

# Perspectives on Integrated Child Health Information Systems: Parents, Providers, and Public Health

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The efforts of families, health care providers, and public health programs to optimize health care and health outcomes for children are often limited by the lack of timely, complete, and accurate health information. Families frequently serve as the messenger between providers in providing clinical details that they may not understand, because the paper record of previous care is unavailable. Providers believe in the value of good information, but haven't the time, training, or financial resources to create better data sharing methods. Public health programs often must rely on unacceptably slow, redundant, or otherwise limited data collection efforts to provide population-based assessments of child health problems that inform public policy and program development. Integrated child health information systems allow the appropriate, secure sharing of health data that are critical to improving these processes. Developing such systems will require a strong commitment from these 3 stakeholder groups and attention to human values as well as technical challenges.

**KEY WORDS:** medical informatics, parents, pediatrics, primary care, public health

For many children, health care is a joint effort between multiple private providers and public health programs where they may receive preventive screenings, immunizations, nutrition services, and early intervention services. Parents, physicians, and public health staff have become all too accustomed to working without critical child health information that is in a medical record somewhere, but inaccessible at the time it is needed most. The following typical responses from parents illustrate the information problems that occur

in pediatric and public health settings across the United States thousands of times each day:

I haven't been able to find his immunization card since we moved but I think he still needs a couple of shots.

It's a little pill that he takes once a day for low thyroid but I don't know the dose and we're all out.

The emergency room doctor last night said that all the tests were normal except one.

WIC was worried and has been weighing her every month.

The school already did a bunch of testing.

His dad took her to the surgeon last time, but we're separated.

It is no wonder that President Bush has made "moving American medicine into the information age" 1 of his 5 health care priorities.<sup>1</sup> All of this missing information is recorded somewhere, but neither parents nor staff can track it down when care is needed. Assumptions and guesses then substitute for complete, accurate, and timely information. The most vulnerable children—with special needs, unstable insurance, or changing providers—are most likely to suffer from the resulting errors and missed opportunities. It is hard to decide which is more troublesome, the routine difficulty in obtaining critical information needed to direct appropriate care or the continuing tolerance of these limitations by all involved.

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### ● Family Perspective

Parents of young children are well aware that health care involves complex information from many sources, and they have expressed a number of recurrent concerns about integrated child health information systems. Parents know their children need an orderly series of assessments, vaccines, and preventive services, and they're generally accepting of electronic information systems to manage health care. Families with children in a stable "medical home" tend to assume all this information will be managed in their doctor's memory, chart, or computer.

However, the many families with multiple sources of care quickly learn that information access and transfer can be a recurrent hassle, with delays and difficulties in emergency departments, specialty offices, public clinics, etc. Families also report that they must often be the messenger among providers for test results, consultations, prescriptions, and past treatment experience, trying to prevent inappropriate treatment due to missing information.

Many families are concerned about timely access to their child's health history in emergency situations, and they often name drug reactions as an example of threats that would be averted with an electronic information system. Parents are also aware that getting immunizations on time is important, but face the challenge of frequently changing and increasingly complex schedules, and maintaining records required for child care and school entry.

A small, but often vocal, proportion of parents are suspicious of large central data systems, in private or especially public hands. Some parents actively want to possess and manage their child's medical information, and request access to review and even revise data or add their own comments. However, most simply want the information to be accessible, accurate, secure, and efficiently managed. Every child health information system has recognized privacy and confidentiality concerns, and most have developed educational materials, access protocols, and other measures to assure parents of protections against inappropriate use. A few parents have extra concerns that children's data be kept from employers, noncustodial parents, child welfare workers, etc., and request deletion or selective blocking of information. Most modern child health informa-

tion systems therefore include careful restrictions, and even licensed professionals only have selective access to information they "need to know."

