UNIVERSITY OF
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Resolving Health Disputes Out of Court: A Policy Paper

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Executive Summary

This policy paper focuses on out-of-court resolution of disputes between healthcare professionals (HCPs), patients, and family members in the context of medical care and treatment for adults and children. While disagreements can be a common feature of healthcare decision-making, they can, in some cases, escalate into more serious disputes that culminate in judicial resolution. The personal and financial costs of court action, for all parties involved, have led to calls for consideration of alternative ways to resolve these disputes. This policy paper draws on discussions from a symposium held in March 2026 at the University of Oxford to consider how policy and practice in this area might be developed.

The paper focuses on four main themes: second opinions, Clinical Ethics Committees (CECs), mediation, and resources. Across these themes, a number of cross-cutting issues emerge, particularly relating to communication, trust, access to information, and organisational culture within healthcare settings. Participants' experiences suggest that these factors can play an important role in shaping how disagreements arise and develop. Addressing these cross-cutting issues is therefore essential when considering approaches to resolving healthcare disputes.

The paper sets out a series of recommendations aimed at supporting earlier and more effective management of disputes before cases reach the Family Court (for children) or Court of Protection (for adults). These include:

- Recommendation 1: Trusts or DHSC should develop (or publish if already prepared following the NCOB review) an online package of resources to provide advice and signposting support for next steps for families and patients outlining options when disputes arise with healthcare teams regarding medical care and treatment.
- Recommendation 2: DHSC should provide a package of support for NHS Trusts to help them to resolve disagreements out of court, including funding for communication/mediation training, CECs, independent mediation, and second opinions.

- Recommendation 3: NHS trusts should put in place protocols to ensure patients and families are given access to medical records, where practicable, within a week of the request being made, in the absence of any factors that would prevent disclosure such as lack of consent from the patient with capacity or safeguarding issues.
- Recommendation 4: Families and patients should have access to independent advocacy where challenging best interests decisions of HCPs.
- Recommendation 5: Family members should have a right to obtain an independent second opinion where there is a best interests disagreement, funded by the relevant NHS body. This right could be implemented based on a similar principle to Martha’s Rule and DHSC should investigate this option.
- Recommendation 6: The DHSC should develop a standard process for use in commissioning second opinions where funded by the NHS commissioning body.
- Recommendation 7: All experts providing a second opinion, whether overseas or from within the UK, NHS or private, should complete a standard declaration form and provide information on qualifications, experience, relevant expertise, and any potential conflict of interest.
- Recommendation 8: Government should provide funding for the work of CECs, either at a local level or via a network such as the UKCEN. This funding should include support for the CEC itself to operate and support for patients and families to understand the process and their role in it.
- Recommendation 9: DHSC should develop nationally consistent and impartial information about what CECs are and how they work, which should be developed alongside and be accessible to families and patients.
- Recommendation 10: DHSC should develop a national practice model (possibly based on the UKCEN model) with various options in a toolkit to be responsive to local practice and individual case considerations. These options should include mechanisms for directly involving patients and their families in all CEC meetings where they want to take part.

- Recommendation 11: Any guidance/practice models should provide the option for family members, patients and HCPs to participate directly in all CECs where they wish to do so, albeit this could be in separate parts of the meeting rather than attendance at the full meeting, dependent on local practice and individual case considerations.
- Recommendation 12: DHSC should commission research and monitoring of how CECs operate and work for families and HCPs.
- Recommendation 13: NHS Trusts and families should consider use of independent mediation before proceeding to litigation, except in emergencies. There should be no requirement on family members or HCPs to mediate, only the requirement to consider mediation.
- Recommendation 14: Commissioners should fund independent mediation and should include funded legal and advocacy advice for families taking part in mediation.
- Recommendation 15: Independent mediation should generally be attempted before proceedings are issued.
- Recommendation 16: Independent mediation should be carried out by an experienced mediator, independent of the Trust, with no prior links to either party involved in the disagreement, and by mutual agreement between the parties to the dispute.
- Recommendation 17: NHS Trusts (or other healthcare bodies involved in a dispute) should give information to all parties before taking part in mediation, to help them understand the mediation process and their role in it and to make informed decisions as to whether to take part. This should include anonymised case studies, which should be produced by mediation providers.
- Recommendation 18: All of the above should be contained in DHSC-commissioned national guidance to ensure greater consistency regarding mediation's use across England and Wales.
- Recommendation 19: DHSC should provide funding to support the various recommendations above, specifically for:

- An online package of information resources for families about disputes within the NHS and their options and rights regarding resolution and litigation processes;
- Resources for Trusts to invest in conflict reduction training/processes;
- Families to commission independent second opinions;
- Support to develop CECs nationally;
- The provision of independent mediation in all cases where the family and the HCPs agree to use it;
- The provision of legal advice for families when accessing mediation.

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1 Introduction

This policy paper aims to set out recommendations on resolving disputes between HCPs, patients and their families. Disagreements in such settings are not uncommon and can involve a range of decisions regarding treatment and care, end-of-life, and everyday clinical decisions about healthcare for children and adults. In some circumstances, disagreements can lead to distrust and antagonism and escalate into disputes which reach court. We explore disputes about ongoing care and treatment for adults and children, but we note that disagreements can also arise retrospectively, and it is important to consider how complaints processes respond to concerns, albeit that is not our focus here. The interest in alternatives to litigation for healthcare disputes is reflected in the emphasis placed by NHS Resolution on mediation and early neutral evaluation for medical negligence claims (NHS Resolution, 2020), although again that is not the focus of this policy paper.

There are several mechanisms to help prevent escalation and to resolve disputes; these include second opinions, CECs, and mediation. In this paper, we explore ideas for developing policy on these mechanisms. We also explore the role of resources in disputes: financial resources that can influence care and treatment decisions, investment needed for improving clinicians' skills and improve communication, and funding for dispute avoidance and resolution mechanisms.

