

Disagreements in the care of critically ill children

Presented to Parliament pursuant to Section 177(2) of the Health & Care Act 2022

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Acknowledgements

This report would not have been possible without the insights and contributions of many individuals and organisations working tirelessly to make things better for critically ill children and their families.

The Nuffield Council on Bioethics would like to thank all those who have provided input, guidance and information to this review. In particular, we are grateful to Kirsty Moreton for her comprehensive and engaging literature review; to Together for Short Lives for support in interview design and materials; to the Medical Mediation Foundation for sharing additional interview transcripts and to the Paediatric Critical Care Society for their sterling efforts in collating and anonymising the experiences of their members. We would also like to thank the Paediatric A&E and PICU teams at the Royal Bolton Hospital, for so kindly allowing us to pilot our workshop content, and colleagues at NHS England for giving us the opportunity to contribute to their important work on the training hub for healthcare professionals.

The review has also benefited from the assistance of champions across healthcare, policy and research disciplines. We have not sought to name them all individually here to ensure that nobody is missed out, but we are very grateful to all those who have devoted time and energy to promoting and supporting the review. On a related note, it would be remiss not to extend thanks to officials at the Department of Health and Social Care for their willingness to have open and constructive conversations throughout whilst respecting our independence.

Our gratitude is also owed to everybody who shared their personal experiences and insight of disagreements in the care of critically ill children. This includes the individuals and organisations who responded to our call for evidence, the healthcare professionals who took the time to respond to our surveys, and especially those who shared with us so candidly and reflectively at our workshops. We heard of much great work being undertaken in order to improve the experiences of children and their families, and we hope that our recommendations will bring light to and share this work with a wider audience so that all benefit.

Finally, and crucially, we would like to express particular thanks to the parents who took part in our interviews. Their generosity in sharing their most personal and painful experiences about their children's critical illness, and their motivation to make things less distressing for others was admirable. We were deeply moved by their stories and grateful to be trusted with them.

Executive summary

Critical and intensive care units are naturally high-stress environments. They care for and treat the most seriously ill patients who require support for vital organs, and/or who need to be constantly monitored. Being so unwell has an impact beyond the patient themselves; families and friends will understandably be concerned and anxious that their loved one gets the best possible treatment, and healthcare professionals face the challenge of providing care that will be effective in improving the patient's condition.

It is little wonder, then, that tensions can mount – particularly where the patient is a child. The general social assumption – that youth is synonymous with health, and that illness and injury is something that befalls us as we age – makes it all the more difficult to accept and process serious illness in children. Parents and healthcare teams can disagree with each other about the care of critically ill children. Through the course of this review, we have heard that the majority of these disagreements are about relatively minor issues and quickly resolved between the parties when they happen. On rare occasions, however, disagreements can arise that become entrenched and cannot be resolved between parents and healthcare teams. In some cases such disagreements have required the courts to decide what should happen to a child. The legal process can have significant and lasting impacts on everybody involved, and some such cases have attracted huge media interest and attention both domestically and overseas, which can add to the heightened tensions.

This report was prompted by the incidence and impact of high-profile disagreements, and a commitment from the Secretary of State for Health and Social Care under s177 of the Health and Care Act 2022 to undertake a review of the causes of disagreements between parents and healthcare teams about the care of critically ill children. In December 2022, we, the Nuffield Council on Bioethics (NCOB), were commissioned to undertake that review and this document is the report which will be accordingly laid before Parliament.

The report is thematic, setting out the key themes arising from the research we undertook, as well as detail of how we conducted the research. The report makes recommendations based on our findings which, if implemented, we believe will be to the benefit of all

who find themselves involved in disagreements about the care of children – including, most importantly, the children themselves.

WHAT WE MEAN BY 'DISAGREEMENTS BETWEEN PARENTS AND HEALTHCARE PROFESSIONALS ABOUT THE CARE OF CRITICALLY ILL CHILDREN'

A number of words used commonly in this report may be interpreted differently depending on who is reading it. Our definition of the above phrase is crucial to understanding the report and its recommendations.

For the avoidance of any doubt, when we say “disagreements between parents and healthcare professionals about the care of critically ill children”:

“**disagreements**” means any difference of opinion or belief that cannot be immediately resolved;

“**parents**” means anyone with parental responsibility for a child, whether or not they are the child's biological parent;

“**healthcare professionals**” means anyone working in a healthcare setting that is registered with any of the eight health professional regulators under the oversight of the Professional Standards Authority (PSA);¹

“**critically ill**” means unwell enough to be treated in an intensive care unit;

“**children**” means those under the age of 16, including babies.

For ease of reading, we abbreviate “disagreements in the care of critically ill children” to “disagreements” throughout this report.

We have approached the review with the understanding that some level of disagreement is natural in the human condition and to be expected – and, indeed, there is debate in the academic literature as to whether it is desirable to attempt to eradicate disagreement in a healthy society that

1. Ten professional regulators fall under the PSA's remit, although one regulates social care professionals (Social Work England) and another regulates those in Northern Ireland (Pharmaceutical Society of Northern Ireland), and therefore fall outside the scope of this review.

values equity.² Expecting that disagreement won't happen in situations of high stress is unrealistic and, as we identify in this report, potentially harmful as it results in unpreparedness to manage discord and the subsequent emotional and psychological impacts on those involved. We have therefore sought to explore disagreements with a view to reducing their frequency and adverse impact rather than aiming to avoid them completely.

WHAT WE HAVE FOUND

How disagreements develop

- The subject matter of disagreements is almost always the suitability and appropriateness of care and treatment. There is, however, no single or dominant causative factor which transforms simple differences of opinion about care and treatment into disagreements. The influences on disagreements are multi-factorial and sometimes come from people's pre-existing experiences and perspectives, as well as from questions arising directly relating to the child's care and treatment.
- The complexity of how and why disagreements develop mean that there is no single action which will either improve the experience of disagreements for those involved or reduce the frequency with which they arise. We make sixteen recommendations across a number of areas, these are targeted at a range of groups and organisations. Change will only happen if the recommended steps are taken together. Oversight of the recommendations is therefore crucial to ensuring their effective implementation. **We recommend that 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 (Recommendation 1).**
- Key causes of disagreements, and aggravators of existing ones, include communication issues, mismatched expectations and a lack of information available to parents.
- Communication issues that influence the development of disagreements include problems

with: tailoring communication appropriately to individuals' needs; acknowledging parents as experts in their children; misunderstandings and mixed messages, as well as the timing of sensitive, difficult or distressing conversations. Where healthcare professionals had built relationships with parents, understood their needs and communicated accordingly, this had a positive impact on parents.

We recommend that the DHSC taskforce established as part of recommendation 1 should identify an appropriate body to create and publish guidance for healthcare teams that treat children on how to seek information from children and parents about their communication needs and preferences, ensuring all team members are aware of these and are accordingly providing consistent messaging about their child's care and treatment, particularly where the child is under the care of a multi-disciplinary team (Recommendation 13).

- In particular, diagnostic and prognostic uncertainty about a child's clinical condition was not always communicated well, with healthcare professionals sometimes lacking confidence in expressing uncertainty. Where uncertainty was communicated honestly, however, this was seen to have a positive impact on relationships and the building of trust between parents and healthcare professionals.
- Department culture within hospitals also affects the way that healthcare professionals communicate with parents. **We recommend that healthcare professionals in positions of clinical leadership take responsibility for developing and promoting a team culture that supports and values shared decision-making with parents (Recommendation 11).**
- A lack of information about their child's condition and prognosis, as well as insufficient or variable information about support available for parents with a critically ill child, can sometimes contribute to disagreements developing. **We recommend that 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**

2. Auckland C and Goid I (2020) Resolving disagreement: a multi-jurisdictional comparative analysis of disputes about children's medical care *Medical Law Review* **24(8)**: 643-4.

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 (Recommendation 8).

- Training in ‘good communication skills’ is unlikely to help in reducing the frequency and impact of disagreements and may in some circumstances reinforce the view that there is a ‘correct’ way to communicate well rather than tailoring communications to an individual’s needs and situations. Instead, improving and prioritising relationship-building with parents, and the skills and understanding needed to be able to do this, should be the focus of communications training, to help ensure that individual needs and situations are accommodated. **We therefore recommend that 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 (Recommendation 5) and that 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 (Recommendation 6).**
- Much valuable work is being done by individual healthcare professionals and teams to improve communication and shared decision-making with parents, with initiatives, training and information being developed and implemented at local levels to positive effect. These local initiatives could usefully be adopted by other trusts if they were aware of them and information about them was accessible. **We therefore recommend that 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 (Recommendation 7).

- Mismatched expectations – for example about what is medically possible, what medical information is or is not significant, or about what is involved in the provision of palliative care - are very influential on the development of disagreements. Differing values and beliefs (particularly around quality of life and when life comes to an end) are also influential, and disagreements centred around these beliefs are less amenable to early and informal resolution. **We recommend that 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 (Recommendation 9).**
- Parental access to existing information about a child’s condition, such as their clinical record, is also variable across England. Some parents are able to readily access information whereas others experience considerable difficulties and delays in obtaining this information, despite having submitted formal statutory requests to obtain it. **We recommend that NHS trusts in England should ensure that protocols are in place to ensure parents requesting access to their critically ill child’s medical records are provided, where practicable, with it within a week of the request being made, in the absence of any factors that would prevent disclosure such as lack of consent from a child with capacity or safeguarding issues (Recommendation 14).**

The impacts of disagreements

- Although the majority of disagreements are resolved between parties at an early stage and very few require court intervention, the adverse impacts of disagreements can be profound and enduring, for all involved, no matter the severity or duration of the disagreement.
- The most serious impacts of disagreements are on the child, their parents and the healthcare

professionals caring for the child. There is, however, little published evidence available looking in detail at the impacts on children and their parents. **We recommend that 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 (Recommendation 4).**

- Adverse impacts on the critically ill child arise as a result of focus no longer being solely on the child's care and treatment, but also on management and resolution of disagreement.
- The emotional and psychological impact of disagreements on all involved is extensive and whilst numerous sources of support are often available, awareness of these is variable which can limit accessibility.
- Parents experience long-term emotional and psychological impacts from three particular factors: the critical illness of their child, being within the critical care environment and being involved in a disagreement about their child's care. In some cases, parents can also lose trust in healthcare professionals generally which can persist even after the disagreement has come to an end. More information about parents' experiences of shared decision-making with healthcare professionals would be of benefit to enhance available evidence. **We recommend that 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 (Recommendation 2).**
- Healthcare professionals experience moral distress and moral injury – a sense of internal conflict about being able to provide the care they feel their patients need – as a result of their involvement in disagreements. This results in harm to their emotional and psychological wellbeing, and may have an adverse impact on medical trainees choosing to specialise in paediatrics. They also struggle with feelings of powerlessness emanating from their inability to respond to inaccuracies in the media, or on social media, as a result of the professional duty to maintain patient confidentiality. The culture of individual departments within hospitals

can have an impact on healthcare professionals' ability and willingness to seek support for emotional, psychological and moral distress arising from their involvement in disagreements. **We therefore recommend that healthcare professionals in clinical leadership roles should take responsibility for modelling a team culture which recognises and prioritises relationship-building with children and parents as an integral part of providing good holistic care to a child (Recommendation 11) and that NHS trusts should ensure that their staff are made aware of, and supported and encouraged to access, a variety of sources of emotional and psychological support (Recommendation 12).**

Resolving disagreements

We found from our evidence gathering that there is not a one size fits all action or mechanism that helps address or resolve a disagreement. Different actions or mechanisms were perceived as helpful, or unhelpful, depending on the individual circumstances of a situation. This highlights the need to ensure that there is a range of well-established mechanisms that can be used depending on the individual situation.

- Clinical ethics committees can be useful in providing space for healthcare professionals to reflect and get advice on how to proceed where there is disagreement between parents and healthcare professionals about what to do for a critically ill child, but there is too much variation in their availability, resourcing and how they work which limits how useful they can be. They also often do not involve parents in their meetings and deliberations. **We recommend that guidance for clinical ethics committees (CECs) in England should be produced on how to ensure that parents', and where appropriate children's, views are taken into account in CEC discussions and that parents are supported to provide input to CEC meetings. The DHSC taskforce established as part of recommendation 1 should identify who is best placed to produce or commission this guidance (Recommendation 16).**
- Mediation between parents and healthcare professionals can be helpful in some situations to facilitate open conversations, but there is no current evidence to support mandating its use in every case or in disagreements that would otherwise go to court. Offers of mediation can be delayed and are not always taken up by parents as a result of

it sometimes being presented to them as a way to convince them of the healthcare professionals' way of thinking.

- The role of the Children's Guardian, and what parents can expect from them, is not explained to parents consistently and is often unclear. Accessible information that would help to clarify these questions is not readily available. This has a distressing effect on parents, particularly where they have concerns about the conduct or decisions of the children's guardian but are not in a position to question or challenge it. **We recommend that 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 (Recommendation 10).**
- The current legal threshold for court intervention in cases about medical treatment of a child – the 'best interests' test – has had its merits debated in academic literature, with some proposing an amended or alternative test, but there is insufficient evidence at present to support a change to the law.
- Court proceedings can be intimidating for parents and there is often inequity between the parties involved, for example, parents sometimes being informed of hearing dates at the last minute and not being in a position to obtain adequate legal representation. **We recommend that NHS trusts in England should inform families within three calendar days of taking the decision to initiate court proceedings in order to give them sufficient time to seek independent legal advice and collate necessary information to disclose to the court (Recommendation 15).**
- The court environment itself can be imposing and there is some evidence in other family law contexts (such as the Family Drug and Alcohol Court model) - to show that a less formal environment has positive impacts on parents' involvement in, and satisfaction with, outcomes. Little research has been undertaken at present as to how learnings from such models can be used to good effect in improving parents' experience of going to court about the care of their critically ill child. **We recommend that 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 (Recommendation 3).

Glossary of terms

Best interests

Care and treatment must be in a child's best interests in order to be provided. What is in a child's best interests will vary from child to child. Whether something is in a child's best interests does not just depend on their health-related interests, but also consideration of values, beliefs and wishes of both the child and their family (if the child is too young for their values, beliefs and wishes to be known). The legal test to determine whether care or treatment can be provided to a child is accordingly referred to as the 'best interests' test.

Children and Family Courts Advisory Service (CAFCASS)

The body which represents children in family court cases in England. They will appoint a Children's Guardian in each case who is responsible for acting as the child's voice and writing reports for the court on what they think is best for the child.

Capacity

The ability to understand, retain and weigh up options. An ethical and legal requirement for a person to be able to give informed consent to treatment.

Competency

Often used interchangeably with 'capacity': the ability to understand, retain and weigh up options.

Clinical ethics committee (CEC)

A group of people, often including doctors, nurses, lawyers and potentially others (including lay persons), who deliberate and advise on the ethical issues arising from complex or sensitive medical cases.

Continuous professional development (CPD)

Ongoing learning and education to improve professional practice, and a requirement of being able to work as a healthcare professional in England.

Critical care

Care and treatment provided to the most seriously unwell patients, where constant monitoring is needed. Also known as 'intensive care'.

Department of Health and Social Care (DHSC)

UK Government department responsible for matters relating to health and social care.

Family Integrated Care

A model of healthcare which promotes families as equal partners in their child's care in the neonatal intensive care unit.

Family Drug and Alcohol Court (FDAC)

An alternative family court for care proceedings which aims to work with parents who struggle with drug and alcohol misuse.

His Majesty's Court and Tribunal Service (HMCTS)

The body responsible for the administration of the criminal, civil and family courts in England and Wales.

Intensive care

See 'critical care'.

Life-limiting condition

A medical condition which cannot be cured and will have an impact on how long someone will live.

Life-threatening condition

A medical condition (or conditions) which will result in the patient dying if treatment does not work.

Life sustaining treatment (LST)

Medical treatment to replace or support organ or other vital bodily function, such as a ventilator to support breathing.

Mediation

A form of dispute resolution in which a neutral third party speaks to disagreeing parties, and may facilitate discussion between them. The aim of mediation is to understand the causes of the disagreement, help parties to understand each other and feel heard, and attempt to bring the parties together to find a mutually acceptable resolution.

Medical/clinical records	Documentation of medical history and medical care and treatment.
Ministry of Justice (MoJ)	Government department responsible for the justice system in the UK.
Multi-disciplinary team (MDT)	A group of professionals (usually healthcare professionals) who are responsible for different aspects of a child’s care. The MDT has meetings to discuss a child’s care plan, progress and options for treatment.
Moral distress	Psychological unease where professionals identify an ethically correct action to take but are constrained in their ability to take that action, usually for reasons outside their control. ³
Moral injury	Psychological harm that results from sustained moral distress. ⁴
National Health Service (NHS)	The healthcare system responsible for providing care and treatment for people in the United Kingdom.
Nuffield Council on Bioethics (NCOB)	Independent research and policy centre, author of this report. Commissioned in December 2022 by the Department of Health and Social Care to conduct this review.
Neonatal	Relating to newborn babies (‘neonates’).
Neonatal Intensive Care Unit (NICU)	Hospital department responsible for looking after newborn babies who require critical care.
Paediatric	Relating to babies (but not newborn babies), children and young people under the age of 18.
Palliative care	A type of care which aims to improve the quality of life of patients with life-limiting conditions, and their families.
Paediatric Intensive Care Unit (PICU)	Hospital department responsible for looking after babies, children and young people under the age of 18 who require critical care.
Post-traumatic stress disorder (PTSD)	An anxiety disorder caused by very stressful, frightening or distressing events.
Subject access request (SAR)	The request that someone has a legal right to make in order to access information about themselves that is held by an organisation.
Shared decision-making	A collaborative process between healthcare professionals and patients/their families to make decisions about what care and treatment the patient will receive.
Significant harm	A term used in certain family law contexts to mean ‘serious harm’.

3. British Medical Association (2021) *Moral distress in the NHS and other organisations*, available at: <https://www.bma.org.uk/advice-and-support/nhs-delivery-and-workforce/creating-a-healthy-workplace/moral-distress-in-the-nhs-and-other-organisations>.

4. *ibid.*

Introduction

We, the Nuffield Council on Bioethics, were commissioned by the Secretary of State for Health and Social Care to undertake an independent review of the disagreements that can arise between families and healthcare teams in the care of critically ill children in England. This commission followed a Government commitment to undertaking such a review at s177 (2) of the Health and Care Act 2022. This report is presented to Parliament pursuant to that provision of the Act.

Background

Disagreements between parents and healthcare professionals about the care of critically ill children that have gone to court for resolution have hit the headlines, particularly in recent years, with high-profile cases attracting a considerable level of attention from professionals, policymakers, the press and the public both within the UK and internationally.

As outlined in law and professional guidance, decisions about a child's care and treatment must be made in the child's 'best interests'. Although parents and healthcare staff should ideally agree, cases can be referred to court where there is a lack of consensus.

Despite the recent focus, few disagreements end up in court for resolution. Many are either resolved at an early stage, or are otherwise resolved before court proceedings are issued. It is clear, however, that even where disagreements are resolved locally and without going to court, the impacts of them on the child, their families, healthcare professionals and others involved in their care can be profound, wide-ranging and enduring. The critical illness of a child – in conflict with the general social assumption that youth is synonymous with health, and that illness and injury are things that befall us as we age – is naturally difficult to accept and process. Families, who are already in the difficult position of having a critically ill child, can find themselves having to navigate unfamiliar environments such as intensive care units and courtrooms with little or no support. Healthcare teams can come under intense scrutiny, sometimes feeling compelled to provide care and treatment that they do not believe is in the best interests of a child, that they consider could cause the child avoidable harm, or that has no chance of being effective – in conflict with their moral and professional values. The critically ill child may have the focus on their care and treatment impacted by efforts to resolve the disagreement.

