

Ethical advice in paediatric care

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ABSTRACT

The need for local ethics advice during the COVID-19 pandemic has put a spotlight on clinical ethics committees (CECs) and services. In this review, we focus on paediatric CECs that raise both generic questions and specific issues. In doing this, we acknowledge the broader roles of education, research and staff support some bioethics teams have developed but focus on the main areas of clinical ethics support to clinical teams. We raise 12 questions about the role, remit and responsibilities of CECs, provide preliminary answers to these and set out the next steps for the development of ethics support both in paediatric practice and more generally.

INTRODUCTION

The question of what it means to offer ethical advice in the context of clinical decision making has particular importance now. COVID-19 necessitated the making of extremely difficult decisions in many areas of care. Moreover, in response to the pandemic, we have seen a growth in UK clinical ethics committees (CECs).^{1,2} Now is a good time to assess what CECs do and what it means to offer ethical advice. We review what is known about UK ethics provision drawing on our own experience but do not provide empirical data.

Our concentration on paediatric ethics does not necessarily imply that separate committees should deal with child issues. Many CECs operate in hospitals caring for both adults and children, consequently reviewing both. However, the proliferation of UK children's hospitals, whether stand-alone or nominal entities in a larger hospital, suggests a direction of travel towards stand-alone autonomous children's hospitals.

We believe it essential to recognise the distinct and distinctive ethical issues arising in paediatrics. As we have reported, many UK child healthcare professionals (HCP) have ad hoc ethics support, with some in district general hospitals preferring ethical issues to be managed in tertiary centres.³

It helps here to distinguish between a CEC, whose role is to consider and advise on particular ethical matters, and broader ethics services that may encompass the provision of staff training, commissioned consultancy for other medical teams, public engagement and support for staff at risk of moral distress or injury.

Our particular focus is paediatrics, though many issues are generic. We chose this spotlight for several reasons: first, two authors are members of a children's hospital CEC. Second, caring for children raises particular ethical issues, for example, although children under 16 years are lawfully

presumed unable to consent to medical treatment,^{4,5} clinical staff are enjoined to elicit and heed their views on what should be done. Parents, however, have the authority to decide for children unable to do so, within recognised limits. Third, a recent case highlighted the issue of parental involvement in CEC 'decision-making', characterising this as an 'ethical' issue.⁶

Cognisant of significant variability in ethics support for paediatric HCP,³ we suggest standards to homogenise the support available to children, families and clinical teams facing contemporary paediatric moral dilemmas.

Our approach is to identify critical questions and attempt to provide answers to them. Of course, there may be other questions, but we believe that those we list are the most important.

Are CECs advisory or directive bodies?

No CEC directs clinicians to make particular decisions, which would be inconsistent with their professional obligations to do what they believe best for patients. Certainly, HCP can refer cases to CECs, but no one is obligated to do what is advised. This is true of all forms of advice.

There are other sources of ethical advice for HCP; national bodies such as the National Institute for Health and Care Excellence and professional organisations, for example, the General Medical Council and Royal Colleges, issue guidance on particular matters. Nevertheless, here too, it is a matter of guidance, although with some weight and significance. As such, it is for clinical staff to interpret and use in any individual case as they see appropriate.

In contrast to CEC advice, the law imposes restrictions on clinical discretion. Where best interests are disputed, the family court can determine the child's best interests, incorporating the patient's assumed point of view.⁷ However, the court will not require clinicians to provide treatment contrary to their clinical judgement and conscience.⁸

In what sense should paediatric CECs 'involve' parents?

In the case cited at the outset, which involved a dispute about the care of a seriously ill child unable to decide for themselves, the judge declared that '*... the absence of any prior consultation or participation [with or of the parents] cannot be good practice and should generally be unacceptable*'. Indeed, such involvement in CEC deliberations is declared 'essential'. The judge also asserted that the absence of national guidance on such involvement is '*an issue of medical ethics*'.⁹

Several terms are in play here—'consultation', 'participation' and 'involvement'—so it pays to



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spell out various possibilities on what we might characterise as a 'ladder of parental involvement'. At the bottom of this ladder, and at a minimum, would be informing parents that their child's case was being referred to a CEC and notifying them of the guidance offered and reasons for it. Ascending the ladder would be in order: soliciting parental views and assuring them that these would be reported to the CEC; inviting parents to the relevant meeting as observers; permitting them to attend *and* contribute to discussions about their child; giving parents rights as time-limited CEC members to be part of the final decision-making process; and, as a final rung, providing guidance to the parents but ceding final authority to make any decision on behalf of their child.

