Blood and Transplant
Copy No:
Effective date: 28/02/2023

OTDT Paediatric Manual

Index

Summary of changes

Addition of information regarding the Infant and Paediatric Notification Practice

Updated version of the paediatric donor optimisation care bundle

Addition of >36-week CGA lower age criteria for heart valve donation in Scotland, unchanged in all other areas

Additional maternal microbiology sample where tissue donation takes place.

Inclusion of reference to **SOP5981 –** Tissue and Eye Donation Information for Consenting Nurses

Removal and amendment to changed or obsolete documents and links

Introduction

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.

The purpose of this document is to provide guidance to the Specialist Nurse (SN) and/or Team and Regional Manager (TM/RM) throughout the Paediatric/Neonatal Donation Process.

Organ donation opportunities from infants under 6 months of age and neonates has increased since 2012. The reason for this has been attributed to advances in techniques of en-bloc renal transplantation, development of hepatocyte transplantation from this age group and the Royal College of Paediatric and Child Health Guidance, released in April 2015, on neurological determination of death in infants 37 weeks of age to 2 months.

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.

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.

There should also be consideration for specific end of life care practices in neonatal and paediatric intensive care units, and organ donation may be raised as an option in parallel with other options when planning end of life care.

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

Associated Documents

POLs:

POL188 - Clinical Contraindications to Approaching Families for Possible Organ Donation

POL186 - Kidney Transplantation Deceased Donor Organ Allocation

MPDs:

MPD1043 - NORS Standards

MPD875 - Patient Assessment Family Conversation

MPD865 - Obtaining Coroner/Procurator Fiscal Decision

MPD845 - Family Care

MPD873 - Physical Assessment

MPD891 - Establishing Pregnancy Status and Pregnancy in Donation

SOPs:

SOP4574 - Logistics and NORs Mobilisation Manual – Hub Operations.

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

SOP3630 - Diagnostics - Blood Tests

SOP4746 - DCD Heart Donation Process

SOP5024 - Tissue Referral Process

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 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 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 Only

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

SOP4618 – Receipt and Management of Microbiological Blood Results at the Time of Donation

SOP6039 – Abdominal Wall and Abdominal Fascia Transplantation

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 you Childs Story

INF1602 - Child Donors - Guidance for Sharing Your Story

DATs:

DAT3784 - Rationale for 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

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

Glossary

Definitions

- **SN** - Specialist Nurse Organ Donation, Specialist Requestor, Specialist Requestor Family Care
- **TM** - Team Manager
- **RM** - Regional Manager
- **DCD** - Donation after Circulatory Death
- **DBD** - Donation after Neurological Determination of Death
- **PR** - Parental Responsibility
- **CGA** - Corrected Gestational Age – Age corrected to allow for prematurity. An infant born at 30 weeks' gestation, now 8 weeks old = 38 weeks CGA.
- **Post Term** - age after term (37 weeks gestation)
- **NORS** - National Organ Retrieval Service
- **UKDEC** - UK Donation Ethics Committee
- **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
- **En-bloc kidney retrieval** - relates to the removal of both kidneys together with the aorta and cava remaining attached.
- **En-bloc abdominal or multi-visceral retrieval** - refers to removal of all abdominal organs as a cluster attached to the aorta. Separation may take place on the back table or at the recipient centre under optimal conditions. This technique is predominately used in very small donors. This may be used to facilitate donation of specific organs without the intention or possibility to transplant all removed organs

1. Referral, Notification and Screening

Receive incoming potential Paediatric or Infant donor referral / 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**.

