Policy Statement—Using Personal Health Records to Improve the Quality of Health Care for Children

abstract

A personal health record (PHR) is a repository of information from multiple contributors (e.g., patient, family, guardians, physicians, and other health care professionals) regarding the health of an individual. The development of electronic PHRs presents new opportunities and challenges to the practice of pediatrics. This policy statement provides recommendations for actions that pediatricians can take to support the development and use of PHRs for children.

Pediatric health care professionals must become actively involved in developing and adopting PHRs and PHR systems. The American Academy of Pediatrics supports development of:

- educational programs for families and clinicians on effective and efficient use of PHRs;
- incentives to facilitate PHR use and maintenance; and

Properly designed PHR systems for pediatric care can empower patients. PHRs can improve access to health information, improve coordination of preventive health and health maintenance activities, and support emergency and disaster management activities. PHRs provide support for the medical home for all children, including those with special health care needs and those in foster care. PHRs can also provide information to serve as the basis for pediatric quality improvement efforts.

For PHRs to be adopted sufficiently to realize these benefits, we must determine how best to support their development and adoption. Privacy and security issues, especially with regard to children and adolescents, must be addressed. Pediatrics 2009;124:403–409
BACKGROUND

A personal health record (PHR) is a repository of information from multiple sources (eg, patient, family, guardians, physicians, and other health care professionals) about the health and health care of an individual that is controlled by the individual or designated people. Documentation of personal health information for children has traditionally been managed in a variety of formal and informal formats, primarily by their parents. Some parents may use tools such as the compact, form-based booklet “Child Health Record From Infancy to Adulthood” from the American Academy of Pediatrics (AAP). This book facilitates standardized and concise tracking of a child’s personal health information, including birth and demographic data, physician contacts, medical and family history, and well-child care information. Use of such tools is variable; some parents record nothing, and others maintain extensive and detailed records. For children with special health care needs, similar tools and forms have been developed to summarize clinically relevant information. Two examples are the emergency information form, developed by the AAP and the American College of Emergency Physicians, and care notebooks and medical care plans/assessment forms from the National Center for Medical Home Incentives for Children With Special Needs, which also use electronic forms that have the potential to become interoperable through standard interfaces.

Problems caused by the lack of availability of paper medical records and the lack of data transferability have been well described. Moving these records into an electronic format that is used universally has been proposed as a way to solve some of these problems. As a result, the focus on electronic PHRs has steadily increased over the past several years, with more than 200 systems available in 2006. On the federal level, the American Health Information Community, which advises the Secretary of Health and Human Services, selected a “consumer empowerment use case” including a registration summary and medication history as a first step for the Health Information Standards Panel and the Certification Commission for Health Care Information Technology to standardize the exchange of basic patient data. Many electronic health record (EHR) vendors now offer PHRs as extensions of their products. Health plans, employers, and hospitals are also offering PHRs to their subscribers, employees, and patients, either as stand-alone systems or as part of the institution’s information systems. Cooperation among organizations is beginning, with America’s Health Insurance Plans (AHIP) designing PHRs for their members with “portability” (ie, the ability to transfer and share information between different insurers). Some companies are offering PHR systems to their employees, and an effort to create a common PHR for multiple employers has been launched. Major vendors in the software industry, seeing the opportunities to expand into health care, are establishing various forms of Internet-based PHRs. Electronic PHRs that are populated by a wide variety of organizations, together with health information exchange solutions, may serve as the backbone of efforts to support improved quality of care and a nationwide health information network.

The technical infrastructure of electronic PHR systems may have many forms. In addition to Web-based systems, information in electronic PHRs may be stored on portable computer drives (such as USB “flash drives”), “smart cards,” or other electronic storage devices. Functionally, PHRs are diverse. Some contain tools for managing care, such as delivering electronic test results, providing support for remote monitoring (eg, weight, blood pressure, blood glucose), and providing secure communication services between patient/family and health care professional or access to health-related content. Some PHRs have the ability to transfer information using standardized data formats or to transfer data to a patient-controlled health data record or repository.

