A practical guide for clinical ethics support

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Foreword

In 2001 the UK Clinical Ethics Network was set up to enable the growing number of clinical ethics committees, and other forms of clinical ethics support, that were developing in the UK to share experience and knowledge, and to promote the development of clinical ethics within the UK National Health Service. In the past four years the number of clinical ethics committees and groups in the UK has risen from 20 to 70, and continues to rise, reflecting an increasing awareness of the ethical dimension of health care and the need for support for clinicians, patients, their families, and health care managers, when faced with difficult ethical dilemmas. A frequent message from clinical ethics committees has been the need for a practical guide to assist members of established committees, and those thinking of setting up a committee. This guide has been developed in response to that need, and the aim of the authors throughout has been to ensure that it is relevant and responsive to the experience of clinical ethics support in day to day health care within the NHS. A key feature of this guide is the range of appendices providing first hand experience and examples of policies and protocols from existing clinical ethics committees and groups. These appendices are an integral part of the guide and we strongly recommend that they are used alongside the text in each section. We hope that the guide will provide a useful resource for all those involved in the provision of clinical ethics support.

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In particular we are indebted to all the individual contributors who provided examples of their experience of different aspects of clinical ethics committees. Their contribution has greatly increased the relevance of the guide for all who are engaged in the practical work of clinical ethics support.

A. CLINICAL ETHICS SUPPORT

Introduction

What is clinical ethics support?

Clinical ethics support describes the provision of advice and support on ethical issues arising from clinical practice and patient care within a health care organisation. Initially models of clinical ethics support focused on provision of advice to health professionals working in hospitals, usually through a hospital ethics committee or an individual ethicist. More recently models of clinical ethics support have developed to include support for other groups within the organisation, specifically patients and managers, and to provide support across institutions, for example, area-wide ethics committees supporting primary and secondary care trusts. The most common model of clinical ethics support in the UK is an ethics committee or group. These committees are distinct from research ethics committees (see page A4). As of September 2004, 68 clinical ethics committees (CECs) had registered with the UK Clinical Ethics Network.

55 CECs in Acute and Community Trusts (out of 161 Trusts)
2 CECs in Primary Care Trusts (out of 303 Primary Care Trusts)
6 CECs in Mental Health Trusts (out of 83 Mental Health Trusts)
1 CEC in a Scottish Health Board (out of 3 Scottish Health Boards)
1 CEC in Northern Ireland (out of 39 Hospitals)
2 CECs in Private Hospitals
1 area wide CEC in England

Why do we need clinical ethics support?

There is an increasing awareness among health professionals and the wider public of the importance of ethical issues in health care. In 2001 a study of the provision of clinical ethics support in the UK[1] found that there was a perceived need for advice on ethical issues among senior health professionals and health service managers. An increasing number of legal cases, and two public enquiries (into the conduct of heart surgeons in Bristol and into the retention of organs during post mortem examinations in Alder Hey) have highlighted the importance of ethical considerations in clinical practice, and there is now an expectation that health professionals are openly accountable for their decisions, including the ethical aspects of those decisions.

This section of the Manual covers the following areas:

- Development of clinical ethics support internationally.
- Development of clinical ethics support In the UK.
- The difference between clinical ethics committees and research ethics committees.
- Functions and scope of clinical ethics committees.
- Different models of clinical ethics support, their strengths and weaknesses.
- A step-by-step guide to setting up a clinical ethics committee.

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[1] Slowther A, Bunch C, Woolnough B, Hope T. Clinical Ethics Support in the UK: A review of the current position and likely development. 2001; London; The Nuffield Trust paragraph 3.1.

International development of clinical ethics support

The North American experience

- Clinical Ethics Committees and Hospital Ethics committees have been in existence in hospitals in North America since the 1970s.
- There are a variety of models of clinical ethics support.
- Ethics support may be required by regulation or legislation.

