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Health consumer issues

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This chapter aims to provide the reader with an understanding of the consumer perspective while considering aspects of health informatics. An appreciation of issues of privacy, confidentiality, access, consent and control is included. An awareness is raised of consumer concerns associated with the development and implementation of health informatics. It is argued that the consumer is a partner in the management of their own health care. It is also recognised that, from a consumer perspective, there are benefits associated with the use of health information technology.

This chapter refers mainly to "consumers" who represent and advocate from a particular perspective as distinct to providers and professionals who represent the needs of an industry. "Consumer" may also refer to one individual, or the collective voice. It is a term with less implication of power differences than the term "patient". However occassionally the term "patient' is used where it feels more appropriate.

It may seem self evident that the consumer should be placed at the centre of any new development in health care practice. However they are frequently the last people to be consulted or included in discussions. Health care has traditionally been practiced by "experts" who "know what is best" for their patients, and have felt that it may even be counterproductive to share knowledge and ideas with them. This attitude still prevails in many areas of health care and medicine to-day, but it is increasingly being attacked and challenged by a growing movement of health consumers who feel they have the right to have a say in their health care. This movement has some supporters within the health professions who attempt to influence their more conservative colleagues.

The consumer perspective includes belief in certain rights: the right to information; the right to safe products and services; the right to equal opportunities to obtain services the right to fairness; the right to participate as an active partner in the doctor - consumer relationship. (CHF 1993)

The Health consumer movement in Australia gained momentum in the 1970's and 1980's, growing out of international, consumer, feminist and human rights movements. (Baldry, 1992). The movement operates on several levels: there are individual consumers who may or may not be a member of a group; specific groups concerned with a particular disease or condition; state or national umbrella organizations; and consumer representatives on many diverse working parties or standing committees.

There is, therefore a shifting philosophy of care that is gaining both international and national acceptance. Consumers are being allowed to have a voice in and some influence on health policy and practice. At an individual level of care patients are being encouraged to be more assertive and expect more information and say in decisions that effect them; and there is a gradual but sometimes a grudging acceptance that individuals and communities may have some responsibility for their own health care policy and services.

Ultimately the consumer should be able to assess the benefit derived from any changes in their terms. It may not always be the same as the assumptions made by professionals. For instance, issues of quality and choice are important considerations. Draper states:

> "How quality is defined matters... for health service users, the health product is both process (how I get treated) and outcome (whether I benefit). The experience of quality is also about a continuous, whole process, not just about a part of the body, or what happens in the hospital ward... When healthcare users define quality, as opposed to health care providers, it may look quite different." (HIC 1992,pg 48.)

One of the goals of health informatics is the improvement in communication and management of information. Communication can be rapid and accurate. Important decisions about patient care can be made quickly on the basis of transmitted photo images etc. Due to the rapid development in this field, a number of issues which have been discussed broadly by consumers in the last few years have gained a more immediate relevance. Privacy and security in relation to personal information held by another party are obviously the most crucial and overriding concerns. Related considerations are: the nature of "informed consent"; control of information; ownership; and consumer access to medical records.

Information is of vital importance to the consumer. They need to know about their health status or treatment; have access to their records; and have a say about what happens to their records, (e.g. consent and control over transfer and usage.)

The use of computers in health, particularly medicine, means that a lot of data can be communicated to many different people, for many different purposes in a very short space of time. This process obviously leaves many people feeling very concerned about security and access issues. The fear that a mass of data are being collected and stored about individuals with the potential for cross linking with Government departments, and other bodies, stirs up images of "Big Brother" and loss of civil liberties. It can no longer be assumed that professional ethics and guidelines will be enough to control the use of personal health information.

The ease with which data can be sent and accessed could make it easier to become careless about consent procedures. Some of these crucial consumer issues in relation to health informatics are now examined in more depth. These are organised into three major topics: an overview of some of the major privacy related issues for consumers; research and other issues; and the major benefits for consumers.

Privacy and the consumer

Although computer technology in health will be used to send and access a wide variety of data: educational; research; drug information; community information; marketting etc, it is obviously the ability to send personal information relating to individuals that is of most

concern to consumers. Consumers who have been advocating to strengthen privacy controls in terms of manually compiled medical records, now have to tackle the more complex privacy aspects of personal information held on computer based records.

