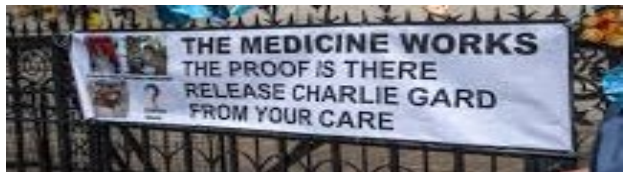


# Conflict and the Paediatric Intensivist

27 February 2024

Prof Stephen Playfor DM



# The changing face of Paediatric Critical Care



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EDITORIAL



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## Tools for revealing uncomfortable truths? Measuring child-centred health-related quality of life after paediatric intensive care

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The benefits of paediatric intensive care units (PICU) are self-evident. Mortality rates for critically ill children have declined dramatically [1]. The greatest gains are occurring in higher-risk groups in whom the appropriateness of critical care was previously questioned. For example, those with malignancies [2] fare better and require a more optimistic approach than hitherto thought [3].

In this edition of *Intensive Care Medicine*, Dr. Aspesberro et al. [4] further this point: that mortality per se has ceased to be a meaningful outcome measure for the majority of paediatric intensive care admissions. Their response is to attempt to identify more meaningful outcome measures from the health-related quality of life (HRQL) literature published between 1980 and 2015 in the context of paediatric critical care.

The review is timely, important and uncomfortable. Timely, because there is a growing appreciation that the

provision of paediatric intensive care is associated with increased morbidity [5]. Why? Perhaps at least in part because there has been a shift in PICU casemix from 'acute' to 'acute on chronic' critical illness. A recent study from the USA identified that 53 % of critically ill children had pre-existing chronic complex illnesses [6]. This change has many implications. One major implication is that the HRQL outcomes that might be hoped for many of our patients are becoming more distinct from those of previously healthy children [7].

This subject is important, because paediatric intensive care is costly; for the child, their family and society. Equally, the association of increased morbidity with improved mortality should make intensivists uncomfortable, as now we enter an era where the outcomes shift from the "hard" objective, binary 'life or death' outcome to the more "fuzzy" concept of HRQL.

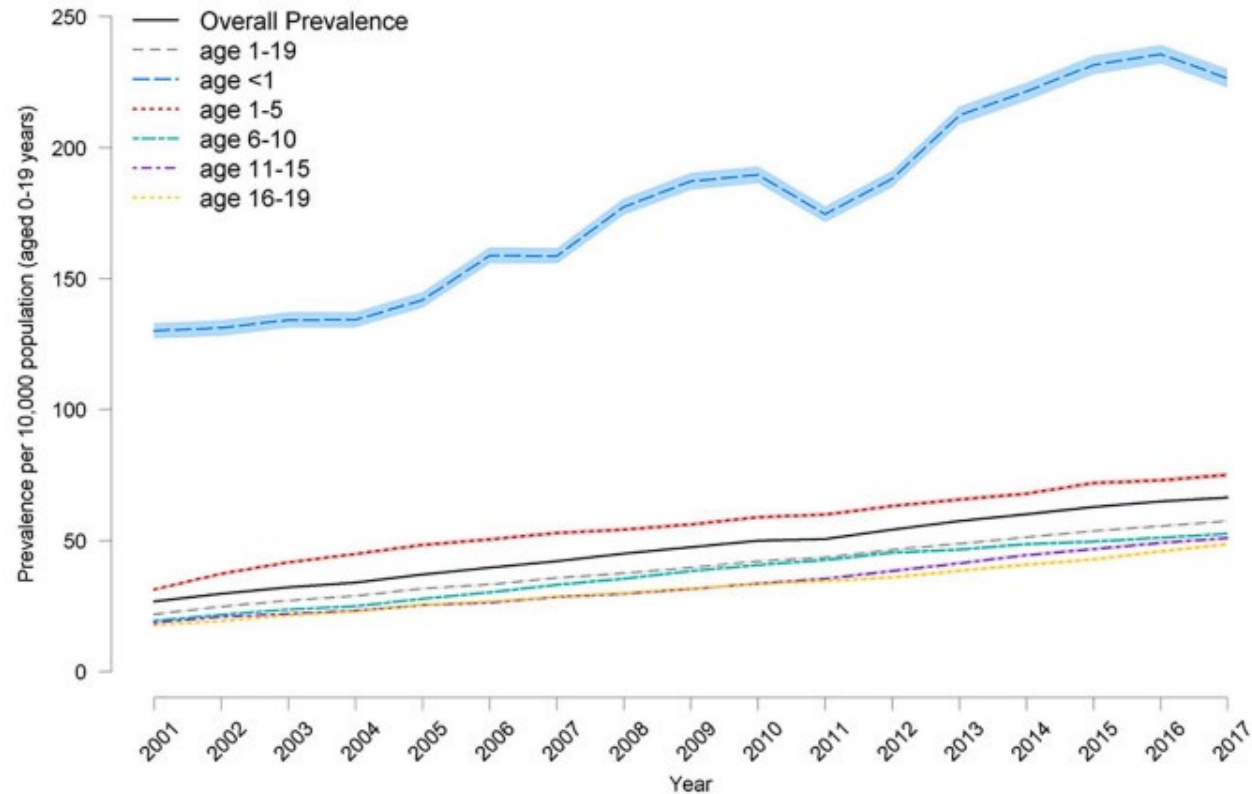
The World Health Organisation (WHO) defines health as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" [8].