Clinical Ethics Committees (CECs) are also known as hospital or health care ethics committees (HECs) in North America. They have been in existence since the early 1970s, much earlier than the European equivalent.

In addition to an ethics committee, many North American hospitals also have formally trained ethicists. Ethics support may be provided by the ethicist, by an ethics team or by the full committee.

In North America it is a requirement for hospital accreditation that the institution has a mechanism for addressing ethical issues arising from patient care. Both the Joint Commission on Accreditation of Health Care in the US, and the Canadian Council on Hospital Accreditation suggest the establishment of a multi-disciplinary ethics committee to meet this requirement[2] [3]. In some US states, for example Maryland, hospitals are required by law to have an ethics committee.

A first hand account of the experience of ethics support in the United States is provided in Appendix A1.

The European experience

- CECs have been in existence since the 1980s in the Netherlands.
- Many countries have committees combining research and clinical ethics.
- Regulation requiring clinical ethics support varies from country to country.

Clinical ethics support has developed more slowly in Europe in comparison with North America. Clinical ethics committees have been in existence since the 1980s in the Netherlands, including ethics committees in nursing homes, but there are still many European countries with no formally recognised ethics support. Some countries have legislation regarding ethics support, for example in Belgium it is a legal requirement that every hospital should have an ethics committee that addresses research and clinical issues[4]. The Norwegian parliament has recommended that all hospitals have a clinical ethics committee and it has funded a national centre to co-ordinate their development.[5]

In several European countries ethics committees consider both research and clinical ethics. However, the experience of this system in the Netherlands was that research issues dominated the agenda, and there has been a move to separate research ethics committees and clinical ethics committees.

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[2] Joint Commission for Accreditation of Healthcare Organisations. 1996 Comprehensive Manual for Hospitals. Chicago: JCAHO, 1996: 95 – 97.

[3] Meslin E, Rayner C, Larcher V, Hope T, Savulescu J. Hospital Ethics Committees in the United Kingdom. *HEC Forum* 1996; **8**(5):301-315 page 301

[4] Slowther A, Bunch C, Woolnough B, Hope T. Clinical Ethics Support in the UK: A review of the current position and likely development. 2001; London; The Nuffield Trust paragraph 9.4.1

[5] Holm S, Clinical Ethics Committee in Norway - Highly Recommended by the Norwegian Parliament http://www.ethics-network.org.uk/international/intlspec/norway.htm

A report on the position of clinical ethics committees and ethics consultation in German Hospitals appears in Appendix A2

The UK experience

- CECs were first described in the mid 1990s.
- There has been a rapid increase in the number of CECs since 2001.
- The main model of ethics support is an ethics committee or group.
- There is a national network of clinical ethics committees – the UK Clinical Ethics Network.
- CECs in the UK are quite different from RECs

Before 2000 there was very little information available about clinical ethics support in the UK. In 1996 Meslin and colleagues[6] described the work of 3 Hospital Ethics Committees and in 1999 Watson[7] described the work undertaken by the Ethics of Clinical Practice Committee in Nottingham. A review of clinical ethics support in 2001[8] found that twenty NHS trusts (4%) had a CEC, and a further twenty were thinking about establishing one. Since 2001 there has been a rapid increase in the number of NHS trusts that have established a CEC. Currently 61 acute and community trusts have a CEC, and in the past 12 months two primary care trusts (PCTs) have registered a committee with the UK Clinical Ethics Network. Unlike North America, and some European countries, it is rare for individual ethicists to work in UK NHS trusts. The most common model of ethics support is a committee / group.

The following table shows the range of trusts that have a CEC as a percentage of the total number of CECs in the country (based on 2004 data).

