

White Paper ■

Information Technology for Children's Health and Health Care:

Report on the Information Technology in Children's Health Care Expert Meeting, September 21–22, 2000

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Abstract In September 2000, the Agency for Healthcare Quality and Research and the American Academy of Pediatrics Center for Child Health Research sponsored a meeting of experts and knowledgeable stakeholders to identify 1) the special information needs of pediatric care and 2) health service research questions related to the use of information technology in children's health care. Technologies that support the care of children must address issues related to growth and development, children's changing physiology, and the unique diseases of children and interventions of pediatric care. Connectivity and data integration are particular concerns for child health care workers. Consumer health information needs for this population extend beyond the needs of one individual to the needs of the family. Recommendations of the attendees include rapid implementation of features in electronic health information systems that support pediatric care and involvement of child health experts in policy making, standards setting, education, and advocacy. A proposed research agenda should address both effectiveness and costs of information technology, with special consideration for the needs of children, the development and evaluation of clinical decision support in pediatric settings, understanding of the epidemiology of iatrogenic injury in childhood, supplementation of vocabulary standards with pediatrics-specific terminology, and improvement in health care access for children, using telemedicine.

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The field of medical (health) informatics broadly addresses the cognitive, information processing, and communication tasks of medical practice, education, and research by focusing on the development of computer-based patient records, decision support systems, information standards, data aggregation systems, communication systems, and educational pro-

grams for patients and health providers.¹ This expanding field is facing challenges to develop, for special populations, technology solutions that acknowledge the unique needs of these groups.

On September 21 and 22, 2000, the Agency for Healthcare Research and Quality (AHRQ), with the assistance of the American Academy of Pediatrics' Center for Child Health Research, convened a meeting of experts and knowledgeable stakeholders to identify special information needs of pediatric care and health service research questions related to the use of information technology in children's health care. Participants included representatives from the informatics, health care provider (pediatrics, family practice, and nursing), public policy, business, and consumer communities (see Appendix). Several background papers were prepared to serve as a foundation

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on which participants' comments and suggestions could be built.¹²⁻¹⁵ This commentary is intended to highlight the special characteristics of the pediatric population and recommendations made at the conference of which informatics professionals should be aware.

Children constitute a large and heterogeneous population whose health care needs are distinct from those of adults. In 1999, there were 70.2 million children under the age of 18 in the United States, representing 26% of the population.² Several characteristics of this population—and the health care system that provides for these patients—mandate special consideration in the design and deployment of enhanced information technology solutions. Describing the unique health needs of children explicitly, with respect to the health care community in which they receive service, should help explain why “one size fits all” solutions are not applicable to children's health.

Information systems for pediatric care must take into account three special considerations to meet this population's information needs effectively: 1) widely divergent pediatric subpopulations, as well as the unique physiology and diseases of children and special interventions for them; 2) connectivity and system integration at the community level, since it is imperative for pediatric practices and institutions to be connected closely to the public health authority and the schools; and 3) consumer health information that addresses the needs of the whole family.

Managing the Special Health Care Needs of Children

Pediatric health maintenance accounts for a large proportion of the activity of child health providers, who care for a diverse pediatric population that includes premature and term neonates, infants, toddlers, preschoolers, schoolchildren, and adolescents. Well-child care includes assessments of growth, nutrition, cognitive, motor, and language development, behavior and school progress, sleep, elimination, and social and family issues; universal screening for common problems, such as hearing and vision defects, anemia, and scoliosis; targeted screening of subgroups for conditions such as tuberculosis and lead poisoning; provision of anticipatory guidance regarding a multitude of topics; and vaccination with a large (and increasing) armamentarium of immunizing agents.

One of the most important functions of well-child care is the monitoring of growth. Most child health care providers maintain a graphic representation of

each child's growth over time, superimposed on a set of normative data. Conventional paper systems for recording growth data make plotting a chore and prone to error.⁵ They limit clinicians to a single set of comparison norms, which may be inappropriate for children born prematurely or for children with recognized growth disorders.

Electronic medical records oriented to the care of adults often omit graphic growth monitoring or reference to norms. They also may fail to support recording of measurements on a sufficiently granular scale to be useful for newborn or infant care (e.g., rounding weights to the nearest tenth of a kilogram, rounding age to the nearest year). Systems intended for primary and specialty care of children should support graphic growth monitoring, choice of appropriate norms and scale, and a capacity for supplementary growth-related calculations, such as growth velocity and body mass index.

