Ethics in practice

Background and recommendations for enhanced support

Report of a Working Party

June 2005

Royal College of Physicians
Setting higher medical standards
Members of the working party

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In 1987, the Royal College of Physicians published its guidelines for research ethics committees, under the supervision of Professors Desmond Laurence and Aubrey Diamond. At the time, there were sceptical voices who doubted the wisdom or necessity of formal mechanisms to review research. A quarter of a century later, these guidelines stand out as a significant contribution to the regulation of research involving human subjects.

In this new report, a working group consisting of members of the College’s Ethical Issues in Medicine Committee, with contributions from other medical royal colleges, has examined the need for local support for ethical judgement in clinical practice. Not so long ago, ‘ethics in medicine’ referred to little more than professional relationships among doctors. An American physician famously said of medicine that its ‘morals were about sex and ethics about money’. Those days are long past. The increasing complexity and therapeutic possibilities of medicine, the changing relationships between physicians, patients and other professionals, the advent of consumerism in the ward and the consulting room, debates about values themselves in a profession that draws its membership from a variety of cultural backgrounds: all these factors make ethical judgements harder. With this comes the need for advice that is reliable, thoughtful and informed as well as sensitive to local needs and mores.

This report discusses how such advice might be provided. I hope it will lead to wide discussion and, where necessary, action.

June 2005

Professor Carol Black
President, Royal College of Physicians
Executive summary

Background

1 Medical practitioners are encountering ethical uncertainties and even dilemmas in their daily practice with increasing frequency. This has many causes: advances in medical technology; developments in the law; more intense scrutiny of and challenge to medical decision-making by patients, the public, the media, politicians and regulatory bodies; the breakdown of consensus in a culturally diverse society; and the emergence of a multiplicity of guidelines and advisory bodies.

2 The perceived need to ensure that decisions are ethically as well as clinically defensible has led to uneven development of different kinds of ethics support for clinicians in the United Kingdom, most notably a proliferation of clinical ethics committees (CECs). For these reasons, the Royal College of Physicians’ Ethical Issues in Medicine Committee established a working party to consider the forms of ethics support that would be most appropriate for individual clinicians, clinical teams and healthcare institutions.

Methods

3 The working party was established in 2004 and met five times. Membership was drawn from the College’s Ethical Issues in Medicine Committee and, in addition, several medical royal colleges and the Royal College of Nursing. It included members from lay and management backgrounds.

4 Evidence was taken from witnesses chosen for their experience and expertise. They gave personal presentations or written submissions. There were visits to two hospitals, one with and one without a CEC. Information was also obtained from a questionnaire survey of specialist registrars represented by the College.

5 An initial draft report was sent out for consultation to an outside expert, Dr Anne Slowther. A subsequent draft was the subject of a wider consultation which sought the views of our original witnesses, the members of the Ethical Issues in Medicine Committee, the College’s Council, and representatives of the other Colleges who had contributed members to the working party.

Findings

6 Traditional sources of ethics support and advice include discussion with senior colleagues and peers, and guidelines issued by organisations such as the General Medical Council or the royal colleges. This guidance covers topics such as withdrawing and
withholding life-prolonging treatments, and the responsibilities of doctors in child protection cases with respect to confidentiality. It has been supplemented by advice from specialist groups such as the Human Genetics Commission, focussing on specific areas.

7 The boundary between medical ethics and the law is becoming more complex. Matters formerly regarded as 'purely ethical' are now subject to common law and shaped by decisions in specific cases (eg the Bland and Egdell decisions). An increasing number of statutes (for example the Mental Health Act and the Data Protection Act) impact directly on medical practice. For these reasons, written guidelines may be inadequate. Increasingly, clinicians may need a knowledge of the law and guidance in the interpretation of the law in individual cases. One response to this increasing complexity has been the development of clinical ethics committees.

**Clinical ethics committees (CECs)**

8 CECs have a variety of functions: educating, developing policies and guidelines within institutions, providing advice on particular cases, and participating in matters relating to ‘organisational ethics’ (for example policies on eligibility for treatment or the management of waiting lists). The 70 CECS in the UK are linked through the UK Clinical Ethics Network. There has, however, been little evaluation of their work.

9 CECs may work in different ways and have different positions within the organisations they serve, in particular with respect to the clinical governance structure. They may meet formally and regularly or be convened *ad hoc*. They may provide only non-urgent advice but some may have a ‘rapid response’ facility. Membership and the range of expertise also vary, as does the balance between ‘core’ and ‘co-opted’ members. Members have a variable amount of specific training in clinical ethics and adjacent disciplines such as medical law. The role of the CEC is to provide advice rather than serve as a proxy decision-maker or quasi-regulatory body. A wide range of issues is addressed, for example the refusal of life-saving treatment, the use of covert therapy, and the retention of organs. In some cases, the CEC may act as the ‘ethical conscience’ of the institution.

10 The working party identified twenty separate challenges facing CECs. They included: being able to provide timely advice; ensuring that there was sufficient expertise to guarantee the quality of the advice; making clear what they had to offer; dealing with clinician’s concerns about the loss of autonomy; having and maintaining a significant impact within the host organisation; and securing sufficient funding and administrative support.

11 There has been insufficient research into the value of CECs, in part due to uncertainty about the appropriate outcome measures.

**Other sources of ethics support**

12 In addition to CECs, there are other important sources of ethics support. The British Medical Association’s Ethics Unit provides comprehensive phone support, a website and a variety of publications, most notably *Medical ethics today* (available on CD). The Medical Defence Union and the Medical Protection Society offer 24-hour advice lines for their members. Both of these bodies are seeing a sharp rise in consultations. In addition, ethics
Executive summary

advice is provided through the guidelines published by medical royal colleges, regulatory bodies, and non-governmental bodies such as the Nuffield Council on Bioethics. There are national specialty- and disease-specific ethics support groups. Clinical ethicists have played an increasing role both within institutions and in shaping policy and guidelines at a national level.

13 A survey of 1,146 specialist registrars training in medical specialties and represented by the Royal College of Physicians revealed that many trainees had had little ethics training, that they frequently encountered ethical dilemmas in clinical practice, and that their training did not provide them with the skills to address these issues. The preferred mode of additional support was through senior colleagues, clinicians with an interest in ethics, or clinical ethicists or clinical ethics committees.

Summary of conclusions and recommendations

14 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.

15 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.

16 In many institutions, for much of the time, a combination of current arrangements for informal advice from seniors and peers, supplemented by national sources of advice (such as the BMA Ethics Unit, medical defence organisations and guidelines from the General Medical Council, royal colleges and other bodies) may be considered adequate.

17 It is essential that key personnel who are to provide advice are identified and are qualified to do so, and that ready access to national sources of advice is available 24 hours a day, seven days a week, in a location that is known to all who work in the institution. Information about this should be available in induction packs.

18 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.

19 Where the establishment of the CEC is seen to be necessary, it is essential that the various challenges it is likely to encounter are addressed. These have informed the recommendations which follow. The recommendations should be regarded as provisional and subject to review in the light of further experience.

- Membership should include a wide range of expertise (clinical, legal, ethical, management etc) and should include the patient perspective. If the committee is going to be small enough to function effectively, the necessary breadth of knowledge and
competence may be best achieved by a ‘core plus options’ arrangement, whereby additional expertise (e.g. a clinical specialist or a professional ethicist) is requisitioned as required. There should be between eight and 14 core members.

There should be an agreed statement of core competencies for an effective CEC and the necessary training and education should be provided for members to meet them. The role of independent, lay ethics and spiritual input should be clarified.

CECs should be aware of, and responsive to, the beliefs, languages and practices of the population they serve. A minimal set of training requirements for CEC members should be established, perhaps by the UK Clinical Ethics Network, and the means by which those requirements are to be met should be considered. Training should be ongoing.

All CECs should develop mechanisms to ensure that they are able to respond in a timely fashion and, if necessary, to provide support and advice in urgent cases.

The legal status of any advice — whether guidance, support or direction — needs to be clarified at the outset.

The existence of the CEC must be publicised throughout the host institution and other local institutions which may benefit from its support. There should be a clear procedure for the referral of cases. In order to have an impact the CEC should ensure there are resources available for disseminating guidelines and policies and for feeding back the outcome of discussion of cases to the relevant clinical setting.

The CEC’s activities should be audited to ensure that its advice is consistent and to evaluate its contribution to an organisational ethic, memory and conscience.

From the outset, resources should be agreed to ensure the long-term viability of the CEC. Its ‘location’ within the institution (particularly with respect to governance structures), and its reporting mechanisms should be made clear without jeopardising its independence.

Policies should be established to ensure that case discussions in the CEC are recorded in the patient’s notes in compliance with the Freedom of Information Act, and so that the outcome of instructive cases can be disseminated without infringing patient confidentiality.

In some situations it will be helpful to have CECs of a more specialised kind, particularly in highly technical areas such as fertility and genetics services.

There should be a commitment to developing an effective interface between the CEC and national forms of clinical ethics support, possibly through the UK Clinical Ethics Network.

20 There should a review of the role of clinical ethicists in the NHS.

21 Although this report has focussed on clinical ethics support for practitioners, this must be accompanied by the development of appropriate awareness, skills and attitudes in doctors and other health professionals through effective education. Clinical ethics should be regarded as a core subject in the undergraduate medical and nursing curriculum, in postgraduate training and in the continuing professional development of career grade staff.
Background
1 Introduction

1.1 General background

The practice of medicine involves scientific judgements about the effectiveness of treatments and other interventions.\(^1\) It also involves value judgements. Sometimes value judgements are explicit, as when a doctor reflects on his or her moral views about whether abortion should be permitted. In most cases however, value judgements are implicit in what might appear to be ‘purely clinical’ decisions. Doctors may not always be aware that they are making value judgements – as when, for example, they are considering what would be in an incompetent patient’s ‘best interests’, when they are weighing up whether harm to a third party is sufficiently ‘serious’ to justify a breach of patient confidentiality, or when assessing ‘quality of life’ in intensive care.

Good medical practice requires that value judgements are properly analysed and assessed, just as scientific and technical evidence should be properly evaluated and decisions ‘evidence-based’. Doctors and other health care professionals should be able to justify the value judgements as well as the scientific judgements they make.