Acute Adult	69%
Children	6%
Mental Health	5%
Area Wide	3%
Private	3%
Hospice	2%
Primary Care Trust (PCT)	2%

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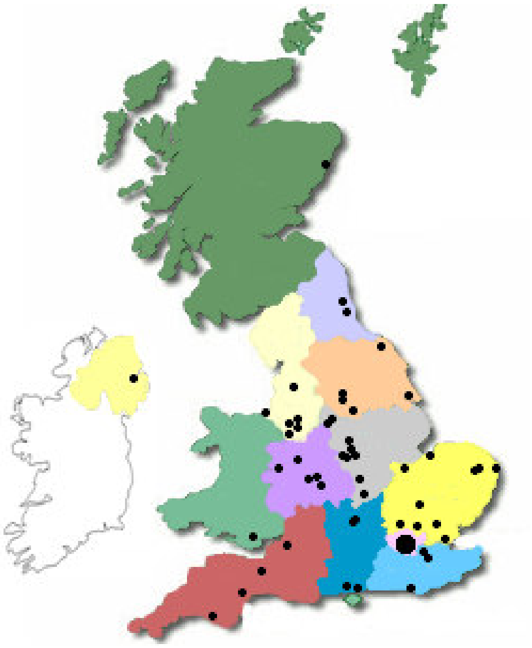
[6] Meslin E, Rayner C, Larcher V, Hope T, Savulescu J. Hospital Ethics Committees in the United Kingdom. *HEC Forum* 1996; **8**(5):301-315

[7] Watson AR. An ethics of clinical practice committee: should every hospital have one? *Proc Roy Coll Phys Edin* 1999;**29**:335-337

[8] Slowther A, Bunch C, Woolnough B, Hope T. Clinical Ethics Support in the UK: A review of the current position and likely development. 2001; London; The Nuffield Trust



There is a wide geographical distribution of CECs throughout the UK

Each black dot represents the location of a CEC

Development of the UK Clinical Ethics Network

In January 2001 representatives of a small group of clinical ethics committees (CECs) met to discuss the future development of clinical ethics support in the UK. This led to the establishment of the UK Clinical Ethics Network, which provides support to CECs in the UK.

See Section B for more detailed information about the Network.

The distinction between Clinical Ethics Committees and Research Ethics Committees

Research Ethics Committees (RECs) were set up to review the ethical issues arising from research within the NHS. It is a requirement under the governance arrangements for NHS research ethics committees (GafREC) issued by the Department of Health[9] that research involving NHS patients or NHS resources receives approval from a REC prior to commencement of the research. The role and conduct of RECs is closely regulated, and is the responsibility of the relevant Strategic Health Authority. There is a central co-ordinating office for RECs that issues guidance and facilitates provision of training of REC members.

In contrast to RECs, clinical ethics committees are advisory and are not governed by government regulation. They sit within individual trusts and often develop as a result of clinician concern rather than managerial directive. There is no requirement for training of members of CECs.

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[9] Governance arrangements for NHS research ethics committees. Department of Health. 2001. http://www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationsPolicyAndGuidanceArticle/fs/en?CONTENT_ID=4005727&chk=CNcpyR

Comparison of clinical and research ethics committees

Clinical Ethics Committees	Research Ethics Committees
Advisory	Decision-making
Ethics of clinical care	Ethics of medical research involving human participants
Not regulated	Regulated
Training not compulsory	Compulsory training for members
Situated within the Trust /healthcare institution	Required to be outside the Trust
No central funding	Funding for training of members and administrative support
www.ethics-network.org.uk	www.corec.org.uk

Functions of Clinical Ethics Committees

The work of clinical ethics committees falls into three broad areas. Some CECs carry out work in all three areas, others focus on just one or two of these areas.

1. Providing ethics input into trust policy and guidelines around patient care.
2. Facilitating ethics education for health professionals within the trust.
3. Providing ethics advice to clinicians on individual cases.

1. Providing ethics input into trust policy and guidelines around patient care

This may take the following form:

- Developing local guidelines for use within the trust, drawing on national guidance or professional guidance where available
- Providing ethics input on guidelines produced by other committees or clinical groups within the trust
- Commenting on and clarifying existing national policies and guidelines

Appendix A3 sets out a list of points for a committee to consider when having input into guidelines.

