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Taking a holistic approach to exchanging health information over a global network

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Introduction

The range of uses of computer technology and systems in the medical field, as in other fields, is vast. They are employed in administrative systems, direct interventions (for example, surgery), diagnostics, communications between health care practitioners, and more recently between patient and professional practitioner, amongst others. Individuals are also taking advantage of the technology to seek information, advice, support groups, and for buying health care products (including drugs) via the on line shopping facilities offered by Internet Pharmacies. The EU e-Health action plan[1] indicates the extent to which information technologies can be used in health care, and current research projects funded by the EU cover a range of applications: data processing, monitoring patients, providing health care using robotics, and 'smart' clothing, to name but a few[2]. Many of these projects address the problems of geographical proximity between experts, between experts and patients, and refer to accessing information 'remotely'. Other experiments have been conducted into the use of computer implants in humans and their effects (Warwick and Cerqui, 2005), and current research in the area of nanotechnology suggests that more of these technologies will be used within the human body in the future (Klerkx, 2005).

Thus we can see that there are a number of computer-based technologies in use for health care, and within institutions conducting research in the biological sciences. The benefits of these technologies are substantial, and their impact on social constructs immense. As research progresses in this field, it is clear that the achievements so far are only the tip of the iceberg and the potential of this technology is still largely unexplored. As new developments and techniques emerge and challenges are overcome, our vision of what is possible widens and our expectations increase. It becomes easy to envisage a world where technology is employed to resolve many of today's challenges.

However, whilst technology can, and does, provide many benefits its wider social and ethical impact should be understood. Although social impact and related questions such as privacy and security are often taken into account when assessing research and development, there is a lack of vision concerning the scale and inter-connectedness of the proposed applications. Individual projects provide solutions within a narrow frame of reference, but the system as a whole has an impact beyond the instant access and fast exchange of information that is facilitated by these new technologies. It is the further management of information and its interpretation that has an impact on all concerned.

[1] http://europa.eu.int/information_society/activities/health/policy_action_plan/index_en.htm
last accessed 20/10/05.
[2] Details of these and other current projects can be found at:
http://europa.eu.int/information_society/activities/health/research/projects/index_en.htm
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The theme of this chapter is on the use and management of information via the medium of computer technology, the impact of computer technology on information, and the issues that arise from this 'information flow'. Personal privacy, information privacy, patient competence and informed consent are just some of the ethical concerns within the health care communication environment. The focus of the discussion that follows concerns the accuracy, integrity of systems and information, confidentiality and the interpretation of health information – all of which have consequences for the patient. These are investigated against a background of current and future applications. Descriptions of current research in the area are given to ground the discussion, and give the reader concrete examples of the ways in which information is exchanged and the purposes to which it is used. In showing how these networked technologies are in use today, and taking into account existing research programmes, it becomes possible to hypothesise future uses.

The context of information

Information concerning individuals, and how it is handled, is not a new issue – particularly since the advent of computerisation and the digitisation of information. We now have a far greater capability of collecting, storing, manipulating and disseminating information about people than has ever been available before. For this reason, and with the aim of protecting the privacy of individuals, the EU in particular has issued guidelines to nation states regarding the collection and handling of personal information.[3] It is not the intention here to deliberate on the various enactments of the data protection directive in the different states, but to emphasise the high level of concern regarding third party use of personal information, and by implication the degree to which it impacts on the individual to whom it relates.

In terms of processing data, and in particular personal data, most organisations are aware of data protection legislation and the requirement to take precautions regarding processing, storage, and dissemination. Personal information is commonly understood in terms of name, address, and associated personal details, as well as sensitive data such as medical information and religion, amongst others. In the United Kingdom the Data Protection Act[4] refers to personal data as:

> Data which relates to a living individual who can be identified
> - from those data, or
> - from those data and other information which is in the possession of, or likely to come into the possession of the data controller.
> It includes any expression of opinion about the individual and any indication of the intentions of the data controller or any other person in respect of the individual.

Thus data extends to any information about a persons physical make-up from which they can be identified, including at the biological level. For the purposes of this chapter the context of information is as it is used in the health care domain, with the focus primarily on individuals as citizens participating (knowingly or unknowingly) in a global environment.

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[3] For information on the various EU directives on data protection (including electronic communications) see: http://europa.eu.int/comm/justice_home/fsj/privacy/ accessed 19/10/05.

[4] Source: Information Commissioner's Office http://www.informationcommissioner.gov.uk/ last accessed 20/10/05.

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Where technologies are used in the collection, storage, and transmission of information about individuals it becomes important to understand the processes involved. In the discussion that follows a 'whole-system' view is taken, one that includes not only the various technologies involved but also includes the human element – which is after all where the 'data' becomes information. In line with this position, aspects of concern arising from the transmission of information (for example, its integrity) are highlighted, as well as important aspects regarding the interpretation of information. Both of these aspects, the technological and human, when set in a complex networked environment become relevant in the information context.

To explain in more detail, it may be helpful to consider the path of information from its initial collection, to transmission and final interpretation. The table below gives a simple illustration of the path of information in communication.

