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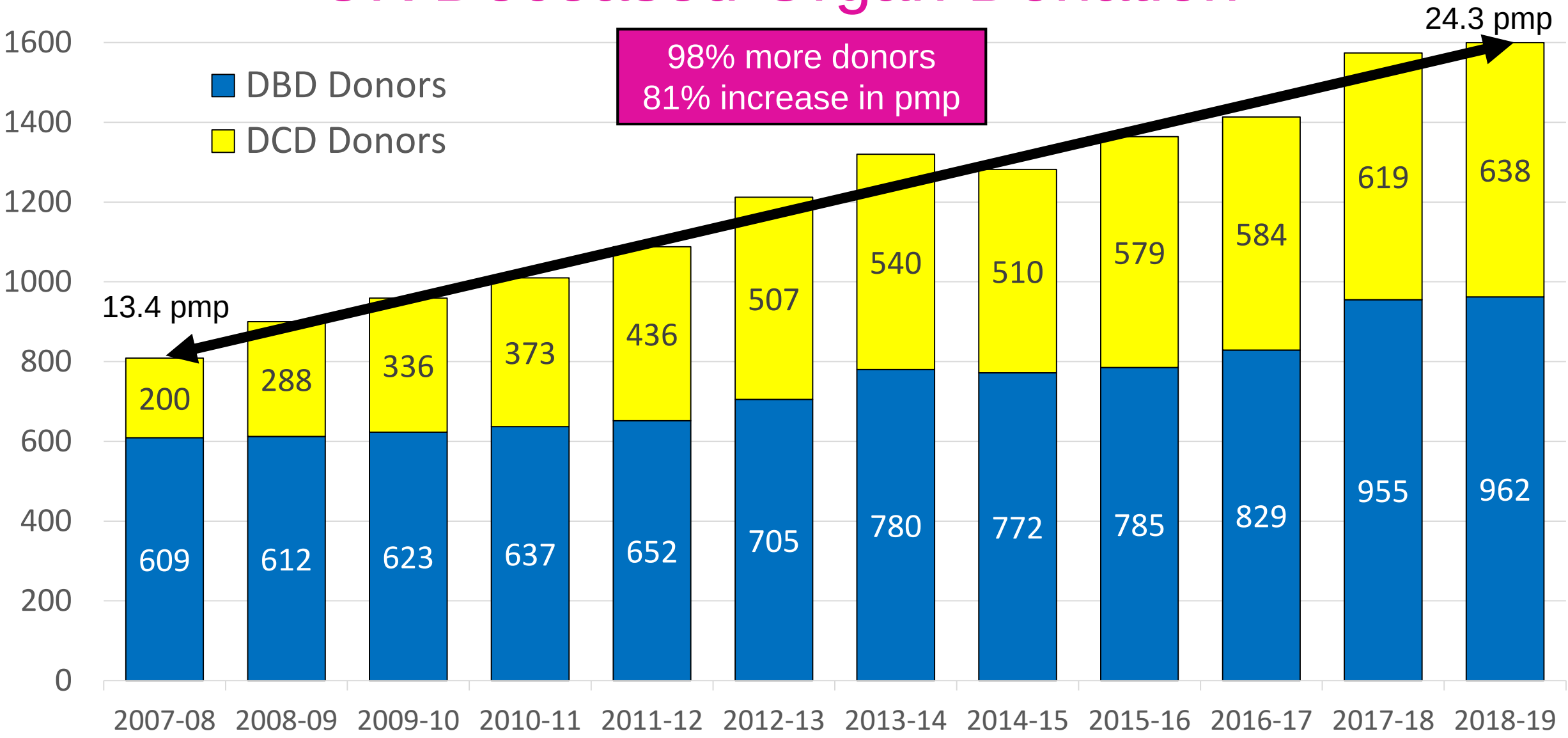
A National Paediatric and Neonatal Deceased Donation Strategy