Appendix A4 describes one ethics committee's experience of developing a policy on advance directives.

2. Facilitating ethics education for health professionals within the trust

In order to raise awareness of ethical issues arising in clinical practice, and to support decision-making in difficult areas, a CEC may provide or facilitate ethics education and training for healthcare professionals.

This could be achieved in a variety of ways including:

- An outline of ethical considerations / frameworks to be included in an induction booklet for new members of staff.
- Examples of ethical issues arising in clinical cases discussed in a grand round, facilitated by a member of the CEC.
- The CEC hosting an 'open day' or session advertising its work and highlighting common ethical issues and ways of addressing them.
- Producing an ethics booklet for the trust.
- Workshops for groups of healthcare professionals to talk through issues of concern arising for them. For example midwives may have concerns about the ethics of informed consent and antenatal screening.
- Seminars / lectures for healthcare professionals covering specific issues, e.g. consent, consent and vulnerable patients; consent and children; confidentiality.

3. Providing ethical advice to clinicians on clinical cases

Many CECs provide support to clinicians by way of identification and discussion of ethical issues arising in particular cases. Such 'case consultation' arises from individual clinicians approaching the committee, or often in the first instance the committee chair, for advice about a case that is causing them concern. These cases may be retrospective, where the situation has now been resolved but the clinician is not sure that the decisions made were the right ones; or current, where the decisions are still to be made. Committees that deal with current cases will need to develop a mechanism for responding quickly to requests for advice, including requests that occur out of hours. Discussion of the case will include identification of the ethical issues, consideration of current professional guidance and legal requirements, formulating a view on the most appropriate course to follow, and justification of that view. A key consideration in developing a protocol for dealing with case referrals is the involvement of members of the health care team, patients and / or family members in the discussion.

Where cases frequently arise on the same topic the CEC may identify a need for general guidance on this issue by the trust, and can then provide ethics input into the development of such guidance.

Frameworks for thinking about ethical issues are discussed in section C

Appendix A5 provides a list of issues to consider in setting up a case consultation service

Appendix A6 gives an example of one CEC's protocol for emergency referral of cases to the committee.

Example of the range of cases presenting to one CEC

Autonomy of a patient lacking capacity
Breaching confidentiality
Conflict within team on best treatment for patient
DNR Orders
Duty of care
Experimental treatment with an unlicensed drug
Health tourism
Patient decision to refuse treatment
Need for consent to treatment
Informing patient of status when test done in error
Treating disruptive patients
Rights of a foetus
Refusal to perform treatment requested by patient
Treating violent patients
Treating prisoners
Treating a patient without his / her consent
Treatment of Jehovah's Witness
Withdrawing treatment
Withholding treatment
Withholding information from relatives

Example of the range of referring specialities presenting to one CEC

Care of the Elderly
Chaplaincy
Fertility Clinic
General Medicine
Haematology
Intensive Care
Paediatrics
Psychiatry
Urology

Scope of work undertaken by Clinical Ethics Committees

The scope of work undertaken by CECs is extensive and could include:

- Clinical care.
- Management issues, for example treatment of staff.
- Resource allocation at both individual patient and population level.
- Innovative treatments and the boundary with clinical research.

Some committees will focus on a particular area and not all committees undertake involvement in all areas. The scope of work that a committee is prepared to deal with will probably depend on the perceived need within the trust, but may also depend on the expertise of the members of the CEC. The scope of work that a CEC will undertake should be delineated in its Terms of Reference.

A recent survey of Clinical Ethics Committees identified the range of work undertaken by them, although not all CECs consider the whole range.

The questionnaire findings are summarised in Appendix A7.