The ethical dimensions of health care practice have become more prominent in recent years, initially in the United States in the 1970s and 1980s and subsequently elsewhere.\(^2\) This has been due to a number of factors. Firstly, public attitudes to the professions have changed and there is an expectation that decisions made by doctors should be based on more than tradition or authority. Increasingly, nurses and other health professionals also expect to be involved in ethical decisions. Secondly, technological developments such as those in organ transplantation, intensive and critical care and assisted reproductive technologies have created new ethical problems and exacerbated old ones. Thirdly, high profile cases presenting difficult ethical challenges – for example the Karen Ann Quinlan case in the mid 1970s in the United States,\(^3\) the Cox and Gillick cases in the UK\(^4,5\) and the reports of the Bristol and Alder Hey inquiries – have increased media and public scrutiny of medicine and led to calls for health professionals and managers to justify their practice in ethical as well as scientific or technical terms.\(^6\) Aspects of medical practice which present important ethical challenges have included consent, competence, patient autonomy, rights of conscience, resource allocation, medical futility, the treatment of children, withholding and withdrawing life-prolonging treatment, reproductive choice, genetic testing, confidentiality, conflicts of interest, financial incentives, disclosure of medical error, and surrogate or proxy decision-making.
This increased awareness of the ethical dimension of medicine has been reflected in four major developments:

1. laws and guidelines designed to regulate medical practice in ethically sensitive areas
2. a greater emphasis on ethics in the medical curriculum
3. innovative forms of ethics support in the clinical setting, and
4. increased use of existing sources of ethico-legal support such as the British Medical Association (BMA), the Medical Defence Union (MDU) and the Medical Protection Society (MPS).

Legal developments have included statutes such as the Children Act, the Human Fertilisation and Embryology Act, the Mental Health Act, the Human Tissue Act, and the Human Rights Act. Further bills such as the Mental Capacity Bill and the Assisted Dying for the Terminally Ill Bill are currently under consideration. There have also been significant developments in common law with influential cases such as Gillick,5 Bland,7 Bolitho8 and Sidaway.9 Numerous guidelines have also been published, including those from the General Medical Council (GMC) on confidentiality,10 withholding and withdrawing life-prolonging treatment,11 and consent,12 those from the Department of Health,13 those from the BMA,14 those from the medical royal colleges, those from government advisory committees such as the Human Genetics Commission, and those from patient organisations.15

Although ethics education has been part of medical training for many years (some courses originating from initiatives of the medical ethics groups and the Institute of Medical Ethics in the 1970s (see below)), the publication in 1993 by the GMC of *Tomorrow’s doctors*,16 identified education in ethics as a core requirement of medical education: medical ethics education took off. In 1998, a consortium of medical ethics teachers in United Kingdom medical schools published a consensus statement setting out a core curriculum.17 In subsequent years, ethics and communication skills have also featured in higher professional examinations.

The rapidly increasing use of existing forms of ethics support is an indicator of the growing importance of ethics concerns. The BMA, for example, has noted a sharp rise in enquiries from doctors and in calls to the telephone advice line of its ethics unit. Similar trends have been seen by the MDU and the MPS.

The 1980s and 1990s also witnessed the dissemination of innovative forms of ethics support and consultation.18 By 2000, a Nuffield Trust report19 identified twenty clinical ethics committees (CECs) in UK NHS trusts and commitments by 20 additional trusts to establish committees.

1.2 Why the working party was established

A perceived need at the clinical level has, over the last decade, prompted ‘bottom up’ developments of a variety of forms of clinical ethics support. There have also been important recent proposals in medical law (eg the Human Tissue Act, the Assisted Dying for the
Terminally Ill Bill and various cases currently with the Official Solicitor). Taken in conjunction with the fact that the last authoritative review of CECs (the Nuffield Report) was published as long ago as 2001, a reconsideration of the current ethics support and its possible future development is timely.

In 2004, therefore, the Royal College of Physicians Ethical Issues in Medicine Committee established a working party to consider the forms of ethics support that would be most appropriate for individual clinicians, clinical teams and healthcare institutions.

The working party considered the following questions.

- Is there a need for ethics support in all clinical settings?
- If there is a need, how can such support be provided in a timely manner in what are often rapidly evolving clinical situations?
- How can ‘quality control’ in ethics support be ensured? In particular, how can it be ensured that ethics support is informed by current law, regulations and guidelines, that it is shaped by appropriate methods of thinking about ethics and ethical frameworks, and that it remains up to date despite rapid changes in the legal and ethical framework of medicine?
- Good quality ethics support needs to be sensitive to the cultural beliefs and mores of local populations. How is it possible to ensure that local support is appropriately nuanced?
- Ethics support and advice should be independent of the clinical setting (so that there is a place where issues can be discussed freely) and of institutional pressures. How can this independence be secured?
- How would ethics support provide or facilitate education and promote organisational ethics in addition to helping with particular cases?
- What should the key competencies of ethics committee members be? How would adequate education and training most effectively be provided for them?
- How would ethics committees support policy development within their parent institutions?
- Can the involvement of CECs sometimes cause problems?
- Finally, what would be the appropriate institutional location of CECs? How would they relate to, for example, disciplinary structures and clinical governance?

Although the proliferation of CECs was one of the most important reasons for setting up this working party (see the working party’s remit in Appendix 1) it soon became evident that a variety of forms of clinical ethics support would be necessary to meet the needs of different clinicians, in different kinds of institutions, facing different problems. It was also clear that it would be necessary to consider the interface between ‘in-house’ forms of clinical ethics support and regional or national support such as that provided by the BMA.
1.3 Membership of the working party

The membership of the working party was drawn from the clinical and non-medical members of the College’s Ethical Issues in Medicine Committee. In addition there were representatives from the Royal College of Physicians’ Patient and Carer Network, and the Royal Colleges of Nursing, of Psychiatrists, of Paediatrics and Child Health, and of Obstetricians and Gynaecologists. The non-clinical members included bioethicists, a barrister and a senior hospital manager.

Details of working party members can be found at the front of this book.

1.4 Method of working

After a preliminary meeting in December 2003, the working party had its first full meeting in May 2004. The work plan involved:

- discussion between members of the working party
- written or oral evidence from witnesses
- visits to two hospitals (one with a well-established CEC and one with no CEC)
- a questionnaire survey of specialist registrars
- a literature search.

There were two rounds of consultation. An initial draft of the report was sent to Dr Anne Slowther (co-author of the earlier Nuffield Report) for comment. Once these comments had been incorporated, alongside further reflections from members of the working party, the draft was circulated more widely to members of the Ethical Issues in Medicine Committee and to the Royal College of Physicians’ Council. Because the membership of the working party was drawn from several Colleges, a subsequent draft was then submitted for approval to the Royal Colleges of Nursing, of Obstetricians and Gynaecologists, of Paediatrics and Child Health, and of Psychiatrists.

1.5 Witnesses and visits

Witnesses were chosen on the basis of their expertise and knowledge (see Appendix 2). Many had been actively involved in either establishing or running CECs or had been long-standing members of such committees. The working party received presentations in person or written submissions.

The working party undertook the following hospital visits.

- **Hope Hospital, Salford**, which does not currently have a clinical ethics committee. This visit was attended by approximately 25 members of staff including nurses, consultants, junior doctors, senior managers and those in professions allied to medicine.
St Mary’s Hospital in Paddington, London, which has a well-established clinical ethics committee. This meeting was attended by members of its CEC and other members of staff.

The report was, therefore, based upon multiple sources: information provided by witnesses, observations and discussions at hospital visits, the findings of the questionnaire of physicians in higher training and the deliberations of the working party.

1.6 Outline of this report

Chapter 2 briefly describes traditional forms of ethics support and advice at the national level. Chapter 3 describes, again briefly, local forms of such ethics support. Chapter 4 reports the findings of the working party on the role of CECs (or forums) and sets outs some of the challenges that were identified as facing such committees, including the need for their work to be evaluated. In Chapter 5, other forms of ethics support, such as that provided by the BMA, are considered. Chapter 6 reports on a questionnaire survey of 1,146 specialist registrars about the need for ethics support. Chapter 7 summarises our conclusions and recommendations. There are several appendices.
2 Ethics advice at the national level

Doctors, in common with other professionals, have traditionally sought ethical advice through discussion with senior or more experienced colleagues. On occasions, however, the complexity of regulation and professional guidelines, and dissent about what constitutes ‘good practice’, have led doctors to seek out more expert help. External sources from which such help has been sought have included regulatory bodies such as the GMC, professional bodies such as the BMA and medical royal colleges, other advisory bodies and the courts. The Healthcare Commission and the National Institute for Health and Clinical Excellence (NICE) are more recently-established bodies guiding ethical decisions, such as resource allocation.

As a regulatory body, the GMC is particularly important for doctors and publishes a series of frequently updated guidelines.10,11,12,20,21 For doctors in highly specialised areas, bodies such as the Human Fertilisation and Embryology Authority provide more specific guidance.22

Medical royal colleges have also published ethical guidance,23,24 much of which is available on the Internet. Some colleges also offer ad hoc advice to their members.

Non-governmental, voluntary and governmental bodies such as the Nuffield Council on Bioethics, the Genetic Interest Group and the Human Genetics Commission also provide advice, which is, again, often available on the Internet.

In addition to the role played by guidelines and these other sources of advice, both common and statute law inevitably play an important role in shaping ethical practice. For example, medical practice in relation to treatment withdrawal, consent and confidentiality has been crucially informed by common law cases such as Bland,7 Gillick5 and Egdell.25 Moreover, in more recent cases, the courts have increasingly adopted the role of final arbiter in ethical disputes, as for example in Re F.26,27 Increasingly too, statutes such as the Mental Health Act, the Children Act, the Data Protection Act and the Human Tissue Act shape medical practice.

However valuable they may be, law and professional guidance may nonetheless fail to dictate what ought – or even must – be done in individual cases. Professional guidance and law can sometimes be in conflict – as happened recently in the Leslie Burke case28 – but even where this is not the case, guidance and the law may well require local interpretation. If doctors are advised by professional guidelines, such as those of the GMC, that confidentiality may be breached where there is a risk of death or serious harm to a patient or third parties,20 the question of what is to count as ‘serious harm’ in a particular case is left unanswered. Similarly, what does ‘best interest’ mean for a particular incompetent patient? The
requirement for ethical judgement in relation to individual cases means that doctors may need access to appropriate forms of ethics advice, complementary to legal and professional guidance.

Some advice of this kind is available nationally from the BMA’s Ethics Unit (see Appendix 3) which offers a telephone helpline and in 1993 published its book, *Medical ethics today*.30 This was updated in 2004, when it also became available on CD.31 In addition to the ethico-legal advice offered by the BMA, medical defence bodies also offer advice at the national level (see Chapter 5).
Ethics advice at a local level

The most notable result of the increasing awareness among health professionals of the need for appropriate local forms of ethics support and advice, to complement guidelines, the law and national forms of advice, has been the local innovation, often led by doctors themselves, of various forms of clinical (as opposed to research) ethics committee. In the USA, the committees were first established in the 1960s in Catholic hospitals with committees for the discussion of morals in medicine. Over the next 20 years review committees for abortion, infant care and kidney dialysis selection developed in various states. In addition, the growth of ethics support was driven by the courts following the Karen Ann Quinlan case and by a President’s Commission. By 1987, 60% of American hospitals had either a CEC or a formal ethics consultation service. The 1992 recommendations of the Joint Commission on the Accreditation of Healthcare Organisations made a mechanism for addressing ethical issues in patient care mandatory. As a result, such provision is now universal.

