

# UK Paediatric and Neonatal Deceased Donation

## A Strategic Plan

by the Paediatric Subgroup of the National Organ Donation Committee





## Acknowledgements

We are grateful to those who have contributed to the development of this strategy.

Our thanks go to the following groups and individuals, for their advice and support.

- Children's Palliative Care Services (NHS)
- Commissioning Team (NHSBT)
- Communication and Media Teams (NHSBT)
- Department of Health Policy Officer (TOT2020 Oversight Group)
- Donor Family Network (Charitable Organisation)
- Donor Family Care Service (NHSBT ODT)
- Lead Nurses and Team Managers (NHSBT ODT)
- Marketing Team (NHSBT)
- Neonatologists (NHS)
- Neonatal Clinical Nursing Teams (NHS)
- Paediatric Intensivists (NHS)
- Paediatric Clinical Nursing Teams (NHS)
- Paediatric Cardio-thoracic Transplanting Teams (NHS)
- Paediatric Transplanting Centres (NHS)
- Professional Development Team (NHSBT ODT)
- Transplant Commissioners (NHS England)
- Transplant Recipient Co-ordinator Teams (NHS)
- Transplant Recipient Families
- Regional Managers (NHSBT ODT)
- Scottish Government (NHS Scotland)
- Senior Management Team (NHSBT ODT)
- Specialist Nurses in Organ donation (NHSBT ODT)

The strategy is available on line via the following link:

<https://www.odt.nhs.uk/odt-structures-and-standards/key-strategies/paediatric-and-neonatal-donation-strategy/>

# Contents

|   |    |
|---|----|
| <b>Foreword</b>   | 3  |
| <b>Introduction</b>   | 4  |
| <b>Paediatric Strategic Plan</b>  | 8  |
| Overview of Paediatric Donation in the UK   | 8  |
| <b>Outcomes</b>   |    |
| 1: Organ and Tissue Donation as a routine part of End of Life Care                      | 10 |
| 2: Support for Paediatric Intensive Care Units  | 11 |
| 3: Paediatric Screening and Assessment  | 12 |
| 4: Post Donation Care   | 13 |
| 5: Paediatric Data and Key Performance Measures   | 14 |
| 6: Training and Education   | 15 |
| 7: National Organ Retrieval Service   | 16 |
| 8: Organ Offering, Allocation and Utilisation   | 17 |
| <b>Neonatal Strategic Plan</b>  |    |
| Overview of Neonatal Donation in the UK   | 18 |
| <b>Neonatal Outcome</b>   |    |
| Supporting Donation from Neonatal Intensive Care Units                                  | 19 |
| <b>Next Steps</b>   | 20 |
| <b>Conclusion</b>   | 21 |
| <b>References</b>   | 22 |
| <b>Appendices</b>   |    |
| Appendix A: Paediatric Strategy – Outcomes, Recommendations, Actions and Responsibility | 23 |
| Appendix B: Neonatal Strategy – Outcomes, Recommendations, Actions and Responsibility   | 34 |

## Foreword

Organ and tissue donation saves and improves the lives of thousands of UK citizens of all ages every year. It can offer comfort to the families of donors through the knowledge that something remarkable came from their loss.

In the UK in 2017-18, 17 children died while waiting for an organ transplant. The acute need for organs for donation in children is demonstrated most clearly by those requiring an urgent heart transplant; their waiting period is 2.5 times longer than adults on average. Despite this, not every family is given the opportunity to explore donation, even where it may have been possible.

Discussing the possibility of organ donation where the potential donor is a child demands specific and sensitive communication skills. This strategic plan for *Paediatric and Neonatal Deceased Organ Donation*, aims to build a framework that embeds organ donation as a routine end of life care choice for every family facing the death of their child, in circumstances where donation may be possible.

The proposed legislative changes for organ donation in the UK will most likely have the greatest impact on donation from adults. This strategic plan is therefore crucial in maintaining a focus on organ donation from children.

This strategy has been written in partnership with paediatric and neonatal professionals, the families of child donors, retrieval and transplant professionals and other partners. The recommendations found in this Strategic Plan are designed to assure health care professionals, families, children and society, that every gift of donation is precious and will be explored.

Only with your help can we achieve this.

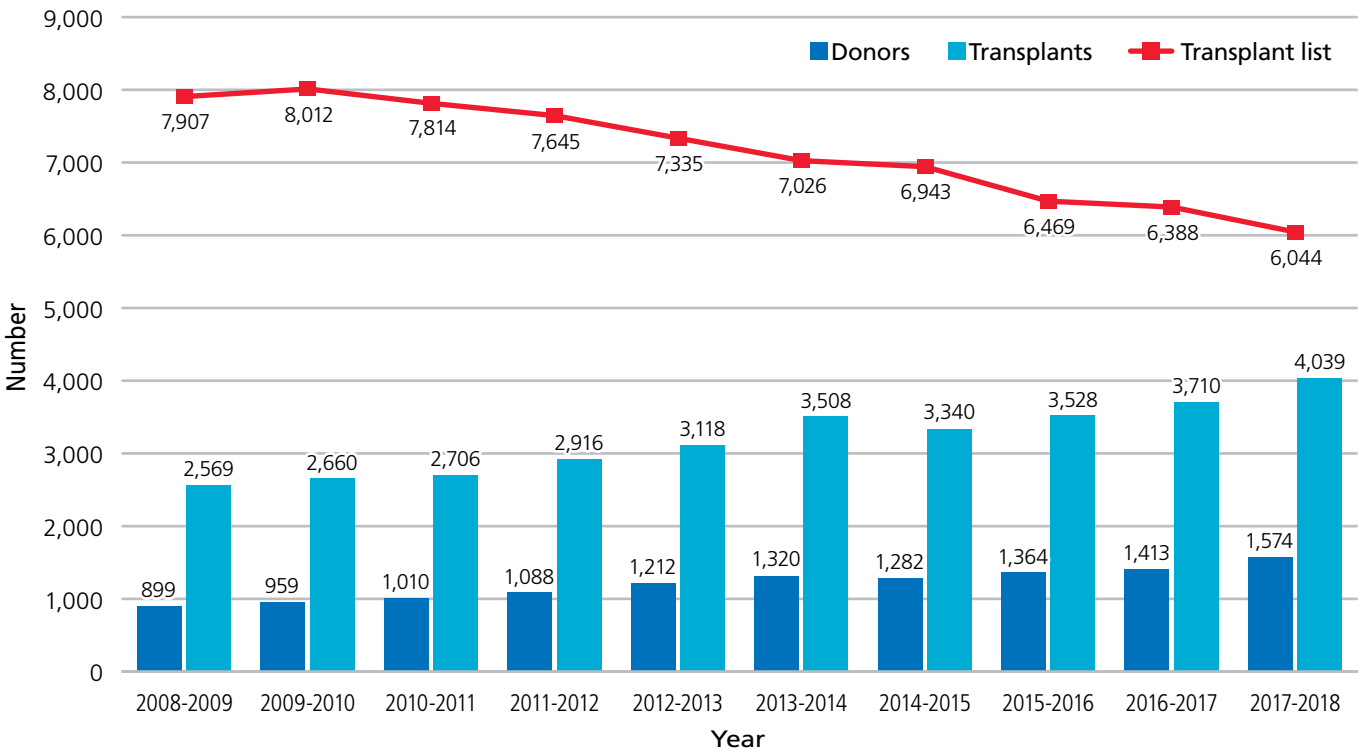
We commend this Strategic Plan to you.



# Introduction

Since 2008/09, UK deceased donation has risen 75% and the transplant waiting list has fallen for eight consecutive years (see Figure 1). In children deceased donation has not grown at the same rate and the same transplant benefits have not occurred (see Figure 2).