Range of support provided by CECs (shown as a percentage of CECs surveyed)	
Advice to clinicians by way of case discussion	82%
Contribution to trust policies and guidelines	84%
Provision of ethics education within the trust	76%
Interpretation of national guidelines	66%

Range of issues on which CECs provide ethical advice (shown as a percentage of those surveyed)	
Withholding/withdrawing treatment	87%
Issues of consent to treatment	82%
DNAR orders	79%
Advance directives	79%
Issues of capacity	79%
Refusal of treatment	82%

Different models of clinical ethics support

While a clinical ethics committee or group is the most common model of ethics support in the UK, it will not necessarily be the most appropriate model for some settings or some functions. Other models of ethics support may have advantages in some areas. Below we consider a range of models of ethics support, their strengths and limitations, beginning with the committee model.

- Clinical Ethics Committee / Group / Forum
- Sub Committees
- Case consultation groups
- Hub and spoke model
- Ethicist

Clinical Ethics Committee / Group / Forum

A clinical ethics committee (CEC) is multi-disciplinary, usually with lay membership i.e. non-clinical members who are not employed by the trust.

The number of members of CECs in the UK varies from 6 to 26. Medical members tend to outweigh nursing members by two to one.[10] The majority of CECs have a clinician as chair, which has a possible advantage of facilitating access by clinicians to the committee. Committees meet on average once a month for between one and two hours.

The range of membership within one UK CEC	
Management	**Nurses**
Medical Director	Family Liaison Nurse, Paediatrics
Chief Executive	Staff Nurse, PICU
Ward Manager	Clinical Support Nurse, Surgery
Unit Manager for Day Surgery	Mental Health Nurse
Consultants	Team Leader, Palliative Care Team
Anaesthetist	**Professions Allied to Medicine**
Gynaecology	Senior Occupational Therapist
Physician	**Academics**
Paediatrician in Intensive Care	Lecturer in Medical Law
Transplant Surgeon	Bioethicist
Physician, Care of the Elderly	Postdoctoral Research Associate
Psychiatrist	Professor of Medical Ethics
Junior Doctors	**Other**
SpR, GUM / HIV	Chaplain
HO, Paediatrics	Lay Member
SHO Care of the Elderly	Secretary to the Committee
SHO, Ophthalmology	Senior Occupational Therapist
SpR, Department of Medicine for the Elderly	

Referrals to CECs are mostly commonly made by clinicians but other healthcare professionals, managers, and increasingly GPs, will bring issues for consideration. Current practice of most

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[10] UK Clinical Ethics Network, Report on the Network Questionnaire, 2003, see **Appendix A7**

UK CECs does not usually involve patients or their families and carers in the committee's discussion but some committees have considered cases at the request of a patient's family or carer.

Strengths of the committee model

- A formal Committee is easily recognised as part of the institutional structure and therefore may have more influence with both clinicians and managers.
- Multi-disciplinary membership provides different perspectives.
- Group thinking promotes wide discussion.
- Relatively easy to set up.

Limitations of the committee model

- A Committee may be seen to be part of the management structure and disciplinary procedures within the trust and not as a source of support to clinicians.
- It may not be able to respond rapidly to a request for ethical advice.
- Case discussion by committee may be intimidating for a clinician (and even more so for the parent or partner of a patient) who has asked for advice and support.
- Discussing and drafting policies and guidelines in a large group may be unwieldy.

In order to address the limitations of the single committee other models of support may be developed in addition to, or in place of a committee.

Sub committees

A sub-committee may be constituted to consider a particular issue, for example to discuss implementation of a hospital policy or to consider and draft policy or guidelines.

Strengths of the sub committee model

- Flexible.
- Small groups of individuals may quickly build up areas of expertise.
- An efficient way to develop policy and guidelines.
- Can engage in consultation with specialist groups as necessary.

Limitations of the sub-committee model

- More limited range of representation / views.