We organised a one-day event to discuss these issues in March 2026 at Oriel College, University of Oxford, and this policy paper draws on those discussions. The day-long symposium brought together approximately 30 participants comprising family members of patients and HCPs, all with lived experience of healthcare disputes, as well as academics and mediators, to discuss the four themes that are the focus of this paper: second opinions, CECs, mediation, and resources.

Before the symposium, the authors circulated a briefing paper with background information and links to further reading to focus participant contributions. The symposium was structured in three main sessions: one session each focused on families’ experiences and perspectives and on HCPs’ experiences and perspectives, and a roundtable discussion focused on the key themes where all contributed.

We established the symposium as a confidential space. We committed to not sharing the names of participants outside of the symposium, and we asked participants to do the same. We explained that comments and ideas would be included in our policy paper, but we would not attribute them to individuals. The aim was to create a safe space for open and honest discussion. This paper is our interpretation of some of the ways that policy could be developed to improve the ways that healthcare disputes are approached. While it is informed by the discussions and contributions of participants, it reflects the views of the authors.

2 Background

Most commentators acknowledge that it is not possible to avoid conflict completely in healthcare settings. Indeed, some note that conflict and disagreement can be beneficial in ensuring all options are explored, which in turn can give patients and/or families confidence in decision-making (Parsons and Darlington, 2021). It has been suggested that the legal system of England and Wales, in allowing for open, sometimes acrimonious, debate reflects a pluralistic and tolerant society in which differences of values and belief can be discussed (Auckland and Goold, 2020). At the symposium, one participant said that disagreement 'is not a big bad wolf'; it can be a catalyst for positive change. Further, in cultures in which outright conflict is avoided by consensus decision-making, there might be undue deference to one party's view, which could be to the detriment of the patient – a form of coercion and 'conflict burying' rather than conflict resolution (Auckland and Goold, 2020).

Conflict is, however, also potentially damaging, especially where it contributes to relationship breakdown and disrupts good communication, which can have a detrimental impact on the care of the patient. Some of the most high-profile and emotive disputes on medical treatment that have been heard in English courts reflect acrimonious and polarised views between parties that not only cause psychological distress to the parties but contribute to delay in decision-making and potentially cause harm to the patient at the heart of the dispute (and other patients) (Parsons and Darlington, 2021; Moreton, 2023; Auckland and Goold, 2020).

Many of these high-profile disputes have involved critically ill children, and most of the literature reflects that focus on paediatric healthcare, but the symposium considered a wider range of disputes including everyday clinical decisions and medical treatment concerning adults. Since the case of Charlie Gard, proposals have been made to strengthen family access to legal aid and to medical records as well as to CECs, second opinions and mediation (Nuffield Council on Bioethics, 2023). Means-tested legal aid is now available for those with parental responsibility of a child in withdrawal of treatment cases and is available in some cases concerning adults in the Court of Protection (CoP). However, other proposals were ultimately rejected by

Government, which commissioned a further review of the evidence specifically in paediatric end-of-life disputes (Nuffield Council on Bioethics, 2023; Moreton, 2023). The Nuffield Council on Bioethics review of the literature on disagreements about critically ill children is a key source of information on the causes and impacts of disagreement and conflict and the means of resolution (Moreton, 2023). Yet many of their recommendations remain unadopted and there has been no public update from the Government regarding this work, nor has there been, as far as we understand it, any private update to family members.

Disputes concerning medical treatment for adults have also been the focus of research (Clough, 2016; Ruck Keene et al, 2019; Kong et al, 2020; Lindsey, 2023), albeit there has been less focus on the conflict between family members, patients and HCPs in that literature. Yet many of the same issues arise when considering disputes about an adult's care and treatment; the best interests test framework is similar and family members of adults often feel excluded from the decision-making process, sometimes more so than for parents of children as the legal framework gives adult relatives even fewer rights in most cases. Where we refer to parents in this paper, this is not only parents of children but, in some instances, we are reflecting the experiences of parents of adult children who were in dispute with the CoP or at a local level with HCPs.

As we were told at the symposium, 'No parent wants to go to court.' Although there will always be disputes involving medical treatment, of both children and adults, that require determination by the court, increasingly there is interest in alternative means of resolving such disputes. In the symposium and preparatory briefing paper we explored four issues that relate to out-of-court resolution of disputes: second opinions, CECs, mediation, and resource allocation. We also identified that resources is an overarching issue that affects many of the other themes.

In addition to discussion of these themes, the symposium highlighted issues that have an impact on healthcare disagreement. These include the need for access to medical records and impartial information for patients and families on court procedures and out-of-court resolution processes. Religious belief and the role it plays in disagreement is a specific issue that requires exploration (Lindsey, 2025d); one participant at the symposium suggested that where spiritual or religious beliefs are present, family and

HCP views may never align, and it may be inevitable that these go to court. Another is the issue of organisational culture within the NHS, both culture that exists across the NHS as a whole and the cultures of individual Trusts, which influences the way clinicians relate to patients and families and the degree of trust in these relationships. In this policy paper we include recommendations addressing these some of these overarching issues as well as the four key themes.

3 Themes

3.1 General themes

NHS culture: Does the culture within NHS organisations contribute to a lack of trust and poor communication between HCPs, patients and their families? The issue arose at the symposium, with many parents describing not being listened to and even attempts at 'character assassination' by clinicians within the NHS. Family members said they recognise and acknowledge caring clinicians, but 'group think is a juggernaut'. Many families experience safeguarding processes not as neutral protective mechanisms, but as tools that can escalate conflict, silence criticism, or delegitimise dissenting family members.

These concerns raised at the symposium reflect wider concerns about NHS culture, many of which have been extensively considered in other reports. For example, Rob Behrens, former Parliamentary and Health Service Ombudsman, describes a 'toxic' culture within the NHS and cites a number of factors (Behrens, 2023). One is resistance to revisiting clinical decisions; Behrens cites the importance of medical education, 'especially when it comes to relationships between doctors and patients. He has heard doctors say that their education was based on the premise that they had to stand by their decisions and not "back off just because people don't like them."' Behrens calls for less defensiveness and more collaboration within the NHS, a theme that clearly emerged from the symposium too.

