

# **Organ and Tissue Donation Consent Manual**

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## 1. Summary of changes

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- The pager device has been removed from use. It has been replaced by utilising the messaging service available on the new iPhone (text messages and emails). Therefore, references to the pager holder have been replaced with Donation Points of Contact (DPoC).
- Planning section 7 updated to include paediatric and infant considerations.
- In the case of a child, person who has 'parental responsibility' has been added into Highest Qualifying Relationship.
- Signpost added to SOP4859 to advise what to do in the event of technology and ODR related outages.
- Reference to INF1546 included in the Digital Information Links section. So the Specialist Nurse can access the document and give to families to access the digital link, by scanning the QR codes.

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## 2. Introduction and Purpose

Consent is required for organ and/or tissue donation in the UK with the exception of Scotland who require Authorisation. This document does not cover the specifics for Authorisation in Scotland, see further information. Specific legislation for each country/territory sets out who can provide lawful consent for organ and/or tissue donation, which are outlined below:

### England and Northern Ireland

- Human Tissue Act 2004 (HT Act);
- Also, for England the Organ Donation (Deemed Consent) Act (2019), which amends the Human Tissue (2004) Act

### Wales

- Human Tissue Act 2004 (HT Act);
- Human Transplantation (Wales) Act (2013), (HT (W) Act), which amends the Human Tissue (2004) Act

### Jersey

- Human Transplantation and Anatomy (Jersey) Law 2018.

*Note: Jersey work within their own Act, however they refer to the English HTA CoP F for guidance.*

### Scotland

- Human Tissue (Scotland) Act 2006.
- Human Tissue (Authorisation) (Scotland) Act 2019 amends the prior Act (2006) and will provide a system of 'deemed authorisation' for organ and tissue donation for transplantation purposes.

The Specialist Nurse: Organ Donation (SNOD), Specialist Nurse: Family Care (SNFC), Specialist Requester (SR), Specialist Nurse: Tissue Donation (SNTD), where applicable, must ensure that they understand the requirements of the legislation relevant in their geographical area and to their roles.

All the above roles will for the purposes of this document be referred to as Specialist Nurses (SN).

This document is to guide the SN when approaching families for organ and/or tissue donation, following assessment for donation potential. The aim is to inform the SN on practical aspects of the donation conversation which are not covered in the Human Tissue Authority Code of Practice (HTA CoP), and to signpost to relevant aspects of the HTA CoP or other resources that may be useful for application in practice.

This document is for use in conjunction with the below HTA CoP for all UK territories excluding Scotland\*:

- [HTA CoP \(Code A: Guiding Principles and the fundamental principle of consent](#)
- [Code E: Research, standards and guidance](#);
- [Code F: Donation of solid organs and tissue for transplantation, Part two: Deceased organ and tissue donation](#); and,
- [Code of Practice on the Human Transplantation \(Wales\) Act 2013](#)).

This document is also to be used in conjunction with the Mental Capacity Act (2005) legislating for England and Wales, and the Mental Capacity Act (NI) (2016) for Northern Ireland.

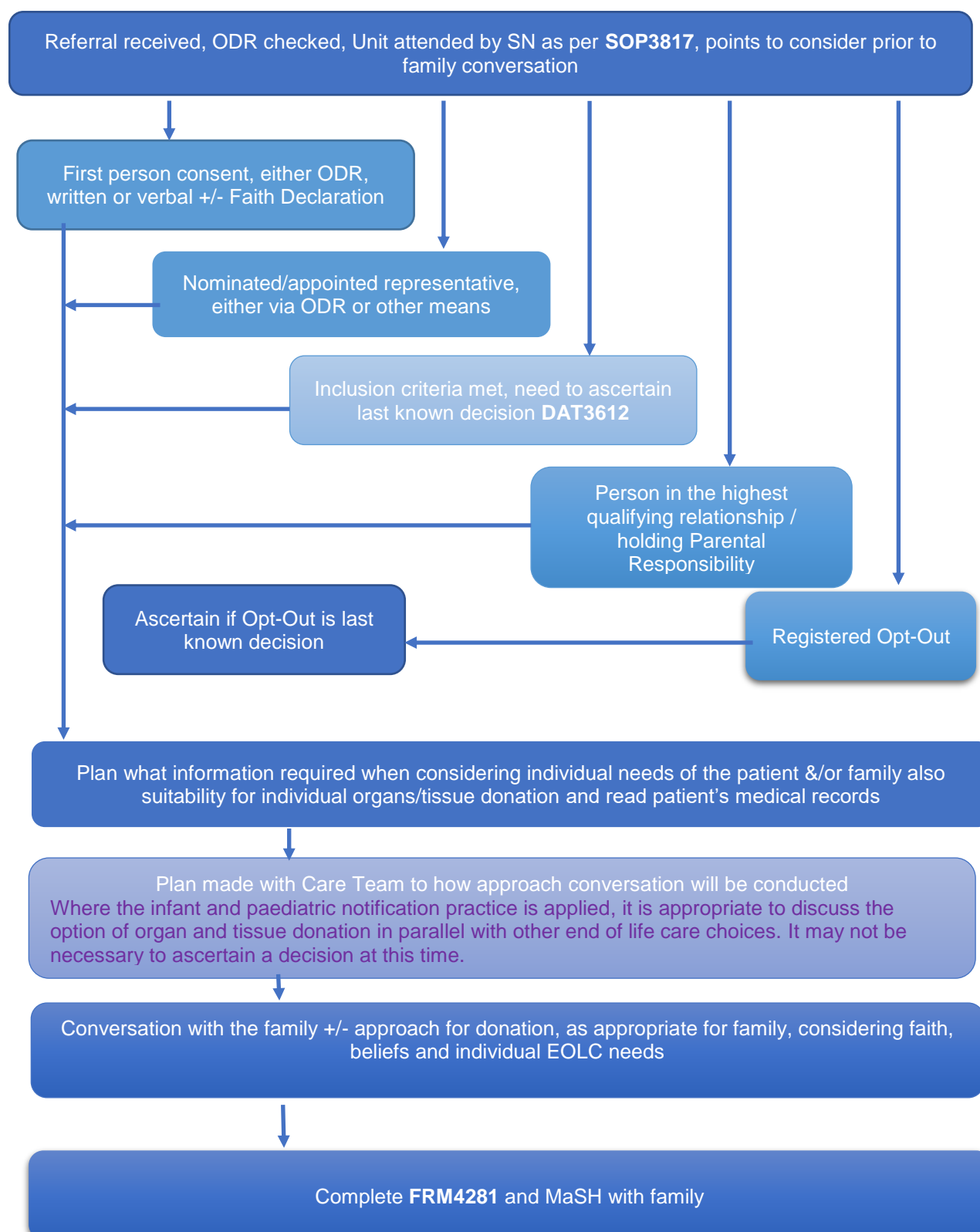
Throughout this document, paragraphs relating to English or Welsh CoP are referenced for additional information or explanation. However, these are not exclusive in each document.

## Further information

- **DAT3612** - Key Legislation Differences for Consent/Authorisation per Country / Territory.
- **INF1370 – Rationale for Authorisation - Solid Organ and Tissue Donation (Scotland).**
- **SOP5878 – Organ and Tissue Donation Authorisation Manual (Scotland)**
- \*Guidance on authorisation in Scotland:

<https://www.legislation.gov.uk/asp/2006/4/contents>

## Flowchart for approach for donation



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### **3. Considerations for planning following a referral**

#### **H.M. Coroner – Lack of objection/restrictions**

The SN should establish H.M. Coroner lack of objection (where necessary) and clarify any coronial restrictions to donation for the retrieval of organs/tissue for transplantation and removal of organs/tissue for Scheduled purposes (if applicable).