**Figure 1:** Number of deceased donors and transplants in the UK, 1 April 2008 – 31 March 2018, and patients on the active transplant list at 31 March



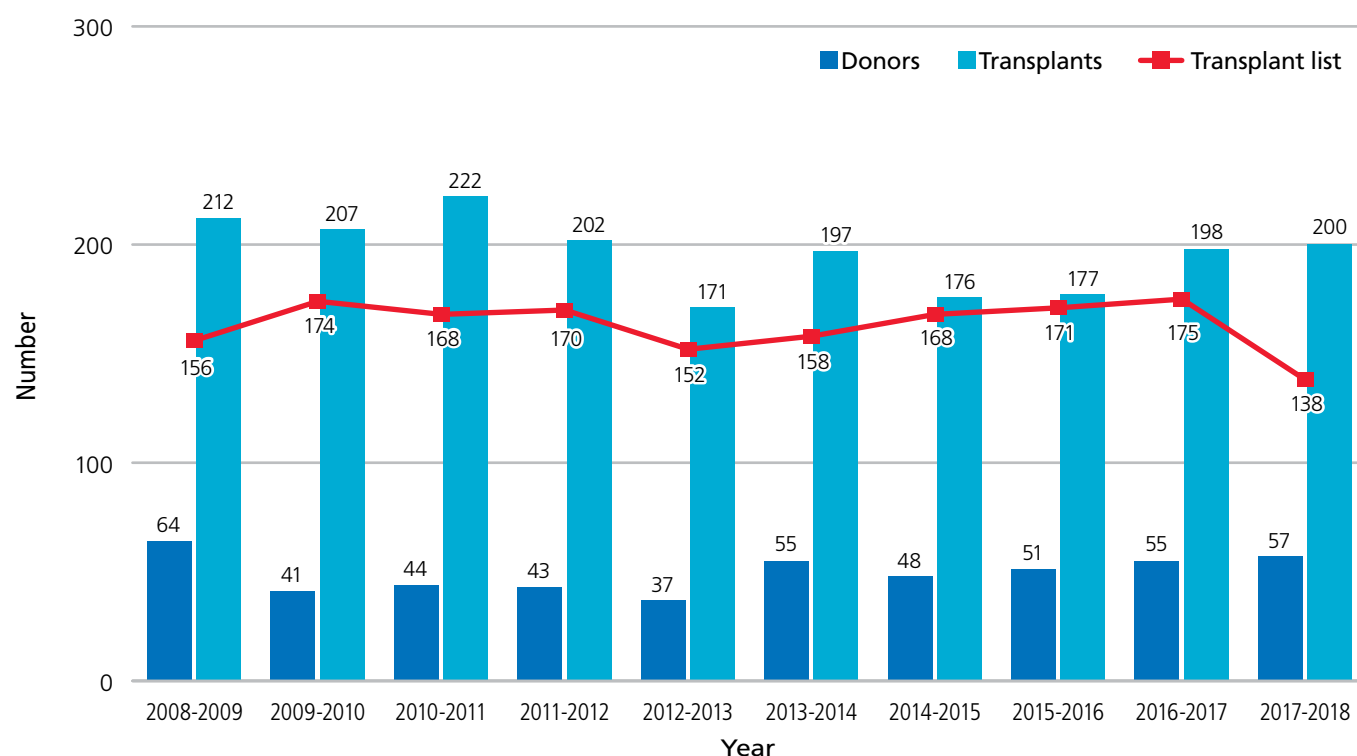
Source: Transplant activity in the UK, 2017–2018, NHS Blood and Transplant.



*“Our daughter died aged four while waiting for a heart transplant and we decided to allow her organs to be donated in the hope she can give the gift of life to others.”*

Aoife

**Figure 2:** Deceased paediatric donors (<18 years), transplants and active transplant list in the UK, 1 April 2008 to 31 March 2018



Source: Clinical Statistics NHSBT

The primary aim of this Strategic Plan is to significantly increase the rates of paediatric and neonatal deceased donation in the UK. The outcomes and recommendations of this Strategic Plan were constructed in partnership with colleagues from paediatric and neonatal specialties, donor and recipient families, and colleagues across NHS Blood and Transplant (NHSBT) and UK Transplantation centres. It reflects the shared ambition of embedding excellence in organ and tissue donation as a routine part of end of life care for children and families in paediatric and neonatal intensive care.

Children are not little adults. This Strategic Plan recognises that paediatric and neonatal donation has unique considerations, challenges and opportunities when a child is the potential donor; even if many of the technical aspects of the donation process remain unchanged. These considerations are especially true with regard to the role of parents who have the ability to provide fully informed consent/authorisation for their child.

The death of a child will not only have a profound impact on the child's family but will also impact on any professional involved in the child's care. The death of a child organ donor is no different. This Strategic Plan makes recommendations which will help support families and healthcare professionals through this tragedy as donation is explored, offered and facilitated. It is recognised that retrieval and theatre teams are an essential part of donation and transplantation and this Strategic Plan makes recommendations to support their involvement with child donors.


In this document a paediatric patient refers to a child from 28 days of life to the day of their 18th birthday.<sup>1</sup> A neonate is a child in the first 28 days of life.<sup>2</sup> However it is important to acknowledge that UK Paediatric Intensive Care is currently commissioned for children up to the age of 16 years and many Neonatal Intensive Care Units will look after children over 28 days old.



This strategic plan will consider donation from paediatric and from neonatal intensive care units separately, recognising the differing practices and needs of these environments and the families and professionals therein.

1. The Paediatric Strategic Plan will focus upon donation from children of all ages treated in Paediatric Intensive Care Units. Eight outcomes with recommendations are made. A summary and action plan can be seen in Appendix A.
2. The Neonatal Strategic Plan recognises the way Neonatal Intensive Care Units have recently embraced the opportunity for donation choice for families of infants as well as the impact on neonatal practice following the 2015 publication of the Royal College of Paediatrics and Child Health recommendations for 'The diagnosis of death by neurological criteria in infants less than two months old'. Though many of the paediatric recommendations are relevant in neonatal care, one specific outcome with recommendations is made to guide and support the exploration of donation in neonatal practice while recognising the rarity of this situation. A summary and action plan can be seen in Appendix B.

A small number of potential child donors may be cared for in critical care areas other than paediatric and neonatal units e.g. Emergency Departments and Adult Intensive Care Units. As a national strategy the aim is that donation is considered a routine part of a child's end of life care, it is therefore essential that all professionals caring for a potential child donor ensure that this option is considered, wherever the child is cared for.



*"If anything ever happens to me, I want to give my whole body away to save other children."*

Erin



## How the Strategic Plan relates to current and future Strategies

The Taking Organ Transplantation to 2020 (TOT 2020) UK wide Organ Donation Strategy published in 2013 commits NHSBT and the wider NHS and UK Governments to develop a world class service for organ donation and transplantation.<sup>3</sup> As stated above, considerable success towards this goal has already been made. While the TOT2020 does not specifically address paediatric and neonatal donation, it does provide the background direction and impetus behind all aspects of this Strategic Plan.

The call to action and the four outcomes from TOT2020 are given in Table 1. Each of these outcomes are appropriate for paediatric and neonatal donors.

**Table 1:** The four outcomes of the TOT2020 UK Strategy.

| Call to action                            |  |
|---|--|
| Who                                       | Outcome  |
| Society and individuals                   | Attitudes to organ donation will change and people will be proud to donate, when and if they can.  |
| NHS hospitals and staff (donation)        | Excellent care in support of organ donation will be routinely available and every effort made to ensure that each donor can give as many organs as possible. |
| NHS hospitals and staff (transplantation) | More organs will be usable, and surgeons will be better supported to transplant organs safely into the most appropriate recipient.                           |
| NHSBT and commissioners                   | Better support systems and processes will be in place to enable more donations and transplant operations to happen.  |

Action by society is a key element of TOT2020 and children can be pivotal drivers to both discussions in the home and long term societal change. Their representation is fully incorporated into current NHSBT and other behavioural change programmes that support the outcomes of TOT2020; this area is therefore not repeated in this Strategic Plan.

In line with the TOT2020 ambition for a world class service, donation and subsequent transplantation from smaller infants and neonates has increased. Historically such cases were rare. However, donations from these patients bring a number of technical and ethical challenges. The Strategic Plan makes recommendations in the Neonatal Strategic Plan for addressing this emerging area.

TOT2020 will come to an end in 2020 and a new UK strategy will be adopted. This Strategic Plan is written with the flexibility to develop action plans in line with any future UK strategy.

From the experience in Wales and considering the current legislative proposals in other parts of the UK, the benefits of an opt out system are most likely to be realised in adult patients. The impact of any legislative change to paediatric and neonatal organ donation may require the development of an individualised action plan specific to this area.

# Paediatric Strategic Plan

## Overview of Paediatric Donation in the UK

The current structure and practices for deceased organ donation was established in all acute NHS Trusts and Boards following implementation of the Organ Donation Taskforce recommendations in 2008.<sup>4</sup>

Table 2 provides a detailed breakdown, by age group, of multiple paediatric donation metrics from the Potential Donor Audit. For comparison data from children and young adults (aged 16-25) is given where deaths occurred predominantly in adult intensive care units.