In the Morecambe Bay investigation, Dr Bill Kirkup examined deaths and failures in the maternity department of Furness General Hospital (later part of University Hospitals of Morecambe Bay NHS Foundation Trust). Among other significant issues relating to clinical competence, the review identified a failure to be honest and open with patients and relatives when concerns were raised, echoing the culture of defensiveness that Behrens describes (Kirkup, 2015). Two years before the Morecambe Bay review, the Francis report identified significant issues with culture within the NHS (Department of Health, 2013). The review found that the Trust failed 'to listen sufficiently to its patients and staff' and failed 'to tackle an insidious negative culture', and among its many recommendations was increased openness, transparency and candour (the statutory duty of candour arose from the Francis report). Although primarily concerned with patient safety as opposed to disputes over medical treatment, these reviews expose some of the cultural problems within NHS organisations that can contribute to, and obstruct prevention and resolution of, conflict between patients, families and HCPs.

More recently, the Messenger/Pollard review (Messenger and Pollard, 2022) explored the internal and external pressures, including inadequate training and top-down political pressure, on NHS organisations. These pressures cause stress and 'inevitably have an impact on behaviours in the workplace', with the review citing 'too many reports to ignore of poor behavioural cultures and incidences of discrimination, bullying, blame cultures and responsibility avoidance'.

The siloed working and messy accountability described in the Messenger/Pollard review reflect the experience of many symposium participants. We were told of conflict among professionals from different clinical disciplines, and of clinicians not working with colleagues in social care. One of the most frequent experiences described by parents was being vilified by the HCPs and not having their expertise recognised. Situations of distrust can 'catastrophically snowball', with a massive effect on patients and their families. One who experienced what she described as retaliatory safeguarding action said, 'I wish they had put as much effort into caring for our daughter instead of vilifying us.' These are reflections of wider institutional failures within the NHS which are not exclusive to best interests decision-making.

These cultural behaviours also have an impact on professionals. For HCPs at the symposium, decision-making can be difficult and even traumatic, and clinicians can struggle to deal with uncertainty ('Things that keep me awake at night because of not doing the right thing'). Being subject to a complaint can also be challenging for HCPs and impact their practice. For HCPs, an expectation that they will comply with parents' wishes and act against their own view of what is in the patient's best interests can cause 'moral injury', as we were told at the symposium. HCPs told us that clinicians feel love for their patients, which isn't always recognised by families, and in some situations it can feel burdensome to provide treatment for no benefit to the patient.

This perhaps reflects another aspect of culture within the NHS, one not often discussed explicitly – that their training teaches HCPs to prioritise quality over quantity of life, and that extending life at any cost can feel abhorrent (an ‘emotional turmoil’, as one participant described). This belief system can clash with those of families who feel the life of their loved one, even if compromised, is worthwhile.

Information provision: Participants described a lack of information for families about the care and treatment of their loved one, as well as a lack of information about some of the out-of-court processes described below. One key aspect of this is access to medical records. We learned at the symposium that patients and families can experience difficulties in accessing medical records, and this can be an obstacle when seeking advice on treatment or second opinions. This was previously acknowledged by the Nuffield Council on Bioethics, and we support their recommendation for information sharing with families within one week of a request which, as we understand it, has not yet been implemented (Nuffield Council on Bioethics, 2023).

Disputes about the value of second opinions can also arise when families and HCPs are not working with the same information. For example, some parents were not informed about what information was sent to an expert when commissioning a second opinion. There should be transparency regarding what information is provided to experts, and families should be kept informed about this.

Family members also told us that they were not given information about the options of CECs and mediation, nor did they understand what these processes were. Where a CEC took place in their case, family members were not always told it was happening or what information was shared, and they often relied on the treating HCPs to report on the outcome of the CEC’s discussion. Information is also key as a resource for patients and families to understand the court process and the alternatives, including second opinions, CECs and mediation. We learned that impartial information is scarce, and that families would welcome an online resource, something that we recommend should be commissioned. However, it is important to recognise that information provision may not be enough for many families, and independent advocacy would also be beneficial so that they have ongoing support from an independent professional during disagreements. In fact, many family members felt that independent advocacy would help to resolve many of the problems that arise in these cases, including poor communication, lack of trust and transparency. In that respect, funding of independent advocacy can be a cost-effective investment.

3.2 Second opinions

Second opinions are considered to be increasingly important in decision-making in complex clinical cases (RCPCH, 2022), and the Nuffield literature review suggests they may be appropriate when third-party involvement is needed for disagreements that have escalated to ‘moderate disputes’ (Moreton, 2023). There is a lack of evidence on the effectiveness and frequency of use of expert second opinions (Moreton, 2023). There is also a lack of clarity about what second opinions are used for, given their role in various aspects of clinical care as well as their role in litigation.

One example of where there is a ‘right’ to a second opinion in the NHS is Martha’s Rule (named after Martha Mills, a 13-year-old who died from sepsis in 2021 after her family raised concerns about her deteriorating condition). Piloted in 2024-25, Martha’s Rule is a right to seek an urgent review of a patient’s care where the patient’s condition appears to deteriorate (RCPCH, 2022; Fraser et al, 2024). The review is conducted by a different treating team although is not necessarily independent from the Trust. NHS England has reported that such reviews have led to potentially life-saving changes in treatment (Thornton, 2025). For many of the cases in which the symposium participants were involved, however, Martha’s Rule has limitations: it does not help in cases where there is no deterioration but only disagreement about treatment options, and it is not an independent review from outside the Trust, only independent of the treating team. However, we refer to it here because it may reflect a model on which to develop a right to an independent second opinion in other scenarios, such as in cases where family members disagree with the HCPs about the patient’s best interests. This should be explored further to consider whether something similar to Martha’s rule could be adopted to give family members a right to request an independent second opinion of a best interests decision.

