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# Health informatics: current issues and challenges

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## Abstract

Health informatics is a new field and although there are no formal definitions, it concerns the use of information and communication technologies (ICTs) for health and in health care. This review discusses health informatics in relation to medical informatics and health information management. The development of information systems and the advent of electronic records within health are major areas within health informatics and account needs to be taken of the information needs and behaviours of all users in these developments. The private and sensitive nature of personal health data raises ethical concerns for developing electronic records. Further challenges to be faced include the financing of developments, the importance of gaining user acceptance, and ensuring the quality of data. However, health informatics also has the potential to make an important contribution to the ageing society and to reducing the digital divide and health divides within society. Three themes emerge throughout the review: health informatics and information science need to take account of the unique aspects of health and medicine; e-health initiatives must actively involve users in the design, development, implementation and evaluation, and information science can contribute to understanding the needs and behaviours of user groups; there is a need for an appropriate evidence base within health informatics to support future developments, and to ensure health informatics reaches its potential to improve the health and well-being of patients and the public.

Keywords: health informatics; medical informatics; health information management.

## 1. Introduction

Health care is a complex and information-intensive process in which data concerning the health and medical conditions of individual patients are stored and used for clinical care and management. Additionally, data are aggregated for secondary purposes, such as the management of local health services, the monitoring and surveillance of diseases, and for planning the delivery of health services at regional, national and international levels. Within health care organisations, services and systems, large volumes of data are collected, stored, analysed, transferred, and accessed on a daily basis. In addition to data on individual patients, up-to-date information on how to prevent, diagnose, treat and manage diseases from research is being published and is

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required by healthcare professionals to provide effective and safe care for patients and the public. Health informatics is a relatively new field that has emerged in the last twenty years and has assumed a growing importance as a discipline. From a Donabedian perspective<sup>2</sup> [1], health informatics can be regarded as being concerned with the structures and processes, as well as the outcomes, involved in the use of information and information and communications technologies (ICTs) within health. The term 'e-health' has been coined to describe the application of these technologies in health and medicine.

The aim of this paper is to review health informatics and to consider how information science can contribute to this field. The review commences by considering how health informatics, and the closely related areas of medical informatics and health information management, are defined. It discusses current developments in health informatics and particularly what it is about health and medicine that requires special consideration from an informatics perspective, as well as the contribution that informatics has to health and medicine. It considers the implications of developments in health informatics and e-health for patients and healthcare professionals, and discusses the challenges faced within health informatics, as well as the opportunities health informatics has to offer in the twenty-first century.

## 2. Defining Health Informatics and related areas

Despite numerous attempts to define informatics [3], medical informatics, health informatics and health information management, no widely-accepted definitions exist for these areas [4, 5]. Related to these three areas are other specific fields, such as nursing informatics [6], dental informatics and primary care informatics [7], which consider informatics applications related to specific professions or health sectors. These can be considered sub-groups of health and/or medical informatics and whilst they are not considered in this review, they make an important contribution in health and medicine and might be considered as subsets of health and/or medical informatics. The relationship between health and medical informatics, as well as with health information management is less clear. Research and developments in information and the use of ICTs in health and medicine may fall into one of these areas, or may overlap across two, or all three, areas. This relationship is represented in Figure 1.

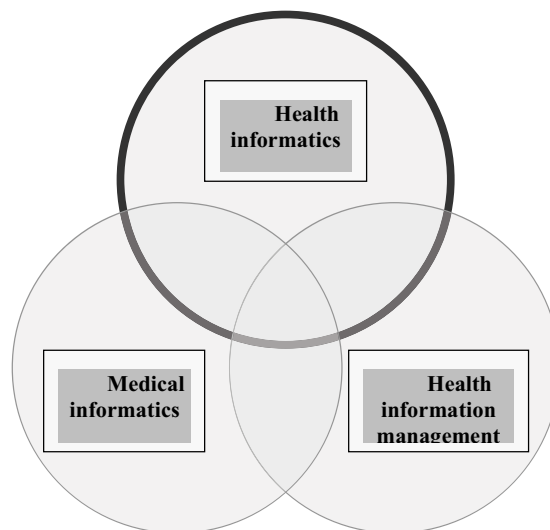
Figure 1 illustrates the point that health informatics, medical informatics and health information management can be considered as three separate, but related, fields with overlap among them. Here they are first considered separately, before the overlaps between, and among them, are discussed. While there is no widely accepted definition of health informatics, in its broadest sense, it concerns how information and communication technologies (ICTs) are used in the health sector. The overall aim of health informatics is to develop and improve the organisation and management of information and thereby improve the overall quality of care for patients [8], and to this group should be added their families and carers, and the general public. Implicit in this aim is the need to consider health informatics developments from the perspectives of these groups, at an individual, group and societal level. In addition, the impact of ICT applications on health and information professionals and on the interaction between healthcare professionals and patients [9] requires consideration within health informatics.

Although medical informatics has no formal definition either, it can also be considered to include the use of information technology, and to a lesser extent, ICT, to improve the care of patients. However, medical informatics is concerned more with the use of information and computing technologies for specific clinical applications in particular settings, for example, storing medical images [e.g., 10], decision support tools for patient management, architectures for electronic medical records [e.g., 11], data mining techniques for diagnosing clinical conditions [e.g., 12] or predicting clinical outcomes [e.g., 13]. Research and developments within medical informatics focus

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<sup>2</sup> Avedis Donabedián is widely regarded as one of the leading figures of quality assurance in public health in the twentieth century. His seminal paper entitled "Evaluating the quality of medical care" (cited above) introduced the idea of evaluating quality of care and services in terms of the structures (e.g., number of beds in a hospital), processes (e.g., number of operations conducted over a period of time) and outcomes (e.g., the survival rate of patients). This article is one of the most cited articles in public health and is a Current Contents Citation Classic [2].

more on the technical issues and pay less attention to the human and societal implications of these developments. There use of the word “medical” in this name also implies a specific clinical focus and the involvement of clinicians/doctors, whereas the word “health” in the other areas implies greater generality and the involvement of other health professions. This may have contributed to the rise of health informatics and health information management. Health information management is a relatively smaller area, and is more restricted conceptually, being concerned with how information is organised and managed within health, for example, by patients or health professionals, or within a hospital, an organisation, service or at a national (e.g., the level of health literacy within populations [14]; surveillance systems for public health).