Ideally, an electronic PHR prevents duplication and delays in services. It may be part of a comprehensive strategy to empower patients to understand the care they are receiving while fostering a closer collaboration with their health care team. For pediatricians, PHRs can provide pediatricians information on events occurring at home and in school between encounters to supplement secure messaging features that may facilitate doctor-patient communication. PHRs integrated with medical devices may allow for direct, automated reporting of important information for real-time clinical management and for evaluation of clinical outcomes, especially for patients with chronic medical conditions. In addition, improved documentation and reporting of electronic clinical interactions and patient-physician communications can be beneficial for reimbursement. PHRs are increasingly being designed to integrate patient data, communication, and management interventions. They have the potential to provide improvements in quality (ie, safety, timeliness, effectiveness, efficiency, equity, and patient-centeredness, as defined by the Institute of Medicine). Assurance of consumer control of privacy is essential to the acceptance and adoption of PHRs. With appropriate access controls, patients and families can allow portions of the PHR to be
made available to family members, school nurses, and others, with emergency access ("break-the-glass") functionality for use during medical crises or in disaster situations.

Few, if any, PHRs offer the privacy controls that are necessary for adolescent medical care. Adolescents are typically excluded from PHR use because of the wide variation of state laws regarding access to adolescent medical information and to limitations in the ability of adolescents to enter into contracts independently. In general, adolescents should have access to their records as well as control over who else may access these records. The approach to adolescents could start with parental access for records of young adolescents while parents remain in control. Older adolescents who are authorized to seek care alone may start a separate private PHR for those episodes of care, subject to local mandatory disclosures to their parents. At the appropriate time (to be determined by convention and law), a copy of the parent-maintained PHR should be transferred to adolescent control (although special consideration to issues, such as genetic susceptibility known only to parents, might be withheld until the adolescent reaches the age of majority). Because of laws limiting the authority of adolescents to enter into contracts independently in many states, it is likely that such a separate PHR would need to be a part of the original contract agreed to by their parents.

STATEMENT OF THE PROBLEM

Electronic PHRs have the potential for great impact on the medical care of children, especially children with special health care needs. To realize the potential of PHRs in pediatrics, 2 needs must be addressed: (1) standards for content, information assurance, and data exchange that meet the health needs of children, including adolescents; and (2) incentives for adoption and use by pediatric providers and families. There are still many unanswered questions regarding PHRs, including who will bear the costs of their development and adoption, but key issues for children and adolescents must be clarified, because they are not being addressed in the current development of PHRs.

The Need for Standards

Pediatricians have a critical role in defining content standards for PHR use in child health care. Lack of adequate pediatric-specific content standards for PHRs may result in incomplete products (eg, a PHR that lacks immunization functionality). Content requirements for pediatric EHRs and for emergent care for children with special health care needs have been articulated and may be used as a basis for developing pediatric PHR standards.

In addition to developing minimum content standards, pediatricians should support the creation of data-exchange standards that are detailed enough so that the data can be:

● transmitted and received correctly (ie, technical interoperability [eg, using the ASTM/Health Level 7 Continuity of Care Record/Document format]);

● interpreted correctly after transmission (ie, semantic interoperability [eg, vocabulary standards to allow determination whether “fundus” refers to a part of the eye or of the uterus]); and

● shown and used in the correct context (ie, process interoperability [eg, data are presented via consistent, useful, and efficient user interfaces that fit workflow]).

It is highly desirable for pediatricians to be involved in standardization efforts at all of these levels. If successful, PHRs will have reliable and transportable data that are presented in a consistent interface, resulting in decreased time and errors in use, higher adoption rates, and increased medical quality.

Pediatricians must also play a central role in defining PHR information-assurance standards for PHR use in child health care. Such standards include requirements for PHR confidentiality and access controls, for data and source integrity including audit trails, and for physical and functional availability of PHR content. An example of information assurance relevant to pediatrics is the definition of standards to protect the privacy of adolescents and children in foster care. Other information-assurance standards ensure the integrity of the data and source information (ie, who entered it, including nonrepudiation [the prevention of a user’s denial that he or she has entered information]) as they are moved between/among health care professionals, health systems, and electronic health information environments.

The Need for Incentives

Despite the promise of improved care through the adoption and use of electronic PHRs, acceptance by patients, parents, and physicians has been slow. In addition to the lack of pediatric standards for PHRs, the business case for a PHR is currently weak, especially if it is not linked to an EHR (for which pediatric adoption is also low), making financial incentives important. Many PHRs do not currently fit physician workflow, often adding steps to an already onerous information-recording and -transfer process. Other issues that must be addressed include language barriers to PHR use for non–English-speaking families, literacy barriers in patients’ understanding of
their health information to make decisions, technology-access (ie, “digital divide”) barriers, and the lack of coordination between Medicaid, State Children’s Health Insurance Programs (SCHIPs), private insurers, and employers with respect to PHRs.