At the symposium, family participants expressed support for a legal right to a second opinion, although precisely what this would involve was not explored in detail and there are many complexities in how this right would or could be framed. There are different types of second opinion, including:

- A brief focused conversation between the treating clinician and another clinician/expert about treatment, investigations, and diagnoses;
- A detailed opinion obtained from another HCP on a specific question based a review of the medical records, which will be used to inform clinical decision-making;
- A thorough in-person review and written opinion about the treatment options, including meeting with patient and/or family members, provided by an independent (external to the Trust) HCP with relevant expertise;
- An independent expert report commissioned (jointly or individually) as part of a litigation process;
- Second opinions regarding an adult patient's mental capacity, for example, if a capacity assessment has not been undertaken correctly, recently or there is a disagreement about the approach of the assessor.

There are also different meanings of a 'right' to a second opinion, which we explored at the symposium. All patients and families have the freedom to seek second opinions by, for example, seeking it themselves, but there is a lack of legal right to do so, or any right to have a second opinion funded. This can create several difficulties for family members including: difficulty in identifying appropriate experts, obtaining access to the patient and/or medical records for the second opinion, funding the second opinion and getting the second opinion listened to by the treating team where it reaches a different opinion. Giving family members a right to obtain a funded second opinion will not resolve the latter issue because HCPs are still bound by the best interests test such that if they do not believe the commissioned second opinion reaches an opinion that is in the patient's best interests then they ought not to follow it. This is further complicated in adult cases because the HCPs, rather than family members, have the right to make best interests decisions on behalf of their patients, in the absence of any authority for the family member to do so such as a lasting power of attorney. In cases concerning children a second opinion may be more effective because parents usually retain decision-making authority unless the treating team challenges their approach through a court process.

Some family members described being ‘railroaded’ when requesting a second opinion, and others described not being offered the option of a second opinion at all. Families told us that HCPs have refused to consider second opinions from experts overseas. Some family members wanted a right to a second opinion, including from overseas, which would be binding on HCPs. This latter aspect is not possible within the current legal framework as HCPs would always be able to take the matter before a court for a judicial decision and in cases concerning adults, the HCPs would also be able to make best interests decisions for the patient using s 5 Mental Capacity Act 2005. HCPs also expressed concern about overseas second opinions as they told us that a second opinion has to have value in their eyes and an expert from abroad may not have the appropriate qualifications. Moreover, a request for a second opinion can increase conflict where it triggers a disagreement about the quality and neutrality of the opinion, which is particularly prevalent for overseas opinions.

As noted above, there are many ways that second opinions can be obtained and used. However, second opinions raise ethical and practical challenges. There are currently no formal procedures for commissioning an expert second opinion and no consistent framework across the NHS. Providing a second opinion can be time-consuming and is often unremunerated, yet experts must demonstrate they have the specialist knowledge and training and provide evidence to support their opinion. Experts abroad might find it difficult to meet the qualification requirements of the regulator.

A further important issue is how HCPs should respond when a second opinion comes to a different conclusion regarding the patient’s best interests, particularly where that second opinion is from abroad. For example, some HCPs told us that where parents have ‘entrenched beliefs’, they can seek second opinions from different jurisdictions with different values system. There were differing opinions about whether overseas expert opinions should be permitted, with family members expressing support and some HCPs expressing reservations. Families argued that there might be limited expertise in this country, especially with rare conditions, and therefore seeking opinions from overseas is necessary. HCPs argued that there will be different ethical values in different jurisdictions (such as values relating to sanctity of life) and potentially different legal obligations around the best interests of the child, and in such cases an opinion that departs from that of the treating clinicians might present an ethical or legal challenge more than a clinical one. At the symposium we were told of examples of HCPs regretting having agreed to a family's treatment plan, because in their view the patient suffered as a result. HCPs worry about being able to do the job they were trained to do, and to keep the patient's best interests at the centre; they can ask themselves, 'Should I have been braver, more challenging, should I have stopped sooner?'

This can also be difficult with 'experimental or novel treatments' on which an opinion is sought about which there may be no clear consensus (RCPCH, 2022; Fraser et al, 2024). It was suggested that in the Raqeeb case, for example, the outcome may have been influenced by the views of a different but highly reputable team of medical practitioners who proposed a treatment plan not offered by the treating clinicians (*Raqeeb v Barts NHS Foundation Trust & Anors* [2019] EWHC 2531 (Admin), [178]). Macdonald J noted that the court considered that a 'contrary view from a centre of paediatric excellence' compared favourably to 'the clandestine involvement of inappropriately qualified foreign medical practitioners' (Auckland and Goold, 2020), which may have been the approach in other cases. This highlights the importance of second opinions for families as they can be determinative in a case, which perhaps explains the strong desire among family members at the symposium for a stronger right to a second opinion.

Resources also have an impact here; there is a cost to commissioning second opinions, especially in terms of the support for families in understanding the process and in training for clinicians. We heard at the symposium that patient families sometimes must pay for second opinions. We also heard that they distrust the independence of second opinions within the NHS, even if commissioned from an expert outside the hospital trust treating the patient, because of the perceived close networks of HCPs within the NHS. We were also told it is important for the expert providing the second opinion to meet with the family to discuss the opinion and its implications, which has resource implications. While there was no consensus on these issues, there was agreement generally that it would be beneficial to have clarity over who is providing the second opinion, their qualifications and any conflict of interest they may have. We make recommendations about how to provide that clarity as well as supporting a right to a funded, independent second opinion in best interests disputes.

