

Call for evidence: disagreements in the care of critically ill children

Open from	15 February 2023
Closes on	14 April 2023
Questions/submissions to	children@nuffieldbioethics.org

Background

The Nuffield Council on Bioethics (NCoB) is running an open call for evidence to inform its independent review of disagreements in the care of critically ill children in England, as commissioned by the Secretary of State for Health and Social Care.

Our review is looking at the causes of disagreements between parents/carers of a critically ill child and the healthcare teams responsible for the provision of care or medical treatment for the child; assessing how these disagreements can be avoided; and how their resolution might be handled more sensitively and collaboratively.

The review will be completed by October 2023 and will result in:

- evidence-based advice on the causes of protracted disagreements between healthcare professionals and parents or carers about the care and treatment of critically ill children, and the ethical issues these raise;
- recommendations for interventions to help avoid such disagreements or resolve them more quickly in future; and
- the identification of any gaps in the evidence base.

What we mean by 'disagreement'

When we say 'disagreement', we mean any breakdown in trust or communication between parents/families and healthcare professionals providing care to a critically ill child. Disagreements may be about minor issues or more serious ones.

Why we are calling for evidence

The evidence of those with personal, professional or research experience of disagreements in the care of critically ill children will be crucial to ensure our advice is robust and meaningful and that our recommendations are practically implementable. Previous work we undertook on this subject in 2019, culminating in the production of our [policy briefing note](#), highlighted the far-reaching effects that protracted disagreements can have. Our current review builds on this work, and that of others in the field, to provide further advice on why disagreements happen and to make recommendations for how they can be avoided or resolved more quickly. We want to ensure that everyone who wants to contribute their evidence to this current review, has the opportunity to do so.

What we are looking for

Our [policy briefing note](#) identified four themes common to evidence and discussions about why disagreements develop:

- **communication issues** between parents/carers and healthcare teams;
- **differing perspectives** as to the interpretation of medical information, justifiable risk, who should make decisions and what makes a life worth living;
- **feelings of powerlessness** on the part of parents and healthcare professionals alike; and
- **delays in seeking help** meaning that disagreements are already entrenched when third party support is sought or offered.

We welcome evidence to update and improve our understanding of these areas.

In addition, we would also welcome evidence around any of the following subjects:

- **Effectiveness of dispute resolution mechanisms/third party interventions** such as mediation, obtaining expert second opinion and clinical ethics committees;
- **Suggested changes from current approaches to handling disagreements**, which may be changes to the law, policy, processes, information provision or alternatives to the traditional court model, with evidence to support their potential effectiveness;
- **Examples of good practice in avoiding, reducing, managing and resolving disagreements between parents/carers and healthcare teams**, whether they relate to communication, information, support mechanisms or other factors;;

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- **The impact of media attention** (whether on those involved in a disagreement about the care of a child, or more broadly), including television and print media reporting and sharing of information on social media platforms (via 'groups', video channels or otherwise);
- **Social and cultural factors influencing parent/carer views or understanding about matters relevant to the care of a critically ill child**, such as trust in healthcare professionals and systems, health literacy and access to information, and palliative care;
- **Factors influencing healthcare professionals' ability to navigate disagreements**, such as training, support or access to resources; and
- **Local differences in the way disagreements are handled**, whether between regions/nations of the UK or internationally in comparable countries, and if there is any associated difference in effectiveness, impact or outcome.

What we will do with the evidence

We will carefully consider and analyse all responses to the call for evidence. A summary of insights will be published on our website in May 2023, and the themes and issues identified will inform our other research activities to be undertaken directly with stakeholders. The call for evidence summary will also feature in our final review report (to be laid before Parliament by 1 October 2023) and will help to inform its advice and recommendations. Where relevant and appropriate, we may also publish extracts from call for evidence responses in the review report.

Responding to the call for evidence

The call for evidence will be open for 8 weeks from 15 February 2023. Responses should be in the written word and sent as an email attachment to children@nuffieldbioethics.org by **midday on 14 April 2023**.

Please limit your response to a maximum of 3,000 words.

Responses to our call for evidence will be most effective where we are able to quote from them and attribute the quotes to the person responding. There are circumstances, however, where you may want your response to be anonymous. If you ask us to treat your response anonymously, we may refer to what you say in your response, but will not reveal that the information came from you.

If you have any questions about responding to this call for evidence, including requests for alternative formats, please contact us on children@nuffieldbioethics.org.