

Data Sharing Review

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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

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.

Comments: This response was prepared by the Histocompatibility and Immunogenetics (H&I) Subcommittee of the Royal College of Pathologists on behalf of all professional colleagues supporting H&I services within the UK. H&I laboratories routinely provide tissue matching (HLA typing) services to support transplantation and transfusion. H&I laboratories also perform services critically important in the diagnosis and management of some disease processes.

Personal data is collected from both potential recipients and donors in support of solid organ transplantation (including kidney, pancreas, thoracic organs, liver, cornea) and Haemopoietic Stem Cell (Bone Marrow) Transplantation. From patients requiring transfusion, from blood donors and from patients undergoing immunogenetic testing to aid disease diagnosis and drug treatment. Personal data includes patient identification data (name, date of birth, home address, patient identification numbers, etc) and clinical data relevant to Transplantation (blood group, tissue type etc). These data are shared between Transplant Units, H&I laboratories, UK Transplant, Bone Marrow Donor Registries, Hospital Departments and GPs within the UK and overseas.

Data is held electronically or as paper records. It is shared electronically (by email using

NHS.net, or by direct password-protected connection to UK Transplant), by mail, or by fax or verbally by telephone.

Data is held only to facilitate the processes of transplantation, transfusion, or disease management.

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

Question 2.

Comments: Benefits to the individual of storing data with UK Transplant include immediate notification upon the availability of a suitable organ.

Benefits of sharing data between hospitals and blood services to individuals requiring transfusion are supply of appropriate blood products to treat/prevent haemorrhage

Benefits to society include that organs in short supply are transplanted into the most appropriate recipient.

Question 3.

Comments: We can identify no risks in the established system of data transfer.

Question 4.

Comments:

Question 5.

Comments:

Question 6.

Comments:

Question 7.

Comments:

Question 8.

Comments:

Section 3: The legal framework

Question 9.

Comments:

Question 10.

Comments:

Question 11.

Comments:

Question 12.

Comments:

Question 13.

Comments:

Question 14.

Comments:

Question 15.

Comments:

Section 4: Consent and transparency

Question 16.

Comments: Consent for the sharing of information is assumed to be included within the general consent of the individual to the tests being undertaken. Information provided to patients/donors does specify what information will be stored and with whom it will be shared. However, as with most pathology testing consent for H&I tests is generally obtained by the referring clinician or their representative and not by anyone within the H&I department where the information is processed and stored.

Question 17.

Comments: If specific written consent were required to be held by every department handling patient/donor information this would likely cause major difficulties in the recording of patient information as some requests would inevitably be received without an accompanying consent document. The laboratory would not know if this was due to error or withholding of consent. There would be an inevitable delay in processing and reporting patient results until it could be established that consent was given. This could have significant implications for patient care.

Question 18.

Comments:

Question 19.

Comments:

Section 5: Technology

Question 20.

Comments: The use of a secure email system to communicate with clinical teams has been much more efficient than faxing reports or leaving telephone messages which may be prone to transcription errors.

Email communication ensures that the message is read only by those for whom the message is intended, or named individuals with rights to manage their mailbox. The use of generic email addresses ensures that messages are processed in the absence of individual staff absence.

It is necessary for staff covering an “Out of Hours” service in support of solid organ transplantation or transfusion to have immediate access to limited clinical data of patients and donors. These data are kept in possession of the scientist providing this service throughout the “On Call” period. Typically, the information may be carried on paper as a printed file, or using a portable device (PDA/ Laptop/ Memory Stick). When using a portable device, the file would normally be password protected or encrypted.

Question 21.

Comments: Personal information held on any portable device should be password protected or encrypted.

Question 22.

Comments:

Section 6: International comparisons

Question 23.

Comments:

Question 24.

Comments:

Question 25.

Comments:

Question 26.

Comments:

Section 7: Additional questions

Question 27.

Comments:

Question 28.

Comments:

