Cristoph U. Lehmann George R. Kim Kevin B. Johnson *Editors*

Pediatric Informatics

Computer Applications in Child Health



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Pediatric Informatics

Computer Applications in Child Health



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Series Preface

This series is directed to Health care professionals who are leading the transformation of health care by using information and knowledge. Historically the series was launched in 1988 as Computers in Health Care, to offer a broad range of titles: some addressed to specific professions such as nursing, medicine, and health administration; others to special areas of practice such as trauma and radiology; still other books in the series focused on interdisciplinary issues, such as the computer based patient record, electronic health records, and networked Health care systems. Renamed Health Informatics in 1998 to reflect the rapid evolution in the discipline known as health Informatics, the series continued to add titles that contribute to the evolution of the field. In the series, eminent experts, serving as editors or authors, offer their accounts of innovations in health Informatics. Increasingly, these accounts go beyond hardware and software to address the role of information in influencing the transformation of Health care delivery systems around the world. The series also increasingly focused on the users of the information and systems: the organizational, behavioral, and societal changes that accompany the diffusion of information technology in health services environments.

Developments in health care delivery are constant; most recently developments in proteomics and genomics are increasingly becoming relevant to clinical decision making and emerging standards of care. The data resources emerging from molecular biology are beyond the capacity of the human brain to integrate and beyond the scope of paper based decision trees. Thus, bioinformatics has emerged as a new field in health informatics to support emerging and ongoing developments in molecular biology. Translational informatics supports acceleration, from bench to bedside, i.e. the appropriate use of molecular biology research findings and bioinformatics in clinical care of patients.

At the same time, further continual evolution of the field of Health informatics is reflected in the introduction of concepts at the macro or health systems delivery level with major national initiatives related to electronic health records (EHR), data standards and public health informatics such as the Health care Information Technology Standards Panel (HITSP) in the United States, Canada Health Infoway, NHS Connecting for Health in the UK.

We have consciously retained the series title Health Informatics as the single umbrella term that encompasses both the microscopic elements of bioinformatics and the macroscopic aspects of large national health information systems. Ongoing changes to both the micro and macro perspectives on health informatics will continue to shape health services in the twenty-first century. By making full and creative use of the technology to tame data and to transform information, health Informatics will foster the development and use of new knowledge in health care. As coeditors, we pledge to support our professional colleagues and the series readers as they share advances in the emerging and exciting field of Health Informatics.

> Kathryn J. Hannah Marion J. Ball

Foreword

Clinical informatics by its very nature is flexible, interdisciplinary, and dynamic. Ever changing, ever adjusting to novel clinical needs and emerging information technologies, it focuses upon a constantly moving target. If the field is so dynamic, why is a text still useful in a Web 2.0 era? Two major reasons come to mind.

First, pediatric informatics is a new and emerging field and it is crucial that learners have access to a definitive source that lays out the boundaries of the discipline. This book does just that for the first time and does it well. It will be very apparent to the reader that the discipline is growing exponentially, supporting routine clinical care, offering more timely communications with parents and patients via personal health records, transforming practice through dynamic decision support, linking data to population and public health objectives, and supporting clinical and informatics research.

Second, clinical informatics can enhance equity, safety, efficiency, timeliness, and effectiveness and can make the patient, the child or adolescent along with his or her loved ones much more the center of action. While the book contains chapters on informatics topics that are not unique to pediatrics, its authors focus on the direct linkage of informatics and information technology to pediatric clinical work. They illustrate through many examples the transformative potential of informatics to impact positively on pediatric practice by addressing longstanding weaknesses of solely memory-based clinical care and strengthening connections among families and caregivers through communications technology.

Clinical informatics will play a vital role in defining new standards for clinical excellence. The American Medical Informatics Association (AMIA) believes the pool of health professionals who bring informatics knowledge, attitudes, and skills to clinical domains such as pediatrics must expand and deepen. For the last several years, AMIA has worked (with support from the Robert Wood Johnson Foundation) to create a medical sub-specialty of clinical informatics for all 24 boards recognized by the American Board of Medical Specialties. In 2008, it began active work to strengthening training and establishing informatics certification for other doctorally-prepared clinicians (e.g., nurses, pharmacists, and dentists among others).

