Health Informatics

(*formerly Computers in Health Care*)

Kathryn J. Hannah Marion J. Ball
Series Editors

Health Informatics Series

(formerly Computers in Health Care)

Series Editors
Kathryn J. Hannah Marion J. Ball

Dental Informatics
Integrating Technology into the Dental Environment
L.M. Abbey and J. Zimmerman

Ethics and Information Technology
A Case-Based Approach to a Health Care System in Transition
J.G. Anderson and K.W. Goodman

Aspects of the Computer-Based Patient Record
M.J. Ball and M.F. Collen

Performance Improvement Through Information Management
Health Care' s Bridge to Success
M.J. Ball and J.V. Douglas

Strategies and Technologies for Healthcare Information
Theory into Practice
M.J. Ball, J.V. Douglas, and D.E. Garets

Nursing Informatics
Where Caring and Technology Meet, Third Edition
M.J. Ball, K.J. Hannah, S.K. Newbold, and J.V. Douglas

Healthcare Information Management Systems
A Practical Guide, Second Edition
M.J. Ball, D.W. Simborg, J.W. Albright, and J.V. Douglas

Healthcare Information Management Systems
Cases, Strategies, and Solutions, Third Edition
M.J. Ball, C.A. Weaver, and J.M. Kiel

Clinical Decision Support Systems
Theory and Practice
E.S. Berner

Strategy and Architecture of Health Care Information Systems
M.K. Bourke

Information Networks for Community Health
P.F. Brennan, S.J. Schneider, and E. Tornquist

Informatics for the Clinical Laboratory
A Practical Guide
D.F. Cowan

(continued after index)

James E. Demetriades Robert M. Kolodner
Gary A. Christopherson
Editors

Person-Centered Health Records

Toward HealthePeople™

Foreword by Janet M. Corrigan

With 42 Illustrations

Springer

James E. Demetriades, BS, MS, PE
Chief Health Information Architect
Department of Veterans Affairs
Veterans Health Administration
Albany, NY
USA

Robert M. Kolodner, MD
Chief Information Officer
Department of Veterans Affairs
Veterans Health Administration
Washington, DC
USA

Gary A. Christopherson, MS
Senior Advisor to the Under Secretary for Health
Department of Veterans Affairs
Veterans Health Administration
Washington, DC
USA

Series Editors:
Kathryn J. Hannah, PhD, RN
Adjunct Professor, Department of
Community Health Science
Faculty of Medicine
The University of Calgary
Calgary, Alberta T2N 4N1
Canada

Marion J. Ball, EdD
Vice President, Clinical Informatics
Strategies
Healthlink, Inc.
Baltimore, MD 21210
and
Professor
Johns Hopkins University
School of Nursing
Baltimore, MD 21205
USA

Library of Congress Cataloging-in-Publication Data
Person-Centered Health Records: toward healthepeople / James E. Demetriades,
Robert M. Kolodner, Gary A. Christopherson, editors.
p. cm.
Includes bibliographical references and index.
1. Medical care—United States. 2. Medical economics—United States.
3. Health care reform—United States. I. Title: Healthy people. II. Demetriades, James E.
III. Kolodner, Robert M. IV. Christopherson, Gary A.
RA395.A3H432 2005
362.1′0973—dc22 2004052211

ISBN 0-387-23282-6 Printed on acid-free paper.

Health*e*People is a registered trademark of the Veterans Health Administration, Number 2,732,137 in the U.S. Patent and Trademark Office, effective July 1, 2003. The bold-underscore-italic formatting is standard usage in the Department of Veterans Affairs; the style was simplified to italics only for the purposes of readability in this book.

Printed in the United States of America. (BS/SB)

9 8 7 6 5 4 3 2

springeronline.com

This book is dedicated to all those around the world committed to transforming health care by

- *Creating systems that are truly person centered*
- *Empowering individuals to participate directly in managing their own health*
- *Making it possible to exchange health records electronically, effortlessly, and securely.*

Foreword

In 2001, the Institute of Medicine released the report, *Crossing the Quality Chasm: A New Health System for the 21st Century*, calling for fundamental change in the American health care delivery system. The IOM report identified six aims for improvement: health care should be safe, effective, patient centered, timely, efficient, and equitable. The IOM report laid out a vision of a future health system that is carefully and consciously designed to respond to the needs, preferences, and values of patients *and* one that ensures that patients are fully informed, retain control, and participate in care delivery, whenever possible.

Person-Centered Health Records: Toward HealthePeople further refines this vision and provides a blueprint for moving forward. Focusing on people—as consumers, patients, enrollees, and members—the report makes a compelling case for the creation of a "virtual health system" that encompasses the full range of services available to assist people in managing their health and health care.

The goal is better health, but the critical enabler is information technology. Building on the extraordinary e-health accomplishments of the Veterans Health Affairs, the editors have brought together contributors from public and private sectors alike. These authors provide an ambitious, but achievable, agenda for establishing an electronic infrastructure that includes personal health records for individuals, electronic health records for providers, and the necessary information standards and supports to enable appropriate health information exchange.

The "virtual health system" will fundamentally alter the interactions among the members of a care team, and the relationships between health care providers and patients. There is little doubt this new health system will open up many opportunities to improve the health of populations and individuals, but the journey will not be an easy one.

The contributors to this book recognize the magnitude and complexity of the change process, and the importance of attending to both technological and human factors. Building a virtual health system will require talented and committed leadership at all levels of the health system. Through their collective knowledge and experience, the editors and authors of *Person-Centered Health Records* provide a wealth of information and excellent guidance to all who are involved in the journey of *Crossing the Quality Chasm*.

Janet M. Corrigan

Series Preface

This series is directed to healthcare professionals who are leading the transformation of health care by using information and knowledge to advance the quality of patient care. Launched in 1988 as Computers in Health Care, the series offers a broad range of titles: some are 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 focus on interdisciplinary issues, such as the computer-based patient record, electronic health records, and networked healthcare systems.