In mainland Europe, developments have been slower. However, CECs now exist in countries such as the Netherlands, Belgium, France, Spain, Italy, Norway and Germany, as well as in some central European countries. They are closely regulated in Belgium, Spain and Norway.

In the UK, the development of CECs was initially sporadic. A major early influence came from the London Medical Group, a conglomeration of medical student societies organised under the guidance of Edward Shotter of the Student Christian Movement. By the mid 1970s, most medical schools had a medical group of this kind. From the London Medical Group came the Institute of Medical Ethics which, with GMC encouragement, investigated the teaching of medical ethics in the 1987 Pond Report. One of the first CECs was established in 1983 by the Royal Bethlehem & Maudsley Special Health Authority, and was followed by those at Great Ormond Street Children’s Hospital (1992), Leeds (1993), Oxford, Nottingham and West Glamorgan (1994), St Bartholomew’s & the London (1995), St Mary’s Hospital London (1997). By 2000, the Nuffield Report (see below) identified 20 NHS trusts with established CECs and 20 others planning to establish one.

The Nuffield Trust report, Clinical ethics support in the UK: a review of the current position and likely development (henceforth ‘The Nuffield Report’) was published in 2001 on the basis of empirical research carried out by the Ethox Centre at the University of Oxford. Supporting the claim that CECs were most often initiated by doctors themselves, it found:

Most of the committees were established because of concern by clinicians about difficult cases that they had encountered. Two committees developed… when it became clear that here was a need to consider ethical issues arising in the trust that did not relate to research. One
committee was established on the initiative of the trust board and one on the initiative of the health authority Chief Medical Officer. The Nuffield Report found significant variation in the form of ethics support in trusts. Some CECs were located within the trust’s management structure; others less formally as an independent ‘forum’ or discussion group.

Although recently they have considered ethical issues of a more organisational or institutional kind, CECs have hitherto served three main functions.

1 **Education**: raising the awareness of ethical issues and aiding the development of skills to identify and analyse issues in daily practice.

2 **Policy and guidelines**: developing and providing input to policies originating from either the trust or the Department of Health (e.g., advance directives), identifying areas where a written policy would be useful and reviewing existing policies from an ethical perspective.

3 **Case consultation**: assisting with individual cases, not by a prescriptive ‘solution’ but by analysis and advice. Some CECs offer a rapid response service for urgent cases by making a contact number available.

‘Organisational ethics’ refers to issues such as resource allocation, working rotas, eligibility for treatment and the management of waiting lists. Most UK CECs have avoided involvement in these areas, but in the USA organisational ethics is of increasing importance.

The Nuffield Report noted that there was little contact between CECs. This led, in 2001, to the establishment of a national network facilitated by the Ethox Centre, with an annual meeting, newsletter and short training courses. This initiative aimed to:

- promote development of ethics support in clinical practice
- promote a high level of ethical debate in clinical practice
- facilitate communication between all UK CECs.

In 2003, the Ethox Centre received Department of Health funding to develop support for the network, a website and a manual for CECs ([www.ethics-network.org.uk](http://www.ethics-network.org.uk)). By 2004, the number of CECs had increased to 70, despite the fact that some of the earliest committees had dissolved or become something less formal (see Chapter 4). The Nuffield Report noted some published evaluation of CECs, but added that:

> there [had] been little rigorous evaluation of outcomes with most research looking at process data such as satisfaction of health professionals and patients.

While general satisfaction among users appeared high, longer-term evaluative studies using outcome as well as process data are needed. There have been other calls for research on CECs (see section 4.2.16).
Findings
Clinical ethics committees:
key competencies and characteristics

The working party did not prejudge whether the requirements of clinicians would best be addressed by an ethics committee, by another form of ethics support or by no formal ethics mechanism at all. Nevertheless, given the prominence of CECs, the working party did place the effectiveness and use of CECs at the centre of its deliberations. These deliberations were directed by the questions set out in section 1.2, although we were by no means able to provide answers to them all.

4.1 Current provision of clinical ethics committees

What kinds of CECs exist and what do they do? The working party drew on the evidence provided by the literature, interviews and site visits.

4.1.1 Models of ethics support

Most CECs meet regularly (typically once a month), are formally constituted and often report to clinical governance committees. Some committees were initially created as a discussion forum for the consideration of difficult cases and were only subsequently adopted into the governance structure, while others were located there from the start. In other trusts a committee within the governance structure has been resisted and ethics support continues to take the form of an independent forum. Some feel that it is important for the CEC not to be seen as having a regulatory or managerial function so that health care staff feel able to attend and, once there, speak freely. In other cases it was felt that the committee would be taken seriously only if it was part of the institutional hierarchy. Some committees have moved in the opposite direction, replacing formal regular meetings with less formal ad hoc gatherings.

In order to be able to provide timely advice and support some committees (notably those at St Mary’s in Paddington, Great Ormond Street Hospital and Bath) have created a facility for ‘rapid response’ whereby a contact person is available to take calls and bring together at relatively short notice an ad hoc team of committee members to help with a particular case. Aware of the limited expertise of any committee, other committees have adopted a ‘core plus options’ approach (see section 4.1.3).

Less commonly, CECs have obtained the services of a ‘clinical ethicist’, either part-time or full-time, perhaps through a link with a clinical school or university department, who is
able to provide ethics support and education in the clinical setting and a link between the CEC and the ‘front line’.

One committee has proposed combining the CEC with a network of clinicians willing to act as link persons in the clinical settings.

4.1.2 Ethics committees based outside hospitals

Ethics committees and other forms of ethics support are also being developed outside hospitals. Examples include an ethics committee established by an ambulance trust, priority setting groups and ethics committees established by primary care trusts (PCTs). The Human Fertilisation and Embryology Authority recommends that fertility clinics should have access to ethics support and this has also led some such clinics to establish an ethics committee. Mental health trusts have also expressed interest in developing specialist CECs. As of January 2005, six mental health trusts have committees. There are also some regional committees.

4.1.3 Membership

CECs usually have between 10 and 25 members. They have at least one lay member and usually more. In at least one case the chair of the committee is lay, and in others the deputy chair is lay. Committees will usually have at least one member, and usually more, who is a consultant (sometimes the medical director). Many committees include a trust manager, and others include some combination of the following: junior doctor, nurse, nurse manager, lawyer (sometimes the trust solicitor but usually not), GP, trust board member, chaplain, other clinical professional (eg a physiotherapist), representative of the patient advisory and liaison service (PALS) or social worker. Some committees also include an ethicist or moral philosopher with an academic background as a member. One committee has three such members.

In some cases a core membership meets regularly, while individuals with special expertise are co-opted when a case raises issues beyond the competence of the core members. Typical membership includes some or all of the following:

- two or three lay members
- two or three senior hospital doctors
- a GP
- an ethicist/moral philosopher
- nurses
- representatives from professions allied to medicine (eg physiotherapist)
- a social worker
- a chaplain (or faith representative)
- a lawyer
Clinical ethics committees: key competencies and characteristics

- a patient advisory and liaison service/community health council representative
- a member of the trust board.

4.1.4 Expertise

In many cases the core and ‘add on’ competencies required of a CEC have been identified largely in terms of specific disciplinary expertise (for example the need to have representation from nursing). Currently there is not, however, either an agreed set of required disciplines or any standard educational training for those who provide ethics consultation either singly or as a member of a committee. This is why the model described in a recent position paper has emphasised ‘competencies’ rather than disciplines.45

The competencies include skills, knowledge and attitudes. Under each heading one could identify a formidable list of desiderata. CECs should include members with the ability to:

- identify the nature of the value judgement, uncertainty or conflict underlying the need for ethics consultation
- build a moral consensus
- listen well and communicate interest, respect, support and empathy to involved parties
- recognise and address various barriers to communication.

Collectively the committee should know about moral reasoning and ethical theory, how healthcare systems work, local policies that are relevant for ethics consultation and, of course, key guidelines and the law as it applies to health. Other attitudinal traits are necessary, such as tolerance, compassion, integrity, patience, and a willingness to consider and take seriously opposing views and to concentrate on the details of a difficult case. Honesty, courage and humility are also important.

4.1.5 The education and training of committee members

The education and training of committee members will continue to be a key determinant of the success of any mode of ethics support.

Some members have a formal qualification in ethics, such as a postgraduate degree. The Nuffield Report19 found that in one committee 30% of members had had some ethics training. The ethics training of committee members can vary between attendance at a one- or two-day course on clinical ethics (such as the workshops run by the Ethox Centre) or a one-week course such as Imperial College’s annual intensive course in medical ethics, through to a two-year masters degree.

Regional courses and training are also beginning to develop. Some committees have instituted annual training days for committee members. One key event is the annual national CEC conference organised by the UK Clinical Ethics Network.

Our evidence suggests that the situation has improved since 2000, when the Nuffield Report found that few committees had anyone with expertise in ethics. Most CECs now have at least one member with such expertise.
4.1.6 The role of committees in clinical decision-making

All of our witnesses emphasised that the CECs of which they were aware did not see themselves as proxy decision-making or quasi-regulatory bodies. What they aim to offer is a multidisciplinary forum for the discussion of difficult cases and ethical issues in a way that is supportive rather than directive.

The reasons for adopting this stance vary. In most cases, committees argue that a multidisciplinary deliberative forum is the best way of arriving at reasoned and reasonable options for ways forward in difficult clinical situations. The committees also allow those who approach them a certain amount of distance from pressures, such as fear of judgement by colleagues, although some of our witnesses felt that these benefits would be felt only if it were made very clear that the committee’s role was purely advisory, so that clinicians could bring cases to it without fearing that their clinical judgement or autonomy were being undermined.

Nevertheless, our witnesses indicated two reasons for caution. Firstly, clinicians sometimes do want the CEC to come to a conclusion and make a recommendation. Secondly, even where the CEC makes it clear that it is not a decision-making or regulatory body, there is a potential for its advice to be seen as binding (see 4.2.7). This could produce difficulties if a clinician were to override the CEC or to even fail to consult it at all and subsequently be sued for negligence. Another, opposite, problem might arise if the CEC’s advice were to be followed by a clinician who is then the subject of a legal action. In a situation such as this, the committee might be concerned about its legal liability.