Our review builds on previous work that NCOB have undertaken in this area, which includes publication of a policy briefing note in 2019. In that briefing note, we used information gathered from two literature reviews and a multi-disciplinary workshop to identify four broad themes as to why disagreements develop: communication issues, differing perspectives, feelings of powerlessness and delays in seeking help.

Scope

This review, which ran from December 2022 until September 2023, focused on three interconnected research questions:

- 1 Causes:** what are the causes of disagreements between healthcare teams and parents about the care of critically ill children?
- 2 Impacts/influencing factors:** where disagreements have already happened, or are already happening, what aggravates or entrenches them further, or helps to resolve them?
- 3 Resolution mechanisms:** where disagreements cannot be resolved between parties directly and are referred to a third-party mechanism for decision-making (such as mediation, or the courts), how effective are these mechanisms in resolving disagreements?

The review looked at disagreements arising in England only, although some of the conclusions we draw and recommendations we make may be applicable in other nations of the UK.

The terms of reference for our review, agreed in advance with the Department of Health and Social Care (DHSC), stated that the review would consider:

- The causes of disagreements between parents/carers and healthcare staff, including those related to the strains of the situation on the people involved, the healthcare environment and culture, and the wider societal context.
- Examples of good practice in shared decision-making and the features of healthcare environments that foster good, collaborative relationships between parents and healthcare staff.
- Potential barriers or challenges to good practice related to, for example, the provision of specialist services and dispute resolution measures, workforce capacity, capability and training, public information and education, and healthcare leadership.
- Gaps in knowledge relating to, for example, the effectiveness of dispute resolution interventions, that could be addressed through further research.

- National or regional level solutions and actions that could help avoid disagreements or resolve them more quickly in future.

A NOTE ABOUT LANGUAGE AND TERMINOLOGY

We know that some of the language we use in this report can have multiple meanings, or be interpreted differently depending on who is reading it. Some terms we use may also be technical, medical or otherwise complex. We have included a glossary of terms at the start of this report, but for clarity we include definitions of our most commonly used words and phrases here.

When we say “disagreements between parents and healthcare professionals about the care of critically ill children”:

“disagreements” means any difference of opinion or belief that cannot be immediately resolved;

“parents” means anyone with parental responsibility for a child, whether or not they are the child’s biological parent;

“healthcare professionals” means anyone working in a healthcare setting that is registered with any of the eight health professional regulators under the oversight of the Professional Standards Authority (PSA);⁵

“critically ill” means unwell enough to be treated in an intensive care unit;

“children” means those under the age of 16, including babies.

For ease of reading, we abbreviate “disagreements in the care of critically ill children” to “disagreements” throughout this report.

5. Ten professional regulators fall under the PSA’s remit, although one regulates social care professionals (Social Work England) and another regulates those in Northern Ireland (Pharmaceutical Society of Northern Ireland), and therefore fall outside the scope of this review.

Research activities

Our priority in undertaking the review was to ensure that all those with experience of disagreements – whether personal or professional – had the opportunity to have their voice heard. This was particularly the case in relation to parents of critically ill children who have disagreed with healthcare teams, as current research has not explored their experiences in detail – a fact highlighted by the literature review we commissioned.

We accordingly sought to undertake research activities directly with those who had experienced disagreements and designed them to maximise meaningful contribution within the timescales available for the review.

LITERATURE REVIEW

We commissioned a thematic literature review from Dr Kirsty Moreton at the University of Birmingham to explore literature and published evidence between 2017 and 2023, relating to disagreements between parents and healthcare teams about the care of critically ill children. The literature review excluded material covered by previous literature reviews we had commissioned as part of our briefing note development, and focused on examining three questions:

- 1 What are the causes of disagreements in the care of critically ill children in England?
- 2 What is the impact that these disagreements can have on the child, their family, healthcare professionals, the NHS and wider society?
- 3 What are the possible mechanisms for avoiding, recognising, managing and resolving disagreements?

The literature review can be found on our website and is linked to at Annex 4 to this report.⁶

CALL FOR EVIDENCE

We ran an open call for evidence from February to April 2023, seeking evidence in the following areas from those with personal, professional or research experience of disagreements about the care of critically ill children.

- Evidence to update and improve our understanding of the themes identified as part of our previous briefing note (communication issues; differing perspectives; feelings of powerlessness and delays in seeking help);
- Effectiveness of dispute resolution mechanisms/third party interventions;
- Suggested changes from current approaches to handling disagreements;
- Examples of good practice in avoiding, reducing, managing and resolving disagreements between parents and healthcare teams;
- The impact of media attention;
- Social and cultural factors influencing parent views or understanding about matters relevant to the care of a critically ill child;
- Factors influencing healthcare professionals' ability to navigate disagreements; and
- Local differences in the way disagreements are handled.

We received 38 responses from a variety of stakeholders. Where consent has been given to publish the identity of respondents, details can be found at Annex 3 to this report.

6. Moreton K (2023) *Disagreements in the care of critically ill children: Causes, impact and possible resolution mechanisms*, available at: <https://www.nuffieldbioethics.org/news/literature-review-on-disagreements-in-the-care-of-critically-ill-children-now-available>.

INTERVIEWS

To ensure that parents had the opportunity to contribute in an accessible and meaningful way, we held a series of semi-structured interviews with those who had disagreed with healthcare teams about the care of their critically ill child. We chose not to approach parents directly due to the sensitivity of the subject but instead invited them to express interest, through sharing information with charities who work with parents, and other stakeholders, and also via our social media channels. Our interview guides were designed with the sensitivity of the subject in mind and with an awareness of the potential for trauma in discussing distressing experiences. Accordingly, we collaborated with Together for Short Lives in producing our interview materials and ensured that emotional support was available via their helpline for any parent who needed it following their interview.

We undertook six interviews, four with individuals and two with couples.

Our interview data has been bolstered by the addition of 9 transcripts from interviews undertaken by the Medical Mediation Foundation which also explored disagreements about the care of children. These interviews were undertaken prior to our review with both parents and healthcare professionals, and we are grateful to participants and the Medical Mediation Foundation for their willingness to share the transcripts.

SURVEYS

We ran two surveys from April to June 2023: one for healthcare professionals with experience of disagreements, and the other for non-clinical professionals. Questions explored both causes and impacts of disagreements, as well as good practice in their resolution.

We received 280 responses to the healthcare professionals' survey and 20 to the non-clinical professionals' survey.

WORKSHOPS

To explore themes arising in the surveys in more depth and obtain further qualitative data, we held two workshops with healthcare professionals in June 2023. The first was held in London and explored topics including: feeling unsafe at work; mismatched expectations between parents and healthcare professionals about what can be done for a child medically; confidence and trust; access to second opinions and clinical records and the role of clinical ethics committees. The second was held in Manchester and topics explored included the (in)evitability of disagreements; what good communication looks like; support mechanisms for healthcare professionals and provision of accessible information for families.

Engagement programme

In addition to the above we sought to engage with as many stakeholders as possible to increase awareness of our review, and more generally of the issues arising in disagreements. We met with a variety of audiences including charities, professional bodies, researchers, clinicians and family support services.

Ethical challenges

A number of ethical challenges arise in the care and treatment of critically ill children, whether or not disagreements arise between parents and healthcare teams.

SANCTITY AND QUALITY OF LIFE

Many cases attracting media and public attention involve disagreements about the introduction, withholding or withdrawal of life-sustaining treatment (LST). LST has the potential to prolong life, and includes mechanical ventilation, clinically assisted nutrition and hydration as well as other, more experimental treatments.⁷ Withdrawal of LST will lead to a patient's death if they cannot maintain the vital functions independently that were sustained by the LST.

Sanctity of life – the idea that there is intrinsic value in being alive and human life should be preserved at all costs – can often feature in debates about the care and treatment of critically ill children. This is because some perceive withdrawal of LST as an action which brings life to an end, which would be impermissible under a strict adherence to the sanctity of life principle. The legal position is that whilst there is a general presumption in favour of preserving life, and that actions with the primary purpose of causing death are unlawful, withdrawing LST will be lawful if it is not in the patient's 'best interests' to continue providing it.

Quality of life (what makes life worth living for the individual) is also a consideration in such debates. Those who believe in a sanctity of life principle might consider that life is always worth living, regardless of how much a person is able to interact with the world or experience pleasure, because of what they see as the inherent worth of human life. Others consider that there comes a point where life is no longer tolerable for a person; that they have no quality of life. This can arise where a person is so critically ill that they are

7. Larcher V, Craig F, Bhogal K, Wilkinson D, and Brierley J (2015) Making decisions to limit treatment in life-limiting and life-threatening conditions in children: a framework for practice (Royal College of Paediatrics and Child Health) *Archives of Disease in Childhood* **100(Suppl 2)**: s1-s23.

permanently unconscious or unresponsive, unable to experience pleasure or are in unmanageable pain, and where their condition will not improve. In court cases involving the treatment of the critically ill, having no or insufficient quality of life is often cited as a reason why introduction or continuation of LST is not in the patient's 'best interests'.

MAKING DECISIONS ABOUT CHILDREN

Parents are accustomed to making day-to-day decisions about and on behalf of their children. In medical situations, they do not have as much agency over what happens to their child as they would outside of a healthcare environment. Whilst parents are required to give consent to treatment offered where a child lacks capacity to provide it,⁸ they cannot choose which treatment options are offered to them. Healthcare professionals will outline options that are clinically indicated and what they consider to be in a child's best interests.

Our research has primarily focused on children who cannot consent to their own treatment or provide their own views, due to their age, or the nature of what makes them 'critically ill'. The literature review we commissioned reflected that the vast majority of literature and cases around disagreements focused on children that did not have capacity. As such, our report focuses on, and is informed mostly by instances where disagreements occur between parents and healthcare professionals.

However, it is important to note that some older children may be able to consent to care and treatment or voice their opinion. Such cases are often complex and may give rise to additional considerations which are not within the scope of our review.

Debate continues in the academic literature and in wider society about who should make decisions about

children when they are critically ill. Some take the view that primary responsibility should remain with parents regardless of the circumstance and others see healthcare-related decisions as the responsibility of healthcare professionals and parents working together.

TRUST AND TRUSTWORTHINESS

Trust, and what renders someone or something trustworthy or untrustworthy, underpins many disagreements, including those about the care of critically ill children. Reciprocal trust is necessary in order to share decision-making meaningfully and effectively. However, there are multiple potential barriers to trust being established and maintained. A lack of trust in individuals, combined with decreasing trust in public institutions such as the NHS and the court system⁹ may further influence disagreements. 61% of healthcare professionals responding to our survey think there is generally less trust in healthcare professionals as a result of their involvement in disagreements.

EQUITY AND JUSTICE

Issues of equity and justice can potentially arise when one party to a situation is at a disadvantage to another. A number of factors render parents potentially vulnerable when their child is critically ill – the stresses of a child being dangerously unwell are clear, but there are additional vulnerabilities resulting from being at a disadvantage in terms of having relevant medical knowledge and understanding to process what is happening to the child clinically. These may include not having access to all relevant information about their child's condition, navigating an unfamiliar system, and the impacts of spending a lot of time in a physical space outside of one's comfort zone (both healthcare

8. The exception to the need for parental consent is emergency treatment for the purpose of saving a child's life or preventing a serious deterioration in their health, and where a child or young person is competent to consent; See General Medical Council (GMC) guidance: <https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/0-18-years/making-decisions>.

9. NatCen Social Research (2022) *British social attitudes 39*, available at: <https://bsa.natcen.ac.uk/latest-report/british-social-attitudes-39>.

The nature of disagreements about the care of critically ill children

environments, and potentially, the courts).

The healthcare professions' familiarity with the healthcare system and environment, despite the profound and wide-ranging psychological impacts that some disagreements can have upon them, means that there can be a lack of equity between the parties and, therefore, the potential for a lack of justice in the resolution of disagreements. Going to court, however, can still be a daunting experience for healthcare professionals if they are unfamiliar with it.

Additionally, there may be instances of other inequalities that need to be addressed. We heard from some families about their experiences of discrimination within the healthcare system.

Before reading the perspectives of those who contributed to our review, it is important to note that disagreements about the care of critically ill children are situations in which there are no winners – even if the disagreement is resolved, either between the parties or by way of a court decision, the child at the centre remains critically ill.

Also of note is that some disagreement is natural in the human condition – and, indeed, there is debate in the academic literature as to whether it is desirable to attempt to eradicate it.¹⁰ Expecting that disagreement won't happen in situations of high stress is unrealistic and, as we identify in this report, potentially harmful as it results in unpreparedness to manage dissent and the subsequent emotional and psychological impacts on those involved.

We have therefore approached the review with a view to exploring what might make the experience of disagreement less distressing for all involved, as well as seeking to identify where they might reasonably be avoided or resolved more quickly, collaboratively and compassionately.

10. Auckland C and Goold I (2020) Resolving disagreement: a multi-jurisdictional comparative analysis of disputes about children's medical care *Medical Law Review* **24(8)**: 643-4.

How disagreements develop

At their core, the foundation of most of the disagreements we heard about concerned a child's care and treatment options. Although disagreements at this level are not always avoidable, many of the adverse impacts and escalation are. When a disagreement about these options arises within a relationship of trust and openness between healthcare providers and parents, they can often be resolved through communication. Even when they cannot, the subsequent legal process of resolution can be much less adversarial and traumatic.

Bringing together all the evidence we heard during our review - through, for example, the literature review, call for evidence, surveys, workshops and interviews - we have identified a range of issues that either directly brought about disagreements or contributed to their development and escalation. Many of these issues are interconnected and, as we understand from our research activities, rarely occur in isolation. For example, if there is a lack of information given by healthcare providers to parents about their child's care and treatment this limits parents' ability to participate in decision-making, which in turn may create a breakdown of trust, the need to turn to other sources for information, misgivings about the child's treatment plan, and further miscommunication. As such, the foundation of a disagreement and its escalation are intertwined. Our literature review identified these as a mix of 'internal and external factors' - the former being those that the parties to a disagreement bring with them before a child's hospitalisation, and the latter being those that come about as a result of something that happens during the treatment of a critically ill child.¹¹

Our recommendations reflect the multi-factorial influences on disagreements, and it is therefore necessary for all of the recommendations to be addressed together to ensure that meaningful change is achieved. Accordingly, our first recommendation is that there is appropriate oversight of implementation.

RECOMMENDATION: 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.

COMMUNICATION ISSUES

Parents and healthcare professionals alike told us that poor communication was both a cause of disagreements and an exacerbator of existing ones. We identified a number of different issues arising within this theme which affected the building of relationships.

One size does not fit all – treating people as individuals

A particularly strong theme arising was around parents and children feeling that they were being treated as a homogenous group rather than as individuals with distinct needs and preferences.

One way in which this manifested was by calling parents 'mum' or 'dad' instead of by their names, which felt dehumanising to some parents we spoke to. Campaigns to raise awareness of this have been set up by charities working with children and families, such as the Don't Call Me Mum initiative.¹² Parents too told us that they found being called 'mum' or 'dad' to be disrespectful of the role they played in their child's care and in partnering with healthcare professionals. This can create tension between parents and healthcare professionals, which may lead to bad relationships and disagreements being more likely to arise, or become entrenched.

A common issue raised by parents was that they felt communication from some healthcare professionals lacked warmth and compassion for the situation

11. Moreton K (2023) *Disagreements in the care of critically ill children: Causes, impact and possible resolution mechanisms*, available at: <https://www.nuffieldbioethics.org/news/literature-review-on-disagreements-in-the-care-of-critically-ill-children-now-available>.

12. Born at the Right Time (2023) *Don't call me mum: Parents as parents*, available at: <https://www.bornattherighttime.com/dont-call-me-mum/>.

parents were in and did not always account for the information being imparted being difficult to hear. We also heard of parents feeling like communication was hurried and did not allow for time to check understanding, seek clarification or ask questions. Parents generally understood that communicating difficult information might be routine to healthcare professionals, but noted that it was not routine for them as parents to hear and so it was particularly harmful to relationships when this was not taken into consideration; they also acknowledged that the reasons behind healthcare professionals seeming cold and rushed might be a reflection of their finding it difficult to have such conversations with parents. Some parents spoke of feeling like a 'number' or a clinical case rather than a person, with one in particular reflecting that their 'convincing' a healthcare professional to see the people behind the illness had positive impacts on their relationship with them.

“ She came into a room and said your child's very poorly [...] and he's not going to make 24 hours. So I'm just sitting there, basically [in] shock [...]. And she was gone. Just very cold. Just like it's just a run of the mill thing, you know, which I do appreciate to doctors it might be, but that's my child, that's my life that you've got there. There was no empathy at any stage from that hospital. No empathy, no compassion. Everything was just very, very rushed.
Parent

“ From a communication perspective, it was just, I would class it as [...] we were just a number. We were just a part of their job, with a lack of empathy. Something they did every day in terms of delivering [Child's diagnosis] to me, they'd come in, deliver that message and get out again. Now whether that individual themselves struggled with that social interaction and couldn't deal with it and had to leave or they were hard faced, delivered the medical message and then just left, I don't know. Could be either way.
Parent

“ [The doctor] was quite distant and so I think I was just me because by then I was a really experienced parent of a child with complex needs. And so I, I know it's ridiculous, but I almost kind of did a sort of a sales pitch. You know [...] I need you to understand what our life is, that I need you to know us as a family and I need you to know [Child] and I need you to know the impact of these seizures.
Parent

Parents spoke of wanting healthcare professionals to relate to them and their children on an individual, human level and build relationships accordingly, although their attempts to do this were not always well-received.

“ So, some doctors didn't mind being called by their first name. I remember one doctor being, like, really offended that I called her by her first name, said 'it's doctor whatever.' OK, well, I'm Mrs [Last Name] then.
Parent

“ I've got the nurses some presents. [...] You know, as a parent, I see it as you're looking after my child [...] I think I was doing my bit to try and build a relationship with hospital staff and it just, it wasn't a two-way thing. It was like, you're here, you're a nuisance to us, we want the room back.
Parent

“ It was just that lack of understanding that [Child] also had feelings and there was this real transition - that this whole thing - could you talk to [Child] as well, please? She's not just a blob in a wheelchair. She is a sentient being, you know, has feelings. And also, you know, because we had all this stuff going on in our life. Is really feeling it here. And you need to acknowledge that.
Parent

RECOMMENDATION: 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.

Parents also highlighted the issue of communicating information about a child's condition in ways that were understandable and respectful of the parents' knowledge and background. A number of parents reflected that whilst use of medical jargon without explanation was unhelpful and prevented good relationships from being formed, oversimplification of information could be equally unhelpful and seem condescending – particularly if a parent is medically literate as a result of their child's complex needs, or as a result of their professional or academic background.

“ I think [healthcare professionals] have to [...] use jargon appropriate to the individual [...] Parents with children with complex needs, they read a lot into their child's condition and they know about blood values and LFTs and FBCs and U&Es and they know all about blood gases. [...] So, if a doctor pitches it at a very, very low level, they could actually offend the parent. Then on the other hand, if the doctor assumes that the parent knows more than they do know, then they could actually confuse the situation. So, the doctors need to find out the level of knowledge.
Parent

In relation to communication with parents, healthcare professionals often acknowledged that there was no single 'correct' way to communicate with families and that each would need a personalised approach. Some communication issues were attributed to the innate difficulty in communicating (and, on the parents' part, processing) difficult news. Other issues were seen to arise from a lack of continuity in leadership and confusion about how decisions are made. Healthcare professionals may benefit from guidance to support them in finding out parents' communication needs and

preferences, so that they can tailor their approaches accordingly.

RECOMMENDATION: The DHSC taskforce established as part of recommendation 1 should identify an appropriate body to create and publish guidance for healthcare teams that treat children on how to seek information from children and parents about their communication needs and preferences, ensuring all team members are aware of these and are accordingly providing consistent messaging about their child's care and treatment, particularly where the child is under the care of a multi-disciplinary team.