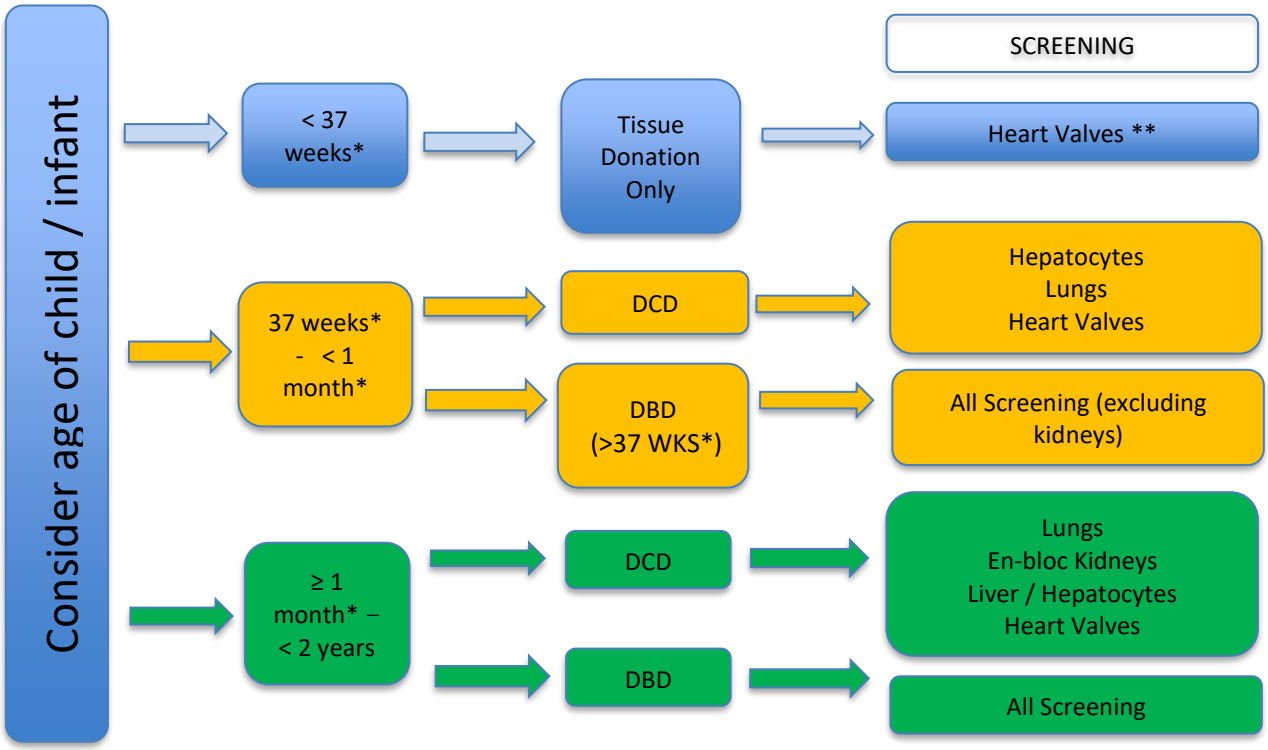
1.2 Determine a plan for attendance where appropriate in line with the Infant and Paediatric Notification Practice (iPNP). This includes consideration for inclusion of the option of organ and / or tissue donation as part of end-of-life care planning. See Appendix 2 for more information.

1.3 Ensure that information collected during notification / referral includes all relevant required information. Ensure that you have access to Donor Path and **FRM5510**

1.4 All infants > 37 weeks corrected gestational age (CGA) /post term should be considered for organ donation.

1.5 Less than 2 years of age complete **FRM5510** in all cases, refer to flowchart below for additional guidance Greater than 2 years old complete Donor Path suitability assessment section.

Figure 1: Screening Flowchart < 2 yrs old



* Age must be as corrected gestational age / post term

***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	Tick
1	**Arrival and plan** - Collaborative discussion with bedside nurse, nurse in charge and consultant - Determine plan in line with the iPNP - Consider EOLC options and agree expectations collaboratively as an MDT - Obtain family information - establish persons with parental responsibility, note any specific considerations, ensure local legislation / law followed and document appropriately - Is there any child protection / child in need / 'looked after children' considerations? - Bedside patient assessment - Check ID - Check Organ Donation Register Complex cases please discuss with Team or Regional Manager / Paediatric Lead (Regional / National)	
2	**Coroner/ Procurator Fiscal** **Is coroner/Procurator Fiscal referral indicated?** *If yes…* - Has the potential of organ donation been discussed with the Coroner/Procurator Fiscal? - Has the outcome of coroner/Procurator Fiscal conversation been documented? - Are there any other agencies involved such as Police, are they aware of potential organ donation? Please ensure that all discussions are clearly documented.	
3	**History** **Review ALL medical notes** - *Electronic and paper notes* – medical entries, nursing notes, clinical observations, MDT entries including any related to child protection / child in need - *Medical history*- speciality notes, clinic appointments, previous surgeries - *The Personal Child Health Record 'Red* Book'- weight and immunisation history for children <5 years old - Given to parents when a child is born (ask bedside nurse if parents have it with them) - *All test results (current and historical)* Note: Any difficulty accessing any of these records needs discussion with the medical/nursing team and clearly document on Donor Path	
4	**Multi-disciplinary teams** **Has the child been under the care of any other speciality? (Such as Community Paediatrician, Genetics, Metabolic, Infectious Diseases, Bone Marrow Transplant or Rheumatology)** - 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.	
5	**GP** - GP summary - GP discussion If available: - Health visitor summary (Children <5 years old) - Midwife summary (Infants <10 days old)	