The practice of our CEC is to listen to the views of the family and indeed usually invite them to attend the relevant CEC meeting. However, this is not widespread practice. Some CECs would regard such an invitation as inappropriate or unhelpful, inasmuch as parental presence would inhibit open discussion or frank presentation of possible options.

For CECs that do involve patients/representatives, we caution that multiple medical teams or CEC members can become overwhelming for them and suggest limiting the total numbers present with patients/representatives.

The penultimate rung needs nuanced evaluation, meriting further careful consideration. It is the entirely desirable end of medical decision making that the final decision should be shared. A CEC may help clinicians decide what *they* think is best; indeed, this is its primary function. Parents' views must play their part in this process, but parents cannot decide for clinicians. Sharing a decision must mean each group agreeing for their own part on the same outcome.

It should not need saying that no clinician nor member of a CEC should be exposed to hostile public treatment—in social media, for instance—in consequence of decisions taken or advice given conscientiously and carefully. Consideration should be given in particularly difficult or high-profile cases to withholding the names of CEC members.

The last rung is to be avoided. Where the best interests of the child are disputed, parents do not have final authority to decide. Where parents and HCP cannot agree, further steps need to be taken to resolve the disagreement or secure a final decision from an appropriate third party such as a court.

Is the absence of national guidance regarding the extent of parental involvement in ethical processes an ethical issue? It is, of course, a matter of good practice to ensure a partnership of care between doctors, nurses, other HCP, children and parents.^{10 11} However, it is not clear how it might be thought morally wrong to not involve parents in ethics processes. Or at least more would need to be said about what that means in terms of the envisaged ladder.

Should the creation and operation of CECs be subject, as research ethics committees (RECs) are, to national regulation, oversight and guidance?

UK RECs are subject to national guidance and oversight by the Health Research Authority (HRA). The HRA provides '*robust, proportionate and responsive ethical review of research through RECs, ethical guidance to RECs, a managed structure to support RECs, a quality assurance framework, a training programme, and a UK-wide framework for ethical review*'.¹²

By contrast, in the case of CECs, the UK Clinical Ethics Network (UKCEN) is a coordinated group of CECs and its aims—more modest than those of the HRA—are '*to promote*

the development of ethics support in clinical practice, promote a high level of ethical debate in clinical practice, and to facilitate communication between all UK clinical ethics committees'.¹³ For all the excellent work it does, UKCEN has no powers of oversight or regulation, and its membership is entirely voluntary.

The HRA declares that the reason for ensuring ethical research is that it thereby '*protects the rights, safety, dignity and wellbeing of research participants*', goals equally relevant to patients in clinical practice. It is also evident that the line between research and treatment can be unclear, especially in the case of innovative or unproven treatment. There is a case then for subjecting the use of innovative therapy, which also generates potentially generalisable new knowledge, to similar ethical review standards.

However, the adoption of the REC model to CECs would need to take into consideration several differences. For example, RECs make determinations, whereas CECs offer advice and National Health Service RECs operate independently of organisations sponsoring or conducting research. In contrast, CECs are usually attached to a hospital or group of hospitals. Of course, nuanced models are required in each case, but there is value in considering how a more robust model of regulation and oversight might benefit the promulgation of consistent, transparent and fair advice in clinical ethics.¹⁴ As a first step, our hospital is commissioning what we understand to be the first peer review in UK clinical ethics, a process we hope will be both challenging and encouraging and that can act as a stimulus for the development of support, development and governance of UK CECs.

What should be the training for CEC membership?