3.3 Clinical Ethics Committees

CECs are not a form of dispute resolution but advise on ethical issues. They are a potentially valuable resource for addressing disagreement in healthcare settings and may be best placed to consider ethical dimensions of values-based medical disputes (Auckland and Goold, 2020; Moreton, 2023). They are usually made up of clinical and lay members, and sometimes those with religious or legal expertise. A survey in 2020-21 found there were at least 45 such committees – clinical ethics support services, or CESS – in the UK, with membership ranging from 7 to 33 individuals (Dittborn et al, 2022). CEC activities include individual case consultation and advice and organisational input on policies and leadership (Slowther et al, 2012). In the UK, the number of CECs has grown, and although the way they operate is not formalised, a set of core competencies was developed by the UK Clinical Ethics Network (UKCEN) in 2010 (Larcher et al, 2010; Dittborn et al, 2022). Parents can make a request for a CEC case consultation, but most requests come from HCPs, and given that CECs have come about primarily from interest by Trusts, their primary focus is clinician support in decision-making (Slowther et al, 2012). At the symposium there was support among some HCPs for a mandatory model to be used, in which the CEC makes binding decisions, although others noted the CECs they were involved in were advisory only and should remain so. Most people agreed that CECs should be available to Trusts, but noted that access was variable across the country.

Concerns have been expressed about the lack of transparency of CEC discussions and advice, lack of impartiality, the potential for power imbalance, and in particular the lack of patient and/or family voice (Auckland and Goold 2020; Moreton 2023; Austin 2018). Patients and/or family are not routinely invited to take part and they are not always informed about the discussion of their case (Archard et al, 2023); this was a common experience of the family members participating in the symposium, with family participants noting the importance of having ‘someone there in person’ even if not for the whole duration of the meeting. In *Re X* [2020] EWHC 1958 (Fam) Russell J criticised the Trust for not involving the parents in the hospital’s CEC process, stating, ‘There should be guidance on patient/family participation and a clear protocol of how and when they are informed as to the arrangements being put in place for an Ethics Committee to meet along with being informed as to the outcome.’ Further guidance was provided in subsequent cases such as *Manchester University NHS FT v Verden* [2022] EWCOP 9 (see also Archard et al, 2023). It has been noted that ‘[i]f parents are not informed or asked to provide input into pre-court processes such as CECs, then that potentially does not prioritise their wellbeing as participants in the process. They may feel excluded or deceived about what is taking place, which would be distinctly anti-therapeutic.’ (Lindsey et al, 2025b). Further analysis of what is needed to develop CEC processes has been undertaken and also informs this paper (Brierley et al, 2022). However, it is important to note that while we do recommend clearer guidance is required at a national level, there will always be the need to tailor the process for the specific ethical question; not all CECs concern best interests disagreements nor will all patients have family members who want or can be consulted.

Most of the experiences reflected at the symposium suggested that family members did not directly participate and more typically only provided a statement. There was less discussion of whether patients participated, presumably because much of the discussion concerned patients with serious health conditions, albeit there was one example of videos of the child patient being presented to the CEC, showing that patients can still be helpfully ‘brought into the room’ in indirect ways. The limited participation was seen as problematic by family members, some of whom were not even notified of the meeting or given the opportunity to make representations. This was problematic for the types of disputes explored at the symposium because those who had not been involved were all family members who were actively engaged with their child’s care. There was no consensus at the symposium on the extent to which patients and family members should participate in CECs, despite the criticism that they have been subjected to in case law and academic commentary. However, this is not necessarily surprising from a clinical perspective as CECs are primarily designed as a form of support for clinicians in making treatment decisions. As these difficult decisions require frank and honest discussion, CECs can be a means of providing a space where these discussions can take place and where clinicians can seek practical and ethical advice from a range of perspectives. If parents are present for the whole of the meeting, then it could impact negatively on the space that clinicians need to reflect on their ethical and professional practice.

There were some concerns among family members that CECs were a tick-box exercise to rubber stamp clinical decision-making. To address those concerns, membership could be expanded, with clear and accurate minutes taken. Most attendees also agreed that there was a need to address the ‘postcode lottery’ in how CECs operate and to have less ‘patchy experiences’ of the process. Participants strongly emphasised the need for capacity building for CECs, both to support and develop their work and to ensure that they are properly resourced consistently across the country. There is, however, a dilemma in formalising the way CECs operate. The informality of CECs, the varied composition of committees, and the differing role of patients and/or families means they can be responsive to individual needs and flexible to the circumstances and needs of the health setting (for example, a small district hospital may have different needs from a large tertiary Trust). However, it can also suggest that CECs lack the procedural rules and safeguards to achieve justice. As CECs are advisory, these concerns may be less important and the lack of rigid procedural rules of both CECs and mediation can be valuable and can save time, money and heartache (Huxtable 2018).

If, as suggested by the Nuffield Council on Bioethics literature review (Moreton 2023), CECs require a ‘major reorientation’ of role and remit, how can this be achieved? Several options have been suggested:

- From our review of the literature (this was not shared with us at the symposium), we understand that, at Great Ormond Street Hospital (GOSH), the CEC process is referred to as Ethics Case Review (ECR) and is formalised in three stages: pre-brief, ECR, and post-ECR. The practice is to invite patients and/or families to meet with the chair of the ECR, to attend the middle third of the ECR meeting, and to meet with the chair and lead clinician following the ECR meeting. The purpose of breaking the ECR meeting into sections, and inviting the family for one section, is to allow for confidential matters to be discussed and to encourage open and frank discussion by clinicians. It is believed this also helps avoid creating an antagonistic confrontation of patient and/or family views and those of clinicians (Archard et al, 2023).

- Another process described to us during the symposium involves a meeting with HCPs and invites patients and family members to communicate their views by speaking with an HCP who will attend the meeting and asking them to pass on the patient/family views; speaking with a member of the CEC before the meeting; writing a letter to the CEC; and sharing a photo or video to be shown at the meeting. The process for conveying the outcome of the meeting involves the treating clinicians reporting back to the patient and family. This offers a method for contributing patient and family views but is a more passive form of participation and does not automatically allow for direct involvement in the discussion.
- Children's Health Ireland have recently set up a clinical ethics support service (CES) for decisions about children. This model 'aims to ensure clinicians have timely access to ethical support and advice when required. The function of CES is to assist the healthcare team in navigating such complex decisions, adopting a children's rights lens as its primary framework'. It is most similar to the GOSH model above in that engagement with the service is optional and provides advice to clinicians, but family members/the child will be notified it is taking place and will be invited to attend part of the meeting, and a member of the ethics service will meet with the child and family if there is sufficient time to do so. Its membership is typically between 14-30 and is made up of clinicians, lay members, external members with bioethics of healthcare law expertise, legal and patient advocacy and non- members of the organisational executive. The CES is partially resourced.

