

# OTDT Paediatric Manual

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## ***Summary of changes***

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Correction of errors to flowchart in figure 1 caused by formatting on previous version.

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## ***Introduction***

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The purpose of this document is to provide guidance to the Specialist Nurse (SN) and/or Lead Nurses / Regional Heads of Nursing (LN/RHN) throughout the Paediatric/Neonatal Donation Process.

The donation process is clearly set out in MPD/SOP guidance, this remains unchanged and applies to the donation process where the donor is a child. However, there are specific considerations which the SN need to be aware of when facilitating donation from children. Setting these out more clearly in this SOP should assist the SN in the facilitation of organ donation from this cohort of patients.

Organ donation opportunities from infants under 6 months of age and neonates continue to be limited; SN are encouraged to work to optimise any opportunity and support units to determine death by neurological criteria (DNC) whenever a patient meets the criteria to optimise these options.

The infant and paediatric notification practice should be applied for all notifications from PICU areas (and NICU where established) in order to ensure suitability for organ and tissue donation can be assessed and any opportunity incorporated into end-of-life care planning discussions in parallel with additional options the family maybe considering.

The flow charts should be used in conjunction with the stated controlled documents and additional guidance documents as referenced.

All users of this Standard Operating Procedure must act in accordance with legislative frameworks in place across all territories of the United Kingdom where deemed consent/authorisation applies. Please note that deemed consent legislation does not apply to donors under the age of 18 years in England Wales and Northern Ireland and 16 years in Scotland, and/or scheduled or other purposes.

There is a potential need for additional support strategies for all professionals involved in the process, including unit staff, National Organ Retrieval Service (NORS) teams, theatre staff and donation services teams (ODST) and this should be considered fully following each process.

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## ***Associated Documents***

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### **POLs:**

**POL188** - Clinical Contraindications to Approaching Families for Possible Organ Donation

**POL186** - Kidney Transplantation Deceased Donor Organ Allocation

### **MPDs:**

**MPD1043** - NORS Standards

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

**MPD845** - Family Care

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

### **SOPs:**

**SOP5003** - Suitability Assessment Guidance for Specialist Nurses (Adult DCD and Paediatric DCD/DBD)

**SOP4746** - DCD Heart Donation Process

**SOP5024** - Tissue Donation Manual

**SOP5981** – Tissue and Eye Donation Information for Consenting Nurses

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

**SOP5931** - (QUOD) Donor Family Conversation and Collection of Samples for Quality in Organ Donation Research in Scotland – Specialist Nurse Role

**SOP3781** - Receipt of Referral of a Potential Organ and/or Tissue Donor

**SOP5499** - Theatre Manual for Deceased Organ Donors

**SOP5048** - Forearm Sentinel Skin Flap Donation to Detect Rejection

**SOP5818** - Organ and Tissue Donation Consent Manual

**SOP5878** – Organ and Tissue Donation Authorisation Manual

**SOP5869** - SARS-CoV-2 Deceased Organ Donor Screening

**SOP5567** - Process for Consent for Removal and Storage of Organs/Tissues/Samples for Research and other Scheduled Purposes in QUOD Licensed Hospitals within England, Wales and Northern Ireland.

**SOP5663** – Process for Authorisation for Removal and Storage of Specific Organ/Tissue/Samples for Research and Other Purposes within Scotland

**SOP6039** – Abdominal Wall and Abdominal Fascia Transplantation

**SOP6405** - Donor Characterisation Manual

**SOP6514** – Clinical Microbiology Manual

## **INFs:**

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

**INF1081** - List of NHS Hospitals with a Satellite License Under the Extended NHSBT Research License (12608)

**INF1503** - Regional Research Studies Requiring Centre/Centre-Licensed Specific Authorisation/Consent

**INF1370** - Rational for Authorisation - Solid Organ and Tissue Donation

**INF1600** - Child Transplant Recipients and Children Awaiting Transplant - Guidance for Sharing your Child's Story

**INF1602** - Child Donors - Guidance for sharing your child's story.

## **DATs:**

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

## **FRMs:**

**FRM5510** - Infant Donor Assessment and Organ Screening

**FRM5499** - SN to DFCS Handover Form

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

**FRM1538** - Authorisation – Solid Organ and Tissue Donation

**FRM7352** – Donation After Death Using Neurological Criteria – Donor Optimisation Care Bundle – Paediatric

## **OTHER:**

**NHSBT Advanced Communication Guide**

**Human Tissue (Authorisation) (Scotland) Act 2019**

**Guidance on Deceased Organ & Tissue Donation in Scotland:** Authorisation Requirements for Donation and Pre-Death Procedures

**Human Tissue Authority Code of Practice A**

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## Glossary

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### Definitions

- **SN** - Specialist Nurse Organ Donation, Specialist Requestor, Specialist Requestor Family Care
- **LN** – Lead Nurse
- **RHN** - Regional Heads of Nursing
- **DCD** - Donation after Circulatory Death
- **DBD** - Donation after Neurological Determination of Death
- **PR** - Parental Responsibility (UK excluding Scotland)
- **PPRR** – Persons with parental rights and responsibility (Scotland)
- **CGA** - Corrected Gestational Age – Age corrected to allow for prematurity. An infant born at 30 weeks' gestation, now 8 weeks old = 38 weeks CGA. Generally, applies to prematurely born infants until their 2<sup>nd</sup> birthday.
- **EOLC** – End of Life Care
- **Post Term** - age after term (37 weeks gestation)
- **NORS** - National Organ Retrieval Service
- **UKDEC** - UK Donation Ethics Committee
- **NRC** – National Referral Centre
- **SNBTS** - Scottish National Blood Transfusion Service
- **PCCS** - Paediatric Critical Care Society
- **ODST** - Organ Donation Services Team
- **SaBTO** - Safety of Blood, Tissues and Organ
- **JPAC** – Joint UK Blood Transfusion and Tissue Transplantation Services Professional Advisory Committee
- **RCPCH** - Royal College of Paediatric and Child Health
- **AoMRC** - Academy of Medical Royal Colleges
- **TBV** - Total Blood volume
- **PDA** - Potential Donor Audit
- **iPNP** – Infant and Paediatric Notification Practice
- **MDT** – Multi-disciplinary Team