Privacy legislation in Australia is piecemeal when it comes to protecting health information. The Commonwealth Privacy Act(1988) only covers Commonwealth government departments and funded bodies. Although States generally have privacy clauses in their Health Acts, they do not cover private practitioners and organizations. Professional codes of ethics provide some protection but are not enforceable and do not give the consumer legal right of redress. A working party of the Commonwealth privacy commission has drawn up privacy guidelines relating to HIV/AIDS patients and has recommended that these be adopted more broadly.

The relationship between patient and doctor has long been based on trust, where the patient trusts the doctor not to disclose any personal information without their permission, and where it may cause them harm. Exceptions exist when information is subpoenaed or there is the likelihood of harm to a third party. For the consumer to feel secure therefore, privacy principles need to be extended to make sure that they take into account the increased risks associated with computers.

Privacy also covers notions of access, control, ownership and consent.

Access

Who can access information depends on the nature of the information and the terms of consent. Patient access to files has only been possible under the vaious forms of Freedom of Information Legislation, and only in the public system. Even then information may be edited or summarized for patient consumption. Other countries have recognized a patient's right to access medical records, for instance England has recognized this right for computerized records, both public and private since 1984, (1990 for manually created records.)(Carter 1994).

Consumers argue that access to files enable them to be more informed about their condition and care and play a more active role in their own health care. Research by the Health Issues Centre has shown that far from being upset and confused by such information, consumers are less anxious and more cooperative with treatment when they know why certain decisions are made.(Loftus Hill , pg 4, 1993) Access to personal records can therefore enable consumers to be more responsive and to make informed choices.

Health providers and professionals have generally opposed consumer access fearing possible litigation as well as the assumption that patients will become too anxious and will not understand the information. These outcomes have not proved to be the case in other countries, patients have been able to alter inaccuracies in the files, gain peace of mind, and work in partnership with doctors. (Southgate, 1991,pg 24) In fact there is probably less likelihood of litigation where consumers can amend and comment on their own file.(Carter, 1994,pg9.) However these paternalistic attititudes are still very ingrained in the Australian medical fraternity. According to Carter the Australian Medical Association (AMA) is concerned about the possibility of litigation and is opposed to complete access to files suggesting that doctors may end up keeping two files, one for the doctor and one for the patient. (Carter, 1994, pg. 10) These arguments were also put forward when Freedom of

Information legislation was being developed, but there does not seem to be any evidence to support them.

Certain groups may require added protection and a more differential approach to access; for instance children, or severely mentally ill patients.

Patient held records and smart cards

The optimum access arrangement for consumers would be to allow patients to hold their own records. Consumers groups and some professionals support the concept of patient held records. (See for example, Evans, 1994). There are useful precedents already in the pharmaceutical area, where patients hold information relating to the pharmaceuticals they use.

The advent of computer technology makes this more practical and possible through the use of integrated circuit cards, or"Smart Cards". Such cards, would be able to process and store the personal health records of the consumer, in a card similar to an electronic banking card. Providers could access this information when allowed to do so by a consumer during a consultation. Consumers would hold certain access codes, or a PIN number. Such a system has the obvious advantage for a consumer as it gives them control over, access to and some degree of ownership of the information. Consumers would therefore be able to ensure consistency and continuity of care. However there are reservations by consumers at present, as to how accessible and understandable these would be to consumers. Consumers would need to see that they are "consumer friendly".

These cards are being trialled overseas at present, and contrary to expectations, relatively few problems have been reported.

Paradoxically a need to prevent abuse of the system may also indicate a need for a centralized personal identification number for verification. An attempt at a national identification system, (the Australia Card), has been resisted in the past. The community has felt that tax file numbers and Medicare numbers are more than sufficient methods of government control.

The "Smart Card' also raises issues over who can change it, who has the technology to read and access it. It is difficult to envisage a medical profession ready to give up a perceived right to keep information collected by them about their patients.

There is a danger, therefore, of multiple sets of information residing in a number of sites, e.g. with the GP, specialist; hospital etc.

Control

Just as in the past it was recognized that knowledge represented power. To-day control over information represents power. It is difficult to encourage people to relinquish power, and all professionals are very reluctant to do so. It is, afer all, the basis of their position in society. Computers represent an extra dimension to this power, as information has the potential to be "hidden" and only accessible through highly complicated processes.

"Smart Cards" may be a way to overcome issues of access but they do not remove control of the input away from health professionals. Data that are encoded or transformed in some way are harder for consumers to have any control over. It is also harder for consumers to be

able to amend or retract information from computerized records. It is understandable therefore that consumers feel that there is a risk of losing any gains so far achieved in accessing their records.