Neither the Taskforce, its implementation or the subsequent TOT2020 Strategy addressed the specific issues that relate to paediatric practice.<sup>3,4</sup> In a 2018 review of organ donation from UK Paediatric Intensive Care Units (PICUs), wide variations were noted between PICUs in each stage of the organ donation process.<sup>5</sup>

The outcomes and supporting recommendations set out in this Strategic Plan aim to normalise practice, minimise variation and promote excellence in care, ensuring that donation is considered a routine part of end of life care on PICU. These recommendations are in complete alignment with national guidance as provided by the General Medical Council, the National Institute for Health and Clinical Evidence and the UK Paediatric Intensive Care Society.<sup>6-8</sup>

**Table 2:** Potential Donor Audit data April 1st, 2016 – March 31st, 2018; all donors by age group.

**Table 2a:** Referral by age group.

| Age group                     | Patients referred to SNOD |           | Referral rate (%) |           |
|-------------------------------|---------------------------|-----------|-------------------|-----------|
|                               | 2017/18                   | (2016/17) | 2017/18           | (2016/17) |
| 0 – <2                        | 106                       | (92)      | 80.9              | (73.6)    |
| 2 – <5                        | 27                        | (27)      | 93.1              | (81.8)    |
| 5 – <10                       | 32                        | (23)      | 88.9              | (79.3)    |
| 10 – <16                      | 55                        | (70)      | 85.9              | (89.7)    |
| All paediatric patients (<16) | 220                       | 212       | 84.6              | (80.0)    |
| 16 – <25                      | 226                       | (188)     | 97.8              | (93.5)    |

**Table 2b:** Death by Neurological Criteria by age group.

| Age group                     | Death by neurological criteria suspected |           | Neurological death tested |           | Neurological death testing rate (%) |           |
|-------------------------------|--|-----------|---------------------------|-----------|-------------------------------------|-----------|
|                               | 2017/18                                  | (2016/17) | 2017/18                   | (2016/17) | 2017/18                             | (2016/17) |
| 0 – <2                        | 20                                       | (18)      | 10                        | (12)      | 50.0                                | (66.7)    |
| 2 – <5                        | 11                                       | (15)      | 6                         | (10)      | 54.5                                | (66.7)    |
| 5 – <10                       | 15                                       | (15)      | 11                        | (12)      | 73.3                                | (80.0)    |
| 10 – <16                      | 33                                       | (39)      | 25                        | (26)      | 75.8                                | (66.7)    |
| All paediatric patients (<16) | 79                                       | (87)      | 52                        | 60        | 65.8                                | (69.0)    |
| 16 – <25                      | 131                                      | (103)     | 117                       | 86        | 89.3                                | (83.5)    |

**Table 2c:** Consent/Authorisation by age group.

| Age group                     | Families of eligible donors approached |           | Consent/authorisation ascertained |           | Consent/authorisation rate (%) |           | Consent/authorisation rate where SNOD present (%) |           |
|-------------------------------|--|-----------|-----------------------------------|-----------|--------------------------------|-----------|---|-----------|
|                               | 2017/18                                | (2016/17) | 2017/18                           | (2016/17) | 2017/18                        | (2016/17) | 2017/18   | (2016/17) |
| 0 – <2                        | 34                                     | (35)      | 12                                | (10)      | 35.3                           | (28.6)    | 50.0  | (43.5)    |
| 2 – <5                        | 15                                     | (16)      | 10                                | (5)       | 66.7                           | (31.3)    | 81.8  | (45.5)    |
| 5 – <10                       | 19                                     | (13)      | 9                                 | (6)       | 47.4                           | (46.2)    | 61.5  | (75.0)    |
| 10 – <16                      | 44                                     | (47)      | 20                                | (24)      | 45.5                           | (51.1)    | 57.1  | (58.3)    |
| All paediatric patients (<16) | 112                                    | (111)     | 51                                | (45)      | 45.5                           | (40.5)    | 59.3  | (53.8)    |
| 16 – <25                      | 161                                    | (127)     | 106                               | (87)      | 65.8                           | (68.5)    | 67.5  | (74.8)    |

**Table 2d:** Coroner/Procurator Fiscal (decline rates) by age group.

| Age group                     | Coroner/PF decline rate where requested for eligible donors (%) |           |
|-------------------------------|---|-----------|
|                               | 2017/18   | (2016/17) |
| 0 – <2                        | 46.4  | (48.2)    |
| 2 – <5                        | 23.1  | (15.4)    |
| 5 – <10                       | 6.7   | (30.0)    |
| 10 – <16                      | 8.0   | (13.5)    |
| All paediatric patients (<16) | 23.5  | (26.4)    |
| 16 – <25                      | 7.7   | (9.8)     |

**Table 2e:** Actual Donors by age group.

| Age group                     | Actual donors |           | Eligible donors by type DBD/DCD (%)* |
|-------------------------------|---------------|-----------|--------------------------------------|
|                               | 2017/18       | (2016/17) |                                      |
| 0 – <2                        | 4             | (6)       |                                      |
| 2 – <5                        | 9             | (5)       |                                      |
| 5 – <10                       | 7             | (5)       |                                      |
| 10 – <16                      | 18            | (19)      |                                      |
| All paediatric patients (<16) | 38            | (35)      | 22 /78                               |
| 16 – <25                      | 99            | (75)      | 58 /42                               |

\*DBD (Donation after the diagnosis of death by neurological criteria), DCD (Donation after circulatory death).

# Organ and Tissue Donation as a routine part of End of Life Care

## Outcome 1: Organ and Tissue Donation will be a routine part of end of life care on PICU

Every PICU strives to ensure excellence in end of life care and this should be reinforced through the offering of organ and tissue donation. Specialist Nurses in Organ Donation (SNODs) and PICU teams should work together to manage end of life care to ensure no opportunity is missed to offer organ or tissue donation.

Every family of a child who is approaching the end of life and has the potential to donate organs or tissues after death, should be offered this choice. Variations in PICU practice should not obstruct the offer and approach of families for deceased donation. All families in this situation will need additional communication and support and this can be achieved through an optimal combination of specialist knowledge from the local PICU and SNODs. Families and clinical staff will also benefit from clear explanations where donation may not be possible.

As part of the ongoing commitment to supporting paediatric donation, excellent relationships between every PICU and their NHSBT Regional Organ Donation Services Team will be needed to maximise local knowledge and build long-lasting professional relationships. Similar relationships are required with local coroner/procurator fiscal (PF) with the intention of minimising declines to donation proceeding.

## Recommendations

- 1.1 NHSBT should continue to support the provision of a National Paediatric Clinical Lead for Organ Donation (CLOD) and a Paediatric Subgroup of the National Organ Donation Committee to oversee and support this Strategic Plan.
- 1.2 As per existing national recommendations every PICU should have a named lead consultant with responsibility for organ donation.<sup>7,8</sup> NHSBT should consider the possibility that these consultants have their role formally recognised as a Clinical Lead for Organ Donation (CLOD), so that the consultants can receive reimbursement for this role. In every region a PICU Consultant should be identified to take on a regional role and represent the region on the Paediatric Subgroup of the National Organ Donation Committee.
- 1.3 The exploration of organ and tissue deceased donation should be incorporated into all PICUs end of life care practice.
- 1.4 National triggers for the identification and notification to NHSBT of potential paediatric donors should be developed and implemented in conjunction with key professional bodies. This will ensure that a SNOD is notified at the earliest point that end of life care options are being considered and will allow an appropriate and timely assessment of donation potential.
- 1.5 NHSBT should ensure that a SNOD is mobilised to support a potential paediatric organ donor at the optimal point in that process. Defining this point should form part of the ongoing implementation work of this Strategic Plan.
- 1.6 NHSBT will continue to work alongside Coroners/Procurator's Fiscal and Paediatric Pathologists to ensure that wherever possible, potential child donors should be allowed to proceed.
- 1.7 Families should be given the opportunity to consider organ and tissue donation, when donation is a possibility. This should be facilitated by collaborative discussions between the clinical team and SNODs to plan the most effective and supportive approach to the family. Consent/authorisation approaches for families where a child is the donor should be considered in light of research-based evidence and service evaluation.
- 1.8 SNODs should consider ways in which 'family time' can be maximised and least disrupted during the donation process, supporting key end of life care practice in PICU.

## **Outcome 2: All paediatric intensive care units will have specific support from NHSBT to achieve excellence in donation practice.**

.....

The taskforce recommendations in 2008 and the subsequent TOT2020 strategy have underpinned the increase in donation from adult areas.<sup>3,4</sup> This success was supported and delivered in a large part through the training and hospital engagement work of NHSBT SNODs. While there is ever increasing pressure on the SNOD resource and workforce it is essential that NHSBT provides the necessary SNOD personnel to PICUs. The role of the SNOD engaging with a PICU is to continue to embed excellence in donation practice through education, staff support and carrying out and acting on findings from the UK Potential Donor Audit. A key aspect of this will be for the SNOD to build the mutual trust and confidence with PICU staff to support end of life processes, that can lead to a family feeling empowered to embrace a donation choice. To achieve this the SNOD will need support from the named lead consultant with responsibility for organ donation in the PICU, the local CLOD (if a different person), the PICU Consultant with a regional role, senior nurses from the PICU, the Trust/Board Organ Donation Committee and regional and national SNOD structures.