## 1. Notification and Screening

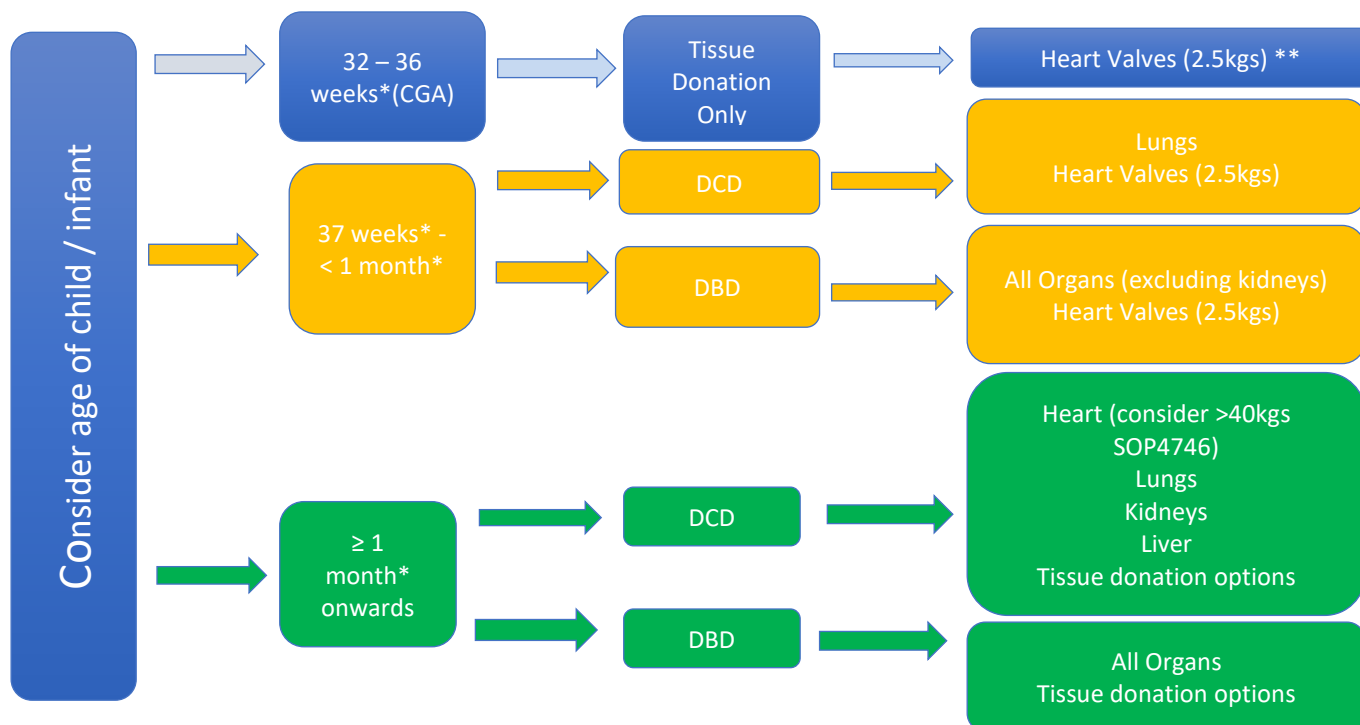
Receive incoming potential Paediatric or Infant donor notification:

- 1.1 Follow procedure for receipt of a referral from critical care areas **SOP3781**. Complete the Donor Path assessment pathway for referral of any age as per **SOP5003**.

Determine a plan for attendance where appropriate in line with the **Infant and Paediatric Notification Practice (iPNP)**. This includes consideration for inclusion of the option of organ and/or tissue donation as part of end-of-life care planning. See **Appendix 2** for more information.

- 1.2 Ensure that information collected during notification includes all relevant required information. Ensure that you have access to Donor Path and **FRM5510** for children under 2 years.
- 1.3 All infants > 37 weeks corrected gestational age (CGA) /post term should be considered for organ donation. These patients should also be included in the PDA (there is no requirement for audit <37 weeks CGA)
- 1.4 Less than 2 years of age complete **FRM5510** in all cases, refer to flowchart below for additional guidance. The form should be fully considered, two centres may need to be contacted where a decline is given (i.e. renal and cardio-thoracic) as there maybe differences in opinion / suitable recipients. In DBD cases fully consider both cardio-thoracic centres and multi-visceral, there have been cases were MV or heart have been the only organs retrieved.  
Greater than 2 years old complete Donor Path suitability assessment section.

Figure 1: Screening Flowchart



Hepatocytes maybe considered where at least one other organ is being retrieved for transplantation.

\* Age must be as corrected gestational age / post term (generally applies for premature infants until their 2<sup>nd</sup> birthday)

\*\*Please note in Scotland where heart valve donation is processed by SNBTS the lower age criteria is 36 weeks CGA.



## 2. Paediatric 10 Point Checklist

Figure 2: Paediatric Organ Donation 10-point Checklist

Paediatric Organ Donation 10 Point Checklist	
1	<p><b>Arrival and plan</b></p> <ul style="list-style-type: none"> <li>- Collaborative discussion with bedside nurse, nurse in charge and consultant</li> <li>- Determine plan in line with the iPNP</li> <li>- Consider EOLC options and agree expectations collaboratively as an MDT</li> <li>- Obtain family information - establish persons with parental responsibility/rights, note any specific considerations, ensure local legislation / law followed and document appropriately.</li> <li>- Is there any child protection / child in need / 'looked after children' considerations?</li> <li>- Bedside patient assessment</li> <li>- Check ID</li> <li>- Check Organ Donation Register</li> </ul> <p>Complex cases please discuss with LN / RHN / Paediatric Lead (Regional / National)</p>
2	<p><b>Coroner/ Procurator Fiscal</b></p> <p><b>Is coroner/Procurator Fiscal referral indicated?</b></p> <p><i>If yes...</i></p> <ul style="list-style-type: none"> <li>- Has the potential of organ donation been discussed with the Coroner/Procurator Fiscal?</li> <li>- Has the outcome of coroner/Procurator Fiscal conversation been documented?</li> <li>- Are there any other agencies involved such as Police, are they aware of potential organ donation?</li> </ul> <p>Please ensure that all discussions are clearly documented.</p>
3	<p><b>History</b></p> <p><b>Review ALL medical notes</b></p> <ul style="list-style-type: none"> <li>- <u>Electronic and paper notes</u> – medical entries, nursing notes, clinical observations, MDT entries including any related to child protection / child in need</li> <li>- <u>Medical history</u>- speciality notes, clinic appointments, previous surgeries</li> <li>- <u>The Personal Child Health Record 'Red Book'</u>- weight and immunisation history for children &lt;5 years old - Given to parents when a child is born (ask bedside nurse if parents have it with them)</li> <li>- <u>All test results (current and historical)</u></li> </ul> <p>Note: Any difficulty accessing any of these records needs discussion with the medical/nursing team and clearly document on Donor Path</p>
4	<p><b>Multi-disciplinary teams</b></p> <p><b>Has the child been under the care of any other speciality? (Such as Community Paediatrician, Genetics, Metabolic, Infectious Diseases, Bone Marrow Transplant or Rheumatology)</b></p> <ul style="list-style-type: none"> <li>- For up-to-date information, ensure the potential of organ donation is discussed with the speciality and any possible implications noted - This is particularly important for example when the child has been under the care of the genetics team.</li> </ul>
5	<p><b>GP</b></p> <ul style="list-style-type: none"> <li>- GP summary</li> <li>- GP discussion</li> </ul> <p>If available:</p> <ul style="list-style-type: none"> <li>- Health visitor summary (Children &lt;5 years old)</li> <li>- Midwife summary (Infants &lt;10 days old)</li> <li>- Neonatal Transfer form if previously on a Neonatal Unit</li> </ul>
6	<p><b>Screening additional information required</b></p> <p>Infant &lt;2 years</p>

	<ul style="list-style-type: none"> <li>- Details of past medical history</li> <li>- Patient's length of stay in hospital (consider pre- transfer from other hospitals)</li> <li>- Pregnancy history – pre or post-natal diagnosis, pregnancy complications, sepsis concerns, NICU admission details</li> <li>- Gestation at the time of birth in weeks (&lt;37 weeks would be considered as premature)</li> <li>- Corrected gestation / post term age at the time of referral (if born prematurely)</li> <li>- Weight at the time of referral –Please note if this is actual or estimated</li> <li>- Height or length at the time of referral (will be required for screening with lung centres)</li> <li>- Blood group</li> </ul> <p>Note: Lung collapse is a frequent finding on paediatric chest x-rays, continue to include lungs in the screening process.</p> <p>Consider multi-visceral screening in DBD cases</p> <p><i>Complete infant Donor Assessment and Organ Screening <b>FRM5510</b></i></p>
7	<p><b>Diagnosis of death using neurological criteria</b></p> <ul style="list-style-type: none"> <li>- What is the child's gestational/ post term age (if born at &lt;37 weeks)?</li> <li>- Check Neurological Death Testing form is completed correctly</li> </ul> <p>Forms:</p> <ul style="list-style-type: none"> <li>- Infants between 37 weeks of corrected gestation/ post term to 2 months</li> <li>- Children from 2 months to 17 years' old</li> </ul> <p><i>NHSBT DBD paediatric optimisation bundle given to the bedside nurse (section 4)</i>  <a href="https://nhsbt.dbe.blob.core.windows.net/umbraco-assets-corp/28257/paediatric-optimisation-of-care-bundle-v2.pdf">https://nhsbt.dbe.blob.core.windows.net/umbraco-assets-corp/28257/paediatric-optimisation-of-care-bundle-v2.pdf</a></p>
8	<p><b>Bloods</b></p> <p>Contact Microbiologist and Tissue Typist about the volume of blood required this will vary on the child's age (ask for the minimal amount required to ensure that the child's circulatory volume is not significantly compromised)</p> <p>Note:</p> <ul style="list-style-type: none"> <li>- In cases where a child does not have IV access for bloods. Please take ESSENTIAL bloods together to minimise distress to the child and family.</li> <li>- If additional bloods are required, please enquire with labs to see if tests can be added to pre-existing samples (such as Gamma GT, AST etc.) before requesting new bloods. HbA1c is not routinely completed – contact lab to confirm rationale/requirement.</li> <li>- EGFR is not recorded in children.</li> <li>- Large blood volume requests should be rationalised and discussed fully.</li> <li>- DCD bloods should be taken just prior to withdrawal / DBD just prior to x-clamp.</li> </ul> <p><b>See section 3.6 for further information.</b></p> <p><u>Additional testing:</u>  <i>Maternal bloods may also be required refer to <b>SOP6405</b> and <b>INF947</b></i>  <i>COVID19 refer to <b>SOP5869</b></i></p>
9	<p><b>Respiratory and Cardiac tests:</b></p> <p>For potential cardiothoracic donors the following will also be required</p> <ul style="list-style-type: none"> <li>A formally reported Chest x-ray</li> <li>A reported ECG</li> <li>A formally reported echocardiography</li> </ul>
10	<p><b>Pregnancy test</b></p> <ul style="list-style-type: none"> <li>- <b>Patients over 12 years of age with reproductive capacity – require a B-HCG blood test</b></li> </ul> <p><b>Note: This should ONLY be done AFTER discussion with the family, refer to <b>MPD891</b></b></p>

*\*In Scotland the SN should undertake the Duty to Inquire before any form of testing is undertaken*

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### 3. Consent/Authorisation and Characterisation

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#### 3.1. Preparing for consent/authorisation conversation

Preparation for the donation conversation should be completed in line with the Infant and Paediatric Notification Practice (iPNP) see Appendix 2.