#### **Further information**

- **MPD865** - Obtaining Coroner/Procurator Fiscal Decision
- Coronial guidance: <https://www.judiciary.uk/wp-content/uploads/2017/12/guidance-no-26-organ-donation.pdf> England - 219

#### **NHS Organ Donor Register (ODR)**

The function on the ODR enables an individual to register:

- An opt in decision (including specifying organs/tissue)
- An opt in decision with a faith and beliefs declaration (including specifying organs/tissue also any faith considerations to be noted)
- An opt out decision
- A nominated/appointed representative to make a decision about organ/tissue donation on their behalf

ODR registration does not cover consent for scheduled purposes; express consent from the family is required for this and for any applicable novel/rare therapies. (*England – 64, 76 - 78, 108 – 119*)

The SN must check the ODR to ascertain if there is a registered decision regarding organ and/or tissue donation or if there is a nominated/appointed representative.

Interpreting the ODR print-out:

Several outside sources, including the Driver and Vehicle Licensing Agency (DVLA) and Boots Advantage Card, feed into it the Organ Donor Register and it must be noted that not all outside agencies present every organ /tissue as a preference to the registrant. Therefore, the organ preferences detailed on the ODR print out, should be interpreted as below:

Yes-means a decision to donate a particular organ/tissue

No-means a decision not to donate a particular organ/tissue

Not stated-warrants a discussion with the family member in the Highest Qualifying Relationship (HQR) to ascertain the individuals most recent decision regards donation

The ODR printout will display '*Not Stated*' for a particular organ/tissue when the individual has not been presented with the option. For example: the DVLA does not provide the option to opt-in for Small Bowel donation, therefore Small Bowel donation would need specific discussion with the family.

## Further information

- For checking the ODR, see **SOP3817** - Access for SN-ODs and other external approved users to the ODR.
- [In the event of technology and ODR related outages, please refer to SOP4859 for business continuity plans.](#)
- **Section 7 – Planning with the Care Team.**

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## **4. Faith Declaration**

A faith and beliefs declaration has been introduced on the ODR to provide assurance to registrants that their values in line with faith and beliefs would be acknowledged and discussed at the time of their death when organ and/or tissue donation is a possibility.

When an individual registers an 'opt-in' decision on the ODR, they have the option of completing a faith and beliefs declaration. The question is not mandatory, and the response will be displayed as either: 'yes', 'no', or 'not stated'; If registrants do respond, it can provide additional information for the SN during family discussions.

- The faith and beliefs declaration is only available to individuals who opt-in via the NHSBT website or the NHS App.
- As the faith and beliefs declaration was not introduced until December 2018; any ODR registration prior to this date will show a declaration response as 'not stated'. (England - 92-102).

If a registrant has stated 'yes', indicating faith and beliefs were important, the SN should explore the loved one's faiths/beliefs with family members and establish what (if anything) needs to be taken into consideration during the donation process and end of life care. This may include seeking advice from a faith leader.

If the faith and beliefs response is 'not stated', or even if a registrant has responded 'no', indicating that they did not require faith and beliefs to be considered, a sensitive discussion should still take place with the family. This is because faith and beliefs are unique to every individual, and SNs' overarching aim is to identify and meet these bespoke needs as part of routine person-centred care at the end of life, ensuring any individual or cultural customs are considered.

A summary of this conversation should be reflected in the medical records and documented on DonorPath. Below is an example of an ODR registration with a faith declaration:



## Registration Details

Name	Mr Thomas John Hodgett (Tom)
Address	NHS Blood & Transplant, Fox Den Road, Stoke Gifford, BRISTOL, BS34 8RR, England
Date of Birth	24/03/1994
Gender	Male
Original Sign date	31/07/2017
Original Registration Source	the NHSBT Website
Latest Registration Source	the ODR Team
Latest Registration Campaign	

## Registered Decisions

Decision	Opt-In, Any Organs and Tissue
Faith Declaration	Yes

## Previous Details

Sign Date of Change	Details
1. 13/08/2018 the ODR Team	Change: Registrant Updated, Decision Updated, Decision Updated  Faith Declaration changed From: (Not Stated) To: (Yes)
2. 13/08/2018 the ODR Team	Change: Decision Updated, Organ Updated  New Decision: (Opt-In, Any Organs and Tissue) Old Decision: (Opt-Out) Faith Declaration changed From: (Not Applicable) To: (Not Stated)
3. 06/08/2018 the NHSBT Website	Change: Decision Updated  New Decision: (Opt-Out) Old Decision: (Opt-In, Any Organs and Tissue) Faith Declaration changed From: (Not Stated) To: (Not Applicable)
4. 11/06/2018 the ODR Team	Change: Registrant Updated
5. 01/06/2018 the ODR Team	Change: Registrant Updated

## Further information

- For SNs supporting patients/families with faith/belief requirements: **DAT3743**
- For individuals registering: <https://www.organdonation.nhs.uk/helping-you-to-decide/your-faith-and-beliefs/our-faith-and-beliefs-commitment/>
- A Jewish perspective on organ donation: <https://www.organdonation.nhs.uk/helping-you-to-decide/your-faith-and-beliefs/judaism/>

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## 5. ODR Registered Opt-Out

There may be occasions where the Care Team (this will be the term used throughout the document to describe those caring for the potential donor) will need to inform a patient's family of a registered 'opt-out' decision.

It is important to recognise that in England there is the opportunity to explore if this was a last known decision, whereas in Wales, it is the role of the SN to inform the family of the 'opt-out' decision without the exploration component, (*England - paragraphs 76 to 114; Wales - paragraphs 82 to 101*).

The planning and communication of this information should be undertaken as all other donation conversations, as discussed above in section 3. A summary of any family conversations should be reflected in the medical records and documented on DonorPath.

Each opt out referral should be assessed on a case-by-case basis by the **Donation Point of Contact (DPOC)**, considering the following points:

- If SN is onsite or nearby and donor activity allows, SN could attend the opted out potential donor to discuss the opt out status (in Wales) and establish if this was a last known decision (in England)
- If no SN is nearby or it is a busy period of activity, the clinician contacts the **Donation Point of Contact (DPOC)** to discuss the case, the **Donation Point of Contact (DPOC)** coaches the clinician in the discussion to have with the family and agrees actions;
- If the family may speak to the **Donation Point of Contact (DPOC)**/ SN over the phone (whomever is most appropriate)
- If it looks like there is further information or a later decision (family advise the potential donor had changed their mind on the opt out decision), a SN will attend to have further discussions with the family. ***It is important that any opt-out 'override' is escalated to Team Manager (TM) / Regional Manager (RM) for discussion and appropriate action.***

### Opted out patients in England

In England it is permissible to inform the person in the highest qualifying relationship (HQR) of the opt-out decision, and how that decision will be respected, unless they are aware of a more recent decision.

