

Recognising, preventing and resolving ethical dilemmas in health care:

The need for clinical ethics support in the NHS

Executive Summary

This document provides an overview of the case for formally establishing access to ethics support for clinicians in the NHS.

Over the past decade there has been a progressive increment in the number of clinical ethics committees (CECs) in the UK - now numbering more than 80 – Most have been established spontaneously within Trusts, driven by professionals with an interest in and concern for ethics in clinical practice.

Most NHS trusts do not provide any mechanism for formal ethics support of clinicians – even those with CECs often lack formal recognition of their existence. Consequently their case-analyses (of complex clinical cases or ethically ambiguous policies) do not feed into the governance system of the trust.

Given the size and aspirations of the NHS - to regain its status as a world leader in health care - the UK is an outlier in our lack of formal recognition of the fact that clinicians need support in ethical decision making. In North America ethics committees have been in place for several decades; while the UK was a leader in Europe 10 years ago in the field of clinical ethics support, several countries in Europe have outstripped the UK in this respect.

The Royal College of Physicians and the Nuffield Council for Bioethics have issued reports encouraging the NHS to establish ethics support for clinicians. The Francis Report contains extensive recommendations regarding professional obligations and values.

Over the past 10 years the UK Clinical Ethics Network (UKCEN) has provided leadership for the establishment and coordination of ethics committees and other forms of ethics support to trusts in the NHS. In our view the current voluntary system, based on the goodwill of enthusiasts, is not robust or sustainable. We believe the case for the NHS creating a formal system of ethics support for clinicians is now compelling. It is noteworthy that the UK has an excellent research ethics infrastructure – but these committees do not advise on NHS practice or policies and do not support clinicians in their practice.

This paper makes the case for formal recognition of the fact that there is a need in the NHS for ethics support at all levels. UKCEN seeks formal recognition by the Department of Health in our efforts to develop ethics support for Trusts and healthcare professionals throughout the NHS.

Introduction

This document is in six sections:

- a brief overview of recent reviews by authoritative bodies regarding the need and possible models for ethics support for clinicians in the NHS;
- an outline of grassroots developments within the NHS in response to the need felt by clinicians for ethics support;
- an outline of the functions and scope of currently established ethics committees in the NHS;
- a summary of the activities of the UK Clinical Ethics Network (UKCEN);
- an outline of developments in other countries;
- some comments about the imbalance of resources currently allocated to 'evidence based medicine' and clinical ethics.

1. UK reviews of the need for ethics support

Although two influential bodies have made recommendations regarding the desirability of *formally* establishing a system for ethics support for healthcare staff in the NHS, little progress has been made.

In 2005 the Royal College of Physicians published the report of a working party that investigated the need for, and provision of, support for clinicians in dealing with the ethical dimension of their work in providing high quality care for their patients. The report's recommendations included the following:

'Ethics support is needed everywhere healthcare is provided. On the basis of the trends outlined above and the findings (in particular the experiences reported by trainees in the survey), the working party concluded that the provision of timely, comprehensive ethics support should no longer be left to chance or be dependent on the enthusiasm of individuals.'

Healthcare institutions should review their existing arrangements for providing advice and education, and developing and implementing guidelines on the recognition and handling of ethical uncertainties and dilemmas in clinical practice. This should be carried out by an identified lead individual working with others and should have the full support of management.

