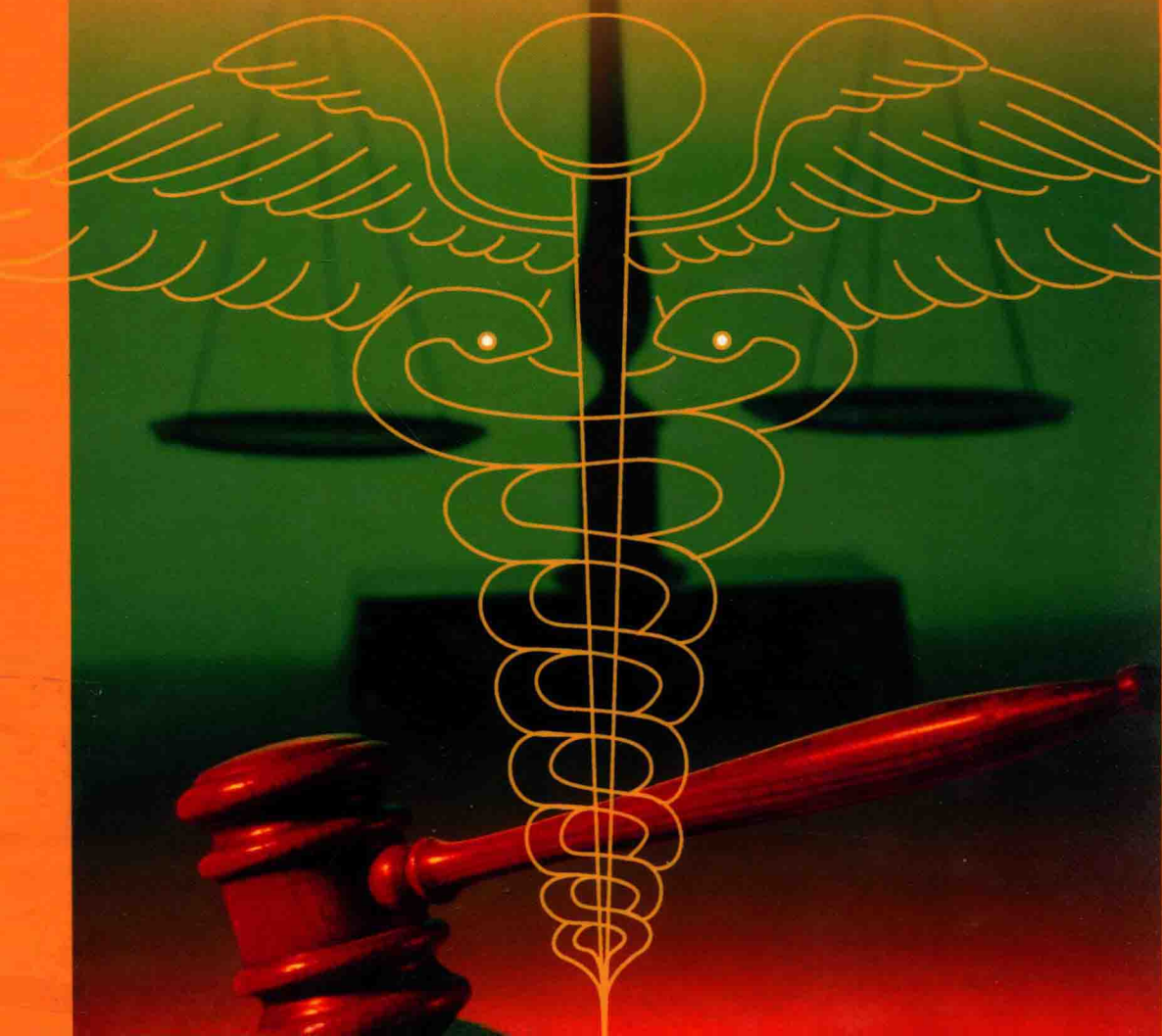


Penny Duquenoy, Carlisle George, & Kai Kimppa

# **ETHICAL, LEGAL, AND SOCIAL ISSUES IN MEDICAL INFORMATICS**



# **Ethical, Legal, and Social Issues in Medical Informatics**

Penny Duquenoy, Middlesex University, UK

Carlisle George, Middlesex University, UK

Kai Kimppa, University of Turku, Finland

Acquisition Editor: Kristin Klinger  
Development Editor: Kristin Roth  
Senior Managing Editor: Jennifer Neidig  
Managing Editor: Jamie Snavelly  
Assistant Managing Editor: Carole Coulson  
Copy Editor: Larissa Vinci  
Typesetter: Chris Hrobak  
Cover Design: Lisa Tosheff  
Printed at: Integrated Book Technology