**Figure 1: Diagrammatic representation of the relationship between health informatics, medical informatics and health information management.**

The overlaps between, and among, medical and health informatics and health information management are represented by the intersections of the sets in Figure 1, and are extensive but, again, not readily defined. Specific medical informatics applications within a particular clinical setting may have implications for other aspects of a health service or organisation or may consider the needs of patient, or other, user groups. For example, the Violet Technology for prioritising relevant information for diabetes patients both specified the technical details and also considered how the information needs and preferences can be individualised for patients [15]. Medical informatics applications may also affect information management within an organisation, e.g., understanding the effect of electronic medical records on how doctors manage and use health information [16]. Developing methods of identifying patterns of disease and deprivation is a medical informatics challenge [e.g., 17], but also has important implications for the management of information within public health.

Developments and advances in health informatics may also improve the organisation and management of information for healthcare and information professionals, health service managers and planners, as well as patients and the public, and so overlap conceptually with health information management. For example, the development of portals for patients to provide access to health information on the web has implications for the way in which people access and manage health information [18]. Information management strategies may be used to reduce problems associated with use of information systems within the health environment [4, 5], for example, to decrease dependency on paper-based systems and therefore reduce redundancy of information.

The intersection among all three areas may include those developments that have a specific medical application, but which have to be considered within the wider health context and have implications for the information management. For example the development of electronic records, may consider different electronic records architectures (medical informatics), their impact on the doctor-patient relationship (health informatics) and how data might be extracted for management purposes (health information management).

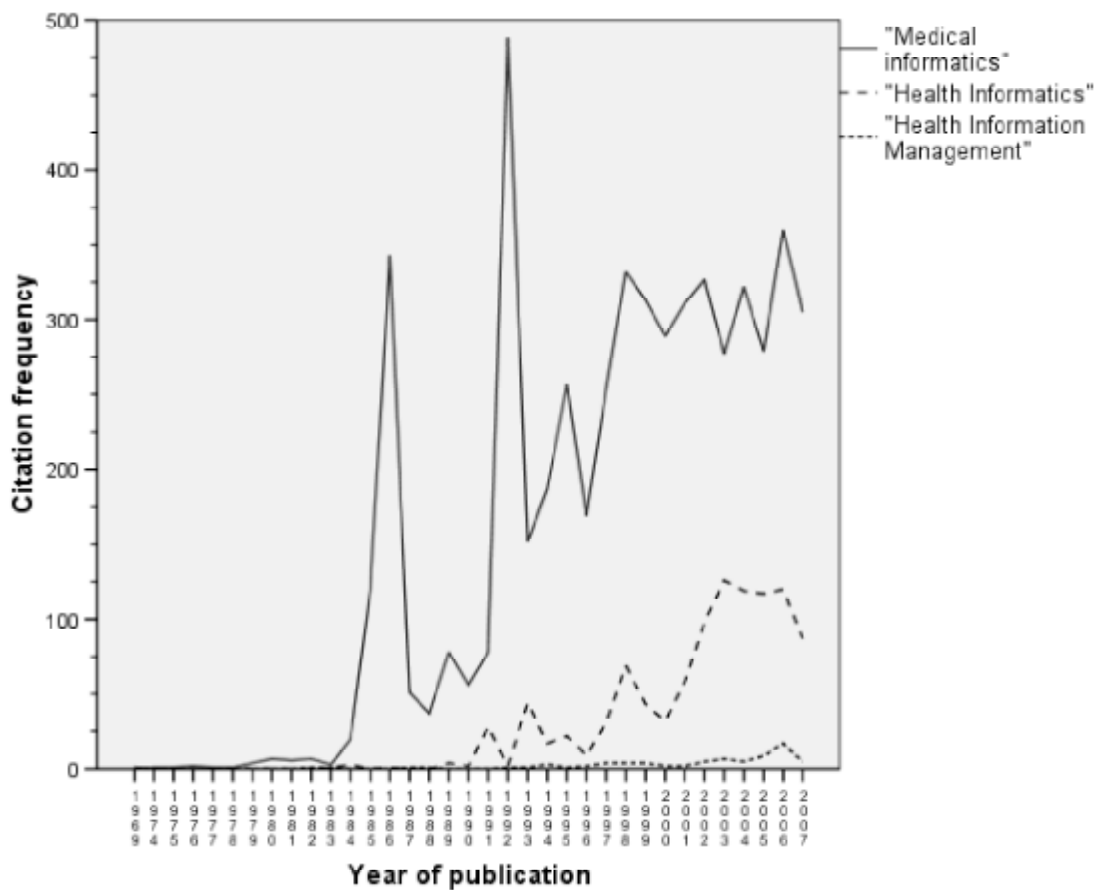


Figure 2: Line graph to show the frequency of articles including the terms “health informatics”, “medical informatics” and “health information management” (Source: Web of Knowledge, 2008).