Choice is a further aspect of control. It is important that the use of computer technology is not used to limit choice of consumers. That is in terms of how much and to whom they disclose information, and the availability of second opinions is not determined by information already recorded.

Consent

There are several usual circumstances where patient information may need to be shared with a third party;

- for direct referral and continuity of care purposes. E.g. GP to specialist/hospital; hospital to GP on discharge
- for research. The information may or may not be identified and collectively passed on for research purposes.
- for a registry of conditions or procedures, e.g for Breast screening purposes, or where a new drug or treatment was introduced.
- where a condition is a publicly notifiable disease
- for consultation, when a doctor may need to confer with a colleague.
- for teaching and learning purposes

These circumstances would as a rule require consent of the patient before communication could take place.

Consent must be "informed", that is a person must understand why the information is being passed on, and also there is no undue pressure or coercion applied. Sometimes pressure can be subtle or consent assumed by implication. Practitioners need to be aware of the effect of the power imbalances between a health provider and consumer. Patients are generally vulnerable and anxious to please and they may later regret a decision. "Opt out" clauses in registries are important, as they give consumers a greater degree of control. Reassurance and an opportunity to review consent (if the process is long term,) would ensure less initial anxiety and greater trust.

Most consumers are happy to allow this information to be transferred, especially when it will lead to better care for them, or the community in general.

Consent is not always sought in cases of risk to an individual or third party and when legally subpoenaed. Files may also be accessed for fraud control and professional standards monitoring.

Both the Commonwealth and several state governments are preparing privacy guidelines that relate directly to medical records.

It is also important that the content of medical records is relevant and succinct, free of unnecessary social, personal information and subjective opinions, and it must be accurate.

The Health Services Commissioner in Victoria receives complaints about accuracy, where treatment and ongoing care is based on the wrong assumptions and information.

Confidentiality

The opportunity and temptation for Government departments and other bodies to cross link information, or adopt surveillance techniques is also of concern to consumers. At present information from the Dept of Social Security can be cross referenced with taxation information to overcome welfare fraud. If this is extended to health there are concerns that insurance, superannuation etc may be affected, and represent a gross personal violation.

"Function creep", is a term coined by Americans to describe how information collected for one purpose may eventually be used in other ways. Obviously there will have to be strict guidelines and administrative procedures to make sure that there is no unauthorized or unnecessary access to data on all levels. There is a well founded fear of unauthorized access to data banks. According to Kidd (1992,p.23) the World Health Organization resolved that medical data banks be only available to the medical profession, and not linked to central databanks.

In an attempt to identify "health care policy and practice, and provider views on consumer access and privacy" the Health Issues Centre conducted a survey of public health agencies in Victoria. Results showed that although most centres were aware of the need for privacy and security of medical records, few could give a clear account of their procedures, and were not aware of all the relevant legislation and guidleines. They did however support in principle the notion of patients having a right to view their records. (Loftus Hill, 1993)

Ownership

It has until recently been generally accepted that providers own health information they enter into records to help their patients. Under Freedom of Information (FOI) legislation consumers have had access to this information for several years. They have demanded the right to comment and change this information. However in many cases only summaries or selections of files have been released. There appears to be no way of enforcing complete access. In the private sector this is even more difficult. The laws around ownership appear to be vague and ambiguous. In a case recently heard in Victoria it is not even clear whether records belong to individual practitioners or to a practice where he worked. Relatives of deceased practitioners maintain they own records. In a case study recorded in HIC a woman with a genetic disorder that can be related to a drug taken by her mother (DES) was unable to access files held by the widow of her late doctor. (Vickers Kerr, 1986)

With the advent of medical entrepreneurship some private practices are now owned by non - medical business men. It has not yet been established legally to what extent these practice owners "own" or have access to medical records. Consumers are very keen to see anomalies around ownership resolved.

Consumers and Research

Consumers are keen to encourage productive research, and are in general, very willing to consent to allowing access to personal information for these purposes. The NHMRC have ethical guidelines (currently being trialled and under review) which must be adhered to by

researchers. Proposed research in health must be passed by an ethics committee. Requirements include the necessity to obtain consent from all individuals and strict practices governing the handling of personal data. Research may involve accessing files retrospectively and cross matching data, or ongoing longitudinal studies. It is important for consumers that results of research is made available to them. This also provides accountability and recognises the contribution of consumers.

The use of computers has obvious benefits for research, far more data can be collected on a national level, the opportunity for good public health research is therefore much improved. For example a researcher may wish to look at whether a particular medical procedure or drug may be associated with a disorder occurring at a later period in time. Computers enable faster and more comprehensive crossmatching and analysis.

