

Giving consent for use of your information

Your questions answered

The NHS Code of Practice on Confidentiality requires that we ask your consent to use your personal information. This leaflet has been designed to help you to make that decision.

Q1 What is NHS Blood and Transplant?

A1 NHS Blood and Transplant (NHSBT) is a special health authority of the NHS. It is responsible for providing a reliable, efficient supply of blood, organs and other services to the NHS. Within NHSBT the Organ Donation and Transplantation Directorate is responsible for ensuring that donated organs are well matched to patients who need a transplant and are used in the fairest way.

Additionally NHSBT collects information about patients for use in analysis aimed at bringing about improvements in transplant survival rates in the transplant service.

To enable us to do this we need to have good quality information and therefore information is collected and stored in a computer system called the National Transplant Database.

Q2 What is the National Transplant Database?

A2 The National Transplant Database held by NHSBT was set up more than 30 years ago to store information about transplant patients. It is a computerised system that helps us to match organs.

Q3 What information about me does NHSBT need to have?

A3 To make sure that the donor organ you receive is the right match for you we need certain personal details and clinical information such as:

- Name
- Address
- Date of Birth
- Ethnic Group
- Blood Group
- Tissue Type

NHSBT's specialist advisory groups agree the specific information that should be collected. Different information is collected for different organs and there is an advisory group for each.

Q4 How does NHSBT collect this information?

A4 Your personal and clinical details will be sent to us at the time you are registered for a transplant. The details you provide at this point are important as they will be used to help us match your needs with a donor organ. It is therefore vital that this information is recorded accurately and kept up to date. Your records will be updated as necessary if your circumstances change.

At the time of your transplant, further information will be provided to us. There is a legal requirement to record your full name, and date and time of the

transplant and other information relating to the operation will also be sent to NHSBT. Details of the organ donor will be reported separately.

Once you have received your transplant, information about your progress will also be sent to us. This will be provided three months after your operation and then once a year. Such information provides important clinical evidence that is used to improve your care and helps to benefit future transplant patients.

Q5 What will NHSBT use my information for?

A5 Information about you will be added to the National Transplant Database and used for the following purposes:

- To maintain the national transplant list of patients needing a transplant.
- To assist in the allocation of donor organs.
- For statistical analysis.

The information used for statistical analysis will help to ensure that:

- Organs are allocated fairly.
- Donor organs are used in the best way.
- Transplant centres care for their patients in the best possible way.
- Others who need a transplant can benefit in the future.

Where possible your personal details will not be included in any statistical analysis.

Q6 How will my information be transferred to NHSBT?

A6 Your information will be sent to us on forms sent through the post, or electronically with appropriate security measures.

The particular method for transferring your details will depend on the arrangements that the hospital caring for you has made with us.

Q7 Who will see my information at NHSBT?

A7 Only certain members of staff are authorised to see your information and very few are allowed to see your personal details.

Those who are authorised include:

- The administrative team responsible for maintaining your information on the National Transplant Database.
- Staff in the Duty Office who will look at your information when donor organs become available.

Other staff who may have access to your information, but will only very occasionally have the need to see your personal details include:

- Statistical staff, who will use your clinical information to carry out specific analysis.
- IT support and development staff, who are responsible for maintaining and improving the National Transplant Database.

Q8 How will my information be stored and protected by NHSBT?

A8 The information, whether supplied on paper forms or electronically, will be stored on the National Transplant Database. The database can only be accessed by authorised users who have been given appropriate security clearance.

If your information is provided to us by means of a paper form it will be entered onto the National Transplant Database and then shredded securely on the premises. The following forms are also stored on a secure document imaging system before being shredded:

- Registration information
- Transplant operation details
- After-care details

Information security is very important to us, and we have put in place a range of measures to protect your information. NHSBT complies with the principles of the Data Protection Act 1998 and is working towards accreditation under the International Standard for information security management.

To avoid any delay in searching for your information you are given a unique identification (ID) number. Whenever possible, we will use this ID number and/or your NHS number in any communications about you. Your personal details (e.g. name and date of birth) are only used by us for allocation purposes and on occasions when your ID number would not be enough to identify you with certainty and maintain your safety.