CASE STUDY 1

Using name tags to promote parents as partners in their child's care

The Rosie Hospital (Cambridge) has introduced numerous measures, including '#CallMe' name tags, to promote better 'family integrated care' within the neonatal intensive care unit (NICU). Family integrated care is a model which incorporates families as equal partners in NICU care.

Many of the measures implemented were as a result of recommendations from Rosie Maternity and Neonatal Voices (RMNV), an independent group of parents, volunteers and staff aiming to improve the services at the Hospital. Other learnings have been taken from others practicing 'family integrated care' within the neonatal community in the UK and internationally.

What are '#CallMe' name tags?

'#CallMe' name stickers have been introduced for parents with babies in the NICU to put their preferred name onto wearable sticky labels so that healthcare professionals treating babies know how they prefer to be addressed. They were introduced in response to negative feedback from parents who were being called 'mum' and 'dad' by staff. The stickers also aim to provide a visual recognition of a parent's equal role in the care of their baby in the NICU, so that both parties involved in decision-making about care have name badges, and not just the healthcare professionals.

Other supportive measures:

In addition to the '#CallMe' name tags, parents also have 24-hour access to NICU and are provided with the appropriate training and autonomy to undertake certain types of care within the NICU, such as feeding and cleaning their baby. The aim of these is to promote parental involvement whilst freeing up healthcare professionals to focus on providing more complex care.

Medical students at the Rosie have also previously used other measures underpinned by a similar philosophy. These included the provision of childcare for siblings of babies in the NICU and a 'comfort club' which involved providing comforting care to babies (holding during uncomfortable procedures, reading stories and talking to them) when parents were not able to be present to do so. Photo and video updates were also provided as part of this initiative.

Implementation tips, reflections and feedback from the Rosie:

- ✓ Available resources are an important consideration for other organisations looking to implement similar measures - many are/were provided on the goodwill of healthcare professionals and RMNV, rather than through additional funding and governance.
- ✓ '#CallMe' name tags, however, need not require additional resource and could be effected using simple sticky labels (as the Rosie did), particularly given that parents and children might not stay on the ward for very long.
- ✓ Capacity of healthcare staff to ensure uptake is a key challenge to implementation.
- ✓ Current feedback reflects that relationships between staff and parents have improved since the introduction of name tags – healthcare professionals have expressed that they feel more comfortable having conversations about a baby's care, and parents are generally keen to engage – particularly where they did not want to be called 'mum' or 'dad' by staff and where the positive impacts on healthcare professionals have been made clear.
- ✓ Parents tended to stop wearing the name tags after around two weeks or so, usually once relationships have been built with healthcare professionals.

Whilst failure to treat parents and children as individuals was recognised as an issue by some healthcare professionals, they identified a number of barriers in the way of their ability to build relationships with families. These included a lack of time, lack of understanding amongst some about the importance of tailoring approaches to individuals and a hierarchical culture that perpetuated the importance of the role of the doctor in comparison to the parent in the provision of care. Exploring these issues in our workshops highlighted that communications training on offer to healthcare professionals was widespread. We heard that training was of some use but tended to reinforce that there was a 'right' general way to communicate and therefore might embed the issue of failing to treat parents as individuals further.

RECOMMENDATION: Healthcare professionals in clinical leadership roles should take responsibility for modelling a team culture which recognises and prioritises relationship-building with children and parents as an integral part of providing good holistic care to a child.

The importance of meaningful partnerships between parents and healthcare professionals

Parents and healthcare professionals acting in partnership with each other to share decision-making about a child's care is broadly acknowledged as essential in providing good care to a child. Our work, however, highlighted a number of issues with partnership and shared decision-making which, instead of being helpful in the provision of good care, were obstructive to it and causative of disagreements. These included, in some circumstances, a lack of recognition and respect for parental expertise; shared decision-making as potentially burdensome to parents at a time when they are already experiencing distress and failure to meaningfully involve parents.

Parents were clear about the expertise of healthcare professionals in clinical matters but highlighted that their own expertise – that of being experts in their child – was not often acknowledged and taken into account in decision-making. We were told about gatekeeping of care by healthcare professionals, where parents who provided

routine care to their children were being prevented from assisting in doing so within a hospital environment, even where this would have been of benefit to the child and reduced their being in pain or discomfort. We were also told that in other scenarios, parents offered to help overstretched healthcare professionals with their child's care, but were then criticised when they got it wrong.

“ I had to learn all that stuff because [...] it was the only way we could be at home and manage [Child's] care at home. [...] You become such an expert that then it's really difficult when you go into hospital and [...] on some shifts [...] they'd be like 'we set that up here.' There'd be a bit of a standoff and I'd had to get it in her notes – '[Mother] will manage her drugs because it keeps things safe'.

Parent

“ So one day I helped a nurse because they said they were short staffed, and they were on holiday. [...] And I said, 'do you want me to help you change him?' 'Well yes please.' I'm like, OK. [...] I do keep saying I'm happy to help. I'll do everything, he's my child. [...] take the pressure off of the NHS because I felt like we was really inconveniencing them. [...] That that's how they made me feel. So like I'm helping and then it really got to me because it just hit me all of a sudden that he had lost so much weight. [...] it really hurt and I just sort of stopped and looked at him [...] and I just went I can't do this [...] So [Father] said 'he doesn't look very comfortable like his neck.' [...] [The nurse] ignored him. So he said it again. Like, 'can you just move his head up, please, he doesn't look very comfortable.' And she ignored him. So [Father]'s then gone to move him. 'Don't touch him!' Really shouted at [Father]. So [Father]'s obviously said 'Well, I did ask you, you know, he's not very comfortable and you're not doing it' [...] And then she put all the blame back on me. 'Well, [Mother]'s supposed to be helping me change him.' [...] And she shouted at everyone, went out of [Child]'s room and slammed the door so loud.

Parent

We also heard about the failure to acknowledge parental expertise in some circumstances as a potential barrier to appropriate treatment being offered. One parent described knowing the subtle signs that their child had sepsis, but they were not taken seriously.

“ With [Child] you’d go ‘oh god she’s gonna be septic, I can tell’ you know, it’s so because these children compensate so well they live with a degree of disease for so long that [...] you need to see that subtlety, and it used to really frustrate me that medical professionals, those that weren’t experienced or didn’t respect my input didn’t see that. And the ones that I respected as ‘we’re peers here’ [...] I would always say ‘Absolutely. Put my hands up saying I am not a doctor. I am not trained to be a doctor.’ What I am is someone that knows a huge amount about this child.”
Parent

Some healthcare professionals had experienced that shared decision-making, whilst having many benefits generally, could place a huge burden on a parent who may feel that they have to make life-or-death decisions about their child which they may not be in a position to make. Reasons for inability to be part of or make such huge decisions were varied, although some highlighted that it may be very difficult for parents with faith-based beliefs to actively agree to treatment options that they felt went against the principles of their faith, and so it might be preferable for a third party (such as the courts) to make the decision instead. Others pointed out the enormity of emotions involved in a parent making a decision that would likely result in their child’s death.

“ Every family is different- but sometimes the language we use almost feels like we burden families with an intolerable burden of feeling like they are ‘giving up’ on their children which no parent could ever do.”
Paediatrician (Midlands)

“ I think there needs to be a recognition that sometimes we cannot expect families to agree to withdrawal of life-sustaining treatment if it against their culture or religion. For some families, going to court and having someone else make the decision is what is needed for them to be able to accept it and cope going forward.”
PICU nurse (London)

We heard that parents are often not involved in meetings of healthcare professionals about their children, which can lead to parents feeling excluded from the decision-making process and reinforce feelings of powerlessness within the hospital environment. These feelings of powerlessness at being excluded from decision-making about their own children were also identified by our previous briefing note.¹³

“ I’m trying to have a proper conversation with them. Because it’s my son. You can’t just make a decree. And say, well, that’s it. I will have the highway. No. We need to engage in a dialogue and to explain things to me.”
Parent

13. Nuffield Council on Bioethics (2019) *Disagreements in the care of critically ill children*, available at: <https://www.nuffieldbioethics.org/publications/disagreements-in-the-care-of-critically-ill-children/briefing-note>.

“ It was very much like they’d have a meeting... Make a decision... and discuss, yeah, [Child’s] care and then they’d make a decision and come and tell us rather than it being a collaborative, you know, discussion or debate about what was the best way forward. They’d get together, make a decision, come and tell us. If we weren’t happy with that decision...tough.
: **Parent**

Parents also reported that they are not invited to clinical ethics committee meetings or even told that they are happening until afterwards.¹⁴ Whilst some parents are supported to get involved in clinical ethics committee meetings, they are not routinely invited to meetings in the majority of settings despite the High Court Judge, Ms Justice Russell, remarking in a 2020 case that such a lack of parental involvement “cannot be good practice and should generally be unacceptable”.¹⁵

“ Only in the past couple of years I found out that [Child’s case] was discussed at one of the ethics panels. I didn’t even know that until after [Child] died.
: **Parent**

“ There would be an MDT meeting and you’d be sitting outside it’s like ‘[...] I know what’s going on here but you’re not talking to me.’
: **Parent**

“ They invite you in after [the ethics committee meeting]. They said you don’t need to be concerned about that, because [...] it’s just more of a rubber-stamping exercise.
: **Parent**

Misunderstandings and mixed messages

Parents told us that they were given mixed messages about their child’s care and treatment, often from a very early stage in their child becoming unwell. We heard that language was used inconsistently between different members of (and specialties within) multi-disciplinary teams; for example, overly positive messages (such as “he had a good night”) were confusing when their child’s prognosis was poor, and treatment plans were changed with no explanation.

“ Because nothing was rushed or come across as urgent, it kind of made, didn’t sink into me how serious like the outcome of this was going to be because everything was so laid back [...] Just- it didn’t make sense as well considering [Hospital 1] had been like, ‘oh good news. [...] then to go up there [...] just to be told he’s got 24 hours.
: **Parent**

“ Just things weren’t making sense you know, it’s-what they were putting in front of the court to what we were experiencing now and the evidence we had there was very, very different and it just gave me, I think it gave me a cause of concern to- I need to look into exactly every, well, I need to look into everything that was going on in that hospital room, really, because, yeah, there were so many mixed messages.
: **Parent**

14. Moreton K (2023) *Disagreements in the care of critically ill children: causes, impact and possible resolution mechanisms*, available at: <https://www.nuffieldbioethics.org/news/literature-review-on-disagreements-in-the-care-of-critically-ill-children-now-available>.

15. Great Ormond Street Hospital for Children NHS Foundation Trust v MX [2020] EWHC 1958.

“ They assumed [Child] would die within a year or so. So they were very sympathetic, very supportive, very whatever, you know, they felt very sorry for us, it was a lot of whatever. And actually, when [Child] didn’t die as they expected her to, it started to fizzle out [...]. We were a bit confused because we were like ‘why is there a shift? Why is there a change in attitude?’ And, you know, they should be pleased.
Parent

Healthcare professionals recognised the difficulties of communicating consistently about a child’s care, particularly where the child has complex needs and is under the care of a multi-disciplinary team. Exploring the reasons for this at our workshops gave insights into consistent communication often being more difficult in larger specialist children’s hospitals than in local children’s wards because of the large number of staff and consequent lack of continuity of care.

“ Clear communication when different team members are not saying very different things to parents is also important.
Paediatric intensive care doctor (East of England)

“ Better communication between consultants before talking to parents. Parents become frustrated when they are told a different thing every day by a different consultant.
Paediatric critical care nurse (North East and Yorkshire)

“ Having one or two points of contact. It is when many people are involved that there appears to be miscommunication.
Paediatric critical care nurse (Midlands)

Many organisations and individuals highlighted the benefit of appointing a single person to act as the primary point of communication between parents and healthcare providers to avoid these unintentional mixed messages across and between treating teams. The value of a single ‘named consultant’ who takes responsibility for and ownership of a patient’s overall care while they are hospitalised is well-established, having been recommended by the Francis Inquiry in 2013¹⁶ and supported by guidance from the Academy of Medical Royal Colleges in 2014, which states that the named consultant “is the person to whom a patient or their relative/carer would ultimately address concerns”.¹⁷ We heard that a single named point of contact might help to provide stability and continuity for patients and their families, and help to establish positive relationships.

“ [The Francis Report] believed this move would create a more transparent, co-ordinated care experience for patients and families, with a single point of contact to cut through the confusion of multi-disciplinary teams. Where relationships might be fleeting and shifts change as staff come and go, a named consultant provides important continuity.
Polly Curtis & Claudia Wood, Demos

Whilst recognising the potential value of a single point of contact, many also reflected to us that taking responsibility for building relationships and ensuring good communication with parents ought to be the job of every member of staff coming into contact with parents in a clinical care environment.

RECOMMENDATION: 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.

16. Mid Staffordshire NHS Foundation Trust Public Inquiry 2013 (‘The Francis Inquiry’) (2013) *Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry*, available at: <https://www.gov.uk/government/publications/report-of-the-mid-staffordshire-nhs-foundation-trust-public-inquiry>.

17. Academy of Medical Royal Colleges (2014) *Guidance for taking responsibility: Accountable clinicians and informed patients*, available at: <https://www.basw.co.uk/resources/guidance-taking-responsibility-accountable-clinicians-and-informed-patients>.

CASE STUDY 2

Using a 'consensus grid' to communicate consistent messages

Oxford University Hospitals' (OUH) Children's Hospital have introduced a 'consensus grid' to address mixed messages being communicated to parents with children in the neonatal and paediatric intensive care units (NICU and PICU). Developed and led by the Palliative Care team, the grid aims to provide a common structure for multiple healthcare teams involved in a child's care to collate their medical opinions in a single document to facilitate harmonised multi-disciplinary decision-making and consistent communication to families. We spoke to the team to find out more.

Why was the grid introduced?

Multiple teams are often involved in the care of a critically ill child at any one time, and the team recognised that parents were often receiving unintended mixed messages from these teams around prognosis, treatment options and future care planning. Each team involved in a child's care had varying levels of familiarity with the family and were focusing their care plans on their own speciality without necessarily considering how this may impact or interact with other team's care plans. For example, one team may advise that an operation is required, but may not have considered or appreciated other clinical factors which might lead another team to suggest to a family that it is not possible or advisable.

For families, this fragmented approach to receiving information often resulted in misunderstandings (e.g. where parents heard the most optimistic messaging and were then upset when the outcome did not align), distress and distrust. In turn, this mixed messaging also undermined care planning and fostered an environment where disagreements were more likely to occur.

What's involved?

A consensus grid is a simple document visually presenting the clinical facts about a child's condition and the medical opinion from each treating healthcare team about a child's care plan in a grid format. The palliative care team will co-ordinate circulation to all teams involved, who will each fill it in with relevant

information they have about the child's care. Once all teams involved have completed it, it is then circulated around them all and followed up by a face-to-face discussion to better understand how different clinical facts relate to each other and how consensus about next steps might be achieved.

The outcome is a set of consensus points presented on the grid, which can then be drawn upon by all healthcare teams interacting with families to ensure clear messaging, including for new teams/professionals becoming involved in a child's care. Parents are also given a copy of the grid and are informed about the process throughout.

Implementation tips, feedback and reflection from the OUH team:

- ✓ In addition to improved consistent messaging, another benefit has been that families have a clear and transparent record to keep around why a particular clinical action has been taken. One family in particular has expressed how valuable having the grid has been for revisiting the reasoning behind the difficult decision to remove life-sustaining treatment.
- ✓ Multiple meetings might be required if a case is particularly complex, and parallel planning may be needed if the child's condition unexpectedly changes.
- ✓ Palliative care should co-ordinate the consensus grid approach ideally, but any healthcare professional trained in complex care planning and skilled at communicating with families could do so.
- ✓ If the co-ordinator has not had the benefit of building a strong relationship with the child's family, someone else who has built such a relationship should be included to ensure the family's individual communication needs and preferences are accounted for.

Timing of sensitive conversations

Poor timing of sensitive conversations about a child's prognosis was seen to be a contributory factor to some disagreements by all involved.

The timing of when and how to introduce the involvement of palliative care services into a child's care was one area in which this arose, as was the timing of conversations about organ donation. Some were of the view that doing this early was upsetting and gave the impression that the child was being 'given up on'. This was particularly hard when mixed messages had been received and therefore parents had not appreciated the seriousness of their child's condition, or where parents had only just received distressing news about their child's diagnosis and were introduced to palliative care in the same conversation. Other areas in which timing of communication could play a part in damaging relationships were highlighted as choosing to have difficult conversations at a very early stage of hospitalisation when parents might still be in a state of shock, or by asking non-urgent questions shortly after a child's death.

“ PPC [paediatric palliative care] teams should not be involved in early stages as families feel we have given up on them and it can come across forceful & lead to carers distrust in the team providing care.
: **PICU doctor (London)**

“ It was at the diagnosis meeting [...] they go round and introduce everyone and [...] they were like this is [Name] the palliative care consultant and we're like 'what?!'
: **Parent**

“ In that special room when [my child] passed, I was still carrying him. [...] The next day, in the morning I was still carrying him when this gentleman walked in. [...] He said he was sent to ask us if we wanted to sue the hospital. I was still carrying my son [...] what came to my mind was to tell him, are you serious!?
: **Parent**

“ They're giving you this entire diagnosis which they should understand is a life-changing impact, and then to jump right into suggesting, like, end of life, that feels just really inappropriate.
: **Parent**

There was a strong feeling expressed via our surveys that difficult conversations more generally about a child's limited lifespan were being instigated by healthcare professionals far too late, making the news shocking to parents at an already traumatic time and therefore causing friction and disagreement. Proponents of this view were mainly healthcare professionals themselves, who identified that those outside of intensive care and palliative care seemed to avoid such conversations.

“ Many parents are shocked when a child ends up in PICU and it is very clear to the professionals that the child is life limited— so why do they not discuss it with the parents before the child is in extremis. All paediatricians should have a duty to discuss end of life.
: **PICU doctor (London)**

“ Very early discussions around shorter lifespan of children with significant neurodisabilities. Ideally to be started electively in some way, and not when the child is already in intensive care or needing long-term ventilation.
: **Paediatrician (London)**

“ Early input and support for families of children who have life limiting conditions so there is a shared understanding of outcomes. Children often present having been looked after [by] community services for years with little or poor understanding of the illnesses that often end up increasing morbidity and more frequent hospital stays e.g. chest infections. It's left to acute clinicians who have only met the family once to have these difficult discussions and then trust and relationship is lost.
: **Paediatrician (South West)**

“ Earlier discussions in their illness about the challenges so it doesn’t come as a shock/parents have to make sudden decisions esp[ecially] with someone out of hours who doesn’t know their child.
: **Paediatrician (Midlands)**

Characterisation of behaviour

We heard of certain behaviours from both parents and healthcare professionals being characterised as negative by the other party. Healthcare professionals sometimes described being seen as ‘cold’ when trying to maintain professional detachment; parents told us that their being upset or emotional was seen as problematic and a sign of being a ‘difficult parent’ by healthcare professionals, or that their asking questions was perceived as being obstructive.

“ If you did ask a question [...] you were just met with eye rolls, and huffs and puffs, we were accused of ‘you’re making our jobs hard’. It was kind of that vibe. Stop asking questions because you’re causing us problems.
: **Parent**

“ And time and time again, there were things that, you know, you start to think we’re being labelled, and it was only afterwards when [...] we asked for minutes, we were sent a letter summarising what was discussed and it was quite a friendly letter, and, you know, very supportive [...] But the note of the meeting that was put in the notes was very critical of us, commented on us, was rude, made out that we were very rude and aggressive and non-cooperative. So anybody, a professional picking up our daughter’s file and reading it would think “[gasp] what kind of people are these?
: **Parent**

“ That huge, huge sense of frustration or people not talking to each other and conversation not happening, things not happening, that you needed them to do those things for you, but felt so incredibly disempowered. How do I get through all of this? Nobody’s listening to me, and now I bet they’re writing in their notes ‘neurotic mother’, you know ‘oh she’s a bit emotional today’. Yeah, because you’re bloody emotional. Yes, you know, it’s like, and not only that, I haven’t had a shower in five days, got my period, husband and I have had an argument, school’s phoning cause my son’s playing up and my daughters got her GCSEs.
: **Parent**

We also heard that hope for an improvement in their child’s condition could sometimes be seen by healthcare professionals as parents’ unwillingness to face reality or a lack of understanding about a grave prognosis. The literature review we commissioned noted that the presence of hope in parents can be seen by healthcare professionals as incompatible with an ability to be realistic about their child’s prognosis, but that this may be erroneous as there is evidence to show that hope and realism co-exist.¹⁸ Parents told us of instances where they had been characterised as unrealistic or irrational for wanting certain treatment options to be explored, and that incorrect assumptions had been made about their motivations as a result.