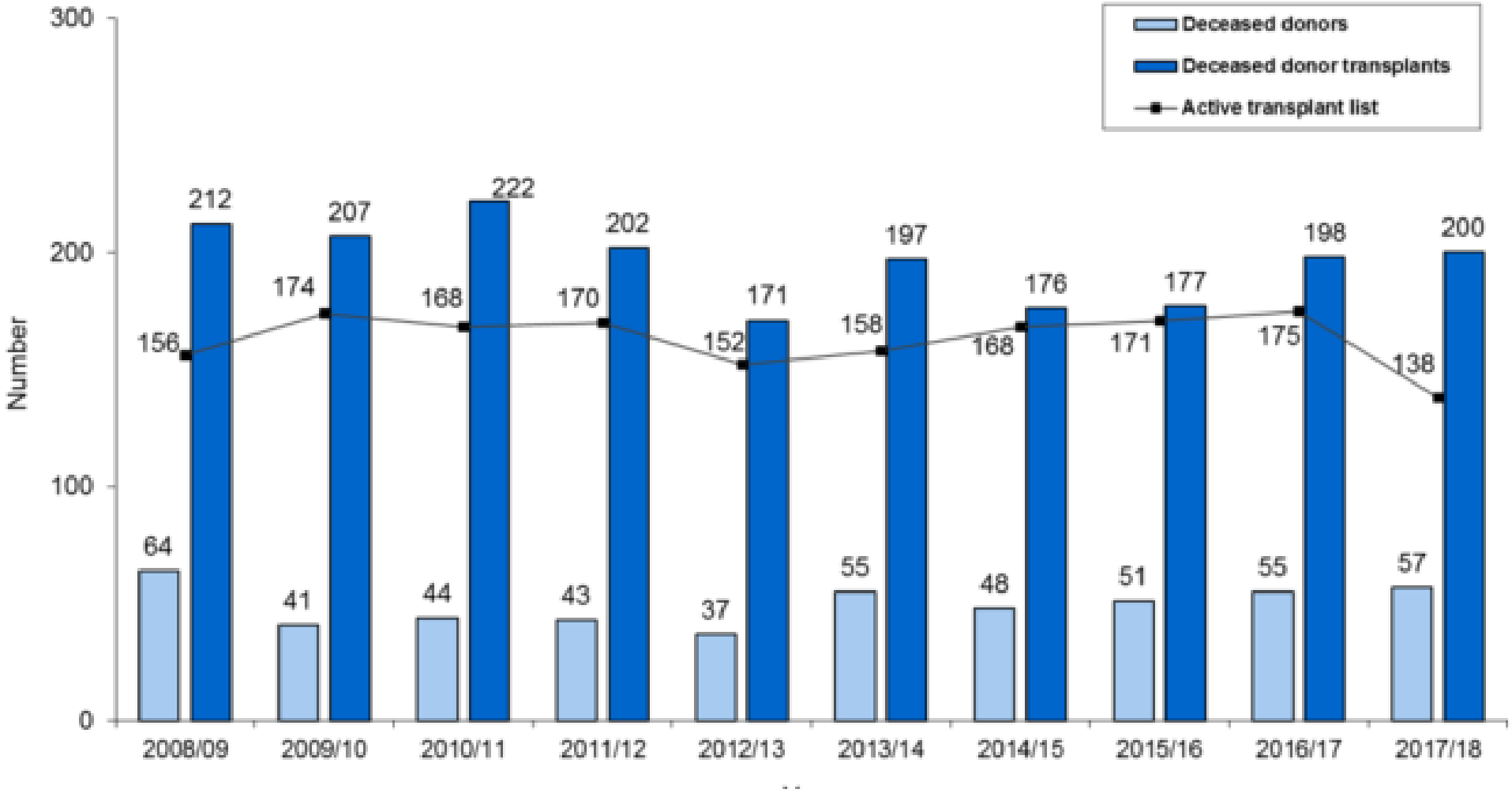
Angie Scales
Lead Nurse: Paediatric and Neonatal Donation
NHSBT

Caring Expert Quality

UK Deceased Organ Donation



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



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

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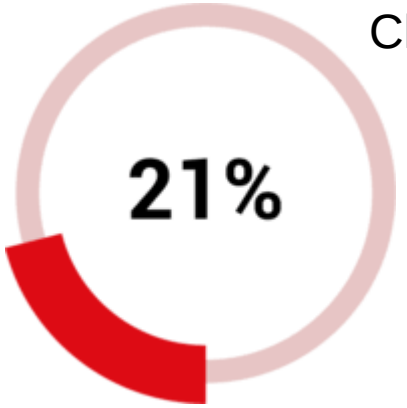
Children died on the transplant waiting list last year