Published in the United States of America by  
Medical Information Science Reference (an imprint of IGI Global)  
701 E. Chocolate Avenue  
Hershey PA 17033  
Tel: 717-533-8845  
Fax: 717-533-8661  
E-mail: [cust@igi-global.com](mailto:cust@igi-global.com)  
Web site: <http://www.igi-global.com>

and in the United Kingdom by  
Medical Information Science Reference (an imprint of IGI Global)  
3 Henrietta Street  
Covent Garden  
London WC2E 8LU  
Tel: 44 20 7240 0856  
Fax: 44 20 7379 3313  
Web site: <http://www.eurospanbookstore.com>

Copyright © 2008 by IGI Global. All rights reserved. No part of this book may be reproduced in any form or by any means, electronic or mechanical, including photocopying, without written permission from the publisher.

Product or company names used in this book are for identification purposes only. Inclusion of the names of the products or companies does not indicate a claim of ownership by IGI Global of the trademark or registered trademark.

Library of Congress Cataloging-in-Publication Data

Ethical, legal, and social issues in medical informatics / Penny Duquenoy, Carlisle George, and Kai Kimppa, editors.

p. ; cm.

Includes bibliographical references.

ISBN 978-1-59904-780-5 (hardcover)

1. Medical informatics—Moral and ethical aspects. 2. Medical informatics—Law and legislation. 3. Medical informatics—Social aspects. I. Duquenoy, Penny. II. George, Carlisle. III. Kimppa, Kai.

[DNLM: 1. Medical Informatics—ethics. 2. Access to Information—ethics. 3. Confidentiality. 4. Medical Informatics—legislation & jurisprudence. 5. Medical Records Systems, Computerized—organization & administration. 6. Social Responsibility. W 26.5 E837 2008]

R858.E82 2008

174.2—dc22

2007049519

British Cataloguing in Publication Data

A Cataloguing in Publication record for this book is available from the British Library.

All work contributed to this book is original material. The views expressed in this book are those of the authors, but not necessarily of the publisher.

*If a library purchased a print copy of this publication, please go to <http://www.igi-global.com/reference/assets/IGR-eAccess-agreement.pdf> for information on activating the library's complimentary electronic access to this publication.*

## Foreword

Over a century ago, with the work of Alexander Graham Bell, the motivation underlying the first use of the telephone in communication had a health-related origin: a doctor attempted to be in contact with his deaf mother and sister. Early developments in electronic patient records took place over 40 years ago through the pioneering work of Ed Hammond and his interest in community and family medicine. Very soon, the European Union will be celebrating a 20-year history of co-financing eHealth research and development initiatives. Multiple eHealth programmes and projects around Europe have been the result.

Since the publication of the European eHealth action plan in 2004<sup>1</sup>, many more concrete steps have been made in European countries towards deploying and implementing medical informatics whether in primary, secondary, or tertiary healthcare. Today, all the European Member States have a strategy or vision for the achievement of eHealth in their country and many are well on their way towards the practical implementation of these roadmaps.

A vast amount of other work on eHealth is also being undertaken in a very concrete and practical way around the whole globe. While the countries of the European Union and the Organisation for Economic Cooperation and Development are among the pioneers in the application of physical eHealth systems and services, the World Health Organisation also endeavours to ensure that the health systems and services of its worldwide members are also well-served by information and communication technologies.

eHealth is a topic that lies at the crossroads of multiple disciplines, both hard and soft: including, on the one hand, engineering and computer science and, on the other, psychology and the social sciences. It can therefore be seen as an academic discipline, or rather, being at the crux of several academic disciplines, that underpin these activities and interests. These key specialisms are often reflected in the discourse outlined in the papers in this volume.

