

Carl Whitehouse reflects on the National Programme for IT in the NHS

Records, Confidentiality and Computers

Over the next few years there will be a revolution in the way personal information about patients is managed in the NHS. We are told that: '...every patient's medical and care records will be held electronically and will eventually be available securely online. The information will be safely and easily accessible to healthcare professionals and patients, whenever and wherever it is needed.'¹ There is intended to be a central spine, a national electronic record for each individual, containing summary information such as allergies and major ongoing conditions. This will be available anywhere in the country, whilst more detailed information will continue to be held locally. The specifications are complex and aimed to deal with many concerns about security and confidentiality: information will only be available on a need to know basis, there will be 'patient sealed envelopes' containing sensitive information only accessible with permission from patients, all access will be monitored and there will even be an 'alarm' system alerting the Caldicott Guardian of any unauthorised attempts to access sealed envelopes.

There is every reason to believe the level of confidentiality will be greater than with existing systems, whether paper or computer. However, concern has been expressed about the extent of information that will be centralised and the use to which it might be put. Coupled to this is an anxiety that patients may be less likely to trust the care-giver and provide necessary information if they are unsure who might access that information, even in the distant future.

Christian caregivers need to respond to this changing situation with a mixture of support and vigilance.

The health care situation of biblical times was vastly different from that of the 21st century, but we cannot claim scriptural justification for a total ban on centrally held information or for absolute confidentiality between caregiver and patient. Censuses, with centralisation of personal information, were acceptable² although not if the information was being gathered for the wrong reasons.³ Leviticus delineates a responsibility to report many diseases to central authorities,⁴ a rule which Jesus himself accepted.⁵ Loving concern for neighbours will make us anxious to avoid damage through inappropriate sharing of information, but modern health care means there are many more situations where communication is right. We have to remember the greater mobility of people, increasingly individuals do not remain with one practice and/or hospital for all their medical care. Health and care problems are increasingly complex, requiring an ever-larger team to manage them - secondary care episodes are

no longer contained within a single unit and the primary health care team often extends well beyond a single surgery premises. All this requires sharing of information. This is brought out in the specification, which states that consumers of care services should 'feel confident that information about them and their history of care is accurate and *easily accessible* to any other professional involved with their care and with a need to know, except where the patient has expressed a view to the contrary'⁶ (emphasis added) before any mention of security.

There is a strong assumption that patients will feel more confident if all caregivers have access to appropriate information without the need to tell the same story. Where patients may need help and vigilance is in ensuring that the information available is appropriate and not likely to cause more harm than good. We may have to think much more clearly what information may be considered redundant and therefore need pruning or putting into sealed envelopes.

Over recent years there has been strong pressure to strengthen individual patient rights. The pendulum is now swinging towards a more communal ethic. This comes out in the early pronouncements of the Ethics Advisory Group of the Care Record Development Board (responsible for developing the new system). Their statement of ethical principles emphasises our responsibilities as citizens as much as individuals' personal interests. They talk of finding an appropriate balance and emphasise that 'in accordance with the Human Rights Act 1998, public interests should only prevail over individual interests when it is necessary that they should do so in order to achieve a legitimate aim in a proportionate manner', but they are in no doubt of the importance of public interest.

Perhaps there is a need, whilst ensuring that we can give the right care to individuals, to also encourage and teach our patients to be more open and freer in sharing information, working to reduce the stigma of sickness. A reading of Paul's letters will soon remind us that he did not consider confidentiality about his state of health 'something to be grasped', but rather was prepared to share with others in order to bring them comfort.⁷

We need watchfulness as this progresses. The Care Record Development Board, its action groups and ethical advisory group are only just beginning work. They welcome input, and perhaps now is the time to consult their website⁸ and contribute our thoughts on these complex issues.

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