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Immunization Registry Information Systems

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Nationally, more and more school nurses are encountering immunization registries or Immunization Information Systems as they search for immunization records on children attending their schools. Given the rise of immunization registries, the difficulty for parents to produce complete records, and the ongoing need of school nurses to gain access to this information, this is the time to bridge the gap between school nurses and immunization registries. The following article aims to help bring more information about immunization registries to school nurses.

Following are excerpts taken from a special edition of Snapshots, the newsletter for the American Immunization Registry Association to help explain what registries are and how they might help.

What Is an Immunization Registry?

Immunization registries are confidential, computerized systems for maintaining information regarding children's vaccinations. When providers report immunization data on all children in their geographic area, registries provide a consolidated immunization record for each child.

Information in the immunization record most commonly includes a child's name, birth date, sex, mother's name, vaccine type, vaccine manufacturer, vaccination date, and vaccine lot number.

Why Were They Created?

The U.S. currently enjoys the highest immunization rates and lowest disease levels in its history. However, as recently as 1993, this country experienced the largest outbreak of pertussis (whooping cough) in more than 20 years. And from 1989 to 1991, a measles epidemic resulted in 55,000 cases and 123 deaths, principally among young children.

Sustaining high immunization rates is a challenging task. Nation-wide, immunization rates hover at 74% (for 4:3:1:3:3). However, in some pockets of the country, immunization rates are even lower among children aged 2 and under. The reasons are many: parents lack complete and accurate information about their children's immunization status because they frequently change providers, insurers and employers, or they move. With new vaccines added each year, the immunization schedule is increasingly complex. Because we so rarely see these diseases, we may lower our guard against them.

Immunization registries help sustain high immunization rates and low disease levels by managing information more efficiently. Since 1992, over \$200 million has been invested in the development of registries by federal, state, and local governments and by private foundations. Currently, immunization registries are being developed or are operational in all 50 states and the District of Columbia. Twenty-two states have laws or rules specifically authorizing immunization registries, and 11 require healthcare professionals to report immunizations to their registries. In 39 regions with population-based operational registries, almost half of the children under 6 years old are enrolled, and have two or more immunizations in their record.

Editor's Note ~ Researching state legislation related to immunization registries in 2001, Horlick, Beeler and Linkins found that of the 50 states that had laws specifically authorizing immunization registries, only 9 had laws or rules specifically addressing the sharing of immunization information. This leads us to question what has happened in the years between 1992 and 2001. In the September 2003 issue of School Nurse News a summary of questions about immunization exchange was presented in The Impact of FERPA and HIPAA on Privacy Protections for Health Information at School. Issues of privacy appear to have created more barriers to obtaining

immunization records. Does this protection help the public? It certainly makes the school nurse's job more difficult. But school nurses have always been sensitive to protecting the patient and they certainly understand the need for clear, foolproof protection of confidential information. They are prepared to explain this to parents and students. They want to understand the reasons why these layers of protection are needed.

Benefits to Schools, Communities & the Public Health System

- Maintains immunization records required by various children's services
- Assists in controlling vaccine-preventable diseases by identifying populations at high risk for illness
- Reduces administrative time and allows staff to focus on other important activities

Benefits to Providers

- Provides an accurate immunization history for all patients
- Prints immunization records
- Produces reminders and recalls for immunizations due or overdue
- Provides current immunization recommendations
- Completes required school, camp and day care immunization records
- Produces various clinical information reports, such as monthly shot counts and vaccine usage reports
- Increases ease of compliance with federal vaccine recording laws
- Reduces paperwork
- Facilitates introduction of new vaccines or changes in the immunization schedule
- Helps manage vaccine inventories
- May track contraindications and adverse reactions
- Eliminates manual record pulls when health plans conduct record reviews, such as for HEDIS reports
- Reinforces the concept of the medical home (an established relationship with a primary care practice)

Benefits to Parents

- Consolidates all immunizations a child has received into one report
- Helps ensure that a child's immunization schedule is up-to-date
- Provides reminders and recalls when an immunization is due or has been missed
- Eliminates need to maintain and provide new healthcare providers with complete immunization history
- Prevents over-immunizations
- Provides an accurate copy of a child's immunization history for personal, day care, school, or camp entry requirements

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Registries and Schools Working Together

In Arizona, school nurses are using the Arizona State Immunization Information System to keep track of their students' immunization records. According to Annett Heasman, from the Roosevelt District, "This year I have all but four kids completely caught up on their immunizations for school. ASIIS helps me fill in the holes on the missing records. Families bring in multiple record books and very often not everything is recorded. I'm able to look those missing shots up very quickly using ASIIS." Shirley Hawkins, from the Wilson District, said, "ASIIS was a Godsend! I use it all the time. When families bring in their records the first thing I do is check ASIIS." And Candy Vogel, from Arizona School for the Deaf and Blind, said, "We have students from all over the state. I'm able to go online to ASIIS first, and many times the records are there. I like to print off the record for a school copy and one for the parents. I just wish more doctor's offices were reporting."

