American Academy of Pediatrics

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AMERICAN ACADEMY OF PEDIATRICS

Statement for the Record before the House Committee on Small Business Hearing

"Cost versus Confidentiality: The Unforeseen Challenges of Electronic Health Records in Small Specialty Practices."

July 31, 2008

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Thank you very much, Chairwoman Velasquez and Members of the Committee. I am honored to represent the American Academy of Pediatrics before you.

My name is Edward Gotlieb and I am a practicing pediatrician in Stone Mountain, Georgia. I have a strong interest in health information technology as it relates to pediatrics and in adolescent privacy. I have served as an Executive Committee member of the Academy's Council on Clinical Information Technology as well as on the Academy's Committee on Adolescence.

Pediatrician Concerns about Implementing Health Information Technology

Sixty percent of pediatricians practice in small businesses. But we are different from other doctors because the major government program that pays for the health care of children is Medicaid, not Medicare. Medicaid has a major impact on children's care, paying for 40% of births in the United States. More than 30 million children are covered by Medicaid. Medicaid faces fiscal problems, but not because of the children that are covered by the program. While more than 50% of the people covered by Medicaid are children, these children account for only 25% of the cost of the program.

Pediatricians provide the best care that we can for our patients, and many of us are using a variety of tools to improve care. Pediatricians find it very hard to purchase health IT systems on our own. A real factor in our inability to afford these expensive technologies is the payment rates that pediatricians receive under Medicaid. American Academy of Pediatrics' surveys show that payment rates under Medicaid average 69% of Medicare. Let me say that again – the average pediatrician is paid by Medicaid only around 2/3rds of the average payment received by adult doctors from the government for the same service. Thus, the margins under which most pediatric practices operate are much more severe than those of our adult colleagues.

The conclusion that I hope you draw from what I've told you so far is that if incentives for health IT adoption are structured only to flow through the Medicare program, more than 60,000 practicing pediatricians will be excluded from the opportunity to qualify for these incentives. The already inequitable system of funding programs for children will only be worsened. This is not a good investment in our future.

Importantly, Congress has passed legislation and overridden a Presidential veto as part of the recent Medicare Improvements for Patients and Providers Act of 2008. This will help pediatricians in private practice because many private payer contracts are based on Medicare rates. But the bill also includes two important health IT- related provisions. One, based on the E-Meds legislation introduced on the House side by Representative Allyson Schwarz, provides incentives to physicians to purchase E-Prescribing systems by paying these physicians more under Medicare. Another expands a large demonstration project to incentivize the use of health IT by paying more to primary care practices that submit medical home codes. Even though our Academy originated the idea of the "Medical Home" in 1967,

neither of these provisions applies to pediatricians, whose patients are generally not part of Medicare.

Pediatricians are concerned that Congress has not overridden the veto of the SCHIP reauthorization, which would have some real impact on the adoption of health IT systems in pediatrics. Title IV Section 401 of H.R. 976, versions of which the House and Senate have both passed twice, would address pediatric health information technology by making available more than $200 million in grants to help spur the development and adoption of health information technology systems in pediatrics and also to measure and improve the quality of pediatric care.

SCHIP reauthorization must become law, and soon, especially in the face of shrinking state Medicaid budgets. If pediatricians do not receive real funding assistance, we may not be able to adopt health IT as quickly as the national healthcare system needs.

Special Concerns for Pediatric Electronic Health Records

Even if we do receive help to adopt health IT systems in our practices, pediatricians face special constraints because of the rules governing privacy for our patient population. Child health care providers often find that clinical information systems have diminished usefulness in pediatrics because EHRs are frequently designed for adult care and do not take into account the specific needs of pediatrics. There are a number of special functions that a pediatric health record requires that must be implemented in an EHR. In their absence, pediatricians are hampered in their ability to properly document care. The EHR vendor community frequently asks us to pay extra for these capabilities, if they will provide them at all. The major areas in which these needs arise are in immunization documentation, immunization registry management, growth tracking, medication dosing, privacy in special pediatric populations, and providing normative data by age, Body Mass Index, or developmental stage.

Privacy Concerns for Adolescents and other Special Pediatric Patients

Of immediate concern in today's discussions of health information technology incentives are adolescent privacy concerns. The HIPAA Privacy Rule and its implementing regulations defer to state and other applicable law on the issue of adolescent privacy. Commentary to the final regulations explained that state law governs disclosures to parents. In cases where state law is silent or unclear, the regulation would preserve state law and professional practice by permitting a health care provider to use discretion to provide or deny a parent access to such records as long as that decision is consistent with state or other law. HIPAA also allows the minor to exercise control of protected health information when the parent has agreed to the minor obtaining confidential treatment. HIPAA also allows a covered health care provider to choose not to treat a parent as a personal representative of the minor when the provider is concerned about abuse or harm to the child. Finally, HIPAA states that a covered provider may disclose health information about a minor to a parent in the most critical situations. Disclosure of such information is always permitted as necessary to avert a serious and imminent threat to the health or safety of the minor.