4.1.7 Cases consulted

CECs address a wide range of cases, including:

- advance directives
- use of assisted reproductive technologies
- confidentiality and HIV testing
- treatment of children
- confidentiality in genetics
- conflict between relatives of an incompetent patient
- use of covert therapy
- discussion of ‘do not attempt resuscitation’ (DNAR) orders with patients
- neonatal care
- non-heart-beating organ donation
- organisational ethics (eg effective dissemination of policies)
- violence in accident and emergency
- refusal of life-saving treatment
refusal of spouse to give permission for life-saving treatment because of patient’s previously expressed wishes

use of restraints to allow treatment

use of scarce resources

retained organs

withdrawal of treatment.

4.1.8 Level of demand

Most CECs deal with at least one case per monthly meeting. Sometimes, as with the Genethics Club which deals with up to 20 cases per meeting, the workload may be greater. The vast majority of cases discussed are retrospective, or relate to ongoing, ‘non-emergency’ cases. These tend to be brought to the committee because they proved (or are proving) difficult to deal with in their own right, and sometimes also because there had been similar cases which led clinicians to recognise a recurring issue. In retrospective cases the discussion aimed to be educational, or to help clinical teams to deal with similar issues in the future or to prompt the formulation of a policy.

Some cases are more urgent. Between its inception in 1997 and 2004, the committee at St Mary’s Hospital dealt with 60 ‘hot’ cases – approximately eight per year. The committee at the Pennine Acute Hospitals trust dealt with three emergency cases in six months. Great Ormond Street Hospital’s committee has received roughly one case per month, although this has been increasing recently.

4.1.9 Policy and organisational work

All of the CECs surveyed have been involved in the development of policies or guidelines. This comes about in a variety of ways.

In some cases the CEC will identify an area of practice (perhaps arising out of discussion of a difficult case) in which a policy or guidance might be helpful. An example of this might be a policy on advance directives following a case in which clinicians have found it difficult to decide whether such an advance statement was valid. In other cases, the CEC is invited to contribute to a policy being developed elsewhere; for example by another committee in the trust such as the resuscitation committee. In still others, the CEC has looked at existing policies within the trust to see whether there are possible improvements or important ethical implications. Finally, some CECs have responded to national guidelines, or developments in law and attempted to interpret these for the local context, for example by developing a policy on the discussion of DNAR following the Department of Health directive.

The kinds of policies and guidelines to which committees have contributed cover a wide range of clinical practice, including:

- abuse of services by member of the public
- advance directives
- confidentiality
- commercial use of tissue
- consent (procedures)
- consent for DNA testing
- consent to participate in the education of medical students
- dealing with the media
- do not attempt resuscitation
- elective ventilation
- guidelines for HIV testing
- possession of illicit drugs
- the rights and duties of relatives
- the use of restraints

A reasonably comprehensive list of policies, along with examples, can be found on the UK Clinical Ethics Network website (www.ethics-network.org.uk).

4.1.10 Educational role

All of the committees listed education as one of their key aims. In practice, however, few had been able to provide much substantial education in their trust, often because of a lack of resources and, most importantly, time.

The Oxford Radcliffe Hospital’s ethics committee has run a series of in-house, one-hour lunchtime seminars on the legal and ethical issues surrounding consent, confidentiality, resuscitation, competence and end of life decision-making. These were run twice in 2002 but, despite having proved very popular, have not been repeated because of workload pressures. In Bath, the CEC has published and distributed a leaflet setting out key policies. Many CECs see their primary educational role as making sure that trust staff are aware of current guidelines and policies.

Some CECs have been more adventurous. The Brighton committee has successfully run an open ethics forum on two occasions, attracting around 100 members of staff. Some of the most successful educational activities have involved members of the committee presenting seminars in clinical teams; or, in some cases, running regular ethics discussion groups for a clinical team. In Oxford an ethics group, created to discuss cases that have arisen during the past month and run by a clinical ethicist, has been in operation in the clinical genetics unit for the past four years. This has proved extremely effective at a local level and has led to calls from other units for the establishment of a national forum (see 5.4). This kind of specialty-focused education is, however, very labour intensive and only possible because the group is funded by the university.
4.2 Challenges facing clinical ethics committees

4.2.1 Timelines

It is not possible to predict the time and clinical setting in which ethical issues will arise. Sometimes urgent advice is required, often outside normal working hours. In other cases, perhaps the majority, ethical issues will arise in ongoing cases and, while immediate ethics input may not be required, something more flexible than that provided by a monthly committee meeting may be needed. Our evidence suggests that whilst acute cases requiring immediate ethics input do occur, they are only quite rarely brought to CECs. This may, however, reflect the fact that urgent ethics support is not always available. If such a service were provided, it is likely in our view that it would uncover an unmet need and result in increased demand. In any case, an effective ethics support system will need to be able to respond reasonably quickly – even if this is most likely to be a matter of hours or days rather than minutes. Some of the CECs we heard about had developed mechanisms for responding rapidly. The St Mary’s committee releases the contact details of a few readily available committee members. These members hear the case, provide preliminary reflection and discussion, and consult other members of the committee and sometimes figures from outside the committee.

4.2.2 Sensitivity to clinical reality

Good quality ethics support needs to be sensitive and responsive to the clinical reality surrounding the individual case. This is why national resources, whilst extremely useful (as evidenced by the services offered by the BMA, the MPS and the MDU), have to be complemented by local support.

4.2.3 Sensitivity to local populations and their beliefs, languages and practices

Support intended to help health professionals work both ethically and sensitively will need to take into account and be responsive to, the needs, beliefs and practices of the local community. This has training implications.

4.2.4 Quality of advice

The quality of advice depends upon:

- the appropriate multidisciplinarity of the membership
- whether lay committee members are actively involved
- the quality of the CEC’s chairman and administrative support
- the ethical skills and training of committee members
- the availability of additional advice about ethics and the law
- appropriate faith input.
4.2.5 *Clarifying what is on offer: support or advice?*

At the moment, most ethics committees see their role as supportive and advisory rather than regulatory, managerial or directive. They identify and help to clarify the uncertainties or conflicts that have prompted ethics consultation and help to make explicit the legal implications of different options and the relevant fundamental principles of biomedical ethics. It is difficult to find a path between being unhelpfully indecisive on the one hand, and ‘laying down the law’ by giving an ‘unequivocally correct’ course of action on the other.

4.2.6 *Professional autonomy*

Formal clinical ethics support may seem to threaten professional autonomy. This anxiety can best be addressed by making sure that the advisory and supportive nature of the committee’s role is clear.

4.2.7 *The legal standing of CECs*

The legal status of the decisions, advice and guidance offered by CECs in the UK is currently uncertain, raising important questions about the long-term feasibility of the current ‘advisory’ or ‘supportive’ role of committees. It is important that the legal status of the advice given by CECs should be made clear. This lack of clarity became apparent to the working party as it received conflicting views from expert witnesses!

Because there is so much uncertainty about the legal responsibilities and liabilities of members for the effects of their advice on clinical practice, it is reassuring that in all CECs we heard about, indemnity had been secured for their members through the trust.

4.2.8 *Ethics reports in patient records*

When cases are brought to the CEC for discussion, how should this be recorded? Should it be obligatory for a record of deliberations and their relevance to the final decision to be recorded in the patient’s medical notes? If so, how should they be recorded?

4.2.9 *The clinical ethics committee’s location within the institution*

Some healthcare institutions have taken the view that, in order to be effective, a CEC must be as free as possible from outside pressures. Health professionals may feel reluctant to seek the advice of a committee if they perceive it to be an instrument of regulation or another way of managing their practice. Others have argued that CECs ought to aim to bring about institutional change, and that this requires that they should have a clear location within, for example, the clinical governance structure. There is a need to come to an agreement, perhaps locally, about the balance between independence and influence.

4.2.10 *Publicity accessibility, and effectiveness*

The effectiveness of a clinical ethics support system depends upon those who work in, and are treated by, its healthcare institution knowing of its existence and the service it provides, so that it will be the natural port of call for anyone facing an ethical dilemma. A key challenge
for CECs will be to ensure that when health care professionals are confronted by morally difficult decisions they know where to turn to for help. CECs will need to publicise their own existence.

The working party heard and read of instances where CECs spent time and effort developing policies, patient information leaflets and so on which did not reach their target audience. In other cases, policies were developed and disseminated but there were no resources to determine whether they were implemented or effective. Impact depends in part on publicity. An effective source of ethics support and advice will be known to those whom it could benefit, and will effectively disseminate its output: its policies, educational material and so on. These two functions are intertwined: the effective dissemination of policies developed by the committee is a good way of raising awareness of the committee’s existence and role.

Successful ethics support and advice depends upon a clear policy on how cases are to be referred and by whom they may be referred. Is the support and the advice of the CEC available only to health professionals? If so, is it available to all health professionals equally? Is it, for example, acceptable for a junior member of a clinical team, or another health professional, to refer a case to the CEC without the permission of the consultant in charge of the case? Is the CEC willing to accept referrals from patients themselves, or from their relatives? Is it willing to accept referrals from children or young people?

4.2.11 The role of the committee’s chair

Many committees owe their existence and continued effectiveness to the energy of a respected and influential chair. Our evidence suggests that the role of the chair is central to a committee’s success and needs to be clarified. In many cases, the chair ought to be a person who is already widely-respected within the trust. The confidence of key clinicians and managers may depend on this.

This may bring challenges of its own. Firstly, if a committee is too dependent on the energy and commitment of one person it may not survive when that person moves on. Secondly, if the chair and the committee are too closely associated with senior managers or doctors it may be an institution with which nurses, junior doctors and patients find it difficult to identify.

Some CECs are chaired by a lay member or an ethicist. This may bring increased independence, but sometimes comes at the cost of less influence within the trust.

4.2.12 The committee’s role in conflict resolution and management

All the CECs the working party heard about had made a distinction between their own activities and those of the complaints service, but maintaining this distinction may be difficult in the future. Many of the cases we heard about and many of the ethical problems in health care practice have an organisational element. Some arise because of differences of opinion between health professionals, because of concern about inappropriate priority setting or because of ‘external’ policy making such as the rules around ‘eligibility for treatment’. Some CECs have accepted that their role may include mediation or conciliation. CECs seem likely to come into increasing contact with ethical issues with an organisational
or political dimension. Establishing clear, or reasonably clear, boundaries to their role in this kind of case will be a key challenge.