**Suggested sentence:** *"Your husband recorded a decision on the Organ Donor Register to say he did not want to donate (specific organ/tissue/be an organ/tissue donor). That is the decision we'll be respecting, unless there is a more recent decision that you are aware of".*

### Opted out patients in Wales

In Wales an opt-out cannot be explored if this is the last known decision; the family may however volunteer information)

**Suggested sentence:** *"We have checked the ODR and your husband has recorded a decision not to become an organ donor."*

## Patients where opt out decisions are registered during their admission

Should a decision to 'opt-out' be registered during a patient's admission and whilst they were unconscious, a sensitive conversation should take place with the family to understand why this decision was registered on the patient's behalf.

**Suggested sentence:** *"Your husband recorded a decision on the Organ Donor Register to say he did not want to donate (specific organ/tissue/be an organ/tissue donor). When checking, I noted the date of the registration to be during this admission, we will respect this decision however I would like to reassure you that donation would not proceed without your support. I would like to understand why you made this decision so I can reassure you..."*

## Further information

- **DAT3612** - Key Legislation Differences for Consent per Country / Territory
- **SOP3781** - Receipt of Referral of a Potential Organ Donor

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## 6. Nominated/Appointed representatives / Highest Qualifying Relationship (HQR)/ Person/s with Parental Responsibility

All conversations regarding organ donation should take place with the person in the HQR or in the case of a child, the person/s who have parental responsibility, who will usually, but not always, be the child's parent.

A person can be omitted from the hierarchy if:

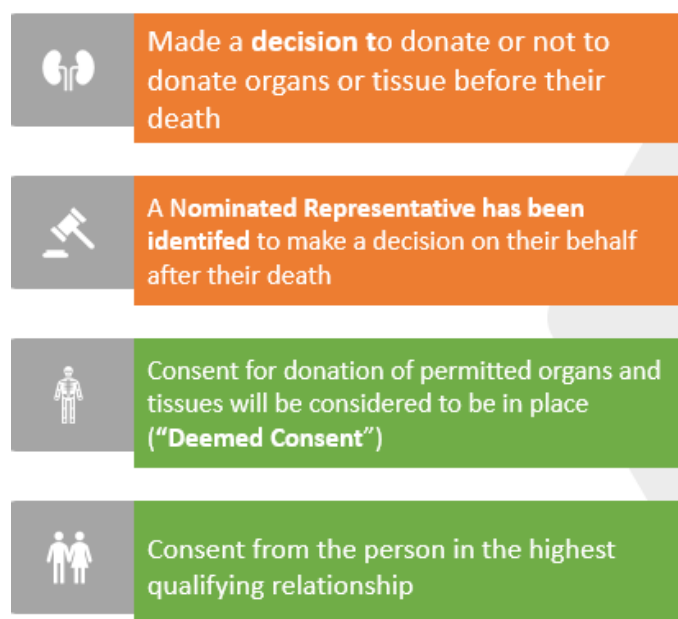
- it is not reasonably practicable to communicate with them in the time
- they do not wish or are unable to make decisions regarding consent, or are not available

In such cases, the next person in the hierarchy would become the appropriate person to give consent (*HTA CoP A England – 39*).

### Deemed Consent

Deemed consent is applicable in Wales, Jersey and England currently. The SN should consider specific inclusions and exclusions which apply to the country/territory in which they are working. The SN must be trained in the appropriate deemed consent legislation and HTA CoP to deem an individual's consent (*HTA CoP England – 103 – 239; Wales – 12-161*).

Deemed consent now sits between first person consent; nominated/appointed representatives; and consent gained from HQR. Where deeming consent is possible, this should be undertaken in conjunction with those in HQR to ascertain any last known decision the potential donor may have made as per below illustration below:



### Nominated/appointed representatives

The ODR registration will indicate if the patient has nominated or appointed a representative to make a decision about organ and/or tissue donation on their behalf.

- England and Northern Ireland: a representative can be **nominated**
- Wales and Jersey: a representative is **appointed**.

If there is a nominated/appointed representative to provide consent information to they must be the first point of contact (*HTA CoP England – paragraphs 110, 120 to 133; Wales – page 25, paragraphs 86 to 109*).

This is not the same as the Lasting Power of Attorney (LPA). The SN may come across a person acting as the LPA; however, the LPA ceases at the point of death. This is also the case with Independent Mental Capacity Advocates (IMCAs) (*HTA CoP 3 p160 England*), an IMCA is not lawfully entitled to give or refuse consent for organ donation.

Nominated/appointed representatives do not have to be registered with the ODR. Therefore, if there is no nominated/appointed representative, the SN should check during the family conversation that the family are not aware of anyone who has been nominated/appointed (either verbally or in writing) to make decisions about organ/tissue donation.

The decision to nominate/appoint a representative will be displayed on the ODR as follows:



Registration Details	
Name	Mr Timothy Test
Address	NHS Blood and Transplant Fox Den Road Stoke Gifford BRISTOL BS34 8RR England
Date of Birth	01/01/1999
Gender	Male
Original Sign date	13/09/2019
Original Registration Source	the ODR Team
Latest Registration Source	the ODR Team
Latest Sign date	13/09/2019
Registered Decisions	
Decision	Appoint Representatives
Appointed Representatives	
Appointed Representative	Mrs Teresa Test
Address	NHS Blood and Transplant Fox Den Road Stoke Gifford BRISTOL BS34 8RR England
Mobile	07777 456789
Phone	01234 567899

## Further information

For deemed consent in different countries/territories and roles of nominated/appointed representatives, see **DAT3612** - Key Legislation Differences for Consent per Country / Territory.

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## **7. Planning with the Care Team**

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The approach and donation conversation should be planned in conjunction with the Care Team and should include:

- The SN
- The Medical Practitioner and Nursing staff responsible in the Care Team
- Advocates/Counsellor/local faith representatives (where required)

The SN should plan and discuss all relevant clinical history and cause of the patient's anticipated death, clarifying mode of WLST or plan for NDT / confirmation of DNC result with the Medical Practitioner and Nursing staff.

In cases where the potential donor is a child on a Paediatric or Neonatal ITU, the Infant and Paediatric Notification Practice (see **SOP5874**) is applicable. The option of organ and tissue donation should be incorporated into end-of-life care planning as a choice in parallel with other appropriate options.

The Care Team should discuss and agree roles within the conversation, deciding **what** shall be communicated by **who**, taking into consideration **when** it is appropriate to discuss donation. Prior discussion about the timing of donation conversation allows the SN the opportunity to 'park' the conversation until the family are ready to talk about donation, where appropriate.

To ensure that the Care Team understand how the SN will conduct the conversation, the SN should discuss any communication techniques they intend to use with the family (such as 'planned pauses' or 'clean language') in this planning conversation with the Care Team. Please refer to regional planning tools, as appropriate.

Other aspects to be discussed during the planning conversation with the MDT:

- ODR status / known decisions.
- Which family members will be involved in the donation conversation (name/relationship)
- What information the family have already been given about the patient's prognosis and what their understanding is.
- Identification of key and appropriate family members to direct the donation conversation to in line with those in HQR.
- Agreement of how anticipated death will be communicated to the family and by whom.
- Planning the most appropriate time to discuss donation once the family are understanding/accepting that death is imminent or has occurred.
- Where the infant and paediatric notification practice is applied it is appropriate to discuss the option of organ and tissue donation in parallel with other end of life care choices. It may not be necessary to ascertain a decision at this time.
- Faith and belief considerations (see section 4 for full details)
- Where the donation conversation will be conducted.
- If applicable, which HCP will communicate with the coroner, as per **MPD865** (see also *HTA CoP England – 219*).
- Whether a donation discussion has already occurred and sharing of details of who was involved and the conversation's context.



- If the family have raised the topic of donation / come forward to offer donation, and what was discussed and in what context.
- For Cases where there is Police involvement, see **POL172** Release of Information in Response to Request from Police.

## Prior to speaking to the family

The SN should ascertain (utilising **POL188** and where appropriate discussing with Hub Operation) the suitability of any potential organs/tissue (e.g. multivisceral). This includes (if applicable) centre-licensed specific studies, medical history and accessing [JPAC](#) to check relevant tissue donation is suitable using specific criteria.

It is best practice for SNs to have an independent HCP to act as witness to the donation conversation, particularly the 'core information' aspect of the conversation. If there is not an independent witness available, then wherever possible, another SN should witness the conversation. If no witness is possible, document the reason for this on DonorPath and **FRM4281** - Consent - for Organ and/or Tissue Donation.

Consideration should be given if the family conversation needs to be conducted via an interpreter or translator, as per **SOP5017** - Use of Interpreter and Translator Service.

## Conducting the donation conversation virtually/by telephone

Wherever possible, the conversation should be conducted with the family face to face. This may not be possible for all cases; for example, when consenting for tissue only donation. There is increasing use of virtual communication methods to hold donation conversations with persons in HQR who are unable to visit Intensive Care Units in person, or for other circumstances where it is not possible to hold the donation conversation face to face. When communicating with families, SN should, in **order of preference**:

1. Use a method of digital communication already established by the donor hospital and get the consent/authorisation conversation witnessed.
2. **Only if the SN has set-up a unique NHSBT Apple ID using either their NHSBT email address or alternative.** use FaceTime to call the person in the HQR via their NHSBT iPad and ensure the conversation is witnessed.
3. Send the person in the HQR an invite via Teams (as described below) and join the meeting from their NHSBT iPad. As above, ensure the conversation is witnessed:
  - SN to set up a diary invite either via their NHSBT calendar (selecting Teams) or the Teams app and invite persons in the HQR using their email address.
  - Persons in the HQR receive an email and click on the 'join meeting' link; they will then be asked to give permission for Teams to use their webcam and microphone and join the meeting.
4. If none of the above is possible, or the family prefer a call, follow the normal call recording process.

If the donation conversation is conducted via telephone, the SN should refer to **SOP3649** - Voice Recording of Organ Donor Clinical Conversations (Organs) or **MPD394** - Management of the Deceased Donor Referral and Selection Process (Tissues) (where applicable).



If consent is obtained by telephone or virtual means and consent for organ, tissue and/or scheduled purposes (including research, QUOD and/or any centre licenced specific studies), is in place, as with a face-to-face approach, all research leaflets including QUOD and centre licensed specific studies MUST be offered to the family along with the organ and tissue donation Family Information Leaflets (FIL's).

It is important to confirm with the family that they agree to receiving the leaflets and donor family follow-up i.e. recipient outcomes, the specifics of their response must be documented in the free-text box on FRM5499 – [SN to DFCS](#) handover form. This may include all FIL's or specific leaflets only, depending on consent restrictions.

## **8. Communicating with family**

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Each family conversation and situation are unique, and the time period required for each conversation will vary in length.

Once the family understand there is no hope of survival and that death is imminent or has been diagnosed by Neurological criteria, the SN should then discuss the opportunity for donation.

For consent to be valid it must be given **voluntarily** by an **appropriately informed** person who has the **capacity** to understand and agree to organ and/or tissue donation (*HTA CoP A point 40*). The consent process should follow consistent national practice, based on the training undertaken by the SN.

The consent conversation should be supported by information (see **INF1164** - Tissue Consent Leaflet, **INF1165** - Organ Consent Leaflet, **INF1166** - Eye Consent Leaflet, **INF1167** - Research Consent Leaflet, if applicable) tailored to meet the needs of the family and prioritising the decisions of the potential donor. If consent is obtained via telephone or virtual means, then the family should be offered the supporting information to be sent by post.

Mental capacity of the individual can be assumed unless there is reason to believe otherwise. Any concerns of mental capacity should be discussed with the Care Team and/or TM/RM on call, if appropriate. Mental Capacity Act training is available on MyESR, which will provide further information to increase knowledge and is an optional module.

### **Information to include in family conversation (*not exhaustive*):**

- Any coronial decisions and/or planned procedures to the family, if not already communicated by the Care Team
- Faith and beliefs (see section 4 for full details) and any known EOLC decisions (*HTA CoP P92*)
- Approach sensitively for organ and tissue donation for transplantation +/- scheduled purposes (if applicable) including centre-licensed specific studies
- ODR status – opt-in / opt-out with details
- A registered decision not to donate a particular organ/tissue on the ODR should be shared with the family in order to understand if that was the patient's last known decision
- Any 'not stated' information on the ODR and explore what the family believes the patient would have wanted to happen
- Any last known decisions, to ensure ODR status reflects the decision the patient would have wanted
- In **all** DCD cases when discussing the incisions required for organ donation it must also be mentioned that there **may** be a femoral incision to aid transplantation of the organs. (Utilise usual gesture for the abdominal incision and a hand span as shown



for the femoral incision). This is to ensure the family have an awareness of this at the time of consent whether or not Abdominal Normothermic Regional Perfusion goes on to be utilised and saves a further conversation at a much later time.

- Withdrawal of consent should be discussed at the outset when consent is being sought. The practicalities of withdrawing consent and the implications of doing so should be made clear:
  - Tissue: Withdrawal of consent cannot be acted upon where tissue has already been used.
  - Organ: consent cannot be withdrawn once the retrieval of the organ from deceased donor has commenced, (*HTA CoP A point 51*).
  - Scheduled purposes: Withdrawal of consent is possible up to the point at which donated organ(s)/tissue(s) are used
- Any restrictions on areas of public concern, for example where research is known or is likely to involve the commercial sector, genetic testing or the use of human tissue in animals.
- Information included in the 'core information' on **FRM4281** (this information should be provided following verbal consent and during the completion of **FRM4281**).
- Any incision information relevant to the patient. The standard practice for organ retrieval is a mid-line incision; there may however be occasions where a different incision is required, and this will need to be communicated to the family.

## Always Explant Approach

- In order to assess the abdominal organ(s) thoroughly, in accordance with best practice guidance, the "Always Explant" approach will be adopted, carefully removing organs from the body to allow for inspection as this may impact upon the ability to transplant each abdominal organ.
- The family should be informed that if any organ, following careful inspection, is deemed unsuitable for transplantation by the lead transplant surgeon, then the organ could be considered for an NHSBT approved Research programme, if consent for scheduled purposes is in place.
- Families should be informed that consented organs which have been placed with potential recipients will be explanted to examine to ensure suitable for transplantation.

## Inclusivity

- At the outset of family conversations, the SN should check which pronouns the potential donor would have preferred (i.e. he/him, she/her, they/them), and additionally whether the family members have pronoun preferences. This could be ascertained by asking the family how their relative liked to be addressed.

- With respect to individuals who identify with a gender different to that assigned at birth e.g. Transgender. The gender that the individual identifies with should be recorded within patient demographics on DonorPath and ensure details of gender assigned at birth and any gender reassignment surgery and/or hormone therapy are clearly documented on DonorPath and Medical and Social History (MaSH) questionnaire.
- Certain hormone therapies received during gender reassignment may prohibit Tissue Donation, discussion with NRC is therefore recommended prior to offering the option of Tissue Donation.

