



Great Ormond Street  
Hospital for Children  
NHS Foundation Trust



# **1<sup>st</sup> Clinical Ethics Service Report**

The Child First and Always

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# Message from the Chief Executive

The Great Ormond Street Clinical Ethics Service (CES) forms a crucial part of the Trust's vision to deliver world-class clinical care to the children we treat, to undertake innovative research that will lead to new and improved treatments for children everywhere and to share our expertise through education and the training of children's healthcare professionals so that more children benefit from our work.

Delivering world-class care coupled with innovative research and new therapies means that we are at the leading edge of developing new treatments (with the UCL Great Ormond Street Institute of Child Health) often used in the sickest children, who sadly may have run out of other conventional options. Increasingly invasive therapies are being used to help children. Associated with this, some very hard decisions about ceasing life-sustaining treatments sometimes have to be made by our staff with parents, families and children themselves. Making decisions to limit treatment or to try very experimental treatments in children can carry a great burden; the CES helps all those involved in making these decisions in the most difficult circumstances – helping all involved to know they've made the best decision in the best way for the child.

The CES also contributes to the third element of our vision in educating and training children's healthcare professionals who work with us, and attend the training sessions our Service runs alone or in association with other bodies.

The CES's innovative work in engaging children and families in discussions about the most difficult healthcare decisions supports Great Ormond Street's specific objective to consistently deliver an excellent experience that exceeds our patient, family and referrers' expectations. It also meets the government's vision for shared decision making in healthcare: 'No decision about me, without me.'

Many Trust members of staff have given – and continue to give – their time to develop the Service you will see highlighted over the subsequent pages. I would also like to thank those who come to our Hospital from outside to help our Ethics team, bringing their valuable expertise – whether as healthcare practitioners, philosophers/bioethicists or simply – but crucially – as 'lay members' who have been parents of both well and sick children.

On behalf of the Trust board, our hospital staff and most importantly the children and families we serve, I am delighted to commend this first Ethics Report to you.

**Dr Peter Steer**  
Chief Executive  
Great Ormond Street Hospital  
for Children NHS Foundation Trust

# Great Ormond Street Hospital for Children NHS Foundation Trust

**Great Ormond Street Hospital (GOSH)** is one of the world's leading children's hospitals, with a strong academic link to the University College London Institute of Child Health. With around 50 paediatric specialities on one site GOSH cares for children with the most serious and sometimes the very rarest diseases. Because of this, the nature of the hospital is to push the boundaries of what is medically possible, whilst delivering compassionate care for the children and families it serves. Many of the inpatient children are extremely unwell and need to be cared for in one of the hospital's three critical care units.

**Leading research and development** – due to this unique cohort of patients GOSH has both a particular opportunity as well as a responsibility to undertake pioneering research to discover and improve treatments and find cures and better treatment for life limiting and life threatening conditions in children, often carrying out this research with international partners. GOSH has developed a number of new clinical treatments and techniques that are now used around the world and is the UK's only Academic Biomedical Research Centre specialising in children. The new Centre for Research into Rare Disease in Children is a partnership between GOSH, UCL and GOSHCC with the Trust the prime provider for the national 100,000 Genomes Project.

## The GOSH Clinical Ethics Service

The Clinical Ethics Service (CES) is a multidisciplinary group of both lay and professional members, many of whom have advanced training in decision-making and ethics. It comprises the Clinical Ethics Committee, the Rapid Response Service, and education and research roles and recent ethics drop in session, for junior staff.

The Clinical Ethics Service membership includes lay members, including a previous parent, an academic philosopher, bioethicists, physicians, surgeons, anaesthetists, nurses, member/s of the spiritual care team, ethicists and legal experts all of whom have qualifications and/or experience in ethical matters.

The GOSH Trust Board has delegated authority to the CES to operate as a forum to which members of staff, children and their families can bring ethical issues for confidential discussions. The CES can provide urgent advice and support on ethical matters through its Rapid Response service which is crucial in the fast-moving clinical environment of acute children's medicine. The CES also advocates for, and undertakes, the education of clinicians, other hospital staff, medical students and trainees in ethical matters.

# What is Paediatric Bioethics?

Whilst many definitions exist, paediatric bioethics can be thought of as how to provide medical treatment for children when it might not be clear what is in their best interests, or what is the right course of action. Whilst most frequently involved with complex and sometimes controversial issues, it is at its heart an applied ethical field which aims to provide holistic, compassionate, practical support to children, families and healthcare professionals.

Recent advances in technology and specialist medicine have had a huge impact in allowing us to keep children with even the most complex and serious illnesses alive for much longer. In many cases this has led to marked improvements in children's outcomes, but for some children this has sadly served only to prolong life for a short period of time and sometimes resulted in significant suffering.

## **'Just because we can, should we?'**

This has led to the concept that 'just because we can provide a particular treatment for a child does not necessarily mean that we should.' This area is an increasing concern for child-health professionals, children and their families who may all have different concepts of how much is too much and whether the burdens to the child of an aggressive therapy with a small chance of long-term survival are bearable. This can be difficult and distressing for staff, children and families. It is in these tough situations when a particular treatment might cause more harm and suffering than benefit that we need to challenge, in a rational fashion, our instincts to preserve life at all costs and to try all treatments possible before 'giving up' on a child. This phrase does not accurately represent a considered decision to embrace a palliative approach.

The Clinical Ethics Service acknowledges that it can often be very challenging for clinical staff to separate their emotional attachments to children and their families when confronted by such difficult decision-making. The situation is made more complicated by the fact that it is not always clear what the correct and appropriate treatment might be for any particular child. As medicine has advanced, clinical teams have also evolved into working as more specialist albeit multi professional teams. Whilst this has undoubtedly improved outcomes it not infrequently leads to differences in opinions within and between different teams involved in a child's care. With these complex patients we must bring our human and emotional sides to the decision making table, but we cannot and should not underestimate the importance of how these decisions are made, as well as what the ultimate decision is, because of the long-lasting impact on the child and family but also on the individual professionals and crucially on future intra and inter team relationships.

## **Invasive life-sustaining therapy**

Many of the acute cases medical teams seek CES help over involve children dependent on life-sustaining therapy, often in the form of technological organ support in the intensive care unit. Here the burden to the child and to the staff and family seeing the child possibly suffering needs careful balancing against the potential benefits to continuing organ support and of maintaining the family's continued involvement in decision-making.

These ethical dilemmas are now a daily part of modern medicine, and particularly in a hospital such as Great Ormond Street, which is often seen as the place of last resort for children with the most complex and severe conditions.

