

Gwybodaeth y Derbynnnydd

**Rhoi caniatâd i
ddefnyddio eich gwybodaeth**



organdonation.nhs.uk

Atebion i'ch cwestiynau

Yn unol â Chod Ymarfer y GIG ar Gyfrinachedd, mae'n rhaid i ni ofyn i chi am ganiatâd i ddefnyddio eich gwybodaeth. Mae'r llyfryn hwn wedi cael ei gynllunio i'ch helpu chi i wneud y penderfyniad hwnnw.

C1 Beth yw Gwaed a Thrawsblaniadau'r GIG?

A1 Mae Gwaed a Thrawsblaniadau'r GIG yn awdurdod iechyd arbenigol yn y GIG. Mae'n gyfrifol am ddarparu cyflenwad effeithlon a dibynadwy o waed, organau, meinwe a gwasanaethau eraill i'r GIG. Yn Gwaed a Thrawsblaniadau'r GIG, mae'r Gyfarwyddiaeth Rhoi a Thrawsblannu Organau yn gyfrifol am sicrhau bod organau a meinwe a roddir yn cael eu paru â chleifion y mae angen trawsblaniad arnynt a'u bod yn cael eu defnyddio yn y ffordd decaf.

Yn ogystal â'r uchod mae Gwaed a Thrawsblaniadau'r GIG yn casglu gwybodaeth i'w dadansoddi i helpu i wella'r gwasanaeth trawsblaniadau, cyfraddau goroesi a helpu i gynnal diogelwch y gwasanaeth trawsblaniadau.

I'n galluogi ni i wneud hyn, mae angen i ni gael gwybodaeth o safon dda ac felly cesglir gwybodaeth ar system gyfrifiadurol o'r enw Cofrestrfa Trawsblaniadau'r DU.

C2 Beth yw Cofrestrfa Trawsblaniadau'r DU?

A2 Sefydlwyd Cofrestrfa Trawsblaniadau'r DU dros 30 mlynedd yn ôl er mwyn cadw gwybodaeth am roi a thrawsblannu organau. Mae'n system gyfrifiadurol sy'n ein helpu i baru organau/meinwe a chynnal ymchwil i wella gwasanaethau trawsblannu.

C3 Pa wybodaeth amdanaf i mae ar Gwaed a Thrawsblaniadau'r GIG ei hangen?

A3 Mae angen i ni gasglu rhai manylion personol a gwybodaeth glinigol amdanoch megis:

- Enw
- Cyfeiriad
- Dyddiad Geni
- Grŵp Gwaed
- Math o Feinwe
- Gwybodaeth glinigol arall.

Mae grwpiau ymgynghorol arbenigol Gwaed a Thrawsblaniadau'r GIG yn cytuno ar yr wybodaeth benodol y dylid ei chasglu. Cesglir gwahanol wybodaeth ar gyfer gwahanol organau/meinwe a cheir grŵp ymgynghorol ar gyfer pob un.

C4 Pam mae angen yr wybodaeth hon ar Gwaed a Thrawsblaniadau'r GIG?

A4 Anfonir eich manylion personol a chlinigol atom pan fyddwch yn cael eich cofrestru ar gyfer trawsblaniad. Mae'r manylion a roddwch yn bwysig iawn oherwydd cânt eu defnyddio i'n helpu i baru eich anghenion ag organ a roddir. Bydd angen yr wybodaeth hon hefyd os ydych yn dymuno cymryd rhan yn y Cynlluniau Rhannu Arennau Rhoddwyr Byw Cenedlaethol.

Adeg eich trawsblaniad, mae'r gyfraith yn mynnu bod eich enw llawn ynghyd â dyddiad ac amser eich llawdriniaeth yn cael eu rhoi i Gwaed a Thrawsblaniadau'r GIG.

Cofnodir eich cod post er mwyn helpu'r GIG i gynllunio'r ffordd orau o ddefnyddio gwasanaethau trawsblannu. Dim ond pan fydd hynny'n gwbl angenrheidiol y defnyddir eich cyfeiriad cartref er mwyn helpu i gadarnhau pwy ydych chi.

Bydd manylion eich grŵp ethnig, eich oed a'ch rhyw yn cael eu casglu, ynghyd â gwybodaeth glinigol arall, er mwyn helpu i fonitro ac i ddatblygu cynlluniau dyrannu organau teg ac effeithiol. Fel rhan o'r GIG, mae'n rhaid i Gwaed a Thrawsblaniadau'r GIG hefyd gasglu gwybodaeth am eich grŵp ethnig at ddibenion rheoli a monitro.