The consent conversation should be conducted in conjunction with the Medical and Social History (MaSH) questionnaire, as per **INF947** - Rationale Document for Medical and Social History Questionnaire and **MPD875** - Patient Assessment (Family Conversation). Ensure a summary of the donation conversation is documented within the medical entry and/or DonorPath (see **MPD910**).

Individuals receive and process information in different ways, therefore using a variety of techniques during the donation conversation can aid family understanding. Visual, auditory and digital tools can be used. Links are provided in the Useful Documents section for all Information Digital Links (IDL), which are available in a number of languages, and cater for conversations with families of potential donors both on the ODR and not on the ODR. For potential donors where consent can be deemed, the IDL for donors not on the ODR is recommended.

The SN should escalate to a TM or on call RM should they need further advice or support regarding any part of the donation conversation.

A printed copy or electronic screenshot of the ODR (if available) and a copy of **FRM4281** - Consent - for Organ and/or Tissue Donation should be offered to the family. In instances where the family have received a copy of **FRM4281**– Consent for Organ and/or Tissue Donation, which is subsequently amended with additional information, the family must be offered an updated copy of the Consent form. For this reason, best practice would be for a copy of **FRM4281**– Consent for Organ and/or Tissue Donation to be sent to the family at the end of the donation process by the Donor Family Care Service (DFCS). Ensure this request is documented on the [SN to DFCS Handover](#) **FRM5499**.

If no known decision has been made about organ/tissue donation, the SN should consider if consent can be deemed during the conversation with the family by ascertaining if the patient meets the inclusion criteria, as per relevant legislative framework (*HTA CoP, England – 61, 214*); see Section 6 of this document for more information.

There is no legal requirement for the family to sign a consent form, however it is considered best practice. By signing the form, the family indicate their support for either first person consent or deemed consent, and acknowledgement of additional requests which may have been discussed (e.g. novel/rare transplants, scheduled purposes, microbiological testing and storage of material).

Sometimes families may not support a known decision regarding donation. The family have no legal right to veto a known decision regarding donation, therefore, wherever

possible the SN should try to gain family support for the decision made in life by the potential donor. (HTA CoP England – 87- 89).

Consent is only required from one family member, usually from the person in HQR, however, if a family decision is split, the SN should try to align the family (HTA CoP, England - 91). **This principle also applies to consent for children where the person/s with parental responsibility are giving consent.**

Below is an example of the consent form. Please see **DAT3784** - Consent Form Rationale for full details of how to complete all relevant sections of the form, and more details of which sections are completed under different consent circumstances.

<b>CONSENT FOR ORGANS AND TISSUE</b>		<b>Section 3</b>
Complete <b>Section A</b> if the patient is giving/has given <b>first person consent</b> <b>OR</b> Complete <b>Section B</b> if consent is given by <b>nominated/appointed representative</b> or the <b>person ranking highest in the qualifying relationship</b> <b>OR</b> Complete <b>Section C</b> if consent is able to be <b>deemed</b> in accordance with the appropriate legislation *		
<b>Section A</b> The patient named in <b>Section 2</b> gave/gives* first person consent for the donation of the following organs/tissue for transplantation via the Organ Donor Register/donor card/expressed wish/will* (*Delete as appropriate) Healthcare Professional signature <span style="border: 1px solid black; display: inline-block; width: 300px; height: 20px; vertical-align: middle;"></span>		
<b>Section B</b> <div style="display: flex; justify-content: space-between; align-items: flex-end; margin-top: 10px;"> <div style="border: 1px solid black; width: 25%; height: 20px;"></div> <div style="text-align: center;">the</div> <div style="border: 1px solid black; width: 25%; height: 20px;"></div> <div style="text-align: center;">of</div> <div style="border: 1px solid black; width: 30%; height: 20px;"></div> </div> <div style="display: flex; justify-content: space-between; font-size: small; margin-top: 5px;"> <span>(Name)</span> <span>(Relationship to the patient)</span> <span>(Patient's name)</span> </div> <p>Gives consent for the donation of the following organs/tissue for transplantation as detailed on page 2 of this form.</p> <div style="display: flex; justify-content: space-between;"> <div style="width: 60%;"> <p>Did the patient have a nominated/appointed representative? <span style="margin-left: 20px;"><b>Yes</b></span> <span style="margin-left: 20px;"><b>No</b></span></p> <div style="display: flex; justify-content: space-around;"> <input type="checkbox"/> <input type="checkbox"/> </div> <p>Was consent obtained from the person ranking highest in the qualifying relationship? <span style="margin-left: 20px;"><b>Yes</b></span> <span style="margin-left: 20px;"><b>No</b></span></p> <div style="display: flex; justify-content: space-around;"> <input type="checkbox"/> <input type="checkbox"/> </div> <p>If no, please give details below:</p> <div style="border: 1px solid black; height: 20px; width: 50%; margin-top: 5px;"></div> </div> <div style="width: 35%; font-size: x-small;"> <p>Persons are ranked in the following descending order:</p> <p>A) spouse or partner (including civil or same sex partner)</p> <p>B) parent or child</p> <p>C) brother or sister</p> <p>D) grandparent or grandchild</p> <p>E) niece or nephew</p> <p>F) stepfather or stepmother</p> <p>G) half-brother or half-sister</p> <p>H) friend of long standing</p> <p>Jersey only – before (it) For person of whom a care order is made: - the Minister for Health and Social Services</p> </div> </div>		
<b>Section C</b> <b>For Countries and Territories where Deemed Consent applies</b> The patient named in <b>Section 2</b> is deemed to have given their consent to deceased organ and/or tissue donation under the applicable legislation*. Please insert Country/Territories ..... Healthcare Professional signature <span style="border: 1px solid black; display: inline-block; width: 300px; height: 20px; vertical-align: middle;"></span>		

## Further information

- Mental capacity and organ/tissue donation consent: HTA CoP F (England 33, 58, 111, 176, 178 – 184, Wales 62 to 74).
- Inclusion criteria for deemed consent: **DAT3612**
- Rationale and assistance in completion of Consent Form: **DAT3784**

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## **9. Approach for Tissue Only Donation**

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The National Referral Centre (NRC) for Tissue Donation has Service Level Agreements with Alliance Site hospital trusts whereby they notify the NRC by email referral of any deaths that have occurred. This enables the SN to clinically assess suitability for potential donation and to make the initial approach to the family to discuss possible donation options.

Approaching families for tissue donation only should be undertaken by SNs trained or working under direct supervision. The NRC conducts all deceased tissue donor approaches and consent interviews by telephone. This is referred to as a Specialist Family Approach, with the flow as follows:

- Salutation and association to NHS Blood and Transplant
- Condolences offered
- Ascertain pre-emptive information received
- Bridge to donation option as agreed by NRC Team

The SN must ascertain if the potential tissue donor has registered a decision on the ODR regarding tissue donation prior to the family conversation. The family must be informed of any decision made.

The approach and consent conversation should be with the person in the HQR (when deemed consent does not apply) **or person/s with parental responsibility in the case of a child**. The approach should be prioritised so that time is allowed for the family to discuss their preferred outcome and to enable tissue donation to be facilitated. Conversations with families should be documented on **FRM942** - Deceased Referral History Sheet.

The aim of the initial approach conversation should be to gain agreement with family to discuss tissue donation, when timing is convenient. This may be during the same conversation or may be later, providing timescales would still allow the retrieval of tissues to proceed.