# GOSH Clinical Ethics Service (CES)

## Vision

**Parents want their children to be referred to GOSH because of its reputation as the UK's and one of the world's leading children's hospitals.**

GOSH pushes the boundaries, can offer novel therapies and is often the place of last resort for the sickest children. However, because of this its clinical teams and the children and families they serve are sometime faced with very difficult decisions about treatment. This is the area of clinical ethics. We believe that GOSH has a responsibility and is ideally placed to become one of the leading paediatric bioethical centres in the world.

Great Ormond Street Hospital for Children strongly believes that the continuing and rapidly developing technological advances need world-class ethical support to ensure things remain child-focussed.

A referral to the Clinical Ethics Service can help an individual clinician or team to make the right decision with an individual child and their parents/those able to consent based on sound ethical principles and in a rational and compassionate way.

The Clinical Ethics Service can fully engage with patient-support groups, advocates and others, such as spiritual leaders, if this is helpful for the child and their family.

An opportunity to provide a helpful way of reviewing the alternatives and deciding what is the best way forward. The Care Quality Commission Report recognised the important role of the Clinical Ethics Service at GOSH in its January 2016 Report:

*"The ethics committee was regularly available and played a key role in considering difficult treatment decisions."*

It is worth remembering that the recent Francis Inquiry Final Report highlighted what can happen if these issues are not prioritized.

"Where there was an issue of disagreement over consent, the Trust Ethics Committee was involved to discuss and help teams to agree an appropriate course of action."

*Care Quality Commission  
Report January 2016*

"When decisions were made to stop treatment, this was done thoroughly and with good governance via the ethics committee and always with maximum consultation with parents or carers."

*Care Quality Commission  
Report, January 2016*

## The CES today

The Clinical Ethics Service today is dependent on an annual application to the GOSH Children's Charity for funding of a part time service manager and some Physician-Ethicist time – for which the team is grateful. However the CES largely functions due to the good will and commitment of its volunteer members.

**Our local journey as a CES since 2012** has seen the demand for the service increased substantially and the cases are certainly increasing in complexity. A greater proportion of consultations now surround use of New and Innovative treatments, often for compassionate use. It is now normal practice for a family and sometimes a child to attend a rapid response and actively contribute to the conversation. We are the first ethics committee we know of in the world to do so – recognising the 'Liberating the NHS: No decision about me, without me' document on patient engagement ([www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/216980/Liberating-the-NHS-No-decision-about-me-without-me-Government-response.pdf](http://www.gov.uk/government/uploads/system/uploads/attachment_data/file/216980/Liberating-the-NHS-No-decision-about-me-without-me-Government-response.pdf)). And we have been asked to run the UKCEN workshop on this in 2016.

## Process

With a bespoke referral form, email address and crucially a dedicated administrator, referral to the CES has become easier. At the request of a referring clinician/s, allied health professional or other member of staff, and often at short notice, the CES will hold a review of an ethically challenging case with the child's multidisciplinary team, to which the child and family are routinely invited try to help determine the best way forward based on the child's best interests. Before the meeting takes place, a member of the PALS or Spiritual Care team will meet with the parents to look through the dedicated Information Sheet for Families which shows how we help parents to understand what an ethics referral for their child means and how they will be supported when they attend.

Increasing numbers of referrals are being made for the CES's Rapid Review service which enables timely ethical support for children, families and clinical teams faced with challenging decisions about the right course of action, often in the situation of very rare diseases in what are practically unique circumstances. There were 15 such referral in 2015 and 23 as of November for 2016.

Some referrals have come from other UK paediatric centres and whenever possible we support clinicians from other hospital Trusts facing the same challenges but without their own Clinical Ethics Service.



# How a 'unique' ethics committee wrestles with dilemmas of life and death at GOSH

News article  
by Jamie Merrill,  
Independent

Published:  
4 December 2015

**The Clinical Ethics Committee allows parents and doctors to discuss issues caused by advances in modern medicine**

A sick child is nearing the end of their life. Treatment options have been exhausted and all that remains is pain and distress in their final days on an intensive care ward. The medical team wants to withdraw treatment, discuss end-of-life care and prepare the family for death, but the parents want to fight on.

Few parents will ever have to face this awful decision or many of the other terrible dilemmas created by modern medicine's ability to keep the critically ill alive for longer in intensive care, but at Great Ormond Street Hospital (GOSH) they will at least be supported by a "unique" ethics committee dedicated to helping doctors and families discuss their concerns.

"We are using machines to support children who would have died 10 years ago," said Dr Joe Brierley, an intensive care consultant at GOSH. "But because of that, death is becoming increasingly technological, leading us to ask just because we can do it, should we do it?"

Dr Brierley is the vice-chair of GOSH's Clinical Ethics Committee, and along with a multi-disciplinary panel of medical experts, academics, religious representatives and lay people, he wrestles with the ethics of life and death in an age of rapidly changing paediatric medicine.

The committee was set up in the late 1990s in response to the "unique nature" of GOSH and the cutting-edge care it offers, but in recent years, thanks to funding from the hospital's charitable arm, it has expanded its role to provide on-call ethical guidance for critical care and to consider the ethics of using experimental new treatments.

"At GOSH we are at the cutting edge of new techniques and treatments, but at the same time we have to ask ourselves: is being able to offer a treatment the same as whether or not we should offer it," said Dr Brierley.

The committee he chairs meets monthly and discusses cases that are referred to it by clinicians from across the hospital. Where possible it seeks input from parents and even young patients, but also meets at short notice for critical cases. "We are not a decision-

making body; that responsibility rests with the clinicians alongside patients and their families. What we are is a space to give clinicians and families a place to discuss their concerns."

Ellen Schroder, co-chair and lay member of the committee, whose daughter was treated at GOSH, said: "Generally we are trying to help decide whether to continue treating a child or whether to stop. Medical science has moved so far so we need to look at the burden on the child, versus the benefit of more treatment. We also talk about possible access to lawyers if there's a fundamental disagreement."

A handful of cases a year from GOSH do end up in the courts when a family and doctors are unable to agree on the best course of action, but Dr Brierley says the aim of the committee isn't to avoid costly court battles or to save the NHS money. "It's about making the right decision for the right reasons," he said.

He added: "Parents can often feel they need to fight on beyond a point that a doctor will. They have often had to fight to get to GOSH, and society and the media often present that as their role, but what we do is try to defuse that and listen to the family. That is where ethics and mediation come together."