A citation search of the terms “health informatics”, “medical informatics” and “health information management” in article titles and topics in Web of Knowledge demonstrates the relatively recent development of these fields. The results of this search are illustrated in Figure 2. The terms “health informatics” and “health information management” first appeared in the research literature in 1969 and the term “medical informatics” first appeared in 1974. However, as shown in Figure 2, the term medical informatics rose to prominence in the mid-

eighties, whereas it was not until the nineties that “health informatics” started to appear more frequently in the research literature, and even then it has not reached the levels of the term “medical informatics”. The term “health information management” started to appear more often at the start of the twenty-first century and it remains to be seen whether this term becomes more widely adopted.

Whilst it is helpful to highlight specific aspects of health and medical informatics and health information management, it must be emphasised that the distinctions and areas of overlap are not clear. This is evidenced in medical/health informatics/health information management and medical literature, which all cover these areas: for example, the *Journal of the American Medical Informatics Association* (JAMIA) and the *International Journal of Medical Informatics* include papers that relate closely to health informatics, and the *Health Informatics Journal* publishes papers that overlap with medical informatics and health information management. This journal also publishes papers from the International Symposium for Health Information Management Research (ISHIMR), organised each year by the University of Sheffield in collaboration with other information science and health/medical informatics centres. The difficulty in the distinction between the three areas is further compounded by the limited professionalisation within the field and the lack of a clear career structure. Some national organisations exist, such as the well-established American Medical Informatics Association (AMIA) and Health Informatics New Zealand (HINZ), and these provide a forum for informaticians within the health services to discuss issues and share their work. However, such organisations include the other areas within their remit; while this inclusive approach is very positive, it makes the distinctions between these areas less clear. Having a sharp distinction between the three areas is not necessarily helpful, anyway, given that the purpose of all of these areas should be to improve the use of information and ICTs for the health and well-being of patients, their carers and families.

For the purposes of this review and more generally, I will use the following working definition of health informatics: health informatics is the use of information and information and communication technologies (ICTs) to improve the quality of care and health and well-being of patients, their families and carers, and the general public. From a Donabedian viewpoint [1], this includes the structures (i.e., the information and the technologies, e.g., decision support tools, web-sites containing health information), the processes by which these technologies are developed, implemented and evaluated, and the outcomes of using information and ICTs within health (e.g., the impact on patient well-being and quality of life, user satisfaction). While this definition does not include health care professionals and managers, these are important in the overall process. However, the emphasis in health informatics should be on the ultimate benefit to patients and the public. This review concentrates on health informatics, i.e., the area within the bold circle in Figure 1, and pays less direct attention to pure medical informatics and/or health information management issues and developments.

### **3. Information systems and electronic records**

A major focus of activity in health informatics (and medical informatics/health information management) has been the development of information systems for medical and health care. During the last ten to twenty years the focus has moved away from departmental or ward-based systems to institutional/hospital-based systems to operate at a regional, national or global level [4, 5]. The earlier development of individualised systems that fulfilled specific functions for their unit resulted in legacy systems that successfully met the objectives of that unit but were unable to exchange or transfer data to other parts of the service or organisation due to incompatibility [19]. The increasing realisation that this exchange of information is important, if not vital, for continuity of care and multidisciplinary care of patients has been a major driver for the development of organisation or service-wide systems. However, this transition has not been without problems and there are notable examples of huge financial investments in IT systems in health care that have been wasted. System developers have been faced with the choice of either developing systems to integrate existing legacy systems, or of developing completely new systems that meet the needs of all parts of an organisation. Integrating existing systems has proved problematic due to incompatibility of different systems and developing new systems has to overcome ways of incorporating previous data from a variety of systems. This has been compounded by mixtures of paper-based systems and

electronic systems [4, 5] resulting in continuing problems of data redundancy and duplication of data collection and information storage. Further problems occur when integrating systems developed for, or in, different geographical locations, or use different operating systems.

A further change in recent years in the development of information and communication systems has been the move away from systems that collect data for management purposes to patient-centred systems. The problem with systems developed for collecting management data is that clinical staff perceive little benefit for patient care, and are reluctant to add data and to use systems for which they feel there is little purpose. The UK White Paper, *"Information for Health"* [19], presented an Information Management and Technology (IM&T) strategy for the National Health Service and two key principles underlying this strategy were that systems should be person-based and that management data should be collected from these operational systems. Although the implementation of the IT strategy was beset with problems and difficulties [20], and the strategy has since been replaced by the National Programme for IT (NPIIT) the movement towards a national patient-based system has continued.

The issues in developing electronic records for patient care help to illustrate the complexity of health information, and issues faced, within health informatics. The volume and range of information collected within a single episode of health care for an individual patient can be large. The required information can include textual, numeric, high resolution image and complex signal data [4,5] collected by different health professionals, including doctors, nurses, radiologists, pathologists, physiotherapists. These data record the personal details and medical history, symptoms and clinical measurements, diagnosis and prognosis, and treatment of the patient. An additional level of complexity is that health professionals are used to recording their observations as free text and using annotated diagrams, and incorporating such data into an electronic format is not straightforward [21]. These data may be collected and may be required in different locations, e.g., in an Emergency Department, on a hospital ward, within a radiology department, in the home, and appropriate devices need to be available for entering and accessing these data. These requirements must be considered in developing electronic records. However, the parallel development of new technologies, for example, personal computers and laptops, increased computer disk storage, mobile telephony, wireless networks, PDAs, satellite television, has facilitated the development of electronic records and helped overcome some of the challenges outlined here. The technology requirements themselves are not the limiting factor in the development of electronic records; rather it is the human, management and organisational issues that are key to the successful integration of electronic records into health care. A lack of consideration of these types of issues has been a significant factor in the failure of past systems.

