AIMS For a better birth...

Share with care!

People's views on consent and confidentiality of patient information, London, 4 November 2002

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The NHS Information Authority is steaming ahead with proposals to develop an all-singing, all-dancing computerised system to allow medical records to be shared among health professionals.

Having conducted a qualitative research study, the Information Authority established that there was a high level of trust in the NHS to protect confidentiality, but low awareness of how the NHS uses patient information. I wondered how many of those sweet innocents had ever had incorrect information written on their files, or a condition they did not want anyone else to know about? And if so, perhaps their views would have been slightly different.

The day-long conference gathered together a disparate collection of representatives from a wide range of user groups and some companies.

Three speakers described how the new computerised systems would work and what was happening thus far. This was followed by a 15-minute question-and-answer session. We then withdrew into workshops to discuss the morning's presentations.

I found myself the only maternity group representative and would have welcomed a meeting with other childbirth groups. I suspect some of the representatives of the groups for the elderly or mental health probably felt similarly.

The whole system gives the impression that Nirvana has arrived. Your details would be put into the computer, you could have a 'sealed envelope' into which you could insist certain information be put and which could not be accessed without your permission. Similarly, the GP, for example, would also have a 'sealed envelope' into which s/he could put information that would not be released without his/her permission.

All of which should be fine, until one begins to muse on the kinds of false, and sometimes malicious, information that is already put on case notes - how can the patient challenge this when the information is contained in a 'sealed envelope' that cannot be accessed without permission.

Similarly, suppose Mrs Smith wishes to conceal the fact that she has had a period of serious depression. It might be very relevant to a consultation in future but, if she insists that it remain sealed, the practitioner

to whom she is referred by her GP would be completely unaware of it.

In the consultation exercise, patients were asked whether they would be willing to share their medical records with various groups who may need to see them. A depressingly long list was highlighted: GPs, hospital doctors and consultants; other health professionals at a GP's surgery and at hospital; private-sector care providers; ambulance staff; NHS Direct nurses; voluntary care providers; university researchers; social-care staff; GP clerical staff; hospital managers; hospital clerical staff; commercial researchers; and hospital chaplains. Not quite "and Uncle Tom Cobleigh and all" - but almost.

I left feeling that there was a determined drive to introduce this 'wonderful' system and, although they were interested in hearing the public's concerns, I doubted it would deflect them from introducing the system as soon as possible.

It is difficult enough to chase the paper trail at the moment, let alone chase the superhighways of the NHS, Social Services or any other 'appropriate' authority's computerised system. In this Brave New World, the opportunity for errors, distortions, downright lies and malicious entries will find a superhighway to insinuate themselves into all sorts of nasty little nooks and crannies that will take an awful lot of time and effort to winkle out.

On the other hand, why not give the patients their own case notes and trust them to keep them safe?