The physiology of children is clearly different from that of adults. Organ function develops as children mature, and normal test values change with age and size. The most basic clinical observations (heart rate, respiratory rate, blood pressure) require different interpretation in childhood. This effect is also seen in the interpretation of blood tests, diagnostic images, electrocardiograms, and electroencephalograms, all of which are age-dependent. Likewise, because of this unique physiology, health interventions for children require special consideration. Many new drugs and procedures have unknown safety and efficacy profiles for children when first introduced. Drug dosing in children is based on weight or body surface area; physiologic differences result in special pharmacokinetic considerations.

Threats to children's health are clearly different from those to adults. Birth defects, infectious disease, and the “new morbidities”—social, psychological, and educational problems—constitute a major component of children's health care.⁶ In the last decade, the identification of psychosocial problems in childhood has increased substantially.⁷ Atherosclerotic heart disease and stroke, major killers of adults, are rare in children; however, opportunities for primary prevention of these common adult catastrophes present themselves during childhood. The common cancers of adulthood (breast, colon, lung) are rare in children, replaced by hematopoietic cancers and tumors of the central nervous system, bone, and kidney. Many common diseases—roseola, bronchiolitis, birth defects—appear uniquely in the pediatric patients, and other disorders that are shared with the adult

population have unique manifestations in childhood. Trauma and accidents, including motor vehicle and firearm-related injuries, are a major source of childhood morbidity and mortality.

In 1988, the National Health Interview Survey on Child Health estimated that 31 percent of children under 18 years of age suffered from one or more chronic conditions, of which 20 percent were mild, 9 percent moderate, and 2 percent severe.³ Only a few decades ago, 80 percent of children with serious chronic disease died.⁴ Yet today, most of these children survive, although they often require complex, ongoing care supplied by multiple health providers, thus creating new challenges for their health care providers and the information technologies that support their care.

Clinical decision support systems must be developed to include knowledge about pediatric pathophysiology and must include electronic support for clinical care of the "new morbidities"; systems designed for adult care currently do not. In addition, systems for pediatric care should facilitate embedding anticipatory guidance reminders into patient care systems and make it possible for providers to tailor anticipatory guidance to each patient.

Community Connectivity to Support Pediatric Care

Currently, the two major health information forces—public health information systems and private health information systems—could greatly benefit from integrated technology solutions that link information about the health of the public with data specific to the care of an individual patient.⁸ Both clinicians and public health officials need access to information about health status, public health risks, and population health issues, including trends in community-centric markers of health.⁸ This need is especially urgent for those providing care for the pediatric population for two major reasons: 1) as the largest group of poor people living in the United States, children require prevention and care for the mental, cognitive, and physical disorders and social problems to which poverty predisposes them; and 2) children receive care for their health needs at diverse sites within their community.

Promoted by the high prevalence of poverty, low birth weight, infant mortality, contagious disease, developmental delay, poor school achievement, childhood injury and death are common problems in pediatric care. Furthermore, 15 percent of children had no health insurance coverage at any time during 1998,

thereby limiting access to health care for 11.1 million children. The communities in which these children live are vital in supporting their health needs, particularly through the public health authorities and the public schools. Therefore, efforts to promote data exchange, information sharing, and electronic communication in the health care communities of these children are essential for meeting their health needs.

Health care for children is provided at sites different from those where adults receive care. Pediatric ambulatory care commonly occurs in the offices of primary care pediatricians and the children's areas of public clinics; inpatient care occurs in children's hospitals or in specially designated areas of adult hospitals, including nurseries and pediatric or neonatal intensive care units. In 1998, 1,157 school-based health centers in the United States provided care for kindergartners through adolescents in both urban and rural areas.⁹ Optimal management of care across these sites requires integration of data collected in ambulatory patient record systems, practice management systems, public health registry systems, school health databases, image retrieval systems, inpatient medical record systems, and systems designed to store the clinical data generated in the intensive care environment.

Data from all these sources are not readily accessible by everyone involved in the health care of a child, nor is there a dynamic communication pathway for information sharing or exchange. One example that demonstrates the need for these technologic enhancements is that pediatricians are called on regularly to generate health summary reports for school entry, summer camps, after-school programs, the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC), and Head Start programs. Such reports typically include immunization records and results of screening tests but may include data on the history of infectious diseases, chronic medications, special health care needs, and physical limitations.

The emphasis in pediatric practices on immunization compliance necessitates efficient and flexible data transmission and communication services. Currently, there is a national movement to develop statewide immunization registries that facilitate data storage and exchange. Immunization recommendations change annually (or more often), requiring a capacity to update these recommendations in information systems quickly and effectively.¹⁰ Immunization practice can benefit greatly from intelligent alerts that provide advice about appropriate immunizations based on

age, immunization history, and contraindications.¹¹ Finally, the substantial costs of data entry to primary care providers must be recognized and the burden shared by the likely beneficiaries.