I am confident that pediatricians will constitute a solid part of this expanded pool of clinical informaticians. Indeed, until such properly trained pediatric informaticians working in interdisciplinary teams can integrate informatics and communications technology into practice, children and their families will be the lesser for it. This text will prove useful to a wide set of readers interested in clinical informatics and serve as an anchoring text for the emergence of a new full member of the health care team, the well-trained clinical pediatric informatician.

Don E. Detmer, MD, MA, FACMI, FACS President and CEO, American Medical Informatics Association, Bethesda, MD Professor of Medical Education, University of Virginia, Charlottesville, VA

Preface

This book is the product of over 2 years of collaboration by colleagues who have been involved in pediatric informatics. The evolution of this community has been driven by common interests of pediatricians that have coalesced because of increasing concerns about patient safety, the desire to improve and measure the quality of patient care and the growing realization that health information technology has much to offer to improve child health, but that it must be tailored to meet those needs. The growth of the community has been facilitated by the increasing availability and use of e-mail and other communication tools by pediatricians, which has kindled interest.

Many pediatricians became acquainted with pediatric health information technology (health IT) and informatics through a special interest group (SIG), the Section on Computers and Other Technologies (SCOT) in the American Academy of Pediatrics (AAP). This informal group of pediatricians, assembled by pediatrician Byron Oberst, MD FAAP, met once or twice yearly, sharing explorations and experiments with "new" computing technologies (remember the Newton?) in practice. Through the 1990s, the AAP moved from being primarily a paper-based information organization to a "wired" one, moving publications, member notifications (of events such as changes in immunization schedules) and child advocacy to the electronic superhighway. SCOT and the affiliated Task Force on Medical Informatics (TFOMI) became the Steering Committee (SCOCIT) and currently is the Council on Clinical Information Technology (COCIT). Membership grew and COCIT is now a source of educational programs, policy statements, and technical expertise on health IT as it applies to child health and pediatric management.

The community has been buoyed by connections to other communities, ranging from university informatics training programs (supported by the National Library of Medicine), health information exchanges (HIEs), government agencies, patient safety groups and other domains, including pediatric nursing, pediatric pharmacy, and medical education. In all these arenas, there have been pediatric leaders who have helped shape the agenda of pediatric informatics.

We live in an "interesting time" as the US faces many challenges. Pediatric practices face new and growing pressures for accountability and reporting of quality measures as well as the need to improve practice and demonstrate value. Health IT can provide solutions but currently has low adoption in practice and requires financial investment and risk that practices that operate at low margins including safety net clinics may not be able to afford, given the current economic climate and the increasing costs and complexities of care (such as interruptions in vaccine availability). In addition, for pediatric practices, some aspects of health IT and standards is still in development. These factors, among others, have been the driving force for the creation of this text.

The intent of this book is twofold. One is to introduce pediatricians to current concepts in health IT relevant to child health and to provide linkages to available literature, resources and expertise and experience on the various topics covered. The second is to introduce informaticians and other health IT professionals to the needs and nuances of child health with regard to technology and information standards development. It does not replace authoritative texts in pediatrics or medical informatics, but creates necessary connections in this area of clinical informatics.

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How to Use This book

This book is the first attempt at a comprehensive text on Pediatric Informatics. Compiling the information took over two years and fifty authors. Pediatrics is an ever changing science and research in Pediatric Informatics continues to generate new knowledge. While this book represents the compiled knowledge of the editors and authors of the field, readers are advised to use the information as a basis for further research. This book will serve as a starting point for health IT implementation endeavors, but it does not absolve readers from conducting further due diligence efforts. The editors and the authors are not endorsing any of the products mentioned in this book.

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