In some institutions, complex ethical dilemmas occur frequently enough to justify establishing a CEC. This should be regarded as a resource available to neighbouring institutions that do not have a CEC, so that all clinicians have access, whether directly or indirectly'.¹

In 2007 the Nuffield Council on Bioethics, in its report, Critical care decisions in foetal and neonatal medicine: ethical issues, recommended that:

'The NHS should explore ways to ensure that all neonatal intensive care units have rapid access to a clinical ethics committee for advice. The best mechanisms for providing such advice need to be determined and implemented on the basis of equal accessibility for parents and all professionals involved in the health or social welfare of the child. Clinical ethics committees may sometimes be able to play a limited role in resolving disputed cases. Whether a decision is disputed or not, rapid support

¹ Royal College of Physicians. Ethics in Practice: Background and recommendations for enhanced support. RCP. 2005

will be needed if clinical ethics committees are to play an effective role in this area of medicine. We propose that clinical ethics committees should appoint on-call facilitators for more active resolution of differences in critical care decision making before they become entrenched as a dispute.²

These two reports reflect a growing awareness among clinicians, professional organisations, and policy makers of the ethical as well as the clinical dimension of decision making in relation to patient care. They draw attention to the need to provide support for clinicians, patients and their families, and health care managers, in dealing with situations that are often complex, ethically difficult and time consuming to resolve – aspects which would benefit from focussed input by an appropriate body with expertise. More recent examples of the importance of recognising the ethical dimension of health care at an organisational level are the cases of Mid Staffordshire and Basildon and Thurrock NHS Trusts^{3 4} where the regulatory authorities found extensive failings, including disregard for patient privacy and dignity and a lack of patient and public involvement. Failure to recognise and engage with the ethical dimension of health care can have serious consequences for patients, their families, and the health care professionals looking after them, as well as wider consequences for society in terms of the costs of reparation.

Since 2005 the General Medical Council has revised and expanded much of its guidance to doctors with increasing emphasis on the ethical aspects of their work. The most recent edition of *Tomorrow's Doctors* states that:

'Graduates will make the care of patients their first concern, applying their skills in a competent and ethical manner, and using their ability to provide leadership and analyse complex and uncertain situations.'⁵

2. The Francis Report

Following the appalling events that were brought to light at the Mid-Staffordshire Hospitals Trust, the Francis Report clearly indicated a failure of professionalism at many levels, including among healthcare professionals. In Volume 3 of the report there is a section dealing with "Values" and other sections dealing with "Standards" and "Professional Obligations".

Among the many recommendations, the following (derived from the Nolan principles) is particularly relevant to UKCEN's objectives:

Recommendation 173

Every healthcare organisation and everyone working for them must be honest, open and truthful in all their dealings with patients and the public, and organisational and personal interests must never be allowed to outweigh the duty to be honest, open and truthful.

² Nuffield Council on Bioethics. Critical care decisions in fetal and neonatal medicine: ethical issues. Nuffield Council. 2006. http://www.nuffieldbioethics.org/go/ourwork/neonatal/publication_406.html accessed 25.6.10

³ Dirty Essex hospitals prompt call for system reform. BBC. 27 November 2009

⁴ Concerns raised over conditions in Essex hospitals. 27 November 2009. [cited 2 December 2009] Available from: <http://www.leighda.co.uk/news/news0archive/concerns-raised-over-conditions-in-essex-hospitals>

⁵ General Medical Council. *Tomorrow's doctors*. GMC. 2009. http://www.gmc-uk.org/undergraduate_education_publications.asp#1 accessed 25.6.10

⁶ Report of the Mid-Staffordshire NHS Foundation Trust Public Inquiry. Chair: Robert Francis, QC. HC898-III.

3. Development of clinical ethics committees in the UK

In parallel with the increasing recognition of the shortcomings of ethical support in the NHS described in section 1, clinicians in many NHS trusts have simply proceeded to establish clinical ethics committees (CECs) on a voluntary basis. These committees are one of a variety of models of clinical ethics support that exist in different health care systems internationally.

CECs are multidisciplinary groups, almost always with lay membership, who provide advice on ethical issues relating to clinical practice within their institutions. Their functions include providing a consultation service for individual case referrals, commenting on or contributing to the ethical dimension of the organisation's policies and guidelines, bringing to the attention of management ethical issues that may require their consideration, and education of staff⁶. [Please see box one for some examples of CEC activities.]

