

Recipient Information

**Giving consent for use
of your information**



organdonation.nhs.uk

Your questions answered

The NHS Code of Practice on Confidentiality requires that we ask your consent to use your information. This booklet 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, tissues and other services to the NHS. Within NHSBT the Organ Donation and Transplantation (ODT) Directorate is responsible for ensuring that donated organs and tissues are matched to patients who need a transplant and are used in the fairest way.

As well as the above NHSBT collects information for use in analysis to help make improvements to the transplant service, survival rates and also to help maintain the safety of the transplant service.

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

Q2 What is the UK Transplant Registry?

A2 The UK Transplant Registry was set up more than 30 years ago to store information about organ donation and transplantation. It is a computerised system that helps us to match organs/tissues and carry out research to improve transplant services.

Q3 What information about me does NHSBT need to have?

A3 We need to collect certain personal details and clinical information about you such as:

- Name
- Address
- Date of Birth
- Blood Group
- Tissue Type
- Other clinical information.

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

Q4 Why does NHSBT need this information?

A4 Your personal and clinical details are sent to us at the time you are registered for a transplant. The details you provide are very important as they will be used to help us match your needs with a donor organ. This information will also be required if you wish to participate in the National Living Donor Kidney Sharing Schemes.

At the time of your transplant, the law requires that your full name, along with the date and time of your operation, **are** reported to NHSBT.

Your postcode is recorded to assist the NHS in planning the best use of transplant services. Your home address will only be used when absolutely necessary as an aid in confirming your identity.

Details of your ethnic group, age and sex are collected, along with other clinical information, to help with monitoring and developing fair and effective organ allocation schemes. As part of the NHS, NHSBT is also required to collect ethnic group information for management and monitoring purposes.

Q5 How will my information be transferred to NHSBT?

A5 By sending a completed paper form in the post/fax or by electronic transfer of computer records.

Depending on the arrangements that the hospital caring for you has established with NHSBT, your information may be sent by means of approved data collection forms, or electronically, with appropriate security measures.

Q6 Who will see my information at NHSBT?

A6 Only certain members of staff are authorised to see your information and very few are authorised to see your personal details:

- The administrative team responsible for maintaining your information on the UK Transplant Registry
- Staff in the Duty Office, who will look at your registration information when donor organs become available that may be suitable for you
- Statistical staff, who will use your clinical information to carry out specific analysis but will only very occasionally have the need to see your personal details
- IT support and development staff, who are responsible for maintaining and improving the UK Transplant Registry but will only very occasionally have the need to see your personal details.

Q7 How will my information be stored and protected by NHSBT?

A7 The information, whether supplied on paper forms or electronically, will be stored on the UK Transplant Registry. The database can only be accessed by authorised users who have been given appropriate security clearance.

If your information is provided to NHSBT by means of a paper form it will be entered onto the UK Transplant Registry, following which the paper form will be disposed of by shredding in a secure manner on the premises. Those forms which provide information relating to your registration, your transplant operation and immediate after-care will additionally be stored on a secure document imaging system before being shredded.

Information security is very important to us, and we have put in place a range of measures to protect your information. The database can only be accessed by authorised users who have been given appropriate security clearance.

To avoid any delay in searching for your information you are given a unique (ID) number. Whenever possible, we use this ID number and/or your NHS/Community Health Index (CHI) 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 other occasions when it would not be safe enough to only use your ID number.

Q8 How long will my information be held by NHSBT?

A8 Indefinitely.

NHSBT has a legal responsibility for recording the use made of all organs offered for transplant. It is therefore important that all patients who receive a donor organ can be identified. Records maintained by NHSBT enable tracking of all organs from a donor in cases of identification of donor disease. It is essential, therefore, for patient safety that personally identifiable information about patients is retained indefinitely on the UK Transplant Registry.

Q9 Will NHSBT share my information with anyone else and, if so, why?

A9 Currently NHSBT shares information with other professional organisations which have an interest in improving transplantation.

Your details also enable us to track donated organs, which is a legal requirement.

None of the reports or publications produced by any of these organisations identifies individual patients. The information is used purely for the purposes of statistical analysis.

The information transferred to the majority of organisations is restricted so that it cannot identify individual patients. There are a few exceptions to this ruling where your personal details may be sent once, in order to set up collaborative links. Once this has been done, a unique ID number is used when sending further clinical information about you.

If you are participating in the National Living Donor Kidney Sharing Schemes information will be shared between Transplant Units and the Human Tissue Authority to enable you to participate in the scheme(s).

If you are a Liver/Cardiothoracic registrant your data will be shared with the Royal College of Surgeons to enable the review of the care transplant patients receive.

Q10 What will happen if I refuse consent for the use of my information by NHSBT?

A10 NHSBT is responsible for allocating donated organs based on nationally agreed criteria designed to ensure safe and fair allocation. In order for you to fully participate in these national arrangements NHSBT needs to hold your information. If we do not hold your information it is only possible for you to be considered for donated organs allocated at a local level. This can significantly reduce the possibility of you receiving the offer of a suitable organ and you are likely to wait longer.

There may be significant implications for your safety if subsequent investigation of a donor identifies the possibility of serious disease in the organ you have received. Not holding your information may create real practical difficulties in tracing you.

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

If you are part of any of the National Living Donor Kidney Sharing Schemes personal information will be shared between Transplant Units and the Human Tissue Authority to enable you to participate in the scheme(s).

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

Q11 What happens if I say “yes” to some information being used and “no” to other information?

A11 If you refuse consent for the use of some key pieces of your information by NHSBT (see answer to Question 2), 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.

The UK Transplant Registry, which contains information on all organ donors and all patients who are waiting for or have received a transplant, is a unique and immensely important resource for the NHS. All the information that NHSBT collects has a direct benefit for all existing and future transplant patients. It is essential for developing more efficient and fairer organ allocation schemes and contributes to improving the effectiveness of transplantation and making this treatment available to more patients.

In addition to these implications for you personally, the withholding of information will also affect the quality of the work we do on behalf of all transplant patients.

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

Q12 Can I change my mind about giving consent for my information to be held and used by NHSBT?

A12 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 NHSBT, or you can decide to withdraw consent completely. However, by that stage, certain information about you will probably have already been used by NHSBT for statistical analysis purposes.

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

Q13 How can I tell NHSBT that I want to change my mind?

A13 By completing a “Change of Mind” form and sending it to NHSBT.

Along with the consent form that you will be asked to complete, you will also be provided with a “Change of Mind” form to enable you to notify NHSBT directly if you subsequently decide to change your original consent for the use of all or some of your information.

Q14 Can I see the information about me that is held by NHSBT?

A14 Yes. The Data Protection Act 1998 gives you the right to see the 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 Systems Security Manager

NHS Blood and Transplant

Organ Donation and Transplantation Directorate

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 NHSBT gives the correct information to the right person.

NHS Blood and Transplant staff will not disclose any personal information to you over the telephone.

Q15 If I have any further questions who can I speak to?

A15 If you have further questions regarding consent, you can speak to a member of the clinical team caring for you. Alternatively you can contact the Information Systems Security Manager on 0117 975 7555.

NHS Blood and Transplant

Fox Den Road, Stoke Gifford, Bristol BS34 8RR

Tel: 0117 975 7555 Fax: 0117 975 7577

Email: info.manager@nhsbt.nhs.uk

Organ Donor Line: 0300 123 23 23

Web: www.organdonation.nhs.uk