



Royal College
of Physicians

Setting higher medical standards

From The Registrar

Data Sharing Review Secretariat
5.26 Steel House
11 Tothill Street
London
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15 February 2008

Dear Sir or Madam

Re: Use and sharing of personal information in the public and private sectors

The Royal College of Physicians is grateful for the opportunity to respond to the above consultation. We wish to make the following comments many of which are raised by the Joint Specialty Committee for Genito-urinary Medicine where the sharing of personal information is vitally important.

Question 1 - Please explain what your interest in information sharing is. If you have an active involvement in personal information sharing, we would be grateful for the following information:

- **What kinds of personal information do you collect, hold and share?**
- **How do you collect, hold and share such personal information?**
- **For what purposes do you collect, hold and share such personal information?**

The College has an interest in information sharing firstly to organise its own work (e.g. the MRCP exam and coordinating this with other Colleges); but more generally in promoting both the highest standards of health care and in promoting ethical research, especially in this context epidemiological research. The latter has given rise to concerns of restrictions due to the over strict interpretation of the Data Protection Act by investigators.

In Sexual Health Medicine:

- Information is collected for clinical management of the patient.
- It can be shared anonymously with other sexual health clinics for partner notification.
- Aggregated information, and some disaggregated information with no patient identifiers is shared relating to diagnoses and activity to the health protection agency

Question 2 - What in your view are the key benefits of sharing personal information to a) individuals and b) society? Please provide examples.

The advantages of data sharing in research are readily apparent. Large data banks enable better and more wide ranging conclusions of great public benefit. Epidemiological surveillance, research and audit all benefit from the accumulation of large data bases. Small ones may

mislead: data sharing enable larger databases with greater confidence in the findings. Although such advantages may appear societal, they impact on individual lives. In the context of sexual health:

- Allowing partners to be treated for infection without the index case having to disclose the diagnosis and to ascertain that partners have been treated reducing the risk of reinfections and complications
- Sharing anonymised data on infection rates allows for monitoring of outbreaks, planning and public health interventions

Question 3 - What in your view are the key risks of sharing personal information to a) individuals and b) society? Please provide examples.

The biggest risk is the threat to individual privacy. A wrong is done, even when no harm is done, when personal data is shared without consent or knowledge. (An intruder to one's house does one a wrong by entering even if they steal nothing and even if one does not know of the intrusion). This means that there should be efforts to publicise where data will be shared, as individual consent may not be practical or economic.

The sharing of information on consultations about sexually transmitted infections, other than in the circumstances mentioned above (question 2) would deter people from seeking advice and treatment for these conditions. This will be harmful to both the individual and to society. Generally it is not appropriate to disclose other than to sexual contacts. Confidentiality is essential for young people, as has been shown in many studies. Young people would not tolerate their personal information being passed to relatives, social services, or the police unless they had given consent. However, if the child had learning difficulties or was otherwise vulnerable, there might be a case for disclosing to the key worker/guardian.

Question 4 - As mentioned in the introduction, there are wide variations in the scope and methods of personal information sharing. What scope and what methods, in your view, pose the greatest opportunities or risks? Please explain the reasoning behind your response.

The greatest risks are electronically due to the volume of information that can be shared very easily and very widely if security mechanisms are not in place and strictly adhered to.

Question 5 - Please provide examples of where, in your view, the public authorities hold too much data or not enough personal information, and the reasoning behind your response.

On a topic of the moment, we believe that public authorities should hold data on personal choices for use of organs after death and that this information should be provided by law. The reasoning is, of course, to save lives by maximising transplants with the support of the potential donor's wishes.

It may also be beneficial if there was revision of diseases registered by law as for some infectious diseases (e.g. measles) but not others.

Q6 - Please provide examples of where, in your view, private sector organisations hold too much personal information or not enough personal information, and the reasoning behind your response.

Private sector organisations appear to have easy access to financial information based on credit card shopping etc. Although we have no expertise in this area, it may be that legitimate privacy is transgressed.

Q7 - Please provide examples of cases where you believe the sharing of personal information between two or more bodies would be beneficial, but where it is not currently taking place.

Please explain as fully as possible why information is not being shared, detailing what the barriers to the sharing of personal information are – e.g. legal, cultural, financial, institutional – and how these barriers can be overcome.

See the recent BMJ editorial (2008;336:106-7) 'Maximising research opportunities of new NHS information systems'. We are sympathetic to the points made in this.

Q9- 11 The biggest problem with the Data Protection Act is the lack of understanding about the Act. In particular the absence of case law has led to widespread anxieties about activities that might transgress the Act. The result has been an overcautious interpretation in the regulation of research, especially by research ethics committees. This has been detrimental to ethical research studies.

Question 13 - Are there any other aspects of UK or EU law (such as EU Directive 95/46/EC) that impact positively or negatively on data sharing or data protection? Please provide examples.