Other hospitals across the country are now studying the committee, which offers guidance on broader ethical challenges. "For example, we help doctors to decide if they are doing the right thing by putting a child on a machine to keep them alive for a transplant that may not happen if they are what we call a marginal recipient," said Dr Brierley.

The committee's work isn't all about "end of life" care though, and increasingly it is called in to meet with doctors and families to discuss "compassion and innovative" therapies. This is where doctors are considering using a cutting-edge but unproven drug or technique as a treatment of "last resort" for a patient who would otherwise die.



## The revolutionary treatment that gave a future back to little Layla



The Great Ormond St Clinical Ethics Service (CES) evolved from an ethics Committee that discussed healthcare issues with an ethical component into a Service that supports Clinical teams, families and children facing challenging healthcare decision-making. Sometimes this can occur at the monthly meeting at which broader ethical issues continue to be discussed by members, however more frequently given that there are often time constraints the Rapid Review group of the CES can be quickly constituted when a referral is received and hold a review within days, sometimes sooner. Whilst there is limited information about other Trusts the Committee seems unique in its adherence to the DH mandate 'No decision about me, without me' in always inviting parents (those with PR) and where possibly the child involved to the meeting. One such recent case illustrates this approach well, and with permission of the family and clinical team involved I will discuss Layla Richards's Clinical Ethics meeting in 2015.

Layla Richards was only 3 months old when she was diagnosed with leukaemia (high risk infant B-cell ALL). She underwent the standard treatment for this rare disease with chemotherapy and then a bone marrow transplant when she was only 9 months old; but sadly after this the leukaemia was still found on a bone marrow test a few months later. The disease failed to respond to increasingly experimental therapy with first a cellular immunotherapy trial and then a rare antibody – but the leukaemia would not go away.

Things were looking really desperate, and discussions about referring to palliative care started with Layla's mum, Lisa and her Dad, Ashleigh.

There was just one more possibility – but this treatment with specially 'designed immune cells' had never been tried in humans before.

The CES have developed a framework to review the ethical issues around the use of such innovative, novel or compassionate therapies being used in this way – and have published it to allow other teams to consider its use. Despite doctors & nurses wanting to do absolutely everything they can to help children get better – sometimes that just isn't possible. In these circumstances how fair is it to try experimental treatment with an unknown chance of working, but also with unknown chances of harming the child due to unknown side effects?

Well, the ethics meeting was convened and Layla with her family after initial briefing with support of the GOSH PALS team came into the middle section so the CES and teams could meet with them together, and listen to their views and thoughts.

A clear consensus decision to go ahead, as long as the remaining elements of the framework were completed, emerged. The treatment worked beautifully, with almost no toxicity and Layla remains disease free and well.

On a lovely summer's day, a year later Lisa and Ashleigh – carrying Layla – reflected on their experience of the ethics process. One aspect they understandably struggled with initially was the need to meet with the palliative care team. This is because for the informed consent standard for such treatment in the CES framework those consenting need to understand fully the alternatives to the treatment being discussed. This means a clear understanding of relevant standard/conventional treatment in this case palliative care. 'It was hard when you said we had to meet the palliative care team as we had to understand all the options to consent, but when we met them it was actually OK and we are now really glad we did meet them as we were better prepared for taking our decisions.'

For Ashleigh looking back, one major memory was 'Layla actually coming into the room was very special, and we knew at that stage how much you all valued her.' For Lisa the process worked because 'You put our voice in the room.'

**Dr Joe Brierley**

Consultant in Critical Care and Ethics  
Co-Chair, Clinical Ethics Service

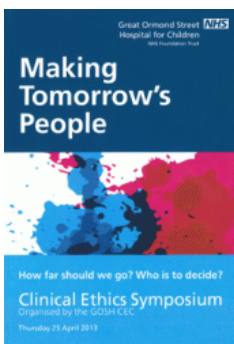


# Conferences & Symposia



## June 2016 – THE ETHICS OF FULL FACIAL TRANSPLANTATION IN CHILDREN.

A seminar examining the ethics of full facial transplantation in children. Speakers: Mr JONATHAN BRITTO (GOSH Consultant Craniofacial and Plastic Surgeon). Mr Britto's specialist interests are in aesthetic and reconstructive surgery of the face. He has developed many techniques in facial aesthetic and reconstructive surgery which crossover for the benefit of patients in both fields, and has a specialist interest in facial rehabilitation after facial palsy, tumour and trauma, and the unfavourable primary surgical result. He is the author of 40 papers in research based and clinical plastic surgery. JOHN PARIS S.J., Michael P. Walsh Professor of Bioethics, Boston College, USA. Professor Paris's academic background extends to history, government, education, and philosophy. With over 150 publications in the areas of law, medicine, and ethics, he has made an extensive impact in the field of medical ethics, participating in over 80 court hearings and additionally has been consulted by over 500 organizations to comment on the ethics of medical treatments, procedures, and practices.



## August 2015 – NEONATAL BIO-ETHICS SYMPOSIUM

A half day symposium examining Viability, Gestation and Brain Injury, Decision making for Critically-Ill Infants and Organ Donation. Speakers included: PROFESSOR DOMINIC WILKINSON (Director of Medical Ethics, Oxford University Uehiro Centre for Practical Ethics), DR JOE BRIERLEY (Consultant in Paediatric Intensive Care and Ethics, Co-chair GOSH Clinical Ethics Committee), GEOFF MILLER (Professor of Paediatrics and Neurology, Yale University Medical School, member of the Yale Bioethics Center) and JOHN WYATT (Emeritus Professor of Ethics and retired Consultant Neonatologist, University College London)

## June 2015 – NATIONAL CLINICAL ETHICS SYMPOSIUM

A one-day symposium chaired by James Naughtie, broadcaster and writer, explored the ethical issues facing clinicians who are making decisions and developing policy on children's health. Are children's rights and their needs always the focus for policy makers? Are children's voices listened to when their needs are being defined and decisions taken about their best interests. Speakers included: JANE ELLISON MP, Parliamentary Under-Secretary for Public Health, ANNE LONGFIELD OBE (Children's Commissioner for England), Sir MICHAEL RUTTER (Professor of Developmental Psychopathology, Kings College London), Dr JOE BRIERLEY (Consultant in Paediatric Intensive Care and Ethics, Great Ormond Street Hospital for Children NHSFT), JONATHAN MONTGOMERY (Professor of Healthcare Law, UCL), NEENA MODI (Professor of Neonatal Medicine, Imperial College London and President RCPCH), DAVID ARCHARD (Professor of Philosophy, Queen's University, Belfast)

## April 2013 – NATIONAL CLINICAL ETHICS SYMPOSIUM

A one-day symposium examining the complex ethical considerations around the use of new technologies and clinical practices related to reproduction and the treatment of neonates, children and adolescents drew 220 people from across the UK. Chaired by James Naughtie, writer and broadcaster, its 15 eminent speakers tackled topics which included the limits of congenital correction, decision making around treatment of extremely premature babies and the treatment of gender and body dysphorias – and included Robert Wheeler Consultant Surgeon at Southampton, HILARY CASS President of the RCPCH, Lord ROBERT WINSTON, DEBORAH BOWMAN Professor of Ethics, St George's Hospital Medical School and JANET RADCLIFFE-RICHARDS, Professor of Practical Philosophy, Oxford University.