C5 Sut caiff fy ngwybodaeth ei throsglwyddo i Gwaed a Thrawsblaniadau'r GIG?

A5 Drwy anfon ffurflen bapur wedi'i llenwi drwy'r post/ffacs neu drwy drosglwyddo cofnodion cyfrifiadurol yn electronig.

Yn amodol ar y trefniadau sydd gan yr ysbyty sy'n gofalu amdanoch gyda Gwaed a Thrawsblaniadau'r GIG, efallai bydd eich gwybodaeth yn cael ei hanfon drwy ffurflenni casglu data cymeradwy, neu'n electronig, gyda mesurau diogelwch priodol.

C6 Pwy fydd yn gweld fy ngwybodaeth yn Gwaed a Thrawsblaniadau'r GIG?

A6 Dim ond aelodau penodol o staff sydd â'r hawl i weld eich gwybodaeth, ac ychydig iawn sydd â'r hawl i weld eich manylion personol:

- Y tîm gweinyddol sy'n gyfrifol am gynnal a chadw eich gwybodaeth ar Gofrestrfa Trawsblaniadau'r DU
- Staff yn y Swyddfa Ddyletswydd a fydd yn edrych ar eich gwybodaeth cofrestru pan fydd organau gan roddwyr ar gael a allai fod yn addas i chi
- Staff ystadegol, a fydd yn defnyddio eich gwybodaeth glinigol i gynnal dadansoddiad penodol, ond dim ond yn bur anaml y bydd arnynt angen gweld eich manylion personol
- Staff datblygu a chymorth TG, sy'n gyfrifol am gynnal a gwella Cofrestrfa Trawsblaniadau'r DU, ond dim ond yn bur anaml y bydd arnynt angen gweld eich manylion personol.

C7 Sut caiff fy ngwybodaeth ei storio a'i diogelu gan Gwaed a Thrawsblaniadau'r GIG?

A7 Bydd yr wybodaeth, p'un ai ei bod ar ffurflenni papur neu ar ffurf electronig, yn cael ei storio ar Gofrestrfa Trawsblaniadau'r DU. Dim ond defnyddwyr awdurdodedig sydd wedi cael caniatâd diogelwch priodol sy'n cael gweld y gronfa ddata.

Os rhoddir eich gwybodaeth i Gwaed a Thrawsblaniadau'r GIG ar ffurflen bapur, caiff yr wybodaeth ei bwydo i Gofrestrfa Trawsblaniadau'r GIG, ac yna caiff y ffurflen ei rhwygo'n fân a'i gwaredu'n ddiogel yn yr adeilad. Bydd y ffurflenni hynny sy'n darparu gwybodaeth sy'n ymwneud â'ch cofrestrriad, eich llawdriniaeth trawsblaniad a'ch ôl-ofal yn syth wedyn, yn cael eu storio'n ddiogel ar system delweddau dogfennau cyn eu rhwygo'n fân.

Mae diogelwch gwybodaeth yn bwysig iawn i ni, ac rydym wedi rhoi ystod o fesurau ar waith i ddiogelu eich gwybodaeth. Dim ond defnyddwyr awdurdodedig sydd wedi cael caniatâd diogelwch priodol sy'n cael gweld y gronfa ddata.

I osgoi unrhyw oedi wrth chwilio am eich gwybodaeth, rhoddir rhif adnabod unigryw i chi. Ble bynnag y bo modd, byddwn yn defnyddio'r rhif adnabod hwn a/neu eich rhif GIG/Mynegai Iechyd Cymunedol (CHI) mewn unrhyw ohebiaeth amdanoch chi. Dim ond at ddibenion dyrannu ac mewn achosion pan nad yw eich rhif adnabod ar ei ben ei hun yn ddigon i ddangos yn union pwy ydych chi yn ddiogel y byddwn yn defnyddio eich manylion personol (e.e. enw a dyddiad geni).

C8 Pa mor hir bydd Gwaed a Thrawsblaniadau'r GIG yn cadw fy ngwybodaeth?

A8 Am gyfnod amhenodol.

Mae gan Gwaed a Thrawsblaniadau'r GIG gyfrifoldeb cyfreithiol dros gofnodi sut caiff yr holl organau a gynigir i'w trawsblannu eu defnyddio. Mae'n bwysig felly bod modd adnabod yr holl gleifion sy'n derbyn organ. Mae cofnodion a gedwir gan Gwaed

a Thrawsblaniadau'r GIG yn golygu bod modd olrhain bob organ gan roddwr mewn achosion o ganfod clefyd rhoddwr. Mae'n hanfodol felly, er diogelwch cleifion bod gwybodaeth sy'n golygu bod modd adnabod cleifion yn cael ei chadw am gyfnod amhenodol ar Gofrestrfa Trawsblaniadau'r DU.

C9 A fydd Gwaed a Thrawsblaniadau'r GIG yn rhannu fy ngwybodaeth ag unrhyw un arall ac, os byddant, pam?

A9 Ar hyn o bryd mae Gwaed a Thrawsblaniadau'r GIG yn rhannu gwybodaeth â sefydliadau proffesiynol eraill sydd â diddordeb mewn gwella trawsblaniadau.

Bydd eich manylion hefyd yn ein galluogi i olrhain organau sydd wedi cael eu rhoi, sydd yn ofyniad cyfreithiol.

Nid oes dim o'r adroddiadau na'r cyhoeddiadau a gynhyrchir gan unrhyw un o'r sefydliadau hyn yn enwi cleifion unigol. Defnyddir yr wybodaeth at ddibenion ystadegol yn unig.

Nid oes dim o'r adroddiadau na'r cyhoeddiadau a gynhyrchir gan unrhyw un o'r sefydliadau hyn yn enwi cleifion unigol. Defnyddir yr wybodaeth at ddibenion ystadegol yn unig.

Mae'r wybodaeth a roddir i'r rhan fwyaf o sefydliadau wedi'i chyfyngu fel nad yw'n enwi cleifion unigol. Ceir rhai eithriadau i'r rheol hon pan ellir anfon manylion personol unwaith, er mwyn sefydlu cysylltiadau cydweithio. Ar ôl gwneud hyn, bydd rhif adnabod unigryw yn cael ei ddefnyddio wrth anfon rhagor o wybodaeth glinigol amdanoch chi.

Os ydych chi'n cymryd rhan yn y Cynlluniau Rhannu Arennau Rhoddwyr Byw Cenedlaethol bydd gwybodaeth yn cael ei rhannu rhwng Unedau Trawsblannu a'r Awdurdod Meinweoedd Dynol er mwyn eich galluogi chi i gymryd rhan yn y cynllun(iau).

Os ydych chi'n aelod cofrestredig Iau/Afu/Cardiothorasig bydd eich data yn cael ei rannu â Choleg Brenhinol y Llawfeddygon er mwyn gallu adolygu'r gofal bydd cleifion trawsblaniad yn ei gael.

C10 Beth fydd yn digwydd os gwrthodaf roi caniatâd i Gwaed a Thrawsblaniadau'r GIG ddefnyddio fy ngwybodaeth?

A10 Mae Gwaed a Thrawsblaniadau'r GIG yn gyfrifol am ddyrannu organau sydd wedi cael eu rhoi ar sail meini prawf y cytunwyd arnynt yn genedlaethol sydd wedi'u dylunio i sicrhau dyrannu diogel a theg. Er mwyn i chi gymryd rhan lawn yn y trefniadau cenedlaethol hyn, mae angen i Gwaed a Thrawsblaniadau'r GIG gadw eich gwybodaeth. Os nad yw eich gwybodaeth chi gennym ni, dim ond ar lefel leol bydd hi'n bosibl i chi gael eich ystyried ar gyfer organau a roddwyd. Mae hyn yn gallu lleihau'r posibilrwydd eich bod yn cael cynnig organ addas ac rydych chi'n debyg o orfod aros mwy.

Efallai fod goblygiadau sylweddol i'ch diogelwch os bydd ymchwiliad dilynol i roddwr yn nodi'r posibilrwydd bod clefyd difrifol yn yr organ rydych chi wedi'i gael. Gall peidio â chael gwybodaeth amdanoch greu anawsterau ymarferol o ran cael gafael arnoch chi.