The first advances in eHealth were often based around the computer science or engineering tools and techniques used to progress the field of medical informatics. eHealth may be related to either medical or health informatics. It is however always concerned with an understanding of the skills and tools required to use and share the information appropriate to the provision of healthcare services and the promotion of good health. Given the essential grounding of health and medicine in the human condition, ethical, legal, and social issues did not remain long outside the field of endeavour, discussion, and debate.

United Kingdom and Finnish-based academics, Penny Duquenoy, Carlisle George, and Kai Kimppa, have brought together a set of contributors from largely Scandinavian, United Kingdom, and eastern and southern European countries to explore a number of key non-technical issues surrounding eHealth. All are deeply concerned with the ethical, legal, and social issues surrounding eHealth, whatever the relative range of complexity of the technologies involved: some of these applications are very simple, others complex and futuristic. The authors' themes are principally three: the Internet; today's ethical, legal, and social issues; and the challenges of future developments in eHealth.

A 15-year journey has taken place since a canine in a *New Yorker* magazine cartoon warned early online users, "On the Internet, no one knows that you're a dog"<sup>i,ii</sup>. While this observation is pertinent to many areas of public service information, it is especially important in the health sector where health information needs to be valid, appropriate, vetted, and often confidential. The focus on Internet and Web-based technologies is self-evident throughout this volume. Its collection of papers has special relevance for the concerns of citizens, patients, health consumers, and healthcare professionals, given recent announcements made by some of the most internationally well-known software and health service-related companies, institutions and not-for-profit associations on keeping health data safe and sound<sup>iii</sup>.

Contemporarily, trust, responsibility, and the quality of information are all major concerns that lie at the foundation of eHealth. As the technologies that support healthcare increasingly mix, merge, and converge, giving us "connected" or "connecting" health, these matters grow progressively, sometimes even disruptively, in importance. Patient safety and reduction of medical risk is a perceived basic benefit of eHealth<sup>iv</sup>. Work undertaken in developing tentative recommendations on the interoperability of eHealth systems and services, at least in Europe, due for publication in spring 2008 by the European Commission<sup>v</sup>, goes further to cover the provision, connectivity, equity, quality, cost, and safety offered by the various technology applications involved. As some of the most obvious and yet profound ethical, legal, and social issues in healthcare information, these matters are all given due attention in this volume.

Educationalists and policy-makers do not care to look only at contemporary developments, they also examine their crystal balls to see what future developments are emerging. The latter chapters of the book therefore focus on issues relating to

bio-medical developments, new genetic and proteomic data, sensors, engineering initiatives, implantations and close-to-body devices, and the way in which these advances are considered today and could be perceived tomorrow.

Currently, these research and application topics are to the forefront in Europe's laboratories and research centres. Data information, which originates as our own, may lead to profound insights into health—and, particularly, public health—trends, threats, and challenges.

Contemporary studies, such as Scenarios4Health<sup>vi</sup> on ICT-enabled healthcare developments, will surely lead to interesting and provocative visions as they publish their final reports this year or next. It is perhaps not surprising, therefore, that a 13 September 2007 foresight workshop held at the home of the Institute for Prospective Technology Studies in Spain, rather than focus on the developing applications and technologies that underpin eHealth, deliberately concentrated on the ethical, legal/regulatory, and social challenges that need to be faced in electronic support of the health domain.

As we look towards the future, and particularly that peak in the West of baby-boom ageing around 2030, all citizens in our societies need to ask themselves certain basic questions<sup>2</sup>. How in a flat world<sup>3</sup>, will societies find a balance between those populations which are ageing and those which are relatively young and healthy; between those of whatever age who are experiencing more and more chronic diseases; between those who need care and support and those few(er) who are economically active; between those regions and states which are blessed with abundant healthcare professionals and those which have insufficient; between those countries and institutions which extract the benefits of advanced telemedicine and teleconsultation and those which remain as yet unconnected? How too can we move towards a more innovative and evolutionary view of thinking about and organising our healthcare systems and services?<sup>4</sup>

Let us look forward eagerly to a continuation in this kind of debate and dialogue. The preliminary questions outlined in this volume are preliminary, concrete, but fundamental, steps on a journey, which will permit the asking of many more challenging and provocative questions. We will all need to face a health-permeated future that, while it is full of aspirations about technological and scientific possibilities, at the same time is replete with ethical, legal, and social challenges. A structured debate and dialogue on these questions is now of pending, and indeed of major, concern.