“ We knew there was a chance this treatment might not work. We’re not stupid. We weren’t blinded by emotion. It wasn’t just a case of ‘we don’t want to lose [our child]’, there was something out there that could potentially help.
: **Parent**

Inaccurate and negative characterisations of parental behaviour have also featured in other court cases about the treatment of children. In the case of

18. Moreton K (2023) *Disagreements in the care of critically ill children: Causes, impact and possible resolution mechanisms*, available at: <https://www.nuffieldbioethics.org/news/literature-review-on-disagreements-in-the-care-of-critically-ill-children-now-available>.

Lancashire County Council v M and Ors (no. 2), where a disabled child's parents had been characterised by a care provider as exhibiting difficult behaviours indicative of irrationality and mental illness, the court ordered that the parents undergo psychological assessment which found no evidence of mental illness and that they were simply having normal human responses to stress and upset.¹⁹

Acknowledging uncertainty

Both parents and healthcare professionals noted diagnostic and prognostic uncertainty where a child has complex medical needs. We heard from both as part of our evidence gathering that communicating uncertainty honestly was not always commonplace. On the occasions where uncertainty was communicated honestly, it was seen to have a positive impact on relationships and mitigate the risk of disagreements happening. Parents described having a greater level of trust for healthcare professionals who could admit that they didn't know something, and this is further supported by published literature.²⁰

“ When I've spoken to lots of other parents, that's come up over and over: the ones they trusted were the ones that said 'I don't know'. And I'm not sure how well healthcare professionals understand the impact of that, that actually that's not a negative, it's a positive. That you don't have to save face.
: **Parent**

“ Key is to be open and honest at all times and admit when there are things we just don't know. [...] Admitting when professionals don't know all the answers.
: **Paediatrician (South East)**

“ It was just immediately a whole relationship of trust, and she was very open, you know, she talked about 'I don't know what's going on with [Child], but let's work together and find out.' You know, it's immediate and she also called me by my first name. You know the way she even chatted to me about [Child]. She took me out of the ward. We sat in her office, we had a cup of coffee and it's just like, I absolutely trust you. Even though half the time because she was in the [different] Hospital, there wasn't a lot she could do, I trusted her to advocate for [Child].
: **Parent**

Taking things personally

Healthcare professionals' reflections on their and their peers' behaviour as part of our evidence gathering activities revealed that they can take parents' questions and dissent very personally, which they recognised as potentially causing disagreements and aggravating existing ones. Many were of the view that trying to get past this, and normalising differences of opinion would have a positive impact on resolving disagreements.

“ We are frightened of discord...this is a normal part of looking after patients and families who are critically unwell – but we don't like discord or conflict and see this as a failure. [...] Also, [we] take challenges and questions personally.
: **PICU doctor (Midlands)**

19. Lancashire County Council v M and Ors (no.2) [2022] EWHC 2900 (Fam)

20. Brouwer MA, Maeckelberghe ELM, and van der Heide A, *et al.* (2021) Breaking bad news: What parents would like you to know *Archives of Disease in Childhood*; **106**: 276-81.

“ I think people become defensive about it and they’re like, ‘I’m the nurse, I know when they need suctioning, how would you know?’ With other parents, when they haven’t had that conflict, they might actually be saying to them, ‘when do they usually need suction? How do you get them to cough? What’s the position like?’ You’re very much working with them and asking the parents a lot of questions. I’ve heard people say and I say it, ‘you’re the expert on your child’. Whereas, that other parent who had conflict wasn’t given the same outlook.
Nurse, interview transcript

“ When we most often asked questions around his care or raised concerns [...] I think there was disconnection between the medical team and the nursing team with their perceived ideology were already with our own feelings or our own beliefs. They felt like we were all questioning them, but no, what we’re asking them was, please, could you just listen. Listen to our concerns around him. Listen to our fears. We’re not questioning you. You are the experts, but at the same time, we are his parents and we’d love you to listen to us. Just listen. Don’t talk over us, don’t try to justify any mistake. Don’t try to give us reasons while things were happening. Just listen and empathise that this little person here was struggling.
Parent

MISMATCHED EXPECTATIONS

Different expectations about the care and treatment of a child, or about the child’s prognosis, were seen by both parents and healthcare professionals as a major contributory factor to disagreements developing. Two main reasons for a mismatch in expectations were given: the first being misperceptions about what is medically possible; the second being the receipt of conflicting information about a child’s condition or prognosis.

Misperceptions about what is possible

We heard from healthcare professionals that the limitations of medicine are not well understood by wider society, and that remedying this would help to reduce the frequency and impact of disagreements:

“ There is a perception that everything can be fixed or there is a discriminatory approach limiting resources for some.
PICU doctor (South West)

“ Honest dialogue with the public and press about cases [is needed] so [...] people are realistic that not all children can be “saved” and that breathing and living are not the same thing.
Palliative care doctor (London)

75% of healthcare professionals told us via survey that mismatch of expectations about what can be done for a child medically has a high impact on disagreements about the care of critically ill children.

A common view among healthcare professionals was that such misperceptions were caused or fuelled by inaccurate representations in the media:

“ A change in media narratives [would be helpful] to manage expectations.
PICU doctor (South West)

“ A change [is needed] in the current misrepresentation by the media which omits information, can state serious untruths and is accepted by all who read or watch it. We have a number of key media sources that seem to enjoy scaremongering [...] to the detriment of patients and staff.
PICU doctor (Midlands)

Views of palliative care

We heard that palliative care – defined by the World Health Organization as “an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-limiting illness”²¹ is often misunderstood or misperceived. Inaccurate perceptions of palliative care were emphasised by healthcare professionals and others working in the sector who contributed to our research activities as being a major influence on disagreements happening; in particular, the common societal understanding of palliative care meaning ‘symptom control when the end of life is imminent’. Professionals explained that in their experience, where this understanding persisted, parents were upset by what they saw as an overzealous attempt to introduce palliative care too early, leading to a lack of trust from parents towards the healthcare team. These misperceptions and their impacts are pervasive, having been highlighted by our previous briefing note.²²

Where parents had greater knowledge about the benefits of palliative care, and where it was introduced early into a child’s care, it was seen to be very beneficial to both the child and in reducing the risk of disagreements arising. Improving access and awareness of palliative care and providing timely referral to children’s palliative care was identified as an ‘area of action’ in our 2019 briefing note for those involved in leading NHS trusts and hospitals.

84% of healthcare professionals responding to our survey had found early involvement of palliative care services helpful or very helpful in resolving disagreements. Misunderstandings about the role of palliative care do not just persist in wider society – it was also noted that there is not a consistent and realistic understanding of it amongst healthcare professionals. This resulted in non-palliative care clinicians being reluctant or afraid to have such conversations with parents, preferring to ‘leave it to the experts’ which in turn led to palliative care being introduced very late, with less benefit to the child than might have been gained from an earlier introduction.

“ I spoke to a palliative consultant, and she told me about [being seen as] ‘those ones that move around the chairs and hand out the tissues’ [...] and that’s interesting [...] even within the consultants there’s levels of hierarchy.

Parent

“ [...] We were lucky again in our experience as [palliative care] was very much framed as ‘we need to get on top of [child’s] pain - we need to manage this and find you a regimen that’s workable at home’ as opposed to end-of-life care [meaning] give up. [...] I remember mentioning to one of the consultants probably when [Child] was about 4, ‘can we talk to palliative care?’ and they said ‘well you’re not at that stage yet’. I was like ‘well what stage?’

Parent

Further work is therefore recommended to ensure that parents and healthcare professionals alike have access to accurate and clear information about the role of palliative care, so that informed decisions can be made and healthcare professionals outside PICU are equipped with the knowledge and understanding to be able to initiate conversations at an appropriate point in a child’s care pathway. The Royal College of Paediatrics and Child Health (RCPCH), as the representative body for doctors working with children, would be well-placed to work with palliative care experts to collate this information and to ensure it reaches as many people as possible.

RECOMMENDATION: 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.

21. World Health Organization (2020) *Palliative care*, available at: <https://www.who.int/news-room/fact-sheets/detail/palliative-care>.

22. Nuffield Council on Bioethics (2019) *Disagreements in the care of critically ill children*, available at: <https://www.nuffieldbioethics.org/publications/disagreements-in-the-care-of-critically-ill-children/briefing-note>.

Differences in values and beliefs

Differing values and beliefs, whether or not they stem from religious or spiritual convictions, were seen to be a particularly significant source of disagreement by healthcare professionals. 97% of respondents to our survey for healthcare professionals reported that differences in belief about quality of life, end of life, decision-making and other values have a high or medium impact on disagreements about the care of critically ill children.

Fundamental differences in beliefs around when life ends, what that looks like and who has agency over it were viewed as intractable and reflective of early resolution (and other pre-court resolution mechanisms, such as mediation) being ineffective. Some healthcare professionals described trying to ‘talk someone out of their beliefs’ as being both an impossible challenge and inappropriate in a pluralistic society.

We also heard from interviews and workshops that the assumptions surrounding perceived difference in values and beliefs contribute to the development of disagreements, not simply differences in belief themselves.

“ So, there were so many things and the way they perceived my religious belief as well was not acceptable because it was classified under mental health. [...] When ethics asked them in one of their questions on the form I saw ‘is there any mental health challenge?’ So, the answer that was put there was ‘the mother believes in God.’ Then [...] under it, ‘however, it could also be associated around the stress’.

Parent

“ They were just dismissive, you know, it was like they were almost like ‘she’s too complex, why are you even bothering. It felt like they were thinking, ‘why are you even bothering? Just enjoy your child.’ Whereas for me it was like [...] I know [Child’s] life is gonna be short, but I want to ensure that she has good quality of life, whatever the length of it, because none of us know how long our life is gonna be. So, let’s optimise the good bits so you know, so that she can stay at home, so that she can stay out of hospital, so she can have dignity.

Parent

Some healthcare professionals reflected that on occasion, it might seem that there are differences of value and belief between parents and healthcare teams, but that common ground could be identified which would help both parties to move forward and feel heard. We heard from a healthcare professional about the benefits of conflict resolution training in helping to identify common ground.

“ I recently had a case about a baby whose parents refused antibiotics [...] So this conversation has been had three times already and I’m the fourth person going in. [...] I would previously think my first step would be getting them to accept. If they don’t accept, I’ll tell them that their child is at risk of having sepsis and dying or being severely neurologically impaired. And my third step would be [...] safeguarding and legal actions. [...] When I went in recently, I went in with the idea in mind that actually what I want is this baby to be safe and to be well. [...] It may sound that these two things are synonyms, having antibiotics and being safe, but I don’t think they are. What actually worked in this case was just being able to align ourselves in the same desire of this baby to actually be well and, and being able to talk about it. [...] That’s what brought us together and that’s what was, you know, that’s how we were able to provide care for the baby.

NICU consultant, interview transcript

Pressure to ‘fight’

We heard from a range of participants that the pressure on parents to ‘fight’ for their child in order to feel like they are being a good parent, and are doing all they could possibly do, is considerable and influential on the development of disagreements. The need to be a good parent to their child, and the distress resulting from parents feeling prevented from fulfilling their own personal definition of being a good parent, was highlighted by our literature review as being of particular influence.²³ Non-clinical professionals told us that, in their experience, the biggest challenge for parents when disagreements escalate is feeling the need to do everything possible for their child. Parents told us that feeling the need to fight stemmed from both a lack of control they had over making decisions about their child’s wellbeing whilst hospitalised, and feeling that their (and by extension, their child’s) needs and wishes were not being heard by the healthcare team. Healthcare professionals took the view that ‘fighting’ and other, loaded adversarial language in describing the role of a ‘good parent’ arose from media portrayals in high-profile disagreements cases and beyond.

“ It just makes you think like ‘is this why we have our children then to just hand them over to the state’ you know, in cases like this? Like, he’s my child. I grew him in me. I’ve catered for his daily needs, you know. I’ve loved him. I’ve cared for him. I’ve done absolutely everything for him, but now you’re telling me ‘Actually, no, you’ve got no rights as his mum.’ You know it it’s just too much to take in while your child’s laying there, in care, and also being through all this. I know people could argue and go well ‘you didn’t have to go to court, did you?’ Well, no, I didn’t have to, but I did. He’s my child and I fought for him.
Parent

“ If we had had the treatment and it didn’t work, we would have a lot more peace now. You know, we’d be able to lie in bed at night and think, you know what, we done everything we could for [Child]. Gave him every chance we possibly could have, and it wasn’t enough. But we will never know.
Parent

“ If a professional isn’t listening to you, they’re not offering the best care to your child. Cos if you’re not gonna listen to someone who cares for this individual day in, day out and knows how it works, what does work, what doesn’t work and what’s needed in a partnership, instantly you know that that person can’t care for your child in the best way because they’ve already made their mind up.
Parent

Media and social media

A considerable number of those contributing to our research took the view that some media reporting and social media commentary about issues around the care of critically ill children caused disagreements to arise and escalate. We heard this in particular from healthcare professionals, who told us that they saw social media especially as ‘fanning the flames’ and, in their experience, only serving to further entrench existing disagreements and create a power imbalance where potentially inaccurate comments could be made but healthcare professionals – bound by their professional duty of confidentiality – would be unable to counter it or otherwise stop misinformation from spreading. There were strong views that preventing or minimising social media commentary about disagreements would reduce the frequency of them arising.

23. Moreton K (2023) *Disagreements in the care of critically ill children: Causes, impact and possible resolution mechanisms*, available at: <https://www.nuffieldbioethics.org/news/literature-review-on-disagreements-in-the-care-of-critically-ill-children-now-available>.

“ Somehow (not sure how) reduce influence of social media and external agencies with an agenda [...] They create an enormous asymmetry of power and their influence is only ever negative.
Paediatrician (North East & Yorkshire)

Parents, on the other hand, gave us mixed views of media and social media involvement, with some saying that they found them a source of support at a time when they felt that they had very little of it, or that they felt it was the only way to be listened to by their child’s treating team. Others said that whilst they had initially sought media attention for practical reasons, such as to fundraise for treatment or legal costs, they had not always been portrayed accurately and it had become much more overwhelming than they had expected.

“ We started fundraising, but [...] nowhere near what we needed. So we have to go to the media, which was obviously the last thing we wanted to do. Didn’t quite realise how much that would blow up, did we? [...] We thought we’d have a little section on page 15 or whatever and we’ve got front page. It kind of snowballed a bit. [...] Stuff that’s been in the media about [family] – they’re not necessarily the best ones, are they?
Parent

“ You know, I don’t like the press normally, but we are where we are. ‘Can you call the trust. Can you talk to them? This is what we want. We want them to do more for [Child]. They just leave him there to wallow in his faeces. And you don’t take care of him. When we come in, we can see his skin is so cold.’ I just felt, you know, we can’t be there 24 hours. We’ve got other kids as well. [...] And] it helped because [the hospital] now took us more seriously [...] they started taking care of [Child].
Parent

LACK OF INFORMATION

Parents told us about a lack of information being available to them, both general information about their child’s condition and more specific information in response to questions they had. Our 2019 briefing note recommended that those involved in leading NHS trusts and hospitals should consider ways in which parents could be more involved in their child’s care, such as having access to their child’s medical records. We heard about barriers to accessing their child’s clinical records and feeling like they needed to seek information from outside the healthcare team to be able to ‘fill in the gaps’. Where they were given information from the team treating their child, it was not always consistent, resulting in confusion.

RECOMMENDATION: 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.

We also heard about examples of healthcare professionals working together with parents to develop accessible formats of useful information for parents, but that whilst these proved useful at a local level, lack of awareness outside the local area was a barrier to wider adoption by other hospitals and trusts. A lack of awareness was also seen as a barrier to broad implementation of existing education and training resources relevant to improving relationships between parents and healthcare professionals.

RECOMMENDATION: 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.

Barriers in accessing records

The Data Protection Act 2018 gives those with legal responsibility for, or consent from, another person the statutory right to apply for access to that person’s health and care records (also sometimes referred to as ‘clinical records’ or ‘medical records’) by way of a formal request known as a Subject Access Request (SAR).²⁴ SARs should be submitted to the organisation that provided the treatment, and the organisation has an obligation to respond under the Data Protection Act within one calendar month from the day the request is received. If the request is particularly complex, or if a person makes more than one request, then the organisation must respond within three calendar months from the date of receipt.²⁵

Anyone with parental responsibility for a child is therefore entitled under this Act to request access to that child’s health and care records, with some exceptions.²⁶ General Medical Council (GMC) guidance states that doctors “should let parents access their child’s medical records if the child or young person consents, or lacks capacity, and it does not go against the child’s best interests”.²⁷

We heard of a number of issues arising where parents had formally requested or otherwise sought access to their child’s records. Parents told us that their requests were not always actioned fully and in a timely manner.

Redacted or incomplete records were sometimes supplied without explanation given as to why, and statutory timeframes for provision were not met, seemingly at odds with the urgency that parents were told decisions needed to be made about their child’s care. Some parents reported feeling that they were treated with disdain for making the request.

“ I’d requested the medical records and they hadn’t given them to us. [...] And they’re supposed to give them within 28 days or something like that, aren’t they? [...] And this is like 11, 12 o’clock the night before [the court hearing].
: **Parent**

“ The request that I made in February for the medical records, they came to me in May [...] so it wasn’t even the 28 days, they took three to four months to send [them] to me.
: **Parent**

We also heard about issues with records kept at a child’s bedside, including parents being prevented from looking at them or taking photos of them by staff members.

“ But we were made an exception. As soon as we got in there [to their child’s hospital room], they used to take the notes away. Other parents, they were given the notes [...] they will tell them what’s happened [and] what’s in the medical notes, the nursing notes. But we were deprived of that.
: **Parent**

24. Data Protection Act (2018), available at: <https://www.legislation.gov.uk/ukpga/2018/12/contents/enacted>.

25. Information Commissioner’s Office (2023) *Right of access*, available at: <https://ico.org.uk/for-organisations/uk-gdpr-guidance-and-resources/individual-rights/individual-rights/right-of-access/>.

26. Exceptions arise, for example, where a child has capacity to make decisions about matters relating to their care and treatment.

27. General Medical Council (2023) *Accessing medical records by children/young people/parents*, available at: <https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/0-18-years/accessing-medical-records-by-children-young-people-parents>.

“ What seems to come from this is that unless you could literally record everything yourself, it's your word against theirs - including down to [the] literal medical chart that's at the end of the bed. We were refused to even take pictures of it every day. Now I don't see what the problem is with that. [...] And we were told don't do it and it's like well, why not? If there's nothing wrong with what you're doing, it's just his medical chart which [parents] should be entitled to, why can't we?

Parent

When access to records was provided, issues still arose. One parent told us that they found out important information about their child's condition from the records that they had not previously been made aware of, and another told us that their child's records were provided, but their perception was that this was because they could not be fully understood by someone without medical training.

“ They gave us [the records], but they can't refuse you that. They know you can't even understand what it is anyway.

Parent

“ [After receiving the records] That's when I discovered that [child] had fluid on [the] brain for the whole month.