Table 1: The information path

	Collection →	Transmission →	Interpretation
Common terminology	Facts obtained	Communicated	Understood
Technical terminology	Data Input	Digital data packets	Output

Throughout this path the information is processed and thus undergoes changes - the facts obtained are articulated (verbally, or transcribed), they are passed to a receiver (person or technical artefact), and finally interpreted (understood or given as output). At each stage there are considerable challenges to maintaining accuracy, integrity and confidentiality whatever the methods of transmission – and processing information using computer technology bring its own particular challenges. The distinction in the table between 'common terminology' and 'technical terminology' is made specifically to highlight the difference between communication between one person and another, and information transfer associated with computer systems. The first encompasses a much richer information environment, and should not be confused with the processing of information that is 'machine driven'. The difference can be illustrated by drawing an analogy between qualitative and quantitative research methods, that is, in the first instance a rich but 'messy' picture and in the second a clearly defined and measurable data, but which is constrained by a predetermined framework. The distinction is often blurred when discussing technology, but it important to recognise it when systems are used to support lifestyles and where there is a clear human-computer interaction.

There are particular considerations to be taken into account where the patient is directly associated with the information flow, especially in circumstances where the patient is managing their own health care. Under these circumstances the patient can be thought of as a novice user (in computing terms) which makes them vulnerable as far as the management of information is concerned. They may not understand that the accuracy, integrity, and interpretation of the information that relates to them could have significant implications.

The following sections describe the transmission of such information, and explore aspects of information integrity and the interpretation of information in a rich and complex environment – such as a global communications network.

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Current applications of technology in health care

The picture is a complex one. To simplify the discussions we begin with a familiar and fairly straightforward example of using the Internet to buy prescription drugs from an 'Internet Pharmacy', and highlight some of the legal and ethical issues involved. Although a simple example, the issues raised can be applied to many other situations where information is exchanged over a global network. The following example summarises a legal and ethical analysis of online medical consultations leading to the purchase of prescription drugs from Internet pharmacies[5].

There is currently a proliferation of Internet sites where drugs can be bought, together with a rising tide of unsolicited emails advertising their availability. The benefits of buying drugs online are noted to be: ease and convenience, increased choice, increased information and information exchange, lower costs, confidentiality, and availability of alternative treatments. However, there are serious problems concerning the sale of prescription drugs, not least of which are the difficulties of enforcing regulations (i.e. professional codes of conduct and legislation). The medical sector is highly regulated, and with good reason. In the case of Internet pharmacies ethical and legal issues are raised relating to the quality of advice given, and the professional competence of the person giving the advice; the quality of drugs being sold; maintaining patient confidentiality (and in the UK/EU adhering to Data Protection legislation, where personal medical information is classed as sensitive data); and whether any case of malpractice could be brought if anything goes wrong – firstly, if there is a doctor/patient relationship as commonly understood in traditional medical practice, and secondly whether the doctor is in fact licensed to practice and therefore subject to professional regulations (George and Duquenoy, 2005).

There are also other, less obvious but nonetheless serious, consequences in moving towards remote medical practice, as exemplified in the Internet pharmacy case. One is the conceptual reduction of prescription drugs to a commodity that can be bought and sold on the basis of no more than the completion of a questionnaire. This undermines the notion that is implicit in drugs requiring a prescription, which is that they should be used with caution due to adverse reactions that may be caused by the drug on its own, or in combination with other drugs or treatments. It also promotes a culture whereby drugs are seen as the first response to a medical condition.

A second concern is with the level of understanding required by the buyer when completing the questionnaire. This is clearly relevant when operating in a global context, and less obvious although equally relevant in a local setting. An online questionnaire does not distinguish between different levels of literacy, competence in the language of the questionnaire, or specific cultural interpretations. Where a lack of these competencies apply it would be easy to misunderstand a question, or guess an answer – with drastic consequences. Such a misunderstanding is more likely to be recognised and resolved in a face to face interview. The personal assessment that takes place in the traditional doctor/patient setting is missing in a purely 'on line' context, and consequently the patient loses the expertise and experience of the practitioner that would normally be available. A further problem when conducting these transactions remotely is that of establishing the authenticity of the patient and controlling the quantity of drugs available to them (Ibid.).

Returning for a moment to the path of information exchange described in Table 1, we can use the above example to demonstrate the pitfalls more clearly.

[5] The example given summarises the key issues identified in George and Duquenoy (2005).

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Consider the facts obtained. We cannot be sure that the initial facts obtained are accurate – either that the doctor involved has the authority or expertise required, or that the answers given by the patient/buyer are informed or correct. The doctor may not be legally allowed to practice, the patient may be confused by the terminology and give incorrect answers, may not be aware of any other relevant existing condition, or may even be a 'bogus' patient, buying on behalf of others.

As far as the transmission of the information is concerned, there are major concerns regarding the security of the transmission which would have implications for confidentiality and privacy of personal data. Data transmitted over a network is at risk from interception, and data stored on a network is at risk of interrogation by third parties. The integrity of the site visited is uncertain, and the integrity of the data transmitted and stored at the end location may have been compromised.