Providers of care to adolescents have worked diligently in their states to create workable solutions within the constraints that the state determines. But as you might assume, the worthy goal of computer data interoperability creates challenges in this context. Laws about age of consent vary from state to state and according to the patient's presenting problem. Adolescents who present for the outpatient treatment of mental health disorders, for example, may consent to their treatment at an earlier age than the age of majority in many states. Some states also have laws regarding parental notification whereby their interpretation is based on the patient's age and presenting problem.

Practices that serve adolescents typically have policies with respect to what portion of an adolescent's care should be handled with special privacy protections. For instance, in some jurisdictions, the adolescent must give explicit permission for the parent to review his or her records. These privacy protections may require the flagging of protected information. Therefore, EHR systems should support privacy policies that vary by age and according to presenting problem and diagnosis, and be flexible enough to handle the policies of individual practices, consistent with applicable law in the jurisdiction. Furthermore, if an EHR system handles record-keeping for consent for treatment, it should provide for the recording of assent for treatment from an underage adolescent or child combined with parental informed permission. It should also provide for consent for treatment from an adolescent combined with a record of parental involvement. The separation of the patient's consent and the parent's or guardian's consent is particularly important in the area of testing for drugs, or in the case of abuse. Screening for sexually-transmitted illness is another area in which the records of patient and parental consent, assent, and permission may be less straightforward than in adult care.

It is particularly noteworthy in this context that concerns about the privacy of information for sensitive health concerns are not limited to adolescents who are minors. Even those adolescents who are adults, that, is, over the age of 18, and many other adults, have concerns about maintaining the privacy of information about sexually-transmitted illnesses, pregnancy, mental health, and substance abuse. These people often wish to ensure that other family members – a parent, child, or spouse -- will not have access to such information without their agreement. We pediatricians continue to care for young people through age 21, and in some cases, beyond. The concerns of our young adult patients are as important to us as the concerns of our adolescent patients who are minors.

Children in Foster or Custodial Care

When a child is removed from the care of his or her parents, as in the case of foster care, complex issues of confidentiality of medical information arise. Licensed foster parents may consent to routine medical and dental treatment for minors placed with them pursuant to a court order or with the voluntary consent of the person having the legal custody of the minor. Pediatricians document the authority of a foster parent to give consent to medical treatment by obtaining a copy of the court order. Parents who no longer have custody may still have the right to access their children's medical records and be involved with health care decisions unless their parental rights have been terminated. EHR systems that purport to manage consent for treatment and information access need to be able to record these details. Systems

must be developed so that the appropriate individuals have access to the relevant information and those who should not have access do not.

Consent by Proxy

Children often present for non-urgent health care in the company of an adult who is not the custodial parent or guardian. The best way to prevent confusion about consent for care in this situation is to record the custodial parents' wishes as to which adult can consent to which elements of the child's care and under what limitations. EHR systems that manage consent for treatment should support this kind of data-recording.

Adoption

Records of children who are undergoing adoption proceedings or who have been adopted may need special privacy handling, as in a case where state law offers special protections for the identity of adoptees. The EHR systems should allow flagging of these data for special privacy protection. In some states, the pre-adoption record may need to be separated entirely from any post-adoption record by using two distinct patient identities.

Guardianship

The identity of a child's guardian and guarantor, although most commonly the parent, can become complicated outside the bounds of the "typical" two-parent household. The EHR system must provide the flexibility to indicate the broad variety of adults in the child's life who may play some role in medical or financial decision making. The system should draw a distinction between the patient's guardian and his or her financial guarantor. In those cases in which a court has appointed a guardian for a minor, the ability of the guardian to consent to medical treatment depends upon the type of treatment being sought and the scope of authority the court has granted. If more than routine care is required, the pediatrician should document the authority of the guardian to give consent by obtaining a copy of the official certified letters of guardianship. The EHR system should support this record-keeping.

Emergency Treatment

When EHR systems support the recording of consent and assent for treatment, they should be flexible enough to allow for the emergency treatment of minors, in which the parent or legal guardian may be absent, and the usual procedures for consent must change

In conclusion, as the Small Business Committee continues its debates and discussion around developing incentives for the adoption of health information technology systems, please keep in mind the special needs of the children. Pediatric practices operate under tighter margins, are not directly supported by the Medicare system, and have more burdensome privacy considerations that we pediatricians must address every day in our practices. Thank you very much for the opportunity to testify before you today.