Parent

43% of healthcare professionals told us via survey that they had found parents having access to their child's clinical records to be either unhelpful or very unhelpful in resolving disagreements. When this was explored further at our workshops, the reasoning given was that by the time parents were at the stage where they wanted access to records, the relationship had broken down so irretrievably that providing that access did nothing to restore trust. Some highlighted that reasons for hesitance in providing records might stem from a concern that they would need to be explained to parents to be meaningful, and that this would take time healthcare professionals did not have; others identified that information might be written in the records that the team would not want parents to see, and that ensuring records were free of such information might be helpful.

Facilitating access to their child's clinical records, in the absence of any factors preventing or inhibiting disclosure, would be of benefit in ensuring that parents have access to all the available information about their child – particularly as we heard that requests for access were often made after disagreements had already arisen or where trust was starting to break down. To ensure that parents are in as equitable a position as possible to seek expert second opinions, or if matters progress to court, access to clinical records should be better facilitated.

RECOMMENDATION: NHS trusts in England should ensure that protocols are in place to ensure parents requesting access to their critically ill child's medical records are provided, where practicable, with it within a week of the request being made, in the absence of any factors that would prevent disclosure such as lack of consent from a child with capacity or safeguarding issues.

CASE STUDY 3

Providing parents with access to electronic records

In 2019, Great Ormond Street Hospital (GOSH) introduced electronic patient records (e-records) with a patient portal called 'MyGOSH.' MyGOSH provides parents and children with a controlled level of digital access to their medical records, accompanied with direct online communication with their care team(s) through 'instant' messaging.

MyGOSH enables access to e-records for (1) young people over 16 who are determined to have mental capacity, (2) children between 12 and 16 alongside their parents, and (3) for parents where their child is under 12. **In this case study we will focus on the latter.**

GOSH told us that improving communication, providing parents with more information and empowering parents to be better involved in their child's care were key reasons behind the introduction of MyGOSH.

What's involved?

We heard that MyGOSH provides a harmonised platform for healthcare professionals and parents to access a child's e-records and interact with each other. Information about a child's care can be viewed by all healthcare professionals responsible for treating a child.

Parents can see the majority of relevant information, including appointments, letters, discharge summaries, test results (with attached comments if helpful), medications and members of the care team. This information is either released automatically or can be controlled by healthcare professionals where extra explanation may be needed.

MyGOSH also enables individuals to communicate with care team(s) via instant messaging, to book and reschedule appointments more easily and have online appointments where appropriate. The ability to see relevant information within their child's e-records equips parents to discuss and ask questions about their child's care with healthcare teams. Parents can also input information relevant to their child, such as dietary preferences and comfort tips (e.g. favourite toys).

The provision of e-records may remove the need for parents to formally request access to medical records, which can take time, by providing relevant information about a child's care from the start.

Implementation tips, feedback and reflect from the GOSH team:

- ✓ Introducing a patient portal like MyGOSH and providing access to e-records takes a long time to introduce – the GOSH team spent a number of years undertaking workshops, interviews and surveys with healthcare professionals, young people and families.
- ✓ Staff preparation, training and use of the system needs to be standardised in order for the benefits to be realised as soon as possible after launch.
- ✓ A system such as MyGOSH requires ongoing resource commitment to ensure staff have capacity to use it as intended and are fully trained, as well as to ensure that technical support and maintenance is available (GOSH have implemented a dedicated helpdesk).
- ✓ Response times to instant messages need to be agreed and communicated clearly to ensure expectations are realistic.
- ✓ Some barriers to access may still persist as the system relies on digital literacy, digital access and is in the English language.
- ✓ For safeguarding purposes, access is limited to those who have legally determined parental responsibility and a 'secure address flag' can be placed on e-records where a patient's address must be withheld. To maintain safeguarding, staff members sign families up to the portal rather than families doing so themselves.
- ✓ Professionalism must be maintained in using such a system and all information (including that within e-records themselves and instant messages) needs to be accessible, transparent and accurate.

Seeking information online and from outside the treating team

We heard of a number of issues arising from parents seeking information, often online, about their child's clinical condition or about care and treatment options. Issues were also highlighted with seeking information from outside the treating team more formally, such as via expert second opinions.

Healthcare professionals were largely of the view that the seeking of information online by parents was a particular cause of disagreements. They noted that the proliferation of information on social media, which could be of varying accuracy, quality and relevance, was difficult to manage, and that parents sometimes seemed to place more value in this than in the healthcare professionals' expertise.

Parents explained that they sought third-party information because they were either receiving mixed messages from their child's treating team, or because their questions were not being answered and so they felt the need to undertake their own research to get answers. Some told us that they had been made to feel that they could not ask questions, or that asking questions was not well-received.

“ Well, I did a hell of a lot of research so that's how I understood it [Child's condition] rather than them [healthcare professionals] explaining it to us. [...] It very much seemed that they were quite irked that [we] had done all this research [...] they were kind of like, you know, 'we've been studying for 20 years with this, we're not going to have you coming in and telling us you know how to do our job' ”
Parent

“ It got to the point where they had made it very clear I'm not allowed to ask questions and they won't be answered. [...] I started researching stuff myself at that point. ”
Parent

“ Yeah, [other parent] is not one of these people [who swear and are rude]. [...] be very dignified, very educated in what she was saying, she wouldn't just say stuff that she thought, she'd done the research into it, [...] she knew what she was talking about. [...] But they couldn't stand it. They couldn't stand people without a medical background going in there and saying 'well we believe you are wrong' ”
Parent

Second opinions

Second opinions can be sought by both parents and/or the healthcare team where there is a disagreement about what is in a child's best interests. This provides either party with the opportunity to seek a clinician not previously involved in the child's care to review their case. This may provide healthcare professionals with reassurance about a certain decision or provide them with a different clinical view on the care of the child. For parents, second opinions may provide clarity around a decision, or support further discussion of alternative options.

A patient's right to seek a second opinion, and a healthcare professional's duty to respect that, is well-enshrined in professional standards and guidance. The current General Medical Council (GMC) standards, that set out the professional standards for doctors, state clearly that “in providing clinical care, [a doctor] must respect the patient's right to seek a second opinion”.²⁸ New professional standards for doctors, to be introduced from January 2024, also clearly state that doctors “must recognise a patient's right to choose whether to accept [their] advice, and respect their right to seek a second opinion”.²⁹

28. General Medical Council (2013) *Good Medical Practice*, available at: https://www.gmc-uk.org/-/media/documents/good-medical-practice---english-20200128_pdf-51527435.pdf, at paragraph 16(e).

29. General Medical Council (2023) *Get to know Good medical practice 2024*, available at: <https://www.gmc-uk.org/ethical-guidance/good-medical-practice-2024/get-to-know-good-medical-practice-2024>.

The impact of disagreements

We heard about potential barriers to parents seeking second opinions about their child's clinical condition, which included a lack of information or awareness about the right to do so; feeling unable to ask for one because parents did not feel that questions about clinical care were welcomed or characterised as being 'difficult'; perceptions of bias or a lack of independence (on the part of both parents and healthcare professionals) and the absence of a clear and simple pathway to directly source an expert second opinion quickly.

We heard of instances where clear pathways to directly source expert second opinions had been introduced in Australia and in some UK hospitals.

“ In the UK, a similar scheme called Call 4 Concern has been adopted by some hospitals. It is another patient escalation system, whereby patients or relatives can call or bleep a hospital's in-house Critical Care Outreach team 24/7 if they are concerned about a change in condition which they feel their care team is not recognising. It was pioneered by the Royal Berkshire NHS Trust, launched with a pilot in 2009/2010. Posters and leaflets are around the hospital, including on every bedside locker.
Polly Curtis & Claudia Wood, Demos, call for evidence response

86% of healthcare professionals responding to our survey said second opinions were helpful or very helpful to navigating, managing or resolving disagreements. Some thought that receiving an external specialist review can reassure families and 'unlock conflict'. Others suggested second opinions could provide helpful challenge to a medical decision, or provide healthcare professionals with further evidence behind their decision.

The potential and actual impacts of disagreements cannot be understated. All those who contributed to our research were clear in underlining the profound and enduring impacts that disagreements have had on them personally and on others who have been through them, as well as – most crucially – the impact on critically ill children themselves.

Our work identified three key impacts of disagreements: those on the critically ill child; emotional, psychological and moral distress of parents and healthcare professionals; and a breakdown of trust.

IMPACTS ON THE CRITICALLY ILL CHILD

There is little published evidence exploring the impacts of disagreements on the critically ill child, which may stem from ethical and methodological difficulties associated with undertaking research with unwell children, further compounded by life-threatening and life-limiting conditions as well as practical difficulties caused by a child being unable to communicate their perspectives as a result of very young age or unconsciousness.³⁰

Discussion in academic literature is limited but centres around the assumption that children suffer physically from being subject to protracted treatment whilst disagreements are in the process of being resolved,³¹ and that there is the potential for psychological suffering too where the child themselves may have the consciousness and understanding to accept that they are dying, but their continued treatment prevents that from happening.³² The potential impacts on children were acknowledged by all who contributed to the review, with a commonly-expressed view being that the time and attention devoted to managing, resolving and 'winning' disagreements had the effect of 'decentralising' the child's care and treatment, as well as having an adverse effect on the team's ability to provide good care to other critically ill children.

30. Moreton K (2023) *Disagreements in the care of critically ill children: Causes, impact and possible resolution mechanisms*, available at: <https://www.nuffieldbioethics.org/news/literature-review-on-disagreements-in-the-care-of-critically-ill-children-now-available>.

31. *ibid.*

32. Abela KM, Wardell D, Rozmus C, and LoBiondo-Wood G (2020) 'Impact of pediatric critical illness and injury on families: An updated systematic review' *Journal of Pediatric Nursing* 51: 21-31.

“ There definitely came a point where it wasn’t about the clinical side of things anymore – it was a legal, reputation [thing]. [Child] got lost in it all somehow. We were these annoying parents who wouldn’t accept what they were saying and, I wouldn’t say it got personal, but it very much became a game to them.
Parent

Whilst there is more published evidence about the impact of disagreements on parents than there is on critically ill children themselves, little of it explores parents’ perspectives directly with them, and there is substantially more published literature looking at the impacts of disagreements on healthcare professionals.³³ We have sought to highlight parents’ perspectives as part of this review, but further work is needed to ensure that their experiences of shared decision-making are properly understood and accounted for.

RECOMMENDATION: 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.

RECOMMENDATION: 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.

EMOTIONAL, PSYCHOLOGICAL AND MORAL DISTRESS

We heard many candid reflections from both parents and healthcare professionals about the emotional, psychological and moral impacts that disagreements have had on them and those close to them.

Post-traumatic stress and other enduring psychological impacts

There is considerable published evidence to show both the short-term and long-term psychological impacts on parents of having a critically ill child. Post-traumatic stress disorder (PTSD) is prevalent as a result of stress reactions to what parents see and hear in the intensive care environment.³⁴ The literature review highlighted evidence to show that the severity of long-term distress experienced by parents correlated with the level of distress they experienced at their child’s admission to critical care, rather than with the severity of the child’s illness itself.³⁵ This could indicate that preparing parents better for their child’s deterioration (where that deterioration is predictable and likely or inevitable) would help in mitigating the impact of PTSD.

Parents gave harrowing accounts of their experiences of PTSD and enduring psychological impacts.

“ We could write a book. It was traumatic enough, as I think I said to you before, down in [city] just being in an intensive care environment for [a long time]. You know we saw babies die? Hearing mums scream when their kids died. [We’ll] never forget that. You hear that alarm go off, you know, we might be making a cup of tea. We’d hear it, and although [Child] was stable, you’d still have that dread come through – ‘oh my God, it’s [Child]’ – and run back and, you know, you felt awful for being relieved that it’s not [Child]. And then you suddenly realise ‘shit, that’s someone else’s child and someone else’s family that’s going to be going through the mill.
Parent

33. Moreton K (2023) *Disagreements in the care of critically ill children: Causes, impact and possible resolution mechanisms*, available at: <https://www.nuffieldbioethics.org/news/literature-review-on-disagreements-in-the-care-of-critically-ill-children-now-available>.

34. *ibid.*

35. *ibid.*

“ I’ve got these questions every single day of my life. These questions just with [Child]. Every single day like. What if they didn’t [do what they did]? What if [...] You know, like these are the questions that go around every day. [...] You know all these different questions. Every single day in my head because the answers have never been there. They’ve never been answered.
: **Parent**

Moral distress and injury

Moral distress is a term used to describe distress brought about from an inability to adhere to one’s own moral values as a result of external constraints outside of one’s control. In healthcare professionals, it can manifest as a sense of unease from being conflicted about the care they can give to patients³⁶ and, in disagreements about the care of critically ill children specifically, tends to arise from having to continue to provide care and treatment that they feel is not in the child’s best interests and/or is actively harming the child unjustifiably whilst a disagreement is being resolved.³⁷ Moral injury is used to describe the psychological impact caused by sustained moral distress.³⁸

Healthcare professionals were candid about the extent to which moral distress and moral injury had impacted them, with 66% of those surveyed stating that they had experienced it as a result of disagreements, and many responses to our call for evidence included moral distress as a central point of discussion. We heard of high rates of burnout, and 49% of professionals reported feeling unsafe at work as a result of their involvement in disagreements. There is emerging evidence to show that disagreements

are having an adverse impact on medical trainees’ willingness to work in paediatrics,³⁹ and we saw a similar impact on experienced healthcare professionals who expressed that they were considering leaving their roles; some had already done so as a result of the moral injury they experienced.

There is also evidence to show that parents experience moral distress when they are in disagreement with their child’s treating team. This arises from being prevented from pursuing what they consider to be the “ethically right course of action for their child and family”.⁴⁰

No right of reply

Healthcare professionals told us that they found it particularly difficult to see public criticism about the care they were providing to a child, either in the press or via social media commentary, and be unable to tell their version of events due to professional duties of confidentiality. This was particularly the case where they felt criticism was not warranted or based on inaccurate reporting of what had happened.

“ [The] effect on the whole team is devastating - massive increase in sickness and stress in the staff. Also impacts on care given to all other children in the unit. I think the media also need better guidance on how cases are reported as I found it very upsetting to be so publicly criticised with no real ability to tell our side.
: **Paediatrician (London)**

36. British Medical Association (2021) *Moral distress in the NHS and other organisations*, available at: <https://www.bma.org.uk/advice-and-support/nhs-delivery-and-workforce/creating-a-healthy-workplace/moral-distress-in-the-nhs-and-other-organisations>.

37. Whilst healthcare professionals cannot be compelled to initiate care or treatment against their will, they are not able to withdraw life-sustaining care or treatment that is already being provided in the absence of parental consent or a court judgment.

38. British Medical Association (2021) *Moral distress in the NHS and other organisations*, available at: <https://www.bma.org.uk/advice-and-support/nhs-delivery-and-workforce/creating-a-healthy-workplace/moral-distress-in-the-nhs-and-other-organisations>.

39. Bell CE, Dittborn M, and Brierley J (2023) What is the impact of high-profile end-of-life disputes on paediatric intensive care trainees? *Archives of Disease in Childhood* **108**: 719-24.

40. Moreton K (2023) *Disagreements in the care of critically ill children: Causes, impact and possible resolution mechanisms*, available at: <https://www.nuffieldbioethics.org/news/literature-review-on-disagreements-in-the-care-of-critically-ill-children-now-available>.

“ Even if the media reporting is skewed, biased, or factually incorrect, then professionals are not allowed to challenge this, as we are obliged to maintain anonymity. Families are under no such obligations, and may choose to utilise the print and/or social media to give voice to their frustrations. The lack of ability to counter this is intensely frustrating to healthcare professionals [...] [having] no right of reply [...] means that professionals feel completely unsupported and powerless.

Paediatric Critical Care Society, call for evidence response

The impact of team culture on healthcare professionals

We heard from a number of sources that the team culture of a particular ward or other clinical environment can have impacts on how healthcare professionals approach and manage disagreements, as well as on how much support they receive to process feelings of distress that arise from their involvement in disagreements.

Healthcare professionals told us via survey that support from peers was readily available and particularly valuable to them but that support from the trust was both less forthcoming and less useful.

LACK OF TRUST

The erosion of trust between healthcare teams and parents was also a clear impact of disagreements. Parents described the receipt of mixed messages about their child’s care as being particularly impactful and meant that they did not know who to trust – if anyone – and this made them start to have more doubts about the care provided to their child.

“ My son’s life was literally in their hands. And you cannot trust these people because you’ve heard them say things about you. You’ve seen things written down about you that are untrue. You’ve seen, they’ve acted in a way that’s obvious, that’s putting your son, if anything, um, detrimental to his health, not promoting his health. So there is no trust. I found myself feeling that I had to safeguard my son in hospital from the people who I should have been able to trust. And again, that meant the ones that we did trust, the kind of handful that were there to support us, you feel like you put everything on them as well. So they, they would come in and get everything from us, from, from other families on the wards who had a good relationship with them.

Parent

“ You feel broken, very broken. There’s just a feeling of foreboding. Where you have the fear that you can’t really trust them to look after your child. You tend to think, can I leave my baby with the medical team, with the nursing team? So, there’s constant questioning, constant stress around this. The trust in a way, is broken. So, you wonder. They are the medical professionals. They are the experts. You have your trust in them that they will actually look after your baby without you being there. When you are in the conflict with them, there’s this gap that is there. The trust is broken that you feel you must be there to look after your child. You have to be there for his best interests to be considered.

Parent

Resolving disagreements

MEDIATION

Mediation is a form of dispute resolution usually offered as an alternative or precursor to court proceedings when parties disagree about a course of action. Where there are disagreements about the care of critically ill children, families and treating teams have the ability to access an independent mediator to facilitate a discussion between all parties. The aim of mediation is to understand the causes of the disagreement, help parties to understand each other and feel heard, and attempt to bring the parties together to find a mutually acceptable resolution. This can occur at any stage of a disagreement, even once the court process has begun. In recent years, there have been calls to require mediation in all cases before reaching court, including in a proposed amendment to the Health and Care Bill, sponsored by Baroness Finlay of Llandaff.⁴¹

Our surveys showed that both clinical and non-clinical professionals have broadly positive views of mediation and its effectiveness in navigating, managing or resolving disagreements. Where healthcare professionals had not had the opportunity to use mediation previously to resolve disagreements, 31% thought that using it would be helpful. In our workshops with healthcare professionals, we heard that the mediation training they had undertaken had helped them to identify emerging disagreements earlier, and that this had been of benefit to them and their teams.

“ Having someone in the hospital, or even better in the department, who is mediation trained would really help. I think mediation training in general should be part of CPD.
Paediatrician (Midlands)

“ Medical mediation has been helpful in developing more rigour in deep listening both at an individual but also at an organisational level, albeit not necessarily helpful in overcoming differences in understanding.

Anonymous call for evidence response

16% of survey respondents said they had found mediation unhelpful or very unhelpful, and some respondents to our call for evidence also found it to be unhelpful. Reasons given for this included a perceived low success rate when disagreements were already entrenched and that pursuing mediation at such a stage might prolong a disagreement unnecessarily. Healthcare professionals explained that mediation tends to be introduced at a fairly late stage of disagreements when trust has already broken down and so, given that its main benefit is in facilitating communication between parties, it would need to be introduced much earlier to have a positive effect. Some also thought that external mediation was unhelpful due to the perception that mediators could not understand the nuances of relationships between parents and healthcare teams.

“ Family belief in the good faith of clinical staff is crucial -- need to maintain openness and transparency. Ultimately these situations resolve through relationship and trust, which is why I personally feel the role of external parties (ethics committees, mediation organ[is]ations) is limited.
Paediatrician (North East and Yorkshire)

None of the parents who spoke to us had gone through mediation with the healthcare teams treating their child, although all of them had either wanted it, but not been offered it, or had been offered it and declined it. Reasons given for declining mediation when it was offered was the way it was presented – as an opportunity to “bring them round to the doctors’ way of thinking” which gave the impression that there was bias in the process.