Finally we come to the interpretation of the information. The brief discussion above raised two problems. One is the device for obtaining the information – the questionnaire. Questionnaires are notoriously restrictive in gathering a rich picture, particularly the closed type of questionnaire that was used in the case above. The doctor in this situation has very limited information on which to base a diagnosis for the prescription, and we are not sure that the information given is correct. Whilst it is possible to make some sort of interpretation of the facts given, mistakes can easily be made. The main problem however lies with the respondent (the patient/buyer). Some of the questions asked use medical terms and refer to drugs by name, as the following extract shows:

- *Do you suffer from or currently have Transient ischemic attack(s) (TIA's)?*
- *Do you use MAO-inhibitors like phenelzine or moclobemide?*
- *Do you use NSAID's (nonsteroidal anti-inflammatory drug - f.i. salicylates, diclofenac, naproxen)?*
  (source: https://meds4yourhealth.com)

The extract above illustrates the need for a certain degree of literacy, language competence, and awareness of the existing medical condition, as well as some local cultural knowledge. Interpretation here is crucial. The purchaser may not know if they suffer from 'TIA's' or whether any drugs they have are the equivalent of those mentioned (they may be, but under a different name or strength). They may not even realise how important it is to give correct answers to these questions, and they may just guess. Under these circumstances the principle of 'informed consent' is in considerable jeopardy – if the patient does not understand the terminology, or the implications of taking a drug, it is hard to imagine they meet any requirements of what informed consent implies. Similar concerns have been expressed by Collste (2002:123) who argues that informed consent (as derived from the principle of autonomy) implies a competence that is based on "an ability to understand and process information and to form a decision on the basis of the information".

The case just described, as noted earlier, is fairly simple in conceptual and organisational terms. It is essentially a transaction between two parties, complicated by remote negotiations and the transference of an existing conceptual model of the doctor-patient relationship (including its inherent protective regulatory framework) to a completely different situation.

Where conceptual models are transferred to a similar, but essentially different domain such as the Internet, key characteristics are lost, and often overlooked (Moor, 1985; Duquenoy, 2000). These existing conceptual models are stretched further as technology progresses, and the interactions become more complex, involving many more participants – including in some cases, automated

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decision-making agents. The following paragraphs describe more complex examples of technologies that are in use now, or planned for the future.

The three examples given below describe technologies that have been produced with the aim of helping patients manage their conditions, thus enabling them to retain some measure of independence in their lives. In the first two the conditions addressed are diabetes, and diminishing cognitive functioning in the elderly. The third example is non specific in its use, but the idea could be implemented for diabetes sufferers. In all cases the fundamental ideas could be applied in other areas. The strategy in this section is to firstly lay out all the examples and then discuss the issues inherent in all three.

Example 1- mobile phone technology and diabetes monitoring
In the UK recently a trial study was conducted that used mobile phone technology to aid diabetes patients in monitoring their sugar levels. Patients monitor their glucose levels using a blood sugar meter in the normal way, and the information is then communicated to their mobile phone using Bluetooth technology. They complete a patient diary (recording food intake and activity levels), the data is sent to a central server and a graph generated which is sent back to their mobile phone, and a personal web page. Patients can see whether their levels are within their daily targets. Any changes in patterns will show, and both the patient and health care professional alerted – the latter being available for advice.[6]

The aim is to allow patients to manage their condition by seeing in graph form the changing sugar levels, and to recognise recurring patterns. Health professionals can assess the patterns and contact the patient to offer advice if necessary. The developers say that future systems may deliver pre-emptive alerts (presumably to the patient, although this is not clearly stated). They say: "The day may come when mobile phone contracts are sold with a health care bundles option alongside the text, Internet and picture messaging bundles we are familiar with."[7]

Example 2 – RFID technology in the home
Work with RFID (Radio Frequency Identity) sensors around the home that monitor activity levels has been carried out with a view to monitoring the elderly - particularly those with, or at risk of, cognitive impairment. Household appliances can be monitored to assess activity levels – so, for example, if little activity is recorded there may be a problem with the elderly person that prevents them carrying out essential daily activities. Where patterns of behaviour alter or where circumstances indicate a problem, status reports or alarms can be raised to alert health carers. Technologies such as these can enable people – in this case the elderly – to remain in their own familiar surroundings, and retain some measure of independence.[8]

Example 3 – "intelligent" materials
Another project has produced material that can be used to produce clothes which have "fibre sensors, portable devices for collection and processing of data, and for telecommunications, thus combining local intelligence and remote decision-support systems"[9]. It is envisaged that the

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[6] The full trial results to be published in the journal *Diabetes Care* end of 2005 (Fleming, 2005). Nic Fleming, Medical Correspondent, "Mobile phone link reduces chance of diabetes problems" 29/08/2005 at http://www.telegraph.co.uk/news Further details available at: http://www.newsfactor.com/news/,
[7] Source: http://www.e-san.co.uk/ last accessed 19/10/05
[8] Pollack, Martha E. "Intelligent Technology for an Aging Population" *AI Magazine*, Vol.26:2, Summer 2005.
[9] EU Project: WEALTHY. Source: Virtual Medical Worlds, Monthly Newsletter. http://www.hoise.com/vmw/05/articles/vmw/LV-VM-06-05-37.html

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clothing produced would be able to monitor "vital health data, communicate with remote health centres and present data in a variety of formats for further analysis by doctors and researchers".

There are many issues that are raised by the applications described above. Taking the points of accuracy, integrity and confidentiality as a starting point we should consider the following.