The movement towards integrated and patient-centred electronic records and information systems will have a major impact on the way that healthcare professionals and service managers utilise information and information systems within health and will transform the way health care is delivered. Whilst data may be collected within a single patient episode, they need to be combined with information collected at previous stages in the patient's life, and this has led to the development of lifelong electronic health records [20]. Berner and Moss [22] described the very real possibility that all the necessary clinical data and information will become available to healthcare professionals for treating individual patients whenever and wherever it is needed. However, a critical factor in the future success of electronic records and information systems is ensuring that the health professionals and patients are involved in the research, design and evaluation of these developments. Health informatics, and more broadly, information science can play an important role in consideration of the information needs of these groups and how they seek, obtain and use information for health care.

#### **4. Information needs and use within health care**

As indicated in the previous section, an important area for consideration in the overlap between health informatics and health information management is information needs and information behaviour in the context of health. Whilst user-based studies of information needs and behaviour might once have been considered pure health information management, or information science, the development of the Web and of Web 2.0 technologies has stimulated interest in understanding how ICTs might be used to benefit patients, the general public, as well as health professionals, for example by providing support and help, education and information [8].

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Research in information science and the development of different models of information behaviour (e.g., by Dervin, Wilson, Ellis, Kuhltau and Savolainen among others [reviewed in 23]) has developed a better understanding of people's information seeking in a variety of contexts. Research in the health, medical and social sciences includes a large number of studies, which have identified information needs of patients, family members and carers for numerous conditions, as well as for the general public, in order to develop interventions, e.g., patient information leaflets, web-sites, to improve information provision for particular groups.

An important conclusion from this body of research is that information needs are not necessarily the same within a particular group, and that one size does not fit all: the information needs of individuals must be considered when designing information interventions and providing information. For example, the acquisition of information is not always beneficial and there are circumstances in which individuals may avoid information [24, 25, 26]. This is particularly true in health and medicine when information needs and behaviours can change during the patient pathway. For example, at the time of diagnosis, when patients are coming to terms with a diagnosis, they may want little or no information about their condition [27], but this may change once they have adapted to their situation, and they may need information on treatment options, prognosis, etc.

Although a large volume of research has been undertaken on information behaviours in general and on information needs for particular patient groups or conditions, there has been relatively little research that has explored the applicability of established information behaviour models in the context of health care. For example, Williams *et al.* used Dervin's Sense-Making framework to examine information behaviour among women visiting their family doctor [28], and Beverley *et al.* examined Wilson's model of information seeking in relation to people with a visual impairment [29]. The numbers of these studies are limited and there is a need to examine how well these and other models of information behaviour can be applied to groups of patients, their families and carers and the general public [26]. There is also a need to increase awareness of models of information behaviours within health and health care. While these models are very well known within information science, they are relatively unknown among health care professionals and health researchers: increasing awareness of these models may help to develop better information-related interventions.

In addition, a growing body of research has reported the information needs of healthcare professionals, for example, doctors [e.g., 30, 31], General Practitioners and family doctors [32, 33], and nurses [e.g., 34, 35, 36]. As in knowledge management there is an understanding that there is both implicit and explicit knowledge within organisations, recently there has been an interest in implicit and explicit information needs within the medical profession [31]. Explicit information needs are the needs for information that are recognised by a healthcare professional, e.g., treatments available for a diagnosed condition; whereas implicit information needs are those of which the healthcare professional is not aware, e.g., the symptoms of diseases which the clinicians does not realise that the patient is suffering from. As a consequence, while healthcare professionals may seek information about explicit information needs, they will not do this for implicit information needs, and the latter needs will only be met through serendipity, or when it is too late, e.g., following a post-mortem. One possible solution to overcome this problem has been to explore how implicit information needs can be made explicit [31].

Braun *et al.*'s literature survey and interview study [31] identified physicians' information needs, before abstracting the information needs to produce natural language representations of these needs and make them context independent. The resulting information needs templates, were instantiated with clinical data from electronic medical records, in order to relate information needs directly to patients. While this approach resulted in too high a level of information need, and therefore possible information overload, across a group of physician and patients, Braun *et al.* proposed ways of reducing this volume to manageable levels by the use of additional knowledge, e.g., relating to the temporal aspects of the patient/condition or using domain knowledge. Clearly using generalised models of information need has the potential to identify implicit information needs, and similarly models of information need and information behaviour developed in information science could help contribute to the understanding of implicit, as well as explicit, information needs.

The possibility of ever more clinical data and information becoming available to healthcare professionals and of patients having greater access to their own health information is likely to lead to the need for ways in which to deal with this information [22]. For example, although clinicians require specific information about individual patients, as well as general information on the interventions etc. available to treat the particular condition [30], there is a danger of having too much information and not being able to use it efficiently [22]. While the



summarising of information, the filtering out of information and the tailoring of it to the needs of individual healthcare professionals takes place routinely throughout the process of clinical care, e.g., during change-over in shifts on wards, or in hospital ward rounds, there is a need to develop tools that will serve this function as more information becomes available electronically [22].

Similarly, patients, their families and carers, and the general public need access to accurate, up-to-date and reliable information [37] on specific health topics; with the advent of the web and the resulting availability of large amounts of information of variable quality at a global level, ways to filter and evaluate this information are required [22, 38]. In addition to information being made available by health care providers, e.g., the NHS Direct online web-site in the UK, other organisations such as charities, non-governmental, not-for-profit and commercial organisations provide information for patients and the public via the web. However, given the differing functions and motivations of these types of organisations there is a need for evaluating and checking the quality of web-based information. Although a large number of tools have been developed to evaluate the quality of information available on the web [39, 40], many of these are generic tools and evaluate technical issues, such as when the site was last updated or the accuracy of information. These tools do not consider the information needs of specific groups, and the number of tools that are designed for specific conditions (e.g., diabetes [41]; Alzheimer's Disease [42, 43]; multiple sclerosis [44], and take into account the needs of individuals, is limited.

