



## **Data Sharing Review**

Use and sharing of personal information in the public and private sectors  
Consultation

### **Question 1: Background**

The Health Services Research Network (HSRN) was established in April 2005 and represents the health services research (HSR) community in the UK. It defines HSR as all research that underpins improvements in the way health services are financed, organised, planned and delivered, and includes health technology assessments and health policy research.

HSRN has over 100 organisations in its membership, including about 60 groups of health services researchers (representing over a thousand people) in universities and other research institutes and around 40 NHS bodies. The HSRN is supported by the Department of Health, the Health Foundation and the Nuffield Trust. HSRN is nested within the NHS Confederation.

We have restricted our response to addressing the broad issues.

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

Personal health data provides a powerful and essential resource for health and health services research. Using personal information is an essential component of the research arsenal for tackling health and health care questions.

Using personal information has helped researchers identify and understand disease, understand the long term effects of treatment, address questions regarding the equity of healthcare and examine trends in the use of healthcare. It is also important to recognise the contribution personal data makes to other vital activities such as quality improvement; strategic planning of services; and improved clinical decision-making (in particular, by increasing patients' involvement).

Although there are many research uses for information and data that is not identifiable (anonymised), there are many crucial questions that can only be addressed by using identifiable data. Examples of where personal identifiable information is necessary are:

- Linkage within a database. It may be necessary to link several episodes or events pertaining to an individual patient. For example, to find out if someone is unexpectedly readmitted to hospital.
- Linkage between databases. It may be necessary to link between databases if the outcome of interest is not available in the database that contains the information on an exposure (such as an environmental hazard or a medical treatment).
- Ensure comparisons are meaningful. Comparisons of patient outcomes based on non-randomised data (as exist in databases) need to be adjusted to take into account potential confounding factors, which commonly include identifiers such as age, sex and socio-economic status.
- Ensure completeness of recruitment. To check that a database has included data on all eligible patients, it is necessary to cross-check against another source, such as operating theatre records. It is also necessary to avoid duplicate entries.
- Investigation of social factors. Any study that needs to take a patient's social circumstances into account must include data on factors such as age, sex and place of residence (often used as a proxy for socioeconomic status).
- Assessing the applicability of research findings. The results of a study may not apply equally to all ages, sexes, ethnic groups and socio-economic groups. Investigation of the effect such factors have on the results necessitates their inclusion in the dataset.

I have attached a recent article from the Journal of Health Services Research and Policy with examples of where identifiable data has been used.

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

The regulatory and legal framework around the use of personal data for research is confusing and complicated. Researchers would benefit from clearer, standardised and harmonised guidance from the various bodies that advise on the use of personal data.

We recognise the need for more rigorous protection of data by researchers (e.g. to prevent theft or accidental escape). This might be achieved through data encryption and password protection of electronic databases, coupled with periodic audit of adherence to standards.

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

There is a tendency from the regulatory community to adopt an overly cautious approach to issues of consent and confidentiality. Although there are genuine public and political concerns over issues of confidentiality, we feel these concerns should not impede the use of personal information, in appropriate circumstances, for health research.

Proposal that requires individual consent to be obtained is sometimes unworkable. They would inflict demands that could not be met and, as a result, the quality and quantity of research would diminish.

The NHS offers enormous potential for health research, especially with the introduction of the NHS national IT programme and electronic patient records. This potential would be severely limited if restrictive demands on consent were imposed.

Presently, the law does not require individual consent to be obtained for health research, provided that such use is necessary and is proportionate in respect to privacy and public interest. The principle of implied consent where, by using the NHS and agreeing to treatment and therefore the use of personal information to provide that treatment, an individual also implicitly consents for this information to be used in health research, is the most workable and sensible approach to this issue.

We believe that the public would support this position if they were properly informed of the role and benefit of research.

### **Section 5: Technology**

As mentioned above, with the increasing use of databases and in particular the NHS programme for IT, there are huge opportunities for research and improving health and health care.

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

No comment