Points to be considered when arranging a time for the consent conversation:

- What eye/tissue donation entails
- Can consent for tissue donation be deemed
- How much time the person in the HQR / **or person/s with parental responsibility in the case of a child needs to consider their options**
- Time of death to the time the referral is received
- The availability of eye retrievers and donation teams
- Coroner and Pathologist consultation and permissions
- Death Certification
- For Tissue Research process see **MPD401**

If the family do not agree a time to be contacted, the national pager number (0800 432 0559) should be offered so that they are able to contact the National Referral Centre.

The family should be given adequate opportunity to ask questions, clarify information and voice concerns which should be answered in an appropriate manner. If donation is declined



by the family they should be supported, provided contact details for the NRC, should they change their decision; ensuring they are aware of time constraints.

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## **10. Other Donation Considerations**

### **Paediatric donation**

When person/s with PR are unable to make decisions, for example incapacitated in the same incident, only then can you defer to the HQR.

- England, Northern Ireland and Wales: HT Act and HT (W) Act defines a child as being under the age of 18.

If a child is considered competent and has expressed a decision regarding donation, this legally is no different from that of an adult. First person consent is possible however is not mandatory and should be considered on a case-by-case basis.

**For example:** A child registers a decision on the ODR aged 17 years and dies before they turn 18 years; or a child who is signed onto the ODR aged 3 years by their parents and dies aged 17 years. Both would involve a sensitive family discussion.

### Assessing competence of a child:

Code A 131 state that the HT Act is 'silent' on how to assess a child's competence. The responsibility for assessing competence rests with the person seeking consent. The Gillick test (paragraph 88) is however considered in Code A to be the appropriate benchmark. The role of the SN is not assessing competence; in practice this will be a discussion with the family to establish if the child understood the meaning of organ and tissue donation.

- An ODR registration should not be confused with age restrictions under deemed

### **Further information**

- **SOP5874** – OTDT Paediatric Manual
- HTA Code A (*England – 67, 68, 72, 87, 111, 147 to 151, 156; Wales – 14, paras 30–43; 62, paras 56–59*).
- UK Paediatric and Neonatal Deceased Donation – A Strategic Plan  
<https://nhsbtdbe.blob.core.windows.net/umbraco-assets-corp/15402/paediatric-and-neonatal-deceased-donation-strategy-final.pdf>

### **Prohibition of Payment**

The HT Act and HT (W) Act prohibits any reward being offered or accepted in exchange for an organ or tissue. In England, Wales and Northern Ireland, nobody may offer payment for an organ or tissue. (Wales – Page 56, Paragraphs 15 to 19).

### **Directed Donation**

This is on a case-by-case basis and investigated further by the SN with guidance from the TM or RM on call (*CoP England – page 85; Wales – page 63, para 64*). See **POL200** - Introduction to Patient Selection and Organ Allocation Policies Appendix 1.



## Restricted Donation

Organs and tissue are matched on a best match, greatest need ratio. Families are unable to restrict the types of recipients who may receive allocated organs based on protected characteristics under the Equality Act (2010) or based on language or clinical condition. An example of this would be if a family did not want the liver to be donated to a recipient who has Alcoholic Liver disease, they would not be able to restrict this type of recipient if they were deemed to meet the best match/greatest need criteria (*CoP England – pages 44-45*).

## Request for Repatriation of Organs and/or Tissue *to the body of the deceased*

Family members for faith related/other reasons may request any untransplantable organ/tissue to be returned to the body of the deceased. Such requests are the exception, rather than the norm and usually not possible, due to practical and logistical considerations. Any such requests must be discussed with the TM/RM, prior to making any commitments to the family, as repatriation is not routine practice. Should repatriation be possible, consideration must be given to organ traceability and recording the details on the HTA A form/operation records/medical records in DonorPath.

## Withdrawal of Consent for Donation

The family may withdraw consent for all or any specific organ(s)/tissue following the consent conversation until the point of knife to skin. The SN must immediately inform Hub Operations of the exact details and document this in the donor record and/or on the additional pages of **FRM4281** - Consent - for Organ and/or Tissue Donation if during the donation process (*CoP England – page 216; Wales – page 14 para 35, page 55 para 10 iii, page 60 para 45, page 63 para 62 iii*).

### Suggested sentence to be documented on FRM4281 and/or DonorPath:

Further conversations with (name), family member of (potential donor). After further reflection they feel unable to support donation due to (reason). I have thanked (name) for considering donation and will follow up with them via letter within 15 days to offer thanks and signpost to any further support required, if applicable.

## Scheduled Purposes

Consent for scheduled purposes should be obtained by following **DAT3784** and specific centre-licensed study SOPs. Deemed consent does not cover consent for scheduled purposes, however consent for organs and/or tissues for scheduled purposes, is still possible. This requires explicit consent from the family member in the Highest Qualifying Relationship (HQR) *or in the case person/s with parental responsibility*.

## Withdrawal of Consent for Scheduled Purposes

The family may withdraw consent for all or any specific organ(s)/tissue for Scheduled Purposes at any point until the organ/tissue is used. The SN must immediately inform Hub Operations of the exact details and document this in the donor record and **FRM4281** - Consent - for Organ and/or Tissue Donation, if during the donation process. Hub Operations then need to contact researchers who have received discarded organs/tissue. The SN may need to contact the researchers directly if the family have withdrawn consent for a centre-licensed specific study.

### Suggested sentence to be documented on consent form and/or DonorPath:

Further conversations with (name), family member of (potential donor). After further reflection they feel unable to support scheduled purposes/research due to (reason). I have thanked (name) for considering donation and will follow up with them via letter within 15 days to offer thanks and any ongoing support required.

Samples are likely to have been sent for QUOD; the first sample obtained is usually at the point of the patient's admission to hospital. The second sample is sent to the laboratory along with the tissue typing samples. The QUOD withdrawal of consent information is in **SOP5930**- (QUOD) Donor family conversation and Collection of Samples for Quality in Organ Donation Research in England/ Wales/Northern Ireland – Specialist Nurse Role and **INF1203** - QUOD non-proceeding donors process flow.

## Novel/Rare Organs for Transplant

There is the opportunity for some organs to be considered for transplant which are not considered 'usual' and classed as rare (e.g. Uterus, Limb) or novel (e.g. Face). Factors such as geographical location to transplanting hospital are considered under these circumstances, and local training is provided for obtaining consent for these organs (*CoP England page 87, 199–202; Wales page 34, 135-137*). These organs are **not** covered under deemed legislation and expressed consent must be obtained and documented on the consent form in applicable cases.

Novel or Rare transplants require specific training prior to consent being sought by SNs; always refer to relevant SOPs for further information and refer to Secondary Legislation ([https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/867918/Government\\_response\\_to\\_opt-out\\_organ\\_donation\\_-\\_organs\\_and\\_tissues\\_excluded\\_from\\_the\\_new\\_system.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/867918/Government_response_to_opt-out_organ_donation_-_organs_and_tissues_excluded_from_the_new_system.pdf))

## Removal of Organs purely for Scheduled Purposes (consent form research section question 3a)

There is an opportunity for removal of untransplantable organs for scheduled purposes in a hospital listed as a satellite hospital on the NHSBT HTA research licence (12608). **INF1081** - List of NHS Hospitals with a Satellite licence Under the Extended NHSBT Research Licence (12608) should be reviewed to ensure the donating hospital is included. The family must not be approached if the hospital is not listed. Utilise **INF1497** INOAR FAQ sheet

**SOP5567** - Process for Consent for Removal and Storage of Organs/Tissue/Samples for Research and Other Scheduled Purposes in QUOD Licensed Hospitals gives process management guidance and which untransplantable organs are currently in scope (*CoP England pages 35-36, 221-226; Wales page 40-41, 160-161, 168*).