CEC membership should be conditional on attendance at ongoing educational sessions. We can insist on this while recognising that such education, like the teaching of ethics more generally, does not consist of providing individuals with the right answer to each and every dilemma. Rather, it provides individuals with the means to understand what counts as a moral problem and of how to evaluate it in the appropriate ethical manner. Additionally, existing professional education provision—such as diversity training and an understanding of equality law—can complement moral training.

UKCEN offers training resources and arranges relevant events, but this falls short of the HRA training required for all REC members.¹⁵ The case for an analogue of the HRA is thus strengthened, especially when it is acknowledged that ethical review of clinical decisions should be robust, defensible and informed by an understanding of the moral issues.

CECs dealing with child-treatment cases must have bespoke training; we have stated the moral significance of the differences from treatment of adult patients at the outset of this piece. Accordingly, our committee developed associate member (AM) status for 10–12 people seeking involvement in ethics, with bespoke monthly 'introduction to ethics' sessions. AM can also attend other training events and rotationally observe case reviews. In addition, specific educational sessions for members precede every monthly CEC, and simulation ethics case reviews featuring professional actors have been successful.

Perhaps CECs could be similarly flagged to paediatric RECs to ensure appropriate expertise in dealing with complex child cases? Mandatory training modules in child health law and ethics would allow a mandated number of 'trained attendees' to review paediatric cases in 'mixed' CECs.

Should CECs be engaged in mediation or conflict resolution and, if not, who should?

In exceptional circumstances where irremediable conflict develops between parents and clinicians concerning what is best for the child, consideration will need to be given to the next steps. Recourse to judicial arbitration may be necessary but is usually the last resort and may leave parties to the dispute bruised, though it ultimately resolves the conflict. In the 2000 case of *Re A (conjoined twins)*,¹⁶ the judge Brooke noted that ‘*It appears that in the United States of America proposals to separate conjoined twins may now be referred to hospitals’ ethics committees, and not to a court, no doubt because of features of United States law that are different from English law*’. Is CEC involvement becoming more common in the UK in 2021?

Mediation is increasingly prevalent but aims to improve relationships rather than address issues of morality. A CEC might provide bioethical mediation in helping those involved identify and address the ethical issues involved, bringing an understanding to parties of the role of faith and differing worldviews, including medical orthodoxy, and openly discussing the issue of cognitive bias. Such a role is not, however, an easy one to fulfil. The CEC may well be seen to be a protagonist in any disagreement. Moreover, CEC members might arguably need to be trained in mediation techniques, though they may be unhappy to take on the role in addition to providing ethical advice. However, CECs should arguably offer the possibility of mediation in circumstances where relations between clinicians and parents have broken down. For some, this should be mandatory.^{17 18} If, and when, this is the case, the body offering mediation should be distinct from the CEC.

Should CECs be independent?

CECs operate independently of the research institution. Would similar independence be helpful for CECs? Given a CEC’s advisory role, this seems unnecessary. It may even be counter-productive given the importance of ongoing relationships and more comprehensive services some committees provide. Any power imbalance perceived between a clinical team and family is unlikely to be successfully addressed by an independent CEC process. We should also note the logistical difficulties of such independence given the volume of referrals and not discount the importance of the particular local knowledge possessed by an in-house CEC. However, as more CECs engage in conflict resolution, the need for greater institutional independence will grow.

Who should be on a CEC?

Though core competencies for CECs were set out in 2010,¹⁹ there is a lack of current guidance about CEC constitution or membership. RECs have a division between healthcare professional and lay membership, yet is this division pertinent in clinical ethics, should there even be ‘ethical professionals’?

Our practice maintains a healthcare/institution affiliated (rather than professional) and lay distinction. We argue that sound paediatric clinical representation is vital when considering complex ethical issues involving a child’s treatment; however, from a predominantly medical model, we now have significant nursing, psychosocial and allied health members, including those early rather than predominantly later in career.

Lay members include the parents of children previously cared for by the institution, a retired lawyer/judge, a moral philosopher and an Islamic/global-health-bioethicist. Other members that ‘cross the divide’ provide invaluable support and wisdom; they include Trust chaplains and an external General Practitioner

ethicist. It is crucial not to seek to secure representativeness from all relevant stakeholders; after all, how many faiths should be represented? Rather, it is a question of ensuring salient viewpoints can be appropriately represented and heard, and also that discussion of matters before a CEC is enriched by each contributor.