The SN should also refer to NHSBT Advanced Communication Guide page 34-36 (available in File Director), and **DAT3784** Rationale for Consent, **INF1370** – Authorisation Form Rationale.

Consider referral to the Coroner/Procurator Fiscal following guidance in **MPD865** with specific reference to Appendix 1.

#### 3.2. Specific considerations when taking consent / authorisation for a child

**3.2.1. In England, Northern Ireland and Wales**, consent for organ donation in the case of children under 18 years should be sought from an individual who holds parental responsibility for that child, this is usually, but not always the parents. In England and Wales deemed consent does not apply to persons under 18 years of age.

If the child made a decision to join the ODR and was competent at that time to do so their decision should be given the same consideration as that of an adult.

The person highest in the HTA qualifying relationship should only be considered if persons with parental responsibility are unable to make this decision (e.g. incapacitated in the same accident). Refer to Human Tissue Authority Code of Practice A, 87– 94 for further information. Any question around suitability to consent/authorisation should be discussed with the local clinical / social work teams and Regional Manager on call.

**3.2.2. In Scotland** under the HT(S) Act 2006, a child is defined as anyone under the age of 16 years. Anyone aged 12 years or over can give self-authorisation. Deemed authorisation does not apply to children aged under 16. Children aged over 12 may provide express authorisation or 'opt out' declarations either on ODR or in writing. Where a child has not made a valid decision or was not competent to do so authorisation is usually taken from the person with parental rights and responsibility (PPRR), this is usually, but not always the parents. The duty to inquire and pre-death procedure framework applies to children as well as adults.

In the event of the PPRR being incapacitated, the legislation has introduced a hierarchy of relatives / individuals who can make a decision regarding Organ Donation in the absence of the PPRR.

There is also an additional framework in place when considering Authorising children in local authority care.

Please Refer to Guidance on deceased organ and tissue donation in **SOP5878** – Organ and Tissue Donation Authorisation Manual, and **INF1370**.

#### 3.3 Completing consent/authorisation paperwork

**3.3.1** When completing **FRM4281/1538** for when a patient is less than 1-year-old document the age in years as zero (0), and the age in months must be entered in the next box. Corrected gestational age (CGA) should be entered where appropriate in neonatal cases, document any additional information on **FRM4281/1538** as appropriate.

Consider multi-visceral, abdominal wall and fascia donation, see **SOP6039**.

Refer to **SOP4746** for specific information relating to criteria for DCD Heart Donation.

- 3.3.2 **Surrounding Tissue / Organs:** Organs in the body are connected to surrounding tissue and to neighbouring organs. Surrounding tissue is always removed with the organ to avoid damaging the organ and its blood vessels. This is to maximise safe and successful transplantation. In certain cases, surrounding tissue will include part/whole organ(s) to be removed for the same reason. This may be required when there is a variation in anatomy, an uncertainty over blood vessel supply, where organs are situated closely together and timely dissection and retrieval is necessary.

In young children this is often seen in the techniques required to remove en-bloc grafts. Here organs and vessels are small and require removal together, with the larger vessels intact to maximise successful transplantation.

For example:

**Renal en-bloc** relates to the removal of both kidneys together with the aorta and cava remaining attached. En-bloc kidneys are generally considered < 5 years of age.

**Abdominal en-bloc technique** refers to removal of all abdominal organs as a cluster attached to the aorta. Separation as required may take place on the back table or at the recipient centre under optimal conditions.

The following details a wording suggestion for use with all families of paediatric donors when seeking consent for surrounding tissue / organs:

*“During the operation to carefully remove the organ(s) for transplant, tissue surrounding the organ will be removed. Sometimes other organs may also need to be removed. These organs and tissues may not be required for transplant and can benefit other patients through research, should you be willing to consent to this? Alternatively, the tissue is appropriately disposed of, as per hospital policy”*

- 3.3.3 For suitability for tissue donation refer to **SOP5981** – Tissue and Eye Donation Information for Consenting Nurses, JPAC and **SOP5024** Tissue Referral Process.

Where a tissue donation referral is accepted there will be a need to gain a further **maternal blood sample** to accompany the tissue (where maternal sampling is indicated) as per JPAC guidance. The mother should be informed that this needs to be taken just prior to theatres.

### 3.4 Specific considerations for scheduled purposes

All paediatric donors should be considered for research / scheduled purposes consent as per guidance, reference should be made to any specific age exclusions that may apply.

**QUOD:** Paediatric donors > 5 years old may be in scope for QUOD at licensed hospitals (**INF1081**). Refer to **SOP5930/SOP5931** for further guidance. Blood volumes for paediatric donors < 30 kgs should be rationalised and any risk to stability discussed with clinical teams refer to sec 2.6 for further details. Smaller sample volumes for QUOD are acceptable.

**INOAR:** Only adults over the age of 16 years (Scotland) or over 18 years (rest of UK) are in scope. Refer to **SOP5567/SOP5663/INF1503** for additional information.