Renamed Health Informatics in 1998 to reflect the rapid evolution in the discipline now known as health informatics, the series continues 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 innovation in health informatics. Increasingly, these accounts go beyond hardware and software to address the role of information in influencing the transformation of healthcare delivery systems around the world. The series also increasingly focuses on "peopleware" and the organizational, behavioral, and societal changes that accompany the diffusion of information technology in health services environments.

These changes will shape health services in the new millennium. By making full and creative use of the technology to tame data and to transform information, health informatics will foster the development of the knowledge age in health care. As coeditors, we pledge to support our professional colleagues and the series readers as they share the advances in the emerging and exciting field of health informatics.

Kathryn J. Hannah
Marion J. Ball

Preface

Ideas and trends can be as contagious as viruses. Seemingly unrelated, small events can mount to epidemic proportions, and "the slightest push" in "just the right place" will change everything. This is what Malcolm Gladwell (2000) calls the Tipping Point, a unique moment "when everything can change all at once."

After decades of changes, health care is approaching this transforming moment—and we want to be among those who deliver the push in the right place, creating a new system, a "virtual health system," that delivers the greatest good to the greatest number. We believe, as does Gladwell, that "In the end, Tipping Points are a reaffirmation of the potential for change and the power of intelligent action."

This belief has led us to join with colleagues from both public and private sectors to write this book about Health*e*People, to share the concept of a new health system that places the person seeking and receiving care at its center. The concept is framed to solve the monumental problems health care faces with the smallest possible amount of effort, time, and cost—"to make a lot out of a little."

Launched as a tightly focused effort within the Veterans Health Administration, Health*e*People stands ready to serve the hundreds of facilities, thousands of providers, and millions of veterans that make up the nation's largest health system. When deployed, it has worked and will work because it empowers *all* those it serves.

And work it must. Health care is the largest single sector of our economy that has yet to reap the benefits of information technology. In what is arguably the most complex professional service industry, where almost every service is a "custom product" supporting very complex human needs, the stakes are high. We all literally bet our lives that we can access the healthcare services we need—and that those services are affordable, safe, and of high quality.

But are they? In its report, *The Quality Chasm* (2001), the Institute of Medicine says no: "Between the health care we have and the care we could have lies not just a gap, but a chasm." We spend almost one-seventh of our economy in the United States on health care, with insufficient return on our investment. For us all, even those of us who are insured (over 40 million Americans are not), "the care delivered is not, essentially, what we should receive."

What we need, the IOM concluded in 2001, is "a system that uses the best knowledge, that is focused intensely on patients, and that works across health care provides and settings." And what we need to do is create a new virtual health system by "taking advantage of new information technologies" and using them as "an important catalyst to moving beyond where we are today."

The good news is that there has been progress in the few years since then—progress that brings us to the "tipping point." Initiatives in the United States, Canada, Australia, and some countries in Europe are using new technologies and new approaches to develop new systems that place the individual at the center of the healthcare universe. These new person-centered systems forge new partnerships between individuals and clinicians. They support the move from episodic care to "seamless" care for the whole person and, ultimately, the world community.

This new view of the healthcare universe represents a profound and massive change—and stands to offer many new opportunities for public and private sector alike. Health care delivery, we believe, will mirror what happened in genomics when new technologies were used to successfully map the human genome. Only now are we beginning to reap the benefits of this new knowledge and use it to treat and prevent disease.

In the words of Alan Kay, who helped develop object oriented programming and the concept of the laptop, and who architected the modern windowing graphic user interface, "The best way to predict the future is to invent it." We agree. By re-engineering health care to function upon a strong foundation of health information systems, we can better tackle the great issues facing health care.

The contributors to this book represent different disciplines, work in different sectors, and come from different countries. They have joined with us to explain what Health*e*People is and what it can mean for the individual and for health care. Some describe the new tools and approaches (many of which are the result of years of effort) that make Health*e*People and systems like it possible. Others report on efforts to put person-centered systems in place, sharing their insights on making them functional realities.

The signs are clear: We are at the Tipping Point, on the cusp of change. The time has come to "electrify" health care as we "electrified" the world in the last century. With healthcare costs and needs growing throughout the world, Health*e*People can help deliver the promise of better health for all Americans and, potentially, for many others.

James E. Demetriades
Robert M. Kolodner
Gary A. Christopherson

References

Gladwell M. 2000. The Tipping Point: How Little Things Can Make a Big Difference. Boston, MA: Little, Brown and Company.

Institute of Medicine. 2001. Crossing the Quality Chasm: A New Health System for the 21st Century. Washington, DC: National Academy Press.

Acknowledgments

As editors, we are privileged to publish a volume in the Springer Health Informatics Series. It has been a remarkable learning experience to work through the many steps involved in producing a contributed volume. Throughout this process, Judith Douglas expertly and patiently guided us. We are truly grateful for her brilliant ability to work with people, schedules, and, above all, words. Her perseverance through this lengthy and complex task has quite literally made this manuscript possible. This was all done with that wonderfully calming style of hers. We are indebted.

We would also like to recognize and thank Marion J. Ball. Her instant enthusiasm when first asked about the merit of a book propelled us forward. Her thoughtful guidance helped us shape its content. It remains a pleasure to work with her.

Finally, we would like to acknowledge and thank all the individual chapter authors. They showed a remarkable willingness to share their expert knowledge and unselfishly contributed time and talent. To each of them we owe a debt of gratitude.