## Centre Specific Studies

All NHSBT approved centre-licensed specific study requires consent documented on **FRM4281** - Consent - for Organ and/or Tissue Donation: research section, question 3b. Only a SN who has received full training in the relevant supporting SOP, where applicable, may approach the family for this.

## Other Deceased Donation

During family conversations they may request further information on other cells, tissues or whole body which may be donated following death, for example [sperm](#), eggs or body for medical research. For any of these to occur, first person consent must be in place prior to death and compliant with the relevant legislation or HTA CoP for this to be valid.

## Further information

- Scheduled purposes: **DAT3784**
- QUOD: **SOP5930** - Process for Consent for Removal and Storage of Organs/Tissue/Samples for Research and Other Scheduled Purposes in QUOD Licensed Hospital
- QUOD: **INF1203** QUOD non-proceeding donors process flow.
- Donation during pregnancy: **MPD891**

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## **11. Useful Information**

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### **Associated Documents**

**POL:**

**POL172** – Release of Information in response to request from police

**POL188** – Clinical contraindications to approaching families for possible organ donation

**POL200** - Introduction to Patient Selection and Organ Allocation Policies

**MPD:**

**MPD865** - Obtaining Coroner/Procurator Fiscal Decision

**MPD394** - Management of the Deceased Donor Referral and Selection Process

**MPD875** - Patient Assessment (Family Conversation)

**MPD385** - Good Documentation Practice

**MPD891** - Establishing Pregnancy Status and Pregnancy in Donation

**MPD910** - Medical Records Entry for Proceeding and Non-Proceeding Organ and/or Tissue Donation

**MPD401** - The Retrieval, Logging, Storage, Supply, Despatch and Disposal of Tissues for Non-Clinical Use

**SOP:**

**SOP4859** - [Emergency Event and Security Procedures - Hub Operations](#)

**SOP5017** - Use of Interpreter and Translator Service

**SOP3649** - Voice Recording of Organ Donor Clinical Conversations

**SOP5567** - Process for Consent for Removal and Storage of Organs/Tissue/Samples for Research and Other Scheduled Purposes in QUOD Licensed Hospitals Only

**SOP5930** - (QUOD) Donor family conversation and Collection of Samples for Quality in Organ Donation Research in England/ Wales/Northern Ireland - Specialist Nurse Role

**SOP3781** - Receipt of Referral of a Potential Organ Donor

**SOP3817** - Access for SN-ODs and other external approved users to the NHS Organ Donor Register (ODR)

**SOP5874** – OTDT Paediatric Manual

**SOP5878** – Organ and Tissue Donation Authorisation Manual (Scotland)

**INF:**

**INF947** - Rationale Document for Medical and Social History Questionnaire

**INF1497** - INOAR FAQ Sheet

**INF1164** - Tissue Consent Leaflet

**INF1165** - Organ Consent Leaflet

**INF1166** - Eye Consent Leaflet

**INF1167** – Organ Donation and Tissue Donation for research

**INF1203** - QUOD non-proceeding donors process flow

**INF1081** - List of NHS hospitals with a satellite licence under the NHSBT extended research licence (12608)

**INF1370** – Rationale for Authorisation - Solid Organ and Tissue Donation (Scotland)

**INF1546** – [Organ Donation - Information \(Digital\) Link](#)

**FRM:**

**FRM942** - Deceased Referral History Sheet

**FRM4281** - Consent - for Organ and/or Tissue Donation

**FRM5499** - [SN](#) to DFCS Handover Form

## DAT:

**DAT3612** - Key Legislation Differences for Consent/Authorisation per Country/Territory

**DAT3743** - Faith, Beliefs and End of Life care

**DAT3784** - Rationale Document for Organ and Tissue Donation Consent

## Information Digital Link (IDL) INF1546

Not on ODR

Organ donation - English <https://youtu.be/cf4UA-MveCU>

Organ donation - Scottish <https://youtu.be/y3qgQofJatM>

Organ Donation - Bengali <https://youtu.be/it57jaytc1k>

Organ donation - Gujarati <https://youtu.be/0RnBY7nZwGE>

Organ donation - Punjabi <https://youtu.be/1lrAjTln-x0>

Organ donation - Urdu <https://youtu.be/up4ca2c9mls>

Organ donation - Polish <https://youtu.be/maRrobYOczc>

## On ODR

Organ Donation - English <https://youtu.be/MB8POs3p-Fs>

Organ donation - Scottish <https://youtu.be/luYe7pLgiM0>

Organ donation - Bengali <https://youtu.be/8oIGbO2-0qw>

Organ donation - Gujarati <https://youtu.be/6U8elAyesVI>

Organ donation - Punjabi <https://youtu.be/0pC2osEgRD8>

Organ donation - Urdu <https://youtu.be/M3WW0t4QsMc>

Organ donation - Polish <https://youtu.be/pXkm5sWcXvU>

## Incident Reporting

An incident may occur within the chain of organ donation, transplantation and scheduled purposes for which there is a legal requirement to report. There may also be an incident from which we could benefit from organisational or national learning. These incidents should be reported to the OTDT Directorate of NHSBT: [NHSBT Incident Submission Form](#)

## Good Documentation Practice (GDP) MPD385

SNs must follow GDP guidelines in MPD385 when completing **FRM4281** - Consent - for Organ and/or Tissue Donation and subsequent notes in the patient's donor record.

**Example:** During the family conversation the HQR is unaware of a known decision and all other criteria is met for deemed consent. The Specialist Nurse would sign section C on **FRM4281**. Following this conversation, the family later state that they had found a donor card, denoting a known decision. The Specialist Nurse would enter the new information on Additional Information pages, dating, timing and signing the conversation and leave the original deemed section completed on the form.

## Resources

Human Tissue Act 2004

[http://www.legislation.gov.uk/ukpga/2004/30/pdfs/ukpga\\_20040030\\_en.pdf](http://www.legislation.gov.uk/ukpga/2004/30/pdfs/ukpga_20040030_en.pdf)

## Consent and authorisation

Clinical guidance around gaining consent and authorisation from a donor family

<https://www.odt.nhs.uk/deceased-donation/best-practice-guidance/consent-and-authorisation/>

<https://www.odt.nhs.uk/deceased-donation/best-practice-guidance/consent-and-authorisation/>

### Human Tissue Authority Codes of Practice: -

- Code A Guiding principles and the fundamental principle of consent  
<https://content.hta.gov.uk/sites/default/files/2020-11/Code%20A.pdf>
- Code F Donation of solid organs and tissue for transplantation Part two: Deceased organ and tissue donation [Code F part 2.pdf \(hta.gov.uk\)](#)

The Quality and Safety of Organs Intended for Transplantation Regulations 2012

<https://www.legislation.gov.uk/uksi/2012/1501/made>

Human Transplantation (Wales) Act 2013

<https://www.legislation.gov.uk/anaw/2013/5/contents>

Human Tissue Authority Code of Practice on the Human Transplantation (Wales) Act 2013