In addition to patients' being able to access to information 24 hours a day [8], ICTs, and the Web in particular, can benefit patients by improving access to health care, e.g., in the UK through NHS-Direct online and NHS Choices, and using Web 2.0 technologies, such as blogs and wikis, that enable patients and the public to interact directly with healthcare and information professionals. Three main groups using the Internet for accessing health information (Cain, 2000, cited in [8]) are:

1. People who are well but who are seeking health-related information;
2. People who are chronically ill, and their informal carers.
3. Newly diagnosed people seeking information about their condition

Perceived benefits of using ICTS include improvements in well-being and quality of life, reduced distress, and increased role or family function [8]. ICTs are being utilised to develop communication and information sharing among patients with similar conditions and this may provide benefits additional to, or even in preference to, support received from healthcare professionals [8]. Not only can patients' retrieving information from the Web and sharing information with other patients, relieve pressures on, and reduce expectations of, healthcare staff, but it also supports the notion of the 'expert patient' and this can increase patient empowerment and strengthen patient autonomy, improving satisfaction with care. Information science models could help to understand better how people are using the Internet to access and share health-related information [44] and to understand how different behaviours may influence the information that is obtained.

There is a danger, however, that ICTs can be used to replace verbal and face-to-face communication, adversely affecting the relationship between the healthcare professional and the patient. In addition, ICTs have the potential to increase expectations on healthcare professionals, and Åkesson *et al.* commented on the need to balance the demands of consumers with the capacity of health care organisations to provide information and services [8]. However, patients' being able to manage their own condition can give a greater sense of coherence, i.e., an ability to cope and manage in their life, which has a mediating effect on the stressful events surrounding their condition [8]. Using ICTs might increase a patient's capacity to live in their own home and improve their quality of life through better interaction with friends, family and healthcare professionals, although these benefits require further research evaluation [8]. A further danger is, however, that developments in health informatics will be focussed on professional groups to the extent that the needs of patients, their families and carers, and the general public are either overlooked or ignored. While the latter groups may still benefit, there is the potential for their care and well-being to be adversely affected. Further, we need to understand how developments in e-health are changing health behaviours [46, 47] and the interaction between a healthcare professional and a patient, i.e., the doctor-patient relationship. The psychosocial aspects of decision-making need to be taken into consideration, e.g., in designing, developing, implementing and evaluating informatics solutions within health care [7].

## **5. Data mining**

Data mining, also called Knowledge Discovery in Databases, is a term used to describe the process of analysing large amounts of data to identify patterns within data or relationships among variables contained within the database. Particular features of data within health and medicine lend themselves to data mining approaches, although there are unique aspects of health and medicine that must also be considered. Because, typically, data in clinical medicine and the health sector relate to individuals, and aspects of their health and well-being, this is a safety critical context, in which analyses conducted, and decisions made, can affect the lives of people, in contrast to other application areas of data mining, e.g., applications in business and commerce [48]. This means that there must be a critical understanding of the process of data analysis and interpretation of the findings by those involved in the process of health care. Furthermore, it is important for those who develop methods of analysing data, that even though there is a statistical relationship among a group of variables, the clinical importance may be quite limited [49]. Although large clinical data warehouses may contain vast amounts of information that can be exploited using a range of data mining methods, many clinical applications of data mining have been based on relatively small data sets, collected in specific clinical situations, and the results from these may not be generalisable to other areas. Additionally, clinical databases may be particularly prone to large amounts of missing data, and although methods have been developed to deal with this problem, or variables or cases containing missing data can be removed prior to analysis, the fact that data may be missing for a specific value and case, may be a key feature in developing a predictive model.

In health and medicine, clinical data warehouses, epidemiological studies and genomic databases, are good examples of large datasets and may therefore be particularly suited to data mining [48]. As noted by previous authors [48, 49], the success of using data mining methods within specific domains, such as health and medicine, is dependent, in no small part, on the involvement of domain experts, e.g., healthcare professionals, in the interpretation of results and application of clinical knowledge derived from the process of data mining.

## **6. Ethical issues**

The collection, storage and retrieval of personal data on the health and medical conditions of individual patients is an important area of ethical concern within health informatics, and more widely in health and medicine [50]. In addition to ethical issues surrounding the way these data are processed, the replacement of the traditional paper-based medical records with electronic records, and the movement to computer-based, and ultimately paperless, systems in health care organisations raises important ethical concerns for those concerned in the care of patients and emphasises the need for respecting human rights, security and privacy of data within health [46, 51]. The development of the 'Spine', a national database containing the personal health data and summaries of patient records, as part of the UK National Programme for IT (NPFIT) will make patient-identifiable health data on fifty million people in the UK available online. While this has considerable potential benefits for healthcare professionals and patients to access data, it also raises concerns about the security of the data and the threats to patient privacy and confidentiality [52]. As Kluge noted [53], there are more fundamental questions about whether the driving force behind e-health technology should be the technology itself, service providers and/or governments, or the interests of patients and the public.

Patient health data and individual medical records are regarded as private, because they may contain sensitive personal details, for example, about the illnesses or medical conditions for which a patient is treated. While there are issues regarding the privacy of personal data and information in other domains, e.g., the financial sector, the education sector, and within the legal system, there is particular concern within the health sector, because of the inherent sensitivity of health. Even for relatively minor, and non-life threatening, medical problems, e.g., acne among teenagers, or an older person experiencing a fall, people are naturally sensitive about these conditions, and information regarding these is considered private. There is even greater sensitivity about more serious, medical conditions, for example, for financial or employment reasons (e.g., experiencing a myocardial infarction (heart attack) or macular degeneration (visual impairment), due to fear or shame (e.g., lung cancer, sexually transmitted

diseases), or because of possible stigmatisation within society (e.g., mental health problems, being HIV positive). Whilst issues connected with privacy and confidentiality have been important since the development of medicine as a profession, for example, the principle of confidentiality extends back to the Hippocratic Oath [54], developments within health informatics have raised new concerns on how health data and information are managed and controlled [53, 55]. Healthcare professionals, patients and the public are rightly sensitive about the ways in which health data are stored and transferred from one location to another [56].