	- Neonatal Transfer form if previously on a Neonatal Unit	
6	**Screening additional information required** Infant <2 years - Details of past medical history - Patient's length of stay in hospital (consider pre- transfer from other hospitals) - Pregnancy history – pre or post-natal diagnosis, pregnancy complications, sepsis concerns, NICU admission details - Gestation at the time of birth in weeks (<37 weeks would be considered as premature) - Corrected gestation / post term age at the time of referral (if born prematurely) - Weight at the time of referral –Please note if this is actual or estimated - Height or length at the time of referral (will be required for screening with lung centres) - Blood group Note: Lung collapse is a frequent finding on paediatric chest x-rays, continue to include lungs in the screening process. Consider multi-visceral screening in DBD cases *Complete infant Donor Assessment and Organ Screening FRM5510.*	
7	**Diagnosis of death using neurological criteria** - What is the child's gestational/ post term age (if born at <37 weeks)? - Check Neurological Death Testing form is completed correctly Forms: - Infants between 37 weeks of corrected gestation/ post term to 2 months - Children from 2 months to 17 years' old *NHSBT DBD paediatric optimisation bundle given to the bedside nurse (section 4)* *https://nhsbtdbe.blob.core.windows.net/umbraco-assets-corp/28257/paediatric-optimisation-of-care-bundle-v2.pdf*	
8	**Bloods** 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) Note: - 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. - 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. (EGFR is not recorded in children) - Please be aware of the volume of blood being requested at one time - nurses may space this out depending on the size of the child - Large blood volume requests should be rationalised and discussed fully - DCD bloods should be taken just prior to withdrawal / DBD just prior to x-clamp Additional testing: *Maternal bloods may also be required refer to SOP3630 & INF947* *COVID19 refer to SOP5869*	
9	**Respiratory and Cardiac tests:** For potential cardiothoracic donors the following will also be required A formally reported Chest x-ray A reported ECG A formally reported echocardiography	
10	**Pregnancy test** - **Patients over 12 years of age with reproductive capacity – require a B-HCG blood test** **Note: This should ONLY be done AFTER** discussion with the family. refer to MPD891	

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

3. Consent/Authorisation and Characterisation

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.**

3.2.3. The following techniques maybe used in small children / infants, the explanation of this to families should be documented on **FRM4281/1538.**

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 may take place on the back table or at the recipient centre under optimal conditions. This technique is predominately used in very small donors. This may be used to facilitate donation of specific organs without the intention or possibility to transplant all removed organs.

3.3. Completing consent/authorisation paperwork

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.

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. Research

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 **SOP4618** 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 [1,2]

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

Age (years)	Average Total Circulating Blood Volume *	Weight range on 50th centile WHO growth charts	Approx. 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 SOP3630 for Organ Donation and SOP5024 for tissue donation.

Where maternal blood sampling has taken place please ensure these details, including 3 points of PID are recorded on Donor Path in line with **SOP3630** 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.

3.7. 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 calculation may overestimate the haemodilution calculation and risk decline of tissues unnecessarily.
See table 1. for the TBV of donors per age and the calculation below to manually work out the haemodilution should this be required.

$$\%\ \text{HAEMODILUTION} = \frac{(\text{CRYSTALLOID RETAINED} + \text{BLOOD/COLLOID RETAINED}) \times 100}{\text{BLOOD VOLUME}}$$

3.8. 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.

3.9. 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.

3.10 Preparing for post donation care

Liaise with the donating unit in relation to any keep sakes 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 liaising/referring 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.

4. Hepatocyte Donation

4.1. Transplant programme and benefits

Hepatocytes are processed for transplantation at Kings College Hospital, London.
The programme treats paediatric patients with acute liver failure and those with metabolic disorders.

4.2. Infant hepatocyte cell benefits

Livers are generally transplanted as a whole organ from approx. 6 months of age unless part of a multi-visceral graft, where it can be much younger. The reason for this is due to technicalities of transplantation, vessel size and an increased thrombus risk.

These small infant livers, however, have been shown to give an excellent yield and quality of cells that is superior to livers declined for transplantation and has been noted as a game changer in hepatocyte transplantation.[3]

4.3. 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
- Liver is removed as a whole and then the cells (hepatocytes) extracted.
- These are checked for quality and infection before being stored for use at a later time.
- Hepatocyte cells can be stored for up to 10 years

4.4. Screening, expectations and logistics

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

It is important to note that as there is only one centre that has a hepatocyte transplantation programme in the UK, logistical challenges sometimes prevent the ability to process/accept livers for processing. This can be due to staff availability, lab resources, lab maintenance etc.

During the screening conversation the logistical ability to process the cells should be explored. Kings hepatocyte team should respond within approximately one hour in relation to any potential logistical challenges, any impact on donation should be considered. If there is any doubt in the ability to process the liver in line with the donation timeframes the decision to stand down at this point may be appropriate. This decision should be discussed with the relevant operational manager.