*Diane Whitehouse*

*October 27, 2007*

*Paris, France*

## Endnotes

---

- <sup>i</sup> COM(2004)356 final. *e-Health - making healthcare better for European citizens: An action plan for a European e-Health Area*. I am indebted for many of these insights to Dr Petra Wilson of Cisco Systems Internet Business Group and her observations made during and industry leaders session at the World of Health IT conference held in Vienna, Austria, 22-25 October 2007. For more information on the conference itself, see <http://www.worldofhealthit.org/>
- <sup>2</sup> I am indebted for many of these insights to Dr Petra Wilson of Cisco Systems Internet Business Group and her observations made during and industry leaders session at the World of Health IT conference held in Vienna, Austria, 22-25 October 2007. For more information on the conference itself, see <http://www.worldofhealthit.org>
- <sup>3</sup> Thomas L. Friedman (2005) *The world is flat: A brief history of the twenty-first century*. Farrar, Strauss, and Giroux
- <sup>4</sup> Although not on the topic of healthcare *per se*, some of the ideas contained in a recent book contain innovative and thoughtful reflections on collaborative ways of working in new fields. See Don Tapscott and Anthony D. Williams (2006) *Wikinomics: How mass collaboration changes everything*, Atlantic Books: London, UK
- <sup>i</sup> Cartoon designed by Peter Steiner. *The New Yorker*. 5 July, 1993. Vol 69 (LXIX), no. 20, p61
- <sup>ii</sup> Although this observation was first made a decade and a half ago, Ms Celia Boyer of the Health on the Net (HON) Foundation, Geneva, Switzerland, very pertinently reminded her audience of it at an ePractice high impact services workshop held in Brussels, Belgium on 10 September, 2007. For more information about HON's work, see <http://www.hon.ch/>
- <sup>iii</sup> See The *Economist*, 4 October, 2007 'The vault is open' on the notion of a 'health vault'.
- <sup>iv</sup> V.N. Stroetmann, J-P. Thierry, K.A. Stroetmann, A. Dobrev (October 2007) *eHealth for safety. Impact of ICT on patient safety and risk management*. European Commission: Brussels
- <sup>v</sup> Based on earlier work published by the Commission Services: European Commission (2006) *Connected Health. Quality and safety for European citizens*. Luxembourg: European Communities
- <sup>vi</sup> <http://www.scenarios4health.org/>



## Preface

Over the last 50 years, the integration of computer technologies within all sectors of society has increased exponentially year on year, providing fast and easy access to information in a timely and cost-effective way. The capabilities of such technologies to manage large amounts of data and provide access regardless of physical distance have been exploited both by commercial enterprise and public sector organizations, giving rise to terms such as e-commerce, e-learning, e-government, and e-health. The drive to fully exploit the potential of this technology together with a keen interest by individuals to use it has resulted in a rapidly changing social landscape—encompassed in the concept of the “e-society” or “information society.”

In the last 10 years, particularly since the introduction of the World Wide Web (WWW), we have seen radical changes within society as more and more individuals and organisations adopt this “digital” world—founded on what are commonly known as information and communication technologies (ICTs). The delivery of information is no longer just within the domain of the traditional computer and keyboard interface, it incorporates the convergence of computer technology with any digitally capable means of transmission, including mobile wireless devices such as mobile phones. What is significantly different in this digital context is the inclusion of the general public in a two-way information exchange, taking a role whereby they are not only the recipients but also the creators of information and who moreover, have a potentially global audience.

The impact of global information exchange on traditional organizational processes and social expectations poses several challenges. When we consider that this exchange spans cultural as well as national boundaries, and that the creators and providers of information include experts and non-experts (in a particular domain, as well as in technology use and understanding) we can see that the challenges to accessing, understanding, regulating, and distinguishing the valid from the invalid are not trivial. However, whilst some of the issues are challenging they are not



insurmountable and great strides have been made in meeting and addressing the issues by those working in the relevant disciplines that include both computer science and the social sciences, and particularly cognitive science, psychology, philosophy, and law.