In 2000 there were 20 CECs in the UK and in 2014 this number had risen to more than 80⁷. In addition there are a handful of clinical ethicists working in NHS Trusts or other hospitals, often in conjunction with a CEC.

CECs in the UK almost all developed as a result of clinicians within the organisation identifying a need for this kind of support rather than as a management or formal governance initiative. Hence committee membership is voluntary and many committees receive little or no administrative support or funding for education of committee members. Several committees have an academic ethicist as a member who can provide some training in ethics, again on a voluntary basis. Moreover because of their voluntary nature, and the lack of any specific requirement for health care organisations to have a mechanism for addressing the ethical dimension of their work, there is no formal regulation, standard setting or evaluation of these committees⁸. Despite these obstacles, new CECs are developing and a national network of CECs (UKCEN) has arisen from the ranks of the CEC membership, aiming to encourage the development of clinical ethics and to contribute to standard setting and evaluation of ethics support services (see below).

Clinical ethics committees are advisory groups who support health professionals, and in some cases patients and family members, in considering the ethical dimension of patient care either at an individual case level or more generally within the Trust. In principle, the CEC aims to identify the key ethical conflicts in a given case, consider the relevant ethical principles, analyse the ethical consequences of different courses of action and record these deliberations in an ethically justifiable manner. In practice the CECs do this by facilitating dialogue between the clinicians and any other parties involved in the case, explicating ethical principles or frameworks, ensuring that all perspectives are considered and providing a forum for reflective discussion on the issue in question. Unlike research ethics committees CECs are not decision making bodies - they advise clinicians of the ethical implications of different courses of action.

⁶ Slowther A, Bunch C, Woolnough B, Hope T. Clinical ethics support services in the UK: an investigation of the current provision of ethics support to health professionals in the UK. *Journal of Medical Ethics*. 2001;27suppl 1:i2-i8

⁷ UK Clinical Ethics Network website. <http://www.ethics-network.org.uk/committees>

⁸ Steinkamp N, Gordijn V, Boreveki A, Gefenas E, Glasa J, Gerrier M, Muelenbergs T, Rozynska J, Slowther A. Regulation of health care ethics committees in Europe. *Medicine healthcare and philosophy*. 2007

Many committees have a process for responding to urgent requests for advice with a small group of committee members convening to consider a case referral. In addition, some individual members of committees, usually also clinicians, are able to provide support on a day to day basis. In these situations the CEC acts as a retrospective reviewer of these cases.

The educational role of CECs can be manifest in their work of case consultation or policy development but may also occur in a more structured way through grand rounds, study days and input into Continuing Professional Development sessions.

Box 1. Some examples of the kind of work CECs carry out

Responding to requests from health professionals for advice on ethical difficulties in individual patient care:

- Questions relating to withholding or withdrawing potentially life sustaining treatment.
- Cases where the patient or members of their family are refusing treatment that the clinical team think is in the patient's interests.
- The use of an innovative or non standard treatment.
- The use of exclusion criteria for some treatments.
- Consideration of the welfare of the future child in IVF treatment.
- Disclosure of information without the patient's consent.

Providing input into Trust policies and guidelines

- Contributing to revision/ development of policies
 - Consent
 - **DNACPR**
 - Pandemic influenza response
 - Blood transfusion
 - Trust involvement with the media
 - Responding to requests for information from the police
- Identifying areas where policies might need developing
 - The use of enteral and parenteral feeding

Education of health professionals in the Trust

- Grand rounds
- Ethics study days or seminars
- Local or regional ethics conferences

Below are two personal views from different clinical ethic services operating in NHS Trusts

Newcastle upon Tyne Hospitals NHS Foundation Trust Clinical Ethics Advisory Group (CEAG)

This CEC was established in 2000, at a time when national support and guidance was not yet available – UKCEN had not yet been established. However, the Chair and founder of CEAG was invited to attend a conference of clinical ethics committees in Bath in 2002 which gave a significant impetus to the development of the CEAG and its continued collaboration with other CECs. Situated in a University city, the Newcastle CEAG has had the advantage of being able to draw on academic ethicists for our membership and this has been hugely valuable. A number of clinician members have higher degrees in ethics and law. Consequently our discussions are ‘formal’, mostly principle-driven. But it is the case that often the wisest judgements are made by members with little or no formal ethical training – CEAG members would then make an effort to express such judgements in justifiable ethical terms.