4.5. Consent/Authorisation and Research

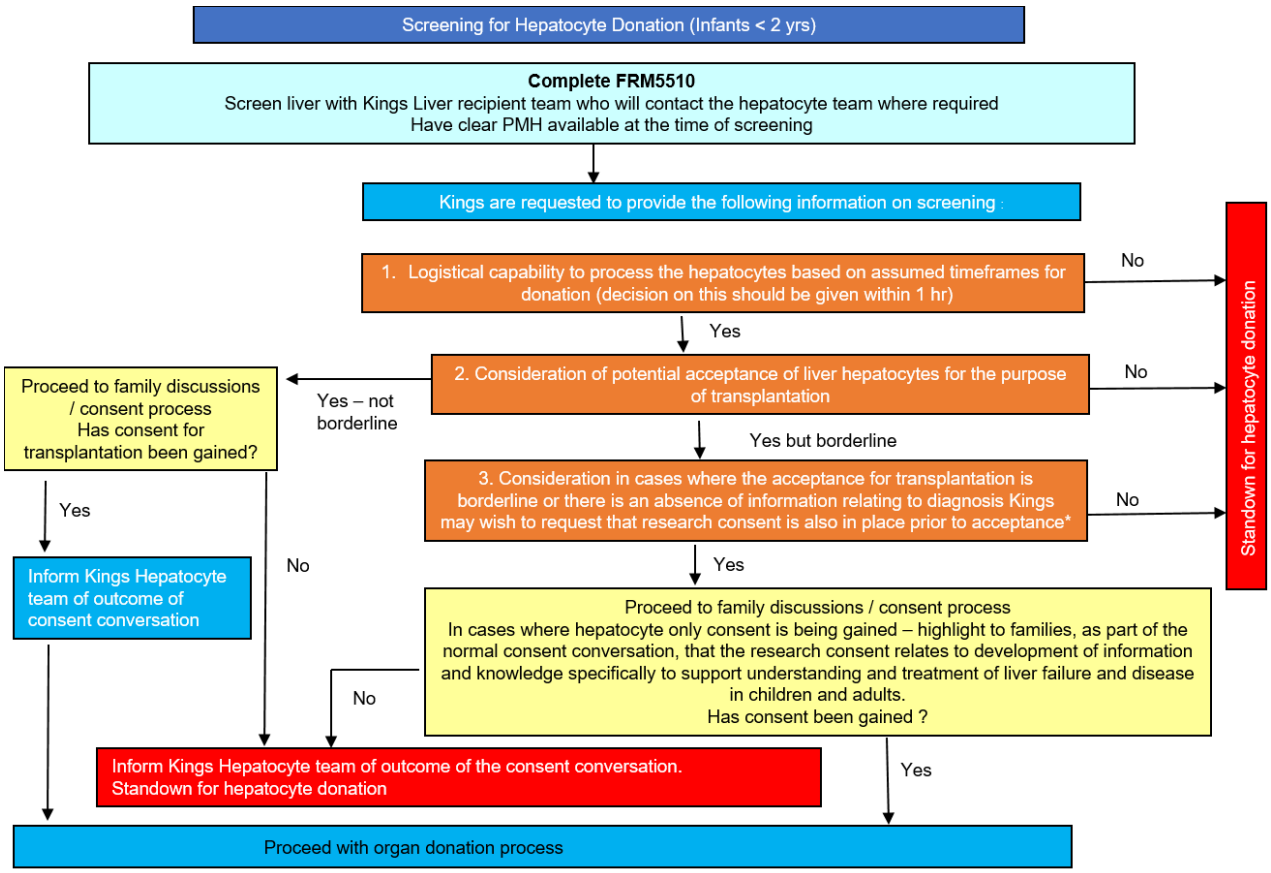
During screening the liver may be considered as borderline for acceptance by the hepatocyte team, for example, unclear diagnosis or possibility of metabolic disorders commonly seen in childhood death, absence of conclusive results associated with any underlying condition, the hepatocyte team may additionally request research consent is also in place prior to accepting the organ for transplantation, this is to ensure the liver can further be utilised for research should the cells be unsuitable for transplantation.

The consent/authorisation should always be sought with the **intention to transplant** and research consent/authorisation sought in the initial consent/authorisation conversation. Consent/authorisation for use in research should never be presented to families as a condition for donation for transplantation and families should not be subsequently re approached for research consent/authorisation.

It is appropriate during the consent/authorisation conversation where the liver is being consented for hepatocyte donation and transplantation to highlight that the research related to the liver specifically supports the development of hepatocyte cells as a treatment option for children with various liver

disorders including acute liver failure and to further improve our understanding of liver disorders in adults and children.