[www.theguardian.com/commentisfree/2013/apr/28/save-babies-any-cost-ethical-debate](http://www.theguardian.com/commentisfree/2013/apr/28/save-babies-any-cost-ethical-debate)

# Projects

## ANNUAL AWAY DAYS

The Clinical Ethics Away Day is attended by members of the Committee, clinicians nursing staff and allied professionals who support the Clinical Ethics Service or have shown interest in its work and specially invited colleagues.

**2016 A bespoke training event** on Moral Argument by Professor David Archard, Professor of Philosophy, Queen's University Belfast.

Topics included:

1. Appeals to intuitions, role of theory, and idea of reflective equilibrium) using thought experiments in moral philosophy
2. Consequentialism as a moral theory
3. Debate on 'Capital Punishment' thinking about the morality of life and death issues, notions of desert and justice, as well as an appeal to consequences, and the role of factual claims in moral arguments.

**2015 A bespoke training event** by Professor Mike Parker, Director of Ethox Centre, Oxford University, and Associate Professor Maureen Kelley, Ethox Centre, to which colleagues from Glasgow Children's Hospital and King's College Hospital also attended.

Topics included:

1. The zone of parental discretion/responsibility/control.
2. The appropriate/ethical use of limited resources/funding for treatments clinicians do not want to use – but parents insist on: for example continuing ICU against recommendations by treating teams – and linking in to the refugee children in dire need whose plight is now more widely covered in the media.

**2014 'What makes a life worth living and who decides?'** with keynote speakers Sir Mark Hedley (retired High Court Judge from the Family Division), Professor Deborah Bowman, and Mr Robert Wheeler (Consultant in Neonatal Paediatric Surgery, Southampton University Hospitals NHS Trust) No pictures sadly

**2013 "Who decides whether A Life Is Worth Living?"** An oversubscribed series of 6 interactive lectures and training sessions on ethics were provided to GOSH staff, local medical students and staff from other centres.

## PhD Supervision.

A UCL PhD candidate, co-supervised by Dr Joe Brierley (Consultant in Paediatric Intensive Care and Ethics) has been exploring the normativity of ethical decision making in neonatal intensive care. Jean-Frederic Menard has attended CEC meetings, neonatal meetings and interviewed members of staff and the CEC as part of his research – repeating these activities in Montreal Children's Hospital and Paris children's hospital – Necker-Enfants Malades Hospital.

## Intercalated BSc

Several UCL iBSc students are, and have, undertaken their degree supervised by members of the CES – this year one is exploring the GOSH rapid review process and another consent processes within intensive care units. Previous work has included the role of religion in critical care co-supervised by Rev Jim Linthicum and children's views of payment for research. Several conference presentations and full publications have resulted.

## St George's University Hospitals NHS Trust

Eight students undertake a four-week ethics project of their choice, supervised by members of the CES and feedback their findings to the CES and more widely so as to improve clinical practice. This project is on-going and each year one or two of the student's work has been of such a high standard that it has been presented at international conferences and one student has produced a joint publication with Dr Joe Brierley, which led to public and governmental debate on infant organ donation. (Charles E, Scales A, Brierley J. Potential for neonatal organ donation. ADC Fetal Neonatal. 2014 Mar 17)

# The Perceptions and Attitudes of Staff Members towards Donation after Circulatory Determination of Death (DCDD)

**Candidate number: 3175**  
Great Ormond Street Hospital, Great Ormond Street, London.

## Aim(s)

- To explore the perception of various staff members on donation after circulatory determination of death (DCDD) in paediatric care.
- To compare the views and outlook of different NHS staff members in donation after circulatory determination of death (DCDD) based on the circulatory criteria and guidelines approved by the HCS.

## Introduction

In the United Kingdom, children suffer of illnesses and die in circumstances where organ transplantation would have been a potential treatment of choice<sup>1</sup>. The whopping incongruity between the number of patients anticipating organ donation and the actual number of transplantable organs remains a pressing issue in the health care sector<sup>1</sup>. With the scarcity of organs for transplantation, there has been an increase in donation after cardiac determination of death (DCDD) within the PICU to try to bridge the gap between the number of organs available for transplant and the patients that need the organs as a cure<sup>1</sup>.

There is no legal definition of death that exists currently in the UK and that is reflected by the difficulties in establishing when death has occurred for the purposes of organ donation which consists closely with the difficulties in trying to define death<sup>1</sup>. However, the UK Donation Ethics Committee (UKDEC) describes donation after circulatory determination of death as an organ donation that takes place following the diagnosis of death by cardio-respiratory criteria as laid down by the Code of Practice for Diagnosis and Confirmation of Death<sup>1</sup>.

As DCDD offers a higher chance for more transplantable organs for the long list of recipients, there are still major ethical concerns that loom over the process, procedures and organs in the paediatric practice especially in regards to the timing of the death and the extent to which preservation techniques for organs can be justified for recipient<sup>1</sup>. The short latent time between declaration of death and the DCDD up to as the environment in which the child is placed during the process of death is a difficult time not only for the families but also the medical team that is caring for it. It is always a struggle between trying to preserve the integrity and dignity of the child and the withdrawal of treatment process and the need to protect the function of organs to be donated<sup>1</sup>.

## Method

A questionnaire was composed to find out the perception of staff members donation after circulatory determination of death (DCDD). These included Registrars, Staff of the Paediatric Intensive Care Unit (PICU), Staff of the Cardiac Unit (CCU) and Specialist Nurses-Organ Donation (SN-OD). It was revised by Dr. Ms. Angie Scallan and approved by Professor Booden.