James E. Demetriades
Robert M. Kolodner
Gary A. Christopherson

Contents

SECTION 2 BUILDING THE FUTURE: ESSENTIAL TECHNOLOGIES AND METHODOLOGIES

SECTION 3 BEING IN THE FUTURE: CASE STUDIES

Contributors

Marion J. Ball, EdD
Member, Institute of Medicine; Vice President, Clinical Informatics Strategies, Healthlink, Inc.; Professor, Johns Hopkins University School of Nursing, Baltimore, MD, USA

Thomas Beale, BE, BSc
Chief Technology Officer, Ocean Informatics; Founding Member, Open EHR Foundation; Senior Research Fellow, CHIME, University College London; Mooloolah, Queensland, Australia

Jeffrey S. Blair, MBA
Vice President, Medical Records Institute; Member, National Committee on Vital and Health Statistics and Vice Chair, Subcommittee on Standards and Security; Albuquerque, NM, USA

Bernd Blobel, PhD, MSc
Director, Associate Professor, Otto-von-Guericke University Magdeburg, Institute of Biometry and Medical Informatics, Magdeburg, Germany

Steven H. Brown, MS, MD
Health Information Architect, Veterans Health Administration; Associate Professor of Biomedical Informatics, Vanderbilt University, Nashville, TN, USA

Gary A. Christopherson, MS
Senior Advisor to the Under Secretary for Health, Department of Veterans Affairs, Veterans Health Administration, Senior Fellow, Institute of Medicine, Washington, DC, USA

Simon Cohn, MD, MPH
National Director for Health Information Policy, Kaiser Permanente; Member, National Committee on Vital and Health Statistics and Chair, Subcommittee on Standards and Security, Oakland, CA, USA

John M. Davis, BS, MS Physics, BS, MS Electronic Engineering, CISSP
Security Architect, Science Applications International Corporation, Encinitas, CA, USA

James E. Demetriades, BS, MS, PE
Chief Health Information Architect, Department of Veterans Affairs, Veterans Health Administration, Albany, NY, USA

Judith V. Douglas, MA, MHS
Adjunct Faculty, Johns Hopkins University School of Nursing, Reisterstown, MD, USA

Shari Dworkin, BA, MES
Senior Consultant, Canadian Institute for Health Information, Toronto, Ontario, Canada

Peter L. Elkin, MD
Internist, Mayo Clinic, Rochester, MN, USA

J. Michael Fitzmaurice, PhD
Senior Science Advisor for Information Technology, Agency for Healthcare Research and Quality, Rockville, MD, USA

David Forslund, BS, MA, PhD
Laboratory Fellow, Los Alamos National Laboratory, Los Alamos, NM, USA

Gerard Freriks, MD
Convenor, Working Group 1, CEN/TC 251; Member, Eurorec Institute; TNO-PG, Leiden, The Netherlands

Thomas L. Garthwaite, MD
Director and Chief Medical Officer, Department of Health Services, County of Los Angeles, Los Angeles, CA, USA

Nancy Gill, BSc
Intern, Canadian Institute for Health Information, Toronto, Ontario, Canada

Dipak Kalra, PhD, FRCGP
Clinical Senior Lecturer in Health Informatics, Centre for Health Informatics and Multiprofessional Education (CHIME), University College London, London, UK

Robert M. Kolodner, MD
Chief Information Officer, Department of Veterans Affairs, Veterans Health Administration, Washington, DC, USA

Michael J. Lincoln, MD
Associate Professor, Department of Veterans Affairs, Veterans Administration, CIO Field Office, Salt Lake City, UT, USA

Blackford Middleton, MD, MPH, MSc
Corporate Director, Clinical Informatics Research and Development, Partners Health-Care System; Assistant Professor of Medicine, Brigham and Women's Hospital, Harvard Medical School, Boston, MA, USA

Tom Munnecke, BS
Vice President and Chief Scientist, SAIC (retired); Visiting Scholar, Stanford University Digital Visions Program; Founder, GivingSpace.org, Encinitas, CA, USA

Jonathan B. Perlin, MD, PhD, MSHA, FACP
Deputy Under Secretary for Health, Department of Veterans Affairs, Washington, DC, USA

Julie Richards, BSc, MHSc
Senior Consultant, Canadian Institute for Health Information, at time of writing; currently Director Standards, Canadian Institute for Health Information, Toronto, Ontario, Canada

Angelo Rossi Mori, MS
National Research Council, Institute of Biomedical Technology; President, PROREC Italy; Secretary, HL7 Italy; Member, Eurorec Institute, Rome, Italy

David Rowlands, BEc (Hons), GDBA, FACHI
Director, National InfoStructure Development, Australian Government, Department of Health and Ageing, Bowen Hills, Queensland, Australia

Kenneth S. Rubin, BS
Senior Systems Architect, Electronic Data Systems, Inc., Bowie, MD, USA

Steven Wagner, BA, MBA
Deputy Chief and Health Information Architect, Department of Veterans Affairs, Veterans Health Administration, Office of Information, Manchester, NH, USA

Acronyms

AA	Attribute Authority
ACHI	Advisory Council on Health Infostructure (Canada)
ACI	Access Control Information
ADF	Access Decision Function
ADI	Access Decision Information
AEF	Access Enforcement Function
ACMI	American College of Medical Informatics
AHRQ	Agency for Health Research and Quality
AMA	American Medical Association
ANSI	American National Standards Institute
API	Application Program Interface
ASC	Accredited Standards Committee
ASTM	American Society for Testing and Materials
ATM	Automated Teller Machine
CAC/TC	Canadian Advisory Committee/Technical Committee
CAP	College of American Pathologists
CBOC	Community Based Outpatient Clinic
CCAC	Community Care Access Center
CCOW	Clinical Context Object Workgroup
CCR	Continuity of Care Record
CDA	Clinical Document Architecture
CDMS	Chronic Disease Management System (Australia)
CDT	Current Dental Terminology
CEN	European Committee for Standardization (Comité Européen de Normalisation)
CEN/TC 251	European Technical Committee for the Standardization of Health Informatics
CEO	Chief Executive Officer
CHCS	Composite Health Care System
CHDM	Conceptual Health Data Model (Canada)
CHI	Consolidated Health Informatics
CHIN	Child Health Information Network (Australia)
CHIPP	Canada Health Infostructure Partnership Program
CIHI	Canadian Institute for Health Information
CITL	Center for Information Technology Leadership
CM	Clinical Modification