Please refer to flowchart below:



* In some circumstances it may be anticipated by the King's team that borderline livers may not provide a high enough yield of hepatocytes and the team will advise that they can only proceed with processing for transplantation if the cells may further be utilised in research studies. If the family do not agree to use in research when presented with the option as part of the normal consent conversation, the donation for transplantation should be stood down. **Consent must be sought for the intention of transplantation, use in research must never be presented as a condition for donation for transplantation in discussions with the donor family.**

4.6. Process and requirements for donation

Hepatocytes are classed as tissues but the process for whole organ donation is required for retrieval.

For hepatocyte only donation Tissue Typing is not required, additional bloods for microbiological testing will be required by the recipient centre.

Measurement of heart rate is used to establish warm ischemic times in small infants as blood pressure norms are at the same threshold to normal ischemic time measurements in adult patients (systolic 50 mmHg). Saturation monitoring maybe difficult to assess.

The normal process for mobilisation of abdominal teams should be applied, refer to **SOP4574** with close liaison with Hub Operations.
The NORS team may still require an abdominal en-bloc technique to remove the organ.

4.7. Processing

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

4.8. 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.

4.9. 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.

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_20) and PIP <30cm H_20
- 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

$PaO_2 \geq 10$ kPa (< 1-month $PaO_2 \geq 8$kPa)	U.O. 0.5 – 2 mls/kg/hr
$PaCO_2$ 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. SNOD to direct.

5.2 Door 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- 0.001units/kg/min (Max dose 4 u/hr)[3]
Vasopressin – treatment for Diabetes Insipidus [4]	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

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.

7. Referral / Notification in the Antenatal Period

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

NHS Blood and Transplant wishes to be supportive of the parent's wishes for their baby to be an organ donor. However, it is also necessary to be realistic in managing expectations. Therefore, parents and referring clinicians should be aware that, at present,

1. Hepatocytes may be prepared from a donated liver and used for transplantation.

2. Heart valves may be retrieved if the baby weighs more than 2.5kg.

3. Often, donation will not be possible, for the following reasons.

- Mode of delivery: to proceed with hepatocyte donation there should be an agreed planned elective Caesarean section irrespective of any discussions regarding organ donation. Heart valve only donation may be possible at the time of death irrespective of the delivery mode.

- The baby may be stillborn.

- As with other forms of DCD donation, the time interval between treatment withdrawal (which is considered to be the point of delivery and placental separation) and asystole may be prolonged.

7.1. Responding to the enquiry or referral

Each case must be discussed with the Team Manager, Regional Manager and Lead Nurse: Paediatric and Neonatal Donation and Transplantation, to define a clear plan of action, ideally prior to any family discussion and prior to any exploration around organ suitability with recipient centres.

The decision regarding proceeding to further planning of the process must be made in conjunction with the Regional Manager. Liaison with the Associate Medical Director (or in their absence the National Clinical Lead for Organ Donation) may be required following the planning meeting and any outstanding items clarified.

Subsequent planning meetings will be identified throughout the process as required. There may be the possibility that Kings College Hospital may accept hepatocytes for their transplant programme and following the initial planning calls timing for screening with Kings Colleague Hospital for hepatocytes will be determined. **FRM5510** Neonatal and Infant Donor Assessment and Organ Screening should be used for assessment. Heart valve donation may be possible should specific criteria be met; requirement can be determined shortly before the planned delivery date to ensure acuate information relating to requirement.

7.2. Liaising with the donor hospital multi-disciplinary team

If donation is a possibility, a local hospital team should be established to ensure that the necessary arrangements and safeguards are in place to support the process further. The team should include:

- SNOD Lead - Donation after Antenatal Diagnosis or Paediatric Lead for the region

- Hospital CLOD and SNOD

Appropriate clinical specialities as appropriate – obstetrics, midwifery, foetal medicine, neonatology, and palliative care.

It may be appropriate to inform the hospital governance (such as Head of Nursing, member of the hospital clinical ethics committee). The role of the team is to:

- Define and implement a pathway for donation which is acceptable locally and consistent with national guidance.
- Ensure that consent/authorisation for donation is fully informed and obtained in a timely fashion.
- Liaise with the retrieval and implanting teams and ensure that as much information as possible is available to guide donor assessment.

7.3. Consent / authorisation

It is vital that parents understand that the likelihood of donation taking place is low and that it may only be possible to use hepatocytes for transplantation.