Ironically, this definition will render most of us unhealthy most of the time as the emphasis is on "complete" well-being. Moreover, the WHO definition of health does not do justice to resilience and the capacity to adapt and function well with chronic disease or disability. This understanding prompted a group of international health experts to reframe health as the ability to adapt and self-manage [9]. Adaptation and resilience are vital attributes to successfully navigate through childhood, and self-management is increasingly relevant to children as they grow older. Thus, the concept of "health" requires a more operational framework, as well as meticulous measurement, in order to better advance our clinical practice to meet these new outcome goals.

Other high-risk paediatric medical specialties have previously confronted this same challenge of evolving a more empirical basis by which to assess the potential

'Paediatric intensive care is transitioning from a specialty that deals with acute illness to one that is part of the multidisciplinary team that looks after children with chronic illness'

# Prevalence of life-limiting conditions in UK children



# Impact on healthcare organisations

- Cost
- Resources
- Reputation

2013-2023; 6 patients from RMCH PICU

£1 million in legal costs

£7.9 million costs in PICU bed occupancy

Bed occupancy = One patient in a bed every day for 9 years

Given median length of stay; 938 other patients could have been looked after if not for these six patients



# Impact on healthcare professionals

- Burnout
- Poor team cohesion
- Negative impact on performance
- Negative impact on wellbeing
- Moral distress
- Time commitment



# Impact on patients and families

- Increased risk of health care errors
- Poor therapeutic relationships
- Worse prognosis
- Impact on those witnessing conflict; other families and children



# The Nuffield Council on Bioethics independent review: Disagreements in the care of critically ill children



## Recommendations 1-4

### Filling gaps in evidence and ensuring lasting change

1. The Department of Health and Social Care (DHSC) should establish a taskforce to oversee the implementation of the recommendations in this report to facilitate collaboration; promote the filling of current gaps in evidence and ensure mechanisms are in place to effect lasting change.
2. The Department of Health and Social Care (DHSC) should commission further research to gather evidence from parents about their experiences of shared decision-making with healthcare professionals about their child's care and treatment, both inside and outside of critical care environments.
3. The Ministry of Justice (MoJ) and His Majesty's Court and Tribunal Service (HMCTS) should convene and report on a round-table discussion with expert stakeholders, including parents, to consider ways in which court proceedings could be handled more sensitively for parents, including exploring the feasibility of using elements of non-traditional court models such as the Family Drug and Alcohol Courts. Following the round-table discussion, they should consider commissioning further research on the efficacy and limitations of existing formal mechanisms, such as mediation and the courts, used to resolve disagreements in the care of critically ill children.
4. Researchers and research funders exploring ethical issues arising in care and treatment of children should ensure that their work is informed by, and inclusive of, available evidence from parents and children (where applicable) about their experiences.

## Recommendations 5-7

### Facilitating continuous improvement

5. Providers of undergraduate and relevant postgraduate qualifications for healthcare professionals (including specialty qualifications) should ensure that core curricula include content on how to build and maintain relationships with children and parents and why this is essential in order to provide safe and effective care to children.
6. The Department of Health and Social Care (DHSC) should require NHS trusts in England to provide all staff working in environments where children are treated, including all support staff, with access to regular training and continuous professional development (CPD) in relationship-building skills and in identifying and managing disagreement.
7. Representative and membership organisations of healthcare professionals working with children, such as the Royal College of Paediatrics and Child Health (RCPCH) and the Royal College of Nursing (RCN) should work together to collate, publish and maintain a bank of resources (including existing education, training and examples of 'good practice' initiatives) relevant to relationship-building and improving communication with families.