The CEAG has strong support from the Trust Board and the Chief Executive: the Trust pays the annual subscription to UKCEN and provides the CEAG with a highly competent “Legal and Committees Administrator” who acts as secretary. Meetings are held out of working hours and the time of the CEAG members is not remunerated in any way.

About 40% of our discussions have related to matters of Trust policy (resuscitation, advance directives, restraint, influenza pandemic etc) and 60% to clinical challenges (transplant issues, intensive care issues, child protection, confidentiality etc).

As an indicator of the sort of case CEAG might discuss, this is an outline of a recent case:

External Corporeal Membrane Oxygenation (ECMO) is a technique to maintain blood oxygenation when there is complete cessation of heart or lung function. ECMO is commonly applied in major heart operations. Until recently the ECMO machine has been extremely complex to operate, requiring continuous attention by a technologist; modern machines are fairly straightforward to operate and could be used in A&E departments. The question arose whether the Trust’s transplant team might use ECMO to preserve organs (particularly the kidneys and liver) of someone who has had an irreversible cardiac arrest – there is ample evidence that this is effective in improved preservation of organs for transplantation. The problem is that applying ECMO in these circumstances may sometimes reperfuse the heart with oxygenated blood, causing it to start beating again - in a patient who will have been declared dead and whose brainstem is almost certainly infarcted. The CEAG was asked to discuss the ethical implications with the leaders of the Trust’s transplant team.

Stephen Louw Chair Newcastle CEAG

Great Ormond Street Hospital (GOSH) NHS Foundation Trust Clinical Ethics Service

Some form of clinical ethics support service (CESS) for staff at GOSH has been present since 1995, initially as a Clinical Ethics Forum and later as a Committee (CEC). Staff surveys had established that ethical dilemmas were frequent and were resolved in an ad hoc fashion. They identified a need to provide a CESS that had primary functions of case analysis and discussion, teaching and training, but also had a role in policy development, research and audit.

Initially the CEC provided these functions, with over 50% of members having degrees in ethics and law. Formal academic ethics input and legal advice is also available. The CEC has undertaken both

retrospective and "hot" case analysis: a rapid response facility for acute cases was introduced in 2003-4. Meetings are held out of hours; members are not remunerated but have Trust indemnity. Essential administrative support has been provided from the Medical Director's office.

In 2005 a "part time" (0.3 whole time equivalents WTE) Consultant in Clinical Ethics was appointed to provide individual consultations and to plan further ethics service developments. Standardised referral criteria have been developed as well as detailed case recording systems and feedback to ensure that the service provided is transparent, accountable and conforms to national benchmarks as set by UKCEN (see www.ethics-network.org.uk). It is estimated that at GOSH a 0.3 WTE consultant has effectively achieved a workload comparable to that of a single full time US ethicist.

The CEC/CESS has encouraged development of subspecialty ethical expertise so that individual clinical units develop their own ethical expertise under the central "umbrella" of the CESS ("hub and spoke" model).

Over the last year the CESS/CEC has provided analysis and opinions on over 40 cases with 24 of those occupying over 240 hours of service time in accordance with its terms of reference. It has provided staff with support and education in addressing ethical issues and provided over 40 hours of specific teaching and training and 20 hours of clinical support in the form of ethical debriefings. It has also reviewed ethical aspects and content of trust policies, protocols and procedures (end of life care, limitation of treatments, pandemic influenza).