A stronger business case from employers and third-party payers is necessary to create financial support for PHRs to help manage employee health and to control costs. Insurers, hospitals, and employers are organizing to support various types of PHRs. Government support is being considered, with legislation introduced on a federal level. To make PHRs a routine part of patient care and quality improvement, incentives to accelerate adoption, such as adjusted reimbursement for the time and work of manual duplicate data entry by pediatricians and their office staff, should be used. A reasonable workaround may be for pediatricians to provide these data to patients for them to enter into their own PHRs or, ideally, to provide automatic electronic updates from an EHR by using standard EHR-PHR interfaces. The financial issues associated with potential duplication of data entry and time spent in review of information in individual patients’ PHRs need to be addressed if pediatricians and other health care professionals are expected to fully participate.

**SUMMARY/CONCLUSIONS**

Electronic PHRs are a platform on which pediatricians can improve the quality of pediatric health care and increase patient/family empowerment—both of which facilitate care that is safer, timelier, and more effective, efficient, equitable, and patient centered. The AAP recognizes the potential of PHRs and supports their adoption and use in pediatric care, especially for children with special health care needs. The AAP also supports efforts to create pediatric-specific standards for PHRs and incentives for their adoption and use in pediatrics.

**BASIC PRINCIPLES FOR IDEAL PEDIATRIC PHRs**

1. **Access**—All children should have a single PHR, either paper or electronic, as an essential component of a medical home to document and coordinate care and to improve communication between their families and health care providers. Children should have equal access to a PHR regardless of income or method of health care financing.

2. **Information Availability**—Personal health information from a PHR should be available at all times, especially in emergent situations or disasters. To support availability, PHR information must be redundant (ie, copies on paper, portable electronic media, secure sites on the Internet, or through centralized electronic data repositories).

3. **Data Exchange**—PHR data should be interoperable as needed at the request of the patient or patient’s medical guardian (ie, it should be easily transferable to and from other PHRs, EHRs, and health information systems, including hospital systems and registries such as those for immunizations, hearing screening, and newborn metabolic testing). PHRs should also include provisions for efficient data entry by health care professionals who do not use an EHR.

4. **Content**—The following should be contained in PHRs for children:
   - demographic data;
   - insurance information;
   - information on family members and other support providers;
   - summary and linkage to advance directives, power of attorney, and other key documents, such as an individualized education plan (IEP);
   - information on health care professionals and encounter lists, including dental and oral health professionals;
   - problem list, including active conditions and illnesses, chronic health problems (such as mental health issues), emergency care procedures (equipment if needed) and contacts, hospitalizations, surgeries/procedures (and current technology support needs [ventilator, monitor, surgical site care, etc]), and privacy issues of individual problems;
   - allergy, adverse-reaction, and other alert data;
   - list of medications and immunizations and date of last reconciliation;
   - anthropometric data including weight, stature, BMI, and head circumference and developmental milestones;
   - results of laboratory, imaging, and other studies including screening results;
   - family health history;
   - birth history; and
   - information on durable medical equipment and supplies.

Pedicatric PHR content standards must be aligned with the special requirements for EHRs for children with regard to presentation of data. All payers who provide PHRs should include the content and functionality described in this policy and in pediatric PHR standards as they are developed.

Given the cumulative nature of information contained in a PHR, a key challenge will be to provide the appropriate types and amounts of useful data to specific profession-
5. Privacy—The personal health information of children must be protected from abuse and unauthorized secondary or commercial uses. Key principles for PHR privacy include:

- Control. PHR data are owned and controlled by the patient or the patient’s parent/guardian, who authorizes access to the PHR. PHR access should include an override function for use by health care professionals in emergent situations (eg, individuals brought unconscious to an emergency department).

- Protections. PHR data (ie, personal health information) require protections (including federal and local jurisdictional laws for oversight, accountability, disclosure, recovery, and penalties), even if the organization hosting the PHR is not a covered entity under the Health Insurance Portability and Accountability Act (HIPAA).13

- Adolescent rights. Adolescents should have the right to exclude parents from their PHRs when law dictates that they may be treated without parental consent. When these features are used, health care professionals need to know that these exclusions are in place.

- Facilitated portability in emergent care. Children in foster care have special legal requirements for portability of personal health information that vary by state and jurisdiction (discussion and agreement among pediatric health care professionals, foster care authorities, lawmakers, and vendors is needed to develop standards for the availability of PHR information of children in emergent care).

- Special protections for specific personal data.

- Specific health information, such as information about sexually transmitted diseases/HIV status, mental health diagnoses and treatment, genetic susceptibility, artificial procreation arrangements, and social conditions such as a family history of parental incarceration, may require special protections that must be enforced by PHR mechanisms.