4.2.13 Ensuring consistency in decision-making: helping trusts, clinical units and the CEC to develop an ‘organisational ethics memory’

Advice provided by CECs should be consistent. Consistency depends on good records of the cases discussed, the ‘conclusions’ arrived at and the reasoning behind the conclusions. This should probably be recorded in an anonymised fashion with the emphasis on the salient features of the cases and of the principles informing the deliberations. Records should be available to committee members for reference. It is, of course, also an important educational process and a bank of cases could provide a resource for the induction of new members.

Related to this is the need for a CEC (or other form of ethics support) to help the trust and the clinical units to develop an ‘ethics memory’. Key cases, the advice given and the rationale underlying it should be fed back to the relevant clinical units (perhaps through a publication or an annual seminar) and should, possibly in an abbreviated form, be made available throughout the trust. A key challenge will be to ensure that the organisation and the CEC develop an ethics memory that reflects clinical reality whilst at the same time respecting the confidentiality and anonymity of the patients, doctors and other health professionals involved in the cases.

This suggests another important role for the CEC: to act as a kind of ‘organisational conscience’. The management of patients by teams of clinicians, drawn from a variety of disciplines and often working on shifts or part-time, means that the ethical focus of patient care may be diffused. This is compounded by two trends: the loss of ‘collegiality’ amongst the clinical staff, exacerbated by a decrease in the number of forums where they meet for other than narrowly practical purposes; and the rise of managerialism removing decisions about clinical priorities from clinicians. The role of ethical support systems as a mirror in which the ethos of the institution is reflected may therefore be of ever-increasing importance.

4.2.14 Failing committees

Although CECs are proliferating in the United Kingdom, some of the earliest have struggled to keep going and some have folded. This has usually been due, either directly or indirectly, to a lack of resources. In others, the CEC depended very heavily on the efforts of one or more key individuals. When these people moved on, it ceased to be effective. More information about the difficulties failing CECs faced and why they folded would provide important pointers to what is required for successful and sustainable ethics support. Whilst the dependence of ethics support upon enthusiastic individuals in the early stages is inevitable, sustainability requires institutional support. This would be a good reason for building ethics support, in part, into the governance structure of the health provider.
4.2.15 Funding and administration

An effective CEC can run only in the initial stages on the enthusiasm of its members and their willingness to put extra, unpaid time into administration, minute-taking and so on. Effective and sustainable ethics support requires adequate funding for dedicated administrative support, the education of committee members and publicity.

4.2.16 Evaluation and audit

Justifying adequate resourcing of ethics support nationally and locally requires evidence of effectiveness. Unfortunately ‘effectiveness’ is not easily defined. A manager might ask, ‘What is the evidence that it makes any difference?’ If ethics is conceived as the attempt to answer the general question, ‘What, all things considered, ought to be done in a given situation?’, we might ask for evidence that the investment in such a service has made a measurable, worthwhile difference to the outcome. Few studies (almost all in the USA) have given a convincing answer to this simple question. Overall there has been a high level of satisfaction among doctors and nurses with ethics consultations, but satisfaction among patients and surrogates has been lower.

In a prospective study, more frequent decisions to forgo life-sustaining treatment and reduced length of stay in the intensive care unit were reported among those who had received ethics consultation compared with the group who had not. In a randomised controlled trial of the effect of ethics consultations on life-sustaining treatments in response to value laden conflicts, no mortality difference was seen between patients offered ethics consultation and those with usual care. In a multicentre randomised controlled trial of ethics consultation, again in the ICU setting and involving 551 patients, there was no difference in mortality, but ethics consultations were associated with reductions in hospital and ICU days and in life-sustaining treatments with ventilation in those patients who did not survive to discharge. In the latter study, 87% of doctors, nurses and patients/surrogates found the consultations helpful in addressing treatment conflicts.

The problem with all such studies is the assumption that the outcome, measured as mortality or length of stay or therapeutic interventions, is important. The goals of ethics consultation are surely broader even than conflict resolution, valuable as this may be. What is more, the same treatment decision (even with the same consequences) may be wrong in one case and right in another. In some cases, the ethically correct action would be to wait and see how things develop. Under such circumstances, the time for decisions to be made may be no indicator of the moral worth of the decision; and an evaluation of CECs based solely on speed of decision or effectiveness of treatment etc may be worse than no evaluation at all. For many observers, ethical case review – and perhaps policy review too – is best seen as a process, a continuing conversation, and hence part of the quality agenda. Of course, quality can be assessed by structured interview, or other forms of qualitative research. We would certainly encourage such research in UK hospitals and other healthcare facilities, a point strongly made by one of our witnesses.

As already noted, CECs, whether functioning as a forum or as a more direct advisory body, may also be seen as having the role of the conscience of the institution – a reminder that
the hospital is a moral community\textsuperscript{52} — or even that of a Greek chorus: ‘beyond the tragic ending, the chorus will store up the memory of the struggle just ended and this will in turn be the stuff of moral reflection on some future occasion.’\textsuperscript{53} The CEC will have its role, not as one of Plato’s ‘golden guardians’,\textsuperscript{54} but as part of the critical intellectual resource required by a liberally educated practitioner in a ‘learned profession’.\textsuperscript{55} Evidence of a functioning body of clinical ethical review should enhance public trust and provide an internal morality that works in the interests of patients.\textsuperscript{56} This would be even more difficult to evaluate.

4.2.17 **Clinical ethics committees and other forms of ethics support**

The evidence provided to the working party by the BMA, the MDU and the MPS suggests a need to ensure an effective, coherent and consistent interface between local forms of support, national forms of support and relevant guidelines, laws and policy. This is a challenge in both directions, with regard to ensuring consistency of advice. It is equally important that the advice and guidance being provided nationally is sensitive, in so far as this is feasible, to the clinical realities of the local setting. Difficult local cases can be of tremendous importance in highlighting both areas where there is a need for a policy at the national level and areas where national policies and guidelines have ceased to be relevant to the realities of practice.

An awareness of these challenges has informed the recommendations in chapter 7.
5 Other forms of ethics support

As noted in chapter 2, doctors have traditionally sought support with difficult decisions from a range of sources other than CECs. It seems likely that whatever the future developments in CECs these sources will continue to be valuable, alongside new ones. At any rate, it seemed to us unlikely that CECs would be required in every clinical setting, for example in every GP surgery.

This chapter reports briefly on resources that may complement, or be useful alternatives to, CECs.

5.1 The British Medical Association Ethics Unit

This is a major resource for practising clinicians. Its role and the services it offers are described in Appendix 3.

5.2 The Medical Defence Union and the Medical Protection Society

Both the MDU and the MPS offer a 24-hour advice line for their members. These each receive something like 20,000 calls each year, mainly from UK-based doctors, covering all sectors of health care.

Some examples of the kinds of problems doctors called these advice lines about include:

- confidentiality
- disclosure
- consent
- the role of relatives in decision-making
- capacity
- end of life decision-making.

The MDU and MPS witnesses felt that these calls reflected a greater ethical and legal complexity in the day-to-day clinical work of doctors. The areas highlighted by these witnesses overlapped those mentioned by the others, suggesting that they are indeed areas in which doctors feel most in need of support. Other areas of importance involved the treatment of minors and issues around genetic testing, therapy and counselling.
The witnesses from both the MDU and MPS were in favour of the expansion of ethics support services and welcomed CECs, arguing that they complemented the legally-oriented service offered at a national level by their two organisations and that they are crucial to the development of local policies.

5.3 Other national forms of ethics support and advice

Ethical decision-making is also informed in practice by a range of other national resources. These include the medical royal colleges, regulatory bodies such as the Human Fertilisation and Embryology Authority and the GMC, the Department of Health, non-governmental bodies such as the Nuffield Council on Bioethics, and patient groups such as the Genetic Interest Group.

5.4 National specialty- and disease-specific ethics support

In some cases, forums for the discussion of ethical issues arising in areas of specialised clinical practice have been established at the national level. One example of this is the UK Genethics Club, a forum for geneticists, counsellors and genetics nurses working in clinical genetics units around the country. The Genethics Club allows them to discuss ethical issues arising in their practice with colleagues in other centres. The meetings take place three times a year in different parts of the country, and are facilitated by an ethicist. They offer an opportunity for the presentation and discussion of cases and for the development of models of good practice ([www.genethicsclub.org](http://www.genethicsclub.org))

5.5 Clinical ethicists

Many CECs include an academic ethicist among their membership, or have links with academics working on ethical issues and based in a local university. In some settings, even where there is no ethics committee, academic ethicists have developed good relationships with clinicians and other health professionals and have been willing to provide ad hoc input into the discussion of cases. Some academics involved in the development of research and teaching in medical ethics in the United Kingdom have for many years been contacted by health professionals facing difficult ethical issues and have offered ad hoc support and advice about ways of thinking such problems through.

In recent years, one or two academic ethicists have developed closer relationships with clinical practice and have begun to assume what might be called the role of a ‘clinical ethicist’. In the vast majority of clinical settings it will not be realistic or appropriate for there to be a dedicated, on-call clinical ethicist. Nevertheless, in some larger hospitals, especially those where there is a good relationship with a medical school or local university, it may be possible for a full- or part-time clinical ethics role to be developed. The working party heard of two examples of trusts in which clinical ethics support of this kind was available and seemed to be working well. In each case the ethicist’s position is funded from sources external to the trust.
5.6 Ethics education

A key determinant of ethical medical practice will undoubtedly continue to be the extent to which doctors have received adequate ethics education as a part of their medical training, and the availability of appropriate postgraduate and professional education in ethics. The survey of junior doctors commissioned by the working party (see Chapter 6) shows that nearly a third of those who responded reported having received no ethics education or training at all. In this context the importance of the availability of both appropriate ethics support and continuing professional education in ethics is undeniable.

5.7 Consistency

The witnesses stressed the importance of sources of ethical advice being consistent and complementary. There are dangers associated with the proliferation of conflicting or competing sources of advice. The regulatory role of the law and of the GMC will continue to be of central importance in medical practice, but so too will the need to interpret such guidance in the light of the clinical facts and the local context. It was felt that it would be important for there to continue to be both local forms of ethics support and advice, such as CECs, and national ethics resources. In addition, and importantly, it would be essential for doctors to have ready access to both sources and for local sources of advice to be informed by developments at the national level and vice versa. Good communication between these two levels of advice would be essential.
6 A survey of specialist registrars

6.1 Introduction

The working party commissioned a survey of specialist registrars training in medical specialties represented by the College, investigating their experiences of and opinions on clinical ethical training and support.

In July 2004, 3,654 questionnaires were sent via electronic mail. Of these, 1,146 were returned by the end of August 2004, a response rate of 31.4%.