The form consisted of 24 questions, which included some general background queries regarding each step of the donation procedures which is elaborated identification/referral of the patients, approaching the patients and their families, withdrawal of treatment during the process of organ donation and the general process as a whole. A mixture of multiple choice questions and Likert scale questions ascertain the necessary information.

The survey was distributed via an email link to the online survey monkey, which the data. The participation information sheet is placed at the very start of this quest indicated that the questionnaire is optional, confidential and anonymous.

## Results

Fifty seven specialised NHS staff members responded to this questionnaire of a specialist nurses in organ donation, 18 worked in the Cardiac Intensive Care Unit, 1 worked in the Paediatric Intensive Care Unit (PICU), 2 consultants and registrars and 1 clinical lead in organ donation. Majority (50%) of the participating staff worked for more than 10 years in the paediatric care. 42.0% of staff had worked in paediatric care for 5 years or less and the remainder of the staff in the ranges of 6-10 years in paediatric care.

## Discussion

The objectives that were set out by this questionnaire was to delve into an examination of the perception of different staff members with regards to donation after circulatory determination of death (DCDD) to control the responses of the identified NHS staff members with the established circulatory criteria and procedures approved by NHS.

The results obtained highlighted a few of the key ethical concerns, some of which were flagged in the article 'Paediatric organ donation in the UK'. It can be seen from Figure 1a that the majority (80%) of respondents agreed that the minimum observation period for a child to be eligible before organ donation procedures is 3 minutes followed by 20% of respondents stating that the minimum observation time is 10 minutes. However, when comparing this finding with Figure 2a, it is evident that although majority (75%) of the individuals thought that 20% of individuals who participated thought that the minimum time observed should be at least 20 minutes. According to NICE guidelines, the minimum observation time period for a child to be eligible before organ donation procedures is 3 minutes. Nevertheless, there is incongruity between the guidelines and the staff's perceptions of the time taken for the determination of death<sup>1</sup>. The code currently is to staff feeling that the amount of time set out by these guidelines<sup>1</sup> are inadequate to determine the time of death before organ procurement begins.

Figure 2b shows that there should be present during an initiation of a discussion regarding donation of circulatory determination of death after a decision of withdrawal of resuscitating measures is made. 53.2% of the people who participated stated that the consultation should be present at the discussion followed by an equal 50.2% of people who agreed that the Specialist Nurse in Organ Donation and the bedside nurse should be present and slightly less than half (44.4%) of the individuals thought that a religious representative should be present. Interestingly, almost all (95%) of respondents had left comments on who they thought should be present and most of them said that the all the involved caregivers as well as the right family members should be present at the discussion. These results are very congruent with the guidelines provided by NHS for organ donation whereby a plan should be devised and during that it is chosen accordingly who should be most appropriate to be present during the discussion<sup>1</sup>. It can be seen that most of the people that should be present are the people who are generally directly involved with the care of the patient and their families.

Figure 3a, Figure 3b and Figure 3c compares the viewpoints of the identified staff members with regards to who should initiate the discussion, whether it should be by the consultant/clinician, the parents or the primary medical care team respectively. An observation that can be made is that generally most would not agree that the consultant in charge should initiate the discussion with the target percentage who disagreed with this view the opposite views in organ donation. As exemplified in Figure 3a, it can be seen that approximately 70% of the staff members who participated in the survey agreed that the consultant in charge should initiate the discussion. Figure 3b, it can be seen that approximately 70% of the staff members who participated in the survey agreed that the parents should initiate the discussion. Figure 3c, it can be seen that approximately 70% of the staff members who participated in the survey agreed that the primary medical care team should initiate the discussion.



# Assessing public knowledge of paediatric organ donation and ways to improve awareness.

Candidate No: 3080 T-Year MBBS

St. George's, University of London

## Aims:

This project aimed to assess the views and knowledge of the general public regarding paediatric organ donation and what could be done to raise awareness.

Regarding the current available information about paediatric organ donation, 89% of participants stated that they believe information should be more widely accessible. 51% said that they felt television adverts would be very effective for doing this, and 58.8% said we needed more education in schools. Participants used that newspaper and internet adverts, television documentaries and leaflets in healthcare centres would also be effective.

## Exploring the Role of Religion and Spirituality for Parents and Staff on a UK PICU

Tasneem Modan, James Linthicum, Joe Brierley  
Great Ormond Street Hospital & University College London

### INTRODUCTION

Religion and spirituality play an integral role for many families and some staff in the paediatric critical care setting. Spiritual beliefs and, by extension, spiritual support have great bearing particularly in an acute setting where treatment decisions have to be made. Parents' religious beliefs may therefore be at the core of treatment and yet the role of faith has never been formally investigated in this setting.

This study used in-depth interviews to determine the role of religion and spirituality for parents and staff on the PICU and to ascertain differences. The findings of this study can be used to inform future practice for pastoral support.

### METHODS

The study took place between March-April 2015

#### Participant Recruitment

Inclusion Criteria:

- Parents of patients who had recently been discharged from the PICU (2014-2015)
- Staff who worked exclusively on the PICU or with parents

Exclusion Criteria:

- Parents of patients currently on the PICU
- Participants who required a translator for either parent

#### Interview

- The interview was semi-structured and participants provide a narrative of their experiences
- Prompt questions were used to establish demographic

### RESULTS

The interview was recorded, transcribed and analysed using Braun and Clark's framework:

- Data immersion
- Coding transcripts
- Arranging codes into themes

Themes were corroborated by an external party

- Fourteen individuals participated (6 parents and 8 staff)
- Recruitment continued until data saturation was achieved

### THEMES

Nine distinct themes emerged from the interviews

#### Parent Themes

- Religion of Faith
- Religion
- Religion
- Religion
- Religion
- Religion
- Religion
- Religion
- Religion

#### Staff Themes

- Religion
- Religion
- Religion
- Religion
- Religion
- Religion
- Religion
- Religion
- Religion

1. 'I guess that one comes up a lot, around the conflicts that families face, around healing or believing that a miracle...'

2. 'Miracles... knowing... that against all odds, you know, God will sustain her, God will keep her.'

3. 'Miracles... knowing... that against all odds, you know, God will sustain her, God will keep her.'

correctly stated that you do not have to be on register. 61% of participants knew that prior to unwell relatives for organ donation. 61% of people correctly identified that become organ donors.

**True or False? questions**

You have to be over 16 years of age to join the organ donation register.

Embryos can be selected to be genetically similar to unwell relatives.

A recipient and donor need to be the same: a) age b) weight c) ethnicity.

Organs for transplant must be retrieved within hours of death.