CMS	Centers for Medicare and Medicaid Services
CORBA	Common Object Request Broker Architecture
CPOE	Computerized Physician Order Entry; alternately, Computerized Provider Order Entry
CPT	Current Procedural Terminology
CPRI	Computed-based Patient Record Institute
CPRS	Computerized Patient Record System
CSA	Canadian Standards Association
CT	Clinical Terminology
CTS	Central Terminology Services
CVS	Concurrent Versions Systems
DBC	Diagnosis Treatment Groups (Netherlands)
DHCP	Decentralized Hospital Computer
DICOM	Digital Imaging and Communications in Medicine
DoD	Department of Defense
DRG	Diagnosis Related Groups
DSM	Diagnostic and Statistical Manual of Mental Disorders
DSTU	HL7 EHR Functional Draft Standard for Trial Use
DTD	Document Type Definition
eCHN	Electronic Child Health Network (Canada)
EDDS	Electronic Decision Support Systems
EDI	Electronic Data Interchange
EFMI	European Federation for Medical Informatics
EHCR-SupA	Electronic Healthcare Record Support Action
eHI	eHealth Initiative
EHR	Electronic Health Record
EHRC	Electronic Health Record Collaborative
EHRi	Electronic Health Record Infostructure
EHRS	Electronic Health Record Solution (Canada)
EHRS	Electronic Health Record System
EHTEL	European Health Telematics Association
EIN	Employer Identification Number
EPRP	External Peer Review Program
ER	Emergency Room
FDA	Food and Drug Administration
FGH	Florida General Hospital (fictional)
GCPR	Government Computerized Patient Record
GDP	Gross Domestic Product
GEHR	Good European Health Record
GNU	GNU's Not Unix (pronounced "guh-noo")
GP	General Practitioner
GPL	General Public License
GPRA	Government Performance and Results Act
GTA	Greater Toronto Area
HCPCS	Healthcare Common Procedure Coding System
HEDIS	Health Plan Employer Data and Information Set
HDTF	Healthcare Domain Task Force
HHS	Health and Human Services, Department of
HIAL	Health Information Access Layer
HIBCC	Health Industry Communications Council
HIMSS	Health Information Management and Systems Society

HIPAA	Health Insurance Portability and Accountability Act
HISA	Health Information Systems Architecture
HISB	Healthcare Informatics Standards Board
HL7	Health Level Seven
HSC	Hospital for Sick Children (Toronto, Canada)
HTML	Hypertext Markup Language
HTTP	Hypertext Transport Protocol
ICD9	International Classification of Diseases Ninth Edition
ICD10	International Classification of Diseases Tenth Edition
ICT	Information and Communication Technology
IDE	Integrated Development Environment
IDL	Interface Definition Language
IE	Information Exchange
IEEE 1073	Institute of Electrical and Electronics Engineers, Medical Device Communication
IHE	Integrating the Healthcare Enterprise
IHS	Indian Health Service
IMIA	International Medical Informatics Association
IOM	Institute of Medicine
ISBT	International Society of Blood Transfusion
ISO	International Organization for Standardization
IST	Information Society Technologies (European Union)
IT	Information Technology
ITS	Implementation Technology Specification
JCAHO	Joint Commission on Accreditation of Healthcare Organizations
LOINC	Logical Observations Identifiers Names and Codes
MBS	Medicare Benefits Scheme (Australia)
MDA	Model Driven Architecture
MeSH	Medical Subject Headings
NACC	North American Collaborating Center
NCG	National Guideline Clearinghouse
NCPDP	National Council for Prescription Drug Programs
NCQA	National Committee for Quality Assurance
NCVHS	National Committee on Vital and Health Statistics
NDC	National Drug Codes
NDFRT	National Drug File Reference Terminology
NEC	Not Elsewhere Classified
NeCST	National e-Claims Standard Initiative (Canada)
NEDSS	National Electronic Disease Surveillance System
NHII	National Health Information Infrastructure
NHS	National Health Service (United Kingdom)
NICTIZ	National Information and Technology Institute in Healthcare (Netherlands)
NLM	National Library of Medicine
NPI	National Provider Identifier
NPRM	Notice of Proposed Rule Making
OASIS	Organization for the Advancement of Structure Information Standards
OECD	Organization for Economic Cooperation and Development
OHIH	Office of Health and Information Highway (Canada)
OMB	Office of Management and Budget

OMG	Object Management Group
OTC	Over The Counter
PACS	Picture Archiving and Communications System
PCS	Procedure Classification System
PFI	Private Finance Initiative
PHR	Personal Health Record
PIDS	Person Identification Services
PIM	Platform Independent Model
PKI	Public Key Infrastructure (Australia)
PMI	Privilege Management Infrastructure
PMRI	Patient Medical Record Information
POMA	Patient Oriented Management Architecture
PSM	Platform Specific Model
QUERI	Quality Enhancement Research Initiatives
RAD	Resource Access Decision
RIM	Reference Information Model
RM-ODP	Reference Model for Open Distributed Processing
SAML	Security Assertion Markup Language
SCC	Standards Council of Canada
SDO	Standards Development Organization
SHEP	Survey of Health Experiences of Patients
SIG	Special Interest Group
SNOMED	Systematized Nomenclature of Medicine
SNOMED-CT	Standardized Nomenclature in Medicine-Clinical Terms
SQL	Structured Query Language
TATRC	Telemedicine and Advanced Technology Research Center
TC251	ISO Technical Committee on Health Informatics
TQS	Terminology Query Services
TS	Technical Specification
UCL	University College London
UML	Unified Modeling Language
UMLS	Unified Medical Language System
UPI	Unique Patient Identifier
UPIN	Unique Physician Identifier Number
URL	Uniform Resource Locator
VA	Veterans Administration, also Veterans Health Administration
VERA	Veterans Equitable Resource Allocation Act
VISN	Veterans Integrated Service Network
VistA	Veterans Health Information Systems and Technology Architecture
VISTA	Veterans Health Information Systems and Technology Architecture
WEDI	Workgroup for Electronic Data Interchange
WHIC	Western Health Information Collaborative (Canada)
WHO	World Health Organization
WS	Web Service
WSDL	Web Service Definition Language
XACML	eXtensible Access Control Markup Language
XMI	XML Metadata Interchange
XML	eXtensible Markup Language
XP	Extreme Programming

Section 1
Inventing the Future: Envisioning a New Health System

1
Inverted Perspectives: Triggering Change

Tom Munnecke and Robert M. Kolodner

Albert Einstein imagined riding a beam of light and discovered relativity. Jonas Salk imagined being a polio virus and discovered a vaccine. Nobel Laureate Richard Feynman discovered new ways of thinking about physics by imagining himself immersed in a messy fog of electrons. In each instance, an inverted perspective triggered a great discovery.