Male SpRs accounted for 56% of the responses, and females 42% (with 2% of respondents not specifying their sex). Most respondents (75%) were between 30–40 years old, as would be expected. The highest response rates were from trainees in geriatric medicine, respiratory medicine and gastroenterology who accounted for 12%, 11% and 10% respectively.

The following results are presented according to the relevant headings in the questionnaire. There are also direct quotations from the SpRs.

6.2 Clinical ethics education or training

Sixty six per cent of respondents indicated that they had had education/training in clinical ethics, but this was only at an undergraduate level in 55% of these responses.

‘The only formal education I have been involved in regarding ethics was in preparation for the MRCP PACES examination.’

‘Ethical training is a regular feature on the agenda at care of the elderly registrar training meetings which occur monthly, and is regularly discussed during all case discussions at these training sessions.’

Approximately one third of SpRs who responded reported that they had never had clinical ethical education or training.

6.3 Ethical dilemmas in clinical practice

‘Facing the ethical dilemmas of my job is stimulating and is a good part of the challenge.’

Of respondents, 78% encountered ethical dilemmas on a daily or weekly basis. These dilemmas are diverse in their origin, but the most frequently encountered were consent,
confidentiality, end of life decision-making, the role of relatives in decision-making and decision-making in incompetent patients. Each of these dilemmas was encountered by between 14% and 17% of respondents.

6.4 Education in clinical ethics

‘[I] did not appreciate either the ethical or legal dilemmas at the time of the situation and would have handled it differently in retrospect.’

Seventy five per cent of respondents believe their exposure to education in clinical ethics did not provide them, or only sometimes provided them, with the skills they needed to address the ethical issues arising in their clinical practice.

6.5 Use of clinical ethics support

Support in dealing with clinical ethical dilemmas from senior colleagues and their peers was accessed by 96% of respondents. This was the most frequently cited source of support, reflecting the traditional in the medical profession of seeking help from experienced colleagues. The next most frequently cited sources of support were written literature (47.9% of respondents) and policies on ethical issues (32.8% of respondents).

‘If training in ethics has been good, further training will not make the decision about an individual patient any easier as each case is specific. I gain most support from colleagues.’

‘Formal lectures about legal matters in common ethical situations have been very helpful. For issues that will affect the trust, I have found the trust legal department useful. However, for most clinical situations I would feel most comfortable having “off the record” discussions about cases with peers I trust. I have found our hospital palliative care service extremely helpful.’

6.6 Accessibility

Of respondents, 82% had never been prevented from accessing ethical support, although 2% had been unable to access support at the time they required it. This was cited as being due to a lack of necessary resources (time for, or access to, information technology for intra- or Internet policies, the availability of senior colleagues) when the support was required, usually out of hours or in an emergency.

6.7 Preferred forms of clinical ethical support

When asked about forms of ethics support they would value, 72% said that they valued ethics support from senior colleagues and 66% listed support from an individual with a specialist interest in ethics. Thirty four percent of respondents said that they would value support from a CEC.
'Access to an individual with an interest in clinical ethics would be more useful to discuss individual cases rather than further generic training sessions.'

'To have someone within a trust with expertise in ethics would be valuable. They could be available for advice and run seminars on useful topics.'

Support from a clinical ethicist, written literature, policies on ethical issues or the legal services department were each chosen by between 14% and 16% of respondents, so there were many categories of a similar popularity.

'I would love to see a senior clinician with an interest in ethics in each hospital who was accessible to discuss cases with for clarification purposes. A CEC would be great provided all the members were adequately trained with a good working knowledge of what it feels like to be sitting there having these [ethical] discussions [with patients].'

'I would find it very difficult to deal with a clinical ethicist who was not a practising clinician with patients of their own as the theory of medical ethics and the practicalities are so different.'

It is important to note that a significant number of respondents would like to be able to access either an individual with particular ethics expertise or a CEC.

6.8 Further education or training in ethical issues

Of respondents, 75% indicated that they would like further education or training in clinical ethics.

'It should be part and parcel of continued medical education for every physician.'

'Clinical sessions in ethics should be a mandatory part of training at various levels and there should be allocated time for this.'

The results revealed that the areas within clinical ethics in which respondents would like further education and training were relatively evenly distributed. The most frequent choices were making decisions at the end of life (16.5%), the role of relatives in decision-making (16.3%) and making decisions about incompetent patients (16.3%).

A wide variety of mechanisms to provide ongoing education or training was thought to be acceptable. Formal lectures/workshops/short courses, Internet-based self-directed learning, case discussions with the clinical team and ongoing training and support from a person trained in ethics were equally preferred. The least popular choices were self-directed learning through books or journals.

'I think that a Royal College training day on ethics that was compulsory to attend for all SpRs would be helpful.'

'[The] most useful training mode is being involved in the discussions/decision-making with a sensible and ethically aware senior colleague. I'm not convinced the training sessions as such are much help as the emotional aspects are removed when there isn't a patient or relatives involved.'
‘Case-discussion, tutorial-type teaching with prepared work beforehand is the most effective way of teaching ethics to doctors.’

‘Ethics courses need to be practice based and not pedantic. They should discuss real life clinical situations, as theoretical knowledge is easily available on the Internet/books if needed.’

Although there is recognition of the need for ongoing training there are also limitations identified, regarding available resources in terms of time and funding.

‘If we are to have all this training, which I think we should, then we should have adequate study budget. We already have to do teaching, management, advanced life support, and professional courses and the budget is consistently being cut. I cannot afford any more.’

‘As an SpR we are required to attend ethics and law courses which are few and far between in local deaneries. Availability, costs and locality of courses all need to be addressed.’

‘[The] deanery should provide funding for attending clinical ethics courses.’

‘Sadly if a course were offered in ethics I would be unlikely to have the time to go. SpR training is squeezed so tight that there is very little room for addressing training issues beyond those demanded of us in the “grey folder”.’

6.9 Conclusions

The survey revealed that a significant proportion (or about one third) of tomorrow’s consultant physicians believe they have never had education or training in clinical ethics. Of those who believe they have received training, three quarters state their education in clinical ethics either did not provide them, or only sometimes provided them, with the skills they needed to address the ethical issues arising in their clinical practice. There is clearly a need for ongoing education and training in all areas of clinical ethics relevant to the practice of physicians in training.

Ongoing support from senior colleagues and peers is used and valued, but in addition to this trainees would value having access to clinical ethical support from a wide range of sources. The preferred mode is through senior colleagues, clinicians with an interest in ethics or clinical ethicists or CECs.

The findings of the survey need to be set in context. There was an overwhelming impression that consultants did not necessarily have the broad understanding of ethical issues and, in particular, the bioethical and legal framework surrounding ethical decisions, to act as an entirely safe resource for junior doctors. While it is traditional that senior colleagues are turned to for ethics support, few of those colleagues appear to have specific expertise. The resource to which trainees should therefore turn needs to be identified, and should be an individual within the trust who has had specific training or, given the range of competencies that is required, a CEC.

A detailed analysis of the survey appears in the publications section of the Royal College of Physicians’ website (www.rcplondon.ac.uk).
Conclusions and recommendations
7 Conclusions and recommendations

R1 Wherever healthcare is provided we believe, on the basis of current trends and our findings, that there will be a need for formal ethics support which is both timely and informed. This can no longer be left to chance or allowed to depend on the enthusiasm of individuals.

R2 Healthcare institutions should review existing arrangements for providing advice and education, and for developing and implementing guidelines on the recognition and handling of ethical uncertainties and dilemmas in clinical practice. The review should be carried out by an identified lead individual working with others, and have the full support of management.

R3 While ethics support may be in part provided by central sources of advice (such as the BMA’s Ethics Unit), there will be a need for complementary and appropriately constituted local ethics support. This is partly because national guidelines will need to be modified to take account of local cultural sensitivities, partly because such guidelines cannot foresee the particular circumstances of individual cases and partly because what is required in some cases is an opportunity for doctors to discuss the ethical issues presented by a case in a local multidisciplinary forum.

R4 In many institutions a combination of current arrangements for informal advice from seniors and peers supplemented by national sources of advice (BMA Ethics Unit, medical defence organisations, and guidelines from the GMC, medical royal colleges and other bodies) may be considered adequate for much of the time. Even in these cases, however, it will be essential that key personnel who are to provide the advice are identified and are qualified to do so. Ready access to national sources of advice should also be available 24 hours a day, seven days a week, in a location that is known to everyone who works in the institution. Information about this should be available in induction packs.

R5 Sources of advice should be widely advertised and accessible via an intranet site with links to national sources of support such as the BMA Ethics Unit, the UK Clinical Ethics Network and relevant guidelines. The intranet site should be kept up to date with a person designated as responsible for maintaining it.

Clinical ethics committees

R6 In many cases, but not all, the local provision of ethics support will take the form of a CEC. In the absence of adequate, prospective studies and retrospective surveys of benefit, these recommendations regarding CECs should be regarded as provisional and subject to review in the light of further experience.


**Membership (‘core plus options’)**

**R7** The membership of any CEC should allow it to provide a genuinely multidisciplinary and informed forum for the discussion of ethical issues likely to arise in the health care settings it serves. There should be input from a wide range of the areas of health care provided by the trust (including related primary care services where the committee is in a hospital). There should be management input, significant lay membership, ethical and legal expertise and, where appropriate, spiritual input. The precise form of the membership of any particular committee will need to be established in the light of local requirements. Its size should depend to some extent upon its proposed function: if conceived as a forum the membership might be larger, if as an advisory body a smaller committee might be more effective. Membership is likely in most cases to fall somewhere between eight and fourteen, however.

**R8** The requirement for a wide range of skills, expertise and appropriate membership must be balanced against the need for the committee to be sufficiently small to function effectively. This suggests that a ‘core plus options’ model may be the most appropriate. It involves the committee having the facility to co-opt appropriate expertise as and when required.

**R9** The members of the committee who are health professionals provide important links to clinical areas and the other activities of the trust. They can be important conduits for ethical issues to be brought to the attention of the committee and can help to raise awareness of the committee’s existence and role in the clinical setting. These benefits ought to be taken into consideration when the committee’s membership is being developed.