<https://content.hta.gov.uk/sites/default/files/2020-11/Code%20of%20Practice%20on%20the%20Human%20Transplantation%20%28Wales%29%20Act%202013.pdf>

The Human Tissue and Transplantation (Bailiwick of Guernsey) Law 2020

<https://www.gov.gg/CHttpHandler.ashx?id=124322&p=0>

Organ Donation (Deemed Consent) Act 2019

<http://www.legislation.gov.uk/ukpga/2019/7/contents/enacted>

The Human Tissue (Permitted Material: Exceptions) (England) Regulations 202

<http://www.legislation.gov.uk/uksi/2020/521/made>

Mental Capacity Act 2005

<http://www.legislation.gov.uk/ukpga/2005/9/contents>

Mental Capacity Act (NI) 2016

<http://www.legislation.gov.uk/nia/2016/18/contents>

The Quality and Safety of Organs Intended for Transplantation – a Documentary Framework

<http://www.legislation.gov.uk/uksi/2012/1501/contents/made>

NICE guidance - Organ Donation for transplantation 2011

**Controlled if copy number stated on document and issued by QA**

(Template Version 07/10/2021)



<https://nhsbtdbe.blob.core.windows.net/umbraco-assets-corp/1336/nice-organ-donation-short-version-2011.pdf>

NHSBT: Consent and authorisation: the family approach

<https://www.odt.nhs.uk/deceased-donation/best-practice-guidance/consent-and-authorisation-the-family-approach/>

A code of practice for the diagnosis and confirmation of Death 2008

<https://nhsbtdbe.blob.core.windows.net/umbraco-assets-corp/1338/aomrc-death-2008.pdf>

The diagnosis of death by neurological criteria in infants less than two months old (2015)

[https://www.rcpch.ac.uk/sites/default/files/2019-03/2015\\_dnc\\_-\\_full\\_clinical\\_guideline.pdf](https://www.rcpch.ac.uk/sites/default/files/2019-03/2015_dnc_-_full_clinical_guideline.pdf)

UKDEC guidance - An Ethical Framework for Controlled Donation After Circulatory Death

<https://nhsbtdbe.blob.core.windows.net/umbraco-assets-corp/1330/academyof-royal-colleges-ethical-framework-controlled-donation-circulatory-death-summary-2011.pdf>

Ethical issues in paediatric organ donation: a position paper

<https://www.aomrc.org.uk/reports-guidance/ukdec-reports-and-guidance/ethical-issues-paediatric-organ-donation-position-paper/>

Human Transplantation and Anatomy (Jersey) Law 2018

<https://www.jerseylaw.je/laws/enacted/Pages/L-27-2018.aspx>

UK Paediatric and Neonatal Deceased Donation: A Strategic Plan <https://www.odt.nhs.uk/odt-structures-and-standards/key-strategies/paediatric-and-neonatal-donation-strategy/>

Equality Act (2010)

<http://www.legislation.gov.uk/ukpga/2010/15/contents>

Chief Coroner Guidance

<https://www.judiciary.uk/wp-content/uploads/2017/12/guidance-no-26-organ-donation.pdf>

Timely Identification and Referral of Potential Organ Donors

<https://nhsbtdbe.blob.core.windows.net/umbraco-assets-corp/1337/timely-identification-and-referral-of-potential-organ-donors-nhsbt.pdf>

Approaching the families of potential organ donors: an audio-visual guide for hospital clinicians

<https://www.odt.nhs.uk/deceased-donation/best-practice-guidance/consent-and-authorisation-the-family-approach/>

Approaching the families of potential organ donors

[https://nhsbtdbe.blob.core.windows.net/umbraco-assets-corp/1462/family\\_approach\\_best\\_practice\\_guide-1.pdf](https://nhsbtdbe.blob.core.windows.net/umbraco-assets-corp/1462/family_approach_best_practice_guide-1.pdf)

Faith Statement on ODR

<https://www.organdonation.nhs.uk/helping-you-to-decide/your-faith-and-beliefs/our-faith-and-beliefs-commitment/>

A Jewish perspective on organ donation

<https://www.organdonation.nhs.uk/helping-you-to-decide/your-faith-and-beliefs/judaism/>

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## **12. Glossary**

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**Appointed/Nominated representative** – England - page 87

**Care Team** – All HCP involved in the patient's care

**CLOD** – Clinical Lead Organ Donation.

**CoP** – Code of Practice which is informed by the relevant legislation

**DBD** - Donation following Brain Death.

**DCD** – Donation following Circulatory Death.

**Deemed Consent** – England page 85, Wales page 51

**DHSC** – Department of Health and Social Care

**DNC** – Death using Neurological Criteria

**DonorPath** – Secure electronic system is utilised to register potential organ donors and upload donor characteristics prior to organ offering using an iPad or PC. DonorPath also creates and stores an electronic donor record of the donation process.

**Donor Record** – Paper and electronic (DonorPath) file

**DFCS** – Donor Family Care Service.

**ED** – Emergency Department.

**EOLC** – End of Life Care

**EOS** – Electronic Offering System.

**EOS Mobile** – Electronic Offering System used by Transplant Centres to review the Donor Characterisation information.

**Family** – England page 47

**Genius Scan** - Genius Scan IPAD Application associated with NHSBT authorised IPADS.

**HCP** – Health Care Professional.

**HT Act** – Human Tissue Act, 2004

**HT (W) Act** – Human Transplantation (Wales) Act 2013

**HTA** – Human Tissue Authority.

**HQR** – Highest Qualifying Relationships

**HUB Operations** – To receive information communicated by the Specialist Nurse in relation to box/tag numbers for kidneys. To arrange transport for kidneys and pancreas. Referred to in this document as Hub Ops.

**ICU** – Intensive Care Unit.

**IMCA** – Independent Mental Capacity Advocate

**INOAR** - increasing the number of organs available for research

**Lead Retrieval Surgeon** - Refers to the Lead Surgeon for Abdominal and/or Cardiothoracic retrieval.

**MDT** – Multi Disciplinary Team – refers to all HCPs/Advocates/Counsellors and local faith representative(s), where relevant, involved in the patient's care

**Medical Practitioner** – facilitates the WLST process.

**NDT** – Neurological Death Tests

**NHSBT** – NHS Blood and Transplant.

**NORS** – National Organ Retrieval Service.

**NRC** – National Referral Centre

**NTLC** – National Transplant Liaison Co-ordinator.

**OD (DC) Act** – Organ Donation (Deemed Consent) Act, 2019

**ODR** – England – page 88; Wales page 51

**ODST** – Organ Donation Services Team.

**ODT** – Organ Donation and Transplantation, a directorate within NHSBT.

**PR** – Parental Responsibility

**Patient** – any patient referred to NHSBT as a potential organ and/or tissue donor.

**PID** – Patient Identifiable Data.

**QUOD** - Quality in Organ Donation

**RCPOC** – Recipient centre point of contact –a nominated nurse or surgeon who is contacted to discuss and consider an organ offer for their transplanting centre.

**RIL** – Relative Information Leaflets – to aid understanding of the organ and/or tissue donation process for families.

**RM** – Regional Manager.

**SN (Specialist Nurse)** - For the purpose of this document all SNODs, SNOD - FCs, SRs and SNTD, will be referred to as SN, unless otherwise stated. England – page 90, Wales page 52

**TM** – Team Manager within ODST.

**WLST** – Withdrawal of Life Sustaining Treatment.

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