Q9 How long will my information be held by NHSBT?

A9 For your safety, personal details about you will be retained indefinitely on the National Transplant Database.

These details enable us to track all organs from a donor, which is important should disease be identified at a later date in a donated organ.

Q10 Will NHSBT share my information with anyone else and, if so, why?

A10 In our work with other organisations we will always seek to establish arrangements that do not require the exchange of information that could identify you. Only if it can be shown there is no alternative, do we consider if it is appropriate to supply identifiable information.

Taking this approach means that for the vast majority of collaborative arrangements the information transferred is restricted so that it cannot identify individual patients. In the very few cases where it is demonstrated

that information that can identify you is essential, this is supplied once in order that unique identification numbers can be created. Once this has been done, the unique number is used when sending further clinical information about you to these organisations thereby further ensuring the confidentiality of your information.

Any reports or publication produced by any of these organisations will not identify you.

Q11 What will happen if I refuse consent for the use of my information by NHSBT?

A11 Whilst you do have the right to refuse consent, this does have implications which you will need to consider carefully.

In order to fully participate in national arrangements for the allocation of donated organs we need to hold your information. If we do not hold your information the implications include:

- Reduced likelihood of finding a suitable organ.
- A longer wait.
- Your access to a donated organ being restricted to only those available locally rather than nationally.
- Difficulty tracing you if subsequent investigation of a donor identifies the possibility of serious disease in the organ you have received.

In addition to these implications for you personally, the withholding of information will also affect the quality of the analysis and audit work we do and which is aimed at improving organ donation and transplantation and maintaining the safety of the service.

As explained in Question 4, certain information about you must be reported to us as a legal requirement. Even if you refuse consent for the use of your information by NHSBT, this information must be reported to us by your transplant unit.

If you are considering refusing consent for NHSBT to hold your information, it is recommended that you discuss the full implications of this decision with a member of the medical team caring for you.

Q12 What happens if I say “yes” to some information being used and “no” to other information?

A12 If you refuse consent for the use of some key pieces of your information by us (see answer to Question 3), this could result in the same consequences as if you had refused consent for all of your information.

You are likely to wait longer for a transplant and may not be offered the most suitable donor organ. Withholding other pieces of information might not have any impact on how long you wait or the suitability of the donor organ. Nevertheless, withholding that information would significantly reduce the value of NHSBT’s statistical analysis.

Q13 Can I change my mind about giving consent for my information to be held and used by NHSBT?

A13 Yes, you can change your mind at any time, either before or after you have received a transplant.

You can decide to increase or limit the amount of information held and used by us, or you can decide to withdraw consent completely. However, by that stage, certain information will probably have already been used by us for statistical analysis purposes.

If you request removal of your personal details, the rest of your information would be retained on the National Transplant Database as a record that could not be linked to you as an individual. However, we would be unable to obtain further information about you following your transplant and this would damage the quality of the data for future analysis.

Q14 How can I tell NHSBT that I want to change my mind?

A14 You can tell us by completing a “Change of Mind” form and sending it to NHSBT. To obtain this form write to us at the address below or ask your Transplant Unit.

Q15 Can I see the information about me that is held by NHSBT?

A15 Yes. The Data Protection Act 1998 gives you the right to see information about you that is held on computer

or in paper records.

This is known as “right of subject access”. If you wish to see the information that NHSBT holds about you, your request should be made in writing (by letter or email) to:

Information Manager
NHS Blood and Transplant
Fox Den Road
Stoke Gifford
Bristol BS34 8RR

Email. info.manager@nhsbt.nhs.uk

The Information Manager may ask for more details from you to make sure that we don't give your information to the wrong person. NHSBT staff will not disclose any personal information to you over the telephone.

Q16 If I have any further questions who can I speak to?

A16 If you have further questions regarding consent, you can speak to a member of the medical team caring for you. Alternatively you can contact NHSBT on 0117 975 7555.



NHS Blood and Transplant
Fox Den Road, Stoke Gifford, Bristol BS34 8RR
Tel: 0117 975 7555 Fax: 0117 975 7439
Email: info.manager@nhsbt.nhs.uk

Organ Donor Line: 0300 123 23 23
web: www.organdonation.nhs.uk