

Despite removal of many obstacles, UK child organ donation rates remain low

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Despite the removal of many logistical/professional obstacles, and clear guidance from national bodies, UK child organ donation rates remain lower than in other comparable countries, say experts in a leading article published online in the *Archives of Disease in Childhood*.

Many families of dying children are simply not even given the chance to consider the option, and potentially save another child's life, they argue.

Over the past several years, national drives have cleared the way for organ donation to be made easier, with the appointment of specialist staff and the establishment of organ donation committees in every acute hospital and health board. And guidance on donations specifically from children has been published by national bodies.

Yet the overall rise in UK donation rates has not been replicated in children, where rates haven't budged and are lower than elsewhere, say the authors.

There are wide variations in organ donation rates among children's units across the UK, little research on the topic, and performance and other issues at each stage of the donation process—from identification of a potential donor through to recovery of the organ(s)—all of which compromise the numbers of potential donors, they say.

The latest available audit of organ donation from children's intensive care units in 2015-16 shows that in around one in four cases a child



wasn't referred to the specialist donation team because they weren't even identified as a potential donor, and/or the option was not even raised with families.

But in around one in five cases "no persuasive or legitimate reason could be identified," say the authors.

Although there are some signs of change, the full potential of organ donation from among newborns and infants has yet to be realised, despite clarification in 2015 on the diagnosis of brain death in this group of children, they contend.

While NHS Blood and Transplant audits the potential for organ donation from all adult intensive care units, emergency care departments, and all 27 children's intensive care units in the UK, it doesn't audit <u>neonatal</u> intensive care units, they point out.

These audits, which are carried out by specialists nurses, pinpoint where in the process the potential for donation was lost or whether donation was even considered at all, and the data from each hospital fed back to trusts and health boards every six months, and published on the NHS Blood and Transplant website.

Family refusal remains a major obstacle to organ donation from children, emphasise the authors, but that is where trained staff are key, as they can ensure that "families are given the chance to consider donation, and that it is broached at the most appropriate time by the most appropriate person, and in the most appropriate way," say the authors.

Immediate focus should be given to consent rates and supporting <u>family</u> decision-making, they urge.



And they call for public debate on the acceptability of interventions before the death of a child donor and the development of technologies to enable the retrieval of hearts.

"Many formal professional obstructions to child donation have been removed over the past 5 years in the UK, but [variations in] individual practice still leaves the families of dying <u>children</u> without the opportunity to consider donation," write the authors.

"Addressing this and considering those issues around poor donation consent rates compared with other countries...remain the key next steps in UK child donation."

More information: Current status of paediatric and neonatal organ donation in the UK, *Archives of Disease in Childhood* (2017). DOI: 10.1136/archdischild-2017-313466

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