In the first example, of the mobile phone and diabetes patient, there are several points where accuracy could be compromised: the blood sugar meter, the transference of the data to the mobile phone, and the transmission to the server and back to the mobile phone and web page. At the technical level reliability has an impact on accuracy. To maintain accuracy we must be assured that the hardware is reliable, the software is robust and will continue to work correctly and that transmissions can cope with interruptions. This is a 'critical' system, and every effort should be made to assess any vulnerability in this respect. Where data is held on a central server it is vulnerable to unauthorised access by third parties, and could be compromised. We should also not rule out the possibility of patient error whilst completing their daily diary. In the latter examples, where 'intelligent' systems are used, it should be remembered that one of the characteristics of these systems is to 'learn' behaviour patterns, and make assumptions (and decisions) on the information received. Both the accuracy of the source data and the accuracy of the decision are vital if the systems are to support the patient in their needs.

As far as integrity of the information is concerned, it has been noted earlier that in any transmission of data security is an issue. Data is vulnerable during transmission; it can be intercepted and interfered with, whether Bluetooth technologies or traditional network communications are used. The transmission system must also be robust. If messages are subject to delays, or loss, both the patient and health professional must be alerted.

Confidentiality is also at risk, in the sense of interference during the transmission, storage of data, and also in the type of data that is collected. All of these applications involve monitoring an individual in some respect – either their lifestyle, or their behaviour. This type of data is of great interest to third parties (for commercial reasons, such as marketing products, or insurance reasons), and at the very least assumptions can be made which may not always be in the best interests of the patient. Monitoring a person's behaviour is a particularly difficult area that raises serious questions regarding personal privacy, and systems of this sort must be used with extreme caution. Every effort should be taken to ensure that the best interests of the patient take priority, and that confidentiality is maintained.

In all cases the interpretation of the data is vital, but there are some particular areas of concern. Interpretation relies on the accuracy of the data, and the competence of the individuals involved. Where patients are interpreting data (as in the case of the mobile phone) the possibility of error may be increased. In most cases where technology is implemented the patient will be a novice user and therefore unlikely to be competent in its management. In addition, their illness may from time to time have an impact on their cognitive abilities (as for instance in the diabetes example above) and the correct interpretation of data could be jeopardised. Care should be taken when developing such systems for implementation with other types of illness that the person for whom the information is critical (the patient) has the ability to make an accurate and fully informed interpretation. In the mobile phone example it is noted that a health care professional is at hand to give advice – maintaining this human contact is very important when it comes to interpretation. In discussing the ethical implications involved in transferring information Collste et al. (1999) make the point that transferring information does not necessarily imply *communication*. They remind us that in

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circumstances where information is given to patients that may be misinterpreted, or misunderstood, it "should be imparted in a way that gives the patient the opportunity to ask questions and be given support". It is to be hoped therefore, that health care professionals using such devices are fully trained to use them, both in understanding the impact on the patient, and in understanding the system[10].

Clearly there are benefits to be gained from gathering health information, direct benefits to the patient and health care professional, and indirect benefits resulting from statistical analysis (to record and predict national trends and inform policy). However, caution must be exercised when collecting this type of data – where profiles of patients are assembled (for example, lifestyle profiles) a balance must be found between useful profiling, and invasion of privacy. Particular care must be exercised where several parties are involved in data sharing, and where information is exchanged over a network (cable or wireless).

Extending the scope of application: future developments

Many of the issues discussed in the previous section could be applied to any situation where information is mediated via computer technology, whether it is in a local or a global context. One particular aspect raised above that was not discussed, but one which brings another dimension into the picture is the introduction of intelligent devices, briefly referred to in the clothing example above.

There is a growing body of research in the field of 'ambient intelligence' – that is, the use of intelligent devices in our surroundings (for example, around the home). The home monitoring example above gives a flavour of the ambient intelligence environment, where intelligent devices are used to respond to human activities, and react accordingly to learned user preferences.

One can see the advantages of intelligent technologies in the health care domain – monitoring of vital signs as in the clothing example is just one. The issues of reliability, robustness, accuracy and security have been discussed above, and are all still relevant. There is, however, an additional issue in cases where the technology is designed to make decisions or judgements, and particularly when those decisions and judgements generate actions. In these cases the technology interprets information based on instructions in the programme. It is important therefore to know (a) that the information is correct, (b) what instructions are in the programme, and (c) on what basis (information) decisions are made. The correctness of information has been addressed in previous sections and nothing further will be added here. It is in regard to (b) and (c) that further elaboration is needed – firstly, the instructions in the programme, and secondly, the basis of decision-making. The first concerns embedded values and the second refers to the decision-making procedure.

It has been argued that programmes have values embedded within them, that is, the values expressed in the requirements and interpreted by the developers (van den Hoven, 2005; Duquenoy, 2004; Introna and Nissenbaum, 2000; Friedman, 1997). The values can be personally or culturally held values, for example privacy may be valued in certain cultures but not in others. Tim Berners-Lee, the inventor of the World Wide Web, tells us that the World Wide Web is designed to allow

[10] Gell (2001) describes instances that he has been involved in, as a developer of medical informatics systems. From his experiences he has noticed that "users will tend to utilize (sic) systems also for their own goals, to facilitate their work etc." and whilst this may have beneficial outcomes it "may also lead to harmful effects". With this in mind he argues that "medical informaticians" have an extended professional responsibility, and proposes a modification of the Software Engineering Code of Ethics and Professional Practice developed by ACM/IEEE as a guideline.