### **Recommendations**

- 2.1 NHSBT should continue the current role of appointing a National Paediatric Lead Nurse who will support SNODs in a paediatric regional role and work with the National Paediatric CLOD to support the delivery of this Strategic Plan.
- 2.2 A named SNOD should be identified to engage with every PICU. NHSBT should allocate SNOD time and resource to ensure regular SNOD presence on PICUs in order to develop trusted and established relationships between the SNOD and PICU staff.
- 2.3 SNODs should provide PICU staff with the training and support necessary to develop and maintain their confidence in facilitating child donors.
- 2.4 Every Regional Organ Donation Services Team should have an identified SNOD with particular paediatric interest or experience. This SNOD will take on a regional role to act as a support and knowledge resource for local SNODs engaged with PICUs and SNODs in a specialist requestor role. These regional paediatric SNODs should have direct links to the PICUs in their region.
- 2.5 Any review of hospital donation resource allocation for both SNODs and CLODs, must consider the unique nature of children's hospitals/units to ensure that all PICUs receive the required level of support and resources from NHSBT.
- 2.6 NHSBT should support regular meetings for paediatric SNODs and CLODs.

## Outcome 3: Specific screening and assessment processes will be developed to ensure the safe and timely consideration of the potential for paediatric donation

Following PICU notification of a potential child donor to NHSBT, assessment of the child's suitability to donate needs to occur. Screening tools have been developed but these are primarily for adult patients and are not suitable to appropriately screen paediatric patients. Assessment and screening processes need to maximise donation from paediatric patients, give timely advice if donation is not possible and be balanced with the need to ensure the safety of any transplant recipient.

NHSBT is centralising many donation and transplantation processes to a new Organ Donation and Transplantation Operational HUB. The HUB will have oversight of referral, offering, allocation and mobilisation of the National Organ Retrieval Service.

### Recommendations

- 3.1 Assessment processes should be developed to fully support paediatric donation, which includes laboratory and tissue services.
- 3.2 The specific requirements of paediatric notifications and referrals (as well as both small infant and antenatal notifications – see Neonatal Strategic Plan below) must be considered throughout the development of the Organ Donation and Transplantation Operational HUB. Processes built into the work of the HUB should ensure optimal handling of these referrals.
- 3.3 DonorPath (the tablet-based mobile app for SNODs to enter donor data) should be adapted to ensure the inclusion of any additional information required for the assessment of paediatric and neonatal donors.
- 3.4 Development of a rapid and appropriate screening tool for children, in-line with Taking Organ Utilisation to 2020, should be considered.<sup>9</sup> This should ensure that no organ or tissue donation is put at risk by inadequate screening and will minimise delays in the exploration of donation.

*"Strangely enough the decision to donate Kyle's organs was easy. Kyle was a very caring young man and he would have wanted to help someone else."*

Alex and Tracy





## **Outcome 4: Post donation care will be tailored to the specific needs of the family after the loss of a child**

.....

The emotional complexities of child death often result in families requiring an increased level of information and support from both the PICU and NHSBT.

Many PICUs already offer shared bereavement care with local hospice teams, routine ongoing support by telephone and follow up appointments for families. Currently, the post donation contact from NHSBT does not formally differentiate between adult and child donors. More could be done to tailor information to the specific needs of the family of a child donor and integrate into routine PICU bereavement processes. Excellent donor family aftercare also includes ensuring that the gift of donation is fully recognised.

Although outside the scope of this Strategic Plan, support for the children of adult donors could be improved by the creation of specific resources and the sharing of best practice. This should be addressed in the longer term.

### **Recommendations**

- 4.1 SNODs should work with the PICU clinical team to integrate post donation care into routine bereavement processes.
- 4.2 A core level of bereavement resource should be available to families whenever donation from children occurs. This should include appropriate signposting to specialist bereavement support.
- 4.3 Post donation family communication with NHSBT must remain sensitive to the needs of the family and ensure that the gift of donation is fully recognised.



## **Outcome 5: Paediatric donation data and performance measures will be specifically focused to the needs of this patient group**

.....

Data is essential for guiding resource, effort and research. There is a known wide variation in UK PICU practice with regard to the exploration of deceased paediatric donation. Not all of this can be explained by local circumstance. Careful data collection and reflection are required if excellence in donation is to be embedded as a usual end of life care choice for every family facing the death of their child in circumstances where donation may be possible.

The use of such data should support the wider NHS philosophy of open data and transparency.

### **Recommendations**

- 5.1 All PICUs must continue to fully support the UK Potential Donor Audit (PDA). Additionally, paediatric specific data from the PDA should be published in an independent format.
- 5.2 Morbidity and mortality meetings should proactively consider donation in all children who die on PICU. Benchmarking and peer review processes across PICUs should be standard practice.
- 5.3 Paediatric donation should have specific key performance measures. Local actions should be developed by the CLOD and Organ Donation Committee to achieve these measures. Progress should be shared regionally and nationally.
- 5.4 Data from neonatal intensive care units should continue to be excluded from overall key performance measures until established data sets and support processes are in place across these units (see Neonatal Strategy on what actions should be taken).

## **Outcome 6: SNODs and all clinical staff likely to be involved in the treatment of potential child donors will have access to training and education tailored to address the unique considerations, challenges and opportunities of paediatric donation**

.....

Recommendation 11 of the Organ Donor Task Force (2008) is as true today as it was 10 years ago:

*“All clinical staff likely to be involved in the treatment of potential organ donors should receive mandatory training in the principles of donation. There should also be regular update training.”<sup>4</sup>*

TOT2020 emphasises the need for NHSBT to work with professional bodies to:

- Develop training programmes to sustain and increase clinicians’ organ donation understanding and expertise.
- Ensure that families of potential donors will only be approached by someone who is both specifically trained and competent in the role and provide training packages and accreditation to those who wish to develop this competence.
- Promote and support early and effective physiological optimisation of the potential donor (after the diagnosis of death by neurological criteria) through the adoption of the ‘donor care bundle’.<sup>3</sup>

The NHSBT Professional Development Team support all SNODs through a standard training programme. Although the specifics of paediatric donation feature throughout this training, NHSBT recognises that SNODs who are not familiar with the paediatric critical care environment will require additional support to improve their confidence.

NHSBT’s National Deceased Donation Course for Intensive Care Medicine Trainees currently contains limited paediatric specific training but feedback from paediatric intensive care trainees who have attended has been highly positive. Two bespoke paediatric simulation training day courses have been running in Bristol and Sheffield and local, hospital-based simulation courses that cater for paediatric staff also occur in a small number of UK hospitals.

The NHSBT online education tool, *Diagnosing Death using Neurological Criteria*, include paediatric specific videos which should be viewed by all potentially involved with this diagnosis ([www.odt.nhs.uk](http://www.odt.nhs.uk)).

## **Recommendations**

- 6.1 NHSBT should ensure that SNOD training fully incorporates paediatric donation so that all SNODs have the skills and confidence needed to work collaboratively and undertake donations in PICU.
- 6.2 Education and training should be provided to all clinical staff likely to be involved in the treatment of potential child donors.

## **Outcome 7: The National Organ Retrieval Service will ensure that there is consistently available expertise and skill to retrieve organs from all paediatric patients including small infants.**

.....

Organ donation from small paediatric patients can provide additional challenges for retrieval teams as they might only have experience in retrieving from larger paediatric donors/adults.