41. See: *Baroness Finlay of Llandaff's Amendment 172, After Clause 164* (Health and Care Act 2022 - report stage), available at: <https://bills.parliament.uk/bills/3022/stages/16122/amendments/91480>.

“ Mediation is basically to bring you round to our way of thinking. [That’s] what the hospital said. So I said, well, that’s not mediation. Mediation is to listen to what I’ve got to say too, and the middle person tries to come up with something that works for everybody.
Parent

Much of the evidence we received around mediation focused on who could undertake it most effectively. Some considered that there was value in having discussions between parents and treating team members mediated by a member of staff who had been specifically trained, or an internal third party, such as a chaplain, psychologist, or family liaison nurse because the tenets of mediation could be practiced and embedded throughout the unit. An embedded team member may also effect cultural change of communication through developing trusting relationships with colleagues.

Others preferred external mediation due to the perception that they are neutral and independent of the hospital, or that they have special training to handle these sensitive and potentially complicated disagreements. Even when mediation does not result in agreement and resolution of a disagreement, it may still positively impact the process of the disagreement and relationships between those involved.

“ While resolution is the aim, sometimes resolution is not reached with mediation as it is for the parties to decide whether to reach an agreed way forward. However, the mediation may still be viewed as ‘successful’ because of other benefits, such as improved communication, narrowing of the issues, or better understanding of the other person’s perspective.
Margaret Doyle, Jaime Lindsey, Katarina Wazynska-Finck, call for evidence response

“ We felt listened to when mediation got involved. We felt that was the first time with ourselves as parents and the medical team sat down and they listened to us and understood us for the first time. When that happened, we let go. We were able to make the right decisions, we were able to work together.
Parent

We received little evidence to support the mandating of mediation attempts before court proceedings can be instigated. Researchers pointed out that mandating mediation where it is not suitable might unduly limit children’s rights and access to justice.

“ As to the use of mediation, only the CoE [Council of Europe] Convention on the Exercise of Children’s Rights explicitly encourages mediation ‘to avoid proceedings before a judicial authority’. Other sources are more neutral as to benefits of mediation for children. Importantly, the use of alternative dispute resolution systems, such as mediation, should not limit a child’s access to justice. It should be encouraged when in a child’s best interests, but in some circumstances recourse to a court may offer more guarantees to a child. Therefore any recommendation or use of mediation ought to be case-appropriate, rather than mandatory.
Margaret Doyle, Jaime Lindsey, Katarina Wazynska-Finck, call for evidence response

CLINICAL ETHICS COMMITTEES

Clinical ethics committees (CECs), sometimes also known as clinical ethics groups or forums, are multi-disciplinary groups that aim to provide support for decision-making on ethical issues arising from the provision of patient care in NHS trusts and other healthcare institutions. When a challenging ethical issue arises, and/or there is doubt or disagreement

about what should be done for a patient, CECs may be a port of call for healthcare professionals to seek advice. Not all healthcare professionals will have access to CECs, however, and provision varies across the country. Our literature review drew attention to the extent of variability in the format, function and composition of CECs, and the impact of this variability was highlighted by those who fed into our research, as well as being well-rehearsed in academic literature.

We heard from healthcare professionals in our workshops and surveys that they find the use of clinical ethics committees (CECs) helpful in navigating and managing disagreements, in that they served as a 'safe space' to discuss a case, where members feel comfortable discussing their honest view, whether it supports or goes against the perspective of the treating team. In workshops, healthcare professionals described CECs as a useful source of advice and a constructive forum in which differing clinical perspectives could be discussed and evaluated.

We heard that the use and composition of CECs varies widely between hospital trusts, ranging from advisory and rarely called-upon to oft-used, flexible, and only to support-decision making. Some healthcare professionals who were members of CECs themselves suggested that the use of CECs would be improved if they were utilised more, in a more responsive capacity, and that they ensure the inclusion of laypeople and diverse professional perspectives.

“ All secondary and tertiary centres providing complex or critical care to [under 18s] should have access to (and be expected to use) such a service [as a clinical ethics advisory group]. These should be standardised, properly and consistently structured and resourced, and include professional and lay membership and specifically a strong nursing voice.
Alison Taylor, University of Brighton, call for evidence response

“ It would be important for NHS England to ensure that all children's hospitals with critical care units have access to experienced clinical ethics services, and that those services are adequately resourced to be able to provide timely (including urgent) input. In addition, there is a need for clear guidance on the role of clinical ethics in decisions and in the setting of conflict, as well as how such groups should involve and incorporate parents in their review process.
Dominic Wilkinson & Emily Harrop, Oxford University Hospitals NHS Trust, call for evidence response

While CECs were seen to be of overall benefit to healthcare professionals during disagreements, we heard little about their benefit to parents. We heard that many CECs lack parental representation or input, and that there is a general lack of information provided to parents about how CECs work and what their purpose is. As referenced earlier in this report, we heard that parents are often not invited to contribute to CEC deliberations and, sometimes, not even made aware that their child's case is being discussed by the CEC until after it has happened. Where parents are supported to contribute to CEC deliberations, we heard examples of this happening in a structured but flexible way to ensure that individual needs and preferences could be accommodated.

“ We provide families with an information sheet about [the clinical ethics committee] including the role of CES [Clinical Ethics Services]. We currently ask clinical teams to support families to identify ways that they would like to have their views represented at clinical ethics conferences. This can include identifying a member of the clinical team who they are close to who they would be happy to represent their wishes. It can include the family writing a letter to [the clinical ethics committee] (one out of nine cases). In other cases, we offer families a chance to meet with a member of [the clinical ethics committee] prior to the meeting to communicate their understanding and views (five out of nine cases).
Dominic Wilkinson & Emily Harrop, Oxford University Hospitals NHS Trust, call for evidence response

The lack of parental involvement in CECs and transparency about the role, scope and authority of CECs can have a negative impact on parents. Parental involvement in the CEC process and deliberations, via direct input at meetings or by facilitating provision of their perspective via a trusted representative (such as a community nurse or family friend) would help promote transparency and reduce the risk of parents feeling excluded.

RECOMMENDATION: Guidance for clinical ethics committees (CECs) in England should be produced on how to ensure that parents', and where appropriate children's, views are taken into account in CEC discussions and that parents are supported to provide input to CEC meetings. The DHSC taskforce established as part of recommendation 1 should identify who is best placed to produce or commission this guidance.

GAPS IN SUPPORT

Many submissions to our call for evidence highlighted better provision of support and advice for parents as being potentially helpful in resolving or de-escalating disagreements.

Emotional and spiritual support

The provision of one-to-one, confidential emotional and spiritual support, such as that provided by a counsellor, chaplain or trusted religious leader, was generally acknowledged as useful in not only providing parents with emotional support but also in helping them to talk through decisions about what might be in their child's best interests.

“ Disagreements may be avoided if religious leaders are invited to take part in discussions around 'best interests' care.
Christian Medical Fellowship, call for evidence response

“ ...it is important to recognise that, even where disagreements may seem to have become entrenched, 3rd party support through the involvement of a faith leader, a senior colleague or an external second opinion is often productive.
Paediatric Critical Care Society, call for evidence response

Despite this general agreement about the value of emotional and spiritual support, issues can arise when it is used. Some parents told us that where they had sought or been offered much-needed emotional and psychological support from the hospital or Trust, they had believed it to be confidential but had later discovered that what they had shared 'in confidence' had been shared with healthcare professionals and hospital management. This had the impact of further eroding trust and heightening feelings of isolation.

“ He was the hospital chaplain, so a person of God. You would think a person of God would have more morals and more integrity, but he wasn't, and may God forgive me for saying this [...] he was a little spy. He would come and he would sit with us, and he would try to be friendly, but essentially, he was just feeding back to management.
Parent

“ Another thing I found really quite alarming with the hospital is [when] we was sent a support worker, like some sort of counsellor, that you believe is there for you. [...] I did open up a little bit [...] and every single thing I told her, she's then gone back and relayed to the medical team and [...] they tried to use it against me in court. [...] Made me feel like that one trusted person that I could talk to in the hospital – I've got no one now, I can't trust anyone.
Parent

“ Also I had a counselling session. And the next thing I see when I when they start doing the proceeding, when they start giving us medical records, that counselling note is also in the medical records. So that means anything that I have been talking to you about it all has gone back to the doctors. And that’s what- The moment I read that, and I thought ‘no, that’s it, I’m not speaking to anyone in the hospital.’ And since then- I mean not since then. During that time, despite desperately needing to speak to someone, I just refused to speak to anyone.

Parent

Emotional and psychological support was also largely seen as something helpful for healthcare professionals in managing the emotional and psychological impacts of their involvement in disagreements. In our workshops, healthcare professionals shared how their units support each other with informal check-ins via texts from supervisors, but they stressed that this worked because it was genuine and individual. We also heard about more formal support mechanisms being made available for staff in some hospitals, such as dedicated psychologists being employed by individual trusts or departments. These were said to be generally useful where available, but healthcare professionals reflected that smaller trusts or departments may not have the resources to be able to provide dedicated staff.

Awareness of the available wellbeing, emotional and psychological support mechanisms for healthcare professionals, including those provided by professional associations and membership bodies, was variable amongst healthcare professionals and this was seen as a potential barrier to access.

Healthcare professionals also reflected to us that both the availability and type of emotional and psychological support, as well as the willingness and ability of staff to access it, was heavily influenced by individual department culture within hospitals. Some

healthcare professionals told us in our workshops that they were reluctant to access such support at work because they worried it would take time away from providing clinical care to their patients, or that their line managers would see it as such; others told us that they did not feel comfortable admitting that they were struggling emotionally in the workplace and preferred to access support instead from family, friends and formal mechanisms outside work. We also heard that where in-house support was available and valued, it may not meet everyone’s needs and so a variety of support mechanisms would be of benefit.

It was therefore clear that whilst there is no one-size-fits-all solution to providing emotional and psychological support for healthcare professionals, there is a need to ensure that healthcare professionals are both made aware of a variety of options available, and that accessing support is recognised and encouraged at a local level as an essential part of ultimately providing good care to patients.

RECOMMENDATION: NHS trusts in England should ensure that their team members are made aware of, supported and encouraged to access a variety of sources of emotional and psychological support.

Other forms of social support

Parents may also experience socioeconomic impacts as a result of having a critically ill child. They may be subject to financial pressures that can be caused or exacerbated by factors such as long-term hospital stays, requiring specialist equipment, housing adjustments or needing to leave the workforce in order to provide care.

Whilst benefits and charity funds are available to support some parents when they have a critically ill child,⁴² these may be difficult to identify or navigate in stressful times. Parents are likely to be focused

42. With respect to UK Government benefits, see *Universal Credit*, available at: <https://www.gov.uk/universal-credit>, *Disability Living Allowance*, available at: <https://www.gov.uk/disability-living-allowance-children>, Council Housing, available at: <https://www.gov.uk/council-housing>, and *Carers Allowance*, available at: <https://www.gov.uk/carers-allowance>. For charity funds, see for example: Family Fund (2023) *Financial Support*, available at: <https://www.familyfund.org.uk/support/financial/>, Rainbow Trust (2023) *Support for Families*, available at: <https://www.rainbowtrust.org.uk/support-for-families>, and Carers Trust (2023) *Help and Info*, available at: <https://carers.org/help-and-info/introduction>.

on the care of their child and thus may not have time or energy to find and apply for financial support. Identifying support may present practical difficulties for parents who are inexperienced in navigating the benefits system, and it may be emotionally difficult for parents to accept their need for support, especially if they were financially comfortable before their child became critically ill.

We heard from healthcare professionals that the provision of dedicated staff to support families, such as family liaison nurses and welfare officers, was very valuable. The benefits are their ability to get to know a family and to understand their needs and their background, so that appropriate support and signposting can be provided. An added benefit is that these roles can act as a single point of contact between parents and healthcare professionals to reduce the risk of mixed messages being given to parents.

LEGAL TEST

When disagreements cannot be resolved between parents and healthcare professionals themselves, they may be escalated to the courts for a decision. This includes situations where a parent does not actively disagree with or oppose what healthcare professionals are proposing in relation to care and treatment, but they are unable or unwilling to provide explicit consent to what is being proposed. Debate on the suitability of ‘best interests’ as the threshold of intervention was identified in the literature review (Annex 4) we commissioned, and it featured in submissions to our call for evidence. Opponents often suggest the ‘best interests’ test is overly subjective and does not provide parents with the same amount of parental decision-making power available to them outside of the medical context. In contrast, proponents argue that ‘best interests’ is well established in the legal system and encapsulates a wide range of relevant factors, including those suggested by alternative thresholds.

Best interests

The ‘best interests’ test requires that treatment or a course of action is in a child’s best interests in order to be provided. If healthcare teams and parents do not agree about whether the provision of treatment is in a child’s best interests, or if parents are unwilling or unable to provide consent to the course of action healthcare teams are looking to take, the matter can be referred to the courts for a decision. The term ‘best interests’ has its origins in the UN Convention on the Rights of the Child, and has a position in English law as the guiding principle of the Children Act 1989, which provides state protection for children’s welfare.⁴³

The factors which are considered by the courts to determine ‘best interests’ will vary from child to child. However, doctors are provided with guidance from the General Medical Council and the British Medical Association on best interest assessments. These factors include the views of parents, clinical factors, the child’s physical and emotional needs, risks and side effects of treatment or non-treatment.

Some criticisms of the ‘best interests’ test have been that it does not allow for parents’ wishes and views to be taken seriously, and that parents effectively being told that they do not have their child’s best interests at heart, by way of court action being taken or by a court decision, is damaging. The potential subjectivity of what amounts to a child’s best interests has also been raised as an issue.

Significant harm and other alternatives

The ‘significant harm’ test has been proposed as a potential solution to some of the concerns around ‘best interests’ as the threshold for court intervention. Proponents for the ‘significant harm’ test can be found in the literature, case law, proposed statutory amendment and within our call for evidence submissions. This test would require healthcare professionals to prove that the course of action that parents are seeking would cause the child ‘significant harm’. ‘Significant harm’ is a term already used in law, specifically in care proceedings under the Children Act to determine whether or not a child should be removed from their parents’ care.⁴⁴

43. Children Act (1989) (c.41), available at: <https://www.legislation.gov.uk/ukpga/1989/41/contents>.

44. Children Act (1989), section 47(1)(b)), available at: <https://www.legislation.gov.uk/ukpga/1989/41/section/47>.

Some proponents of the ‘significant harm’ threshold convey that this change would promote consistency, ensuring parents are given the same level of decision-making power to make decisions about their child in the medical context, as they are provided in other areas of their child’s life, such as in education. It has been argued that using a ‘significant harm’ test would result in a higher threshold for court intervention than ‘best interests’, which could help remedy the power imbalance between parents and healthcare professionals, by providing parents with more say in their child’s medical care.

The use of the ‘significant harm’ threshold has been characterised by proponents as an addition or amendment to the ‘best interests’ test rather than a replacement of it. Although ‘significant harm’ would be used to decide whether the court could intervene, the ‘best interests’ test would still be used if this threshold was met.

The proposal has sparked considerable debate, however, the result has been inconclusive and legal change has not occurred. An attempt was made to change the law to include the ‘significant harm’ test as the relevant threshold for intervention, by way of the recently proposed amendment to the Health and Care Bill. The test was also proposed in case law in *Yates & Anor v Great Ormond Street Hospital for Children NHS FT*.⁴⁵ Here the court held that ‘best interests’ was to remain as the threshold. Criticisms of a ‘significant harm’ test highlight that in practical terms, the court already consider whether a child will be harmed by treatment when taking into account if it is in their best interests, and so there is no need for statutory change to ensure this is included.

“ We believe that the current legal framework already gives consideration to medical treatment proposals made by those with parental responsibility – and is one which enables the court to decide that parents’ views are in their child’s best interests.
: ***Together for Short Lives, call for evidence response***

We heard from a variety of people and organisations that viewed the ‘best interests’ test as largely fit for purpose, and many of the criticisms levelled at the ‘best interests’ test were echoed as criticisms of a potential ‘significant harm’ test. Concerns that it may be harmful for parents to hear they don’t have their child’s best interests at heart are similarly likely to apply for parents hearing they may cause their child significant harm. Although subjective in nature, proponents relayed that ‘best interests’ is well-understood due to being developed through numerous legal judgements.

GOING TO COURT

Parents described going to court largely as a very difficult experience for a number of reasons. Some told of considerable financial impacts on their family, or needing to crowdfund (and, in turn, solicit media attention for their crowdfunding efforts) to be able to pay for legal and other costs.

We were also told that parents were given very little notice of court proceedings being instigated and therefore insufficient time to prepare their case, despite parents reporting in some cases that the trust had seemingly been preparing their own case for some time.

“ [Parent] was sitting there one night and they just came up to her and handed her some paperwork saying you need to be in court in the morning. So no time to get representation. No time to get prepared. No time for anything.
: ***Parent***

45. [2017] EWCA Civ 410

“ [We weren’t going to court] that’s what we thought. And then we were told ‘it’s up to the judge to decide’...we thought ‘oh my God, we’re still going to court, we’ve got no legal team [...] we weren’t prepared for court at all. And obviously they had in-house legal, they were completely prepared with witness statements and second opinions and we had nothing [except] they gave us a list of legal representatives that they would recommend. I’m not using them so I’m ringing everyone [to get legal representation] when we were in court two days later.

Parent

Having little notice of court proceedings being initiated was not only a considerable source of stress for the parents we spoke to, but also made them feel like they were not able to have their views heard in court as well as they ought to have been. It is essential therefore, to ensure parents are on as equal a footing as possible, that trusts provide parents with notice of the decision to initiate court proceedings as soon as possible after the decision is taken to do so.

RECOMMENDATION: NHS trusts in England should inform families within three calendar days of taking the decision to initiate court proceedings in order to give them sufficient time to seek independent legal advice and collate necessary information to disclose to the court.

Understanding court processes and conventions

The unfamiliarity of the court and its processes was also challenging, with parents telling us that they were not always sure how to behave, what to do, or what to expect.

Parents told us about the difficulties they experienced in understanding the court’s rules and processes, including about what was expected of them as parties to court proceedings. We heard one example of parents being advised that they did not need to dress formally for court but arrived to find everyone else

in smart dress, resulting in them feeling alienated, embarrassed and uncomfortable. Knowing when to speak and how to address points of contention was also highlighted as an issue, as was not having access to evidence laid before the judge.

We heard from some parents that they had benefited from the support of charities and advocacy organisations in navigating the court process.

“ [Parents] don’t know how [the legal system] works, what you need and everything. We didn’t even see the evidence pack, so we didn’t even know what the judge had in front of him.

Parent

“ The only way you can [navigate court] is to have the charities because there’s so many rules, procedures – the legal system is rule-based. And no matter what you say, you can’t water it down. If you go to court, it’s about rules, everything, CPR rules, principles from that case, with this case et cetera. [...] [Parents] don’t need to know the law. They just need to know what they’re there for.

Parent

The court environment

The environment of court was also emphasised as intimidating to parents. It was described as a space in which it was easy to get lost and confused, as well as the formality and traditions making parents feel like it was not a space in which they would have their voices heard.

“ The Royal Courts of Justice is the least friendliest court you will come across for parents. If it was anywhere else - fair enough. But the Royal Courts of Justice, you go in there and you think ‘That’s it. Nothing is happening here for me.’ It is very, very daunting.

Parent

“ I mean obviously it's very daunting. As if, you know, we weren't going through enough with the battle at the hospital. Having to go to this big court, this ancient building where you all have to stand up when the judge walks in and they're all wearing funny wigs.
Parent

Parents told us that feeling unable to participate or express themselves within the court process was a significant source of distress.

“ And you're not allowed to speak in there. Like the barrister speaks on your behalf. You can't say a word, so it's another - not only have you got no voice in the hospital... at least you have some voice in the hospital ... but in the courtroom, you've got zero voice whatsoever. So if you speak, you're out of that room and you're not allowed back in.
Parent

“ You can't ask a judge to start explaining things because they are legally represented, the barristers, and there's only one person that can speak to the judge from one party, so you can't have two people speaking because you've got a legal representative.
Parent

Conversely, we heard from some that whilst going to court was a very stressful process, they were glad to have done so as it allowed them to feel assured they had done everything possible for their child.