6. Data Entry and Integrity—All data, regardless of source, must be auditable as to source, date, and time of the change. PHRs should allow for data entry by patients or parents/guardians that is auditable as to source (including nonrepudiation) and date/time of record modifications. Data from health care professionals and institutions should be subject to review and comment by the patient but should not be modifiable. Health care professionals should not be required to reconcile disagreements between the patient and previous caregivers that are recorded in the PHR (eg, if a patient disagrees with an entry made by a previous physician) except as clinically necessary to provide needed care.

7. Extensible Functionality—Pediatric PHRs may contain functions that add value, including tools that help track and document immunization status, growth (including tools to address obesity), and development. Examples of other functions that PHRs could perform include generating standard reports, such as school and camp forms, using data stored in the PHR. The addition of such functions should be structured in a modular fashion that allows their inclusion without disruption of the structure and/or function of existing PHRs.

8. Continuity—When available, PHRs should be used during all clinical encounters. The health care professional should help the patient update the PHR, including the problem/procedure lists, key measurements, immunizations, and medications that were changed during the encounter. Electronic data should be shared using standard interfaces and printouts produced as needed for patients who do not yet use a PHR.

9. Support for PHR Adoption—Programs should be established to provide incentive payments to health care professionals who use and support patient/family use of electronic PHRs as part of a medical home, including an adjusted reimbursement system that acknowledges the value and services of the medical home.14 Programs with national demonstrations and educational materials should also be established to meet the need for patient and provider education regarding the benefits and proper use of PHRs.

THE VISION OF PEDIATRIC PHR IMPLEMENTATION

The PHR is a lifelong and comprehensive record for a patient and should be used beginning at birth. Newborn infants should be discharged from hospitals and birthing centers with a PHR containing perinatal information, birth history, and relevant medical informa-
tion, including assessments for jaundice. Such PHRs should be available in secure formats that conform to electronic health standards (such as the ASTM/Health Level 7 Continuity of Care Record/Document) for easy export to a medical home EHR from the hospital or at the first office visit. The PHR should interoperate with immunization and newborn metabolic and hearing screening registries and with other stakeholders in regional health information organizations. The PHR should facilitate coordination of care with other agencies (eg, it should help to automate the periodic health assessments collected by school systems and serve as an accurate collection of information about children in foster care). The childhood portion of the PHR should provide a comprehensive view of all aspects of a child’s health status over time, including reporting of growth and development, health maintenance, and relevant issues managed in all clinical care settings. It should facilitate the transition from pediatric to adult health care professionals.

To achieve this vision, pediatric advocacy is necessary in the form of partnerships among professional medical societies (such as the AAP), health care professional organizations, health care information technology vendors, and standards-development organizations to help establish the necessary standards and incentives for widespread PHR use. A strong pediatric presence is also necessary in the legislative arena to ensure the clear and vocal representation of the needs of children and pediatricians in policy development that drive standards and adoption of health information technologies, such as PHRs. Pediatric leadership is needed to lead and to teach patients, families, and health care professionals to use PHRs effectively to promote the good care and good health of children and families.

Finally, to sustain the vision, PHRs must be rigorously evaluated so that their use can be optimized and their value can be documented. Potential metrics include:

- Manual data-entry elimination: Percentage of new patients who do not have to fill out a paper form or questionnaire in the physician’s waiting room, because they have a PHR that can be imported electronically into an EHR or practice-management system.
- Availability of basic history data from other professionals: Percentage of well-child visits that begin with a complete immunization summary, growth chart, problem list, and medication list reconciled from a PHR that contains data from other health care professionals.
- Providing families with up-to-date health information: Percentage of well-child visits that end with the parents receiving an updated PHR with immunization, growth, problem, and medication summaries.
- External PHR updates: Percentage of emergency department, inpatient, or referral visits that update a PHR with the date, location, health care professional, problem, medications, test results, or outcomes.
- External PHR use: Percentage of emergency department, inpatient, or referral visits that access a PHR to review patient data at the time of the encounter.
- Hospital-office newborn continuity: Percentage of newborn first office visits that include a PHR with the birth history, birth and discharge weight, hearing test results, hepatitis B immunization data, bilirubin and blood type (if determined), any newborn problems, and newborn screening results as they become available.
- Completeness of medical providers list: Percentage of preterm infants or children with special health care needs (including foster care children) who have a list of all health care professionals in a PHR, including contact information, date of last visit, and date of next appointment (as applicable).
- EHR adoption rates: Percentage of practices with an EHR that offer a patient Web portal to their patients.

**REFERENCES**

2. American Academy of Pediatrics, Committee on Pediatric Emergency Medicine; American College


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