Babies born up to 8 weeks prematurely can become organ donors.

answered each 'True or False' question.



# Should genetic screening be routine on Intensive care? Staff views at Great Ormond Street Hospital for Children

A questionnaire to find out the views of members of healthcare professionals on Paediatric (PICU) and Neonatal (NICU) Intensive Care Units

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## Aims

A questionnaire based survey that sought the views of healthcare professionals on the Paediatric and Neonatal Intensive Care units at Great Ormond Street hospital on 3 different areas:

- Routine genetic screening
- Routine DNA storage
- Routine genomic analysis

## Introduction

Currently, genetic screening is done in all UK newborn babies and looks for several common diseases such as cystic fibrosis<sup>1</sup>. Neonatal screening also occurs in Europe, USA, South America and Asia and the benefits are widely accepted<sup>1</sup>. Genetic screening is undertaken on everyone, regardless of family history of a disease or any clinical signs, whereas genetic testing is performed when a genetic disease is clinically suspected in an individual.

Newborn screening looks at specific genes, with known mutations for diseases that occur in infancy. As only a few genes are screened, the amount of data to analyse is limited, so only known mutations can be looked for, a solution to this is to screen the whole genome (WGS). Previously this was expensive, but cost is decreasing and is now <£4000<sup>1</sup>. The main problem with WGS is the huge amount of data needing interpretation and this prevents cost from falling further. Another problem with considering WGS for a screening program is with no family history or clinical signs you cannot always link a mutation with the disease<sup>1</sup>.

Despite this, WGS has huge potential to improve our understanding of genetic disease, and individual response to illness, drugs and nutrition during critical illness (genomics). Saunders et al showed that a differential diagnosis of a genetic disorder using WGS can be achieved within 50 hours<sup>1</sup>. This, along with the fact that children in ICU have sampling lines make it an ideal place for a screening program, however nothing is known on ICU staff views about this.

In November 2013 DNA storage began on all admissions on the unit, without consent. In ICU the data-sustaining interventions are the focus, and there are a number of children who do not have genetic samples taken due to resuscitation translocations, death before the disorder is considered or just oversight. Routinely storing DNA would allow genetic testing following translocations, death or in the future. It could also be used to help research into genetic diseases. How long to store DNA and its use in research is the main ethical consideration, and with tobakins now becoming more widespread regulations on genetic storage must be updated<sup>1</sup>.

## Method

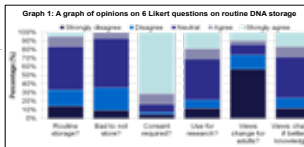
A 4-part questionnaire was created, each part focusing on a different aim. It was decided to only refer to genetic screening, rather than more specialist terms to allow all staff participate. 120 questionnaires were distributed by hand to all staff on PICU and NICU and were returned to a box on ICU. Simple statistical analysis was performed using Microsoft Excel 2011.

## Results

42 completed questionnaires were returned (35% response - 62% nurses, 5% junior doctors, 25% registrars and 8% consultants). 70% were female and 21% male. The mean length of time in NHS was 8.75 years (range from 2 weeks to 30 years). 31% stated genetic knowledge on 5 out of 10 (31%), with only 21% saying it was 5, 24% said genetic screening should be routine in ICU, 83% said it would need consent, and 50% wanted further counselling (Table 1).

The main benefit to patients was early diagnosis and treatment (24%) and genomics (12%), though 12% said it had none. The main benefit to relatives was family planning (25%) and to form a better treatment plan (20%). 24% said it would give parents better understanding of the disease. The biggest disadvantage was cost (33%) and the biggest concerns unnecessary worry for parents (33%), paternity (21%), lack of support after testing (10%). Only 7% said using data without consent.

Question	Yes	No	Don't know
Aware that genetic testing is available.	88%	2%	0%
Know who to refer patients to for genetic testing.	87%	20%	5%
Know genetic screening is not routine on ICU.	80%	0%	5%
Have a basic understanding of genetics?	83%	12%	5%
Comfortable to discuss genetic issues with patients.	33%	55%	12%
Spoken to parents about genetics in the last year.	50%	50%	0%
Involved with referral for genetic tests in the last year.	50%	45%	0%
Genetic testing should be done on all ICU patients.	24%	62%	24%
Change of views if I was on an adult ICU.	5%	83%	2%
Consent should be required.	83%	2%	5%
Should wait to be discussed with the patient.	17%	67%	17%
Parents to be told if an unexpected disease is found.	83%	2%	5%
Routinely counselling should be offered.	80%	0%	5%
Comfortable interpreting genetic results.	76%	12%	12%
Comfortable discussing genetic results with parents.	12%	76%	10%
Want more training if genetic screening was routine.	93%	5%	2%



Graph 1 shows 50% are unsure about storing DNA, however 72% strongly agreed consent is required. Graph 2 shows that had no ethical objection, which rose to 70% if certain conditions were achieved: no cost, 38% said their view would change with a better knowledge of genetics, whilst 38% said their view would change if testing was cheaper. 69% said consent must be given for genomic testing, although 7% said it could be verbal. The biggest reason against consent was that genetic screening did not cause harm (12%).



## Discussion

### 1. Genetic Screening

Surprisingly only 24% of ICU staff felt routine screening should take place despite understanding its benefits. 10% this was because they were worried who would follow up abnormal results, a serious consideration as ICU doctors don't have a day of care after discharge. If the patient dies before results, do you inform the family of abnormalities? If they recover and genetic conditions are found later, who contacts the family? 83% said consent was required. Consent mandates full explanations to families and permits refusal. Without it staff may not have time to explain what is being done. However, consent for screening is not the norm. The USA newborn screening is compulsory, although parents can refuse for religious/personal reasons and Canada has an opt-out system<sup>1</sup>. The UK newborn screening requires consent based on an informed choice, however Nichols et al showed 73.8% felt it was expected, and under pressure to agree<sup>1</sup>. I also observed parents thought they made an informed choice if they understood the reasons and had time<sup>1</sup>. On ICU families are likely to feel rushed and less informed so it could be argued informed consent is not viable. Perhaps it could be waived and sought later. Nearly all wanted further training. This needs urgent attention due to imminent responsibilities staff will have in explaining this to families.

### 2. DNA Storage

Most staff were neutral about DNA storage and 70% believed consent must be given (Graph 1). As consent is not currently gained, this is something that needs discussion with staff and families. Although most were neutral about its use in research (Graph 1), 21% said they would want DNA to be removed after discharge and 12% said they are worried DNA would be used for research without consent (Graph 2). In the USA, newborn blood is sometimes treated as 'residual material' and can be used in research without consent, as long as it is anonymous and has ethical review<sup>1</sup>. If there is prompt information and clear boundaries on how long data/samples are stored, when it would be used and who has access, parents would be more likely to be accepted.