The potential adverse impacts on healthcare professionals of going to court were also reported to us. We heard that court proceedings tend to invite greater media and social media commentary, compounding the feelings of powerlessness healthcare professionals experience in not being able to respond

to criticism. We also heard that the duration of court proceedings can also have the effect of increasing moral distress. Some expressed serious concerns about a recent court judgment which has the effect of time-limiting reporting restriction orders (RROs). These are legal restrictions on the ability to identify persons or organisations involved in a court case publicly – when previously they were of indefinite duration. Concerns centred around fears of targeting, reprisals and abuse, as well as anxieties about jeopardising the safety of other children being cared for by healthcare teams.

“ Hospital staff may also experience a sense of powerlessness if matters do go to court. Almost always there is a long delay. Generally, staff are not allowed to talk to the press and cannot thereby limit misinformation. Sadly, they may not experience understanding and support from their employers. A recent Court of Appeal judgment ([2023] EWCA Civ 331) ended life-long anonymity protection for doctors in medical cases including controversial end-of-life scenarios. Decisions made around end-of-life care for critically ill children are nuanced. Even trained professionals may struggle to grasp their complexities, let alone newspaper editors and online platform gatekeepers.
Christian Medical Fellowship, call for evidence response

Our previous literature review found “that courts are the least satisfactory method of dispute resolution due to their cost and adversarial nature, which can irreparably damage the relationship of trust between families and healthcare professionals,” and that existing literature did “not address how court proceedings could be altered to overcome these problems”.⁴⁶

46. Bhatia N (2018) *Disagreements in the care of critically ill children: emerging issues in a changing landscape*, available at: <https://www.nuffieldbioethics.org/publications/disagreements-in-the-care-of-critically-ill-children/literature-reviews>.

The role of the Children's Guardian

We heard from parents that the role of the Children's Guardian – a social worker appointed to represent the interests of the child in court – was not always explained or introduced tactfully, resulting in confusion about what could be expected from such a role and a lack of clarity around how to raise concerns about them. Some parents we spoke to felt that the Children's Guardian (and CAFCASS, for whom Children's Guardians work) was biased.

“ CAFCASS – you need to mention that they are seen as for the child, but I don't think they are for the child. They just capitulate all the time, blockade for the trust.
Parent

RECOMMENDATION: 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.

Non-traditional court models

We received new evidence in support of the use of non-traditional court models, such as those from the Family Drug and Alcohol Court (FDAC), in family court proceedings more generally. FDACs are an “alternative family court for care proceedings [...] designed to work with parents who struggle with drug and alcohol misuse”.⁴⁷ Judges and a team of multidisciplinary professionals meet informally and work closely with parents, with a holistic view towards other difficulties they may be experiencing. FDAC focuses on solving the problems that have led the local authority to bring the parent to court, and ultimately make a recommendation to the Local Authority and court on the parent(s) fitness to safely care for their child.⁴⁸

We were told that the FDAC model allowed for parents to build a relationship with judges, by having access to one-to-one meetings with them to discuss issues connected to their case without lawyers present and outside of scheduled hearings. We were also told that the court environment can be less imposing than a traditional court as a result of parties all being positioned at the same level (such as being seated around a table) and with judges and lawyers wearing less formal attire than the traditional wigs and gowns.

Benefits of the FDAC model were said to be potential cost-savings, greater transparency, a less intimidating environment than a traditional court, as well as positive feedback from families who had been party to proceedings, who described feeling that outcomes were fair even where decisions had not been what they wanted.

“ There is strong qualitative evidence that FDAC provides a more humane, compassionate and procedurally fair court process, with the relationship between the judge and the parents playing a particularly powerful role. Parents talk to the judge, are listened to, offered choices [...] Experiencing the court process as fairer is likely to be the reason why fewer FDAC cases are legally contested at the end of proceedings where parents do not have their children returned.
Centre for Justice Innovation, call for evidence response

“ I have never heard parents speak so openly in court... You see them build a relationship with the judge.
Local Authority Social Worker quoted in Centre for Justice Innovation call for evidence response

Whilst elements of non-traditional court models such as FDAC seem to allow for a more collaborative

47. FDAC (2023) *What is FDAC*, available at: <https://fdac.org.uk/what-is-fdac>.

48. *ibid.*

resolution process and may be welcomed by parents involved in disagreements about the care of their children, there is limited evidence available at present about their transferability to other contexts than those in which they are currently used. This was affirmed by our literature review. Further research in this area would be useful to fill this gap in knowledge and to determine whether any of the benefits of non-traditional models can be realised by parents involved in disagreements court cases.

RECOMMENDATION: 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.

LEGAL AID

Our 2019 briefing note⁴⁹ outlined that action required was by those responsible for national policy making in relation to healthcare around the provision of financial support, such as legal aid, for parents involved in legal disputes with hospitals. Although legal aid might be available to some families, the provision was means tested, excluding a significant number of parents from support in an already difficult time. The cost of legal action, and the effects this has on families was highlighted to us in our parent interviews.

Since the publication of our briefing note, a review was undertaken by the UK Government to address legal aid means testing. In May 2023 the UK Government responded to this consultation, stating that means testing of legal aid would be removed for three areas of civil legal aid: “civil representation for under-18s, civil representation for parents or those with parental responsibility facing the withdrawal of life-sustaining treatment from their child, and legal help for inquests involving a potential breach of rights under the European Court of Human Rights (within the meaning of the Human Rights Act 1998) or where there is likely to be a significant wider public interest in the individual being represented at the inquest”.⁵⁰

As these changes will come into force by 2025, we have not included their recommendation in the report. We welcome this revision however, and recognise the benefit it will have to families where disagreements do arise, and court action is necessary.

49. Nuffield Council on Bioethics (2019) Disagreements in the care of critically ill children, available at: <https://www.nuffieldbioethics.org/publications/disagreements-in-the-care-of-critically-ill-children/briefing-note>.

50. UK Government, ‘Government Response to Legal Aid Means Test Review’ (2023), available at: <https://www.gov.uk/government/consultations/legal-aid-means-test-review/outcome/government-response-to-legal-aid-means-test-review--3>.



Recommendations

In light of the findings detailed and conclusions drawn in this report and the conclusions drawn as part of our previous briefing note, we make a number of recommendations which we believe will either help to:

- **avoid disagreements arising;**
- **resolve them more quickly, collaboratively and compassionately where they cannot be avoided;**
or
- **ensure they have less of an adverse impact on all involved.**

As highlighted earlier, some level of disagreement between persons is both inevitable, and to a certain extent, desirable in a functioning society, and so we have not sought to avoid differences of opinion completely.

We worked with an expert group to develop our recommendations. This group's membership included parents and healthcare professionals with direct experience of disagreements as well as researchers and other professionals working to support unwell children and their families. Details of the expert group and its membership can be found at Annex 2.

The changes we recommend will help to reduce the frequency of disagreements arising and, where disagreements do still arise, ensure they are less difficult for those involved. The recommendations represent a 'first step' in making things better for children, their families and the healthcare teams looking after them, and will need to be implemented alongside further collaboration, research and discussion of the issues arising.

Our recommendations are targeted at various individuals, authorities and organisations, and focus on filling gaps in evidence; facilitating continuous improvement; improving information sharing; promoting a supportive and collaborative culture, and ensuring consistency and fairness. All of our recommendations need to be addressed together to improve the experience of disagreements for both parents and healthcare professionals, and our first recommendation – focused on overseeing the implementation of the remaining recommendations – will be particularly crucial in achieving this.

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.

Recommendations 11-13

Promoting a supportive and collaborative culture

- 11.** Healthcare professionals in clinical leadership roles should take responsibility for modelling a team culture which recognises and prioritises relationship-building with children and parents as an integral part of providing good holistic care to a child.
- 12.** NHS trusts in England should ensure that their team members are made aware of, supported and encouraged to access a variety of sources of emotional and psychological support.
- 13.** The DHSC taskforce established as part of recommendation 1 should identify an appropriate body to create and publish guidance for healthcare teams that treat children on how to seek information from children and parents about their communication needs and preferences, ensuring all team members are aware of these and are accordingly providing consistent messaging about their child's care and treatment, particularly where the child is under the care of a multi-disciplinary team.

Recommendations 14-16

Ensuring consistency and fairness

- 14.** NHS trusts in England should ensure that protocols are in place to ensure parents requesting access to their critically ill child's medical records are provided, where practicable, with it within a week of the request being made, in the absence of any factors that would prevent disclosure such as lack of consent from a child with capacity or safeguarding issues.
- 15.** NHS trusts in England should inform families within three calendar days of taking the decision to initiate court proceedings in order to give them sufficient time to seek independent legal advice and collate necessary information to disclose to the court.
- 16.** Guidance for clinical ethics committees (CECs) in England should be produced on how to ensure that parents', and where appropriate children's, views are taken into account in CEC discussions and that parents are supported to provide input to CEC meetings. The DHSC taskforce established as part of recommendation 1 should identify who is best placed to produce or commission this guidance.



Annex 1

Nuffield Council on Bioethics executive staff and council members

Council Members

David Archard (Chair)
Muhammed Afolabi
Ruchi Baxi
Carol Brayne (Deputy Co-Chair)
Simon Burall
Victoria Butler-Cole
Melanie Challenger (Deputy Co-Chair)
Clare Chambers
John Coggon
Frances Flinter
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Michael Reiss
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Executive staff

Danielle Hamm (Director)
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Claudia Corradi
Molly Gray
Catherine Joynson (until March 2023)
Richella Logan
Jade Maclure
Sophia McCully (from August 2023)
Natalie Michaux
Allison Milbrath (from March 2023)
Peter Mills (until May 2023)
Rebecca Mussell (from April 2023)
Carol Perkins
Maili Raven-Adams (from May 2023)
Dan Steer (until July 2023)
Jay Stone (from August 2023)
Sarah Walker-Robson

Annex 2

Task and Finish group members

Debbie Finnie

Parent Expert and Social Worker

Carli Whittaker (President) / Patrick Davies (Treasurer)

Paediatric Critical Care Society (PCCS) Council

Emma Nottingham

Reader in Law, University of Winchester; Clinical Ethics Advisory Committee Member, University Hospital Southampton NHS Trust

Fiona Lynch

CNO Senior CYP Nurse Fellow, NHS England

Sally Flatteau Taylor

Founder and CEO, The Maypole Project

Steph Nimmo

Parent Expert, Writer and Together for Short Lives Trustee

Tara Clancy

Honorary Consultant Genetic Counsellor/Senior Lecturer, Manchester; former member of the Nuffield Council on Bioethics

Annex 3

Methodology

The Nuffield Council on Bioethics carried out research activities for this report from February 2023 to August 2023. Each key stakeholder group identified has important but differing evidence to contribute, as well as different needs. Our methodology focused on synthesising existing evidence and gathering perspectives of people with lived and professional experience of these disagreements. We therefore used a variety of research methods to ensure these needs were met and the best possible evidence were obtained from each stakeholder group within the time constraints of the project:

- 1 **Rapid literature review**
- 2 **Open call for evidence**
- 3 **Surveys for professionals**
- 4 **Interviews**
- 5 **Workshops for healthcare professionals**

Inclusion criteria for participation in research:

- Over the age of 18
- Capacity to provide consent to participation in research
- Falling within one of these four categories of participant: families, healthcare professionals, non-clinical professionals, researchers
- Experience of disagreements is within NHS care in England (excepting researchers, where expertise may relate to care in another relevant jurisdiction)

Exclusion criteria for participation in research:

- Subject of, or party to, any active court or professional regulatory proceedings involving the care of a critically ill child, whether in this jurisdiction or others

1. RAPID LITERATURE REVIEW

We commissioned a rapid literature review, Disagreements in the Care of Critically Ill Children: Causes, Impact and Possible Resolution Mechanisms researched and authored by Dr Kirsty Moreton.

The scope of our rapid literature review was designed to build around and update our previous work on the topic of disagreements in the care of critically children: two commissioned literature reviews⁵¹ published September 2018 which, alongside a multi-disciplinary workshop, resulted in a briefing note published in November 2018.

This included literature published between 2017-2023 relating to the causes, impact, and possible resolution processes in disagreements between parents and healthcare professionals about the care of critically ill children. This review focused on examining three questions:

- 1 **What are the causes of disagreements in the care of critically ill children in England?**
- 2 **What is the impact that these disagreements can have on the child, their family, the healthcare professionals, the NHS and wider society?**
- 3 **What are the possible mechanisms for avoiding, recognising, managing and resolving disagreement?**

51. Bhatia N (2018) *Disagreements in the care of critically ill children: emerging issues in a changing landscape*: The review explores key challenges for future legal, social and policy development that emerged from the literature - the role and impact of social media/internet in treatment decisions, innovative treatments, and child medical tourism; Austin L (2018) *UK processes for resolution of disagreements about the care of critically ill children*: The review explores the effectiveness and appropriateness of UK processes for the resolution of disputes about the care of critically ill children, focusing upon five mechanisms for resolution - discussions between families and clinicians, second-opinion experts, clinical ethics committees, mediation, and court proceedings.

2. CALL FOR EVIDENCE

We ran an open call for evidence for 10 weeks from 15 February to 28 April 2023 to inform the design of our subsequent research and ensure that everyone who wanted to contribute their evidence had the opportunity to do so. We received a total of 38 unique submissions, and analysed their contents through thematic coding. The list of respondents to the call for evidence can be found in Annex 3.

We welcomed submissions up to 3,000 words to update and improve our understanding of the areas identified in our [policy briefing note](#), namely:

- **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.

And to introduce new evidence regarding:

- **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;

- **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.

3. SURVEYS FOR PROFESSIONALS

We ran two surveys for nine weeks over April to June 2023 to capture professionals’ perspectives and direct expertise about disagreements in the care of critically ill children. One was aimed at members of healthcare professionals. The other sought to capture professional experiences of disagreements outside of the clinical setting, such as those working in charities, mediation, social work, non-clinical patient services, and similar, which resulted in 280 responses and 20 responses, respectively.

The surveys asked primarily closed questions in a mix of question types with two qualitative short responses. This design aimed to balance the limited time of professionals and high number of interested respondents, to ensure all who want to contribute could do so whilst keeping analysis manageable within the time available. Members of treating teams had the opportunity to contribute further and elaborate on emerging key themes in two workshops held in June 2023. The survey questions can be found in Annex 6.

4. INTERVIEWS

Direct narratives from parents and family members of critically ill children or children with life-limiting conditions is largely absent from published evidence. To reflect the importance of families lived experience and create a more balanced evidence base on which to develop recommendations, the research team conducted 8 semi-structured, in-depth interviews with 10 parents who had experienced disagreements with healthcare professionals about the care of their child. Interviews were conducted over June and July 2023, and scheduled for about 90 minutes with flexibility depending on the amount a parent wished to discuss.

Research was designed in part to facilitate the obtaining of narrative evidence, focusing on personal experience of disagreements in the care of their child and how they think disagreements might be managed or resolved more quickly and sensitively (evidence which is largely absent from published literature, despite families being an obvious key stakeholder in such disagreements). It is also to ensure that the provision of evidence on such emotive topics as critical care, illness, and death of a child can be managed appropriately, allowing participants to have greater control over the interview's direction and therefore avoid unnecessary distress. Conducting interviews with families also provides a route for obtaining rich evidence in the absence of time to obtain statistically significant data.

The information sheet and interview question guide, found in Annex 8, were drafted in accessible language and carefully in recognition of the sensitivity of the subject matter, and we obtained input and final approval of these from a trusted charity, Together for Short Lives, with experience of supporting families with critically ill and life-limited children. Information sheets were provided to potential participants at least 7 days in advance of the interview date. Interviews were conducted in person where possible, but were available online depending on the needs and preferences of the participant. Interviews were conducted in private, neutral locations.

We shared the opportunity for family members to

express their interest in an interview indirectly through third party organisations like Together For Short Lives. Our approach to recruitment involved promoting our work via charitable organisations that support children, parents, and families, such as Together for Short Lives, in recognition of the sensitivity of the subject matter and the potential for causing unintended distress or pressure resulting from a direct approach.

We also had the benefit of including in our analysis anonymised interview transcripts of four parents and five healthcare professionals conducted by the Medical Mediation Foundation's (MMF) and shared with the participants' informed consent. These interviews examined the impact of disagreements and potential usefulness of early conflict recognition and training. All interviews were anonymised, transcribed, and then analysed thematically.

5. WORKSHOPS

Two workshops for healthcare professionals were held in June 2023 to explore the themes emerging from the survey results more deeply. To ensure appropriate geographical distribution of attendees, we held one in the north of England and one in London with nine and seven attendees respectively. This smaller sample size of treating team members allowed for robust discussion on a number of sensitive topics.

The workshops were chaired and small discussions facilitated by the research team with notetaking undertaken by other Council staff members. Workshops were not recorded to ensure participants felt safe and comfortable sharing honestly.

Annex 4

Literature review

The literature review we commissioned to inform our work, 'Disagreements in the Care of Critically Ill Children: Cases, Impact and Possible Resolution Mechanisms' can be [found here](#). This was researched and authored by Dr Kirsty Moreton, who is an Associate Professor in Law at the University of Birmingham.

Annex 5

Call for evidence respondents

INDIVIDUALS

Alice Cavolo, PhD, Center for Biomedical Ethics and Law, KU Leuven; Chris Gastmans PhD, Center for Biomedical Ethics and Law, KU Leuven

Alison Taylor, Registered Nurse (Child) & Senior Lecturer for BSc Nursing, University of Brighton

Professor Dominic Wilkinson, Consultant Neonatologist, John Radcliffe Hospital

Dr Emily Harrop, Consultant in Paediatric Palliative Care, Helen & Douglas House, Oxford University Hospitals

Professor John Wyatt, Emeritus Professor of Neonatal Paediatrics, University College London

Dr Clare Bell, Stoke Mandeville Hospital;
Dr Joe Brierley, University College London Paediatric Bioethics Centre, Great Ormond Street Institute of Child Health, NIHR Great Ormond Street Hospital Biomedical Research Centre;
Dr Mariana Dittborn, University College London Paediatric Bioethics Centre, Great Ormond Street Institute of Child Health, NIHR Great Ormond Street Hospital Biomedical Research Centre

Lord Richard Balfe, House of Lords

Lord Phillip Hunt, House of Lords

Professor Julian Savulescu, Director of the Centre for Biomedical Ethics, National University of Singapore

Margaret Doyle, Visiting Fellow at the University of Essex School of Law; Jaime Lindsey, Associate Professor of Law, University of Reading; Katarzyna Wazynska-Finck, Senior Research Officer, University of Reading

Professor Maria Brenner, Professor of Children's Nursing, University of Dublin School of Nursing and Midwifery

Dr Neil Snowise, Visiting Senior Lecturer, King's College London School of Cancer & Pharmaceutical Science

Paula Parfitt

Professor Raanan Gillon, Emeritus Professor of Medical Ethics, Imperial College London

Dr Raj Mohindra, Consultant Cardiologist South Tyneside and Sunderland NHS Foundation Trust

Dr Richard Hain, Consultant in Paediatric Palliative Care & Clinical Ethicist, All-Wales Paediatric Palliative Care Network; Honorary Professor of Medical Ethics, Swansea University

Dr Tutku Ozdogan, Associate Professor of Pediatrics, Istanbul Arel University Faculty of Medicine

Dr Sarah Sivers, Associate Dean for Research, The Law School, Robert Gordon University

Anonymous Respondent 1

Anonymous Respondent 2

Anonymous Respondent 3

Anonymous Respondent 4

Anonymous Respondent 5

ORGANISATIONS

Anscombe Bioethics Centre

Bios Centre

Centre for Effective Dispute Resolution (CEDR)

Charlie Gard Foundation

Christian Concern

Christian Medical Fellowship

Centre for Justice Innovation

Confident Conversations

Demos

**Great Ormond Street Hospital (GOSH) Paediatric
Bioethics Centre**

**Newcastle upon Tyne Hospitals NHS Foundation
Trust**

**The National Institute for Health and Care
Excellence (NICE)**

Paediatric Critical Care Society (PCCS)

**Royal College of Paediatrics and Child Health
(RCPCH)**

Together for Short Lives (TFSL)

Annex 6

Surveys of professionals

SURVEY FOR HEALTHCARE PROFESSIONALS

Page 1: About your role

Knowing what your role is and where in England you work, or were working at the time of your experiences, will help us to identify if there are any differences in experience between roles and regions.