Whether or not research data should be de-identified in all cases, is problematical. Obvious research problems of replicability and reliability must be addressed. Consumers are divided on this issue and the debate will continue for some time.

The establishment of national registries will also help both the individual consumer as well as the community. Breast screening registries will aid in the regular recall of women, as well as show general trends and problems. According to a worker at the Victorian Breast Screening Program only 10 women out of approximately 80,000 have refused to have their name on a registry in the first two years of screening. Health consumers cautiously support the access of researchers to data that may be seen to be for the good of public health when it is not possible always to obtain consent, but only if assured of good quality assurance procedures. This means that consumers would expect to participate in the monitoring of the research and involved in decisions about defining the nature of the "public interest and health" being presented.

Coding

Coding practices are necessary to enable data to be transmitted and accessed appropriately. At present there seems to be difficulty in developing a coding system that is not too unwieldy but can capture the complex nature of health information and enable accurate and unambiguous decoding. It is clear to consumers that coding is of major importance, but they are concerned that it doesn't "dehumanise" the consumer, or the nature of the patient - doctor contact. They share the professionals concern about security of encryption codes and the need to understand the technology to a level that enables them to have input into discussion and implementation. Like professionals, consumers need to work with software manufacturers and academics to fully ensure that coding meets everybody's needs.

Health Informatics and general consumer issues

The health consumer movement is also vitally interested in quality assurance, accountability and evaluation issues. Applied to health informatics, consumers are anxious to see proper quality assurance mechanisms in place, where professionals have to take account of the nature of outcomes in relation to their practice. This could be by peer review, but preferably by boards or panels representing a cross section of perspectives, including consumers.

Evaluation of technologies in terms of outcomes should always include some account of the impact on consumers. This will help avoid the tendency to become taken with or carried away by the "glamour" of the technology. Measures need to be developed that show the nature of improved patient care.

Benefits for consumers

Here the aim is to look at some of the positive outcomes for consumers through the use of information technology. Some of these benefits have already been discussed but others may not be so obvious.

For the individual patient, improved communication between providers of health care can only improve continuity and consistency of care, as long as confidentiality and consent procedures are respected. It should relieve them of having to undergo repeated tests with different providers. Often a patient will be forced to undergo the same tests in a hospital that they may have just had with their GP. This can be particularly harrowing with some procedures. On discharge they can be sure that follow up care is co-ordinated and consistent. Community support agencies, such as the Royal District Nursing Service and Community Health Centres as well as GPs, will be able to be more easily co-ordinated to offer appropriate post - hospital care.

Information technology can enable better quality drug prescribing; doctors can have access to on line data bases which could inform them of the most recent allergy or adverse drug interaction information.

As discussed above, better quality research is possible. Consumers will also be able to use this research to inform their own self-management., and access data banks and information for their own research.

Indirect benefits for consumers are obvious through having providers better informed about current medical findings and other relevant information, (for instance changes in government requirements and guidelines.)

Consumers will benefit from better education opportunities offered to them and practitioners by computers. It may also be possible to link either seriously ill or isolated patients at home together for support, and/ or to health providers for ongoing monitoring or education.

The ability to offer rapid and appropriate care to a seriously ill or injured patient in an isolated geographical area is often cited as one of the major advantages for consumers. Isolated practitioners can also confer and consult with colleagues to improve their own practice. This of course assumes the use of appropriate consent protocols.

Other indirect benefits for consumers will be that costs of health care can be better tracked which will increase efficiencies and reduce the overall costs of health care to the community.

Summary and conclusion

It is important that the patient or consumer is placed at the centre of any discussion about health informatics. The ultimate goal of any new development in health is an improved health outcome for consumers. Information technology promises many benefits for consumers but not without some serious hazards.

This chapter has looked at some of these hazards and benefits for the consumer. There are no easy solutions but it is important that there be continuing dialogue between all parties concerned. In order for this dialogue to take place there has to be an acceptance of the consumer as a serious player with a right to be fully informed about the technology and its application in health care services. This has to occur at all levels, from the individual doctor and his/her patient, to policy makers, professional associations, consumer and advocacy groups.

The advent of information technology in health represents an opportunity to transform the traditional paternalistic doctor patient relationship to one of mutual co-operation, with the patient gaining a greater degree of responsibility in managing their own health care, due, in part, to the right to contribute to and access their own health information.

Note

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