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Thomas Wetter

Consumer Health Informatics

New Services, Roles, and Responsibilities

With contributions by
George Demiris, Amanda K. Hall, Andrea Hartzler,
Jina Huh, Georgios Raptis and Lisa M. Vizer



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Thomas Wetter
Institute for Medical Biometry
and Informatics
University of Heidelberg
Heidelberg, Germany

Department of Biomedical
Informatics and Medical Education
University of Washington School of Medicine
Seattle, WA, USA

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Foreword

After years in the making, consumer health informatics is coming of age. People measure their physiological reactions, monitor their diets, network with others, track their physical activity, search the Internet, communicate with clinicians, and otherwise use information technologies to support taking care of themselves. Enthusiastic reports tout this key area of health informatics as the way to patient empowerment and improved health care. In this welcome and refreshingly balanced book, Thomas Wetter thoughtfully reflects on the promise and potential of these new technologies and examines attendant social changes and ethical considerations.

This book was some years in the making. Thomas had been working on it since before he asked me to participate in a panel at the 2013 American Medical Informatics Association (AMIA) Annual Symposium [1]. He became cochair of the International Medical Informatics Association's Working Group on Consumer Health Informatics in 2007 and chair in 2010. The group's focus on, in the 1996 words of the US General Accounting Office, "the use of modern computers and telecommunications to support consumers in obtaining information, analyzing unique health care needs and helping them make decisions about their own health" dates from its founding in 2000 [2]. AMIA's Consumer and Health Evaluation Working Group (renamed the "Consumer Health Informatics Working Group" and, most recently, the "Consumer and Pervasive Health Working Group") already was operating. Then-president Patricia Flatley Brennan asked me to head a Consumer Informatics Task Force to help guide AMIA more into this emerging area. The following year, AMIA's 2000 Spring Congress included a track on consumer health informatics. It was apparent that patients could be empowered and enlightened while forging new relationships with providers by using computers [3].

During the previous ten years, investigators had developed a variety of applications. They were for medication adherence, smoking cessation, appointment reminders, health behavior counseling, and more. By 2004, consumer health informatics was mature enough for Springer books highlighting the accomplishments. Springer published *Consumer Informatics: Applications and Strategies in Cyber Health Care*. Its preface credited pioneers of the previous decade, including Warner Slack and Thomas Ferguson, who presented a tutorial at the 1993 AMIA annual

symposium. Tom Ferguson coined the term “consumer health informatics” [4]. *Consumer Health Informatics: Informing Consumers and Improving Health Care*, to which I contributed, came out the following year [5]. *Investing in eHealth: What It Takes to Sustain Consumer Health Informatics* followed soon after [6]. Such books included chapters on patient empowerment and collaborative health care, designing and delivering patient-centered information, home care technologies, patient perspectives and expectations, patient-patient and patient-provider communication, ethical issues, evaluation methods, privacy and security, implementation models, and case studies.

Interest kept growing and technologies kept developing. Companies and health care organizations set up patient portals, personal health records, and social networks among patients. More and more, people got and shared health information from the Internet and Web-based services. In the USA, the 2009 Health Information Technology for Economic and Clinical Health (HITECH) Act promoted electronic medical records. They were envisioned to be linked eventually to patient portals, personal health records, and other patient-provided information. Part of the Patient Protection and Affordable Care Act of 2010 established the Patient-Centered Outcomes Research Institute (PCORI) with a mandate “to improve the quality and relevance of evidence available to help patients, caregivers, clinicians, employers, insurers, and policy makers make informed health decisions.” Patients were included in order to ensure that PCORI focused on questions and concerns patients considered most relevant [7]. Health-related smart phone applications and wearable devices became popular, and Springer published a recent volume on mHealth [8].

Consumer Health Informatics: New Services, Roles and Responsibilities reflects the burgeoning interest in meeting collaborative health information needs of consumers and providers. It admirably achieves several purposes. For those wanting an overview of consumer health informatics, it provides a helpful classification scheme based on the roles of consumer and clinician. It also gives a detailed accounting of numerous studies, products, applications, and trends that characterize the consumer health informatics landscape.