- 1 Which category best describes you? If you hold more than one role, please choose the option that best describes the role in which you have had the most experience of disagreements about the care of critically ill children.

District nurse or other community-based nursing role
Paediatric intensivist or other doctor working in PICU/NICU (any grade)
Paediatric critical care nurse or other nurse working in PICU/NICU (any grade)
Other healthcare professional working in PICU/NICU (including physiotherapist, psychologist, physician associate, nursing associate, occupational therapist, healthcare assistant)
Paediatrician or other doctor working in paediatrics (non-critical care, any grade)
Paediatric nurse (non-critical care, any grade)
Palliative care doctor (any grade)
Palliative care nurse (any grade)
Doctor working in the emergency department (any grade)
Nurse working in the emergency department (any grade)
General practitioner
Other (please specify)

- 2 Which region of England do you work in or did you work in at the time of your experiences? If you work across multiple regions, please choose the region where you do most of the work in the role identified above.

East of England
London
Midlands
North East and Yorkshire
North West
South East
South West

Page 2: Your experiences of disagreements about the care of critically ill children

We would like to know about how often you have seen disagreements happen, how much time you spend on them, and what factors you think influence them.

- 3 How often, in your experience, do new disagreements arise between parents and healthcare professionals about the care of critically ill children? By disagreements, we mean breakdowns of communication or differences of opinion between families and healthcare professionals that cannot be immediately resolved.

More than once a week
Weekly
Monthly
Quarterly
Less than quarterly

- 4 How much time do you spend on navigating, managing or resolving disagreements about the care of critically ill children?

A lot (at least some time each week)
Some (at least some time every 2-3 weeks)
Not much (at least some time every month)
Very little (less than monthly)

- 5 Please rate the following factors according to their influence on disagreements about the care of critically ill children. *Response options: High impact, Medium impact, Low impact, No impact*

Mismatch of expectations about what can be done for a child medically
Communication issues between families and professionals
Differences in belief about quality of life, end of life, decision-making and other values (religious or non-religious)
Distrust of healthcare professionals and/or the NHS
Third parties becoming involved (via media/social media or otherwise)
Desires for alternative or experimental treatments not available in England
Disagreements between staff members about proposed care or treatment

Page 3: When disagreements escalate

In this section, we want to know more about what happens when disagreements about the care of critically ill children become more challenging to navigate, manage or resolve. This would include **ANY** challenging disagreement about the care of a critically ill child, including those that are escalated to court for a decision.

6 Have you ever been involved in a disagreement that has had to be escalated to a third party for resolution, such as the courts or mediation services?

Yes, more than once
Yes, once
No

7 Have you ever felt unsafe, either physically or emotionally, at work because of a disagreement with a family about the care of a critically ill child?

Yes
No

8 In relation to the impact that your involvement in disagreements about the care of critically ill children has had on you, do you agree or disagree with the following statements? For a definition of moral distress/injury see [here](#).

I have experienced moral distress and/or moral injury
I practise my profession more defensively
My team is closer after working together to resolve disagreements
I have a better understanding of families' perspectives and priorities
I have little, or less confidence in my communication skills
I feel anxious about coming to work
I am better at dealing with unexpected events/outcomes
I am considering, or have considered, leaving my job or my profession
I am worried about reprisals on me and/or my family, friends and colleagues
Morale is low in my team
I have undertaken, or want to undertake, further training to be better equipped to deal with disagreements
My colleagues and/or I have been misrepresented in the media or on social media
I have little, or less confidence in my clinical skills
I would like to share my story but am constrained by my professional responsibilities
I can recognise when I need emotional support more easily and give myself time and space to process my feelings
I feel there is less trust in healthcare professionals generally
I do not think disagreements with families can be avoided
I am confident in how to assess and identify what is in a child's best interests
My physical and/or mental health has been impacted
There is tension or division in my team/between staff as a result of our experiences
I share more information with families than I used to

9 When a disagreement about the care of a child escalates, where do you receive support from? Please select all that apply.

My team/ colleagues
Senior clinicians
Employee support services
Counselling services not connected to work
NHS Trust
Other (please specify)

10 Have you or your team been subject to comments, criticism or other coverage in the media or on social media as a result of a disagreement about a critically ill child?

Yes
No

Page 4: Good practice in resolving and managing disagreements

We know that many healthcare professionals across the country are doing their part to ensure that disagreements about the care of critically ill children run more smoothly and are resolved amicably so that all voices are heard. We would therefore like to know about what you have found helpful in resolving such disagreements, or what you would find useful if it was available to you.

11 Have any of the following been helpful to you in navigating, managing or resolving disagreements about the care of critically ill children, or do you think they would be useful to you if they were available?

Conflict resolution training
Other communications training
Advice from a clinical ethics committee/clinical ethics network
Ethics training
Mediation
Dedicated staff to liaise with families (such as Family Liaison Nurses)
Support from senior staff
Support from management/hospital trust
Counselling and/or other emotional support
Accessible information for families about their options when they disagree with healthcare professionals
Accessible information for families about their child's illness/condition
Decision-making tools or frameworks
Early involvement of palliative care services
Families having access to their child's clinical records
Seeking second opinions

Response options for each are as follows:

- Very helpful
- Somewhat helpful
- Unhelpful
- Very unhelpful
- I have not used this/don't have access to this, but think it **would be** helpful
- I have not used this/don't have access to this, but think it **would not be** helpful

Page 5: Optional short response questions

Please limit your answer to 50 words max. Any additional words will not be taken into consideration.

- 12** Is there anything you or your team does that is particularly helpful in de-escalating or resolving disagreements with families about the care of critically ill children? Please provide a short description (50 words max). **Please ensure you do not reveal any identifiable confidential information about patients, past or present, or their families.**
- 13** In your opinion, and based on your experience, what would make the most difference in reducing the frequency and impact of disagreements about the care of critically ill children? (50 words max) **Please ensure you do not reveal any identifiable confidential information about patients, past or present, or their families.**

SURVEY FOR NON-CLINICAL PROFESSIONALS

Page 1: About your role

Knowing what your role is and where in England you work, or were working at the time of your experiences, will help us to identify if there are any differences in experience between roles and regions.

- 1 Which category best describes you? If you hold more than one role, please choose the option that best describes the role in which you have had the most experience of disagreements about the care of critically ill children.

Charity worker
Chaplain
Other spiritual, pastoral or religious advisor
Hospice worker or other palliative care worker (non-clinical)
Journalist
Mediator
Patient advocate, support worker or representative (non-legal)
Social worker
Solicitor or barrister
Other (please specify)

- 2 Which region of England do you work in or did you work in at the time of your experiences? If you work across multiple regions, please choose the region where you do most of the work in the role identified above.

East of England
London
Midlands
North East and Yorkshire
North West
South East
South West

Page 2: Your experiences of disagreements about the care of critically ill children

We would like to know about your involvement in disagreements between families and healthcare professionals about the care of critically ill children, and what factors you think influence these disagreements.

- 3 How often do you encounter new disagreements about the care of critically ill children in the context of your role?

Very often (once a month or more)
Sometimes (once a quarter or more)
Infrequently (once a year or more)
Occasionally (less than once a year)

- 4 Please rate the following factors according to what you think their influence is on disagreements about the care of critically ill children. *Response options: High impact, Medium impact, Low impact, No impact*

Mismatch of expectations about what can be done for a child medically
Communication issues between families and professionals
Differences in belief about the quality of life, end of life, decision-making and other moral values (religious or non-religious)
Distrust of healthcare professionals and/or the NHS
Third parties becoming involved (via media/social media or otherwise)
Desires for alternative or experimental treatments not available in England
Disagreements between staff members about proposed care or treatment

Page 3: When disagreements escalate

In this section, we want to know more about what happens when disagreements about the care of critically ill children become more challenging to navigate, manage or resolve. This would include **ANY** challenging disagreement about the care of a critically ill child, including those that are escalated to court for a decision.

- 5 In your experience and/or understanding, when disagreements about the care of critically ill children escalate, what are the main challenges for families? *Please rank the following (1=most challenging, 7=least challenging)*

Financial impact of legal fees and other costs associated with court action
Media attention, including social media
Feeling the need to do everything possible for their child
Lacking control over decision-making for their child
Not having access to the information they want/need about their child's condition
Non-financial impact of going to court, for example the emotional impact
Feeling that their views, needs and experiences as a parent are not adequately taken into account

- 6 In your experience and/or understanding, when disagreements about the care of critically ill children escalate, what are the main challenges for healthcare professionals? *(1=most challenging, 7=least challenging)*

Providing care or treatment that they think is not in the child's best interests
Media attention, including social media
Disagreement/disharmony within the clinical team
Going to court and giving evidence
Being limited in how they can respond to criticism because of duty of confidentiality
Lacking training in how to handle disagreements
Disagreement/disharmony with families whilst providing care

- 7** With your experience in mind, how much do you agree or disagree with the following statements? *Response options: Strongly agree, Agree, Neither agree nor disagree, Disagree, Strongly disagree*

I do not think disagreements about the care of critically ill children can be avoided
The ways that disagreements are resolved work well in the majority of cases
There is a public interest in being able to talk about disagreements about the care of critically ill children generally
Most disagreements are caused by communication problems

Page 4: Good practice in resolving and managing disagreements

We know that efforts are being made to try to resolve disagreements about the care of critically ill children more quickly, collaboratively and compassionately. We would like to know your thoughts on how helpful different approaches are, or might be.

- 8** To your knowledge, have any of the following been helpful in navigating, managing or resolving disagreements about the care of critically ill children, or do you think they would be useful if they were available?

For healthcare teams and/or families...

Conflict resolution training
Other communications training
Advice from a clinical ethics committee/clinical ethics network
Ethics training
Mediation
Dedicated staff to liaise with families (such as Family Liaison Nurses)
Support from senior staff
Support from management/hospital trust
Counselling and/or other emotional support
Accessible information for families about their options when they disagree with healthcare professionals
Accessible information for families about their child's illness/condition
Decision-making tools or frameworks
Early involvement of palliative care services
Families having access to their child's clinical records
Access to second opinions

Response options for each are as follows:

- Very helpful
- Somewhat helpful
- Unhelpful
- Very unhelpful
- I have not used this/don't have access to this, but think it **would be** helpful
- I have not used this/don't have access to this, but think it **would not be** helpful

Page 5: Optional short response questions

Please limit your answer to 50 words max. Any additional words will not be taken into consideration.

- 9** Is there anything that would help you to better fulfil your professional role in relation to disagreements about the care of critically ill children? (50 words max) **Please ensure you do not reveal any identifiable confidential information about patients, past or present, or their families.**
- 10** In your opinion, and based on your experience, what would make the most difference in reducing the frequency and impact of disagreements about the care of critically ill children? (50 words max) **Please ensure you do not reveal any identifiable confidential information about patients, past or present, or their families.**



Annex 7

Independent review: Disagreements in the care of critically ill children

NUFFIELD
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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?



52%
said **monthly**
or more often*

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



78%
said at least
some time
each month



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...



49%
said they **have felt unsafe**,
either physically or
emotionally, at work



45%
said they **have been subject to**
comments, criticism or other coverage
in the media or on social media

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

Contact: children@nuffieldbioethics.org

Survey: 280 England-based healthcare professionals, May-June 2023

*Full survey data to follow within the final report

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?



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:



What would be helpful if it were available?



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

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 2023.

- @Nuffbioethics
- NuffieldBioethics
- children@nuffieldbioethics.org



Annex 8

Parent interview guide

Questions in bold were asked in every interview for consistency, others were included as relevant and appropriate. Questions were not asked in the listed order, but followed the flow of conversation.

Relationships

Tell me about the relationships you had with the healthcare professionals treating your child? [Further prompts/follow-ups if needed/relevant: did you feel labelled? How did the way they spoke to you affect how much you trusted them?
How did [that] impact on your relationships with family and friends?
Where did you get emotional support from during this difficult time?
What was good and what was not so good about the way that you were spoken to?

Information

Do you feel you had/have a good understanding of your child's medical condition?
What was your understanding of what care and treatment would be given to your child, and how much it would help them?
Were you given access to your child's medical records? (Would you have wanted this/do you think this would have been helpful?)
Would you have liked more information about the treatment that could be given to your child, and how much it would help them? [follow-up if prompt needed: what kind of info would have been helpful – conversations with staff, written info etc]
What resource did you find most useful to find out more about your [child's name] condition? (if so – what did you find, was it helpful?) [Follow-up if relevant: did you consider having your child treated overseas?]
Did you look online for help and support about how to resolve the disagreement(s) with healthcare professionals? (if not – do you think this would be helpful?)

Parental role and feeling heard

How involved were you with making decisions about your child when they were in hospital?
Do you feel that you were listened to by the healthcare professionals looking after your child? Did they take what you said about your child seriously? [Follow up: what does that feel like when you are and aren't)
Had you spent much time in hospital before your child was there? What was the environment like – were you comfortable there? [Follow-up if appropriate: do you think anything could have made it more comfortable for you and your child – privacy, quiet, décor etc]
Were you invited to any meetings with healthcare professionals where your child's care and treatment was discussed?
[If media involved] What are your thoughts and feelings about how your child's care was covered by the media?
[If social media involved] Did you find social media interest helpful? Were there any downsides?

Resolutions

Can you tell me about your experience of trying to resolve the situation?
When and how did you find out that you would need to go to court to resolve the disagreement? How did that feel?
Did you understand what you needed to do, and how to do it, in relation to court proceedings? [Prompts: getting legal representation, giving evidence to the judge, what information the court would need from you to make a decision]
Did you try mediation to resolve the disagreement? [If yes: what was it like, effectiveness, etc; if no: was it offered, would you have taken it up if so]
Tell me about your experience at court? [follow-up: what would have helped, what was not useful, other resolution mechanisms, positive elements to a negative experience overall...]
If you could make changes to the court process to make it easier for other families in a similar position to you, what would they be?
[If no court] Did the disagreement(s) get resolved in a way that you were happy with?
If you had to give a message, or advice, to healthcare professionals as a result of your experiences, what would that be?

Annex 9

Workshop topic guide

LONDON WORKSHOP TOPIC GUIDE

Session 1: Impacts – what impacts how disagreements play out, and what are the impacts of disagreements on healthcare professionals?

TOPIC Safety – almost half of HCPs surveyed to date have felt unsafe at work, either physically or emotionally, as a result of disagreements	TOPIC “Mismatch of expectations about what can be done for a child medically” having a high impact on disagreements (source: our survey data to date)	TOPIC Impacts of personal involvement in disagreements from survey data expressed by respondents – re: decision-making and trust
<p>Questions/prompts for discussion:</p> <ul style="list-style-type: none"> • Can you, or could your colleagues, relate to these feelings of being unsafe? • Does ‘feeling unsafe’ at work extend to feeling that your professional status is also unsafe (i.e. you are left open to disciplinary, legal or professional regulatory action)? • Do you have any examples of how, and why, you or your colleagues felt unsafe as a result of disagreements? Have these had a longer-term impact? 	<p>Questions/prompts for discussion:</p> <ul style="list-style-type: none"> • What are the mismatched medical expectations that you’ve seen/heard about? • How and why do they happen? Where do they come from? • If you’ve experienced this, at what point did you realise that the family’s expectations and yours weren’t aligned? How did it feel? • How do families respond to mismatches of expectations? • What was the impact on you when there are mismatches to expectations? • How often does such a mismatch happen, even if on quite a small scale or resolvable quickly and easily? 	<p>Questions/prompts for discussion:</p> <ul style="list-style-type: none"> • Less than half of respondents to date have said they are confident in how to assess what’s in the best interests of a child...does this surprise you? • (linked to above) why do you think there is a lack of confidence in assessing what’s in a child’s best interests? • Majority of respondents feel there is less trust in HCPs generally – why do you think people feel this way? Have you any examples you’d like to share that illustrate this?

Session 2: Good practice – what helps, or might help, to resolve disagreements so that some of the more serious impacts can be avoided? What are the barriers to resolving them more quickly, collaboratively and compassionately?

<p>TOPIC Palliative care</p>	<p>TOPIC Communication and information provision</p>	<p>TOPIC External mechanisms for resolution outside the HCP-family relationship</p>
<p>Questions/prompts for discussion:</p> <ul style="list-style-type: none"> • Do you think earlier access to palliative care would be helpful in resolving/preventing disagreements? For whom/ which party? Why? • What are the barriers to an earlier introduction of palliative care? • (if misperceptions comes up) What do you think would be effective in challenging misperceptions? 	<p>Questions/prompts for discussion:</p> <ul style="list-style-type: none"> • What communications tools/ techniques have you seen/ used that have been effective in mitigating disagreements, and why? • Does it/would it help to have dedicated expert staff (such as Family Liaison Nurses) to communicate with and provide info to families? Why/why not? • Would it be helpful for families to have access to their child’s clinical records? Do you think this would have an impact on disagreements and their severity? 	<p>Questions/prompts for discussion:</p> <ul style="list-style-type: none"> • Clinical ethics committees vary in structure, composition and scope – have you experience of them? Are they helpful? If so – how? If not – what needs to change to ensure they are helpful? • Should parents be involved in clinical ethics cttee meetings? Why/why not? • Is it helpful to get a second clinical opinion? Does it help both you and the family? Why?

MANCHESTER WORKSHOP TOPIC GUIDE

Session 1:

TOPIC Disagreements as inevitable?	TOPIC Communication issues being a key influence on disagreements happening
<p>Questions/prompts for discussion:</p> <ul style="list-style-type: none"> • Why do you think HCPs feel that disagreements with families cannot be avoided? • In your experience, could some of the disagreements you/colleagues have encountered have been avoided? Why/why not? • Are there any barriers to disagreements being avoided or resolved more easily? What are they and why do they have such an impact? 	<p>Questions/prompts for discussion:</p> <ul style="list-style-type: none"> • ‘Communication issues’ are often highlighted as a major trigger for disagreement/complaint across healthcare more generally – but what are these issues? Are they specific behaviours, styles, words used – or something else? • Survey respondents told us that comms issues are a problem but that they themselves largely have confidence in their communication skills – what do you think this means? • Are there people in your team that are particularly good communicators and are relied upon to communicate about difficult topics or have tough conversations?

Session 2:

TOPIC Support mechanisms	TOPIC Accessible information provision
<p>Questions/prompts for discussion:</p> <ul style="list-style-type: none"> • Almost a quarter of survey respondents tell us that they have not used counselling and/or other emotional support but that it would be helpful in navigating and resolving disagreements if it were available – what, in your view, are the reasons for this not being accessed? • How do you think accessing emotional support might be encouraged? • Support from management and the hospital trust is seen as being less helpful than that of senior colleagues – why do you think this is? • What would ‘good support’ look like, from all angles, for a colleague going through a disagreement? 	<p>Questions/prompts for discussion:</p> <ul style="list-style-type: none"> • When you need to provide information to families about their child’s illness/condition, how do you do this? Are there any resources that you rely on to help? • Do you think there should be more accessible information available for families about their child’s condition? What format should it take? Who is best placed to create/provide it? • What about accessible information for families about their options when they disagree with HCPs? • Are there any circumstances in which you think provision of further information would be unhelpful? Why?

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