### ● Provider Perspectives

Integrated child health information systems exist to move data to and from child health service providers. Indeed, it is the complexities of care and the many different providers who may become involved that have driven interest in the development of these systems. Child health information systems must also connect to ancillary providers such as labs, hospitals, pharmacies, and possibly to child care centers, school nurses, and other sites that need child health information. Understandably, providers think more about information they need to receive than information others request from them, but they recognize the needs and costs of both afferent and efferent channels. They would prefer to have an efficient, friendly, flexible, reliable, integrated source of everything they need to know, and a seamless, costless, HIPAA-compliant transmitter of data to others. Unfortunately, their daily practice reality regarding clinical information is characterized by gaps, overload, errors, non-integrated systems, and an expensive, growing administrative staff trying to manage it all.

Although some providers confuse the two, an integrated child health information system is not an electronic medical record. Integrated information systems create standardized networks that allow for the exchange of selected information with all authorized providers. These systems can exchange essential data with an electronic medical record but will not include all the clinical information in a primary provider's "chart." It is important to be clear and realistic about the promised benefits of such selected data sharing, as opposed to a fully computerized health record.

An integrated child health information system could give providers more complete and timely information on immunizations, medications, and certain tests, enrollments, and services their patients receive outside of the practice. The integrated system should also make it easier for providers to send these sorts of data to other providers, schools, etc. These transfers should be efficient, prompt, and must be compliant with HIPAA. It is often possible for the system to generate parent reminder notices, cohort profiles of immunization gaps, flags for critical lab values or drug allergies, and other important tools for outreach. Some systems also help document lab results, vaccine lot numbers, etc. There are significant quality-of-care dividends for providers, but these systems may not diminish many of the other frustrating information challenges in daily practice. Providers commonly remark that they are eager

for good information about services their patients' receive from other clinics, WIC, early intervention programs, schools, and emergency rooms, and they are very enthusiastic about more efficient ways to transfer information to schools, public health programs, and families.

An integrated information system has great uses for quality assurance in the practice, which is a 2-edged sword. Profiles of clinical practice performance in areas like immunization and screening rates become much more efficient and sensitive for both the practitioners and external stakeholders, such as insurers and health authorities. Physicians sometimes worry that these profiles will be used to evaluate their work, without full knowledge of the environment, or the complex needs of the children they see. Furthermore, the financial benefits accrue mostly to insurers, creating misaligned incentives that may discourage provider investments.

Physicians and their staffs are also quite skeptical about large electronic information systems, after years of frustration with recalcitrant insurer billing and authorization systems. They have been forced to give up nurses and other front-line caring staff, substituting "back office" personnel to "deal with the paperwork." Doctors still see themselves as beleaguered independent professionals and small entrepreneurs, and assume their existing records (and their care) are quite complete and accurate. All this makes some doctors dysphoric about new, demanding data systems in their offices.

## ● Public Health Perspectives

Public health is involved in both delivering personal health care services and implementing population-based interventions and policies. As providers of pediatric health care, public health programs share many of the hopes and concerns regarding integrated clinical information systems mentioned previously. And many of the population-based information needs in public health are similar to those faced by researchers, employers, health plans, and community organizations such as schools and advocacy groups. The unique purview of federal, state, and local public health agencies includes assurance of universal preventive services, disease surveillance, health care regulation, and community-wide health data collection and analysis, and each has specific information requirements that could be better met if integrated clinical information systems were in place.

Assurance of preventive services is the original mandate of most integrated child health information systems, usually as immunization registries. Now, the advantages of integration with newborn screening, lead

testing, nutrition assessments and services, etc., has expanded many of these systems, making them a much richer resource for both community practices and for public health management and leadership.

Community disease surveillance and response involves the epidemiologic investigation of diseases that have preventable infectious or environmental causes, many of them predominant among children. The traditional methods of physician reporting of notifiable diseases are slow and incomplete and are known to have resulted in missed or delayed identification of important disease clusters or outbreaks. Current initiatives to develop electronic laboratory and syndromic reporting to public health agencies are promising improvements, but would be more effective if integrated into a general clinical information network used daily by providers.

Licensing of child health care providers such as hospitals, long term care facilities, emergency medical services, and other settings, including child care, is currently based primarily on a system of periodic routine inspections or testing, and complaint investigations. Unfortunately, there are often gaps and delays in this work, mostly due to understaffing. Aggregated, de-identified, provider-based clinical information would allow regulators and facilities to focus more on outcomes-based health care quality and less on processes, which is all that can now be reasonably assessed. Many providers would resist such "profiling" unless the regulatory model changed to emphasize incentives for improvement rather than merely deficiencies.