In all of the different sectors that have incorporated computer technologies the ethical, legal and social issues that arise have an impact that affect all stakeholders—from individuals within the society through to the professionals working in a particular domain. These issues have not often been clearly seen or anticipated—largely because many of the applications present new ways of doing things in unfamiliar contexts. In familiar contexts, we have in place processes and rules that inform and accommodate work and social practices. Where situations are presented that are unfamiliar it is not clear how the rules we are used to map into the new situation. (Consider, for example, a visit to a culturally different country—the ways of doing things may be quite different and take some time to rationalize.)

These differences are important to understand when technology is introduced to the medical sector. Whilst computers and medicine have for a long time been linked together<sup>1</sup>, for example in monitoring systems, their use has broadened and touches on almost all spheres of patient care that have an effect on practice within the traditional care setting, as well as in radically new areas such as patient “self-help” and embedded chips (see Chapters I and XII respectively).

It is for these reasons that this book has come together. The ethical, legal, and social issues that arise from the introduction of ICT’s in the medical sector need to be considered not only in the specific context of their use, but also in a wider context that highlights the transforming effect of such technologies. The terms that have emerged to cover the convergence of computer technology and medicine are various: health informatics, healthcare informatics, biomedical engineering, e-health, and medical informatics. The areas all overlap and share a common theme, but for us the term medical informatics emphasizes the “technical” information application area that is bound together with the medical profession—a domain to which the ethical, legal, and social aspects are at the moment most relevant.

## **The Scope of Medical Informatics**

Medical informatics touches most people in the world today in the developed and not so developed countries. Its scope is vast, covering the full range of information support to medical practice provide by computer technology—from computerized records in doctor’s surgery’s at one end to decision-support systems in hospitals at the other. In terms of academic research, the scope of medical informatics includes the management of information from a range of healthcare sources: “hospital management information, patient records, clinical examinations, laboratory results, physiological measurements, medical images of all kinds, primary care information, and epidemiology.”<sup>2</sup> Although this list does describe the different types of information

gathered, and considered to be part of the medical information domain, it does not fully capture the complexity or breadth of inter-organisational, cross-organizational, and indeed global, exchange.

With the advent of global communications, in the form of information communication technologies (ICTs), developments in mobile wireless devices and most recently the grid<sup>3</sup>, medical care has been revolutionized bringing new opportunities for improving practice, improving healthcare, and reducing costs. At the same time, these radical changes accentuated by the fast pace of development and innovation, raise significant challenges to traditional health care models. The opportunities offered by the Internet for the sharing of information across the globe on a “many to many” basis has for the first time opened the door to a “do it yourself” type of approach to personal healthcare. Individuals can find their own health information, and act on it without consultation with a healthcare professional (e.g., their local doctor).

The standards and regulations that have hitherto served to protect individuals in such a vitally important area of life can no longer be guaranteed when healthcare moves into the public arena. Agreeing common standards and regulatory procedures across the globe is hard—enforcing them is another matter. At a more local level, the introduction of computer—mediated healthcare changes the processes and practices of the care professionals—not least in learning to operate and manage ICTs, individually and as part of a team.

In all of these different situations and contexts, the ethical, social, and legal environment can be substantially changed but, as mentioned earlier, presented in such an unfamiliar setting that initially the differences may not be clearly seen. In this interim stage difficulties are experienced by the users of the technologies, as well as by those individuals and communities who are impacted by the changes that have been brought about. It is at such a transitional time (i.e., where stakeholders are making adjustments to accommodate new technologies), that discussion, debate, and the exploration of new ways of doing things are common.

With this extension to the availability of healthcare information both within the profession and to the general public, the scope of medical informatics as suggested in the first paragraph above is not enough for current purposes. It excludes the participation of the general public—as current or potential patients—from the information domain. Some might argue that including this aspect is going too far, and that public access to information (that may or may not be scientifically proven or accurate) goes outside the boundaries of the professional field. However, we would argue that the source of the information accessed is not the point—the fact that it is available and widely used by the general public has an impact both on patient health and welfare, and on the profession. Therefore, the definition of medical informatics given by Shortliffe and Blois for example, as “the scientific field that deals with biomedical information, data, and knowledge—their storage, retrieval, and optimal use for problem-solving and decision-making” (2001, p. 21) more appropriately covers the scope, and although it may not intentionally be including the broader

‘self help’ aspects of the Internet or other patient devices and aids, the definition does not constrain the scope to a purely organizational one.