In addition, this book contributes to many areas laid out at early conferences and the founding of the IMIA and AMIA Consumer Health Informatics Working Groups. Chapter after chapter, it addresses topics brought to attention then and still being discussed [3]. Thomas carefully tests and explores both visible and behind-the-scenes aspects of using the technologies. He skillfully dissects what consumers may not know about sources of information they are being provided, contracts to which they are agreeing, and potential effects of applications they are using. He provides pointers to improve usability. As a result, readers can make wiser decisions about the whats and hows of the range of applications and technological platforms. Thomas’s careful and insightful work provides a model for others.

But this book does far more by interweaving a constant thread of ethics into the discussion. Thomas starts with his concern for patients and what will become of them as an aging population faces a shortage of in-person care. His underlying compassion and patient-centeredness permeate this book. He explores social, ethical, and legal issues together with health consequences in consumer health informatics. He laudably goes beyond the more common topics of privacy, licensure,

and regulation, though they, too, are well discussed. For Thomas, patients come first. Their feelings, capabilities, needs, opportunities, achievements, and outcomes are paramount while he also highlights potential risks and limitations of the ways the technologies can be used. I became more sensitive to these concerns when interviewing participants in a trial involving a patient-facing application [9, 10]. I believe them pressing enough to have since reviewed general ethical issues as well as legal ones [11–13]. Thomas’s thoughtful tempered analysis is an important contribution to these growing areas of health information technology ethics.

This volume not only fills a gap in the literature but also lays out ways to think about issues in health informatics. These issues come to the fore in consumer health informatics, but need to be addressed more generally. I know readers will find, as I do, that this comprehensive and useful book is a valuable addition to our field.

New Haven, CT, USA
2015

Bonnie Kaplan, PhD, FACMI
Yale University

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Preface

When I had joined Heidelberg University in 1997 and had developed the classes I was supposed to teach, I started looking around for a long-term challenge that should guide my efforts for the next couple of years. It was the time when large companies sent best agers in droves into early retirement because so many young applicants would fill the ranks and cost less salary. It was, however, also the time of the first reports, e.g., by OECD, that warned of a thinning workforce and an avalanche of retirees. Being in health care and knowing that the avalanche of retirees meant an avalanche of patients, I came to the conclusion that “Affordable Health for Aging Societies” should be my mission. AHAS was written in block letters on my white board to always remind me.

But how to proceed? Before it had taken concrete shape on my mind, I attended a health IT conference in Portland (OR) and heard Enrico Coiera give a keynote address that mounted to the conclusion that, to let the health care system survive the avalanche, 80 % of medical care would have to be self-service medicine in 2020.

Well, keynote is keynote. But Enrico’s central idea was crystal clear to me immediately: My mission would be employing ICT to enable the patient to actively play a safe role in his health care. This is what had been coined Consumer Health Informatics a few years before.

Meanwhile, Consumer Health Informatics is coming of age. Being twenty-some years old it should find its place in health care not too far in the future. I dearly hope that this volume will be instrumental to that end because I believe that from the facts and conclusions about the diminishing future health care workforce, a moral obligation for health professionals to pursue Consumer Health Informatics can be deduced. Following a keynote that Ted Shortliffe gave at the AMIA Annual Symposium 2013 “Informatics Is a Health Profession”: We as a health information profession are not marginal but central to this end. The moral obligation that I feel has been among my personal motives to keep pushing for quite a while to finish this book. It is summarized in the very last section of the book (Sect. 17.12). It builds on progress and consolidation in many fields also covered in this volume.

I believe that this is a necessary book because the field still is in a chaotic state. This is evident from Sect. 1.6 and from countless partially contradictory examples.