Community-wide child health data, currently collected primarily through birth and death certificates and surveys, could be augmented by using clinical data to monitor critical common child health problems like prematurity, obesity, injuries, immunization compliance, and teen pregnancy. And accuracy of existing birth and death certificate data could be greatly improved if supplemented with objective clinical information. This latter application would require public health to use identifiable information demanding careful attention to responding to public concerns about government's use of such data, regardless of the agency's legal authority to do so. An opt-out method of consent could neutralize the very small percentage of the population who object to such public health measures.

In addition to these 3 unique roles, public health also conducts population-based interventions in partnership with the community and private health care system, such as targeted health promotion, chronic disease control, improving access to care, health workforce enhancement, and addressing ethnic and minority health disparities. Each of these activities has a strong emphasis on childhood diseases and could use population-wide clinical information to improve program planning and evaluation. Many public health programs, such as

Medicaid, SCHIP, WIC, and immunizations, already have some form of electronic information systems. It is the connection of these systems with providers of community clinical services that is lacking, limiting the usefulness of available information, and efficacy and coherence of care for both programs and families.

## ● Conclusion

Surveys have documented that that 90% of health care transactions are still conducted by phone, fax, or mail-in forms that cannot be easily captured into a patient record and that an average of 4 pertinent pieces of patient information are missing in 80% of clinic visits.<sup>2,3</sup> This is a curious paradox in an enterprise founded on empiricism and one where the critical data for decision making at the patient and population levels is voluminous, complex, evolving, and interdependent. Some would cite this daunting scope of information management in health care as the very reason we lag behind other industries in developing functional integrated systems. Others speculate that this situation simply mirrors the lack of a logical and integrated organizational structure across health care delivery itself. Special privacy concerns, misaligned returns on investment, and data ownership questions mentioned previously also create unique challenges.

But human barriers, the lack of will, the desire for control, and resistance to change, more than the technical challenges, are also holding us back. As stated at the beginning, the provider and patient must be at the center of this effort. Many physicians are impatient with the kind of extended group processes required to plan and implement such information systems, and families are not well organized for this purpose and, therefore, not easy to engage in more than a token way. Health information has become a commodity that competing health delivery systems use for underwriting and to direct the utilization choices of their patients, and many are reluctant to surrender it to the greater good of improving patient care across the system. And while hospitals and parents are generally comfortable with computer-based transactions, many outpatient providers would need to retrain themselves and their staff and reorganize their offices to adjust workflow and improve their technical support before incorporating electronic clinical information.

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The availability of complete, accurate, and timely health care information is the key to understanding and addressing many of the most significant cost, quality, and access issues we face in child health care. These include both patient and population-based concerns, such as medical errors and quality improvement, compliance with clinical preventive services, chronic care management, clinical research, unnecessary or duplicated care, health care workforce supply and distribution, communicable disease surveillance and response, and patient and family participation in care processes. For young children, these issues are compounded by the reliance on a parent to act as a secondary historian, the high rates of mobility and fragmentation among young families, the complexity of pediatric treatment plans due to developmental issues, and the very number of distinct public and private child health services. Yet, children are the most critical and vulnerable beneficiaries of a coherent integrated system of prevention. By sharing good information among parents, providers, and public health programs, we can deliver the promise of healthy development for all kids.

Experience has shown that there are right and wrong ways to go about the task of creating integrated clinical information systems.<sup>4</sup> Failed attempts can leave participants with years of skepticism and reluctance before they are willing to try again. As communities prepare to go forward, they must first learn the lessons of successful and failed efforts and then proceed in a measured, methodical, and undeterred manner. Parents, providers, and public health officials recognize that integrated child health information systems must be developed as part of rather than separate from general health information integration efforts that solve similar problems for adult patients and their providers. But children are considered a “special population” in most general health care initiatives, and so these 3 major pediatric stakeholders must join together and stay together throughout this endeavor, working around the obstacles to consensus or compromise, and always staying focused on what is the right thing to do for children.

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