

A Convocation of Wizards: Synergies at the Intersection of Child Health Care, Public Health, and Information Technology

Richard N. Shiffman

Although great opportunities for synergies exist, experts in children's health care, public health, and informatics often practice in silos—unaware of advances in related fields. The conference "A Vision for Child Health Information Systems: Developing Child Health Information Systems to Meet Medical Care and Public Health Needs," was held in Atlanta, Georgia, December 3–4, 2003 in an effort to break down barriers. Issues—germane to each group and bridging the boundaries between them—are presented. A vision of health care with obstacles removed is described. Experts should work to diminish the insularity that interferes with effective collaboration, focus on the intersections of child health, public health and information technology, and recognize and promulgate the message that one-size technology solutions that are designed for adult medicine don't fit this area of practice.

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This meeting is a convocation of experts—wizards in the domains of child health, public health, and information technology, whose expertise can lead to almost magical achievements. But, oftentimes it seems as though these wizards work in bubbles, experts in their own domains, yet not aware of advances in related fields even though they are fighting the same barriers to progress.

My goal is to focus on areas of common interest that best take advantage of the varied skills and perspectives these 3 types of wizards bring to this table. Because of the unique character of the meeting, it is important to concentrate on those areas where the 3 perspectives

come together. First, I will briefly review a predecessor meeting that addressed similar topics. Next, I will define common interests because that's where synergies occur. Finally, I will describe a scenario in the near future that illustrates how information technology (IT) can improve health and health care for children.

In September 2000, I chaired a similar meeting of wizards that was sponsored by the Agency for Healthcare Research and Quality (AHRQ) and convened by the American Academy of Pediatrics (AAP) Center for Child Health Research. The Information Technology for Child Health (ITCH) meeting was considerably smaller and its focus was largely on setting a research agenda, to "identify the special information needs of pediatric care and the health services research questions related to the use of information technology in children's health care."

That meeting defined a substantial number of research themes and proposed a wide ranging action agenda. When asked what was the main message from the ITCH meeting from a vantage point 3 years later, a senior policy advisor at AHRQ responded that it was the insularity of the stakeholders who attended. We are indeed experts in bubbles.

● Child Health Care

Child health care deals with a truly heterogeneous group of patients from newborns through infant

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Correspondence to: Richard N. Shiffman, MD, MCIS, 662 Derby Milford Rd, Orange, CT 06477 (e-mail: Richard.Shiffman@yale.edu).

Richard N. Shiffman, MD, MCIS, is Associate Professor, Department of Pediatrics, Yale School of Medicine and Associate Director, Yale Center for Medical Informatics, New Haven, Connecticut.

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and child-sized to adolescents. Each group presents certain unique features and needs—that are quite distinct from those of the adult population.

Children under 18 constitute one-fourth of the US population. Yet in many ways, the unique characteristics of child health care do not get the respect they deserve.

A major theme of this talk is that: One size solutions—particularly those designed for adults—often don't work in children's health care.

Like the children themselves, the provider community that takes care of children is also quite varied and often quite distinct from the adult provider community. Caring for children are generalist pediatricians and family practitioners, subspecialists in pediatric disorders—like pediatric cardiologists and pediatric surgeons, specially trained pediatric nurses and nurse practitioners, and child-focused allied health practitioners—pediatric speech therapists, occupational and physical therapists, respiratory therapists, etc. Reaching out to this group of providers requires special effort.

Another important aspect of children's health care is the range of sites at which it is provided. Inpatient care may be provided at freestanding children's hospitals or on special pediatric units of general hospitals, as well as in newborn nurseries, special care units, and Pediatric Intensive Care Units (PICUs). The lion's share of pediatric ambulatory care happens in practitioners' offices, clinics, and neighborhood health centers. But 1,200 school-based health centers are shouldering an increasing load in urban and rural areas.

Finally, the nature of pediatric care differs from that of adult medicine. Illnesses such as hypertension, stroke, and heart attacks—major killers of adults that are often the focus of public health campaigns—are rare events in kids. When children develop cancer, it is rarely the colon, breast, and lung that are involved.

Many common pediatric diseases like roseola, bronchiolitis, Kawasaki's, and birth defects are unique to children. Others, like obesity and diabetes, that are shared with the adult population—have unique manifestations in childhood.

Moreover, pediatric care emphasizes health maintenance to a degree not seen in the adult community. The "new morbidities"—behavior problems, social and family issues, and educational issues—make up a substantial fraction of pediatric practice. Information systems that support children's health care have to ad-

dress these differences. One-sized solutions designed for adult health care don't fit well.

● Public Health

There is considerable overlap between the children's health care and the public health sectors. Some major public health concerns affect children uniquely.