**Expertise (core competencies)**

**R10** The development of an agreed statement of the core competencies required for an effective CEC would be extremely helpful. It would provide important information for those establishing new committees and designing training and education for the members of such committees. It would also represent a step towards greater consistency between committees and provide the basis for evaluation. There is currently no agreed set of required membership, or core competencies. Nor is there any agreement about the required educational training for members of CECs. The working party would like to see the development of a statement of core competencies, perhaps led by the UK Clinical Ethics Network, and suggests that a good starting point for such discussion is the recent paper in the *Annals of Internal Medicine*.45

**Sensitivity to local populations, and their beliefs, languages and practices**

**R11** The beliefs, practices and languages of the populations being served by a health care institution are important and ethics support will need to be sensitive to them. This underlines the need for local ethics support to complement national advice guidelines and support, as well as for such support to draw upon appropriate local expertise. It also has implications for the training of those providing ethics support and for the membership of the CEC.
The training and education of members

R12 All committee members should have training aimed at providing them with the appropriate awareness, knowledge and skills. In most cases this will be a short course, either provided locally or, where this is not possible, nationally. At least one member of the committee should have more formal ethics training, for example a masters degree in medical ethics.

R13 It is our view that a set of minimal training requirements for CEC members should be established, perhaps by the UK Clinical Ethics Network.

R14 The committee should provide ongoing training for its members. In some cases this will take the form of an annual away-day; in others it might involve bringing in external facilitators or encouraging attendance at meetings about medical ethics issues. It is important that training provides, at least some of the time, the opportunity for members of different committees to meet.

R15 A key element in the training and induction of committee members is the importance of confidentiality. We suggest that all committee members should be required to formally agree to the committee’s confidentiality policy.

Lay members

R16 Committees should clarify at an early stage the role of independent lay members (and this process should itself involve the input of independent lay people). Whilst lay members play an important role in bringing a non-health professional perspective, and by their active participation lend added legitimacy to the discussion of ethical issues, they also bring a range of personal expertise (perhaps relating to their professional lives).

Spiritual input

R17 Ethical issues arising in health care sometimes have a spiritual dimension. In many cases, therefore, it is important that the committee includes someone with expertise in spiritual matters. This will in many cases be a member with a religious affiliation, for example a hospital chaplain, a rabbi or an imam. It is important that these members recognise the diversity of religious belief. The spiritual input needs to be appropriate to the issue under discussion, and this is, perhaps, another aspect of committee membership where a ‘core plus options’ approach is appropriate. It will not usually be appropriate for the representative of one religious faith to be designated as the sole ‘spiritual contact’, irrespective of the requirements of a particular case or of the diversity of the population served by the committee. Nevertheless, faith representatives do often have good mutual contact and where this is the case it may well be appropriate for a member of the CEC to act as ‘spiritual contact’.

Ethics input

R18 At least one member of the committee should have had formal training in ethics. In many cases an academic ethicist or moral philosopher in the committee membership will fulfil this need. In other committees there might be a member, perhaps a health professional, with a qualification in ethics.
This person should not, however, become the committee’s sole ethics ‘expert’. The role of the ethicist in the committee is to facilitate, inform and support deliberation of ethical issues by the committee as a whole.

‘Timeliness’ flexibility and the ability to respond in an emergency

An effective ethics support system will need to be able to respond reasonably quickly – even if this is, in practice, a matter of hours or days rather than minutes. Some existing CECs have developed innovative and well-used mechanisms for the provision of rapid-response ethics support. This shows that such flexibility is both possible and, where it exists, valuable. All CECs should develop mechanisms to ensure that the ethics support they provide is timely and appropriate to the health care settings they serve.

Clarifying of the role of the CEC

If CECs are to be effective they must provide, and be seen to provide, support to health professionals dealing with difficult ethical issues, as well as others affected by such cases. In practice this will usually mean making it clear at the outset that their role is to provide a multidisciplinary forum for the discussion of issues, and thereby to support the decision-making of health professionals. The working party discovered that there is uncertainty about the legal status of the deliberations and minutes of CECs, and that there is an urgent need for this issue to be clarified at a national level. The working party recommends that an expert opinion be sought about the legal status and liability of CECs.

It is the view of the working party that for CECs and other forms of support to be effective they must be genuinely supportive, ie they must provide help as and when required, and avoid becoming simply another committee that must be consulted.

Publicity and accessibility

CECs should ensure the existence and role of the committee is known throughout the health care setting it serves.

Committees need to develop at an early stage a clear procedure for the referral of cases and issues for discussion. Information about this procedure should be widely available.

The input of patients, and awareness of the patient’s values, will need to be at the heart of the resolution of an ethical issue. Some committees may come to the conclusion that there are circumstances in which it is appropriate for a case to be referred by a patient, or for a patient to be present to participate in the discussion. CECs will need to take these factors into account in the development of their referral procedure.

Effectiveness

In order to be effective and engaged with practice a CEC needs to develop mechanisms for ensuring the appropriate dissemination of the results of its deliberations. In some cases this will mean planning in advance, and securing resources, for the effective dissemination of guidelines and policies. In others it will mean ensuring that the discussion of cases is fed back in an appropriate and timely manner to the relevant clinical setting. Effective dissemination is also an important means for raising awareness of the CEC itself.
Conclusions and recommendations

Local audit and evaluation

R27 CECs should keep systematic records of their deliberations and should undertake regular and methodologically sound evaluations of the work they do. This should include evidence of the satisfaction of those who bring issues to the committee for discussion, those who attend education and training events and those who are the recipients of the committee’s policy work.

Location within the institution and reporting mechanisms

R28 The precise institutional location of the CEC is likely to vary between settings. The issue will need to be resolved at an early stage. The advantages of location within the governance structure of the health care organisation are that it provides the possibility of a greater degree of influence on practice, access to resources such as administrative support and training, and appropriate and reasonably effective reporting mechanisms (which allow the committee to raise ethical concerns with managers). A location outside the formal governance structure allows a greater degree of independence for those sitting on the committee and allows those facing ethical issues to bring them for discussion in a forum which is not identified with the management structure and the practices with which they work. In either case, we recommend the CEC provide an annual report to the trust board, or equivalent body.

Institutional support and long-term viability

R29 The long-term effectiveness of a CEC is dependent upon the existence of appropriate levels of dedicated administrative and financial support for the training and education of committee members. Such support should be available to all committees. Our evidence suggests that a CEC is unlikely to be viable in the long term without institutional support of this kind, or enthusiastic local individuals willing to act as members of the committee without financial reward.

Ensuring consistency and promoting an organisational memory

R30 CECs must be consistent in their decision-making and promote, in turn, consistency of practice in the wider context and the development of an organisational ethics memory. They must also remain sensitive to the differences between cases. Good records of the ethical issues and cases a CEC discusses are essential, and will allow recurring themes to be identified. The CECs should report their discussions back to the relevant clinical areas. They should also produce an annual report and perhaps a newsletter reporting on key ethical issues and discussions throughout the trust as a whole. The confidentiality and privacy of those involved in individual cases should be respected and maintained.

R31 Consideration ought also to be given to the development of a resource of this kind at the national level, perhaps facilitated by the UK Clinical Ethics Network. It would enable CECs to learn from others in different institutions and would facilitate an organisational ethics memory and improved consistency in the NHS as a whole.

Ethics reports in patient records

R32 Committees should establish a policy concerning the documentation of case discussions in patient records at an early stage, specifying whether and how cases are to be
recorded in the minutes of the committee and how case discussions are to be fed back to the clinical setting. At the very least, the fact that there was a discussion should be noted and, ideally, its nature and content. CECs should also produce a policy on confidentiality and ensure that all committee members are aware of and formally committed to it.

Clinical ethics committees and other forms of ethics support

R33 Local advice and support needs to take into account national advice, and national advice needs, insofar as this is possible, to be sensitive and appropriate to local clinical reality. This is a challenge and requires the effective sharing of information between committees, and between committees and those providing support nationally (such as the BMA, the MDU and the MPS). The UK Clinical Ethics Network might be able to assist in the sharing of this information.

Specialist clinical ethics committees

R34 In some situations it will be helpful to have CECs of a more specialised kind. These already exist in many in vitro fertilisation units, and a specialist committee may be helpful in other highly technical areas. In some cases it will be necessary to have a committee based in a particular institution, while in others the creation of a national clinical ethics forum, facilitating models of good ethical practice to be shared between institutions, may be appropriate. An example of forum of this kind is the UK Genethics Club. Whichever model is chosen, it will be important for a committee to develop good links with local, regional and national sources of ethics advice and support.

The availability of a clinical ethicist

R35 Trusts and other institutions should consider a role for a dedicated clinical ethicist. This role is most likely to be useful in larger health care institutions such as hospitals, in units where acute ethical problems are more common (eg those which deal with palliative care, intensive care, clinical genetics and so on) or where there is an association with a medical school or university department. An ethicist can be an important link between a CEC and the clinical setting, providing ethics support and education on a flexible and engaged basis and encouraging awareness of the committee and ethical issues in general. A clinical ethicist can also play an important role helping teams of health professionals to gain experience by identifying and addressing the ethical dimensions of their practice over a sustained period.

R36 Whilst an ethicist should not be seen as an adequate substitute for a CEC, he or she can be a useful complementary source of advice, support and education and provide a readily identifiable contact for health professionals and others requiring ethics support or advice.

Alternative to clinical ethics committees

R37 We acknowledge widespread concern about the establishment of what may be perceived as another regulatory body, especially one in which core competencies are poorly defined. Our evidence suggests that the essential prerequisites for a successful CEC or forum
are enthusiastic local clinicians with expertise (upon which credibility depends) willing to devote time and effort to the committee without additional payment, management encouragement and, preferably, involvement, and administrative support. If these criteria cannot be met and sceptical opinion opposes ‘another committee’, other mechanisms for the provision of ethical advice are needed.

**R38** One model is that of a group of nominated professionals with expertise and adequate ethics training, as well as acknowledged wisdom on a register or rota and making themselves available to advise when necessary. These individuals may lack the time or commitment to attend a formal committee, but could constitute a resource that would, for example, meet the preferred options expressed in our survey of physicians in training. The group may also be willing to take a lead in professional education in ethics in the trust if a clinical ethicist is unavailable. The group would still require publicity so that the support is accessed, and might evolve in time into a more formal forum.

**National evaluation, audit and research into ethics support**

**R39** It follows from recommendations 37 and 38 that CECs and other forms of ethics support should be evaluated. This will aid the development of an appropriate methodology, and allow the question of what it is for a CEC to be ‘successful’ to be clarified.

**R40** Two measures are likely to be central to any assessment:

- the extent to which those who use the services of the CEC are satisfied with the support and advice they receive and the quality of the multidisciplinary forum they experience

- the extent to which the CEC facilitates the development of ethical practice.

**R41** The second of these measures is by far the most problematic. Superficially similar decisions (for example the decision to withdraw treatment) may be ‘right’ in one case and ‘wrong’ in another. It is vital, therefore, that any evaluation of the practice of committees identifies not simply outcomes, but also the adequacy of the moral reasoning which led to these outcomes.

