

Iranian-British Medical Communication Association, jointly hosted by Tehran University of Medical Sciences and the British Council. The conference was busy and interactive, and we were struck by the enthusiasm of the audience, and their desire to increase collaborative links between our two countries. The hospitality we received was extremely generous and indicative of their wish to overcome a sense of professional isolation. We would strongly encourage their efforts to transcend current political obstacles to improve professional links between our countries, and hope to find ways to increase collaborative research and exchanges.

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Should our medical records be automatically centralised?

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Like many people I am uneasy about the explosion in the amount of information about us held by others. The proposed centralisation of medical records is yet another example, so I raised it with Charles.

'Charles, I am very concerned about the proposal to centralise the electronic records of all patients and it sounds as though it may be made compulsory.'

He intervened asking, 'Why "electronic", Coe?'

'Why do you ask?'

'Why not "paper" or for that matter any other type of record?'

I hesitated, so he continued.

'Do you think there is such fundamental difference between electronic methods and writing to justify different handling or indeed specific legislation for the former?'

I suggested, 'It is easier to distribute widely electronic information than written notes.'

'That is probably true,' *he replied, adding, 'and when data protection was introduced it was partly in response to this well-conceived impression. However, I am sure that public misconception that electronic data are necessarily less secure than the written word weighed more heavily on the legislators when drafting the bill.'*

When I looked doubtful, he explained: 'As written records are as secure as the strength of the box in which they are kept, so electronic records only as secure as the password and the encryption.'

'And wrong as it may be, just as screens are left on, so clinical notes are often left where anyone might see them.'

'And to labour the point, written notes do not have an automatic time-out!'

As usual he had focused the discussion on the real point at issue.

'So centralisation is the fundamental cause for concern.'

'Yes, Coe, and subsequent data protection legislation has recognised this. But to return to your specific point, would you object if downloading to the centre were voluntary?'

'No, provided the patient has an absolute say,' *I replied.*

'But that could never work well: there is plenty of universally accepted, albeit often unrecognised, precedent to the contrary.'

Seeing my astonishment, he asked, 'Do you ask permission before making written notes about a consultation which automatically becomes the physical property of the Trust or the Secretary of State?'

'Never! If I did I couldn't do my job properly!'



‘What would you do if the patient volunteered a refusal?’

‘It’s never arisen.’

‘I deliberately started at the extreme but there is a continuum from there to what you suggest is proposed. For example, when you ask for a blood test you not only get the result for your information and notes but the result is also held centrally in the laboratory.’

‘For good reason, as a back-up and for quality control,’
I responded.

‘Agreed, but nevertheless it is a remote record without the patient’s express permission.’

I countered, ‘You might argue that this is the primary record and therefore implicit permission has been given by accepting the test.’

‘Even if that is accepted, I remember that you once told me that there are inconsistencies in the way that information may be disseminated.’

‘You mean whether it is for audit or research? I do not see that there are clear cut-offs between scientific, clinical or operational research and audit which are sufficient to justify differences in the ethical approach to dissemination of data, whether fully anonymised or not. Why should research using incidental data require ethical approval and express permission, and audit not?’

Charles did not give a direct answer but responded, ‘Isn’t there an increasing demand for central reporting of data for audit? This may indeed perform its function but it may also be reported in a scientific journal after analysis which is not confined to narrow audit. Haven’t you yourself been involved?’

‘Yes,’ *I confessed, but justified myself by saying,* ‘But the audit was shown to improve patient care and the research conclusions were of great value.’

‘That makes my point: some degree of centralisation already exists and it is of value to the service and so to patients in general, and perhaps sometimes directly to the individual concerned. Our discussion also reflects the fact that piecemeal response to specific concerns leads to anomalies unless care is taken to return to consistent basic principles. This is particularly difficult to do when responding to a crisis or public outrage.’

‘Are you thinking of some of the anti-terrorist legislation or the gun laws following Dunblane?’

‘Yes, whether you agree with these laws or not, panic was a major component in their drafting and it must be avoided here. So what are we trying to achieve and avoid?’

‘Instant access to relevant records at all times,’ *I suggested.*

‘Yes, at a time when for reasons good and bad a patient no longer has access to the same service twenty-four-hours a day. But what are we trying to avoid?’

‘Insecurity leading to prying by government and other agencies including insurance companies?’

‘As a valid insurance contract requires absolute disclosure I have little sympathy with the latter save in specific instances that we might discuss at another time, but I do sympathise with the general feeling of unease that “they” know too much about us. The only too natural emotional objections may be difficult to overcome, but practical implications can be largely addressed by ensuring security in which all have confidence, a daunting but potentially achievable task.’

He continued suggesting that there are more important issues.

‘Even if entry were automatic, I would be much more concerned about the perpetuation of inaccurate information and reluctance to include highly relevant but potentially damaging information, particularly where third parties are involved, or honest opinions that the patient might not like.’

‘And the solution?’ *I asked.*

‘The GP record must be the primary one and the central data base a secondary back-up. It should be accessible only by a dedicated reference number known only to the patient and his GP, with a bypass that could only be used in a time of crisis and justified thereafter. The database, as a secondary record, would only be uploaded by the GP or when the GP had delegated responsibility, for example during hospital admission, to the responsible clinicians. The policy would be to limit the central record to objective data and clinical summaries.’

‘What about the patient’s right to refuse to participate?’

‘Absolute autonomy is incompatible with structure in society and therefore with civilisation. In this instance, the proposal is so much to the advantage of the individual, and refusal so much to the inconvenience of others, that I feel it is worthwhile foregoing a little autonomy in this respect. After all, as we have seen there is already precedent.’

‘Many would disagree with you Charles!’

‘I know,’ *he replied.* ‘But if they prevailed I would make the default inclusion and require explicit refusal if unwilling to participate.’

Although the details require refining, Charles’s solution might be the basis of a satisfactory compromise.

Coemgenus