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[1], 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."[2] 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[3], 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 vulner-abilities 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 medi-cal 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 medi-cal 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* (2nd ed.) (pp. 3-40). New York: Springer Verlag.

Endnotes

[1] 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).

[2] The scope outlined as relevant to the journal *Medical Informatics and The Internet in Medicine*, Informa Healthcare, Taylor and Francis Group.

[3] 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).