The NHS Trusts and the Primary Care Trusts (Sexually Transmitted Diseases) directions 2000 directly affect how data in sexual health clinics is shared and is supported by both those working within the service and using it. A recent review has been carried out by the Department of Health – 2006.

Question 16 - Is it clear whether and when you need individuals' consent to share information about them? Are you clear about the form that consent should take? Please provide examples.

As per our response to Q11, there is a need for better understanding of the Act. Most problems could be solved, in our view, if the Act was understood.

When patients attend a GUM department it is certain that they expect a level of confidentiality which perhaps they would not be so concerned about in the context of other medical consultations. If that confidentiality cannot be assured it could potentially lead to persons being unwilling to attend departments for important sexual health checks, diagnosis and the necessary public health measures to control infection. It could also lead to an increase in false information being given with respect to identification, this in itself would be problematic in the event that patients were not contactable if investigations were positive.

Correspondence with General Practitioners

- If the referral is accompanied with a letter the clinic will normally send a letter back to the general practitioner with details of the attendance. Patients can ask for no letter to be sent.
- If the GP gives a verbal recommendation for attendance a letter is not always sent back to the doctor.
- In the event that a diagnosis is made which is felt to be important for a GP to know about, the patient's agreement is sought for this information to be sent in writing to the doctor but the patient has the right to refuse this. However, the patient must accept the risks involved in this.

- In the case of self-referral or through partner notification it is usually the case that no correspondence will be entered into with the general practitioner unless as stated above there is a significant clinical problem about which the general practitioner should know.

GUM notes

The records of attendance in GU Medicine clinics are kept separate from the rest of the hospital records system. Notes usually can only leave the department with the express agreement of the consultant and consent of the patient.

Sharing information

In addition to the items listed above there may be sharing of information between GUM clinics, for example, for partner notification. This sharing of information will generally be done by Health Advisers and will usually just be clinic registration numbers with diagnoses. Sharing of information between clinics by doctors in the event of a transfer of a patient or other relevant clinic consultations will be done by letter with the patient's agreement.

Laboratory tests

Laboratory tests are usually anonymised using the patient's gender, date of birth and clinic registration number as identifiers.

Information required for the Public Health/Epidemiology

Numbers of diagnoses are returned to the PHLS (HPA) through the KC60 return system. This does not identify patients.

Notifiable diseases

Patients diagnosed with notifiable diseases at GUM clinics are informed that the condition is notifiable and their agreement received for information to be transferred to Public Health as appropriate. In the event that no agreement can be reached with the patient a compromise can be reached by referring the patient with, for example, hepatitis B to a hepatologist who can complete the notification.

Please provide details of any initiative you have been involved in that has been based on consent.

Most GUM departments will at registration give patients written material as to their visit to the clinic. This will usually contain an item reassuring them of the confidentiality of their visit and asking explicitly about how, and with whom information can be shared if at all.

Question 17 - What, if any, barriers would a requirement for gaining consent create to the sharing of personal information? Please explain your reasoning.

If it is anticipated there would be further information sharing detailed information re the confidentiality of the system will need to be given at registration. The patient will subsequently need to confirm they have understood this when they consult the doctor. This will potentially lengthen a consultation quite considerably which will need to be acknowledged in the timing of appointments. If the reassurance as to confidentiality is less than water-tight it is certain that this will deter attendance and information giving which will be potentially detrimental to individual persons and to the public health.

Question 21 - Should the law mandate specific technical safeguards for protecting personal information? For example, should there be an explicit requirement that all personal information held on portable devices be encrypted to a particular standard?

Yes, the increased use of PDAs, laptops and memory sticks, mean that where personal data is held it should be encrypted to

Question 22 - How, in your view, could ‘privacy enhancing techniques’, such as the anonymisation or pseudonymisation of personal information, help safeguard personal privacy, whilst facilitating activities such as performing medical research?

Is sufficient advice about the deployment of such techniques available? Are you confident about using them? What are the barriers to using them?

Yes; these techniques have been used in medical research and have undoubtedly been helpful. It would be helpful if terminology was standardised e.g. ‘pseudo-anonymisation’ versus ‘linked anonymisation’. In practice this causes much confusion.

These methods are already used in Genitourinary Medicine to provide HIV returns to the Health Protection Agency. The provision of non-identifying data and information is used for local and national surveillance of sexually transmitted infections including HIV. Information as to HIV/AIDS diagnoses with relevant details is transmitted by pseudo-anonymised data using date of birth and Soundex Code. No addresses or full postal codes are given. The data is directly uploaded onto a secure website. Despite the confidential nature of the materials there is confidence in the system because of the pseudoanonymisation of the data and the systems in place for data transfer.

I trust these comments will be of use.

Yours faithfully

Registrar