The development of ICTs and electronic records systems, and e-health initiatives, in particular, raise concerns regarding data security, patient privacy and confidentiality because they are making data potentially accessible and available on an unprecedented scale [53]. Although paper-based medical records had limitations regarding security, e.g., their physical nature meant that they could be lost, or left lying on a hospital trolley for passers-by to view, generally they could be stored securely and access could be controlled. Storing medical data on computers coupled with the ability to connect computers via networks and the Web, and the use of wireless systems raise concerns about how safe these data are, whether data can be transferred securely, and how access to sensitive information might be controlled. The increased availability of individual patient information raises ethical questions about who should be allowed access to this information, and whether particular types of information should be made available to different types of healthcare professionals on a need to know basis, e.g., details about HIV status, history of mental health problems, genetic diseases within the family [22]. These, in turn, raise technical questions, about how access to electronic data can be controlled [55].

The potential for providing patients and the general public with access to their medical records via the Web has emerged more recently, and raises further ethical questions, as well as issues regarding ownership and censorship of data. There is a need to avoid what is increasingly regarded as the traditional paternalistic approach of the medical profession [57], in which the doctor knows best, and to give patients and the public greater autonomy and control over the information that is stored about them. It was only with the passing of the *Access to Medical Reports Act* (1988) and the *Access to Health Records Act* (1990) in the UK, that patients and the public were granted the legal right to have access to their own medical record. Prior to this, doctors were under no legal obligation to allow patients to view their own records. While, to some extent, a doctor could control access, and restrict a patient's access if s/he felt it was detrimental to their well-being [54], e.g., for patients with mental health conditions, making patient records available online 24 hours a day potentially removes this control and has led to the development of protocols for developing electronic clinician sealed envelopes, which contain information that the patient is not able to view [52].

In addition to ethical and technical issues arising through the advent of electronic records, Kluge identified the need to ensure that health information professionals who develop and implement e-health initiatives have appropriate ethical qualifications [53]. In the last few years formal qualifications in information governance have been developed to meet this need. Training health informatics professionals in information governance and ethical issues will not only increase understanding of the importance but will empower them to influence decision-making in e-health initiatives [53].

Kluge highlighted the need for international standards for ensuring that health information professionals have appropriate ethical qualifications [53], and educational programmes are now available in information governance for health, for example at the University of Bath in the UK. There is a difference between healthcare professionals and information professionals in terms of their roles in undertaking health care and facilitating this care respectively [53]. This difference has implications for the access they have to information systems and data, the former to data on individuals and the latter the development and implementation of information systems and e-health interventions that affect these data. Kluge pointed out that while there are these differences, the ethical issues that relate to access to these data and systems cannot be separated and there is a need for appropriate qualifications for both health professionals and information professionals regarding the ethical use of information [53]. The very nature of e-health, i.e., electronic communication of health data or information, means that it transcends national boundaries, so that internationally accepted standards are required. This is complicated by the fact that ethical standards and values vis-à-vis patient data and their rights may be very different in different countries, for example, the patients' rights to see their own data may be quite different in western countries compared with developing countries.

## 7. Challenges in health informatics

A major challenge within health informatics is the financial investment required to develop, implement and maintain e-health initiatives, and Anderson identified a lack of financial support and high initial costs as barriers to adopting ICT in health care [56]. While health informatics and information professionals may perceive the future benefits of investments in ICTs, health professionals and managers may be sceptical about such developments, particularly when they are satisfied with current methods of working and wish to maintain the *status quo*, and may perceive such initiatives as diverting financial resources away from under-resourced clinical care. The diversion of funds ear-marked for local developments under the UK White Paper, *Information for Health* [19], was cited by Protti as a major reason for the limited progress with implementing the strategy [20]. Individual and shared feelings about the perceived value of IT systems may lead to a more general resistance to using these systems.

Resistance to the development of ICT systems by health professionals and managers can create further problems once systems are implemented and the limited use of health informatics applications has meant that their potential has not always been realised, for example, decision support systems may be ignored or over-ridden, the limited applicability of evidence-based information to a specific patient. Clinicians are making life-affecting decisions or are acting in life-threatening situations, and if they do not understand enough about the reasoning behind computer-based decision support systems, they will not trust them, nor will they utilise them effectively [22]. This emphasises the need not only to involve clinicians and healthcare professionals in the development of systems and in the interpretation of results, but also to provide sufficient explanation and information at the point of care for healthcare professionals to trust the systems [22]. As noted above, identifying the types of information that clinicians need, and the ways they access and utilise information are important in ensuring that developments not only meet the needs of the users, but that they are also perceived to be of value, so that health professionals and other users will want to maximise their potential. Addressing the concerns of healthcare professionals, patients and the public regarding the security of data and the threats to patient privacy and confidentiality will also be important in developing online access to patient records [52]. Ensuring greater security measures are incorporated into the design of systems [56] will help improve confidence in systems; however, the possibility of third parties gaining access to sensitive patient-identifiable data remains a risk.

Quality within health informatics initiatives is a further issue that can affect successful development and implementation. The quality, both actual and perceived, of data entered into systems and then utilised for health care is critical, not only for ensuring systems are utilised but, more importantly, for the safety and well-being of patients. If data are not entered, or not entered correctly, the accumulation of missing or poor quality data will dissuade others from utilising the system and will create further mistrust, and scepticism about future developments. The imperative for data that are complete and correct will increase as lifelong electronic records are developed [22], for records developed prospectively as individuals are born, and also for those developed retrospectively using data accumulated over an existing person's lifetime to date.