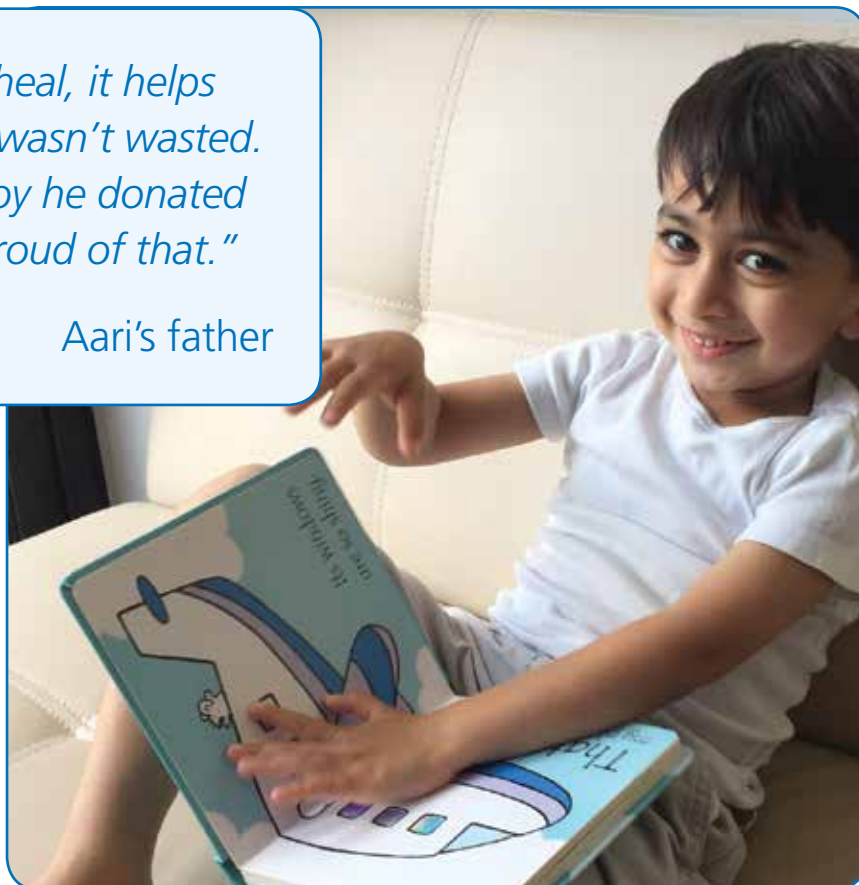
Currently NHSBT commissions specialist cardiothoracic teams to retrieve organs from donors <145 cm in height. There are no similar arrangements for abdominal retrieval.

### **Recommendations**

- 7.1 NHSBT should continue to collaborate with NORS and transplanting centres through clinical governance systems to review and discuss specific challenges in relation to retrieval from very small donors.
- 7.2 NHSBT will work with the NORS leads/National Retrieval Group to scope the need for any specific training strategies which may be required to achieve Outcome 7.
- 7.3 Protocols included in the NORS guidance should be specific where retrieval is from very small donors, for example: a preservation protocol.
- 7.4 In cases where an abdominal team does not feel confident to retrieve from very small donors, a surgeon from the transplanting centre should consider attending the donating hospital to provide additional support to the NORS team. Responsibility for the retrieval remains with the identified NORS team.

*"This one thing helps us heal, it helps us believe that Aari's life wasn't wasted. While we lost our little boy he donated his organs, and we are proud of that."*

Aari's father



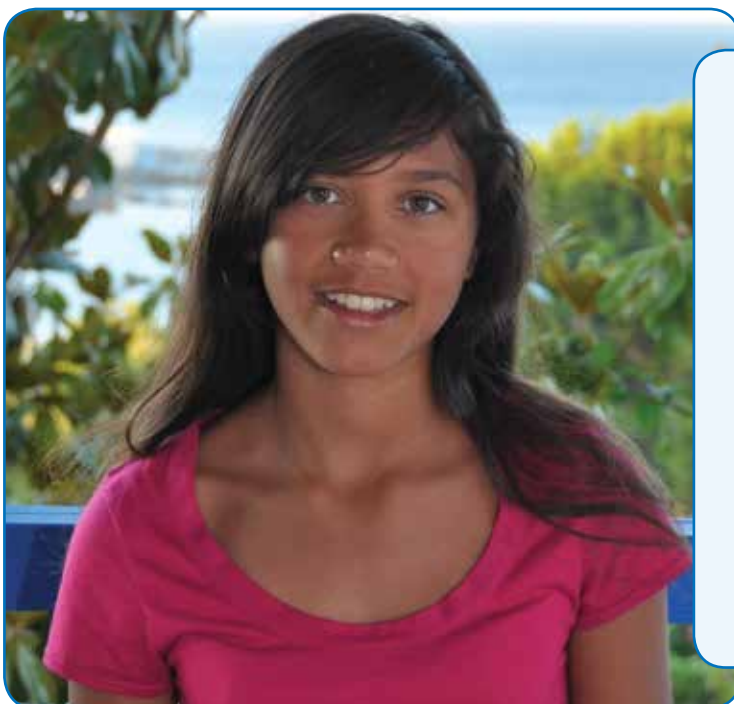
## **Outcome 8: Organ offering, allocation and utilisation policies and practices will maximise donation and transplantation opportunities from every paediatric donor.**

All patients, not only children, can benefit from organs donated by children. Utilisation rates in children >5 years old are high and on average organs per donor are above that seen in adult patients. However, there is a low organ utilisation in donors <5 years old, though this varies by donor and organs transplanted.

Currently cardiothoracic organs from paediatric donors are prioritised to child-recipients listed as urgent ahead of super-urgent adult recipients. In liver allocation super urgent patients of any age take priority and in renal allocation, there is some prioritisation for child-recipients.

### **Recommendations**

- 8.1 There should be specific paediatric representation on NHSBT advisory groups and strategic working groups to ensure that all processes and recommendations are equally addressed for paediatric donors and recipients. This should support delivery of the recommendations in *Taking Organ Utilisation to 2020*.<sup>9</sup>
- 8.2 Work should be undertaken to ensure there is a full understanding of the numbers and types of transplants currently required by children and adults who could benefit from the organ of a donor <5 years old.
- 8.3 Allocation and organ matching policies should consider both the overall aim to increase organ utilisation from paediatric donors and the specific needs of child-recipients.
- 8.4 Clinical teams, SNODs and NORS teams must work together to ensure successful optimal organ utilisation, while maintaining excellence in end of life care for paediatric donors.



*"We had no idea Jemima was the only person to donate eight organs to eight different people until NHS Blood and Transplant informed us. Everyone wants their child to be special and unique and this among other things makes us very proud.."*

Jemima's mum

## Overview of Neonatal Donation in the UK

Donation from infants and neonates has increased in the last few years. Prior to 2012 there were only isolated and rare cases.

Factors influencing this recent increase include:

- expertise in transplantation techniques of smaller sized organs
- family request to consider donation
- a desire by neonatal intensive care units to embrace the option of donation as an end of life choice for their families
- new guidance from the Royal College of Paediatrics and Child Health which allows for the determination of death by neurological criteria in infants under two months of age
- media interest.

While a neonate is a child in the first 28 days of life, many Neonatal Intensive Care Units (NICUs) will look after children over 28 days old.<sup>1</sup> Neonates may also be cared for on a PICU where there are more established processes to support donation. The consequence of this is that a neonate cared for on a PICU is more likely to have organ donation considered as part of their end of life care.

Many NICUs have made it clear that they wish to embrace the option of donation as an end of life choice for their families. There are additional challenges in donation and transplantation from infants. These include ethical challenges, the need to ensure appropriate and timely access to specialist resources to support donation and the need for transplantation teams with knowledge and expertise of the unique techniques required in the transplantation of organs from these patients.

This Strategic Plan is committed to working collaboratively with NICUs to establish processes to support organ donation and allow donation to be considered by families on these units. A key first step is to understand in greater detail the challenges in neonatal donation and transplantation. This will enable future improvements so that excellence in organ and tissue donation is embedded as a routine and usual part of neonatal intensive care when caring for children and families at the end of life.



*"Knowing Minnie was not expected to survive, we asked medical staff if it would be possible to donate her organs to others. Minnie became the first neonatal organ donor in Yorkshire."*

Ami and Liam



## Neonatal Outcome: No opportunity for organ and tissue donation from a neonate will be missed.

Deceased donation is a relatively new concept for NICUs. In cases where donation has proceeded from neonates this has generated strong positive outcomes for donor families as well as media interest. What is less well understood is the potential for organ donation from this group and the implications to transplant recipients.

Currently half the level 3 neonatal units in the UK input audit information. An understanding of the potential for neonatal donation is key to both managing resources and influencing treatment options and therefore impacts on all aspects of the donation and transplantation process.

Moving forward the potential for donation, transplant need and resources required to support these donations requires further exploration prior to more extensive active promotion. However, many of the outcomes, recommendations and actions from the above Paediatric Strategy remain relevant.

## Recommendations

- N.1 NHSBT must provide support from SNODs where there is potential for donation.
- N.2 NHSBT in conjunction with neonatal intensive care units will work to develop a system of undertaking audit and data analysis for determining the potential for donation in all level 3 neonatal units across the UK.
- N.3 Clear guidance should be established on expectations around notification of potential donors and donation from neonatal units.
- N.4. In cases where there is an antenatal diagnosis, discussions regarding the possibility of organ donation should only take place when raised as an option by a family. In these situations, assessment should be on an individual basis and support offered while expectations of professionals and families are managed.
- N.5 The safe diagnosis of death by neurological criteria should be maintained through education, training and the use of standardised forms.
- N.6 The technical and ethical challenges in neonatal donation and transplantation should be more fully explored.
- N.7 The recommendations and actions from the Paediatric Strategic Plan, where relevant to neonatal donation, should be incorporated into NICU practice.