Case consultation groups

This model has been developed to provide a quick response to urgent ethical issues arising within a trust where it would be difficult to constitute a full meeting of the CEC. Those comprising the 'rapid response' group typically include clinical and non-clinical members of the CEC. It is necessary to consider how many people will constitute the case consultation group, which members of the committee would be willing to be contacted in an emergency and whether there is sufficiently wide representation from this pool. Cases considered in this way would then be discussed by, or their outcome reported to, the whole committee at a regular CEC meeting. This model is useful where ethics support is frequently provided for case consultations.

Strengths of the case consultation group

- Responsive to individual cases.
- Answers immediate needs for ethics support.
- Less intimidating than a full committee in stressful situations.
- Group members will develop experience and expertise in case consultation because of increased opportunity to consider cases.

Limitations of rapid response model

- Requires members of CECs to be available for consultation outside normal meeting times.
- Constitution of the group may be limited, resulting in a narrow range of views
- Potential for insufficient review by the committee of individual case consultations. This limitation can be overcome by ensuring a robust process for adequate review of decisions by the full CEC.

Hub and spoke model

In this model the ‘spokes’ are individuals taking the ethics lead within their clinical areas and acting as the first point of contact and ethics resource. If an ethical issue arises within that clinical area the individual lead within that area will facilitate discussion of the issue, and if necessary refer on to the CEC or identify an educational need that requires further attention. Ideally the individual lead will have some ethics education or training. Indeed such training of both ‘spokes’ and members of CECs should perhaps become mandatory. In order to ensure sufficient review, the ‘spoke’ should provide a summary of each case consultation to the next full meeting of the clinical ethics committee (the hub). There should also be a reference back to the hub where the individual lead considers the matter is beyond his / her scope of experience or expertise, or if he / she thinks the discussion would benefit from the wider range of views available in the committee.

Strengths of the hub and spoke model

- Flexible.
- Able to respond quickly and informally.
- Similar cases arising frequently enable a body of experience to build up.
- The individual lead in each clinical area can be identified and contacted easily.
- ‘Ear to the ground’ – able to identify ethical issues in clinical areas that might otherwise be missed.

Limitations of the hub and spoke model

- Potential for insufficient review of spoke deliberations.
- Difficulty of ensuring sufficient level of ethics expertise in all clinical areas.
- Individual leads may provide a limited view of the issues.

Appendix A6 show in more detail how a rapid response model may work in practice and the processes to consider in setting up such a model

Ethicist

It is more common in North America than in the UK / Europe for individual ethicists to provide support to health professionals, patients and carers within a health care institution, although some NHS trusts have benefited from the work of an ethicist, for example the Oxford Radcliffe Hospitals NHS Trust.

A brief description of the work of an ethicist is described in Appendix A8

A guide to setting up clinical ethics support in your trust

In the next section we set out the various stages involved in setting up clinical ethics support in a health care organisation, suggesting things to consider and possible options for an individual or group working their way through the process. It should not be seen as a didactic protocol, rather as a prompt, or aide memoire. Some clinical ethics groups have begun as an informal discussion forum and the following guide may seem too formal an approach for them. However informal forums often evolve into a more formal model and some of the issues discussed will be relevant to all models of ethics support. The related appendices provide examples of the experience of ethics committees as they have worked through various aspects of this process. These are an invaluable resource and we would recommend that you refer to them as you read through this guide.

A detailed account of one group's experience of setting up a Mental Health Trust CEC is shown at Appendix A9

Stage 1: Identifying the need and securing an 'expression of interest'

The perceived need for some form of clinical ethics support in a health care organisation can arise from a range of sources and in different ways. These include:

- Individual clinicians struggling with ethical issues in their daily practice.
- Clinicians or managers with an interest in ethics, or with some knowledge of the development of ethics support elsewhere.
- Managers who wish to incorporate ethics support into the governance structure of the organisation.

Once a perceived need has been identified it will be necessary to gain some expression of interest in the concept from senior managers and clinicians. At this stage this may be no more than support for exploring the issue further within the wider organisation. It could take the form of an approach by clinicians to the chief executive or an approach by a senior manager to clinical directors. One possibility is a brief presentation to a key committee such as the clinical governance committee.

