Pediatric Personal Health Records: Current Trends and Key Challenges

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ABSTRACT

Personal health records may enhance pediatric care and outcomes. Few systems have been developed or customized for pediatrics, and evaluations are scarce. Special considerations in pediatrics include pediatric content such as growth charts, complex privacy and confidentiality considerations, and the changing developmental needs of children and adolescents. *Pediatrics* 2009;123:S97–S99

Pediatricians have long used tools such as immunization cards and well-child booklets to provide families with access to key information about their children's health. In the past 15 years, electronic records and the Internet have become increasingly important and available mechanisms through which to provide families with data about their children's health and to assist families in tracking their children's health and development. Families also create their own paper and electronic records of their children's health and health care needs. Electronic systems, known as personal health records (PHRs), may play key roles in enhancing partnerships between families and health care providers, promoting self-care, and enhancing family decision-making regarding the health of children and adolescents. Furthermore, they can provide key health information when a child becomes ill away from home or in a disaster. This article reviews PHR types and characteristics, summarizes some existing systems, and describes special challenges for PHRs in pediatrics.

PHRs have been defined by the Markle Foundation as an "electronic application through which individuals can access, manage and share their health information, and that of others for whom they are authorized, in a private, secure, and confidential environment."[1] An ideal PHR would be lifelong and would integrate information from many sources, such as health care systems, pharmacies, and insurers, as well as family-entered information such as symptoms, health concerns, and self-monitoring findings. It would be controlled by the patient or family, and it would be private and secure. It would facilitate communication between families and providers, using functions such as secure e-mail.[1] No existing systems meet all of these criteria, partly because of the difficulty of merging data from multiple sources into a single data system. Privacy concerns and lack of a strong business case for PHRs have also hindered their development.

In the early 1990s, many commercial vendors developed Internet-based, stand-alone systems. These systems required consumers to enter and to maintain their own health information. Although some of these systems remain, they have never become popular, likely because of the onerous nature of maintaining the information. Therefore, PHRs linked to electronic health records (EHRs) and other sources of health information have become the preferred model.[1,2] Recently, several large software makers announced their plans to develop secure PHRs that could link to physicians' and hospitals' EHRs.[3,4] Once these systems overcome the technical challenges of integrating information from multiple sources that code and store data in disparate ways, they likely will face consumer concerns about privacy and the security of the health information. Previous consumer surveys found that privacy and security are concerns of 90% of potential users, although many think that adequate technology exists to protect them.[1] These models promise to bring the ease of use and advanced functionality that is widely available in commerce to Internet-based health tracking. The Robert Wood Johnson Foundation has sponsored 8 projects to design and to build a prototype of a new generation of PHRs.[5] Two of those projects focus on pediatric topics.

Most early PHRs linked to EHRs were developed by academic health centers. Nearly all of those systems focused on adult populations in primary care[6–10] or populations with specific chronic illnesses, such as diabetes mellitus[11,12] or heart failure.[13,14] Such systems typically include access to key parts of the EHR, such as laboratory results, medications, and visits. They often allow patients to communicate electronically with providers and to track simple health information. Previous research demonstrated that such systems can be feasible, secure, and well accepted by patients.[6,7,9,11,13,15–17] Laboratory results and e-mail typically have been the most popular features.

Fewer systems have been developed specifically for pediatrics. General pediatrics has lagged behind other specialties in uptake of electronic health tools. For example, Menachemi et al[18] found that only 13.7% of general

pediatricians in Florida were using EHRs in 2005. A national survey conducted the same year found that 21.3% of primary care pediatricians had EHRs in their practice.[19] Large networked practices were more likely to report EHRs. Only 3.5% of solo practices reported using EHRs. The relatively large number of solo and small practices in pediatrics, compared with family medicine and internal medicine, has been hypothesized as a reason for pediatricians' lag in the use of EHRs. Lack of pediatric functionality has also been cited as a reason for the lower rates of adoption in pediatrics.[19] Similarly, many commercial PHRs, including those that are an extension of an EHR, are focused more on the needs of adults and may lack important pediatric functions, such as immunization and development tracking.