## Recommendations 8-10

### Improving information sharing

8. NHS England should collate, maintain and publish a suite of resources, in different formats, available to assist families in navigating healthcare systems, including advice on how to communicate with their child's treating team; how to seek second opinions and raise concerns; and signposting to sources of emotional and practical support. The suite of resources should be accessible online to all and information about it (including how to access print and/or non-English language copies) should be provided to families when their child is admitted to hospital.
9. The Royal College of Paediatrics and Child Health (RCPCH) should collaborate with families, palliative care providers and charities to produce accessible information for families about the role and potential benefits of palliative care, and work with other healthcare professional membership organisations to ensure that all healthcare professionals working with children are aware of and have access to it.
10. The Children and Family Courts Advisory Service (CAFCASS) should provide and promote information for parents about the role of the children's guardian in court proceedings about medical treatment of children, including what they can expect from the guardian and what to do if they have concerns.



# Independent review: Disagreements in the care of critically ill children

NUFFIELD COUNCIL ON BIOETHICS

Healthcare professionals' perspectives

Some findings from our survey for healthcare professionals with experience of disagreements between families and healthcare teams in the care of critically ill children in England\*

## Disagreements and how they arise

New disagreements do not arise very frequently, but take up considerable time when they do

How often do new disagreements arise?



How much time do you spend on navigating or resolving these disagreements?



## What impacts disagreements about the care of critically ill children?

- 75%** Mismatch of expectations about what can be done for a child medically
- 65%** Differences in belief about quality of life, end of life, decision-making and other values
- 65%** Communication issues between families and professionals

\*Proportion of respondents who answered monthly, weekly, more than once a week vs quarterly or less than quarterly

## Impacts on healthcare professionals

As a result of a disagreement about a critically ill child...



- 66%** Have experienced moral distress and/or moral injury
- 61%** Think there is **less trust generally in healthcare professionals**
- 59%** Have a **better understanding of families' perspectives and priorities**

Find out more [www.nuffieldbioethics.org/disagreements](http://www.nuffieldbioethics.org/disagreements)  
Contact [children@nuffieldbioethics.org](mailto:children@nuffieldbioethics.org)  
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# Independent review: Disagreements in the care of critically ill children

NUFFIELD COUNCIL ON BIOETHICS

Healthcare professionals' perspectives

## What is helpful in resolving disagreements?



What have healthcare professionals found helpful?

- 92%** Support from senior staff
- 86%** Seeking second opinions
- 84%** Early involvement of palliative care services
- 74%** Accessible information for families about their child's illness/condition
- 72%** Communications training (other than conflict resolution training)

Proportion of respondents who had tried these methods and found them 'helpful' or 'very helpful'

## What doesn't help?



These factors were also found to be unhelpful or very unhelpful

- 16%** Decision-making tools/frameworks
- 19%** Management/trust support
- 16%** Mediation

## What would be helpful if it were available?

- 31%** Mediation
- 26%** Accessible information for families about their options when they disagree with healthcare professionals
- 31%** Ethics training

Proportion of respondents who had not tried these options, but thought they would be helpful if available



Find out more at [www.nuffieldbioethics.org/disagreements](http://www.nuffieldbioethics.org/disagreements)

We would like to thank all those who submitted a response to this survey. The findings from this survey will be used in conjunction with evidence gathered from other research activities, to help inform this review and produce a final report to go before UK Parliament in September 2022.

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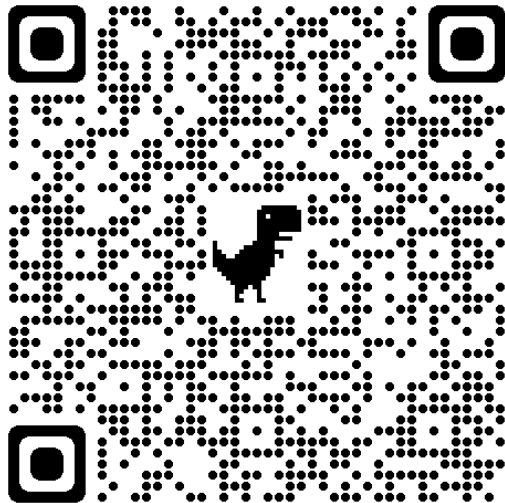
# How can we better recognise and manage conflict between families and HCPs?

- Development of e-platform
- Launched May 2023
- Developed collaboratively with
  - Families
  - HCPs
  - Royal Colleges
  - Charities
- Appointment of seven Regional Conflict Management Champions; Sept 23-April 24



# How to access the e-platform

<https://www.e-lfh.org.uk/programmes/recognising-%20and-managing-conflict-between-childrens-families-%20and-healthcare-providers/>



- Key Points

Free to access

Training modules foundation

Growing repository of resources

Endorsed by PCCS & RCN

- RCPCH approved

# Who are the Regional Champions?



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# Paediatric Intensivist's wish list

- A structured evaluation of early independent medical mediation
- A non-adversarial forum for the resolution of disagreements with families
- A national system for obtaining clinical second opinions
- A system for addressing the best interests of children outside of PICU
- Clarifying the status of children with no balance of burden or benefit



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