Potential DBD consent for OD declined by Coroner / PF

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



Children currently awaiting heart transplant

Potential donors not identified / families not offered opportunity for donation

Children wait longer than adults for cardiothoracic organs

- 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

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UK Paediatric and Neonatal Deceased Donation

A Strategic Plan

by the Paediatric Subgroup of the National Organ Donation Committee

8 Key PICU Outcomes

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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

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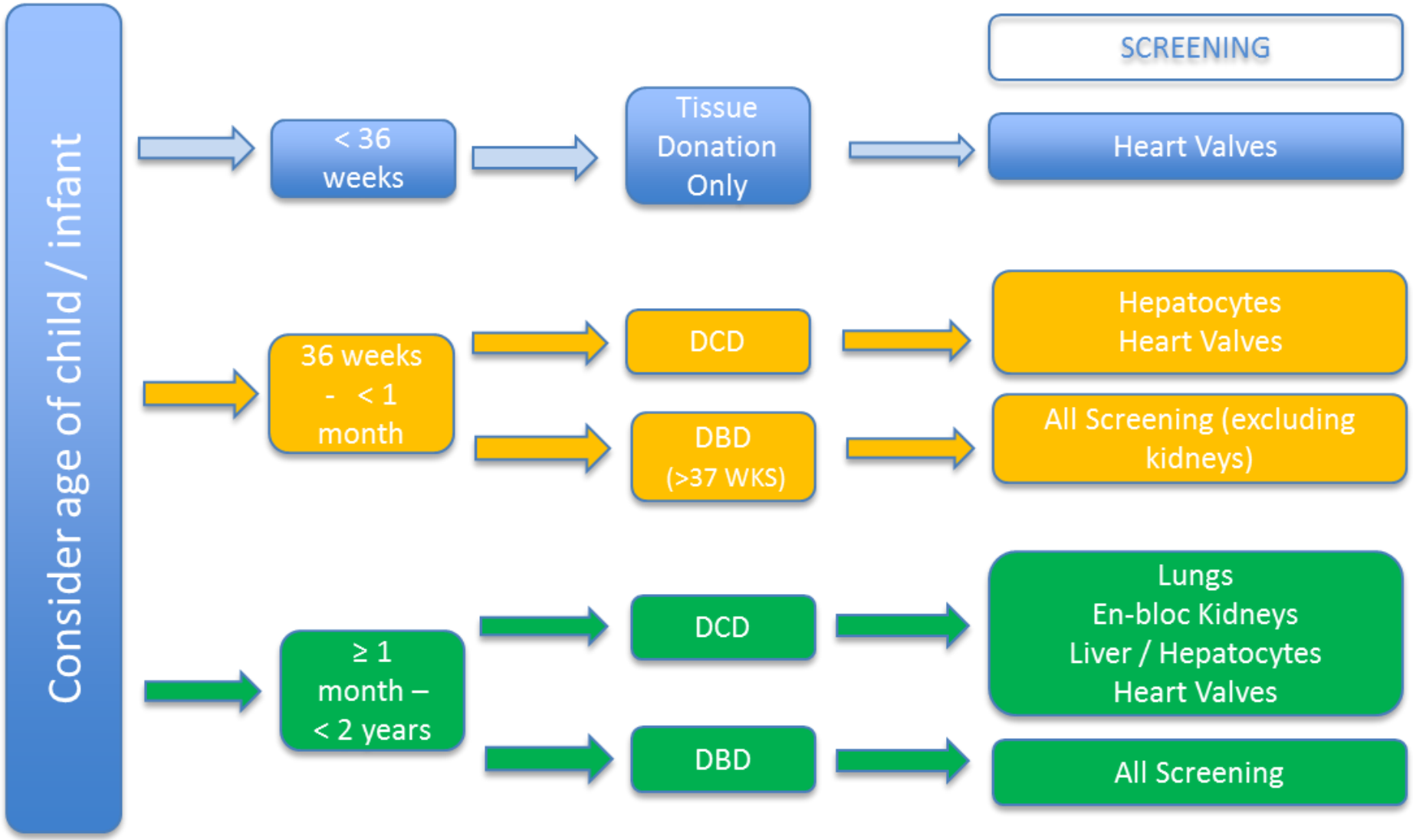