Some PHRs and PHR-like tools have been developed specifically for pediatrics. Since 1998, researchers and developers at Children's Hospital Boston have been developing a PHR (previously called PING and recently renamed Indivo[20]) that can integrate pediatric data from multiple sources, including multiple hospitals' EHRs.[21] Parents and patients can control access to the record, and the architecture and programming are publicly available. Indivo contains a broad range of functions, including encounter records, laboratory results, messaging, family data entry, and decision support.[22]

At Cincinnati Children's Hospital Medical Center, a more-limited, disease-specific approach was launched in 2002. Initially designed for families whose children had undergone liver transplantation and later expanded to juvenile idiopathic arthritis, diabetes mellitus, cystic fibrosis, and kidney transplantation, these Internet-based systems connect families to key aspects of the medical record for the condition, such as laboratory results, radiology reports, secure messaging, and links to relevant health-related sites.[23] Parents can control access to the child's portal data (see below). Like many PHRs, there has been limited evaluation of the impact of these systems on patient and family outcomes.

There are a number of special challenges to the development and implementation of PHRs for pediatrics. First, although standards and interoperability are critical for all PHRs, special attention must be paid to pediatric functions such as growth charts and complex immunization schedules. The American Academy of Pediatrics has issued recommendations for EHR standards,[24] and these should also be applied to PHRs. Second, developmental issues in pediatrics complicate the confidentiality and privacy issues for PHRs. Adolescents' and parents' legal rights to access medical records vary among states in the United States and may differ depending on the PHR content, such as psychiatric issues or reproductive health. These issues typically have been handled at the practice or hospital level, but they become more complex in electronic systems. PHRs will need to develop multiple levels of security and to facilitate selective access to different components of the medical records. Furthermore, these permissions must change as an adolescent ages. Once the adolescent reaches age 18, access must be reassessed and systems developed to ensure that the young adult controls access to his or her PHR. Ad-

ditional complexity arises for those with joint or disputed custody and those in foster care, where access rights may change frequently. Third, an ideal PHR would adapt to changing developmental stages as children progress from school age through adolescence. Different interface styles and information complexity should be designed for children and adolescents. Finally, pediatric PHRs, to be optimally useful, must be customizable for the large number of low-frequency but severe pediatric chronic conditions. Families of children with chronic conditions are likely to be the most-frequent users of PHRs. These customizations are unlikely to be undertaken by large commercial PHR vendors alone. They will require collaboration with pediatric specialists, family organizations, and informaticians. Advocates for children's health and pediatric PHRs can help ensure that pediatric content and standards, privacy needs, and customization are incorporated into PHRs through engagement with vendors, development of incentives for vendors and practitioners, and education of the pediatric community regarding the benefits and challenges of PHRs.

ONE MOTHER'S STORY

Cincinnati Children's Hospital Medical Center's Liver Portal allows me to be an active and informed parent, making shared decisions with Kyle's doctors concerning his care. My 6-year-old son Kyle is the blessed recipient of 2 liver transplants, 8 months apart in 2002. The Liver Portal wasn't yet available after the first transplant. A typical day after we were home from the hospital would go something like this. The nurse would come to the house and draw his labs and I would wait by the phone from noon on, waiting for the coordinator to call with results. When the coordinator finally called, which was usually around supper, I might get "everything is fine" or "his numbers are up a little" or "his numbers are up a lot and you have to be at the hospital at 7:30 AM for a liver biopsy." I was not able to see the numbers to get a full grasp of what they were talking about. I have 3 older children I would have to scramble to make arrangements for, for school transportation and babysitting. My husband would have to make arrangements for work. These days were very stressful for everyone in the immediate and extended family.

Shortly after his second transplant, I was given access to the new Liver Portal. I did not comprehend at the time just how much it would change my life. A typical day now would start off with the nurse drawing Kyle's labs and 2 hours later I could sit at my computer and get those results. I could see how high the numbers were fluctuating. If I had questions, I could click over to the Question and Answer [secure messaging] tab and type out the question. Biopsies were no longer a surprise. I was able to plan. So much of the stress was lifted because of this access. Not only was stress relieved but I was able to become an active partner in Kyle's care. At one point he was hospitalized with pneumonia. I researched his labs and noticed his immunosuppressive drug level was high. I asked the doctor if the high immunosuppressive drug level was a coincidence or correlation. Initially he

thought it was a coincidence, but after he looked more closely he realized there was a correlation and lowered the dose.

Another time Kyle's liver enzymes were creeping a little high and the doctor wanted to raise his immunosuppressive drug. He was looking back at only the last 4 lab draw values and I went back to the last 8 and showed that Kyle has been doing this for ~7 months. The doctor agreed and decided Kyle was stable, and he did not change the dose. There are many smaller incidences like these throughout the years.

The portal has allowed me to travel without bringing Kyle's "Medical Bible" with me. I can walk into any hospital and give the doctor complete access to Kyle's medical history. Overall, the portal has reduced my stress tremendously and it has allowed me to become an important member of Kyle's medical team.

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