Specific practical examples of the work of the CESS/CEC have included:-

- *Discussion of a proposal to perform the first stem cell tracheal transplant in the UK*
- *Development of a Trust wide protocol for the evaluation and use of compassionate and innovative treatments*
- *Ethical implications for the use of the Berlin heart as a bridge to cardiac transplantation and the resource implications of this*
- *Analysis of disputes where the involvement of ethical review was associated with in house resolution without recourse to legal proceedings*

Vic Larcher, Chair GOSH CEC

4. The UK Clinical Ethics Network (UKCEN)

Established in 2001, the UK Clinical Ethics Network has as its aims the promotion of clinical ethics support in clinical practice in the UK, the development of a high level of ethical debate within clinical practice, and the facilitation of communication and sharing of good practice between clinical ethics committees. UKCEN is registered as a Charity and is governed by a Board of Trustees which also functions as the national executive committee. Although the majority of the Board are members of clinical ethics committee, the Network does not consider CECs the only form, or indeed necessarily the best form, of ethics support in clinical practice. However as a CEC is the predominant model in the UK, UKCEN has focussed on CECs in terms of standard setting, education and debate.

The Network has achieved a number of objectives since 2001 including:

1. Hosting an annual conference on clinical ethics.
Recent conference themes include
 - Ethics of healthcare in a multicultural society (Birmingham 2013)
 - Inequalities in Healthcare (Greenwich 2012)
 - Clinical Decision Making at the Beginning and end of life (Glasgow 2011)
 - Disability (Cardiff 2010)
 - Capacity, Responsibility, and Identity (Oxford 2009)
 - Beginning of Life, End of Life (Sheffield 2008)
2. Publishing a regular Network newsletter
3. Development of a statement on core competencies for members of CECs (paper published in Clinical Medicine March 2010)
4. Support for training workshops
5. Development of a website with information and educational materials on clinical ethics that is publicly accessible for health professionals, patients and their families (www.ethics-network.org.uk).
6. Development of a practical guide for Trusts considering developing clinical ethics support.

The UK Clinical Ethics Network has been a model for several other European Networks that have developed since 2001 and in 2010 a national clinical ethics network was established in Singapore using the UK model as its starting point⁹.

5. The international context

Clinical ethics committees have a long history in North America where they have been a feature of health care institutions since the early 1980s. Many health care institutions employ ethics consultants in addition to the ethics committee and some large hospitals have an ethics programme within the hospital. In both the United States and Canada healthcare institutions are *required* as part of their accreditation to have a mechanism for addressing the ethical issues that arise in relation to patient and the model of an ethics committee is recommended as a means of meeting this requirement. The American Society of Bioethics and Humanities has published a core competency statement for ethics case consultation and has recently published an education guide that maps on to the core competencies¹⁰.

The North American model of clinical ethic support has been influential in the development of clinical ethics committees in the UK. However there are now an increasing number of alternative models in Europe from which we can learn. In 2000, when the Royal College of Physicians report into the provision of clinical ethics support in the UK was published (see Section 1), there were very few European countries with active clinical ethics committees or ethics support programmes, with the notable exception of the Netherlands. However in the past ten years several European countries have moved well beyond what the UK has been able to offer in terms of supporting health professionals and patients in ethically difficult situations.

⁹ <http://centres.sg/> accessed 28.6.2010

¹⁰ ASBH. Core competencies for ethics consultation. 1998. <http://www.asbh.org/publications/core.html> accessed 28.6.2010

In Norway the government requires all hospitals to have a clinical ethics committee and funds an academic centre to provide training for committees, evaluation and research into the practice of clinical ethic support. In 2008 the centre was asked to develop ethics support in nursing homes and community care¹¹.

In the Netherlands the government has funded research projects on the provision of clinical ethics support and several hospitals are running moral deliberation programmes, facilitated and evaluated by clinical ethicists. Most hospitals have a clinical ethics committee as do many nursing homes¹².