Well, chaos is not bad in its own right. Great ideas can emerge from chaos. However, when it becomes serious in terms of patient safety, we should at least understand, better, control the chaos. The field is not only at chaos but also wildly dispersed. This relates to the journals where scholarly articles are published (cf. Sect. 1.6.4) and also to numerous underwhelming funding and business models, while the preferred stakeholders (health plans or governments, depending on model of health care finance) are reluctant to commit themselves.

Despite all these concerns it seems doable. So many experiments presented in this volume show promising results, and our understanding of how to address risks grows (cf. Sect. 17.11). And there are great opportunities beyond attenuating the effects of the future health care workforce shortage. Rather than just offering approved knowledge and supporting approved procedures, Consumer Health Informatics sets out to become an independent source of new knowledge (cf. Sects. 6.3.3 and 9.10.3).

A book like this cannot be written in one year. It actually took more than five years, with some on and off due to other obligations that a full professor has. That seems to imply that some parts are five years old, some five days. This is true and false at the same time. It is true that some chapters were conceived five years ago and some three months ago. That seems to imply that some chapters are outdated, while others are up to date. This, again, is true and false at the same time. It is true that not each and every paragraph reflects the absolutely newest state. Rather did we, my coauthors and myself, do our best to write a principled account of the field. We developed arguments about opportunities and risks, methods for safety, effectiveness, human comprehension and literacy, etc. and identified examples that would underline our arguments and illustrate our methods. Some examples indeed vanished while we wrote whereas others came into existence. But the principles and methods do not expire within a pentad. We hope that ours hold for a decade (or so). If that is the case the book will have its value for another five years (or so). The reader can bring up his own new examples and match them against the arguments and methods. As time passes he will find examples that no longer match. That is why we as authors should start now with the next edition. If our spouses allow.

A book like this cannot be written without many people's help and backing up. First of all I have a great publisher. Early on Grant Weston has given me the confidence that I can concentrate to write a nice book and that Springer would make it look nice. Which saved me days, if not weeks, to tweak out millimeters and points to squeeze content on a page. Grant has also given well-appreciated advice where to allocate and where to withdraw effort. And his patience with my ongoing delays was incredible.

I had numerous people who gave their advice in various forms, many serving as critical chapter readers or pointing me to priceless resources. They are (in alphabetical order, and I dearly hope that I do not miss anybody):

- Michael Ashton
- Axel Bauer
- Leslie Berger

- Mike Conway
- Paul Fearn
- Sebastian Grommes
- Marten van der Heijden
- Konstantin Kinzel
- Tugba Kutun
- Marion and Joachim Lammarsch
- Tom Moore
- Peter Nawroth
- Alexander Rieß
- Lou Ann Scarton
- Ulla Wetter
- Gaby Wildenbos
- Thomas Willert

Furthermore I received wonderful feedback and challenges from the students in my classes that I taught in Salt Lake City, Amsterdam, Brisbane, Seattle, and Heidelberg.

My two academic homes also contributed magnificently. I had and still have wonderful discussions with my colleagues in Seattle with Wanda Pratt and Andrea Hartzler giving the most inspired impulse. I also found many articles in the UW electronic library that were nowhere else at my disposal. My colleagues in Heidelberg and Heilbronn tolerated delays and timeouts that I took to an extent that went far beyond what can be expected. Our department head Petra Knaup kept encouraging me and mildly pushing me and never lost her patience.

But above and before all, my family has tolerated my mental absenteeism with unbelievable patience. My parents Paul and Irmgard Wetter, nee Michels, passed away too early to see it finished. They would have been so proud. My grandchildren Josua, Daniel, and Timon probably do not remember at all that there was a time when grandpa was *not* writing a book. My children Anne-Mareike, Miriam, Marius, and Daria do remember, but they, too often, did not dare ask or involve me in activities that took more than a couple of hours.

Comes my beloved wife of nearly forty years, Angelika. For her, I was next door and still far away half an eternity. She has kept things going and has backed me up where I was in charge and whenever I felt really bad comforted me “We’ll do it after the book.”

Angelika, thank you a thousand times.

Heidelberg, Germany
March 28, 2015

Thomas Wetter

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