

# Data Sharing Review

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Richard Thomas and Dr Mark Walport

## Consultation paper on the use and sharing of personal information in the public and private sector

### List of questions for response

We would welcome responses to the following questions set out in this consultation paper. Please follow the question order as set out in the consultation paper, leaving a blank response box for any questions not answered.

Please email your completed form to [contact@datasharingreview.gsi.gov.uk](mailto:contact@datasharingreview.gsi.gov.uk)

Alternatively you can send a hard copy response to:

**Data Sharing Review Secretariat**  
**5.26 Steel House**  
**11 Tothill Street**  
**London**  
**SW1H 9LJ**

Thank you.

### Section 1: Background

Question 1. Examples of data collected :-

For one project - Details of patients with particular conditions (Demographic data, Diagnosis, Investigation results, Treatment, hospital details, outcome)

On another project, Details of training records for registrars

Comments: I work in a management consulting agency. The above examples relate to two separate research projects carried out recently. The first was to investigate why a particular District had a high Standardised Mortality Ratio (SMR) for Coronary Heart Disease and the second to investigate whether there was any evidence of discrimination among foreign Registrars as compared to those of white British origin.

Data for research projects is normally provided to me by email or on CDROM from NHS or training agencies. I do not normally access data held on central computer systems directly.

It is normally shared only with others working on the same project on a named individual basis in the same agency which I work in.

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**Section 2: Scope of personal information sharing, including benefits, barriers and risks of data sharing and data protection**

**Question 2**

. Benefits : The key benefit from my point of view is that data sharing enables Commissioning Agencies such as PCTs or training organisations to investigate further when key Performance Indicators show that there are problems in a particular Locality. There is no point at all in knowing that “Abortion rates are high in Leeds”, for example, if we cannot identify from which neighbourhoods in Leeds women seeking abortions come from.

Examples :-

Investigating inequalities of care (eg areas of high mortality rates, high emergency admission rates, high attendance at A/E departments or high abortion rates  
Investigating unequal provision of particular services (eg support from medical or social services to patients who are elderly or disabled or those with learning difficulties).

**Question 3.**

Comments: An example of advantage to individuals is that those found to be at risk can be offered individual care packages. For example, Primary Care staff often need help in accessing and analysing data to be able to identify which patients are at risk. Two examples I have been involved with are using markers such as Weight, Height, BP, serum cholesterol, enzyme levels etc. to compile a risk index for heart attack, and finding out which children have repeatedly attended A/E departments (by presenting condition) by analysing GP and Hospital records respectively.

**Question 4.**

Comments: By far the best way for information to be shared is for any agency responsible for data (the issuing agency) to send it by email or on CDROM to known and authorised Researchers. Ideally the issuing agency (eg a Hospital) should delete all identifying information for individual patients ( removing NHS Number, Hospital number, name, Date of Birth, demographic details etc.) and replace these with a single serial link number for each individual patient. A few other data items can also be “converted” if really necessary. For example, date of birth can be converted to “Age” and postcodes be given another serial number.

Using techniques such as these, with patients in a given set of records on a CD-ROM being numbered serially 1,2,3,4,... etc. then only the person in the issuing agency who provided that particular data set can re-discover the actual identity of individual patients. New data sets compiled for different research purposes and sent out to researchers on CD-ROMS can have different serial numbers

The greatest risk is to allow researchers to access central computer systems directly. The problem is that once a researcher or secretary etc. sees the name of someone they recognise, it is very difficult to forget or ignore it. If a prominent person is involved (eg the local MP), details of his or her medical record may soon

becomes “known” through the organisation.

Question 5.

Comments: The biggest deficiency in most medical records is the lack of any indication as to whether the patient’s condition improved or not, or when any change occurred. Sometimes changes in clinical data is recorded (such as haemoglobin levels in an anaemic patient) but not problems or symptoms experienced by the patient such as tiredness or pain. If the latter are recorded it is mainly in “Free text” rather than in a coded form which can be analysed statistically.

I have not come across examples where public authorities retain too much information.

Question 6.

Comments: I have not come across instances in which private organisations retain too much information as far as health records are concerned.

Question 7.

Comments: 1. There are problems in linking details of care provided in Private institutions to Medical Records relating to care provided in the NHS.  
2. The Office of National Statistics is very unwilling to release data relating to small areas such as Postcode or Output Area details. They also tend only to release data after a few years have passed. An important example is that of abortion statistics.

Question 8.

Comments: The main instances of illegitimate access to records are where staff in an institution (Hospital, GP Practice etc) obtain access to the personal records of other members in the same (or related) institution. If a consultant goes “off sick”, for example, then many staff are likely to wonder what the problem is, and they often find out !

I have also come across examples where hospital consultants informed GPs of the diagnosis of individual patients, and these patients have objected strongly to this happening without their consent.

### **Section 3: The legal framework**

Question 9.

