NHS
Blood and Transplant

Giving Consent for use of your information

Your questions answered

Recipient Information

Give life
Sign up

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 safely 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 including postcode
- Date of Birth
- Ethnic Origin
- Country of Residence
- Blood Group

- Tissue Type
- Type of Donor
- Gender
- Current and past medical history
- Other specific clinical and physical 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 suitable donor organ or tissue and to ensure your long term care needs are met.**

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, together with specific clinical information about you and the donation **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 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 **On a completed paper form in the post/fax or by electronic transfer of computer records.**

Depending upon the arrangements that the hospital caring for you has established with NHSBT, your information may be sent by means of approved data collections 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 who will look at your registration information when donor organs/tissue become available that may be suitable for you.
- 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 UK Transplant Registry.

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. Paper forms will also 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 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.

Q8 How long will my information be held by NHSBT?

A8 **Indefinitely.**

For your safety, personal details about you will be retained indefinitely on the UK Transplant Registry. Your details enable us to track organs and tissues from a donor, which is important should disease be identified at a later date in donated organs/tissue.

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 care for transplantation patients and maximising transplant outcomes.

The information transferred to the majority of organisations is restricted so that it cannot identify you. There are a few exceptions to this ruling where your personal details may be sent, in order to set up collaborative links or to enable NHSBT to ensure it holds up to date information about you.

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).

Your UK Transplant Registry information may be linked to other information sources, including central NHS databases such as Hospital Episode Statistics (HES), which stores information on when people go to hospital and the care they receive. This helps to provide a fuller picture 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/tissues based on nationally agreed criteria designed to ensure safe and fair allocation. In order for you to fully participate in 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.

Please note if you refuse consent for your information to be held by NHSBT and require a corneal transplant your waiting time will not be affected.

There may be significant implications for your safety if subsequent investigation of a donor identifies the possibility of serious disease in the organ/tissue 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 to us 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 us to hold and share your information it is recommended that you discuss the full implications of this decision with a member of the medical 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 us (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. Please note if you refuse consent for some of your information to be held by NHSBT and require a corneal transplant your waiting time will not be affected.

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 our statistical analysis and the ability to inform clinical practice and benefits patients in the future.

The UK Transplant Registry, which contains information on all donors and patients who are waiting for or have received a transplant, is a unique and immensely important resource for the

NHS. All the information that we collect 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.

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 us for statistical analysis purposes.

If you request removal of your personal details this could damage the quality of the data for future analysis.

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

A13 **By informing the person in charge of your care or by contacting NHSBT directly.**

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

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