Fel yr esboniwyd yng Nghwestiwn 4, mae'n ofynnol yn ôl y gyfraith bod Gwaed a Thrawsblaniadau'r GIG yn cael gwybodaeth benodol amdanoch. Hyd yn oed os byddwch yn gwrthod rhoi caniatâd i Gwaed a Thrawsblaniadau'r GIG ddefnyddio'r wybodaeth, mae'n rhaid cael yr wybodaeth hon gan eich uned trawsblannu.

Os ydych chi'n rhan o unrhyw un o'r Cynlluniau Rhannu Arennau Rhoddwyr Byw Cenedlaethol bydd gwybodaeth bersonol yn cael ei rhannu rhwng Unedau Trawsblannu a'r Awdurdod Meinweoedd Dynol er mwyn eich galluogi chi i gymryd rhan yn y cynllun(iau).

Os ydych chi'n ystyried gwrthod rhoi caniatâd i Gwaed a Thrawsblaniadau'r GIG gadw a rhannu eich gwybodaeth, argymhellir eich bod yn trafod goblygiadau llawn y penderfyniad hwn ag aelod o'r tîm clinigol sy'n gofalu amdanoch.

C11 Beth fyddai'n digwydd petawn yn cytuno ar rai darnau o wybodaeth yn cael eu defnyddio ond yn anghytuno ar ddarnau eraill o wybodaeth yn cael eu defnyddio?

A11 Os byddwch yn gwrthod rhoi caniatâd i Gwaed a Thrawsblaniadau'r GIG ddefnyddio rhai darnau allweddol o'r wybodaeth amdanoch (gweler yr ateb i Gwestiwn 2), gallai hyn arwain at yr un canlyniadau â phe baech wedi gwrthod rhoi caniatâd i ddefnyddio'r holl wybodaeth amdanoch. Mae'n debyg y byddwch yn gorfod aros yn hwy am drawsblaniad ac efallai na chynigir yr organ mwyaf addas ar eich cyfer.

Efallai na fyddai dal darnau eraill o wybodaeth yn ôl yn cael unrhyw effaith ar ba mor hir y byddwch yn aros am organ gan roddwr a pha mor addas yw'r organ. Er hynny, byddai dal yr wybodaeth honno'n ôl yn lleihau cryn dipyn ar werth dadansoddiad ystadegol Gwaed a Thrawsblaniadau'r GIG.

Mae Cofrestrfa Trawsblaniadau'r DU, sy'n cynnwys gwybodaeth am bob rhoddwr organau a phob claf sy'n disgwyl am drawsblaniad neu sydd wedi cael un, yn adnodd unigryw ac eithriadol o bwysig i'r GIG. Mae gan yr holl wybodaeth y mae Gwaed a Thrawsblaniadau'r GIG yn ei chasglu fudd uniongyrchol i bob claf trawsblaniad presennol ac yn y dyfodol. Mae'n hanfodol ar gyfer datblygu cynlluniau dyrannu organau mwy effeithlon a thecach ac mae'n cyfrannu at wella effeithiolrwydd trawsblaniadau a gwneud y driniaeth hon ar gael i fwy o gleifion.

Ar ben y goblygiadau hyn i chi yn bersonol, bydd dal gwybodaeth yn ôl hefyd yn effeithio ar ansawdd y gwaith rydym yn ei wneud ar ran bob claf trawsblaniad.

Os ydych yn ystyried gwrthod rhoi caniatâd i Gwaed a Thrawsblaniadau'r GIG gadw a rhannu eich gwybodaeth, argymhellir eich bod yn trafod goblygiadau llawn y penderfyniad hwn ag aelod o'r tîm clinigol sy'n gofalu amdanoch.

C12 Ga' i newid fy meddwl am roi caniatâd i Gwaed a Thrawsblaniadau'r GIG gadw a defnyddio fy ngwybodaeth?

A12 Cewch, gallwch newid eich meddwl unrhyw bryd, naill ai cyn i chi gael trawsblaniad neu ar ôl cael un.

Gallwch benderfynu cynyddu neu gyfyngu ar faint o wybodaeth y bydd Gwaed a Thrawsblaniadau'r GIG yn ei chadw a'i defnyddio, neu gallwch benderfynu tynnu eich caniatâd yn ôl yn llwyr.

Fodd bynnag, erbyn y cam hwnnw, mae'n debyg y bydd Gwaed a Thrawsblaniadau'r GIG eisoes wedi defnyddio gwybodaeth benodol amdanoch chi at ddibenion dadansoddiadau ystadegol.