We should continue to review any evaluations or outcomes from the above models to consider which is most effective at reducing conflict and supporting HCPs, patients and family members. Further research into these models, including with family members and patients, would be beneficial in the process of developing a national protocol in the UK. We think it should be mandatory for all Trusts to have access to a CEC in their area; capacity building will be required to get to that position, but there was clear consensus that funding is necessary to develop the work of CECs in the UK. All participants at the symposium agreed that CECs are inadequately funded, which limits their ability to adopt a fully participatory process.

3.4 Mediation

Mediation is a process which can be used where any disagreement has arisen to help facilitate communication between people to resolve the disagreement with the assistance of an independent third-party mediator. Mediation is not a legal process and parties are not compelled to reach agreement, nor does the mediator have any role in determining the outcome.

The potential for mediation to deliver benefits for parties in a medical treatment dispute has been highlighted in the research and includes wellbeing benefits, flexibility of process and outcome, greater collaboration, less adversarial and enhanced communication (Lindsey et al, 2025b). Mediation's role has also been highlighted in the case law, including by Mr Justice Francis: 'mediation should be attempted in all cases such as this one, even if all that it does is achieve a greater understanding by the parties of each other's positions' (*Great Ormond Street Hospital v Constance Yates and others* [2017] EWHC 1909 (Fam)) and Mr Justice Hayden: 'A differing opinion may provide a breakthrough in mediation' and that 'mediation, sensitively and skilfully conducted, can be productive and even, occasionally, transformative' (*Manchester University NHS Foundation Trust v M, F, G* [2026] EWHC 812 (Fam) paras 46-47). There are several other reported cases in which mediation was attempted (these include *Re X* [2020] EWHC 1958; *Guy's and St Thomas' Children's NHS Foundation Trust v Pippa Knight and Paula Parfitt* [2021] EWHC 25; and *Newcastle Upon Tyner Hospitals NHS Foundation Trust v H [*2022] EWFC 14).

At the symposium, it was made clear that mediation is not about ‘meeting in the middle’ but was described as a process for resolving conflict that is ‘trauma-informed’, with the capacity to ‘hold’ the trauma experienced by both clinicians and families. It was also described positively by one HCP, although she also noted that in the mediation clinicians were still careful about the language used and felt that some were ‘still holding back’. Interestingly, it was observed that clinicians often recommend mediation but parents are not typically accepting of the offer. If true, this may be due to a lack of knowledge or understanding about what mediation is and its independence from the NHS.

The role of independent mediators was not explored in as much detail as we would have liked at the symposium, and it is important that the mediator is independent from and has no direct link to either party involved in the disagreement. However, the overriding issue in relation to independence is one of trust; being able to trust the mediator is what matters for all parties, and so it is important that the mediator is someone who all parties agree they would have confidence in to conduct the mediation. Mutual agreement on the choice of mediator is one part of this, and it is possible that families have not felt involved in selecting the mediator if, for example, Trusts have mediators who they have worked with previously and recommend. While this does not undermine the independence of the mediator, it may impact on perceptions of independence if the Trust makes the recommendation of the mediator. If families are less familiar with mediation then they may find it difficult to agree to it without the knowledge of its potential value. Therefore access to independent information about mediation is likely to be important, particularly for families.

Timing of mediation was also seen as important, particularly by HCPs who valued it earlier in the process. It may be difficult to identify an ideal time to mediate, however, particularly if information is needed such as a second opinion or the results of tests, but it can be a staged process that accommodates the need to seek further information. It is never too late to mediate, but it should be considered before legal proceedings are issued.

Mediations are conducted ‘in the shadow of the court’, with judicial determination being the backstop, and as when cases do reach the courts judges do, arguably for many reasons, tend to find in favour of Trusts (Lindsey et al, 2025c), there is some concern that mediation of medical treatment disputes will exacerbate power imbalances and will be used as a way to pressure parents into accepting the clinicians’ view. At the symposium, family members expressed some cynicism and asserted that mediation should not be about trying to get the family to agree with the hospital. We heard from a parent who said they had tried mediation, but the Trust entered the process with a fixed position. Another said they requested mediation but were ‘railroaded’ by the Trust. However, it is important to note that use of second opinions and requests for moving a child for alternative treatment can also be facilitated by mediation, where it allows for discussion of the reasons behind the request and potential reconciliation of different views on the value of a second opinion or alternative treatment (Linney et al, 2019).

Another concern about mediation is that it delays decision-making (Lindsey and Francis, 2025e; *Manchester University NHS Foundation Trust v M, F, G* [2026] EWHC 812 (Fam)), which can have a profound impact on the welfare of the patient. The cost of mediation can be another obstacle to its use; this is discussed below under resource allocation. Our view is that Trusts should fund independent mediation.

Due to concerns about trust, independence and transparency, we do not think it is appropriate to place an obligation on Trusts to share information about mediation. However, mediation should generally be available to families if they wish to pursue it. This is contingent on families understanding what mediation is and its role in disputes about health and care. Misperceptions about mediation can partially be addressed by greater transparency around its use and outcomes. Anonymised case studies should be available – produced by mediation providers – to illustrate the process. Impartial information is needed, particularly for patients and families who might perceive that a Trust’s offer of mediation is not well-intentioned. Information should also distinguish between attempts at informal resolution undertaken daily by clinical staff and the involvement of an independent external mediator to facilitate discussions between HCPs and families. Part of the information provision recommendation should include information about mediation with references to independent mediation service providers.