Consumer Health Information Needs of the Family

Serving the health care needs of a child requires collaboration and partnership between the family and the health professionals at all levels of service delivery. It is important that families receive information on the basic and specialized skills they need to help them care for their children.

Because families are racially, ethnically, culturally, spiritually, and socioeconomically diverse, context-specific consumer health information must be developed to provide both the most sensitive and responsive information resources and tools. Families can be connected through technology to their community health care services, including local physicians, schools, and health services agencies. Systems should support the storage and retrieval of relevant educational materials at several reading levels (pre-adolescent, adolescent, and adult). The health care community must seek the participation of families in the planning and evaluation of these resources to best meet their needs. Policy makers and developers must remain cognizant of the prevalence of poverty in this population to avoid widening the digital divide between the poor and the affluent.

One key aspect of consumer health information for children that requires special consideration is provider-patient communication, particularly around issues of privacy, informed consent, and patient identification. Currently, privacy protections for minors vary from state to state. Information about pregnancy, sexually transmitted diseases, and mental health in childhood has special ramifications. Designers of information systems for care of children and adolescents must therefore relate clinical information (diagnosis codes, procedure codes, problem lists, history and physical data) to the security features of the system in such a way that protected information is secured according to state and federal laws. In addition, consumer health information systems must take these precautions as well, ensuring that appropriate authentication, access control, and audit trails protect the privacy of patients seeking health information and communicating with their providers electronically.

While the majority of children remain in the custody of their biological parents until the age of majority,

many—including adopted children, children in foster care, children of divorced parents, and children in state custody—change custody (and therefore legal guardianship) during their lives. Authorization for care, payment for services, and release of medical records all depend on accurate identification of the person who is acting in the role of the parent. Consumer health information systems that link the family to the health care community can greatly reduce the effort in relating the changing role of guardian to the clinical data kept on the child.

Performing research in childhood disease is complicated by the ethics of surrogacy and informed consent. As a result, there is a relative dearth of randomized clinical trials that identify best practices for the care of children. Parents and guardians have the right, and the responsibility, to provide consent for children as participants in research projects. However, children as young as 4 years of age can assent to participation in research; local practice must be congruent with applicable state laws, balancing the needs of the child with the rights of the parent or guardian. Family-centered consumer health information systems would provide an excellent means of informing both families and their providers about current clinical trials and trends in children's health care research.

Conclusions

Ensuring that information technology better serves the needs of children will require both changes in the way technology is currently used and the acquisition of new knowledge. Participants in the expert meeting proposed both an action plan and a research agenda that included the following elements.

Action Plan

- The technology industry should implement features in health information systems to directly support pediatric care, including graphic growth charting, dosing by weight, access to age-based normative values, clinical decision support, customizable report generators, secure hardware with flexible data entry, robust systems for immunization management, capability to track children with changing identifiers, and systems that can maintain varying levels of security based on sensitivity of the data.¹⁶
- Policy-making and standards-setting bodies should involve a representative group of stakeholders from the pediatric health care community to develop child health information technology policies consistent with community health care

objectives. These groups should also establish policies around the integrity of information sharing and exchange as well as ways to ensure the quality of electronic child health information.

- Educational programs for those providing health care to children should include training in effective uses of information technology. In addition, informatics professional organizations should develop pediatric interest groups among their members to foster research and advocacy for better use of information technology for child health.
- Pediatric informaticians can play a catalytic role by bridging the gap between the pediatric and informatics communities. A forum that facilitates ongoing dialog and exchange of information about informatics issues in children's health care should be convened.
- Consumer health information resources and tools should be developed and managed in partnership with the communities they serve.

Research Focus Recommendations

- Measuring the benefits of enhanced information management systems and subsequent health outcomes for children
- Measuring the true costs associated with electronic medical records systems compared with paper-based methods of record keeping
- Measuring the benefits of decision support technology in the domain of pediatric medicine
- Understanding the epidemiology of iatrogenic injuries in pediatric settings. This new knowledge must be followed by development and evaluation of pediatric-specific interventions, e.g., order-entry systems that handle changing dosage and pharmacokinetic considerations as children mature
- Addressing inadequacies in common and approved standard terminologies when applied to pediatric populations
- Assessing the overall effectiveness and availability of pediatric telemedicine services to low-income and medically underserved families

Many of the proposed activities can be undertaken in parallel. The exception are those that depend on functional electronic health records for children. Immediate enhancements to these products are nec-

essary to provide an information infrastructure that is useful to child health care workers. Since pediatric care is generally a low-margin business and public health agencies rarely have flexibility in their funding, options for public funding of these initiatives must be explored.

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Appendix

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