure and depression, may also be missed. Pregnant women who abuse substances may not share this information out of fear of losing custody of their other children if their substance use became known.

Respect for Personal Privacy

While there are compelling reasons to maintain a complete medical record, respect for patients' rights to make their own health decisions and respect for their privacy offer equally compelling reasons to develop a system that stratifies access. Many patients make health decisions based on privacy concerns. Patients may undergo anonymous HIV testing or confidential testing for other sexually transmitted diseases (STDs) in order to keep this information out of their medical records. Other patients seek out a different care provider for a particular service, before returning to their usual care provider. For instance, an adolescent may access a family planning clinic for a birth control prescription, but return to her regular physician for other care paid for under her parents' health insurance coverage.

It is easy for physicians to imagine cases in which knowing very sensitive personal health information (e.g., pregnancy termination in the distant past, an STD in college) will yield some small clinical benefit, but in many cases, it will not. The patient's burden of disclosure (psychological pain, embarrassment, potential discrimination and retaliation) if information is improperly shared should be balanced against what may amount to a very small likelihood of benefit.

And, while a personal record from the NHIN will be useful, it is in no way a substitute for talking with patients and reviewing key parts of the history, including sensitive parts, with the patient during treatment and care. A record may serve as a tool so detailed, complicated or critical information is shared and studies not unnecessarily duplicated, but it should not be viewed as a tool to keep patients honest.

The concept of the NHIN is predicated on the idea that access will be controlled and that information will be secure. For many patients, physician access to sensitive information is not as threatening as outside (employer, insurer) access to health information. This is especially true in burgeoning fields such as genetics. Genetic information, such as certain mutations of the BRCA1 gene that indicate increased risk of breast cancer, carry significant potential for discrimination from employers or health insurers. Adequate protection of the NHIN should ensure that patient records are accessed for clinical use only.

Navigating the Middle Ground on Patient Control

Individual control of health records could take many different forms. At one end of the continuum, patients may have no control over the content of or access to their record. This may be unacceptable to many patients for the reasons above. At the other extreme, the patient may wish to have the record completely wiped clean of a particular item. ACOG would have strong concerns about the ability of patients to delete information from the record entirely. Under current HIPAA regulations, a patient may correct inaccurate information at its source but cannot demand changes for other reasons. If a patient can completely alter a medically-accurate

underlying record, the integrity of every record would be questioned. Physicians knowing that a seemingly complete record may have areas entirely hidden from view may distrust all NHIN records.

If the patient has the ability to block selected sections, will the physician see what they believe to be a complete record or will they be aware that information has been blocked? If the physician sees that information is blocked, will the clinical area be identified (mental health, for instance)? If the provider believes this information is relevant, will they have the ability to view it with the patient's consent? Any option would have to carefully balance the privacy of the patient and the physician's need to know relevant information. These questions create serious liability implications as well.

Blocking access to selected information gives the patient significant control over her record, but may also have implications for diagnosis and treatment. If a record indicates that some information is blocked, but gives no indication of what kind of information this is, many physicians might probe the patient for this information, not knowing whether it is significant to the current clinical situation or not. For instance, an obstetrician might find many areas relevant to the care of a pregnant patient – any medications a patient is taking or has taken throughout her pregnancy, any prior surgeries, or substance abuse issues. Questioning might foster a positive physician-patient interview as the treating physician asks additional questions and explains why certain information may be relevant to current evaluation or treatment. However, conducting the search might also be frustrating for both parties and, on occasion, may reduce trust between physician and patient. If a treating physician suspects that blocked information may be important to a condition, but it is not voluntarily disclosed by the patient, the physician may not view the patient's answers as fully reliable.

A patient is not always the best judge of what information in her record is important and what is not. Seemingly trivial information might have medical significance. For instance, if a woman has a cat, a physician will want to inform her of the risk of toxoplasmosis if she becomes pregnant. Or a physician might want to know the weight of a patient's baby at birth, since the birth of a baby weighing more than 9 pounds increases the patient's risk for diabetes. While this information can be learned as a part of a comprehensive interview, hiding information only to "rediscover" it later loses an opportunity for efficiency created by the electronic record.

In some cases, embarrassment or fear of judgment could lead a patient to block access to critical information. For example, if a woman is prescribed mifepristone for termination of early pregnancy, this may be information she wants kept private. However, if she comes to the emergency department with severe bleeding or signs of an infection several days later, this information would be critical to her urgent treatment and not revealing it could have tragic consequences.

In another instance, if a woman is treated in the emergency department multiple times for physical injuries consistent with domestic abuse, this information is clearly sensitive and the patient might not want it disclosed. But concealing this information only perpetuates a cycle of violence. And if the patient becomes pregnant, a circumstance that often escalates partner violence, this information might be very relevant to an obstetrician.

Specific Methods of Blocking Information

If portions of the health record can be blocked, serious consideration should be given to who has this ability and what method they may use. Options presented in R-7 would allow segmentation based on the age of information, the nature of the conditions or treatments or the type of providers.

Such segmentation sometimes happens in current electronic recordkeeping in multispecialty groups. Partners HealthCare in Massachusetts limits access to certain parts of its record depending on who is viewing it. For example, records from an abortion provider are not generally available to the primary care physician, but may be available to an ob-gyn or in the emergency department. Other multispecialty groups allow a treating physician to access all information about his or her patients.

A decision for the NHIN to block all information in a certain category or by a certain provider may have the effect of reinforcing the stigma carried by some services or providers. Blocking all reproductive health information in every record may imply that it is by its nature shameful or that this information is unimportant to other medical care.

As the NHIN develops, patients may demand the ability to have maximum control over their records. In a recent survey, a significant factor in patient support of electronic health records is their belief that it will allow them greater access to and control over their own health records. A survey by Accenture, a management consulting and technology firm, found that a majority of patients hoped that electronic health records would allow them to ask more informed questions, review information provided by their physicians, and better understand treatment options.

Although initial analysis suggests that older health records might be candidates for suppression, some older health information is vital to a patient's current health care. For example, immunization records must be retained permanently. When a woman becomes pregnant, it is important to know if she has been vaccinated or is otherwise immune to several infectious diseases, including childhood diseases.

Implications for Health Care Providers

Physicians and other health care providers have obligations to their patients that also would be affected by the NHIN. When patient testing is planned, they must inform patients prospectively about policies regarding use of information and legal requirements. The patient must be told what will be communicated, to whom, and the potential implications of reporting the information. Fulfilling this obligation becomes more complex and difficult in the face of an NHIN that both allows for voluntary participation and allows individuals to have varying rights to access the record. Explaining the ability to access and potentially suppress portions of the record may be particularly challenging for clinics or physician offices treating patient populations with low computer literacy.

Implications on medical liability should also be considered if relevant information is in a record, but not accessible to a treating physician and not divulged by the patient. Will a physician be expected to draw inferences based on the knowledge that some information has been suppressed?

Thank you for allowing ACOG to present views on this important and evolving subject.