

# NUFFIELD COUNCIL ON BIOETHICS

## **Disagreements in the care of critically ill children** *Challenges for policy in changing social and medical contexts*

### **Brief for literature reviews**

The Nuffield Council on Bioethics would like to commission reviews of research, evidence and opinion as part of a short project on disagreements about the care of critically ill children.

#### **Project background**

There have been several high-profile cases in the UK recently of healthcare teams and parents fundamentally disagreeing about the care of critically ill children. Disagreements of this kind have happened before, but these cases have attracted an unprecedented level of attention from professionals, policy makers, families and wider communities, and the media, both in the UK and internationally. This short project will explore the wider social and medical factors that might be contributing to how such disagreements about the care of critically ill children develop. Focussing mainly on the UK, we will also explore how disagreements are currently being resolved. We are particularly interested in how parents and families are able to voice their views. The project will result in the publication of a concise 'bioethics briefing note' that will summarise these factors and the potential challenges they pose for policy makers.

The issues raised are challenging for everyone involved in disagreements, but the focus of this particular project will be the challenges raised for policymakers who have responsibilities to try to help all the parties concerned.

The project will explore and describe:

- 1 the wider factors that might be contributing to how disagreements about the care of critically ill children develop in the UK, including changing social contexts and attitudes, and advances in medicine;
- 2 research and opinion on whether current UK processes for resolving disagreements of this kind are effective and appropriate, and any gaps in research in this area; and
- 3 key challenges for policy makers in future.

## **Literature reviews**

A key part of the project will be reviewing existing research and evidence relating to the questions and issues that the Council is interested in. As such, we would like to commission reviews of the literature and evidence in two key areas:

- 1) The wider factors that could have contributed to the way in which disagreements about the care of critically ill children have developed.
- 2) The effectiveness and appropriateness of current UK processes for handling and resolving disagreements.

### **Review 1. Social and scientific factors**

The aim of this review is to help determine whether there is anything new and/or different happening in the world more broadly that might have contributed to disagreements developing in the way they have, and might mean further cases of this kind are to be expected.

We would like to explore relevant research, evidence and opinion on how changing social contexts and attitudes, and developments in science and medical practice, could be affecting communication and decision-making in the healthcare context, particularly in relation to the care of children.

Potential avenues to explore with regard to developments in medicine might include:

- advances in intensive care methods that enable very sick children to be kept alive for increasingly long periods, or indefinitely;
- the availability of novel treatments, such as stem cell and gene therapies, that are still largely in the experimental stage but offer hope of new effective treatments.

Potential avenues to explore with regard to changing social contexts include:

- how people interact with and view professional expertise and institutions such as healthcare systems;
- changing attitudes towards disability, quality of life, and the value of different kinds of lives;
- the role of parents in decisions about their children's medical care;
- how healthcare providers go about establishing, developing and maintaining trust;
- the way patients access medical information;
- the role of social media, global communication and the ability of people geographically removed from the patient to intervene in discussions about care;

- public interest in and media reporting of disagreements about children's medical care;
- the involvement of religious leaders in medical cases;
- awareness of potential, but unproven, new therapeutic options;
- the marketing practices of healthcare companies, and private clinics and hospitals.

## **Review 2. Processes for resolving disagreements**

The aim of this review is to synthesise research, evidence and opinion on how effective and appropriate current UK processes for handling and resolving such disagreements are in today's world. The review is likely to include research from a number of academic disciplines, and the reviewer should seek particularly to include any research that has been carried out involving the perspectives of parents of children who have received critical care. We hope to highlight areas of good practice across the UK and internationally.

Given the size of the task already set out and the proposed deadline (see below), we do not expect the review to gather evidence and opinion, or critique, the effectiveness or appropriateness of current UK law in this area.

Potential avenues to explore relating to current processes for resolving disagreements might include:

- the effectiveness of different processes in resolving difficult questions about the clinical care of a critically ill child, such as mediation services, third party experts, clinical ethics committees, hospital processes for introducing 'new interventional procedures', and the courts;
- whether any common reasons can be identified as to why some cases are resolved through local processes, i.e. within the hospital or NHS trust, and why some are referred to the courts;
- how the interests of different parties, e.g. children, parents and healthcare teams, are represented and supported in decision making processes, for example through the provision of legal guardians for children, advocacy and legal aid for the parents (we are particularly interested in how parents and families are able to voice their views);
- how the notion of 'best interests' is deployed in dispute resolution;
- how the UK approach compares with that taken by other selected countries, such as Australia.

## **Scope of review**

The Council is particularly interested in research and evidence that relates to the UK (other than where international comparisons are requested). However, if research relating to the UK is limited, research conducted in other countries may need to be included.

The Council is interested in research that has been carried out in the past 10 years. However, the review could include earlier studies if they are particularly appropriate or relevant, or there are few recent studies

Each review should be in the region of 4000–6000 words. Each review should include:

- A summary of published research or evidence covering the topics of interest
- An assessment of the quality of the research and evidence.
- Identification of any gaps in the research and evidence.
- A one-page summary of the review at the beginning of the document.

The reviewer is not expected to reach conclusions or take any particular position on the issues.

The review might be published on the Council's website, and so might be read by members of the public with no previous knowledge of this area. Please use appropriate language and explain any technical terms.

### **Fee and timeline**

There will be a fee of £3000 (plus VAT if applicable) for each review.

The reviews should be completed by 30 September 2018.

### **Applications**

Given the short timeline, we would prefer applications from individuals for carrying out one of the reviews, or applications from two or more people who will work collaboratively to carry out both reviews.

This commission would suit those with an existing interest in this area, and a familiarity with the relevant academic literature relating to decision making in the medical care of children.

Applications should comprise a statement of suitability to undertake the work and a proposal outlining the approach to be taken, supported by a CV, a sample of relevant work, and the names of two referees.

Submissions should reach the Council by 5pm on Monday 23 July 2018 and be addressed to Jade Rawling, Office Administrator ([jrawling@nuffieldbioethics.org](mailto:jrawling@nuffieldbioethics.org)).

To discuss the brief in more detail, please contact Catherine Joynson, Assistant Director, by telephone on 020 7681 9619 or by email at [cjoynson@nuffieldbioethics.org](mailto:cjoynson@nuffieldbioethics.org).

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