Apply caution when considering sentinel skin flap donation see **SOP5048**

### 3.5 Medical and Social History including Maternal details

When completing the MASH refer to **INF947** for specific information relating to paediatric donation, page 2.

Record specific details of any immunisations the child has received with as much detail as possible.

Caution maybe required in terms of vaccine induced positive microbiology results in particular for the 6 in 1

vaccine given at 8,12 and 16 weeks of age. This vaccine includes Hep B and although inactivated has been known to elicit a positive result in cases of recent vaccination. Please refer to **SOP6514** for further guidance on positive results.

Vaccine schedule can be found via the following link:

<https://www.nhs.uk/conditions/vaccinations/nhs-vaccinations-and-when-to-have-them/>

Maternal assessment details must be clearly recorded on Donor Path and be accessible to the recipient centres.

For potential donors with reproductive capacity over the age of 12 years refer to **MPD891** regarding the requirement for pregnancy testing.

### 3.6 Blood sampling

Consideration for total blood volume must be considered when collecting blood samples from children, particularly those under 30 kgs <sup>1,2</sup>

Table 1. Total Circulating Blood Volume for Children < 16 years old

Age (years)	Average Total Circulating Blood Volume *	Weight range on 50 <sup>th</sup> centile WHO growth charts	Approx. TBV (Guide only – calculate patient specific TBV )
< 1 year	85 mls / kg	3.5kg-10kg	297 mls – 850 mls
1-6 years	80 mls / kg	10kg-20kg	800 mls – 1600 mls
6-10 years	75 mls / kg	20kg-30kg	1500 mls – 2250 mls
10-15 years	70 mls / kg	30kg-55kg	2100 mls – 3850 mls

For specific information regarding bloods and blood volumes please refer to **SOP6405** for Organ Donation and **SOP5024** for tissue donation.

Consideration should be made when sampling from paediatric patients, especially those under 30 kgs. Cumulative sampling of as little as 5% of the total blood volume can result in cardiovascular instability.

Paediatric blood sampling bottles should be used, and minimum volumes determined with transplanting centres.

Where instability is considered a risk, consider sampling for organs just prior to WLST or cross clamp.

Where maternal blood sampling has taken place please ensure these details, including 3 points of PID are recorded on Donor Path in line with **SOP6405** and ensure these are also included on the Donor Family Care Services Handover **FRM5499**. Additional maternal samples for microbiology will be required to accompany any tissue donation.

Please ensure the labels for maternal sampling are used where required, these should be available in PICU and NICU areas and can be sourced from the DFCS.

### 3.7 Lymph and spleen samples

Donors **16 yrs and older** will have 40 ml blood sent with heart instead of the lymph and spleen samples.

Donors **under 16 yrs** will continue to have lymph and spleen sent as the large volume of blood has the potential to cause donor instability. If necessary, in order not to delay the heart the lymph and spleen can be sent on after the heart has left.

## 3.8 Haemodilution Calculations

Please ensure caution with the calculations for haemodilution calculations in paediatric patients. As their blood circulating volume is larger per kg than adults the generic DonorPath calculation may overestimate the haemodilution calculation and risk decline of tissues unnecessarily.

For patient 12 years and under the following JPAC calculation / assessment tool should be completed and the results documented on DonorPath.

[Appendix 3 - Calculation of Blood and Plasma Dilution \(transfusionguidelines.org\)](#)

## 3.7 COVID-19 Testing

Please refer to **SOP5869** section 4 for specific guidance on testing in paediatric patients.

Note that where maternal characterisation is required in addition to the donor; COVID-19 testing is only required for the donor.

## 3.8 Measurement of weight

It is important that an accurate measured weight is established for all paediatric patients. Primarily this is necessary as all drug dosages are calculated based on weight (kg).

An accurate weight is also required to ensure appropriate offering and allocation particularly in size matched organs.

Ensure an accurate weight is clearly recorded on DonorPath and the reason for any deviation of this practice recorded and escalated as appropriate, refer to SOP6405 for further guidance.

## 3.10 Preparing for post donation care

Liaise with the donating unit in relation to any keepsakes and care after donation/retrieval, including any specific requests from the family. Normal practice is generally to transfer the child back to the donating unit following the retrieval operation.

If applicable in local region, consider working with unit to liaise/refer to local children's hospice to continue end of life care as appropriate post donation. Please note that this referral maybe required prior to death occurring.

Please ensure families are given the resource and bereavement support information contained in the donor pack and any requests for information sent to the DFCS.

For families considering sharing their story please refer to **INF1600** and **INF1602** for further guidance.

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## 4 Hepatocyte Donation

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### 4.1 Transplant programme

Hepatocytes are processed for transplantation at Kings College Hospital, London.

The programme treats paediatric patients with acute liver failure and those with metabolic disorders, the clinical trials are ongoing.

### 4.1 Information for families

- The transplantation programme is a paediatric only programme.
- Hepatocytes are used to treat children with acute liver failure and those with metabolic disorders
- Hepatocytes are then checked for quality and infection before being stored for use at a later time.
- Cells can be stored for up to 10 years

### 4.2 Screening for liver and liver hepatocytes

Liver for hepatocytes can only be donated where there is at least one other organ being retrieved for transplantation.

Screening should be completed using **FRM5510** for infants < 2 years old.

### 4.3 Consent/Authorisation

Consent for hepatocytes should be taken in line with **SOP5818 / SOP5878** and the associated rationale documents **INF1370 / DAT3784**.

### 4.4 Processing and storage

During processing the hepatocyte cells are isolated, quarantined and cryopreserved for later use. The cells can be safely cryopreserved for up to 10 years.

### 4.5 Transplantation

- **Metabolic Disorders:** the cells are infused into the portal vein until a critical mass is reached. Subsequent transplants maybe required to maintain optimal effect.
- **Acute Liver Failure:** the cells are encapsulated into 'beads' and placed in the abdominal cavity. Here they act as mini livers and have been shown to prevent the need for subsequent liver transplantation.