Stage 2: Assessing the level of support / raising interest within the organisation

While it is important to have some champions for the concept of ethics support who will lead its development, it is unlikely to be successful without the interest of a significant number of health professionals working in the trust. A key barrier to the effectiveness of ethics support noted by many CECs is the lack of awareness of the CEC's existence by many people working in the trust. In the early stages of developing ethics support you need to discover what models of support are likely to be useful and relevant to clinicians, patients and managers. This is often done by informal enquiries among colleagues but a more effective method, albeit one that requires some resources, is to hold a meeting within the organisation to provide information about clinical ethics support and gain the views of as wide a range of people as possible on models of support and type of issue requiring support.

Areas to discuss in the meeting could include:

- Key ethical issues identified by health professionals within the trust.
- Description of clinical ethics support, experience from other trusts.
- Different models of ethics support and preferred model for this trust.
- Possible functions and scope of ethics support in this trust.
- Suggestions for membership.
- Agreement of a core group to draft a proposal to the trust Board.

An example of a workshop outline used by one NHS trust can be found in Appendix A12

Stage 3: Developing an outline proposal for the trust Board

Information gained from the meeting / workshop in stage 2 can be used in the drafting of an outline proposal to the trust board/executive. Thus if a particular model of ethics support was favoured in the meeting, the drafting group would need to give this model serious consideration as the recommended model in the proposal. It is possible that the preferred model would not be practically achievable, at least in the short term (for example it may be impossible to appoint a clinical ethicist or to recruit and support enough personnel for a hub and spoke model). Specific issues to cover in the outline proposal include:

- **Reasons for establishing clinical ethics support**

Identify why you, or any of your colleagues, see value in setting up a CEC, or other model of ethics support. What led to your interest in this? What were the specific problems that led you to identify a need for ethics support? More generally, what issues might an ethics support service address? You may wish to point out that CECs / ethics support are developing in many trusts across the NHS and that ethics is increasingly recognised as integral to good governance, both at the clinical and managerial level.

- **Preferred model of support**

It is worth pointing out at this stage that the development of ethics support will be an evolving process, so the initial model may be modified in the light of experience, for example the initial model is often a committee but this may evolve to include a rapid response group or a hub and spoke model.

- **Aims of the CEC / ethics support**

Identify the aims of the CEC / support, what does it want to achieve and what does it want to produce by way of recognisable **outcomes**?

- **Mode of Action**

Will the CEC / support be **proactive** in the sense of promoting ethics education within the trust and providing input into hospital policy and creating guidelines, or is it more likely to **respond** to requests from clinicians regarding case consultation?

- **Role of the CEC**

What range of work is it likely to undertake, for example will it principally provide support for clinicians, will it address managerial and resource allocation issues, will it respond to requests from patients and relatives?

- **Status within the trust**

Where will the CEC fit within the trust structure, for example, will it come under the auspices of clinical governance? A successful committee requires institutional support so it is important to think about how the trust perceives the CEC.

Consider:

- Will the work of the CEC feed into the management structure?
- Where will the minutes of meetings be sent?
- To whom is the CEC responsible?

Once approval in principle has been obtained for the outline proposal, a more detailed document can be developed that will form the basis of formal establishment of clinical ethics support in the organisation.

Stage 4 Detailed formal proposal

At this stage you will need to consider some specific issues in detail, including drafting terms of reference for a CEC / support service and CEC membership requirements.

- **Terms of reference**

These should outline:

- The aims of ethics support.
- The model of support.
- The objectives of the CEC / support.
- The functions and scope of the support.
- Selection of CEC / case consultation group members, and terms of membership.
- Referral process for cases and other issues.