## **The Issues Raised**

---

We have previously said that the increasing integration of ICT within healthcare systems changes traditional processes that have come into use in an evolutionary way to accommodate key healthcare ethical principles and social policies. The issues arising from this changed environment concern the transference of the embedded principles of best practice standards and regulation to the new technologically informed processes and models. For example, the process of delivering prescription medicines have traditionally been mediated by pharmacists who are trusted experts—it is their responsibility to ensure patients receive the correct medication. How does this model transfer to the situation we now see where prescription drugs can be bought from online (Internet) pharmacies? Other issues arise where the trust that has previously been placed in medical personnel is mediated by technology—where is that trust now placed in this situation? How can previous models of trust be transferred to information mediated by technology?

The role played by ICT as mediators of information and as “aides” in working practice is a difficult one to distinguish, where levels of responsibility are blurred. In a process that involves extremely complex negotiations and data retrieval how can practitioners distinguish between the boundaries of responsibility? Understanding these boundaries is important, not simply for staff accepting responsibility but also so that they are aware of displaced responsibilities—and errors that could occur. In including mediating technologies it should be recognized that the cognitive load on users, and difficulties in compartmentalizing “human habit” and “computer characteristics” have an impact on the perceptions of those using the technology. This behaviour is often seen where users attribute human characteristics to machines, resulting in confusion over roles and responsibilities.

Further confusions over boundaries between the human and technical occur when the two become more closely connected. There are differences that need to be thought about when proving personal identity is a choice between using some form of paper card, a computer chip, or parts of the body that have been converted into a digital record (such as fingerprints) as is the case with the security technologies known as “biometrics.” Where computer chips are implanted into the human body what then are the boundaries? Is it important to know and recognize the boundaries?

Physical boundaries inform our thinking, allowing a separation between behaviour and expectations attributed to humans (and animals) and other physical objects. Boundaries have also traditionally distinguished cultural differences and preferences. Laws and other forms of regulation are culturally informed, admittedly with some sharing of principles across cultures. These boundaries disappear when using ICT—either in using the Internet to buy drugs from another country, or exchanging

information with other countries that have different views on privacy and confidentiality. How does this impact on our traditional information processes? What are the areas at risk when regulation may not apply across territorial boundaries?

All of the previous are some of the serious questions that need to be explored, and which the chapters in this book attempt to address.

## **Structure of the Book and Outline of Chapters**

The book is divided into six sections offering different perspectives, or themes. If we take a technology perspective, the book begins with a look at the impact of the Internet on healthcare and doctor-patient relationships and takes us through a technological domain that includes information systems in use in health institutions, new technologies in research, and emerging technologies that connect to the patient. Taking a “human focused” perspective the chapters follow a structure that highlights issues of ethics, trust, quality of care, responsibility, patient confidentiality and regulation, both from an individual perspective and a wider social and legal perspective.

It begins with two chapters that investigate the phenomenon of the Internet in respect of new forms of patient autonomy—that is the increased access to health information and medicines. In the first chapter the focus is on the sale of prescription drugs by online pharmacies and the ethical and social impact of this practice, what it means to traditional models of healthcare practice when patients become “shoppers” and how the regulatory controls manage to control not only the remote delivery of prescription drugs (i.e., without the local physical presence of a dispenser), but also how the law copes with this transnational environment (George & Duquenoy). In the second chapter, Collste takes an ethical perspective and puts the remote and internationalization aspects of Internet healthcare within the context an ethical framework in order to see more clearly how this type of healthcare delivery conforms to the ethical principles that have always been at the core of medical practice.

Section II moves into the domain of medical practice and takes the core aspects of trust and values for investigation. Both chapters in this section use empirical research to further explore these aspects, and understand the perceptions on those immediately involved in using technology in practice. Bisset et al. are interested in how clinical decision support systems (i.e., systems that rely on an existing knowledge base to provide information) are regarded in terms of trust, and whether these perceptions are supported by the chains of responsibility in the system provision. Their study incorporates views from the suppliers of the knowledge base, the software developers, and end users in the context of a New Zealand primary care environment.