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certain values: "Our goal is to assure that the Web accommodates the maximum diversity of public policy choices. In areas like freedom of expression, privacy, child protection, intellectual property, and others, governments do have a role. The kinds of tools we make available can help assure that those laws are effective, while also ensuring that individuals retain basic control over their online experience" (Berners-Lee, 1999). As values are designed-in to the technology, it is important (i) to recognise and be aware of this, and (ii) to consider the values of those using the technologies. Values are culturally specific (the term culture is used here in the broad sense, not necessarily national or ethnic culture), and the technologies we have been talking about will be designed from the perspective of a certain culture, and used in a variety of other cultures.

Values in the programme are clearly important when it comes to decision-making. For example, the programme could be set to value privacy and have an instruction to avoid communication in any compromising situation (whatever that might be deemed to be). However, the operations of some artificial intelligence programmes are based on the concept of neural nets which have specific characteristics that become relevant to this discussion. A set of values are given weights, and based on those weights neural nets are designed to 'learn' from experience, and change behaviour accordingly. In this case, the premises on which decisions are made become obscured. In an interesting discussion on moral agency and artificially intelligent programmes Miller and Larson (2005) argue that "some programs at least approach independent moral agency" based on criteria of interactivity, autonomy and adaptability. They point out that these 'nets' adapt their behaviour according to new inputs, and "once 'launched,' new behaviours can emerge from a neural net, behaviors not even anticipated (much less explicitly programmed) by a human". Where we are designing programmes that over time will behave in unanticipated ways, we clearly have no control over the outcomes, much less any clear idea of the basis on which decisions are made.

The challenges put forward by the use of artificial intelligence, and intelligent agents do not stop there. The complexity increases as intelligent agents interact with other agents (a multi-agent environment) as they learn about other agents in the environment and find ways to negotiate and cooperate with them (Luck and McBurney, 2005). Although these are the technologies of the future there are currently some applications in use (for example, online trading, network management, and simulation applications), and visions of the use of multi-agent systems in e-commerce acting in a legal capacity (Bain and Subirana, 2004, p.50):

> "The long term vision is of legally compliant agent mediated electronic commerce over public global networks, perhaps on the semantic web, involving multi-agent systems or societies. Agents will represent different participants and services and interact to create legally binding agreements, enforceable both on and offline. Negotiation and compliance processes will relate to all legal aspects of a commercial relationship (privacy, intellectual property, contract, consumer protection, tax, etc.), with various agents providing the appropriate processes and taking on functions of privacy protector, consumer protection monitor, contracting assistants, security protocol management (e.g. digital signature mechanism) trust, auditing and recording."

If these systems are brought into use to facilitate e-commerce it is likely that multi-agent systems will be used in health care in some way.

Naturally as these developments are in their early stages there are a number of difficulties to overcome – a major one is the interoperability of systems, so that agents can negotiate with other agents. Agents can be used for simple negotiations – such as ensuring the user's privacy preferences

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match the privacy policy of a particular web site[11] and in that way these systems could be useful, for example, checking data protection legislation in different locations. However, there are other legal difficulties raised by agents that are relevant whether they are used in a local or international context – namely questions of responsibility. If the programme or device goes wrong, or acts illegally, who should be held responsible? In any information systems project there are a number of key participants:

- The person or organisation commissioning the system
- The requirements or specification team
- The development team
- Previous developers (where systems are incorporating existing programmes rather than being designed 'from scratch')
- The provider
- The user (whether an individual or an organisation)

For those involved in developing, managing, or using intelligent agents, the key questions are "does your agent obey the law?" and if so "whose law is it obeying?"

The wider the reach of an information network, and the more complex it becomes, the responsibility for any part of it becomes more difficult to see, and aspects of accuracy, integrity, confidentiality and interpretation of data become more difficult to ensure.

Where these complex systems are integrated into the human body as embedded devices all of the above concerns apply, as well as the extremely difficult ethical issues associated with such implants. The experiments conducted by Kevin Warwick (Warwick and Cerqui, 2005) demonstrate the extent to which implants give rise to radically new situations that require deep ethical reflection. In one experiment neural signals were transmitted to a computer and then to a robot hand that had sensors which transmitted signals back to the nervous system. In part of that experiment signals were sent over the Internet. The authors note: "In our case, the brain was able to directly control a robot hand on a different continent – the body extended across the Atlantic Ocean". In the same paper the authors report evidence of human-to-human communication[12]:

> "The most exciting part of the tests was though when KW's wife, Irena, also had electrodes positioned directly into her nervous system and motor neural signals were successfully transmitted between the two nervous systems. So when KW moved a finger, a corresponding neural signal appeared on IW's nervous system. In this way we brought about a form of telegraphic communication between the nervous systems of two individuals who were both connected into a network"

Some initial thought has been given to the ethical implications of implants by the European Group on Ethics[13], who in early 2005 formulated a new Opinion advocating that: information and communication technologies implants as a form of remote control are unacceptable; information

[11] The World Wide Web consortium's Platform for Privacy Preferences Project (P3P) is a good example of a simple interaction. The concept behind this is to aid users with privacy requirements. P3P will negotiate on behalf of a user with a web site, checking the web site's privacy policy against the user's requirements, and notify of any discrepancies. A warning is given however, that this does not imply the owners of the web site will adhere to their privacy policy.
[12] Documented in Gasson et al, 2005.
[13] The European Group on Ethics advises the European Commission on ethical aspects of science and new technologies http://europa.eu.int/comm/european_group_ethics/index_en.htm

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and communication technologies implants should be based on need rather than economic resources or social prestige; surveillance issues in relation to implants need to be approved and monitored by an independent court; and, finally, there should be a launch of a 'legislative initiative' in relation to the directive on medical devices in relation to implantable devices. This new area of technology calls for continuous and comprehensive discussion and advice from experts drawn from a range of disciplines.[14]

Addressing the concerns

There are several approaches that could, and should, be used to address the concerns we have discussed: at the technical, policy, legal, and the user levels.