### 3. Genomic screening

69% thought consent should be required. However, others argued that as it does not cause harm no consent was needed. One stated that renal function tests, which decide doses of drugs with renal toxicity don't require consent, so why should genetic screening? Arguably the two are similar using a blood test to decide dose and perhaps views would change if more staff knew of this.

### Limitations

There was only a 30% response rate probably due to time constraints and length of the survey. We only surveyed staff from a specialist children's hospital where several patients have rare genetic diseases and there was a disproportionate nurse to doctor and male to female ratio.

## Conclusion

Routine genetic screening in critically ill children offers help with individual treatment plans, family decisions and future individualized therapies. However, ethical considerations remain a concern for ICU staff. Cost reductions and specific follow-up support for families are also important. With future studies DNA storage could be treated in other units even standard for ICU admissions, although consent must be considered. In the future we will seek family views after ethics approval.

## Acknowledgements

I would like to extend my thanks to my supervisor at Great Ormond Street Hospital. I would also like to thank that staff that took the time to answer the questionnaire, and my tutor at St George's.

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# Where next for the Clinical Ethics Service?

**The Clinical Ethics Service at Great Ormond Street Hospital is evolving. With the service currently funded by GOSHCC it is dependent on the Physician Ethicist's extra programmed activities, and a part time administrator. Its function includes a monthly meeting, the Clinical Ethics Committee (CEC), and Rapid Responses (RR) for urgent cases – which it aims to hold within an 'optimal' time frame. The success of the service, however, is already bringing in ethics' referrals from outside GOSH, although the team cannot currently offer outreach.**

The dissemination of 'the work' of the Clinical Ethics Service in terms of both invited and experiential research publications is currently limited by the lack of dedicated time, and absence of any database. A first data research project to be undertaken by a 3<sup>rd</sup> year BSc UCL medical student will take place this year.

Collaborations have enabled some work with the GOSH Louis Dundas Centre for Children's Palliative Care, the GOSH Chaplaincy, Transplant and ICU teams amongst others and with the teams at the UCL Great Ormond Street Institute of Child Health and University College Hospital FT together with initial exploratory work with the children's hospitals of Melbourne and Boston.

To take the Clinical Ethics Service to the next level and offer what is needed would require a substantial increase in funding to establish the infrastructure needed to run a comprehensive Paediatric Bio-ethics' centre.

## Development of a world class Paediatric Bioethics Centre – what we could offer

It is important to recognise that as GOSH aspires to be the world-leading children's hospital in terms of research and innovative care, it is equally necessary to have a parallel bioethics Centre to deal with the clinical, academic and holistic compassionate care issues for children and their families in the 21<sup>st</sup> century, and the ethical dilemmas that are bound to arise from new therapies. The Institute of Child Health/UCL Partners' Rare Diseases Centre is one such venture already looking for ethics support. A Paediatric Bioethics Centre would need to have a central role in ensuring that compassionate care is given equal priority to all the new and exciting advances in modern medicine. GOSH is uniquely placed and we feel has a moral duty to take the national, and international lead in this.

The GOSH CES already has a major role in UK national bioethics, working with Nuffield Council on Bioethics and the Royal College of Paediatrics and Child Health as well as the UK Clinical Ethics Network. Its help has been sought by Leeds Children's Hospital, Birmingham Children's Hospital, Sheffield Children's Hospital and Kings College Hospital, London. It contributes to the national ethical debates through the UK media with members regularly taking part in BBC Radio 4 Inside the Ethics Committee and has active research links with the University of Melbourne (The Royal Children's Hospital), the University of Oxford and Boston Children's Hospital. With appropriate funding, requests for full research collaboration from Boston's Children's Hospital, Toronto Children's Hospital, Lady Cilento Children's Hospital, Brisbane and The Royal Children's Hospital Melbourne could be realised.

The GOSH Bioethics Centre would interface with interested bodies – many of whom have already worked with current GOSH Clinical Ethics Service – the Royal College of Paediatrics and Child Health, The Royal College of Nursing, The Nuffield Council and the Wellcome Trust and other research bodies. We believe that such a Centre must have the ambition to take its position with the other world leading children's hospitals' Bioethics Centres.

We think it would be useful to define the major ethical needs for GOSH, and clarify what a world-class GOSH bioethics' centre could offer, and indeed look like. Our vision is that such a centre would have the capacity to deal with the full array of ethical issues arising in a paediatric medicine and lead the way in education and research for issues such as:

- End-of-life decision-making: including withdrawal and withholding of life-sustaining treatment (with the Louis Dundas Centre for Children's Palliative Care).
- Parents' role in decision-making for their children (what ethical weight ought to be accorded to them if contrary to medical recommendations).
- Children's rights to be informed and to be involved in decision-making.
- The ethics of novel therapies – supporting clinicians working with Institute of Child Health/ UCL partners – especially with disease so rare the Health Research Authority (executive non-departmental public body of the Department of Health) processes are not responsive enough.
- The equitable allocation of resources.
- Compassionate healthcare roles.
- Adolescent care – capacity, consent and confidentiality.
- Organ donation and transplantation.
- Surgical treatment – limitations and experimental operations.
- Ethics of caring for different cultures, religions and nationalities.
- The ethics of private healthcare for children.
- Support hospital Executive with difficult funding decisions.
- Improving children's lives through promoting the rights and responsibilities of children and families.
- Advocate for excellence in patient and family-centred care with the PALS (Patient Advice and Liaison Service) team.
- Educate health care professionals in ethical issues with courses, rotations and support.
- Support ethical best practice in child health – both in and outside GOSH – conduct innovative research in this arena.
- Lead the development of the national and international child bioethics agenda

Our vision is that our Bioethics Centre could also play a central role providing support and (possibly) education to other hospitals in the UK and Northern Ireland – both to other dedicated children's centres and local hospitals. However, we feel the former must be free at the point of use, and for many organisations this service if chargeable would not be used in the current economic climate. There could, however be financial benefits, such as lower insurance to hospitals which show they use an ethics service. There is a substantial gap in the ethical educational for healthcare professionals looking after children and families in these complex situations.

