

Living Donor 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 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
- Type of Donor
- Gender
- Current and past medical history
- Other specific 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 How do you collect this information?

A4 Your personal and clinical details will be sent to us at the time you register to be a donor or after your donation has taken place. The details you provide are important as they will be used in certain cases to help us match you with a recipient, but your information will also enable us to monitor the care you receive. It is therefore vital that this information is recorded accurately and kept up to date.

After you have donated, further information will be provided to us. There is a legal requirement to record your full name, date and time of your donation, together with specific clinical information about you and the donation. Other information relating to the operation will also be sent to us.

To monitor the safety of living donation, information about your progress will be sent to us after one, two and then every five years following donation. This information provides important clinical evidence that is used to improve your care and helps to benefit future donors and transplant patients.

Q5 What will NHSBT use my information for?

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

- To participate in the National Living Donor Kidney Sharing Schemes
- To follow up your progress
- To monitor the safety of living donation
- For statistical analysis.

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

- Clinical Teams care for donors and recipients in the best possible way
- Other donors or recipients who need a transplant can benefit in the future
- Donor organs are matched and allocated to recipients in the best way.

Your personal details will not be included in any statistical analysis.

In recognition of your gift of living donation the NHS would like to show our appreciation with a specially designed silver pin which will be sent to your home address after the donation. If you do not want to participate in this recognition scheme and receive a pin please inform the person in charge of your care. Alternatively you can contact NHSBT on **0117 975 7555**.

Q6 How will my information be transferred to NHSBT?

A6 Your information will be sent to us by your Transplant Unit on forms sent through the post or by fax.

Q7 Who will see my information at NHSBT?

A7 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 use your information if you are participating in the National Living Donor Kidney Sharing Schemes
- 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.

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

A8 The information provided to NHSBT by means of a paper form will be entered onto the UK Transplant Registry to be stored and then the paper forms will be shredded securely on the premises. The following forms will also be stored on a secure document imaging system before being shredded:

- Registration information
- 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. 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 identification (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.

Q9 How long will my information be held by NHSBT?

A9 Indefinitely.

For your safety, personal details about you will be retained indefinitely on the UK Transplant Registry. This enables analysis of long-term donation and transplant outcomes which are important for ensuring the best possible care.

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

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.

If you are participating in any of 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).

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

A11 Whilst you do have a right to refuse consent, this does have implications depending on the type of living donation that is taking place.

In order to participate in the National Living Donor Kidney Sharing Schemes we need to hold your information.

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 details, this information must be reported to us by your Transplant Unit.

Also withholding information will effect the quality of the work we do on behalf of all living donors.

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

A12 For certain living donations, refusing consent for us to hold and use some key pieces of your information could mean that you are unable to donate because we are unable to identify a suitable recipient for your kidney.

But you are able to refuse consent for other information being held without your donation being affected. However, for all living donor transplants, withholding information reduces the value of our statistical analysis and the benefits for all living donors and recipients in the future.

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 donated.

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 UK Transplant Registry 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 donation and this would damage the quality of the data for future analysis and may have safety implications.

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

A14 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.

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 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.

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 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