At the technical level there is continued work to be done in respect of security of data – at the site of storage, in transmission, and authentication for access. Recent initiatives include the use of digital signatures (for citizens to review their own health data, and health care professionals to search for information on their patients), and smart cards for authenticating users accessing medical information[15]. Other work in the area of trusted systems (particularly at the operating system level) is ongoing and making some progress – this type of system would prohibit interference from unauthorised third parties – and can be thought of in terms of the integrity of the system, that is, its *trustworthiness*. All of the security issues referred to above are relevant to e-commerce and the technical solutions developed can be applied to other areas, such as the medical field.

Ensuring the privacy of individuals is an issue that is closely related to security in respect of personal data – especially data that can profile lifestyles or behaviour. It is recognised good practice in research circles to anonymise personal data. This means not only removing someone's name or age, but being very careful that they are not likely to be identified by a combination of other characteristics. Computer technologies are particularly good at collating diverse pieces of information, and whilst one set of data may be considered adequately anonymous, when put together with an entirely different list it could easily be possible to assemble a rich profile of an individual. Such an event could be entirely unforeseen by the developer of the system, therefore such issues should be thoroughly discussed between developers and implementers to make sure all available measures to protect the information have been taken.

Other issues that have been raised, and that need attention at the development stage, are those of robustness and reliability – these are particularly important in the health care sector. Delivery of timely information regarding patient health may be crucial, but even if time is not 'critical' patients who are using self-management technologies are likely to be anxious and put under undue stress if their system is not working as it should, and in response to their enquiries.

One of the major challenges though is with the use of intelligent agents. As we have said, the complexity and lack of predictability in these systems means they should be used with extreme caution especially in this field. Intelligent agents are often characterised as 'autonomous' and

[14] Since the initial writing of this chapter a new project funded by the European Commission that addresses this challenge has begun. The author is a participating member of the project. Project title: ETHICBOTS (Emerging Technoethics of Human Interaction with Communication, Bionic and Robotic Systems). Details at: www.cibernetica.unina.it/ETHICBOTS

[15] The digital signature system has been introduced in Denmark. Plans are for a cross-national Baltic Health Network. The smart card project, requiring patient and health care professional smart cards present in the same place at the same time, is running in Germany. Source: Virtual Medical Worlds.

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"capable of exercising choice over their actions and interactions, and may act to achieve individual objectives" (Luck and McBurney, 2005). An International Workshop announced in 2005[16] on "Autonomous computing and agents for process automation" gives some indication of the work still to be done in this area. Under "technical issues to be addressed" we see the following: autonomous and agent: negotiation, trusts and trust-based actions, communication, security and authentication, reliability and fault tolerance.

Where intelligent agents are acting on behalf of someone (as the name 'agent' would imply) the decisions and judgements they make could have ethical implications. In this case they should continue the principles of other agents we might employ (lawyers, financial agents, estate agents) and be regulated in a similar way – for example some type of code of conduct. This is especially important as these intelligent devices or agents are specifically designed to be out of sight and acting 'behind the scenes' as it were, as envisaged in the ambient intelligence environment (Duquenoy and Whitehouse 2005). It should also be noted in this context that according to the UK Data Protection Act the Data Subject has "The right to prevent decision making solely by automatic means". This implies that the Data Subject (in our case the patient) is fully informed and aware of any automated decision-making process.

This leads to the importance of policy decisions and regulation. There is a need for awareness of the ethical implications of these technologies that will be put into use. There has been some progress in this area, although it is rather tentative as yet. Policies for the ethical review of research and development in new applications of ICT technologies should be introduced[17]. Ethical considerations are naturally accommodated when it comes to research conducted under the auspices of the EU, particularly with regard to the collection and storage of personal data, and the context of informed consent[18]. The reach of such ethical rules should be extended to all institutions conducting research, and consideration given to the various aspects and impacts of technologies. For example, there has been an increasing interest in outsourcing in the IT industry, and this has included the outsourcing of medical data. In one case the medical authorities were not aware that the inputting of patient records had been sent to Pakistan, and the issue only came to light when the transcriber threatened to publish the records online when she hadn't received the promised payment for the job[19]. Another move to outsource the inputting of patient notes to Africa was thwarted by unions in the UK[20]. Outsourcing is an economically attractive option where hospitals are under increased pressure to save money, and wages in less developed countries are much lower, and although organisations that fall under the Data Protection Legislation in the EU work within the guidelines, there is no guarantee that these guidelines will be adhered to in other countries. This situation has serious implications for maintaining patient confidentiality – once personal information is made public, there is no chance to retrieve it, and no going back.