## GOSH CES current educational contribution

**Education** – the clinical ethics team already provides limited education – to Masters Courses at the Institute of Child Health, to Universities around the South East and of course to staff at GOSH – although this is ad hoc. Our aim is to establish a Paediatric Ethics MSc providing one on-going resource stream – and the approaches for MA and PhD supervision which already occur could be realised. Regular courses for GOSH and other London/South East staff in ethical issues could become the norm.

## Collaboration with colleagues from other children's hospitals

The CES will always try and support our paediatric colleagues from other children's hospitals with their ethical challenges. GOSH recent interfaces with other Trusts have included:

- Video conference for a shared care child at another Children's Hospital. The child's parents travelled to our centre with their child's clinicians joining by video-link).
- Joint ethics' consultation about cessation of chronic ventilation in technology dependent child.
- Urgent telephone conference regarding whether a child (from another UK city) should be transferred for ECMO (extracorporeal membrane oxygenation – the use of an artificial lung (membrane) located outside the body, (extra corporeal) that puts oxygen into the blood (oxygenation) and continuously pumps this blood into and around the body).
- Telephone support to discuss extent of surgical major intervention for children with complex underlying issues for colleagues from a number of different hospitals.
- Reviewing cases in which there is disagreement about providing home PN (parenteral nutrition – also known as intravenous feeding, a method of getting nutrition into the body through the veins) for children from two other UK cities.
- Ethical support to clinicians dealing with complex diagnostic and mental health issues in young or adolescent patients.





# Selected Publications

1. **Developing guidance for pregnancy testing of adolescents participating in research: ethical, legal and practical considerations.**  
Larcher V, Brierley J.  
Arch Dis Child. 2016 Apr 22. pii: archdischild-2016-310725. doi: 10.1136/archdischild-2016-310725. [Epub ahead of print] Review.
2. **Premortem interventions in dying children to optimise organ donation: an ethical analysis.**  
Brierley J, Shaw D.  
J Med Ethics. 2016 Mar 30. pii: medethics-2015-103098. doi: 10.1136/medethics-2015-103098. [Epub ahead of print]
3. **Adolescent autonomy revisited: clinicians need clearer guidance.**  
Brierley J, Larcher V.  
J Med Ethics. 2016 Mar 21. pii: medethics-2014-102564. doi: 10.1136/medethics-2014-102564. [Epub ahead of print]
4. **Training paediatric healthcare staff in recognising, understanding and managing conflict with patients and families: findings from a survey on immediate and 6-month impact.**  
Forbat L, Simons J, Sayer C, Davies M, Barclay S  
Arch Dis Child. 2016 Apr 20. pii: archdischild-2016-310737. doi: 10.1136/archdischild-2016-310737gical or other procedures.
5. **Conflict in a paediatric hospital: a prospective mixed-method study.**  
Forbat L, Sayer C, McNamee P, Menson E, Barclay S.  
Arch Dis Child. 2016 Jan;101(1):23-7. doi: 10.1136/archdischild-2015-308814. Epub 2015 Nov 9.
6. **Elective ventilation to facilitate organ donation in infants with anencephaly: perinatal professionals' views and an ethical analysis.**  
Jivraj A, Scales A, Brierley J.  
Acta Paediatr. 2016 May;105(5):494-8. doi: 10.1111/apa.13281. Epub 2016 Jan 8.
7. **Decision making in long-term ventilation for children.**  
Fine-Goulden MR, Ray S, Brierley J.  
Lancet Respir Med. 2015 Oct;3(10):745-6. doi: 10.1016/S2213-2600(15)00377-X. No abstract available.
8. **UK court accepts neurological determination of death.**  
Brierley J.  
Lancet. 2015 Jun 6;385(9984):2254. doi: 10.1016/S0140-6736(15)61064-9. No abstract available.
9. **Pediatric Deceased Donation-A Report of the Transplantation Society Meeting in Geneva.**  
Martin DE, Nakagawa TA, Siebelink MJ, Bramstedt KA, Brierley J, Dobbels F, Rodrigue JR, Sarwal M, Shapiro R, Dominguez-Gil B, Danovitch G, Sweet SC, Trompeter RS, Moazam F, Bos MA, Delmonico FL; Transplantation Society.  
Transplantation. 2015 Jul;99(7):1403-9.
10. **Conflict escalation in paediatric services: findings from a qualitative study.**  
Forbat L, Teuten B, Barclay S.  
Arch Dis Child. 2015 Aug;100(8):769-73. doi: 10.1136/archdischild-2014-307780. Epub 2015 May 4.
11. **Making decisions to limit treatment in life-limiting and life-threatening conditions in children: a framework for practice.**  
Larcher V, Craig F, Bhogal K, Wilkinson D, Brierley J; Royal College of Paediatrics and Child Health.  
Arch Dis Child. 2015 May;100 Suppl 2:s3-23. doi: 10.1136/archdischild-2014-306666.
12. **Clinical trials of contraceptive agents in those under 16 years of age: are they necessary, ethical or legal?**  
Brierley J, Larcher V.  
Arch Dis Child. 2014 Dec;99(12):1070-3. doi: 10.1136/archdischild-2014-306854. Epub 2014 Sep 4. No abstract available.

**13. Fetal alcohol syndrome (FAS) and fetal alcohol spectrum disorder (FASD)-diagnosis and moral policing; an ethical dilemma for paediatricians.**

Larcher V, Brierley J.

Arch Dis Child. 2014 Nov;99(11):969-70. doi: 10.1136/archdischild-2014-306774. Epub 2014 Jul 8.

**14. Guidance on clinical research involving infants, children and young people: an update for researchers and research ethics committees.**

Modi N, Vohra J, Preston J, Elliott C, Van't Hoff W, Coad J, Gibson F, Partridge L, Brierley J, Larcher V, Greenough A; Working Party of the Royal College of Paediatrics and Child Health. Arch Dis Child. 2014 Oct;99(10):887-91. doi: 10.1136/archdischild-2014-306444. Epub 2014 Jun 9.

**15. Ethical considerations in neonatal end-of-life care.**

Larcher V.

Semin Fetal Neonatal Med. 2013 Apr;18(2):105-10

**16. Developing guidance for checking pregnancy status in adolescent girls before surgical, radiolo1.**

Larcher V.

Arch Dis Child. 2012 Oct;97(10):857-60.

**17. Mediation: an approach to intractable disputes between parents and paediatricians.**

Meller S, Barclay S

Arch Dis Child. 2011 Jul;96(7):619-21.

**18. A nudge in the right direction for organ donation--but is it enough?**

Wellesley H.

BMJ. 2011 Sep 14;343:d5726.

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