7.4. Organ assessment

The following information should be made available to the retrieval surgeon

- Ante-natal ultrasound scan
- Report of foetal anomaly scan (performed at 16-20 weeks)
- Presence of any noted complications
- Estimate of foetal weight (this can be estimated by Ultrasound Scan and can be requested by the maternity team).
- Maternal U&Es

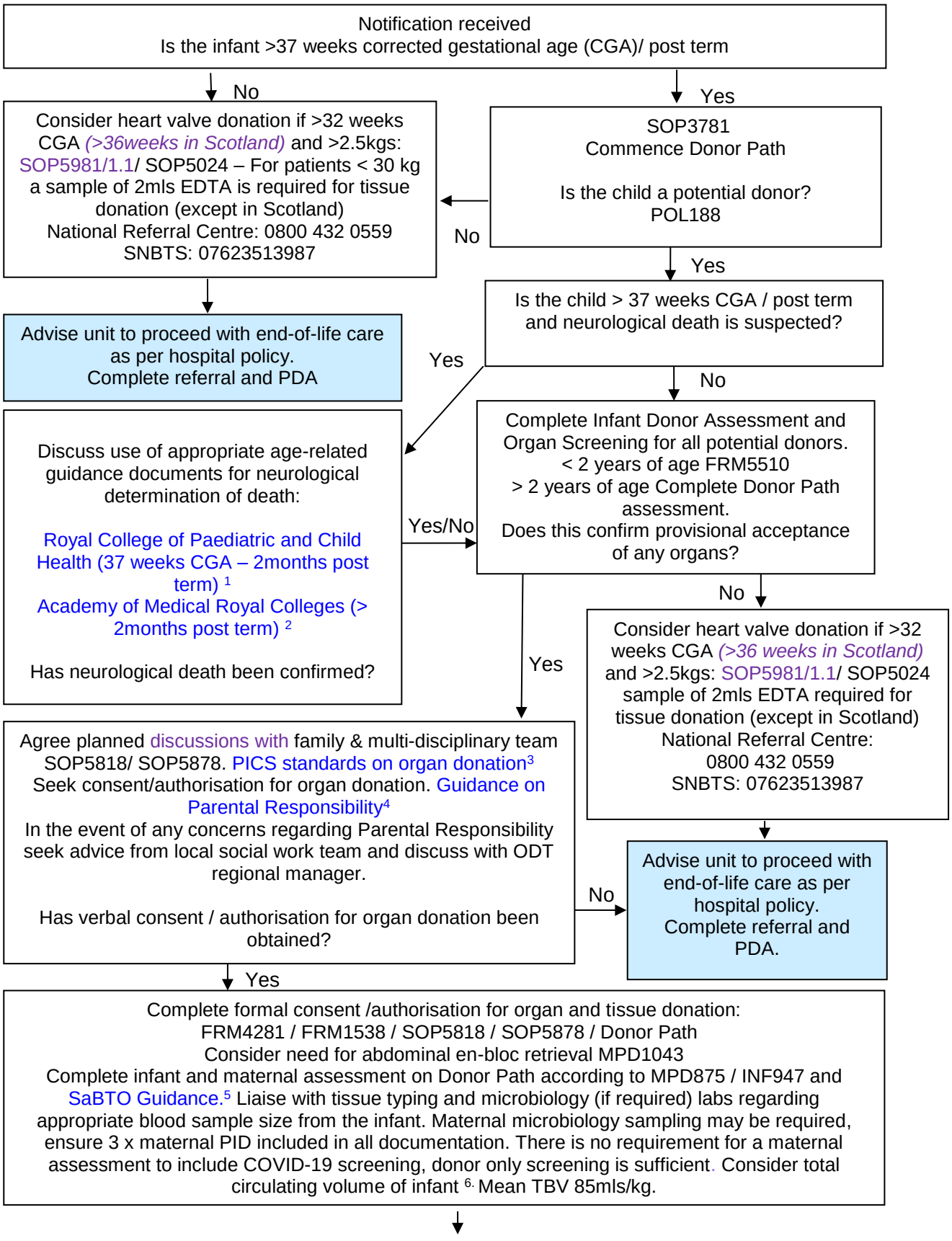
7.5. Post-donation support

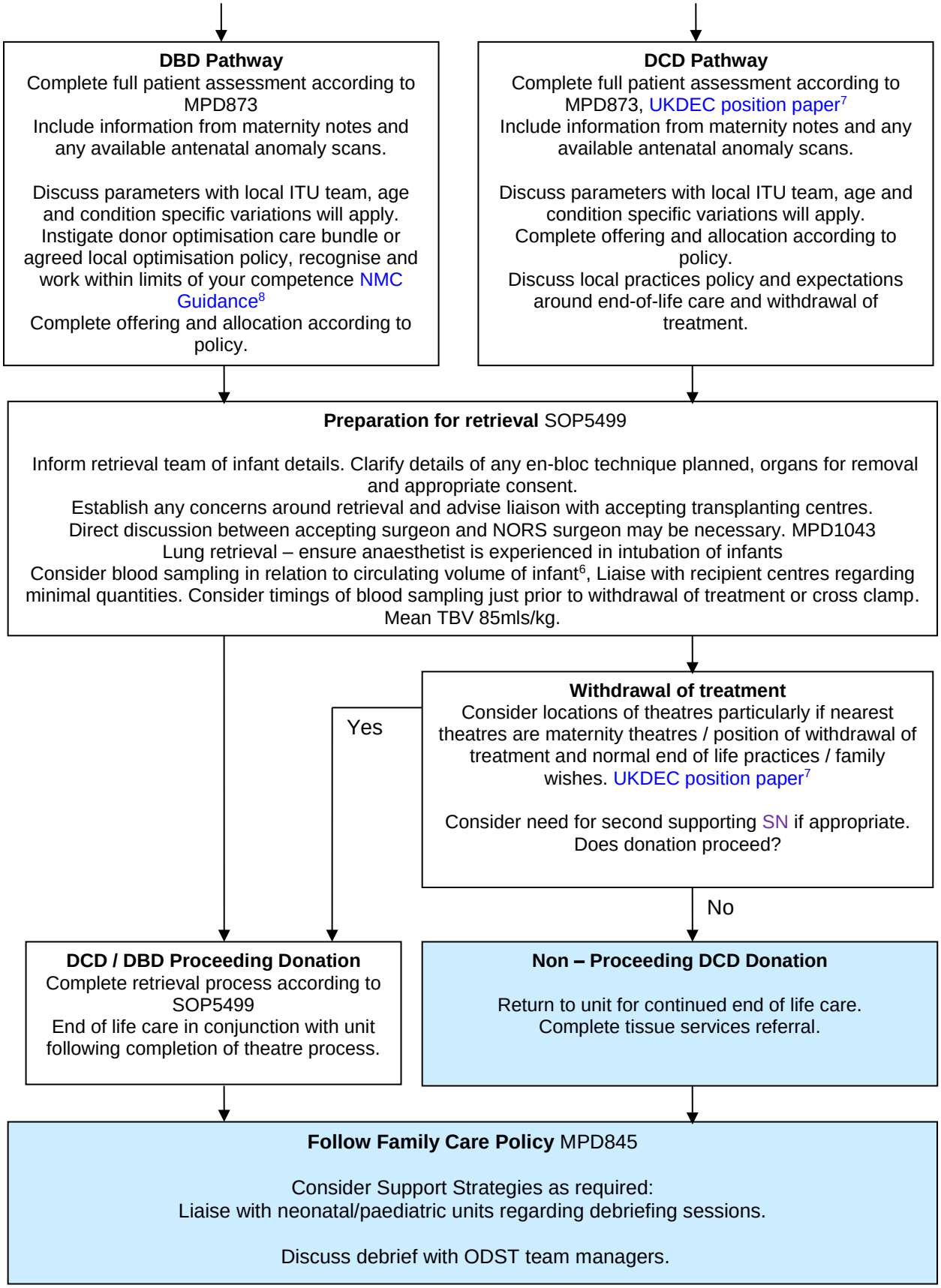
Whether or not donation proceeds, families will need support as is current practice.

Press attention: in some cases, parents or family members have shared their experience on social or other media. Families need to be counselled about the implications and timing of approaching the media. NHSBT Communications should be contacted so that the family can be offered the support they may want or need.

It should be remembered that such donations can have a psychological impact on the SN and retrieval team members and appropriate support may be needed.

Appendix 1: Paediatric Donation Flowchart




DBD Pathway
Complete full patient assessment according to MPD873
Include information from maternity notes and any available antenatal anomaly scans.
Discuss parameters with local ITU team, age and condition specific variations will apply.
Instigate donor optimisation care bundle or agreed local optimisation policy, recognise and work within limits of your competence NMC Guidance[8]
Complete offering and allocation according to policy.
DCD Pathway
Complete full patient assessment according to MPD873, UKDEC position paper[7]
Include information from maternity notes and any available antenatal anomaly scans.