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[16] The 2005 International conference-crossing workshop on Autonomous computing and Agents for Process Automation, June-October 2005. See: http://www.aba-rd.org/

[17] A report following a workshop on ethics and ICTs held by DG INFSO and attended by this author (October 2004) made a number of recommendations in this area. For the report see: http://europa.eu.int/information_society/research/ethics_141004/documents/ethics_report_101204.pdf last accessed 22/10/05.

[18] http://europa.eu.int/comm/research/science-society/ethics/ethics_en.html last accessed 11/10/05.

[19] Kim Zetter, "Outsourcing: Danger to Privacy" February 2004, Wired. http://www.wired.com/news/business/0,1367,62356,00.html last accessed 22/10/05.

[20] Medical union objects to Africa outsourcing, Jenny Legg, 11 October 2005, The Argus. Http://www.theargus.co.uk/the_argus/news/NEWS2.html last accessed 22/10/05.

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Intelligent agents could be utilised as regulators of law, as mentioned above in the privacy and World Wide Web initiative and in the future vision of e-commerce, but we have also seen the difficulties of assigning responsibility, and the complexities of complying with regulation in an international arena. Enforcing the Data Protection Act overseas, for example where data is sent abroad, is something of a challenge – but the greater challenge possibly lies with assuring the rights of the Data Subject who themselves have the right to ensure that the data is correct. How is a citizen of one country to ascertain the accuracy of their data at all points along the data path, when that path may lead to a number of institutions and traverse different countries?

The end user's of these systems, whether they are patients receiving health care or the health care professionals, must be given every support to ensure they receive the benefits that are promised to them. So often systems fail to achieve their potential because the end user has not been given due consideration, and their needs understood. There is much work in computing science aimed at usability of systems which has seen success, but there is much more to be done. It should be remembered that users are novices, but at the same time should not be expected to undergo lengthy training in order to gain competence in operating these technologies, or be expected to be aware of all the pitfalls (in regulation, for example). It should also be borne in mind that their patient care system may not be the only technology they have to master (even now individuals are besieged with various devices, from mobile phones and 'Personal Digital Assistants' (PDA's) to remote controls for television and audio equipment). If technological systems simply add to the stress an ill person is already coping with, they are compounding a problem, not helping it. It should always be understood that the person using the system does not necessarily have the background knowledge of the software engineer, in respect of the design rationale.

Conclusions

The use of information and communication technologies in the health care arena will increase, and new developments bring a number of challenges to the fore. The Internet and mobile technologies create distance between the patient and the health care professional, and the patient is increasingly involved in the self-management of their health. Under these circumstances, where the patient can be classed as a novice, as well as vulnerable user, it is crucial that the essential characteristics of information and communication are maintained. That is, the integrity and interpretation of the information are vitally important, and communication between the patient and practitioner must be assured.

The examples offered for discussion have highlighted the areas of concern in respect of accuracy, integrity, confidentiality and interpretation within these systems. These have a bearing on patient welfare in correct treatment, and understanding of the condition and its treatment. Deficiencies in these areas have a significant impact on the principle of informed consent, an essential principle in the health care field. We must be careful when utilising information and communication technologies that the richness of human communication is not lost by transferring from an essentially 'qualitative' environment to the more quantitative domain of technology. It could be argued that the intelligent devices based on neural net technology have the capacity to have a "richer" approach, but the downside is that they can be unpredictable. Others may argue that humans can be unpredictable, and the benefits that technology provides give more consistently reliable results. However, as a general rule where humans behave unpredictably we have rich all round experience to draw on to compensate. We do not have this experience with artefacts, and medicine is not the area in which to gain experience – too much is at stake. Therefore a balance

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must be maintained by using the best characteristics of the technology in conjunction with the human element – both thus complementing each other.

The examples given have covered a range from the fairly simple (for example, the Internet Pharmacy transaction) to the extremely complex network of intelligent agents. The current trials with existing technology – such as the mobile phone to support people with diabetes – are so far contained within a local environment that is reasonably easy to control and regulate. However, it is possible in all the circumstances described to extend the range to international operation (as we saw with the control of the robotic arm via the Internet). This of course creates additional problems with applying legislation, and ensuring that the protection offered by legislation has some meaning. The problem of global networking is not just that organisations need to attend to legislation in any international dealings; it is also a matter of concern for individuals, in firstly claiming their rights and secondly in understanding the implications of global communications (in terms of language and culture).

The inter-relatedness of diverse technologies makes this development area complex, and the issues are not necessarily obvious, or easily identified. Drawing on existing developments and thinking in abstract terms of characteristics (such as integrity and confidentiality) helps to identify where problems may lie, and linking these insights to the different perspectives of the system – technical, regulatory, and end user – can aid the formulation of approaches that may help to resolve the issues.

Given the complexity of current technology, and unpredictable characteristics inherent in intelligent agents, any applications intended for use in the health care field must be very carefully considered, and measures taken to protect all those involved. Clearly, there is a great deal of research still to be done. More research is needed into extending current scenarios, that is, looking at what is happening today and envisioning the future. There is also a question of scale. The examples discussed and the projects put forward for consideration in terms of research funding are considered in isolation, but little consideration is given to the broader view of many such technologies interacting with each other, or indeed the cognitive load on the user. We have little idea of how the monitoring systems in the example of monitoring the elderly in their homes, react with other technologies in the house, or the impact on the individual from the emissions of these technologies (the debate on emissions from mobile phones, phone masts, and electricity pylons is relevant in this context). It must be remembered that the individuals concerned, i.e. patients, are by definition not in good health, and therefore are more likely to be susceptible to environmental conditions.

