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The Ethics of Online Healthcare

For many people, e-health services and telemedicine provide convenient and flexible ways to manage their healthcare. However, a major enquiry by the uk-based independent nuffield council on bioethics has identified a number of ethical questions and challenges associated with various forms of online healthcare. The council's report, medical profiling and online medicine: the ethics of personalised healthcare in a consumer age, published in october 2010, makes a number of policy and practice recommendations for providers and users of e-health services. This article highlights the recommendations across two of the report's case studies: online personal health records, and telemedicine.

Two key social pressures, 'responsibilisation' and 'consumerisation', were central to the recommendations made in the Council's report. 'Responsibilisation' indicates the trend for people to take more responsibility for their own health, to lead a healthy lifestyle and to actively manage their healthcare.

'Consumerisation' of healthcare and the new technologies available are helping to drive the market for many online medical services.

The Council found five ethical values to be important when considering developments in these areas. These were:

- Private information should be safeguarded;
- Individuals should be able to pursue their own interests in their own way;
- The state should act to reduce harm;
- Public resources should be used fairly and efficiently; and
- Social solidarity (sharing risks and working together to protect the vulnerable) should inform public policy.

These ethical values often conflict with one another but all are important and no one value 'trumps' another. When applying these values to each of the case studies, the Working Party attempted to 'soften' the conflicts by recommending a way of intervening that would allow each value to be respected as much as possible, and making recommendations that were evidence-based, proportionate and feasible.

Online Personal Health Records

Several commercial companies, mainly in the US, provide services that allow people to organise their personal health information, integrate health records from different providers, and share them with other people, including healthcare professionals. Whilst these services allow more convenient and patient-centred control of health records, they also encourage people to upload, access and share highly personal information via the internet, and the Council is concerned about the possible breaches of privacy.

The Council's report states that people should be able to keep information about themselves and their health private and free from unauthorised access or use if they wish to. However, there is potential for misuse of stored information. For example, an online health record system could be used to market products to people and there is the possibility of doctor-patient confidentiality being breached through family members or other contacts demanding or guessing somebody else's password.

More broadly, personal health information entered and accessed online may be commercially valuable. The ease with which electronic files may be transmitted and accessed is a double-edged sword: While this feature increases convenience, it also means that files can be 'lost' or misused as a result of carelessness, fraud or institutional change. And if a provider of online health record facilities were to go bankrupt or change hands, it might be difficult for users to guarantee that their data would continue to be held securely and would not be lost.

If we consider the ethical principles set out in this report, there is a conflict between the value of individuals being able to pursue their own interests in their own way and the value of safeguarding private information. What can be done to ensure that people can use online health services effectively and safely without compromising their privacy?

Recommendations

Currently, it is not straightforward for users to find out how their data will be used, stored, passed on or sold to third parties. The Council recommends that the UK Department of Health should develop an accreditation system for online health record providers. The accreditation system should specify exactly how the details provided by users will be stored, passed on or sold to third parties and the arrangements to ensure the security and confidentiality of data and information if the operator went into administration or changed hands.

The report also states that responsible bodies in the EU, and the Information Commissioner's Office in the UK, establish data protection legislation that applies to online health records held by people who upload and edit their information in the EU.

As an additional safeguard, the Council would like to encourage good practice for the process by which individuals join online personal health records systems. If people are routinely provided with information such as whether or not they will receive information or advertising from pharmaceutical companies on the basis of information they enter, this would help them to assess whether their private information on the system is being safeguarded.

Future Impact

The use of the Internet for health-related purposes is likely to grow as more people gain access to the Internet across the world and as people who are young and middle-aged now (social groups more familiar with using the internet) become elderly (the group that consumes most healthcare). Healthcare providers may fi nd their patients increasingly demand access to their medical records and other services online, and

commercial competition may drive further development of this kind.

Although use of online health records systems outside those offered by public healthcare systems seems limited at present, the European Commission recently offered support for pilot projects to develop systems for individuals to have their personal health information safely stored within an accessible online healthcare system. The Council concludes that it would be prudent to make arrangements that provide for the possible increased use of such records. Telemedicine Although some types of care will always need to be delivered in person, telemedicine has the potential to offer care to people in their own home and increase equitable access to healthcare services. The ethical issues associated with 'responsibilisation' are of key importance for telemedicine, since some telemedicine services lead to patients (or their carers) taking, or being obliged to take, greater responsibility for their healthcare. This raises questions about how far telemedicine should replace traditional forms of healthcare and about liability for adverse events.

One concern that the Council raises about the introduction of telemedicine systems that link patients to remote healthcare professionals or remote systems, is that it may serve to replace time spent in the physical presence of health professionals, an aspect of healthcare valued by many people. A balance must therefore be struck between the value of using public resources fairly and effi ciently and the value of state activity to reduce harm in this case.

Additionally, it is noted that the current legislation for telemedicine does not encourage providers of healthcare services to consider all the factors that are thought to be desirable when deciding whether to introduce telemedicine services, including: Cost-effectiveness; equity; safety; quality; the value of physical time with health professionals, impact upon doctorpatient relationships and the value of global social solidarity.

Recommendations

Public healthcare systems should offer telemedicine services in circumstances where they can assist in a feasible and costeffective manner to reducing inequities in access to healthcare. As when introducing any new health service, consideration should be given to ensuring that inequities of access to care are wherever possible not exacerbated for some groups while they are reduced for others, and any impacts on doctorpatient relationships should be evaluated.

To ensure that public resources are used fairly and effi ciently, the report recommends to providers of public healthcare systems that telemedicine services should be subjected to the same criteria of cost-effectiveness, equity, safety and quality to which other health technologies are subjected. This recommendation may require careful monitoring of changes in the quality and standards of care for patients, for example if people were at risk of being discharged inappropriately early from hospital due to the provision of a telemedicine service for aftercare and follow-up.

The report concludes that telemedicine could have a particularly positive impact in developing countries, for example, by enabling doctors to seek expert opinions from specialists in industrialised countries. It may also have a role in reducing the 'brain drain' effect of doctors moving from developing countries to work in industrialised countries. The Council therefore recommends that The World Health Organization and other international agencies should encourage telemedicine networks in developing countries where they can be shown to be beneficial, cost effective and sustainable.

Future Impact

Telemedicine could be of particular signifi cance when considering the impact of an ageing population on health and social care. Older people use healthcare more than other demographic groups, and therefore healthcare providers will need to assess ways in which telemedicine can be used to improve cost-effectiveness. Some forms of telecare could be particularly suited to the provision of health services to older people, insofar as telemedicine can help promote independence and detect early changes in health status. It has also been argued that telemedicine is important as a way of better supporting vulnerable adults and those with long-term health conditions such as dementia. Hence it is likely that, at least in the UK and other industrialised countries, we will see increased use of telemedicine in many different forms in the future.

To read Medical profiling and online medicine, the ethics of "personalised healthcare" in a consumer age in full, please visit: www.nuffieldbioethics.org/personalised

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