**Undergraduate and postgraduate ethics education**

**R42** Our survey of specialist registrars finding that nearly one third believed they had received no ethics education at all is alarming. While the working party believes that wherever healthcare is provided there is a need for ethics support, the practice of ethical medicine is dependent upon an adequate level of ethical understanding by all healthcare practitioners. Clinical ethics support is essential, but it cannot replace the development of appropriate awareness, skills and attitudes in doctors through effective, and where appropriate multidisciplinary, ethics education. The provision of such education for both medical students and qualified doctors is therefore a matter of considerable urgency.
Appendix 1
Remit of the Working Party on Clinical Ethics Committees

Twenty five years ago, the Royal College of Physicians was instrumental in establishing research ethics committees, and today an extensive network extends through the NHS. There was a clear rationale for their establishment. Clinical ethics committees (CECs), which address ethical issues arising in everyday clinical work, have now been established in many UK hospitals but their aims and purposes were less well-defined. While they have an important role in assisting doctors faced with ethical dilemmas and dealing with differences of opinion about ethical issues relating to the management of individual patients, it was unclear how they might discharge this role and in particular how they might relate to existing governance structures.

Nevertheless, the increasing complaints against litigation involving doctors indicated that CECs might have an important function. Acknowledging the impetus given to the development of CECs by the Nuffield sponsored Ethox survey of 2000, the working party sought to review these committees and, if it seemed appropriate, to develop on the College’s behalf guidance concerning the best way in which they could support doctors addressing complex ethical dilemmas.

While the remit of the working party was ethics support in the broadest sense, it was expected to pay particular attention to CECs and address the following issues:

- the origins and growth of CECs both nationally and abroad, their current prevalence and the functions assigned to them
- the constitution of existing CECs
- the kinds of issues they were asked to address
- the expertise and representativeness of members of the committees
- the way the committees worked and how they responded to particular concerns
- their role in forming ethical policies as well as responding to individual ethical dilemmas.

The working party was expected to make recommendations on:

- whether formal CECs are a useful way of providing support for doctors addressing complex ethical dilemmas and, if not, what the alternatives might be
- the optimal constitution of CECs, their *modus operandi* and their reporting structures
the composition of CECs (including the education requirements of members)
their range of functions beyond responding to individual ethical dilemmas (including ethical responsibilities)
their accessibility to patients and carers
the legal status of the advice that they provide.
Appendix 2
Witnesses

The working party is very grateful to the following people who gave up their time to share their experiences and offer advice:

- Professor Raanan Gillon (Emeritus Professor of Medical Ethics, Imperial College London)
- Ms Nancy Hallett (Chief Executive Officer, Homerton Foundation Hospital)
- Mrs Mary Judge (Lay member of the Oxford Radcliffe Hospitals NHS Trust CEC)
- Dr Gillian Lockwood (Director, Midland Fertility Services)
- Rev Dr Edward Morris (Hospital Chaplain, Hammersmith Hospitals NHS Trust)
- Dr Gerard Panting (Medical Protection Society)
- Dr Peter Schutte (Head of Advisory Services, Medical Defence Union)
- Professor Ann Sommerville (Head of Medical Ethics, British Medical Association).

The working party would also like to record its appreciation of those who submitted written evidence:

- Dr Jim Copper (Chair, Plymouth Clinical Ethics Group)
- Dr John Duncan (Vice Chair and Convenor, Brighton Clinical Ethics Group)
- Dr Jim Eccles (Chair, Leeds Teaching Hospitals CEC)
- Dr James Gilbert (Chair, Clinical Ethics Reference Group, Royal Devon and Exeter Health Care Acute Trust)
- Dr Vic Larcher (Chairman, Royal College of Paediatrics and Child Health Ethics Advisory Committee)
- Mr Tony Moore (Vice Chair, Sheffield Teaching Hospitals NHS Trust, Clinical Ethics Group)
- Dr Clive Richards (Director of Public Health, Rushcliffe Primary Care Trust)
- Ms Gillian Rimington (Chair, Pennine Acute Hospitals NHS Trust CEC)
- Dr Peter Rudd (Royal United Hospital Bath NHS Trust CEC)
- Dr Martin Vernon (Chair, South Manchester University Hospitals NHS Trust CEC)
- Dr Michael Ward (Chairman of the CEC, Sherwood Forest Hospitals NHS Trust).

And finally, the working party is indebted to all the specialist registrars who responded to its survey, and to Dr Anne Slowther, Research Fellow at the Ethox Centre, who reviewed the first draft of the report.
Chapter 8

Appendix 3

The British Medical Association Ethics Unit

The British Medical Association (BMA) has always offered support and advice on difficult cases to its members and others. Professor Ann Sommerville, Head of Medical Ethics at the BMA, stated that the organisation’s Ethics Unit did not aim to provide ‘directive’ advice but rather support and an opportunity for members to talk through cases and issues. The volume of calls and letters concerning cases with an ethical dimension began to increase rapidly from the middle of the 1980s and has continued to rise since.

In recent years the BMA has established an Ethics Unit telephone advice line. In 1993, the Unit published the first edition of Medical ethics today. This comprehensive, single volume text focusses on the problems for which doctors have most commonly sought advice. In 2004 the BMA published a more substantial second edition, twice the length of the first, in hard copy and on CD.

The BMA ethics phone line currently answers about 4,000 ethico-legal queries per year. The vast majority of these are from BMA members but the unit also advises non-members, for example other health professionals and trust lawyers. Enquiries come predominantly from doctors, medical students, others in health care professions, lawyers acting on behalf of members, government departments and non-governmental organisations (both in the UK and overseas). In addition, the ethics unit website (www.bma.org.uk/ethics) averages 5,000 separate visitors (and 16,000 ‘hits’) per month.

Queries tend to fall into three groups: factual questions, dilemmas (eg for example those surrounding a child’s consent to treatment) and ‘hypotheticals’. While the nature of the inquiries varies tremendously, some areas of practice crop up more frequently than others. This has prompted the unit to develop documents addressing the ethico-legal issues arising most commonly in these areas of practice. They fall into two broad categories: discussion documents intended to generate debate, and guidance triggered by demand from doctors. The latter cover:

- child protection
- treating unaccompanied minors
- revised code of practice on advance statements (‘living wills’).

The discussion documents cover:

- consent rights and choices in health care for children and young people
- assessment of mental capacity
The Ethics Unit has also established a website containing information on the most frequent problems and questions. The statistics above show that this website is well used. Nevertheless, there is still a demand for the opportunity to talk ethical problems through on the telephone or in person. Discussions can often last over an hour, a fact that indicates needs that cannot be satisfied by the one-way communication of a website or book.

The headings under which the Ethics Unit categorises calls give some idea of both the coverage and the total breadth of enquiries:

- abortion
- access
- advertising
- asylum seekers
- capacity
- circumcision (male)
- clinical responsibility
- confidentiality
- consent
- consultation
- doctor–patient relationship
- dual obligations
- duty to treat
- end of life (advance statements)
- end of life (assisted dying)
- end of life (CPR)
- end of life (euthanasia)
- end of life (PVS)
- end of life (withdrawing and withholding treatment)
- female genital mutilation
- genetics
- gifts/bequests
- GP issues including relations with solicitors
- human rights
- insurance
- medical records
- mental health
- NHS/private
- occupational health
- organ donation
- prescribing
- prison medicine
- referrals
- relationships with colleagues
- research
- retention of records
- sponsorship
- surrogacy
- treating self/family
- whistle-blowing.

It is the view of the BMA Ethics Unit that interest in local clinical ethics support is likely to continue to grow, as is the demand for central ethics advice and support at a distance.
Appendix 4
The role of the clinical ethicist: an example

What might a clinical ethicist do? The answer to this question will inevitably depend upon the amount of time available for the work, the needs of the particular clinical setting and the skills and experience of the ethicist. But it is likely that the role of the clinical ethicist can be grouped, as it is in Oxford, under the following headings.

Supporting the clinical ethics committee

The clinical ethicist is likely to be a member of the CEC, providing ethics input and helping to set the agenda. A relatively close relationship with the clinical setting would make it possible for the ethicist to identify, and act as a ‘collecting point’ for, ethical issues and cases that might be suitable for discussion at the CEC.

Case consultation

The clinical ethicist might provide a limited amount of *ad hoc* ethics support in the clinical setting. In order to develop a model of what might be achieved, the provision of clinical ethics support has, in Oxford, tended to be concentrated in one or two clinical areas. For example, Professor Parker runs a monthly one-hour discussion in the clinical genetics unit at which ethical issues and cases arising during the past month are discussed in a multidisciplinary meeting for doctors, counsellors and nurses. He also runs a similar discussion group for the cardiology genetics team. In addition to these regular sessions, he provides (time permitting) *ad hoc* support in any clinical areas that require it. In many cases a team simply wants someone who can facilitate a one-off discussion about a particularly problematic issue or case. In some cases this leads (as in genetics) to a more long-term involvement. In addition to genetics and cardiology, the ethicist in Oxford has provided ethics support in the areas of intensive care, prenatal testing, the women’s centre, neuro ITU and paediatrics, and to the resuscitation team and the retained organs group. In most cases the ethical issues can be addressed locally but in some the ethicist has been able to act as a link person encouraging access to the CEC.

Education

The long-term input of an ethicist into a clinical team, in addition to assisting with particular cases, has an educational and development function, helping health professionals to develop
the awareness and skills they need to identify and address ethical issues in their own right. In addition to this, the ethicist has encouraged and participated in the educational activities of the CEC. For example, by running one-hour open training sessions on ethical issues for members of trust staff on issues such as consent, confidentiality and so on.

**Policy and guidance**

In many cases, difficult ethical issues can lead a clinical team to consider developing a new policy. The ethicist can play a role in helping a team to think through the broader ethical issues presented by a case or to consider the ethical implications of new policy initiatives and changes in practice. The same applies to policy and guidelines developed externally (whether nationally or at the level of the trust).
References

3 Re Quinlan (1976).
5 Gillick v. West Norfolk and Wisbech Area Health Authority (1985).
7 Airedale NHS Trust v. Bland (1993) 1 All ER 821, HL.
8 Bolitho v. City and Hackney HA (1997).
9 Sidaway v. Board of Governors of Bethlem Royal Hospital and Maudsley Hospital (1984).
13 For example the Department of Health guidelines on consent, which can be found at www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/Consent/fs/en
15 See, for example, a number of guidelines developed by the Genetic Interest Group and available on their website at www.gig.org.uk/index
22 The Human Fertilisation and Embryology Authority website can be found at www.hfea.gov.uk
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28 R v. General Medical Council (on the application of Lesley Burke) (2004).
References