Screening is a basic tenet of public health practice. But children's health care is not concerned with breast masses, pap smears, and colonoscopies. Screening in childhood addresses disorders of cognitive and physical development, and detects hearing and vision problems, and metabolic disorders. It requires different systems from those that support common adult screening programs to be effective.

Likewise, *prevention* in childhood operates in a different realm. Optimizing immunization practice is a cornerstone. Pediatric public health professionals worry about preventing intentional and unintentional trauma and poisonings, about "Back to Sleep" programs to prevent Sudden Infant Death Syndrome. Prevention of obesity and atherosclerosis begins in childhood.

Concerns about *environmental hazards* are also different in pediatrics. Lead in old paint is a scourge of inner-city children. The miniscule amounts of mercury used as a preservative in vaccines may constitute a toxic load for infants, and arsenic, chromium and other environmental toxins pose unique problems for children. Public health wizards with an interest in child health concern themselves with preconceptional and perinatal risks, with the unique vulnerability of children to radiation, and with understanding how contaminants find their way into human milk.

Infectious disease practice and epidemic surveillance are core public health concerns. At the child health-public health intersection, HIV is addressed—not as a disease whose transmission is sexual or via drug abuse—but rather as one that is acquired via the perinatal route, bringing with it sequelae of critically ill infants and motherless children. The list of infectious diseases with unique importance in child health is long, but includes pertussis and respiratory syncytial virus, listeria, group B streptococcus, and infant botulism.

Finally, wizards in *health services* who work in the child health sphere recognize that children are the largest group of poor people in the United States. Fifteen percent of children have no insurance, thereby limiting their access to care. Government support for these children comes not from the federal Medicare program or the VA, but from Medicaid (the silent M in CMS), with heavy reliance on variable state contributions and from programs like State Children's Health Insurance Program (SCHIP) and Women, Infant, and

Children (WIC). Compared with adult medicine, where there's a wealth of randomized controlled trials from which to derive evidence-based inferences, there's a dearth of such knowledge on which to scientifically base pediatric care. The recent passage of the Pediatric Rule by both houses of Congress requiring pharmaceutical manufacturers to test medications for use in children may help to remedy this. With respect to patient safety, it's been verified around the globe that adverse drug events occur in hospitalized children at rates comparable to or greater than those seen in adult settings. The dangers of adverse drug events in children may be even more serious than in adults because children have less physiologic reserve to buffer errors.

● Intersections With Informatics

The third group of wizards at the conference are experts in information technology. And it's information technology that sets this meeting apart from other meetings of child health and public health specialists. Our goal is to focus on the intersection where all 3 disciplines converge—or at least where child health and IT overlap.

All of the traditional informatics categories can relate to child health and public health. Bioinformatics concerns itself with computational support for unravelling the genome, protein structure, and biologic processes. Bioinformatics wizards are already helping to understand the genetic basis of many pediatric disorders and are beginning to engineer pharmacogenetic solutions for children. There is an increasing number of wizards in child health who are also wizards in clinical informatics. In 2 of the last 3 years, the themes of the Spring American Medical Informatics Association (AMIA) session were "Public Health Informatics" and "Vulnerable Populations," demonstrating recognition of the overlap of interest between informaticians and public health wizards.

A critical informatics subspecialty relates to the electronic health record (EHR) and some informaticians are working to ensure that these systems meet the unique requirements of pediatric practice. Others think about how EHRs can be implemented successfully in pediatric practices, where ambient noise levels often preclude dictated notes, and curious minds and hands may destroy equipment that is not battle-hardened. Other IT wizards help to ensure that privacy and security concerns are met and that the return on investment in child health practice is correctly calculated and disseminated.

For the most part, digital standards development organizations have focused primarily on adult medicine.

But, if IT systems are to work in child health, standard vocabularies have to comprehensively address pediatric concepts, information models have to consider the needs of pediatric practitioners, and interfaces to pediatric systems have to lead to real integration of services.

Knowledge-based systems that provide decision support for clinical practice have concentrated largely on the concerns of adult health. Expert systems to support children's health maintenance and pediatric disorders are needed and are being developed. Likewise, drug prescribing errors in pediatrics relate most often to calculation of the correct dosage, not to drug interactions (as is the case in adult medicine). We need systems that will help ensure the correct dosage—so practitioners don't have to carry a \$5 calculator when they're using a million dollar system.

The AAP has taken a leadership role in the creation and implementation of high-quality, evidence-based practice guidelines for care of children that is being emulated by other organizations internationally. We still need to find ways to effectively translate the knowledge in those guidelines into systems that influence clinicians' behavior.