### 4.6 Outcome information

The hepatocyte team will provide an update on the isolation and processing for the initial family letter should this be required.

A further update following any transplantation can also be gained.

## 5 Paediatric Donor Optimisation

Optimisation of potential donors following neurological determination of death is an important element in ensuring the utilisation of organs for transplantation. Please refer to **FRM7352**.

Bespoke policies that account for the differences in optimisation of paediatric and neonatal donors are essential. The following care bundle provides an agreed and evidence-based optimisation care bundle for patients from 37 weeks (corrected gestational age) to 15 years old.

Paediatric patients >16 years of age are mainly cared for on adult intensive care units and it is acceptable to use the adult policies in this older age group. Please also note that any attendance of scout teams should only be considered for patients greater than 16 years' age who are being cared for in adult ITU areas.

### 5.1 Donor Optimisation Bundle (Paediatric)

#### IMMEDIATELY AFTER DIAGNOSIS OF DEATH

- Perform lung recruitment manoeuvre
- If appropriate use cuffed endotracheal tube and ensure adequate inflation (consider changing to cuffed if indicated)
- Set tidal volume to 6-8mls/kg (<1month old 4-6mls/kg)
- Set optimum PEEP (5 to 10cm H<sub>2</sub>O) and PIP <30cm H<sub>2</sub>O
- Add vasopressin (0.0003-0.001U/kg/min. Max dose 4U/hr) where vasopressors are required. Wean or stop catecholamine pressors as able. Use noradrenaline / dopamine only where vasopressin is insufficient and consider esmolol / labetalol in persistent hypertension in the absence of vasopressors

#### WITHIN 1 HOUR OF CONSENT/AUTHORISATION

- Administer methylprednisolone (15mg/kg, maximum 1g)
- Request an ECG
- Request an echocardiogram
- Request a CXR – post recruitment manoeuvre

#### WITHIN 4 HOURS OF CONSENT/AUTHORISATION

- ECG report complete
- Echocardiogram report complete
- CXR report complete
- Measure cardiac output if appropriate (establishing invasive monitoring is rarely indicated)

#### GOALS

PaO <sub>2</sub> ≥ 10 kPa (< 1-month PaO <sub>2</sub> ≥ 8kPa)	U.O. 0.5 – 2 mls/kg/hr
PaCO <sub>2</sub> 5 – 6.5 kPa	Na < 150 mmol/L
pH >7.25 (<1 month >7.2)	Glucose 4 – 12 mmol/L
MAP – appropriate for age	Temp 36 – 37.5 °C



## CONTINUOUSLY

- Ensure ongoing lung protective strategy.
- Nurse 30-45 degrees head up.
- Continue physiotherapy including suctioning.
  
- Review intravascular fluid status and correct hypovolaemia.
- Wean catecholamine pressors.
- Treat DI with DDAVP.
  
- Continue NG feed, as directed by SNOD and ensure gastric protection as unit protocol.
- Monitor blood glucose and treat as per unit protocol.
- Monitor serum sodium concentration.
  
- Continue use of thromboprophylaxis as per unit protocol.
  
- Continue hourly observations.
- Maintain normothermia.
- Stop all unnecessary medications.
  
- Other tests or therapies may be indicated. SN to direct.

### 5.2 Donor Optimisation Paediatric Drugs

Please note that it is advised where agreed local optimisation policies for drug administration are in place these should be followed.

Drug	Standard infusion	Diluent	Rate of infusion	Dose
Dopamine	15mg/kg in 50mls (max 800mg in 50ml)	NaCl 0.9% OR Glucose 5%	1ml /hr = 5 micrograms/kg/min	<10 micrograms/kg/min
Noradrenaline	0.3mg / kg in 50mls	Glucose 5%/ Na Cl 0.9%	1ml/hr = 0.1 micrograms/kg/min (of standard infusion)	0-0.5 micrograms/kg/min (maximum rate = 5mls/hr of standard infusion)
Vasopressin/ Argipressin – as vasopressor	20 units in 50ml diluent	NaCl 0.9% / Glucose 5%	0.0003 units/kg/min = 0.045ml/kg/hr	0.0003- 0.001 units/kg/min (Max dose 4 u/hr) <sup>3</sup>
Vasopressin – treatment for Diabetes Insipidus <sup>4</sup>	2-5 units / litre diluent	NaCl 0.9% / Glucose 5%	ml for ml replacement of urine output	N/A

Adrenaline	0.3mg /kg in 50ml	Glucose 5%	1 ml /hr = 0.1micrograms/kg/min (of standard infusion)	0-0.5micrograms/kg/min
Dobutamine	30mg/kg in 50mls	Glucose 5%, 10% / Nacl 0.9%	1ml/hr = 10micrograms/kg/min	5-20 micrograms/kg/min

Methylprednisolone	15milligrams/kg (max 1g)	IV infusion over 1 hour
DDAVP (desmopressin)	1 month – 12 years 400 nanograms 12-18 years 1-4 micrograms	IV bolus Repeat as indicated
Insulin (50 units in 50ml)	0.1units/kg/hr	IV continuous infusion – titrated to response

Esmolol	10mg/ml (pre-diluted)	50-300 micrograms/kg/min (max 500 micrograms/kg/min)	IV continuous infusion – titrated to response
Labetalol	5mg/ml (neat)	0.5 – 3 milligrams/kg/hr (max 5 milligrams/kg/hr)	IV continuous infusion – titrate to response