Now invert the traditional healthcare universe, and put the individual at the center instead of the enterprise. The result is a universe where enterprises compete by personalizing the services they offer their customers, not by integrating their internal operations. In this universe, individuals have and control their own health information in a radically person-centered health record that

- is designed around the individual, not the healthcare provider;
- assumes that, over the life of the individual, there will be a large number of providers, suppliers, and other associations involved with the individual's health that will not be physically co-located;
- assumes that information formats will be constantly changing, and that there will not be any static "one correct way" to record health information;
- brings issues of trust, confidentiality, ownership, and access to health information to the forefront, making them critical success factors, rather than side effects of enterprise transaction processing;
- treats health care as only one extreme of the health spectrum—the normal state of the individual is assumed to not be engaged in disease-based activities, but rather, participating in positive, life-affirming activities of society which use and amplify basic character strengths and virtues (Peterson and Seligman 2004);
- supports and enhances the role of communications within a trusted community of interest as a key contributor to the health of the individual.

The record belongs to a person, not a patient. The word *patient* implies a disease state being treated by a provider in a healthcare setting. The new record belongs to the person who ideally is not in a disease state. The goal of the system is to keep the person from becoming a patient, and for that person to live a healthy life independent of disease processes as long as possible. Similarly, it uses the term *health* rather than *health care* to shift the focus on the health process of the individual. Health care is but one portion of the health process.

For the past three decades, informaticians have tried to integrate divergent sources of information into meaningful collections within the confines of the enterprise perspective. During the same time, explosive changes have occurred in biomedicine,

Table 1.1. Comparison of enterprise-centric and person-centric systems.

Issue	Enterprise-centric system	Person-centric system
Purpose	Survival of the enterprise	Survival of the individual
Context	What is necessary for the survival and growth of the organization within its stated goals?	What improves the health of the individual?
Trust	Individual must trust entire system	Individual builds trust in community of interest, trusted third party for holding databases
Organization	Integrated around operating units/functions within the organization	Associated with many different and constantly changing set of providers and sources of information
Typical activity	Episodes of intervention	Adopting healthy behavior, adjusting to injury, self-management, recovery, fitness, compliance with providers of health care
Continuity of care	Management policies and workflow	Concerned people and agents acting on behalf of the individual
Information system	Tied to organization chart	Tied to context of person's needs, computer literacy, and virtual community
Authority	Single and management chain within the organization	The individual
Control	Policies, regulations, management chains	The individual, within constraints provided by regulation; community and social standards

healthcare services, and information technology, in areas from nomenclatures and coding schemes, to government regulations and payer needs. The resulting complexity is incomprehensible to anyone dealing with only part of the problem. Single components appear relatively simple, and constraints seem due to the lack of integration with the rest of the system.

Yet this integration crunch is the core of the problem, not a path to the solution. The end to the search for a viable health information system lies in accepting the divergent and constantly changing nature of health information, rather than attempting to force an enterprise-centric perspective on the field.

The alternative—the inverted perspective—is to design the information system from the point of view of the individual. There are many differences between enterprise- and person-centric health information systems, as Table 1.1 shows. The enterprise sees the person as an object to be acted upon, whereas the person sees the healthcare enterprise as only one piece of a larger puzzle. Simply put, the enterprise is solving one problem while the patient perceives another:

> Health care providers typically define problems related to diagnosis, poor compliance with treatment regimens or continuing unhealthy behaviors, such as smoking or lack of exercise. Patients, however, are more likely to define problems of pain and other symptoms, their inability to function as they once did, emotional distress, difficulty carrying out prescribed regimens or lifestyle changes or fear of unpredictable consequences of the illness. (Gruman and Von Korff 1999)

The healthcare industry is driven by the survival needs of the organizations that comprise it. Stakeholders may be threatened by the person-centered model because it displaces them from the center of the healthcare universe. A trillion dollar industry does

not change easily. The patient-centric model may appear today to be too simplistic and not powerful enough to compete with the established industry. But appearances can be deceiving. In the 1980s, Digital Equipment Corporation dominated the minicomputer industry with their computer systems. They saw little reason to change. Their chief executive officer (CEO), Ken Olsen, denounced personal computers as toys. A decade later, his company was purchased by Compaq, one of those "toy" computer manufacturers.

What appears to be simple and toy-like in its early stages of development can hide tremendous power as it matures. Established models are changing dramatically, industry after industry, as the Internet and the World Wide Web mature. And these changes come from the young upstart attackers rather than the established defenders of the current model. The upstart Amazon.com, not the venerable Barnes & Noble, created the online book sales market.

Recent advances in information technology and complexity theory give new ways to deal with complexity. In what is known as the chaordic model,[1] complex adaptive systems grow organically from simple beginnings, increasing in complexity as a result of interaction with their environment. Complexity grows evolutionarily rather than being built mechanically.

Systems at this level of complexity constantly change and evolve. They are in a state of perpetual novelty, and thus not predictable. As Demetriades explains in Chapter 7, we cannot understand these systems according to traditional mechanical or engineering terms, but must rather seek to understand and shape the environment in which they operate.

Consider the World Wide Web, a major transformational force in the world today. It emerged from a simple "primordial soup" consisting of three simple definitions: the Uniform Resource Locator (URL), Hypertext Markup Language (HTML), and Hypertext Transport Protocol (HTTP). It grew within constraints; the Internet Protocol (IP) delineated the boundaries beyond which the web could not stray. One simple selection criterion controlled its evolution: Web pages to which people paid attention survived, while those that were ignored withered.