3.5 Resources

The issue of financial resources, and how NHS resources in particular should be allocated, is relevant but not widely discussed in the context of medical treatment disputes. To what extent are treatment decisions, which are meant to be made in the best interests of the patient, influenced by resource constraints of a public health system? The Nuffield Council on Bioethics has noted that professional guidance, while requiring that treatment decisions are made in the child's best interests, also acknowledges that treatment decisions can be affected by resource constraints and that 'it is not always clear how limited resources are, or should be, taken into account in decisions about the provision of care and treatment for critically ill children' (Nuffield Council on Bioethics, 2019).

Family members at the symposium described what they perceived to be a postcode lottery, with some treatments available in parts of the country and not in others. This perception was particularly of a north-south divide and reflects perceptions that public spending is prioritised in the southeast of England. This is a resource allocation issue that can create disparity of outcomes for patients depending on where they live, and it suggests that patients and families should have a right to transfer to other hospitals outside of the area in which they live and even abroad if the required care is not available to them.

This postcode lottery also appeared to affect people's experiences of access to palliative care, which is not funded in the same way as other specialist treatment within the NHS. At the symposium, HCPs discussed the need for support for palliative care and for a better understanding of its purpose, including clarification that a referral to palliative care was not synonymous with withdrawal of treatment and can be accessed by any child or young person with a life-limiting or life-threatening condition, often alongside treatment aimed at cure. End-of-life was described as the 'most profound moment of care', and that 'it's not about "withdrawing care" but ending burdensome or ineffective treatment'. Family members highlighted the importance of dignity for their loved one, and one participant described the Trust refusing her request to have her child transferred home to die. But palliative care has resource implications as well.

Where patients fund their care directly or through personal insurance, rather than through a nationalised system like the NHS, patient and/or family views on continuing treatment are more likely to be accepted by clinicians, even where they believe the treatment is futile: 'if the patient has the insurance to pay for a treatment, it would generally be given' (Auckland and Goold, 2020). But if it is considered not in the patient's best interests, then even if affordability is not an option a Trust can refuse to give permission. At the symposium, one parent described offering to pay for additional diagnostic tests, but the Trust refused. Another described how they had raised private funds to cover their child's care and treatment but they were still denied the opportunity to take her abroad. Where HCPs were refusing to agree to patient transfers in such situations, parents described feeling as if their child was 'taken hostage'. However, HCPs told us that simply because another jurisdiction has more resources or different treatment options, that does not mean they can simply agree to transfers, because HCPs work within the legal and ethical framework of England and Wales. Harm, we were told, can still be a risk even if the resources are available. On the other hand, we also heard from an HCP of a positive experience of sending a child abroad for treatment not available here. These views reflected fundamental disagreements about who should be able to decide about a child's health and care where different values were engaged. At the symposium, some HCPs asserted that resource limitations would never enter into their clinical decision-making. Yet, on a wider level, resources are relevant factors that should be considered when determining the law or policy in this area; whether and what should be funded is an issue not for individual clinicians but for politicians to decide. However, it may impact clinical decisions about, for example, who should be admitted to an intensive care unit if there is a perception that treatment will continue while lengthy second opinion, CEC, mediation or legal processes continue. Some commentators have suggested that more clarity is needed about 'arguments to limit treatment on the basis of finite and scarce medical resources' (Wilkinson, 2017) and we agree that a more frank discussion of these issues is required at a policy level.

There is increasing emphasis on conflict management and reduction skills being embedded in healthcare settings and on the need for relationships that build trust between HCPs and families. However, initiatives that were implemented following the NCOB review (Nuffield Council on Bioethics, 2023), such as the NHS regional conflict champions, have since had funding withdrawn albeit conflict management e-learning is still available to those working within the NHS (NHS learning hub, 2024). Yet training on conflict management and reduction requires time, which is a scarce resource in busy hospital environments. Ensuring that support is available for clinicians who face conflict situations may also carry financial and time cost for Trusts. Involvement of palliative care teams as a source of support, as set out in guidance for conflict prevention, is also likely to have resource implications (Linney et al, 2019). A separate family advocate role, independent of the treating team, would require funding (Sivers et al, 2026). Even something as basic as space is at a premium in busy hospitals for what palliative care doctor Katherine Mannix calls ‘tender conversations’: ‘The Compassionate Hospital’, she writes, ‘would offer time, calm spaces and trained, willing companions as a basic right for anyone receiving life-changing news’, as well as quiet spaces for clinicians distressed at delivering that news and confidential spaces for discussing different views (Mannix, 2021). All these – time, support, space – come at a price.

Other prevention methods that have been recommended also carry a cost to the Trust: ‘Concepts such as the “team around the child”, a liaison or “key worker” and a single defined clinical lead are not new but do require some committed resource and intent’ (Birchley et al, 2022). At the symposium, it was suggested that it helps to have a lead clinician, regular multi-disciplinary team meetings, and regular family meetings. Implementing conflict prevention or de-escalation processes also carry a cost to Trusts, as do specialist legal advice and of mediation. At the symposium there was broad agreement, however, in the importance of investing in early prevention and resolution.

HCPs noted that Trusts do not want to go to court, although the appetite for that will depend on the culture of the Trust. Often legal advice is to try to avoid going to court, and it was observed how expensive litigation can be in this area. This was partly also related to the fear of going to court and the impact on the treating team. Even disagreements that are not destined for judicial determination, on everyday communication practices and care decisions on a ward, can be costly in terms of staff time. One study of a children's hospital over two 12-week periods found that nearly 450 hours of healthcare professional time (primarily nurses, consultants and doctors in training) was taken up by these conflicts (Forbat et al., 2015). There were also questions from parents at the symposium about the resources used for going to court and also for accusing parents who disagreed with decisions. We were told of significant sums spent by Trusts on legal fees. Some were aghast at the resources spent on accusing a parent of neglect; one participant said it's 'insane that that amount of money is being used to cause generational trauma to families'. There was a shared sense of the limited resources the NHS is working with and concern about the use of these resources in dealing with disputes rather than frontline care.