The second chapter in this section is also set in the context of primary care, this time in Sweden, where Hedström aims to assess the changes in practice that may arise from the use of electronic journals. In this study, which takes the aspect of

elderly care and the social journal—a device that is used to share information about an individual with those involved in their care. Taking the view that information technology systems are naturally embedded with the values of the development process, Hedström uses a value framework (that incorporates the values relevant to this aspect of the health work) as a tool to compare and assess impact on practice arising from the change in recording medium (i.e., paperbased to digital).

Questions of responsibility are the focus of Section III. Taking the issue of decision support systems (as previously summarised) a step further, Gröndahl (Chapter V) asks where the responsibility for action rests. When computer systems are used to inform and support decision-making and those systems become ever more complex, is it reasonable that practitioners using them should be assigned responsibility for the results of their decisions? Using a series of arguments as leverage for discussion, Gröndahl explores the issue of moral agency in respect of systems using what is known as artificial intelligence techniques, as well as the associated question of legal responsibility. As such systems are infiltrating medical practice more and more answers to these questions become imperative. A similar theme is followed by Lahtiranta and Kimppa where the concept of “agentization” (whereby the technology becomes the agent) is employed to illustrate how easily we are moved to attribute responsibility to mechanical artifacts. They particularly look at how the patient-doctor relationship may be affected when machines are integrated within the healthcare process, to the extent that they may become naturally accepted inclusions in the relationship, and how issues such as informed consent are dealt with in this mediated environment. One recommendation is to make it quite clear to those involved the distinction between human agent and artifact.

The two chapters that make up Section IV emphasise the technical systems in their role as supporting technologies to healthcare practice. In the opening chapter of this section Solomonides introduces a relatively new concept, for example, the grid, which utilizes shared and distributed computer processing power in order to provide the capacity needed for large scale data management (such as medical images). The storing and exchange of medical images is crucial to providing a knowledge base for practitioners, and clearly it is also crucial that the images from which judgments are made are reliable. Quality of information is vital. The grid also raises some challenging ethical, legal, and social issues due to the characteristics of its operation—the same characteristics that inspired its creation.

As such large-scale utilization of ICT becomes more prevalent, and IT projects become more ambitious, the quality of the system becomes more difficult to control and keep track of. This is particularly the case where national programmes are rolled out, as with the NHS (National Health Service) *Connecting for Health* programme in the United Kingdom. This programme is just one of many government projects that have received enormous criticism and bad press in the UK. Suppliers of systems are increasingly under pressure to address issues of quality and reliability, for their own professional sakes as well as in the interests of patient safety. Stanberry (Chapter VIII) gives a comprehensive account of the trials and tribulations of informatics

deployment in the health sector so far, the legal and professional imperatives for improving performance, and the emerging standards and best practice that are being developed in response to these problems.

Section V addresses one of the key issues at the forefront of current debates on medical information. Patient confidentiality has always been at the heart of medical practice, and this is severely challenged by information transfer to digital media, and the global operation of the Internet that allows the exchange of medical information not just nationally, but globally.

Fung and Paynter (Chapter IX) discuss the issue of privacy in relation to patients' medical information and the risks to privacy that the more open electronic exchange facilitated by Internet technology has promulgated. They show that despite legislation and assertions as to the value of privacy (of medical data) there are major vulnerabilities in following this through to strong privacy policies and the upholding of privacy standards using technological means, such as in system set-ups and security technologies. In their analysis of the health information situations in New Zealand and the United States, they categorise the different sources of risk and solutions used to tackle the problems. Their conclusion is that as new technologies appear bringing new risks so strategies must be developed that include a comprehensive approach and utilization of available technologies in order to maintain the benefits that ICTs offer.

Similar concerns regarding personal medical data are raised by Berčič and George in Chapter X. In this case, they focus on Europe (EU) and the collection of medical records in national databases, which are compiled from local databases and file systems. Given the special level of legal protection pertaining to medical data in the EU issues of access, legitimacy of data held and subject access rights, amongst others, need to be considered and addressed.