## Next Steps

This Paediatric and Neonatal Strategic Plan should be considered supplementary to the work already occurring in delivering the *Taking Organ Donation to 2020 UK Strategy*<sup>3</sup> and has been written flexibly to be adaptable to envisaged future strategies. The aim of the Strategic Plan is to embed paediatric and neonatal organ and tissue donation into routine end of life care planning.

A detailed action delivery plan will be developed as each outcome is addressed through the relevant workstreams, led by the Paediatric Subgroup of the National Organ Donation Committee. It is anticipated that workstream development will commence in the final quarter of 2018 and a review of progress will be held on a 6-monthly basis. Annual review and feedback will be given to the full National Organ Donation Committee, NHSBT's Organ Donation and Transplantation Senior Management Team and other key stakeholders.

It is not envisaged that additional funding will be required in the early stages of the Strategic Plan's delivery. As the plan develops some initiatives and developments may require additional resources. These will need to be considered and justified separately.

It is recognised that as a donation focused strategy there are a number of important health and societal considerations around children that are not addressed herein. These include, but are not limited to, children dying outside the PICU environment, supporting children of adult donors and children as change makers in society. Societal issues for children are addressed in the wider NHSBT Behaviour Change Strategy and those interested in engaging in this process are encouraged to participate in that work.<sup>10</sup> Some children will be cared for in scenarios that are not addressed in this strategy, however the delivery of the recommendations in this strategy will provide the environment in which these areas can be supported in the future.



## Conclusion

The ambition of the *UK Paediatric and Neonatal Deceased Donation: A Strategic Plan* is to embed excellence in organ and tissue donation as a routine part of paediatric and neonatal end of life, especially in the intensive care setting. The outcomes, recommendations and associated actions contained within the Strategic Plan are the result of collaborative thinking across NHSBT and the Paediatric and Neonatal professions. As such it marks a clear commitment to ensuring that organ and tissue donation is treated as a fundamental part of end of life care, which should be considered in every child who is dying.

It is incumbent upon all of us, who work with paediatric and neonatal patients and their families, to be able to confidently assert that every family of a child who is approaching the end of their life and has the potential to donate organs, will be offered this choice and this choice will always be fully explored.



*Conner made the decision to register as an organ donor when he was 16. Sadly only two years later his choice became a reality. Three families were given a precious gift from a very precious young man.*

## References

1. National Society for the Prevention of Cruelty to Children: Legal Definitions [online]. Available from <https://www.nspcc.org.uk/preventing-abuse/child-protection-system/legal-definition-child-rights-law/legal-definitions/> [Accessed 26 April 2018].
2. World Health Organisation: Infant new-born [online]. Available from [http://www.who.int/topics/infant\\_newborn/en/](http://www.who.int/topics/infant_newborn/en/) [Accessed 26 April 2018].
3. Taking Organ Transplantation to 2020: A detailed Strategy. NHS Blood and Transplant 2013 [online]. Available from <https://www.nhsbt.nhs.uk/tot2020/> [Accessed 26 April 2018].
4. Department of Health. Organ Donation Taskforce Organs for Transplants: A report from the Organ Donation Taskforce 2008. HMSO. London.
5. Hawkins K, Scales A, Murphy P, Madden S, Brierley J (2018) Current Status of Paediatric and Neonatal Organ Donation in the UK. Arch Dis Child. Volume 103;3 p 210-215.
6. General Medical Council Guidance (May 2010) Treatment and Care towards the end of life: good practice in decision making [online]. Available from [https://www.gmc-uk.org/-/media/documents/treatment-and-care-towards-the-end-of-life---english-1015\\_pdf-48902105.pdf](https://www.gmc-uk.org/-/media/documents/treatment-and-care-towards-the-end-of-life---english-1015_pdf-48902105.pdf) [Accessed on April 26th 2018].
7. National Institute for Health and Care Excellence: Clinical Guidance 135; December 2011. Organ Donation for transplantation: improving donor identification and consent rates for deceased organ donation. Available from <https://www.nice.org.uk/guidance/cg135> [Accessed 26 April 2018]
8. UK Paediatric Intensive Care Society: Standards for Organ Donation. January 2014. [online] Available from <http://picsociety.uk/resources/> [Accessed 13 July 2018]
9. Taking Organ Utilisation to 2020. NHS Blood and Transplant 2017 [online]. Available from <https://www.odt.nhs.uk/odt-structures-and-standards/key-strategies/taking-organ-utilisation-to-2020/> [Accessed 19 July 2018]
10. NHS Blood and Transplant. A strategy for delivering a revolution in public behaviour in relation to organ donation 2014 [online]. Available from <http://www.nhsbt.nhs.uk/tot2020/about-the-strategy/changing-behaviour/> [Accessed on 26 April 2018]

## Appendix A: Paediatric Strategy – Outcomes, Recommendations, Actions and Responsibility

| Outcome 1<br>Organ and Tissue Donation will be a routine part of end of life care on PICU  |  |   |
|--|--|---|
| Recommendation   | Action/s   | Responsibility  |
| 1.1 NHSBT should continue to support the provision of a National Paediatric CLOD and a Paediatric Subgroup of the National Organ Donation Committee to oversee and support this Strategic Plan.  | 1a. NHSBT will support the provision for a National Paediatric CLOD.<br>1b. The National Paediatric CLOD should be involved in the interview of any standalone paediatric hospital CLOD and should give advice to the appointment process for PICU CLODs.<br>1c. NHSBT will support a paediatric subgroup of the National Organ Donation Committee (Paediatric NODC) to support and oversee this Strategic Plan. | NHSBT<br><br>National Paediatric CLOD<br><br>NHSBT  |
| 1.2 As per existing national recommendations every PICU should have a named lead consultant with responsibility for organ donation. NHSBT should consider the possibility that these consultants have their role formally recognised as a CLOD, so that the consultants can receive reimbursement for this role. In every region a PICU Consultant should be identified to take on a regional role and represent the region on the Paediatric Subgroup of the National Organ Donation Committee. | 1d. PICUs will have a named lead consultant with responsibility for organ donation.<br>1e. NHSBT will investigate the possibility that these consultants have their role formally recognised as a CLOD.<br>1f. Every Regional Organ Donation Services Team will identify a PICU Consultant to take on a regional role to support PICU donation and represent the region on paediatric NODC.                      | Trust/Boards<br>Paediatric NODC<br><br>NHSBT<br><br>NHSBT   |
| 1.3 The exploration of organ and tissue deceased donation should be incorporated into all PICUs end of life care practice.   | 1g. All local end of life pathway/ protocols/care guides to incorporate organ and tissue donation as a routine end of life care consideration.   | Named PICU lead consultant with responsibility for organ donation working with local CLOD (if different person) and local paediatric palliative care and chaplaincy services. |

| <b>Outcome 1</b><br><b>Organ and Tissue Donation will be a routine part of end of life care on PICU</b>   |  |   |
|---|--|---|
| <b>Recommendation</b>   | <b>Action/s</b>  | <b>Responsibility</b>   |
| 1.4 National triggers for the identification and notification to NHSBT of potential paediatric donors should be developed and implemented in conjunction with key professional bodies. This will ensure that a SNOD is notified at the earliest point that end of life care options are being considered and will allow an appropriate and timely assessment of donation potential.   | 1h. Establish national identification and notification triggers.<br>1i. Incorporate national triggers into local PICU practice and ensure no opportunities to explore organ or tissue donation are missed.<br>1j. Develop a robust system to assess and act on early notification to NHSBT.          | Paediatric NODC<br><br>Named lead consultant with responsibility for organ donation working with local CLOD (if different person).<br><br>NHSBT |
| 1.5 NHSBT will work to ensure that a SNOD is mobilised to support a potential paediatric organ donor at the optimal point in that process. Defining this point should form part of the ongoing implementation work of this Strategic Plan.  | 1k. Working with key professional bodies define the optimal point for SNOD mobilisation.<br>1l. Ensure timely and appropriate SNOD mobilisation.   | Paediatric NODC<br><br>NHSBT  |
| 1.6 NHSBT should continue to work alongside Coroners/Procurator's Fiscal and Paediatric Pathologists to ensure that wherever possible, potential child donors should be allowed to proceed.   | 1m. Maintain close working relationships with Coroners/ Procurator's Fiscal, Senior Investigating Officer and Paediatric Pathologists and support the development of guidance to mitigate decline rates wherever possible.   | NHSBT   |
| 1.7 Families should be given the opportunity to consider organ and tissue donation, when donation is a possibility. This should be facilitated by collaborative discussions between the clinical team and SNODs to plan the most effective and supportive approach to the family. Consent/authorisation approaches for families where a child is the donor should be considered in light of research-based evidence and service evaluation. | 1n. The national team of SNODs will be supported to continuously develop the skills required to approach a family for organ donation where the potential donor is a child.<br>1o. Research and service evaluation of consent/authorisation approaches to families should be encouraged and reviewed. | NHSBT<br><br>NHSBT<br>Paediatric NODC   |

| <b>Outcome 1</b><br><b>Organ and Tissue Donation will be a routine part of end of life care on PICU</b>   |   |  |
|---|---|--|
| <b>Recommendation</b>   | <b>Action/s</b>   | <b>Responsibility</b>  |
| 1.8 SNODs should consider ways in which 'family time' can be maximised and least disrupted during the donation process, supporting key end of life care practice in PICU. | 1p. Organ donation policies will include ways to enhance end of life care for child donors and their families while balancing adequate time for the completion of the organ donation process. | Named PICU lead consultant with responsibility for organ donation working with local CLOD (if different person) and local SNODs. |