Discuss parameters with local ITU team, age and condition specific variations will apply.
Complete offering and allocation according to policy.
Discuss local practices policy and expectations around end-of-life care and withdrawal of treatment.
Preparation for retrieval SOP5499
Inform retrieval team of infant details. Clarify details of any en-bloc technique planned, organs for removal and appropriate consent.
Establish any concerns around retrieval and advise liaison with accepting transplanting centres.
Direct discussion between accepting surgeon and NORS surgeon may be necessary. MPD1043
Lung retrieval – ensure anaesthetist is experienced in intubation of infants
Consider blood sampling in relation to circulating volume of infant[6], Liaise with recipient centres regarding minimal quantities. Consider timings of blood sampling just prior to withdrawal of treatment or cross clamp.
Mean TBV 85mls/kg.
Withdrawal of treatment
Consider locations of theatres particularly if nearest theatres are maternity theatres / position of withdrawal of treatment and normal end of life practices / family wishes. UKDEC position paper[7]
Consider need for second supporting SN if appropriate.
Does donation proceed?
Yes
No
DCD / DBD Proceeding Donation
Complete retrieval process according to SOP5499
End of life care in conjunction with unit following completion of theatre process.
Non – Proceeding DCD Donation
Return to unit for continued end of life care.
Complete tissue services referral.
Follow Family Care Policy MPD845
Consider Support Strategies as required:
Liaise with neonatal/paediatric units regarding debriefing sessions.
Discuss debrief with ODST team managers.