From the point of view of development, as the skills and practice of professionals become embedded in the technology - acting as a mediator between the professional and the client - so those designing and building the technology need to incorporate the values within the profession. Consequently there needs to be an ongoing, and honest, dialogue with all concerned throughout the development and implementation; not only between the purchaser and the designers on the requirements of the systems, but also vitally between the professional ethicists from the relevant fields (medical and computer science).

Trying to anticipate all eventualities that future technologies will bring is clearly beyond our grasp. Past experience has shown that technologies will be used in ways not anticipated by the developers. For example, as it has evolved the Internet has produced a number of surprises in adaptations of the technologies involved – the uptake on real-time chat applications (such as MSN messenger, for example) – and abuse (the proliferation of SPAM). These examples show how hard, if not impossible, it is to forecast how technologies will be used in the future. Having said that, we have

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the benefit of some experience in certain areas – we have found security and privacy to be issues of concern – something that had not been given consideration at the outset. We are now in a position to use our experience to mitigate against certain aspects of future use. Especially where medical and health matters are concerned – we need to prepare as much as is reasonably possible.

We need long term vision, not short term answers. We are constructing the future today, with no clear idea of how it will turn out. In fact, all involved in this type of research today are involved in Action Research, on human participants. Any research ethics committee would ask some serious questions concerning such a proposal, and would want to ensure that those involved were aware of the ethical implications of their work. Surely we should do the same?

References

Bain, M. and Subirana, B. (2004) 'Towards legal programming: the incorporation of legal criteria in software agent design – current proposals and future prospects'. In *Computer Law and Security Report* Vol.20 no, 1 2004. Elsevier Ltd. 2004. Pp. 44-52.

Berners-Lee, T. (1999) *Weaving the Web: The Original Design and Ultimate Destiny of the World Wide Web by Its Inventor*. HarperCollins Publishers Inc.

Collste, G., Shahsavar, N., Gill, H. (1999) 'A Decision Support System for Diabetes Care: Ethical Aspects' *Methods of Information in Medicine*, **38**: 313-6.

Collste, G. (2002) 'The Internet doctor and medical ethics: Ethical implications of the introduction of the Internet into medical encounters' *Medicine, Health Care and Philosophy* **5**: 121-125, 2002.

Duquenoy, P. and Whitehouse, D. (2005) 'Pursuing Perspectives on Ambient Intelligence' in *The Information Society: Emerging Landscapes,* (Chris Zielinski, Penny Duquenoy and Kai Kimppa, Eds.) Proceedings IFIP WG9.2 International Conference Landscapes of ICT and Social Accountability, Turku, Finland, 2005. In press.

Duquenoy, P. (2004) 'Intelligent Ethics'. In *Building the Information Society*, René Jacquart (Ed.). IFIP World Computer Congress 2004, Toulouse, France. Kluwer Academic Publishers. Pp. 597-602.

Duquenoy, P. (2000). "Internet ethics: changing concepts, changing ethics?" Technical Report CS-00-02, Middlesex University, UK.

Friedman, B. (1997) *Human Values and the Design of Computer Technology*, Cambridge University Press.

Gell, G. (2001) 'Side effects and responsibility of medical informatics' *International Journal of Medical Informatics* **64**: 69-81. Elsevier Science Ireland Ltd.

Gasson, M., Hutt, B., Goodhew, I., Kyberd, P. and Warwick, K., (2005),'Invasive neural prosthesis for neural signal detection and nerve stimulation', *Proc. International Journal of Adaptive Control and Signal Processing*, Vol.19, No.5, pp.365-375.

Citation details:
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George, C. and Duquenoy, P. (2005) 'Online Medical Consultations: Are we heading in the right direction?' in Proceedings Ethicomp2005, *Looking Back to the Future*, Linköping, Sweden, 12-15 September 2005.

Hoven, J. van den (2005) 'Values, Design and Information Technology: The front loading of ethics', Keynote speech Ethicomp2005, *Looking Back to the Future*, Linköping, Sweden, 12-15 September 2005.

Introna, L and Nissenbaum, H. 'Shaping the Web: why the politics of Search Engines Matter' *The Information Society* Vol. 15, No.3 (2000) 169-186.

Klerkx, G. (2005) 'Welcome to the immortal's club' *New Scientist*, Issue 2494, p.38.

Luck, M. and McBurney, P. 'Agent-based computing for next generation apps'
ITNOW, British Computer Society, September 2005. pp.24-25.

Miller, K. and Larson, D. (2005) 'Angels and Artifacts: Moral Agents in the Age of Computers and Networks', *Journal of Information, Communication & Ethics in Society*, Vol.3, Issues 3, July 2005. pp151-157.

Moor, J. (1985) 'What is computer ethics?' *Metaphilosophy*, 16 (4).

Warwick, K. and Cerqui, D. (2005) 'Prospects for Though Communication' in Proceedings Ethicomp2005, *Looking Back to the Future*, Linköping, Sweden, 12-15 September 2005.