As discussed above, the earlier development of small-scale information systems within individual departments or hospitals led to systems being incompatible and problems in exchanging or transferring data when larger-scale systems were subsequently developed; one way to overcome this problem is build greater interoperability and the use of established electronic record architectures into the design of new systems. Allied to this is the lack of standards for data within health which creates further difficulties for transferring and sharing data across systems [56]. Attempts to overcome these problems include the development of standards for managing information (e.g., Digital Imaging and Communications in Medicine (DICOM) and Health Level Seven (HL7) and terminologies and coding systems (e.g., the International Classification of Diseases (ICD), Read coding, Snomed) to standardise the ways in which medical conditions and diseases are represented in computer-based systems and to try codify the natural language used by medical staff in describing patient symptoms. The ICD was developed to provide a standard means of classifying medical diagnoses for epidemiology and health service purpose: originally, it included only causes of death, but more recent versions have included causes of morbidity and is now in its tenth version [58].

## 8. Opportunities for health informatics

### 8.1. Supporting an ageing society

Throughout the developing world the numbers and proportion of older people is increasing, and will continue to rise until at least 2050, and within health informatics there is the opportunity to utilise ICTs and e-health initiatives to benefit older people and ageing populations [4, 5], particularly in those countries in which the ratio of people of working age to those of pensionable age is, or is becoming, low. The increasing population of older people and the associated increase in the prevalence of chronic diseases in society has led to increased demand for health care services, and the need for services that can support individuals in their own home [59]. The parallel developments in ICTs are providing opportunities to meet these additional needs through tele-health services, web-based information resources and interactive digital television [60]. Additional driving forces behind the development of tele-health are patient empowerment and the need for shared care among people with acute and chronic conditions [59].

The focus on developing telemedicine services, which provide remote consultations and diagnosis for patients with acute clinical conditions at a distance, for example for people living in rural areas far from specialist centres, has changed to developing tele-health services, in which chronic conditions can be managed at home through remote data collection and transfer of data through ICTs. This allows a more holistic approach encompassing health promotion and disease prevention [59].

Health-enabling technologies, such as sensor and sensor-based technologies that can collect data on an ongoing basis and transmit the data using ICTs are relatively new. They are of particular value within an ageing society, to help older people, and other groups, to live longer in their homes rather than being admitted to residential/nursing home care [4, 5]. As well as obvious benefits for the patients, in terms of improving health and quality of life, there are potential economic benefits to reducing admissions to these types of care. ICTs also have an important role to play in the detection and prevention of diseases during the stages before clinical manifestation of a disease, as well as in the management of chronic illnesses. ICTs can be used to collect and transfer a variety of data from patients on an ongoing basis, for example, physical and clinical measurements, biochemical markers, respiratory measurements, and combining these data can provide additional value [59]. Applications of health-enabling technologies include the remote detection of falls in older people, reminders for taking medications, or helping to orient people with early-onset dementia [4, 5, 59]. As ICTs and these health-enabling and monitoring technologies develop, the opportunity for health informatics to contribute to the ageing society will increase throughout the 21<sup>st</sup> century.

### 8.2. Spanning the digital divide

Providing access to information on the Internet may improve health care for individuals and for groups but may not meet the needs of all groups, and may lead to these groups being neglected and ignored. This has the potential to increase the digital divide and health divide for particular groups, for example, homeless people, older people, people with specific disabilities (e.g., visual or cognitive impairment), and people in developing countries. This may be because either technology or resources are not available to a group or they do not have the ability to utilise the ICTs or information, so that they are effectively excluded. However, as Åkesson *et al.* reported in their review of consumers' use of ICTs [8], specific groups (e.g., older people, people with early onset dementia, children, people with lower levels of education) did not report difficulties in using the technologies, and it may be that assumptions about their ability to utilise the ICTs are a greater barrier than having access or the ability to use the ICTs/information.

Healy stressed the importance of giving support to developing countries to overcome the digital divide at a global level [45]. Kaporiri and Bondy reported the need to ensure that health professionals in developing countries have access to the Internet, particularly in rural and less affluent areas, in order to provide access to necessary information resources and reduce current inequalities in access to information and health resources [61].

The American Medical Informatics Association has focussed on how informatics might be applied to specific groups with particular needs. Chang *et al.* highlighted the difference between vulnerable groups, i.e., those that are particularly at risk of particular health problems, and underserved groups, i.e., those that receive fewer health care resources than they need for either actual or potential health care problems [62]. While there is some overlap between the groups they are different and it is possible for individuals to be in one group but not the other, e.g., older people with low blood pressure may be at increased risk of falls, but there may be support services available that reduce the risk. However, individuals in groups that are both vulnerable and underserved, e.g., older people from minority ethnic backgrounds living in deprived areas, can be particularly at risk of adverse health outcomes, and Chang *et al.* discussed how the digital divide that has emerged within society, meant that people in both of these groups were even worse off compared to those in only one group [62]. A challenge, therefore, for health informatics is to explore ways in which the digital divide can be reduced, if not removed altogether, for the benefit of people in vulnerable and underserved groups. Barriers to vulnerable and underserved groups being able to access appropriate health information technology include community factors, e.g., e-health applications not being focused on the needs of specific groups and mistrust of health organisations and technology, low levels of computer and health literacy, the lack of financial incentives for developing health information and informatics resources and lack of training in health education and health literacy among informatics professionals [62].

### 8.3. *The need for an evidence base in health informatics*

As has been discussed earlier in this review, further research is necessary to evaluate the experiences of consumers in using ICTs and to investigate the impact of ICTs on consumer satisfaction with health care [8] and to understand the factors that affect information seeking behaviour among healthcare professionals, including those in developing countries [61]. In addition to evaluating information systems within health, there is the need to develop an appropriate evidence base by evaluating information systems in health (Rigby 2001, cited in [63]), e.g., tele-health systems [59], so that future development and implementation of information technology and information systems in health based on the best available evidence.