**Outcome 2**  
**All paediatric intensive care units should have specific support from NHSBT to achieve excellence in donation practice.**

| Recommendation  | Action/s  | Responsibility                             |
|---|---|--|
| 2.1 NHSBT should continue the current role of appointing a National Paediatric Lead Nurse who will support SNODs in a paediatric regional role and work with the National Paediatric CLOD to support the delivery of this Strategic Plan.   | 2a. The National Lead Nurse role should be continued.   | NHSBT                                      |
| 2.2 A named SNOD should be identified to engage with every PICU. NHSBT should allocate SNOD time and resource to ensure regular SNOD presence on PICUs in order to develop trusted and established relationships between the SNOD and PICU staff.   | 2b. A named SNOD for every PICU will be identified and resources allocated to ensure the SNOD has increased PICU visibility.  | NHSBT                                      |
| 2.3 SNODs will provide PICU staff with the training and support necessary to develop and maintain their confidence in facilitating child donors.  | 2c. Develop accessibility of specific paediatric and neonatal advice and resources.<br>2d. Ensure a clear support network is directly available to those managing any donation from a child.  | NHSBT<br>National Lead Nurse<br>NHSBT      |
| 2.4 Every Regional Organ Donation Services Team should have an identified SNOD with particular paediatric interest or experience. This SNOD will take on a regional role to act as a support and knowledge resource for local SNODs engaged with PICUs and SNODs in a specialist requestor role. These regional paediatric SNODs should have direct links to the PICUs in their region. | 2e. Every Regional Organ Donation Services Team will identify a SNOD with particular paediatric interest or experience who will take on a regional role to act as a support and knowledge resource for local SNODs engaged with PICUs and SNODs in a specialist requestor role. | NHSBT                                      |
| 2.5 Any review of hospital donation resource allocation for both SNODs and CLODs, must consider the unique nature of children's hospitals/units to ensure that all PICUs receive the required level of support and resources from NHSBT.  | 2f. Before changing resource allocation of CLOD or SNOD time to any PICU Regional Managers and Regional CLODs will consider the impact such a change may have on achieving the recommendations in this Strategic Plan.  | NHSBT Regional Managers and Regional CLODs |
| 2.6 NHSBT should support regular meetings for paediatric SNODs and CLODs.   | 2g. NHSBT will support regular meetings for paediatric SNODs and CLODs, finance dependent.  | NHSBT                                      |

**Outcome 3**  
**Specific screening and assessment processes for the safe and timely consideration of the potential for paediatric donation will be created.**

| Recommendation  | Action/s   | Responsibility               |
|---|--|------------------------------|
| 3.1 Assessment processes should be developed to fully support paediatric donation, which includes laboratory and tissue services.   | 3a. Review all assessment processes and the implications for paediatric organ and tissue donors.<br><br>3b. Investigate paediatric corrections for haemodilution calculation and blood sampling processes.   | Paediatric NODC<br><br>NHSBT |
| 3.2 The specific requirements of paediatric notifications and referrals (as well as both small infant and antenatal notifications – see Neonatal Strategic Plan below) must be considered throughout the development of the Organ Donation and Transplantation Operational HUB. Processes built into the work of the HUB should ensure optimal handling of these referrals. | 3c. Develop any specific adaptations required for the referral of paediatric (and neonatal) potential donors in the HUB development processes.   | NHSBT                        |
| 3.3 DonorPath should be adapted to ensure the inclusion of any additional information required for the assessment of paediatric and neonatal donors.  | 3d. Review DonorPath to ensure that all specific assessment details needed for paediatric (and neonatal) cases are added and can be safely recorded. The adaptation of DonorPath to be in line with appropriate funding applications and prioritisation. | NHSBT<br>National Lead Nurse |
| 3.4 Development of a rapid and appropriate screening tool for children, in-line with Taking Organ Utilisation to 2020, should be considered. This should ensure that no organ or tissue donation is put at risk by inadequate screening and will minimise delays in the exploration of donation.  | 3e. Develop a screening tool for use following PICU notification of a potential child donor.   | NHSBT                        |



| <b>Outcome 4</b><br><b>Post donation care will be tailored towards the specific needs of the family after the loss of a child.</b>  |   |   |
|---|---|---|
| <b>Recommendation</b>   | <b>Action/s</b>   | <b>Responsibility</b>   |
| 4.1 SNODs should work with the PICU clinical team to integrate post donation care into routine bereavement processes.   | 4a. NHSBT will carry out a scoping exercise to review post donation care provided by SNODs.<br><br>4b. The reviews will be presented to the Paediatric Subgroup of the National Organ Donation Committee where best practice recommendations will be made and disseminated.   | NHSBT<br><br>Paediatric NODC  |
| 4.2 A core level of bereavement resource should be available to families whenever donation from children occurs. This should include appropriate signposting to specialist bereavement support. | 4c. NHSBT will develop resources to enhance post donation family care and make these available to all PICUs, where required.  | NHSBT<br>National Lead Nurse  |
| 4.3 Post donation family communication with NHSBT must remain sensitive to the needs of the family and ensure that the gift of donation is fully recognised.                                    | 4d. All local PICU post donation communication for families after the death of a child at any age will be reviewed and updated as needed to ensure that specific needs are met and best practice occurring.<br><br>4e. NHSBT's Organ Donor Family Aftercare Service will develop communication tools for use with paediatric donor families, ensuring that they receive the sensitive support they require throughout their post donation contact with NHSBT. | Local PICU SNOD.<br>Named lead consultant with responsibility for organ donation working with local CLOD (if different person).<br><br>NHSBT's Organ Donor Family Aftercare Service |

| <b>Outcome 5</b><br><b>Paediatric donation data and performance measures will be specifically focused to the needs of this patient group.</b>   |  |  |
|---|--|--|
| <b>Recommendation</b>   | <b>Action/s</b>  | <b>Responsibility</b>  |
| 5.1 All PICU's must continue to fully support the UK Potential Donor Audit (PDA). Additionally, paediatric specific data from the PDA should be published in an independent format.   | 5a. Paediatric specific data from the PDA will be published annually and summary data incorporated biannually into regional slide sets.  | NHSBT  |
| 5.2 Morbidity and mortality meetings should proactively consider donation in all children who die on PICU. Benchmarking and peer review processes across PICUs should be standard practice.   | 5b. Local CLODs will ensure that donation is incorporated into PICU morbidity and mortality meetings.  | Local CLOD   |
|   | 5c. Establish a peer review process for all PICUs to support development and share practice.   | Paediatric NODC  |
| 5.3 Paediatric donation should have specific key performance measures. Local actions should be developed by the CLOD and Organ Donation Committee to achieve these measures. Progress should be shared locally, regionally and nationally.                  | 5d. Establish specific relevant performance measures for paediatric units with a clear measuring structure in place to identify key areas of focus that are required.                | Paediatric NODC  |
|   | 5e. CLODs and Organ Donation Committee Chairs will be given clear guidance to ensure that paediatric specific actions are developed and reviewed locally, regionally and nationally. | Local CLOD<br>ODC Chair<br>National Paediatric CLOD<br>National Lead Nurse |
| 5.4 Data from neonatal intensive care units should continue to be excluded from overall key performance measures until established data sets and support processes are in place across these units (see Neonatal Strategy on what actions should be taken). | 5f. For the time being exclude neonatal intensive care units from overall paediatric key performance measures.   | NHSBT  |