Having critically assessed, analysed, and discussed the various applications of medical informatics in current use, we end our investigative journey with two chapters that discuss emerging technologies and their prospective uses. In Section VI, the final section in this book, the focus is on the convergence of technology with the human body. The first chapter (Chapter XI) brings together the issues of personal information and privacy together in a discussion on identity and the technical means of identity verification—biometrics. The use of this technology responds to the growing problem of medical identity theft (using unlawfully gained medical information) that provides fraudulent access to health care. Biometric technology is based on using unique personal attributes such as fingerprints, retina patterns, and others to verify identity. Although more effective than many other methods of authentication, biometric information is also medical information and as such provides more than just a positive affirmation of a valid identity. Mordini takes us through the technical characteristics of biometrics, issues of privacy, and the benefits and risks of adopting this technology.



The book concludes with a chapter that describes the integration of computer technology with, and into, the body. Although the title “Prospects for thought communication: Brain to machine and Brain to Brain” has a futuristic implication the chapter describes past research with neural interfaces, which has provided the groundwork for the claims in the title. The focus of the discussion is between the use of this technology for therapy or enhancement—and whether there is a difference as far as ethical use is concerned. As the authors, Warwick and Cerqui, hold different positions on this research (Warwick as the motivator and subject of much of the research and Cerqui as interested anthropologist), the benefits together with the moral issues make for an interesting dynamic.

## Conclusion

---

This book brings together the perspectives of authors from a variety of disciplines: computer science, information science, medicine, law, philosophy, and the social sciences, to offer an international overview of the ethical, legal, and social issues inherent in the application of information communication technologies in the healthcare sector.

As we move into an era that relies more and more on technology to assist work practices, enhance knowledge, improve healthcare, and facilitate patient autonomy and independence it becomes crucial to understand and assess the impact of current and future technologies. In seeking more efficient, faster, and large-scale implementation of our technological creations, we should not lose sight of the human factors—the ethical and social dimensions. We must also pay due regard to the regulatory controls that exist and the challenges that these technologies pose.

Each of the chapters in this book raise key questions that deserve attention and reflection, and through this process can offer recommendations for improving the implementation of new technology in this domain.

The aim of the book, in addition to providing the basis for reflection in its case studies, arguments, and analyses, is to provoke thought, stimulate debate, and provide a foundation for further work in the field—in education, research, and practice.

*Penny Duquenoy*

*Middlesex University, UK*



## References

---

Shortliffe, E. H., & Blois, M. S., (2001). The computer meets medicine and biology: Emergence of a discipline. In E. H. Shortliffe & L. E. Perreault (Eds.), *Medical informatics: Computer applications in health care and biomedicine* (2<sup>nd</sup> ed.) (pp. 3-40). New York: Springer Verlag.

## Endnotes

---

- <sup>1</sup> Shortliffe and Blois note the use of “electromechanical punched-card data-processing technology” which was widely used for epidemiologic and public health surveys during the 1920’s and 30’s (2001, p.23).
- <sup>2</sup> The scope outlined as relevant to the journal *Medical Informatics and The Internet in Medicine*, Informa Healthcare, Taylor and Francis Group.
- <sup>3</sup> The grid is a term used to describe the utilisation of distributed computing power to increase computing capacity (explained further in Chapter VII of this book).

# Acknowledgment

The editors would like to acknowledge the help of all involved in the collation and review process of the book, without whose support the project could not have been satisfactorily completed. Most of the authors of chapters included in this book also served as referees for chapters written by other authors, and thanks are due to them for their constructive remarks and suggestions. Thanks also to our colleagues and experts from the health sector, Diane Whitehouse and Chris Zielinski, who were kind enough to review chapters.

More thanks are due to Diane Whitehouse for agreeing to write the foreword for this book, and finding the time to do it amongst all the other demands on her time.

Special thanks also go to the publishing team at IGI Global, particularly Meg Stocking and Deborah Yanke who provided support throughout the process. Whether it was emails to remind us of deadlines, or in offering help and advice, our communications have not only been at a consistently professional level but have also been conducted in an open and friendly manner.

Finally, to the authors—a thank you for your staying power, insightful contributions, and continued support throughout.

*Penny Duquenoy*

*Carlisle George*

*Kai Kimppa*