Outcome 4 Post Donation Care

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Martin House

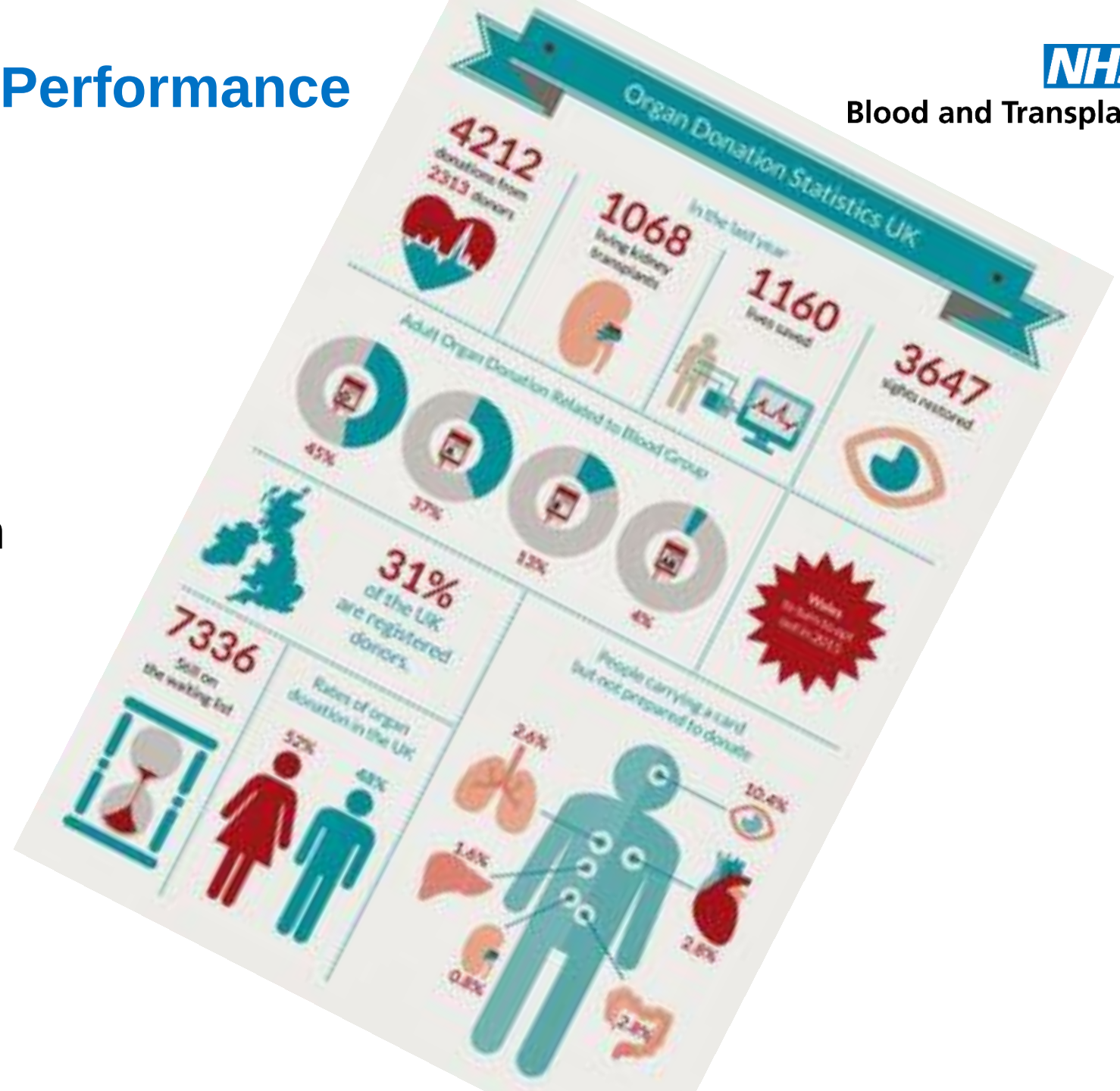
hospice care for children
and young people

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

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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

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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