In Central New York, close to 160 schools have the HealthyShot application provided by the New York State Immunization Information System installed in their offices to help them track down missing shots for children throughout their region. The nurses are able to query the system and quickly find out the child's status, as well as identify the primary care physician if there are additional questions that might need to be answered regarding the child's immunization status. Both school nurses and the physician's office staff in the region comment on the decrease in calls around school registration time because much of the information can be gained directly by querying the registry.

Privacy and Confidentiality

As the partnership between schools and immunization registries develops, there are many aspects that must be understood. One is the legal framework within which this partnership must exist. Security and confidentiality are primary concerns for all entities involved. The Federal Education and Privacy Act protects "educational records," HIPAA protects health information, and many state and local pubic health jurisdictions have their own rules or regulations to protect the information of their citizenry.

Additionally, the records of a student that pertain to services provided to that student under the Individuals with Disabilities Education Act (IDEA) are "education records" under FERPA and are subject to the confidentiality provisions under IDEA (see 34 C.F.R §§ 300.560-300.576) and to all of the provisions of FERPA. When a student reaches the age of 18 or attends an institution of postsecondary education, the student is considered an "eligible student" under FERPA and all of the rights afforded by FERPA transfer from the parents to the student. 20 U.S.C. § 1232g(d); 34 C.F.R § 99.3 "Eligible student." (Rooker, 2004)

Editor's Note: There are legal provisions covering almost all aspects of health information today. With diligence, interpretation of the law will continue to be more defined. Where does this leave you in the legal jargon? Here's one of those questions from the SNN article of September 2003.

Q. In the past we have been able to share immunization information without signed release because it is necessary for school entry, documentation, etc. Will this still be true under HIPAA privacy regulations?

A. Both FERPA and HIPAA regulations are silent on the subject of immunization, and this is a question that may have to be submitted to the HIPAA website or to your state Attorney General. The regulations specify that HIPAA is not meant to supersede existing state or federal laws, and most states have laws concerning exchange of immunization information. The HIPAA website is www.hhs.gov/ocr/hipaa, and questions are invited. FERPA information is available at the Family Policy Compliance Office of the U.S. Department of Education at www.ed.gov/offices/OM/fpco.

Another Thing to Consider

Many school districts' policies on immunization include a clause that addresses exclusion from school for refusal to provide proof of immunization or acceptable legal exemption. Part of this policy includes notification of state or local Health Department. Understanding that the original intent of this practice was to protect the public health from the threat of uncontrolled communicable illness, this action seems reasonable. The question raised now is, how legal is it to continue this practice in 2004? HIPAA was initiated in 1996, signed in 2002 and enacted April 14, 2003. We have a long way to go before all the questions are answered. The more healthcare providers choose immunization registries, the more dilemmas like this one will be addressed and answered. The American Immunization Registries Association (AIRA) actively researches the legalities associated with the disclosure of immunization information. In addition, each school district retains legal counsel to review policy and recommend direction. It is always an acceptable part of your role to ask for clarification, in writing, on issues that seem unclear.

Clarifying Conclusions

The National Conference on HIPAA Privacy Rules sponsored by the Department of Health and Human Services in 2003 was a four-day event. It was designed to provide an opportunity to hear and interact with officials who developed the Privacy Rule and its subsequent modifications. It provided unique insight to those who attended. School nurses were fortunate that Martha Dewey Bergren attended. In her continued diligent approach, Martha writes more, and more, and more about privacy issues to help us understand. She reported on this meeting by saying: The concerns and practical problems faced by school nurses and FERPA-covered entities were heard by both Health and Human Services (HHS) and the Office for Civil Rights (OCR). The conference organizers and presenters were overwhelmed by the barrage of FERPA-HIPAA coverage questions. Officials admitted they had not given adequate technical assistance thus far to FERPA-HIPAA conflicts. They recommended checking their website periodically for guidance (www.hhs.gov/ocr/hipaa/assist.html) (Bergren, 2003).

Finally, nothing in FERPA prohibits school officials from obtaining parental consent in order to disclose personally identifiable

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information on students to state health officials. The written consent required before an educational agency or institution may disclose personally identifiable, non-directory information from education records should

- (1) specify the records that may be disclosed;
- (2) state the purpose of the disclosure; and
- (3) identify the party or class of parties to whom the disclosure may be made. [34 C.F.R § 99.30(b); see 20 U.S.C. § 1232g(b)(2)(A)].

If requested, the agency or institution must provide a parent or student with a copy of the records disclosed. 34 C.F.R § 99.30(c)." (Rooker, 2004).

INFORMATIONAL RESOURCES

For additional information on immunization registries or to find out more about registries in your community try these Web pages:

American Immunization Registry Association: www.immregistries.org

Centers for Disease Control and Prevention: www.cdc.gov/nip/registries

Every Child By Two: www.ecbt.org

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