4 Recommendations

Here we set out our recommendations for practical steps to be taken by the Department for Health and Social Care (DHSC), individual NHS Trusts, health commissioners, and mediation providers. These recommendations aim to improve communication and trust between HCPs and patients and their families; prevent disagreements developing into intractable disputes; and resolve disagreements in a more timely and less antagonistic way than through the courts.

4.1 Overall recommendations

- Recommendation 1: Trusts or DHSC should develop (or publish if already prepared following the NCOB review) an online package of resources to provide advice and signposting support for next steps for families and patients outlining options when disputes arise with healthcare teams regarding medical care and treatment.
- Recommendation 2: DHSC should provide a package of support for NHS Trusts to help them to resolve disagreements out of court, including funding for communication/mediation training, CECs, independent mediation, and second opinions.
- Recommendation 3: NHS trusts should put in place protocols to ensure patients and families are given access to medical records, where practicable, within a week of the request being made, in the absence of any factors that would prevent disclosure such as lack of consent from the patient with capacity or safeguarding issues.
- Recommendation 4: Families and patients should have access to independent advocacy where challenging best interests decisions of HCPs.

4.2 Second opinions

- Recommendation 5: Family members should have a right to obtain an independent second opinion where there is a best interests disagreement, funded by the relevant NHS body. This right could be implemented based on a similar principle to Martha’s Rule and DHSC should investigate this option.

- Recommendation 6: The DHSC should develop a standard process for use in commissioning second opinions where funded by the NHS commissioning body.
- Recommendation 7: All experts providing a second opinion, whether overseas or from within the UK, NHS or private, should complete a standard declaration form and provide information on qualifications, experience, relevant expertise, and any potential conflict of interest.

4.3 Clinical Ethics Committees

- Recommendation 8: Government should provide funding for the work of CECs, either at a local level or via a network such as the UKCEN. This funding should include support for the CEC itself to operate and support for patients and families to understand the process and their role in it.
- Recommendation 9: DHSC should develop nationally consistent and impartial information about what CECs are and how they work, which should be developed alongside and be accessible to families and patients.
- Recommendation 10: DHSC should develop a national practice model (possibly based on the UKCEN model) with various options in a toolkit to be responsive to local practice and individual case considerations. These options should include mechanisms for directly involving patients and their families in all CEC meetings where they want to take part.
- Recommendation 11: Any guidance/practice models should provide the option for family members, patients and HCPs to participate directly in all CECs where they wish to do so, albeit this could be in separate parts of the meeting rather than attendance at the full meeting, dependent on local practice and individual case considerations.
- Recommendation 12: DHSC should commission research and monitoring of how CECs operate and work for families and HCPs.

4.4 Mediation

- Recommendation 13: NHS Trusts and families should consider use of independent mediation before proceeding to litigation, except in emergencies. There should be no requirement on family members or HCPs to mediate, only the requirement to consider mediation.
- Recommendation 14: Commissioners should fund independent mediation and should include funded legal and advocacy advice for families taking part in mediation.
- Recommendation 15: Independent mediation should generally be attempted before proceedings are issued.
- Recommendation 16: Independent mediation should be carried out by an experienced mediator, independent of the Trust, with no prior links to either party involved in the disagreement, and by mutual agreement between the parties to the dispute.
- Recommendation 17: NHS Trusts (or other healthcare bodies involved in a dispute) should give information to all parties before taking part in mediation, to help them understand the mediation process and their role in it and to make informed decisions as to whether to take part. This should include anonymised case studies, which should be produced by mediation providers.
- Recommendation 18: All of the above should be contained in DHSC-commissioned national guidance to ensure greater consistency regarding mediation's use across England and Wales.

4.5 Resources

- Recommendation 19: DHSC should provide funding to support the various recommendations above, specifically for:
  - An online package of information resources for families about disputes within the NHS and their options and rights regarding resolution and litigation processes;

- Resources for Trusts to invest in conflict reduction training/processes;
- Families to commission independent second opinions;
- Support to develop CECs nationally;
- The provision of independent mediation in all cases where the family and the HCPs agree to use it;
- The provision of legal advice for families when accessing mediation.

5 Conclusion

This policy paper has explored the complex and sensitive nature of disputes between HCPs, patients, and families. It suggests that while disagreement is a common and sometimes constructive feature of healthcare decision-making, there are circumstances in which it can escalate and become difficult to manage, with negative consequences for those involved and even for other patients. There are differing perspectives on the causes leading to these circumstances, and therefore we organised a symposium to gather those different perspectives. This paper draws on our symposium and the wider literature to put forward various recommendations for reform and further work.

This policy paper has focused on three main mechanisms for resolving disputes outside of court: second opinions, CECs and mediation. Ways that each of these mechanisms could be developed are included in our recommendations. It was clear from the symposium that resource constraints were also seen to be an important factor across these areas. Limitations in funding, time, and access to services may affect both the emergence of disputes and the options available for addressing them. Participants also highlighted variation in experiences across different regions and services, suggesting that access to support mechanisms may not always be consistent. These factors indicate that resource considerations are likely to remain an important part of any policy discussion in this area.

In addition to the policy issues noted above, a recurring theme from the symposium was that many disputes appear to be shaped by issues of poor communication, trust, and NHS organisational culture. Some family members described experiences of feeling unheard or excluded, while HCPs reflected on the pressures and uncertainties they face in decision-making. These perspectives point to the possibility that improving communication and fostering more open and collaborative cultures within healthcare settings could help to reduce the likelihood of disputes escalating.

The specific recommendations outlined in this paper aim to contribute to ongoing discussions about how dispute resolution processes, and support for using them, might be developed further to avoid going to court when disputes arise. Overall, we suggest that there is value in placing greater emphasis on early engagement between HCPs and family members, transparency of processes, improved participation of family members and patients, and support for all parties involved. We recognise that funding will be required for many of these recommendations. They are not only likely to reduce conflict, however; they may also result in resource savings, as the costs of disagreement and proceeding to litigation are growing.

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