At first, complex adaptive systems appear somewhat chaotic and disordered. Over time, order appears from seemingly chaotic "primordial soup." Features come forth as *emergent properties* of the system; they were not designed into it by a body of authoritative experts. Today, the World Wide Web offers search engines, virtual communities, and electronic commerce of far greater sophistication than we could have imagined. Authoritative strategic planning does not control the future growth of the Internet; an evolutionary process drives it.

Evidence of self-organization exists throughout nature. A cut finger heals itself, the body maintains homeostasis, and predator/prey populations adjust to their environment. We also find self-organization in man-made systems, such as the World Wide Web and many of the companies it has spawned. The greatest threats to Microsoft's dominance in the software market may come from self-organizing groups, such as the programmers creating the Linux operating system and the developers collaborating on the open source approach Kalra and Forslund discuss in Chapter 11.

Before we consider how self-organization may be used in the field of health and health care, however, we have to address two questions:

---

[1] For more on this model, see The Trillion Dollar Vision of Dee Hock at http://www.fastcompany.com/magazine/05/deehock.html.

- What is the self that does the organizing? What is the entity that properly serves as the core around which health organizes?
- What is the scale at which this self-organization takes place? Is it the individual, the family, the nation, the world?

Traditionally, we have focused on the interaction between the healthcare provider and the patient, and measured this interaction in the form of transactions. This approach does not deal well with interaction within the family, community, self-help groups, or with other forms of health assistance. Someone who benefits from attending Alcoholics Anonymous generates no transactions to be measured. Alcoholics Anonymous is a self-organizing group that benefits many people around the world, yet it is "invisible" to the world of transaction processing.

There is no single "self" that should drive self-organization in health, nor is there a single scale that can be exclusively used. We must envision an approach that deals with an arbitrarily large number of "selves," involving from a single individual to large aggregations of people, or "ensembles." And for these ensembles in health, the goal is a transformation, a purposeful flow of activities and information.

It is not a transaction, a single moment in time. Transactions and transactional thinking are ubiquitous in modern society and work very well for certain classes of activities. For example, we insert a card into an automated teller machine (ATM) and get cash with ease and accuracy. Complex problems, like health, are different. When interactions are transactionalized in one context and then analyzed in the context of the aggregate, the context of the individual is often lost. The interaction has many dimensions, yet the transaction measures only one.

A transformation, however, deals with the longer-term flow of activities in the context of the individual. It sees the river as a flow, not a series of snapshots. Transformations are specific to the context of the community where they occur. Ion (1993) describes such transformations in a clinical setting:

> What takes place as the patient and the physician interact. . . . ? One exchange is that of perceptions of reality, what each knows about the problem. Another exchange is that of trust: the physician trusts that the patient both wants to change or solve the problem and is willing to take action to do so; the patient trusts that physician has the appropriate skills to repair damage or advise on the changes necessary to resolution. These are the interactions of healing, older than Hippocrates and consistent still wherever healing is practiced. The exchange is *transformative* in nature, not *transactional*. The patient, and hopefully, the physician both learn and become different consequent to the interaction. Commerce, the purchase of products, is transactional—neither side of the interaction changes in function or ability to function. (Ion 1993, p 118)

In *Knowledge Coupling*, an earlier book in this Springer-Verlag series (1991), Larry Weed related an interview with a hospital patient about to be discharged:

> Dr. Weed: "Do you have a copy of your own medical record?"
> Patient: "No."
> Dr. Weed: "Are all your medications in the bedside stand, and does the nurse come around at regular intervals to see if you are taking the right ones at the right time?"
> Patient: "No. The nurse just comes with little paper cups with pills in them, and I swallow whatever is there."
> Dr. Weed: "Do you know what a flowsheet is? What parameters are we trying to follow? What endpoints we are trying to reach?"
> Patient: "No."

(At this point, Dr. Weed met with the medical staff to relate what he had found):

Staff: "We never give patients their records."
Staff: "We do not have the time to give the medicines that way. It would not be safe to leave her with them unattended. She is on many powerful drugs.
Staff: "The patient is not very well educated, and I do not think she could do all the things your questions imply."
Dr. Weed: "But, she is going home this afternoon. She lives alone. At 2PM you will put her in a wheelchair, give her a paper bag full of drugs, and send her out the door. Are you going home with her?"
Staff: "No. Is her management at home our problem?"
Dr. Weed: "You just said she could not handle it. Who will do it? The patient may not seem well educated or very bright to you, but what could be more unintelligent that what you are doing?" (Weed 1991, p 13)

Larry Weed advocated developing a system in which "all individuals are nurturers of their own health care and have available to them the guidance of an information system and the skills of providers who have demonstrated competence in performing specific tasks that patients who cannot perform for themselves" (Weed 1991, p 19). In his view, health care could not improve unless a system of this sort was in place. It could only grow worse.

According to Weed,

We must consider the whole information system and not just infinitely elaborate on the parts that interest us or fit into a given specialty. Patients do not specialize, and they or their families are in charge of all the relevant variables 24 hours a day, every day. They must be given the right tools to work with . . . After all,

- They are highly motivated, and if they are not, nothing works in the long run anyway,
- They do not charge.
- They even pay for help.
- There is at least one "caregiver" for every member of the population.

(Weed 1993, p 13)

Larry Weed was ahead of his time. As the father of the problem-oriented medical record, he had already changed medical education and practice. But we are only now beginning to act on his answer to what he called "the voltage drop" in medicine—the gap between medical knowledge and medical practice.

The solution for ending much of the discontinuity and isolation of the kind he described is a patient-centered approach, with health providers helping the patient work toward a transformational goal—in other words, joining in an ensemble to help the patient manage her care and her medications at the hospital and at home. The ensemble provides a "home base" for relationships and associations, past, present, and future. It is more than a record of the transactions that have occurred to a given patient; it is a collaborative approach that supports dialogue:

The real value in the sciences, the arts, commerce, and indeed, one's personal and professional lives, comes largely from the process of collaboration. What's more, the quality and quantity of meaningful collaboration often depends upon the tools used to create it. (Schrage 1990, p 27)

Thinking of health as transformations occurring within ensembles allows us to rethink health and how it is supported.[2] The concept is a fertile foundation for innovative thinking about health:

[2] For an in-depth discussion by the author, visit www.munnecke.com/papers/D16.doc.