Summary of Operational Actions

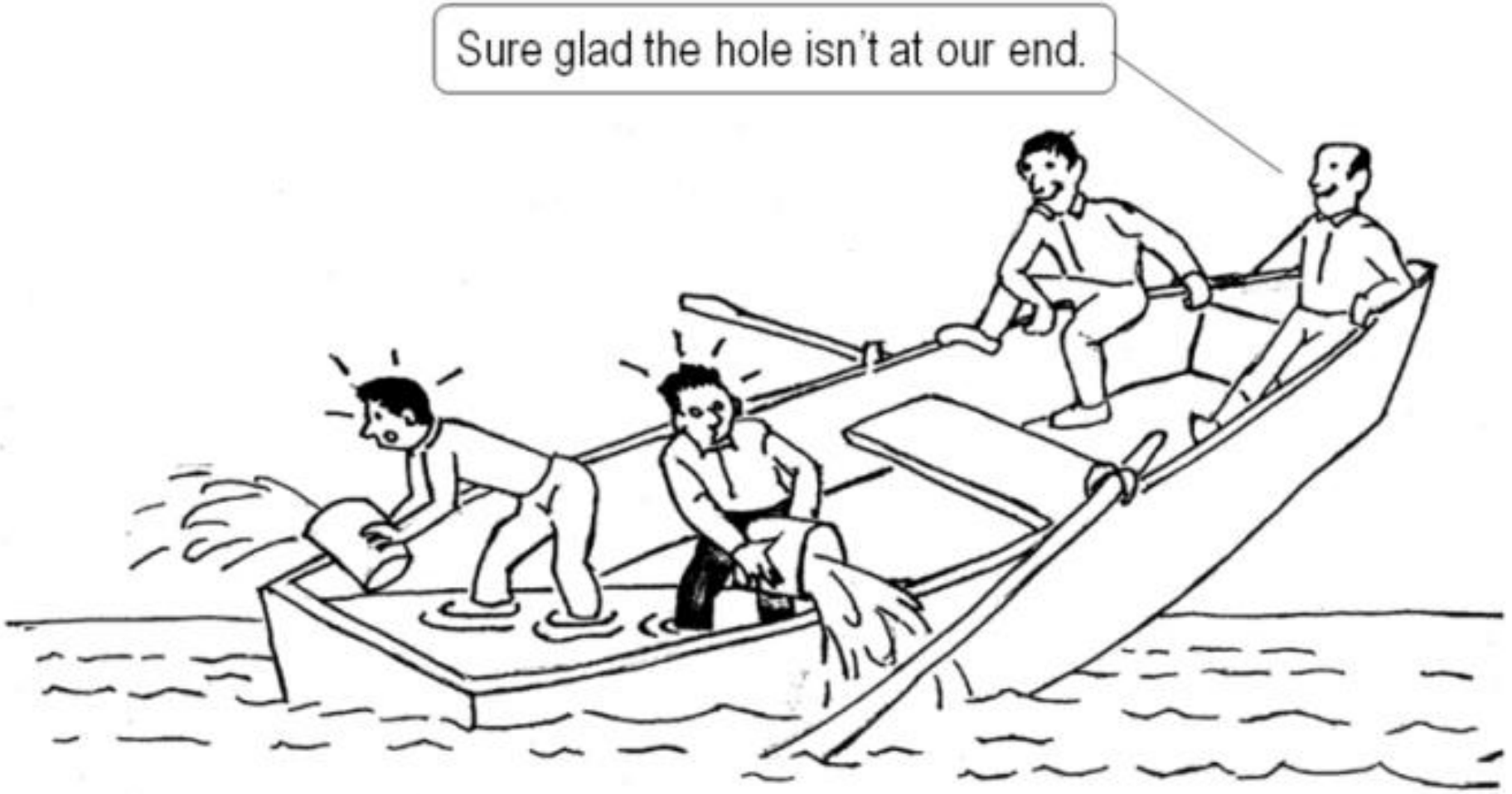
- Overview of EOLC Pathways / Protocols / Care Guides
- Review of Identification and Referral Triggers
- Appropriate Post Donation Care of Paediatric Donor Families
- Review of Abdominal NORS Team Support
- Increase in Organ Utilisation

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


Sure glad the hole isn't at our end.