Appendix 2: Infant and Paediatric Notification Practice (iPNP)

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

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.

References

1. Howie (2011) Blood sample volumes in child health research: review of safe limits Bulletin of the World Health Organization 2011; 89:46-53. doi: 10.2471/BLT.10.080010
2. The Clinical Investigation Policy and Procedure Manual Document: research blood drawing guidelines (2012) Boston Children's Hospital USA.
3. Lee, C.A., Dhawan, A., Iansante, V., Lehec, S., Khorsandi, S.E., Filippi, C., Walker, S., Fernandez-Dacosta, R., Heaton, N., Bansal, S., Mitry, R.R. and Fitzpatrick, E. (2018), Cryopreserved neonatal hepatocytes may be a source for transplantation: Evaluation of functionality toward clinical use. Liver Transpl, 24: 394-406. doi.org/10.1002/lt.25015

References for Paediatric Donor Optimisation

1. European Paediatric Advanced Life Support 4th ed (2016). European Resuscitation Council. Lippincott Williams & Wilkins
2. Zimpfer, D et al. Paediatric Donor Management to Optimize Donor Heart Utilization. Pediatric Transplantation 2020; March 24(1):e13679 doi: 10.111/petr.13679
3. Howie SRC. Blood sample volumes in child health research: review of safe limits. Bulletin of the World Health Organization. 2011; 89:46-53. doi: 10.2471/ BLT.10.080010
4. Rozenfeld V, Cheng JW. The role of vasopressin in the treatment of vasodilation in shock states. Ann Pharmacother. 2000; 34:250-4
5. Ralston C & Butt W. Continuous vasopressin replacement in diabetes insipidus. Arch Dis. Child. 1990; 65: 896-897. doi 10.1136/adc.65.8.896
6. Malleroy GB Jr, Schecter MG, Elidemir O. Management of the Paediatric Organ donor to optimise lung donation. Paediatric Pulmonol. 2009 Jun; 44(6):536-46
7. Paediatric Formulary Committee. *BNF for Children* (2015-2016) London: BMJ Group, Pharmaceutical Press and RCPCH Publications; (2015)
8. Optimisation care bundle paediatric-optimisation-of-care-bundle-v2.pdf (windows.net)
9. Shemie. S. Organ donation management in Canada; recommendations of the forum on medical management to optimise donor organ potential. 2006; Mar 14; 174(6):s13-s30

References for Paediatric Donor Flowchart

1. RCPCH Guidance http://www.rcpch.ac.uk/system/files/protected/page/DNC%20Guide%20FINAL.pdf
2. AMORMC Guidance http://www.aomrc.org.uk/doc_details/42-a-code-of-practice-for-the-diagnosis-and-confirmation-of-death
3. Paediatric Intensive Care Society Standards on organ donation http://picsociety.uk/wp-content/uploads/2015/09/PICS-standards-for-organ-donation.docx
4. Parental Responsibility: Guidance from the British Medical Association, Ethics Department. October 2008. http://www.bma.org.uk/support-at-work/ethics/ethics-a-to-z

5. SaBTO guidance on the microbiological safety of human organs, tissue and cells used in transplantation https://www.gov.uk/government/publications/guidance-on-the-microbiological-safety-of-human-organs-tissues-and-cells-used-in-transplantation

6. Howie (2011) Blood sample volumes in child health research: review of safe limits Bulletin of the World Health Organization 2011; 89:46-53. doi: 10.2471/BLT.10.080010

7. UKDEC Position paper on Donation after Circulatory Death in Children http://www.aomrc.org.uk/general-news/ethical-issues-in-paediatric-organ-donation-a-position-paper-by-the-uk-donation-ethics-committee-ukdec.html

8. NMC guidance – https://www.nmc.org.uk/standards/code/ Recognise and work within the limits of competence Section 13.