

### A National Paediatric and Neonatal Deceased Donation Strategy

Angie Scales Lead Nurse: Paediatric and Neonatal Donation NHSBT

**Caring Expert Quality** 

## **UK Deceased Organ Donation**



2007-08 2008-09 2009-10 2010-11 2011-12 2012-13 2013-14 2014-15 2015-16 2016-17 2017-18 2018-19

The UK Success Story

### Deceased paediatric (< 18 yrs) donors, transplants and active transplant list in the UK



## Why do we need to optimise organ donation rates from children?



Children died on the transplant waiting list last year



Potential DBD consent for OD declined by Coroner / PF



NHS

**Blood and Transplant** 

1/3 of children who met criteria for NDD not tested (25 of 75)



Children currently awaiting heart transplant

21%

Children wait longer than adults for cardiothoracic organs



Potential donors not identified / families not offered opportunity for donation Lower CONSENT in cases where child is a donor

 SIZE matched organs / complex grafts often can only come from other children

• Wide VARIATIONS in practice across PICUs in the UK



#### UK Paediatric and Neonatal Deceased Donation

A Strategic Plan

by the Paediatric Subgroup of the National Organ Donation Committee



### 8 Key PICU Outcomes

1. Organ and Tissue Donation as a Routine Part of End of Life Care

- 2. Support for Paediatric Intensive Care Units
- 3. Paediatric Screening and Assessment
- 4. Post Donation Care
- 5. Paediatric Data and Key Performance Measures
- 6. Training and Education
- 7. National Organ Retrieval Service
- 8. Organ Offering, Allocation and Utilisation







### Outcome 1 & 2 Working to make donation a normal part of EOLC

End of Life is different from adults isn't it?

Getting it right, Trying different!

21% not identified

65% DBD declined by coroner /PF

2017-18 1 in 3 children meeting the criteria for NDD were not tested



### **Outcome 3 Screening and Assessment**





### **Outcome 4 Post Donation Care**



# hospice care for children and young people





### **Outcome 5 Measuring Performance**



What measures should we focus on?

More specific to donation from children

Measuring effect of the recommendations



### **Outcome 6 & 7 Training and Education**



What resources do we have?

What do we need ?

Easy access for all professionals

Ensuring expertise for all professionals involved



### Outcome 8 Utilisation of consented organs

< 5 years utilisation is reduced

**Optimisation tool** 

Need for organs from small infants more clearly defined

Working in line with the recommendations from the utilisation strategy





## Blood and Transplant Outcome 9 Neonatal Units

Last but certainly not least

Huge enthusiasm

Understanding potential / need / technical / psychological aspects

Continue to support and aim to ensure no opportunity is missed

## **Summary of Structural Actions**

- Appropriate and relevant performance measures
- Appropriate representation on all relevant advisory groups / committees
- Clear regional and local responsibilities
- Clear support structure for all individuals involved in OD where a child is the donor
- Consideration of recommendations when reviewing any resource allocation
- Matching and allocation policies consideration of the paediatric donor and recipient



**Blood and Transplant** 



## **Summary of Operational Actions**

- Overview of EOLC Pathways / Protocols / Care Guides
- Review of Identification and Referral Triggers
- Appropriate Post Donation Care of Paediatric Donor Families
- Review of Abdominal NORS Team Support
- Increase in Organ Utilisation



## **Summary of Educational Actions**

- Review of SNOD training to ensure specific support is given
- Review of clinical staff training in paediatric organ donation
- Ensuring all training incorporates a wide range of appropriate tools and resources
- Peer review process
- Endorsement of standardised forms for determination of death by neurological criteria



## **Summary of Neonatal Recommendations**

- Support where there is potential and understand why there is not
- Understand fully need for these organs and potential there maybe
- Managing expectations
- Safe determination of death using neurological criteria
- Technical and ethical challenges
- All outcomes are relevant