## Outcome 6

**SNODs and all clinical staff likely to be involved in the treatment of potential child donors will have access to training and education tailored to address the unique considerations, challenges and opportunities of paediatric donation.**

| Recommendation   | Action/s  | Responsibility   |
|--|---|--|
| 6.1 NHSBT should ensure that SNOD training fully incorporates paediatric donation so that all SNODs have the skills and confidence needed to work collaboratively and undertake donations in PICU. | 6a. NHSBT will review the education and training of SNODs to ensure it fully incorporates donation from paediatric (and neonatal) patient groups.   | NHSBT Professional Development Team  |
| 6.2 Education and training should be provided to all clinical staff likely to be involved in the treatment of potential child donors.  | 6b. NHSBT will provide the opportunity for education and training to all clinical staff likely to be involved in the treatment of potential child donors. This might include a range of national, regional and local courses, e-learning and PowerPoint presentations for local CLODs and SNODs to deliver to paediatric staff. | NHSBT Professional Development Team<br>National Paediatric CLOD<br>National Lead Nurse |
|  | 6c. Faculty/observer spots on national and paediatric courses should support the cross fertilisation of learning and the NHSBT Professional Development Team's National Education CLODs and Medical Education SNOD should provide advice to support the development of current and future paediatric courses.                   | NHSBT Professional Development Team<br>Paediatric deceased donation simulation leaders |

### Outcome 7

**The National Organ Retrieval Service will ensure that there is consistently available expertise and skill to retrieve organs from all paediatric patients including small infants.**

| Recommendation   | Action/s  | Responsibility  |
|--|---|---|
| 7.1 NHSBT should continue to collaborate with NORS and transplanting centres through clinical governance systems to review and discuss specific challenges in relation to retrieval from very small donors.  | 7a. The inclusion of paediatric specific representation will be recommended to the National Retrieval Group.  | Paediatric NODC<br>National Retrieval Group   |
| 7.2 NHSBT will work with the NORS leads/ National Retrieval Group to scope the need for any specific training strategies which may be required to achieve Outcome 7.   | 7b. A scoping exercise will be undertaken to identify training needs for staff undertaking organ retrieval from paediatric donors, with particular attention to retrieval from very small donors.                           | National Retrieval Group<br>National Paediatric SNOD<br>NHSBT Professional Development Team |
| 7.3 Protocols included in the NORS guidance should be specific where retrieval is from very small donors, for example: a preservation protocol.  | 7c. NORS standards in relation to specific retrieval from small donors should be reviewed and any additional actions should be made through appropriate processes and as agreed in line with relevant funding applications. | NHSBT<br>National Retrieval Group   |
| 7.4 In cases where an abdominal team does not feel confident to retrieve from very small donors, a surgeon from the transplanting centre should consider attending the donating hospital to provide additional support to the NORS team. Responsibility for the retrieval remains with the identified NORS team. | 7d. Guidelines for actions to be taken where an abdominal team does not feel confident to retrieve from very small donors should be agreed.   | NHSBT<br>National Retrieval Group   |

| <b>Outcome 8</b><br><b>Organ offering, allocation and utilisation policies and practices will maximise donation and transplantation opportunities from every paediatric donor.</b>   |   |  |
|--|---|--|
| <b>Recommendation</b>  | <b>Action/s</b>   | <b>Responsibility</b>  |
| 8.1 There should be specific paediatric representation on NHSBT advisory groups and strategic working groups to ensure that all processes and recommendations are equally addressed for paediatric donors and recipients. This should support delivery of the recommendations in <i>Taking Organ Utilisation to 2020</i> . | <p>8a. Identify specific paediatric representation within each NHSBT advisory group and who will work in conjunction with the NHSBT Organ Utilisation Leads to achieve the recommendations within the <i>Taking Organ Utilisation to 2020</i> strategy for organs of all children.</p> <p>8b. Paediatric representatives on advisory groups should work collaboratively to ensure that offering and allocation policies optimise utilisation of organs from paediatric donors, fully consider the specific needs of paediatric and adult recipients of these organs and that future policies ensure appropriate and consistent offering is maintained to incorporate developments in transplantation of organs from children.</p> | <p>NHSBT Advisory Group Chairs</p> <p>NHSBT Organ Utilisation Leads</p> <p>National Paediatric CLOD</p> <p>Paediatric representatives on advisory groups</p> |
| 8.2 Work should be undertaken to ensure there is a full understanding of the numbers and types of transplants currently required by children and adults who could benefit from the organ of a donor <5 years old.  | 8c. A scoping exercise in conjunction with transplant centres will be undertaken in order to fully understand the need for organs from child donors < 5 years old.  | NHSBT/Transplant Centres   |
| 8.3 Allocation and organ matching policies should consider the overall aim to increase organ utilisation from paediatric donors and fully consider the specific needs of paediatric recipients.  | <p>8d. Paediatric representatives on NHSBT advisory groups will review current policies to ensure the needs of paediatric donors and recipients are being met.</p> <p>8e. Organ matching and allocation algorithms will include specific consideration for organs from paediatric donors.</p>   | <p>NHSBT Paediatric representatives on advisory groups</p> <p>NHSBT Paediatric representatives on advisory groups</p>  |

## Outcome 8

**Organ offering, allocation and utilisation policies and practices will maximise donation and transplantation opportunities from every paediatric donor.**

| Recommendation  | Action/s   | Responsibility  |
|---|--|---|
| 8.4 Clinical teams, SNODs and NORS teams must work together to ensure successful optimal organ utilisation, while maintaining excellence in end of life care for paediatric donors. | <p>8f. The paediatric optimisation tool will be integrated in care pathways of children whose death has been diagnosed by neurologic criteria and all SNODs trained in its use.</p> <p>8g. All PICUs will investigate options to minimise warm ischaemic damage in paediatric DCD while continuing to improve family and staff experience of DCD donation. This might include the option of withdrawal of life sustaining treatment in anaesthetic rooms to reduce the need for rapid transfer to theatre after death.</p> | <p>NHSBT</p> <p>Named lead consultant with responsibility for organ donation working with local CLOD (if different person) and local SNODs.</p> <p>NHSBT Professional Development Team</p> <p>Local SNOD</p> <p>Named lead consultant with responsibility for organ donation working with local CLOD (if different person) and local SNODs.</p> |

## Appendix B: Neonatal Strategy – Outcomes, Recommendations, Actions and Responsibility.

| <b>Neonatal Outcome</b><br><b>Donation in neonates will always be explored fully to ensure no opportunities to offer organ donation to neonatal unit families is missed.</b>  |  |   |
|---|--|---|
| <b>Recommendation</b>   | <b>Action/s</b>  | <b>Responsibility</b>   |
| N.1 NHSBT must provide support from SNODs where there is potential for donation.  | Na. NHSBT will provide appropriately trained and skilled SNODs to manage any referral or donation from a neonatal referral.  | NHSBT   |
| N.2 NHSBT in conjunction with neonatal intensive care units will work to develop a system of undertaking audit and data analysis for determining the potential for donation in all level 3 neonatal units across the UK.  | Nb. NHSBT will develop a robust mechanism for the collection of Potential Donor Audit data on all Level 3 NICUs in the UK.   | NHSBT   |
| N.3 Clear guidance should be established on expectations around notification of potential donors and donation from neonatal units.  | Nc. Expectations for notification of referrals from Neonatal Units will be agreed.   | NHSBT<br>Local NICU   |
| N.4 In cases where there is an antenatal diagnosis, discussions regarding the possibility of organ donation should only take place when raised as an option by a family. In these situations, assessment should be on an individual basis and support offered while expectations of professionals and families are managed. | Nd. SNODs will explore the donation potential following an antenatal referral and support the clinical team and family where requested.  | NHSBT   |
| N.5 The safe diagnosis of death by neurological criteria should be maintained through education, training and the use of standardised forms.  | Ne. The endorsed standardised forms and the diagnosis of death by neurological criteria education videos will be shared and promoted to NICU staff.  | National Paediatric CLOD                                      |
| N.6 The technical and ethical challenges in neonatal donation and transplantation should be more fully explored.  | Nf. NHSBT will consider hosting a symposium, with appropriate stakeholder involvement, to better understand the challenges in neonatal donation and transplantation.   | National Paediatric CLOD                                      |
| N.7 The recommendations and actions from the Paediatric Strategic Plan, where relevant to neonatal donation, should be incorporated into NICU practice.   | Ng. The paediatric subgroup of the National Organ Donation Committee will review the recommendations and actions from the Paediatric Strategic Plan and where relevant to neonatal donation, help to incorporate into NICU practice. | Paediatric subgroup of the National Organ Donation Committee. |