A problem with the evidence base, in health and medicine as in other fields, is the negative publication bias brought about by a failure to report unsuccessful interventions in the medical and health literature, and in medical and health informatics [64]. A consequence of this is that further money and resources may be invested in information systems that are prone to failure, because previous problems have not been reported. Heeks reported the need for a better understanding of definitions of success and failure in information systems in health, due to the subjective nature of these concepts. The subjectivity inherent in defining partial failure and success is particularly problematic, and positivist approaches to research and evaluation of systems adopt an objective viewpoint, at the expense of more subjective aspects. More rigorous and independent evaluations of information systems are required, as “both the conceptualisation and the evidence base for HIS (health information systems) success and failure are weak” [64, p.127]. A problem with the literature is that individual studies are either too specific, in which case, generalisations to other situations are not possible, or too general, and studies assume that the findings apply to all systems. Heeks proposed a design-reality gap model for more effectively evaluating the success or failure of information systems within healthcare, i.e., the gap between the situation, or reality, as it is now and the intended design of the health information system [64]. This model might be useful in not only evaluating the success or failure of systems that have been implemented, but in predicting the future success or failure of a new information system through risk assessment. Heeks acknowledged the possible influence of other driving forces, e.g., political motivation, that might overcome the problem of a large design-reality gap and contribute to the success of an information system.

Although recent work has reported improvements in the quality of evaluation studies and in increased use of multi-centre trials and increased use of randomised-controlled trials (RCTs) [63], Ball supported the notion that evaluations should look beyond RCTs and consider other forms of research evidence when evaluating e-health interventions [51]. De Lusignan, in his review of the emergence of primary care informatics as a discipline [7], emphasised the need to value the importance of tacit knowledge, as well as explicit knowledge, in primary care and made the important point that an evidence-based approach to medicine ignored the importance of tacit knowledge.

Berg, Aarts and van der Lei [65] and Aarts and Gorman [66] emphasised the importance of sociotechnical approaches to design, implementation and evaluation of information systems within health, indicating that a variety of research methodologies are important in contributing to our understanding how information systems and technologies interact with the social practice in an organisation and that the interaction between humans and systems has to be studied in context. Three questions are emerging: to what extent “technological failures are due to technological system issues”; to what extent are problems encountered when implementing health informatics systems or solutions due to “lack of awareness and understanding of the sociocultural environment in which such applications are implemented”; to what extent do changes in one or other of “people, technologies, and processes of care” cause problems in the other aspects or the interaction between them (systems view) [66 p.S1] .

## 9. Conclusion

This review has considered current issues and developments in health informatics and has discussed the distinctions and overlaps between medical informatics and health information management. It has highlighted some important challenges and key issues that are faced within health informatics, as well as the opportunity to make a difference to how it can make a positive contribution to the health and well-being of patients and the public. Throughout the review a number of themes have emerged which may determine the success of health informatics in the coming years and decades, and which highlight the potential contribution that information science can contribute.

A central theme emerging is that health and medicine is a unique, and highly important, field and requires particular consideration in comparison to other areas, for example, education, finance and commerce. If one accepts this argument [53], it follows therefore, that health informatics requires particular consideration as an emerging discipline within information science. There are several reasons for this. First, personal health data are private and people are very sensitive about the ways in which information on health is stored and processed. Second, the process of health care is complex, and the amount of health information that is collected in an episode of care, and ultimately throughout a person’s life is potentially huge and this information is complex. Third, a large number of people may be involved in the care of a person, and this will be different for each patient, dependent on the condition and circumstances of the individual: these may include generalist and specialist doctors, nurses, therapists, informal carers, family members, as well as the person themselves. The implication of these is that developments in health informatics require particular care and attention: information science can make a valuable contribution to health informatics, but needs to consider issues above and beyond other areas within the discipline.

A second, but related, theme underlying this review is that the success of health informatics applications and e-health initiatives depends on the active involvement of users in the design, development, implementation and evaluation of e-health initiatives. Given the large number and variety of people involved in health care, this is no small undertaking, but it is nonetheless important. Identifying the health information needs and information behaviours of health professionals and other health workers, patient and carer groups, as well as the general public, is an important first step in the process, and research in information science and in the health and social sciences, has made considerable progress towards identifying health information needs. However, further research is required to explore how people search for health information, what the intervening variables are and the barriers to their acquiring information, and how ICTs may help to overcome these barriers. Models of information behaviour developed in information science may help a better understanding of these issues but the applicability of these models in health requires investigation. Models of information use and methodologies for evaluating information systems developed in information science may also help to develop and test e-health initiatives and understand how ICTs can improve the use of information within health. This leads to the third, and final, theme emerging from this review, i.e., the need for independent, and therefore objective, evaluation and research of developments in health informatics [51]. This particular theme follows on from the second theme, and as has been discussed earlier, incorporates the views of users in all phases of health informatics developments. While research and evaluation in health informatics needs to be objective, i.e., independent, they should not be constrained by

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particular paradigms, e.g., positivism, but should be appropriate for the particular situation in question. This will help to ensure that the full impact of ICT on the health and well-being of patients, their families and carers and the general public.

In conclusion, Berner and Moss described the impending golden decade of health informatics [22]: the three themes identified here are key to the development and maturation of health informatics and ensuring that it reaches its full potential. Health informatics is a specialised field and can benefit from multidisciplinary contributions from information science, health and medicine and the social sciences. Health informatics must address the specific issues that are unique to medicine and health. Understanding the needs of all users in the care process through research and evaluation of health informatics developments and e-health initiatives are important for the ultimate well-being and safety of patients.

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