Finally, child health workers need to communicate effectively with children and parents—as well as one another—and IT holds the key to 21st century communication: (1) The world wide Web can be a glue that promotes positive health practice or a carnival of exaggerated claims and deceptive practices; (2) What are the special concerns of successfully using e-mail in pediatric practice, like protecting the privacy of adolescents? (3) Can telemedicine bring the benefits of pediatric subspecialties to areas deprived of specialist manpower? and (4) Can we leverage the success of Nintendo and Game-boy to find creative and engaging ways to improve the health education of our patients?

● Time Machine

Let's use some wizardly magic to move forward 10 years to December 4, 2013.

The National Health Information Infrastructure has been deployed and there is an effectively connected electronic health record in every practice.

Meet Elaine Papadopoulos—17 years old and pregnant at term. She has had a healthy pregnancy with excellent prenatal care provided at her school-based clinic and neighborhood health center.

She plans to raise the baby with her mother, to breast-feed, and to complete her high school education. All would be grand if the baby's father, Eddie Fu, could decide his role.

Before baby girl Papadopoulos is even out of the delivery room, a message has been sent from the hospital

to the Social Security Administration's 24 × 7 electronic system that instantaneously assigns a unique health identifier that is emblazoned in bar code on the baby's and mother's ID bracelets and even on the baby's t-shirt.

On the next morning, the baby receives her first hepatitis B immunization. That information is uploaded to the state immunization registry.

The baby has a heel-stick blood sample sent for screening of 50 now-treatable disorders and receives a hearing screen prior to being discharged.

On the morning after delivery, Elaine names the baby "Rachel." Later that morning, Eddie comes by to say he wants to be a part of the baby's life and wants her to take his name. Luckily, the baby's 3 names in a day (Baby Girl Papadopoulos, Rachel Papadopoulos, and Rachel Fu) are linked to her accumulating health dataset via her stable unique health identifier.

Now comes the time of discharge, a moment associated with serious patient safety concerns because Rachel's care is now being handed off to another care provider. Dropping the baton at transitions such as this can result in serious adverse effects.

Rachel's care is facilitated because she receives—in addition to a birth certificate and footprint sheet—a copy of her neonatal dataset recorded in her personal health record on a smart card. This card can be read and written to by *any* physician, clinic or hospital.

Because of Elaine's age, Rachel's nursery care providers are automatically reminded to put through a referral for a home visit within 48 hours to the local, electronically connected visiting nurses.

It's a good thing they do, because by day of life #4, Rachel is glowing like a pumpkin. Transcutaneous bilirubin measurements transmitted via phone lines and monitored at a central location allow her jaundice to be treated at home and for Elaine to continue nursing.

Elaine takes Rachel to see Dr. Jones for her first health maintenance visit. He inserts her smart card in his reader to automatically update his electronic record. Autonomous agents scour the medical Web looking for pertinent material. Sure enough, the state Metabolic Screening Lab has a report that they've identified: MCADD (medium chain acyl-coA dehydrogenase deficiency), an obscure but increasingly commonly identified disorder. Dr. Jones pushes the InfoButton on his connected EMR to find out more about MCADD and receives a brief summary and then he prints patient information materials for Elaine and Eddie.

Dr. Jones purchased his electronic health record system from a vendor who paid attention to the AAP's

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policy statement on special requirements for electronic medical record systems in pediatrics.¹ In addition to the context specific, decision support for MCADD and other diseases, the EHR offers: (1) easily visible growth charts with norms adapted to special patient populations, (2) systems that facilitate immunization practice, (3) electronic prescribing with integrated dosage calculation based on a patient's weight or body surface area, and (4) effective privacy management with tiered access—especially useful for adolescent health issues, like pregnancy, STDs, and mental health.

As Rachel passed through infancy, she suffered a respiratory infection at 9 months that provided data to the National Electronic Disease Surveillance System, which, in turn, helped to define a background level of disease in the community against which bioterrorism threats and new epidemics could be compared. During a hospitalization at 15 months, a factor of –10 dosing error was prevented by an astute decision support system.

What's important to note is that all of Rachel's care is possible with technology that exists today. What we don't yet have are the systems and infrastructure in place to enable the synergies of child health, public health, and information technologies or the know-how to overcome the social and organizational barriers that impede their successful implementation.

The "take-home" messages are:

- We wizards need to burst our bubbles, to diminish the insularity that interferes with effective collaboration.
- We should focus on the intersections of child health, public health, and information technology.
- We must recognize and advertise that one-size solutions don't fit this area of practice. We need to make our colleague wizards aware that pediatric applications of IT are special.
- And finally, the future is now. Technologies are mature, but the systems to apply them effectively need our attention.

REFERENCE

1. American Academy of Pediatrics. Special requirements for electronic medical record systems in pediatrics. *Pediatrics*. 2001;108:513–515.