Comments: Many agencies are now reluctant to share data because of “confidentiality concerns” even when to do so would obviously be in the patient’s interests. Particular examples relate to elderly or very confused patients when relatives or social service staff in attendance really need to know what the diagnosis and prognosis is but “cannot be told because of data protection”.

As far as some patients are concerned, there should be authorised lists of individuals who “need to know” (agreed by the patients legal carers and guardians) who may have access to such details.

Question 10.

Comments: It is very difficult to know in advance exactly how data can be used to benefit individuals or society. New uses for patient data are being discovered all the time.

Rather than ask patients to consent to the sharing of their data, there should be general and well publicised rules for data sharing in each locality or institution approved by an Information Ethics committee. . Patients should then have the right to Opt-out if they so wish (see response to question 18)

Question 11.

Comments: There are many instances in which details relating to one patient may come to be stored in the records of another with a similar name or address etc. Use of Barcodes etc. to identify patients rather than typing in 10-digit NHS numbers or whatever could help here.

Question 12.

Comments: There is great concern over large centralised government databases to which un-named civil servants or other government authorities (such as immigration or employers or security staff as regards religion) have access to. Perhaps the DPA should insist on oversight by independent publicly accountable equivalents of Research Ethics Committees (such as a national Information Ethics committee) to govern the collection of data stored in national databases, access to them, transfer of data sets derived from them, and end uses.

Question 13.

Comments: no comment (owing to lack of knowledge about these)

Question 14.

Comments: The word "sharing" needs to be more clearly defined. There is a great difference between allowing many users access to a central database through a remote computer terminal and one organisation sending anonymised (or pseudo-anonymised) records to another. The former should be very strictly limited.

Question 15.

Comments: Private organisations need to make a profit, and arrangements for data sharing need to be included in any contract placed with them as regards patient care.

#### **Section 4: Consent and transparency**

Question 16.

Comments: The main difficulty with consent is that vulnerable patients are unwilling to sign consent forms they do not fully understand, but are too frightened of offending institutions responsible for their care not to sign them.

Sometimes patients are asked to give very general consent to almost anything being shared. An example in a genetics clinic was patients being asked to consent to their DNA being stored and then shared with anyone their consultant thought should have it, provided that the consultant considered such sharing to be in

the best interests of the patient at the time.

Question 17.

Comments: There are real problems with patients who do not have English as their first language, and with those who do not fully understand the possible adverse consequences of giving consent.

Question 18.

Comments: Local Information Ethics Committees should set out what use will generally be made of information (and who it will be shared with), and patients should be fully informed about these general rules and be given the opportunity to opt out rather than being asked to sign individual "Consent" forms. The rules should be widely publicised so that patients can obtain advice on them from patient organisations etc.

Question 19.

Comments: Most professionals (let alone individual patients) would never have heard of the Information Commissioner's Framework Code of Practice etc. The great advantage of an "opt out" system as discussed above (Question 18) is that the committee could be made aware of this specifically and take steps to comply with the advice.

## **Section 5: Technology**

Question 20.

Comments: Information Technology provides far greater opportunities for information sharing and illegitimate access to personal details than paper records ever did. Obtaining access to paper medical records for anyone apart from local professional staff caring for patients was always quite difficult. No-one could just walk into a medical records department and find the case notes they wanted, for example. Computer records can be accessed by secretaries, nurses, paramedical staff, laboratory and X-ray staff etc. (without individuals being able to be named because they all work on shift rotas).

The second point is that computer databases can in principle be trawled for information (eg for any details of people living at particular addresses or with particular diseases etc).

Any identification number based on biometric details of individuals (fingerprints, Iris scans. DNA etc) would be dangerous in that unlike a bank PIN number, it could never be changed even if it became widely known to the Press, etc.

Question 21.

Comments: The Public is suspicious of any "technical" means of data protection, believing that all "codes" or "encrypted records" can be "cracked". It would be much better to insist that fully identifiable records should never be stored on portable devices. Serial numbers should always be used as mentioned above. (see question 4)

Question 22.

Comments: See response to question 4 above. The means of allocating serial numbers to datasets is not sufficiently available or publicised or implemented.

### **Section 6: International comparisons**

Question 23.
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Comments:
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Question 24.
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Question 25.
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Question 26.
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### **Section 7: Additional questions**

Question 27.
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Comments:
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Question 28.
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Comments: Please see answers to questions 1 – 22 which specifically state that :-
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| <ol style="list-style-type: none"><li>1. External users to any organisation should not have access to central databases used by that institution</li><li>2. Researchers requiring access to individual patient records should be provided with data sets in which patients are not identified other than by a serial number specific to each data set.</li><li>3. Rather than seeking consent from individuals for data sharing, there should be well publicised local rules which individuals can opt out of if they wish (and after discussion with people they trust beforehand).</li></ol> |
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