- It introduces new notions of scale to health. World Wide Web technology provides an infrastructure for connectivity and mass personalization unthinkable just a decade ago. Systems can be designed to support massive numbers of participants at a relatively low cost.
- It makes self-organization feasible. People can discover their own resources for managing their own health transformation. Providers can direct patients to ensembles and resources as appropriate.
- Things that can be reduced to bits of information can be replicated and communicated at very low cost. One expert's advice can be captured once and communicated many times.
- It puts a new emphasis on patient self-efficacy. Patients will find themselves more responsible for their own health.
- It introduces new notions of management and control. No entity can be expected to manage 100 million things simultaneously. Rather, the transformations must become self-organizing.

This concept raises other issues. It creates new problems of information overload, access, and ability of healthcare organizations to understand and communicate in the information era. This requires innovation to allow access, train assistants and family members, and publicize the process. It also requires answering difficult questions about transformations and the interactions involved in them:

- How are these transformations infused with appropriate clinical expertise and medical knowledge?
- What are the constraints limiting these transformations? How do we protect against fraud and quackery?
- How do we ensure that transformations occur are as safe as possible?
- How do we configure medical knowledge and research to maximize its benefit to this massive number of transformations?

The communications revolution has created new interactive media. People's interaction in this medium can be both positive and negative. When the "I Love You" virus appeared, it caused $10 billion in damages to computers around the world. This form of information virus is a new phenomenon; only in recent years have computers been connected densely enough to allow such rapid spread. In this new environment, a small initial condition can cascade to become a massive global phenomenon—witness the changes brought about by the World Wide Web in just 10 years. Today, our healthcare system is poised for dramatic changes by these forces. Whether it "tips" for the better or worse is a critical issue facing society. If it does tip in a positive direction, the assumptions underlying our health system will flip from transactional to transformational, as shown in Table 1.2.

Whereas the enterprise sees patients flowing through it and seeks to provide the best care at lowest cost, people see a multitude of providers flowing past them. They have a longer perspective, extending out as long as their lives. They see a maze of health information, sometimes reliable and sometimes sensationalized by the media or advertisers. From this perspective, as Dr. Donald Berwick states, "doctors are guests in the lives of patients" (Wysocki 2002).

This inversion has radical implications regarding information, authority, and responsibility in the healthcare process. Speaking in 1997 about a trend that has continued to accelerate, Dr. Kenneta said,

TABLE 1.2. Comparison of transactional and transformation assumptions.

Transactional assumptions	Transformational assumptions
Health can be purchased.	Health is natural and creative process that is based on common human values shared by all.
Financial incentives drive health care.	Transformational energy drives health.
Health care is a matter of a "system" doing things to a "patient."	Health is found from within, supported by the system.
Health care can be understood as the supply and demand of a scarce commodity.	Health and transformation are unlimited in their scope and potential.
We are dealing with an "industry" in which producers "provide" health and people "consume" it.	We are dealing with transformational ensembles; health can grow without bounds, improving everyone's lives.
Patients are only consumers of health, not also producers.	The fundamental source of health is within individuals. Health is contagious.
Decompositional analysis is a way of understanding the healthcare system.	We have little language to express the generative, transformational power of health
The process of analysis does not change the system being understood.	If we look for problems, we will find and create more problems. If we look for solutions, we will find and create more solutions.
The system is linear.	Health is based on a web of interactions; the more healthy associations available to an individual, the healthier the individual.
Inputs don't interact.	Everyone's health is interconnected; the health improvement of any one of us is the health improvement of all of us.
It is possible to define health meaningfully across a whole population.	Health is as unique as the individual experiencing it.
This definition can be used to drive an aggregation of activities.	Health can be improved by aggregating stories of success, replicating them in the context of other individuals and communities.
It is possible to maximize health through coordination, planning, and management.	Health is a self-propelling, self-generating process which can be triggered by the proper conditions.
The patient's sense of self is not a factor in the efficacy of the intervention.	The role and identity of the self is a major factor in our notion of health.
Greater measurement with greater precision will converge on greater understanding of the phenomenon being studied.	The true benefits of health cannot be measured.
Categorized transactions can be "rolled up."	Health is an associative web of interaction. The value of this web is measured by its richness of interaction, not through arbitrary categorizations.
There is specific scale and "yardstick" with which we can measure health care.	As personal as health is, so are its yardsticks.
We can manage the system by understanding and defining its problems.	We can enhance our health by understanding our strengths and creating new ones.
The placebo effect, mind–body interaction, racial, cultural and ethnic backgrounds, personal belief system, and family factors relating to a person's health process are outside of "normal" medicine.	These effects allow health to be "one thought away." The individual's perceptions are the basis upon which the healthcare system can be based.
The system can look ahead and understand future consequences of today's activities.	The system must be grounded in the fundamental human intrinsics of love, peace, wisdom, truth, balance, power, happiness, and purity. An approach based on these intrinsics will generate and reward those who enhance these intrinsics.
The "law of increasing return" is not evident in health.	The intrinsics of health can be magnified arbitrarily without limits, and in so doing, create additional magnification.

As a result of the availability of information on the Web, patients have ready access to research findings. Indeed, it is not unheard of today, and in fact, it is becoming increasingly common for our patients to know more about a given condition or the latest in treatment options than does the physician or other healthcare provider. Instead of being the source of information, or the fount of all wisdom, clinicians now a have a new job of interpreting information and helping patients make up their mind as to what treatment options or what diagnostic modality they want to utilize. This will, again, require a different mind set as we provide these services in the future . . . as professionals, we have had a monopoly on the information about the diagnostic and treatment options of our patients. Now, all that has changed . . . largely as a result of the Internet." (Kizer 1997)

Is There a Free Lunch?