Os byddwch yn gofyn am gael tynnu eich manylion personol, byddai gweddill eich gwybodaeth yn cael ei chadw ar Gofrestrfa Trawsblaniadau'r DU fel cofnod na ellid ei gysylltu â chi fel unigolyn. Ond, ni fyddai Gwaed a Thrawsblaniadau'r GIG yn gallu cael gwybodaeth bellach amdanoch ar ôl eich trawsblaniad a byddai hyn yn effeithio er gwaeth ar ansawdd y data ar gyfer dadansoddiadau yn y dyfodol.

C13 Sut alla' i ddweud wrth Gwaed a Thrawsblaniadau'r GIG fy mod yn dymuno newid fy meddwl?

A13 Drwy lenwi'r ffurflen "Newid Meddwl" a'i hanfon at Gwaed a Thrawsblaniadau'r GIG.

Ynghyd â'r ffurflen caniatâd y bydd gofyn i chi ei llenwi, byddwch hefyd yn cael ffurflen "Newid Meddwl" i'ch galluogi chi i roi gwybod i Gwaed a Thrawsblaniadau'r GIG yn uniongyrchol os byddwch yn penderfynu newid eich caniatâd gwreiddiol ar gyfer defnyddio rhywfaint o'ch gwybodaeth neu'r cwbl.

C14 Ga' i weld yr wybodaeth sydd gan Gwaed a Thrawsblaniadau'r GIG amdanaf i?

A14 Cewch. Mae Deddf Diogelu Data 1998 yn rhoi'r hawl i chi weld yr wybodaeth amdanoch chi a gedwir ar gyfrifiadur neu mewn cofnodion papur.

Gelwir hyn yn "hawl gwrthrych am wybodaeth". Os hoffech weld yr wybodaeth mae Gwaed a Thrawsblaniadau'r GIG yn ei chadw amdanoch, dylech gyflwyno eich cais yn ysgrifenedig (drwy lythyr neu e-bost) at:

Rheolwr Diogelwch Systemau Gwybodaeth

Gwaed a Thrawsblaniadau'r GIG

Cyfarwyddiaeth Rhoi Organau a Thrawsblaniadau

Fox Den Road

Stoke Gifford

Bristol BS34 8RR

E-bost: info.manager@nhsbt.nhs.uk

Mae'n bosibl y bydd y Rheolwr Gwybodaeth yn gofyn am fwy o fanylion gennych chi er mwyn gwneud yn siŵr bod Gwaed a Thrawsblaniadau'r GIG yn rhoi'r wybodaeth iawn i'r unigolyn iawn.

Ni fydd staff Gwaed a Thrawsblaniadau'r GIG yn datgelu unrhyw wybodaeth bersonol i chi dros y ffôn.

C15 Os oes gen i fwy o gwestiynau, gyda phwy y galla' i siarad?

A15 Os oes gennych fwy o gwestiynau ynghylch rhoi caniatâd, mae croeso i chi siarad ag aelod o'r tîm clinigol sy'n gofalu amdanoch. Neu gallwch gysylltu â'r Rheolwr Diogelwch Systemau Gwybodaeth ar 0117 975 7555.

Gwaed a Thrawsblaniadau'r GIG

Fox Den Road, Stoke Gifford, Bristol BS34 8RR

Ffôn: 0117 975 7555 Ffacs: 0117 975 7577

E-bost: info.manager@nhsbt.nhs.uk

Llinell Rhoddwyr Organau: 0300 123 23 23

Y We: www.organdonation.nhs.uk

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

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.

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.

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.

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.

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.

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 or 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? Indefinitely.

A8

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.

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.

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.

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

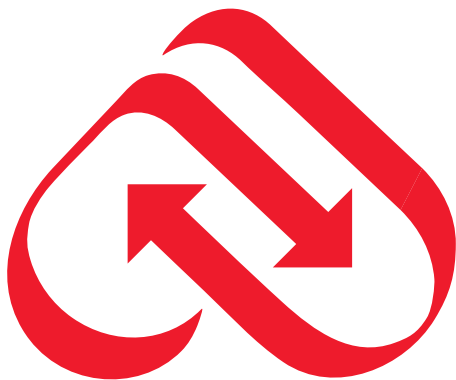
What is the UK Transplant Registry?

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.

Your questions answered

[organdonation.nhs.uk](https://www.organdonation.nhs.uk)



Recipient Information
Giving consent for use
of your information

Blood and Transplant

SHN