## 6 Allocation / Offering and Retrieval

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- 6.1 ODT Hub Operations are responsible for the allocating and offering of organs following the registration of the donor.
- 6.2 SN should be aware of specific allocation rules for kidneys from smaller donors, see **POL186** section 3.2 for details.
- 6.3 Management of the theatre process should be completed as per **SOP5499**. As with all organ retrievals communication is the key but particularly so due to the sensitive nature of paediatric donation.
- 6.4 When considering mobilising of NORS team liaise closely with Hub Operations and refer to **MPD1043** section 2 for specific consideration when retrieving organs from small donors.
- 6.5 Additional blood sampling requests should continue to make consideration for TBV and safe sampling from paediatric patients, large volume requests should be rationalised with the requesting centres.
- 6.6 Bloods to accompany DCD organs should be taken just prior to withdrawal of life sustaining treatment and for DBD organs they should be taken just prior to cross clamp of the aorta in theatre, this is to minimise risk of circulatory collapse prior to retrieval.
- 6.7 Many Paediatric and Neonatal units will wish for the child to be taken back to the unit following retrieval completion. Last offices should be carried out prior to this transfer, even if additional cares by staff and family are planned to take place upon return.
- 6.8 SN should check the appearance of the body with the NORS team prior to them leaving the theatre. This is particularly important in small infants where bones have more cartilage and therefore more flexible, pay particular attention to the chest shape which may need additional closure.
- 6.9 The need for staff debriefs should be discussed with the theatre manager following organ retrieval. NORS teams should also be given the opportunity to attend any debriefing sessions.

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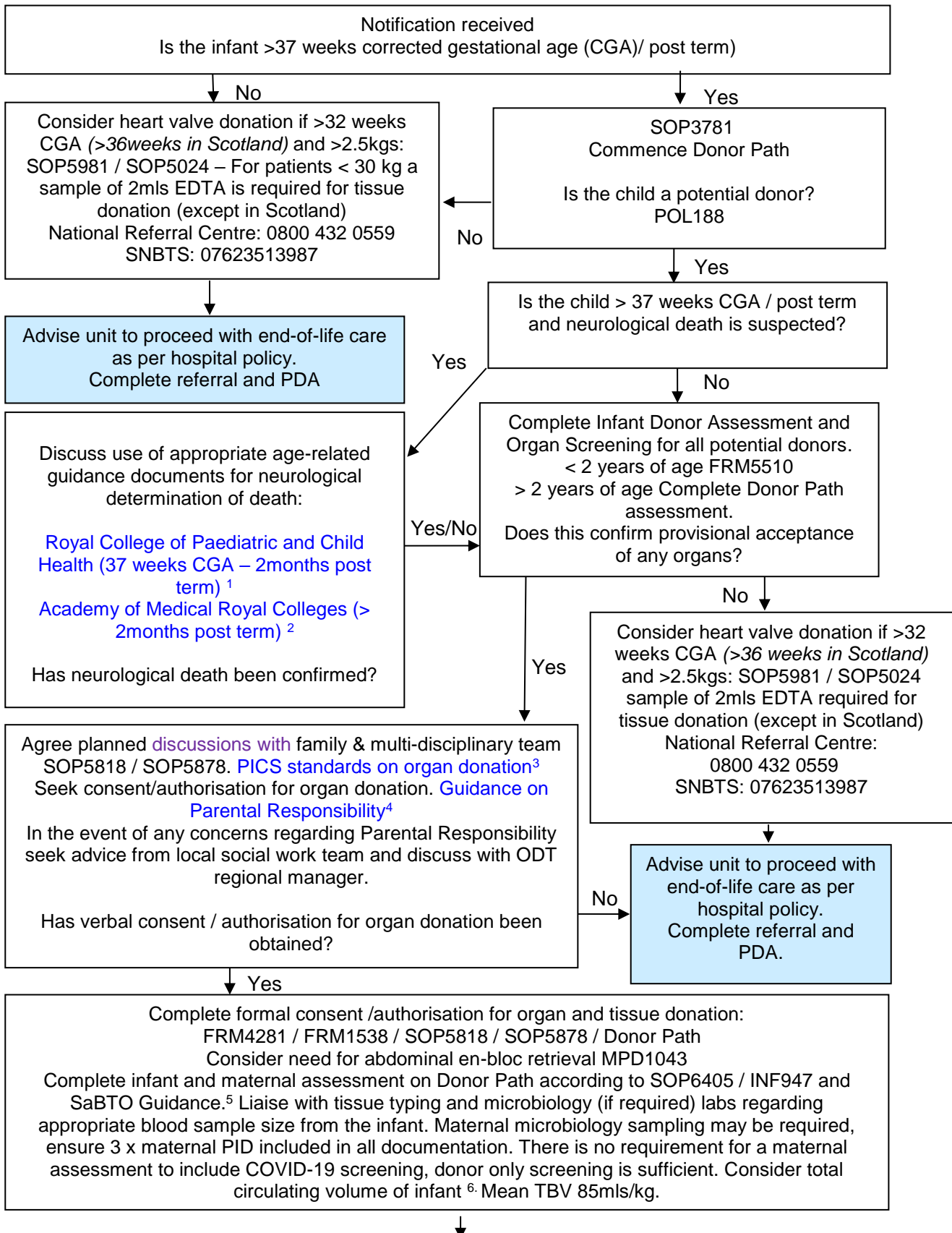
## ***7 Notification in the Antenatal Period***