The inversion Kizer described is a result of the networked economy, which has made many goods and services that used to be the source of market superiority available at low cost—or even "for free." Self-emergent, they do not require conscious creation and specification. This goes against conventional wisdom. Our management structures, accounting mechanisms, and legislative processes are all based on controlling complexity by adding specificity. We have been taught that, as things become more complex, they require more control, categorization, and measurement.

The Encyclopedia Britannica has made its content available on the web: content for free. American auto manufacturers used to think of quality as something to be added on after assembly, until Japanese competitors discovered that they could build quality in at a lower cost: quality for free. Stock brokerage houses offer free information and research, as well as drastically discounted trading services: information for free. The World Wide Web has exploded on the scene: connectivity for free. It is growing explosively with no management committees, interdisciplinary teams, or CEO: *organization for free*. Complexity scientists have discovered that with sufficient diversity and interactivity, systems can organize themselves: *order for free*.

These inversions are revolutionary in each of their industries, yet they contain a common thread:

If goods and services become more valuable as they become more plentiful, and if they become cheaper as they become valuable, then the natural extension of this logic says that the most valuable things of all should be those that are ubiquitous and free.

Ubiquity drives increasing returns in the network economy. The question becomes, What is the most cost-effective way to achieve ubiquity? And the answer is: give things away. Make them free. (Kelly 1998, p 51)

Health is one of the most valuable things an individual, family, or society can possess. Will health and health care follow the logic of network economics? Should they be ubiquitous and "free"?

In living systems, "Astonishingly simple rules, or constraints, suffice to ensure that unexpected and profound dynamical order emerges spontaneously" (Kauffman 1995, p 207). Consider the World Wide Web, whose inventor, Tim Berners-Lee said:

What was often difficult for people to understand about the design [of the web] was that there was nothing else beyond URIs [his name for URLs], HTTP, and HTML. There was no central computer "controlling" the web, no single network on which these protocols worked, not even an organization anywhere that "ran" the Web. The web was not a physical "thing" that existed in a certain "place." It was a "space" in which information could exist. (Berners-Lee 1999, p 36)

The World Wide Web is growing daily in its complexity, with new companies and information sources continuously emerging. This is an example of "order for free." The World Wide Web did not, and could not have, come from an "expensive" managed approach with blue ribbon panels, interdisciplinary groups of experts, and a CEO to make sure that the web operated correctly.

Our notions of correctness and predictability are based on the notion of imposed control. We expect to use expensive processes, management processes, to create policies, procedures, and policing mechanisms to make a system do what we expect. However, self-organizing systems can be found everywhere in nature and in human social structures, and are able to adapt well without these artificial control structures.

In order for these principles of organization to take hold, it is critical that our primary point of focus be on the individual, not the system. This is a major inversion of our perspective within the industry. And it is necessary.

References

Berners-Lee T. 1999. Weaving the web: the original design and ultimate destiny of the World Wide Web. San Francisco: Harper.

Gruman JC, Von Korff M. 1999. Living with chronic illness: when doctors and patients work together. Center for Advancement of Health. Washington, DC.

Ion HW. 1993. Ethical dilemmas in managed care. In: Ott R, Tannes T, Henderson B, editors. Managed care and the cardiac patient. Philadelphia: Hanley & Belfus. p 118.

Kauffman S. 1995. At home in the universe: the search for laws of organization and complexity. New York: Oxford University Press.

Kelly K. 1998. New rules for the new economy. New York: Viking.

Kizer K. 1997. Forms in the fog: information management in the new VA. Speech to the VA Information Technology Conference, 1997 May 19.

Peterson C, Seligman M. 2004. Character strengths and virtues: a handbook and classification. New York: Oxford University Press.

Schrage M. 1990. No more teams: mastering the dynamics of creative collaboration. New York: Doubleday.

Weed LL. 1991. Knowledge coupling: new premises and new tools for medical care and education. New York: Springer-Verlag.

Wysocki B. 2002. Doctor leads crusade to replace office visits as standard procedure. Wall Street Journal 2002 May 20. http://online.wsj.com/article/0..SBI0227211684781360.dim.00.html. Accessed 11/8/2004.

2
A Window of Opportunity

Robert M. Kolodner

Major changes occur in fits and starts, not in a smooth, even flow. Periodically, circumstances, events, and momentum align to provide an opportunity for affecting and influencing such changes. Today, four factors in health informatics are combining to bring us to a window of opportunity, one that offers us a chance to transform health care. The central focus of health and care is poised to shift squarely onto the individual, a move of seismic proportions that can be catalyzed by successfully converging the rapid advances in electronic health records, health information standards, health information exchange capabilities, and personal health records.

To date, despite estimates that only 15% of an individual's health is related to the provision of health care, the vast majority of the activities have been concentrated in the healthcare sector, consuming resources allocated by the economy for health. Moving the focus of health and care from institutions to individuals is a key step in aligning activities and resources to maximize the health status of individuals and communities.

This can change, and for the better, if we act now.

1. To Inpatient and Back: The Evolution of Health Care in the United States

Often described as a cottage industry, much of health care is still delivered in physician offices or small clinics. Yet health care in the United States has changed considerably over the last 40 years. For the first half of the 20th century, the primary emphasis was on the doctor–patient relationship. Other staff were present to support the doctor, and patients came when they were sick or injured to be taken care of by the doctor. Surgery was performed in hospitals, and acute illnesses were usually treated with extended hospital stays. Patients with severe chronic conditions might be cared for at institutions, occasionally little more than warehouses, where they received food and shelter until they recovered or died.

As health care began to have more effective procedures, pharmaceuticals, and technologies for diagnosing and treating medical conditions, the more elaborate treatments were provided in hospitals and medical centers. Medical and surgical specialties sprang up and were formalized as more specific and intense diagnostic and therapeutic procedures were developed.

In the 1960s, the United States government began to cover healthcare costs for the poor and the elderly and to invest more heavily in medical research. Increased revenues fueled a spiraling growth of research, leading to even more high-cost interven-