Germany and Switzerland have active networks of clinical ethics committees and an increasing number of academic ethicists being appointed to provide ethics support and conduct research within hospitals in these countries.

6. Evidence based medicine and clinical ethics

As noted earlier in this document, there is an increasing acknowledgement of the importance of recognising the ethical dimension of patient care and the need to ensure health professionals have the knowledge, skills, and access to appropriate guidance to provide ethical as well as clinically competent care for their patients. However the level of investment (financial and intellectual) that has gone into investigating how best to provide appropriate and effective education, training, and guidance for health professionals in the ethical dimension of clinical practice is vanishingly small compared to that invested in evidence based clinical medicine. The new contract for NHS consultants recognised that consultants need to read, attend seminars etc to maintain and enhance their clinical skills and that such “Continuing Professional Development” required a specific time allocation in their weekly programme, typically four hours. UKCEN would argue that, if clinicians need support in CPD for clinical skills, they also need support to provide high quality ethical care.

Currently ethics teaching in undergraduate curricula and training for health professionals is extremely variable - at postgraduate (or professional) level this variability is even more pronounced. Clinicians in large teaching hospitals may have ready access to ethics support (either through a CEC in the trust or clinicians with training and experience in ethics on the staff, or in some rare instances, formally employed professional ethicists). But in district general hospitals, in primary care trusts or ambulance trust such access to ethics support may simply not be available.

7. The evidence base for the value of clinical ethics support

While it seems ‘common sense’ that ethics support services in the institutional setting may improve the ethical dimension of patient care and so improve the overall quality of health care, factual evidence in support of this contention is hard to come by and in the UK some ethicists are working with colleagues in other countries toward evaluating the benefit of ethics support to enhance

¹¹ Forde R, Pedersen R, Arke V. Clinicians’ evaluation of clinical ethics consultations in Norway: a qualitative study. *Medicine healthcare and philosophy*. 2008;11(1):17-25

¹² H H van der Kloot Meijburg, R H J ter Meulen Developing standards for institutional ethics committees: lessons from the Netherlands. *J Med Ethics* 2001;27:i36-i40 doi:10.1136/jme.27.suppl_1.i36

patient care outcomes. There are several methodological obstacles: firstly, how does one measure the 'value' of a discussion with a CEC that lends support to the clinician's dilemma of whether treatments should be intensified or curtailed; secondly, to show a 'difference' one would need very large numbers of cases and without appropriate resources for such research the studies cannot be done; thirdly, as ethics support is 'rolled out' it does have an impact beyond the immediate clinical domain and thus would tend to diminish the measurable differences in outcomes. That said, the limited research evidence available, and anecdotal evidence show clearly that clinicians who bring their cases to CECs for discussion almost invariably acknowledge the value of the discussion in clarifying their decisions^{13 14 15}.

If we consider ethics support as a potentially important contribution to high quality patient care - and it would seem that many people do (including health professionals, some NHS Trusts, the Royal College of Physicians and several health care regulatory organisations and health care systems in other countries) - it will be necessary to support both the preliminary development of such services and their rigorous evaluation.

Conclusion

We argue that the NHS cannot continue to 'do nothing' in regard to a grassroots need for clinical ethics support in the NHS, given the fact that CECs have arisen in this country and many other countries. We contend that the time is ripe for the formal recognition of CECs (or other models of ethical support for clinicians) within the NHS and indeed that their activities and influence should be extended and regulated. We believe this would be consistent with the modernisation of the NHS, public accountability of the NHS, the ethos of patient-centred care and that it would be the next rational phase in the process of embedding clinical governance.

It could be argued that, in failing to formally recognise that healthcare organisations are moral bodies, where health professionals are daily tasked with making moral decisions and that they need support in this respect, the NHS itself is failing in an important duty of care. UKCEN seeks to highlight this moral hiatus and to work with the NHS towards addressing it.

¹³ Forde et al

¹⁴ Fox

¹⁵ Fox