One final group we include, despite UKCEN caution that ‘*discussions involving lawyers tend to focus on legal and procedural issues and tend to stifle open discussions about ethics*’,²⁰ are our Trust solicitors who participate, lead and stimulate ethics debate. However, the commencement of legal processes precludes their participation in ethical discussions.

What is the source and justification of the principles by which CECs deliberate?

CECs draw on a variety of sources for the principles by which they give ethical advice. There is, as noted, assistance in UKCEN’s online resources, but equally, CECs can look to national statements from professional organisations, academic work and those in other jurisdictions.

There is considerable overlap and congruence between the different formulations of fundamental clinical ethical principles. It would thus be surprising to find startling differences between those used across different CECs. Nevertheless, subscription to any statement of general ethical principles should be accompanied by the following qualifications. First, there should be a recognition of ethical pluralism, of possible differences in moral viewpoints, even within a CEC. Second, it matters that any principles agreed are clear, unambiguous, understandable and open to the delivery of robust advice on particular matters. Third, it matters that the principles a CEC adopts are employed consistently.

In paediatric ethics, consideration of best interests, children’s rights and the significance of hearing the child are critical elements of the moral lexicon.

What should be the mechanisms for referral of matters to any CEC?

It should be open to any member of clinical staff to refer any case or issue to the CEC for timely consideration. However, this requires both that there is an agreed and widely known procedure for referral and that all clinical staff are clearly aware of the existence and role of the CEC. Access to *emergency* ethics support is limited; few CECs before COVID-19 offered out-of-hours support. The use of video-conferencing has burgeoned during the pandemic and can facilitate rapid support, as some CECs demonstrated. A sustainable model requires funding, and arguably there should be formal assessment of the equivalence and governance of new models of ethics review.

What ensures consistency of advice both across CECs and within any one committee?

Within any CEC, consistency is promoted, even if it can never be guaranteed, by some continuity of membership and robust procedures for recording and reporting advice. The former ensures the enduring collective wisdom with which good organisations flourish; to achieve, this we have a fixed core lead group and an emeritus ethicist. Other members serve 3-year terms, renewable once. The latter allows CECs to understand what cases are unique or *sui generis* and which display important commonalities with others.

Consistency of advice across CECs may well depend on there being sufficient congruence between the guiding principles each

uses. While national and professional guidance is promulgated on specific topics, it is not comprehensive. Consequently, during the COVID-19 pandemic, in the absence of national guidance on rationing,²¹ some CECs developed their own. Though top-down guidance promotes consistency, we prefer a more balanced approach: hierarchical concepts can be supported by guidance developed from the more patient-facing area, facilitating consideration of the particularities of the clinical context, moral pluralism and disagreement.

Do CECs need to reach consensus decisions?

CECs are multidisciplinary deliberative bodies, and agreement on key matters may be unlikely, especially those involving morally complex clinical decisions. Nevertheless, committees should aim for consensus, and recommendations have greater authority and weight spoken in a single voice. Conversely, disagreement can send a message that the answer to a particular problem need not be simple or obvious. Disagreement on critical matters may help to reveal the thinking behind any advice and the different reasons that might be given for advising in particular ways.

Do CECs have expertise in making recommendations?

CECs will include individuals with proven and demonstrable expertise in clinical matters. Whether particular members have, or the committee as a whole has, ethical expertise is a different matter. Of course, the existence of ethical expertise is disputed, as is the moral appropriateness of having putative moral experts give advice to which others defer.^{22,23} Nevertheless, CECs should be constituted by individuals whose advice has weight and appropriate influence. To that extent, it should comprise some at least familiar with the arguments, theories and conceptual language with which any problem can be morally understood and evaluated. That alone suggests the importance of ensuring appropriate CEC training.

Finally, it is worth noting that a CEC with stable membership, regularly reviewing and advising on cases, will acquire a certain collective moral wisdom, capable of appreciating what counts as ethically salient in any matter and understanding how it might go about evaluating the relevant issues.

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