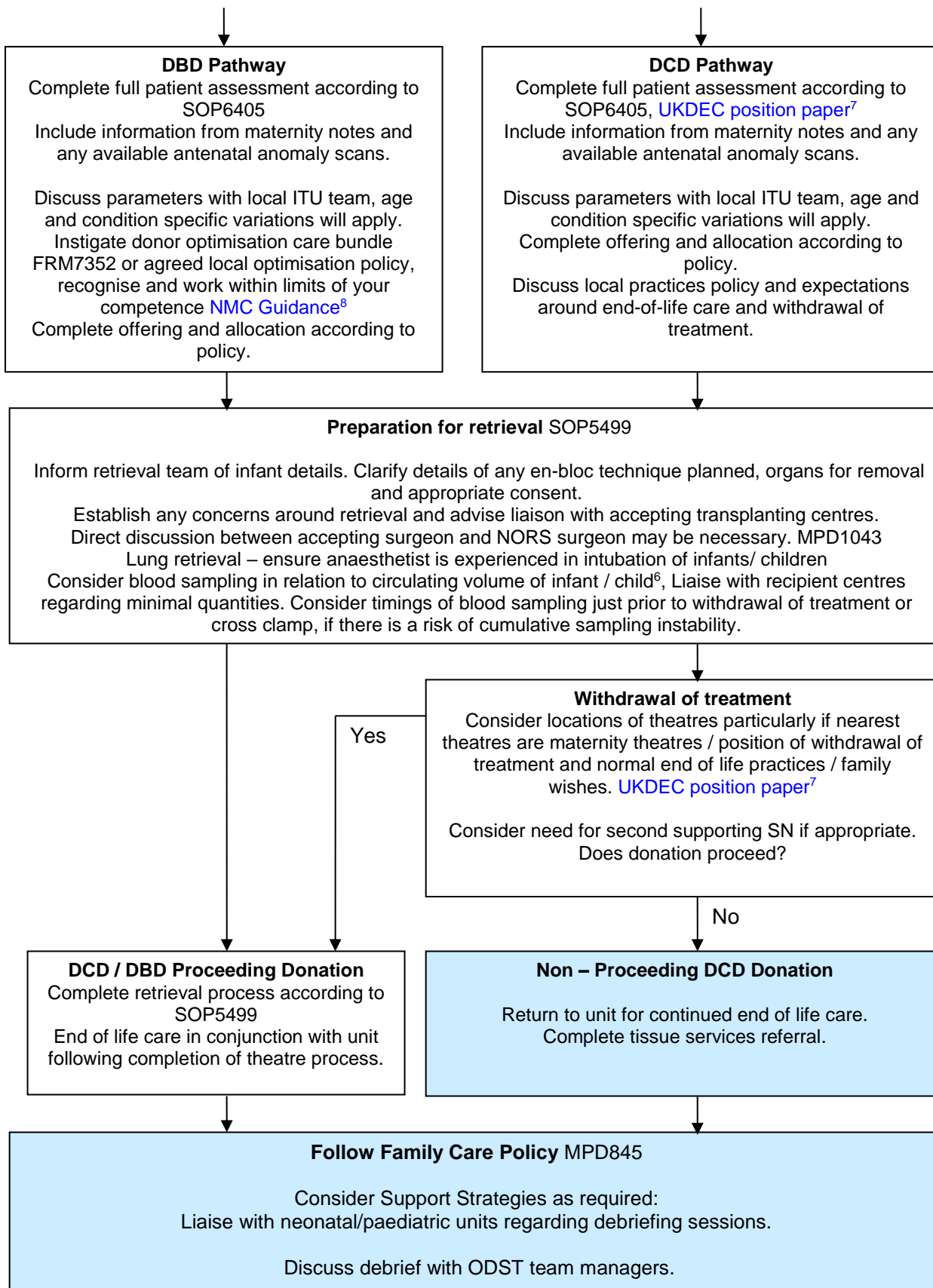
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There are a small but steady number of enquiries from clinicians and parents about the possibility of organ and tissue donation from small infants who have been diagnosed antenatally with anencephaly and other life-limiting conditions.

Currently there is the opportunity for heart valve donation only in these circumstances, this can be assessed in conjunction with the NRC / SNBTS at the time of death.

**Appendix 1: Paediatric Donation Flowchart**





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## Appendix 2: Infant and Paediatric Notification Practice (iPNP)

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### Background

The Paediatric and Neonatal Deceased Donation Strategy (2019) recommended that the triggers for notification to the organ donation services team should be aligned with Paediatric and Neonatal end-of-life care practices.

Extended notification triggers have been trialled with successful results seen, these being an increase in referral, SN presence, consent and a drop in missed potential over the trial period.

The practice gives the opportunity for organ donation to be incorporated into end-of-life care planning at a time appropriate to the family decision making.

### Notification & Assessment

A notification will be made to the OD operational team in line with the triggers below:

***Death is likely in the next 48 hours – either by neurological determination of death through testing criteria or by withdrawal of life sustaining treatment***

***Family have raised organ donation***

***Discussions regarding re-orientation of care – including palliative care discussions***

***Early end of life care planning***

The referral information is taken as per **SOP3781** while considering discussions that are planned with the family. The aim is to ensure that assessment of potential is completed and SN is present when end-of-life care discussions / planning is occurring.

At the time of notification, a clear plan should be determined with the clinical team, including where applicable a planned time for SN attendance.

### Pre-Planning

A clear plan should be agreed with the multi-disciplinary team involved, considering what the possible end-of-life care options / choices are in each case.

Organ donation should be incorporated into the options that are given to the family; a decision is not necessarily required at this time. Families should be given support to consider all options equally, while understanding how these options may also work in conjunction i.e. hospice care following retrieval.

In the trial the DBD pathway generally remained unchanged with the option of OD given following confirmation of brain stem death.

### SN presence

The process of supporting families in end-of-life care decisions can sometimes be prolonged and have an impact on staff wellbeing.

Discretion should be used as to physical attendance of the SN, it is appropriate for the different SN to attend over a prolonged period to ensure staff health and wellbeing is maintained.

### Potential Donor Audit

Please ensure that details of the clinical plan on referral are recorded appropriately and where end-of-life care options are given, these should be recorded as previous conversations and the reason given as end-of-life care planning.

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