Appendix A10 includes examples of Terms of Reference for UK CECs

- **Membership of the CEC**

Chair:

The role of chair is crucial to the effective functioning of a CEC (or of a case consultation group). There are different approaches to selection of a CEC chair, and different approaches may be appropriate for different organizations. These approaches include:

- The trust / organisation executive can appoint a senior clinician or manager to chair the committee and to take responsibility for setting up the committee and any other support processes.
- The trust / organisation can appoint an external chair who takes over the chairmanship when the committee is ready to begin work.
- The committee can elect a chair, once it is established.

These three approaches to selection of a chair have advantages and disadvantages. An external chair provides reassurance that the committee is not an internal clique and emphasises the importance of the patient / public perspective. A senior clinician as chair provides reassurance to clinicians that this is not a quasi-disciplinary process and is more likely to encourage referrals from clinicians. An elected chair reflects a more democratic process, which may be a more appropriate image for an ethics committee to have.

Vice chair

The choice of vice chair can be significant and it is worth considering what the role of the vice chair will be.

- Carrying out the duties of the chair in his / her absence.
- Providing a different perspective, for example specifying that either the chair or vice chair is a lay member and the other is a clinician.

In addition you may wish to consider allocating specific roles to members of the committee, for example raising the profile of the committee, convening case consultation groups, developing an educational programme for the committee.

Other members

As CECs are multi-disciplinary it will be worth considering the range of disciplines and backgrounds you would like to include to ensure that the committee provides a broad range of perspectives. Also consider the ideal size for the committee. Too large a group may result in lack of cohesion between members and the way they work together. But disadvantages of a small committee include a lack of diversity of views and the potential that insufficient members may attend on any one occasion therefore meetings may not be quorate. Some CECs have a small core group and co-opt members with particular expertise relevant to the issue or case to be discussed (core plus option).

Membership of CECs in UK NHS trusts usually includes:

- Doctors
- Nurses
- Other healthcare professionals e.g. dieticians, speech therapists
- Lay members
- A lawyer
- A chaplain or other religious leader
- A patient/user of the service
- An ethicist or philosopher

See page A9 for an example of the membership of one UK CEC.

A **'lay' member** can be described as a person with no clinical experience and who is not employed by the trust.

If there is to be a **legal member** of the committee then consider whether this will be the trust legal advisor. If the trust legal advisor is a member of the committee then his / her role needs to be clarified. He / she will be able to advise the committee on what is legally permissible, but may also channel the discussion along a line that is dictated by legal risk management rather than ethical considerations. It is important that he / she distinguishes his / her role as a committee member from his / her role as legal advisor to the trust. Several CECs in the UK have successfully included the trust legal advisor as a member of the committee. If a non-trust lawyer is a member of the committee, his / her particular area of expertise may have a bearing on his / her contribution. A lawyer who specialises in medical law will be able to comment more authoritatively on legal aspects of the issues brought to the committee than say a lawyer whose expertise is commercial law.

Other issues for membership

- How will you ensure appropriate ethics expertise or experience across the membership of the committee?
- Is there an expectation of a minimum yearly attendance, and if so would non-attendance require resignation?
- What is the length of term of office of a) members, b) chair and vice chair?

- **Secretarial / Administrative support**

Administrative support is important to the smooth functioning of the committee and involves a number of functions:

- Sending out notices of meetings.
- Circulating in advance cases and documents to be discussed at meetings.
- Writing up and circulating minutes and cases discussed.
- Identifying relevant training for members.
- Creating a library of ethics resources.

- **Financial support**

Consider whether the administrator will be paid or have set aside protected time for duties associated with the work of the CEC. Will there be funding available for education and training of members of the committee? A business plan should be drafted with realistic costings for various options depending on the level of CEC activity envisaged.

A formal proposal is then presented to the board/executive

Appendix A11 is an example of a proposal document for the trust.

Stage 5: Getting started

When formal approval is obtained the following practical considerations may be addressed:

• Recruiting members

There is a need to consider *how* members will be recruited. To ensure a diversity of expertise and moral perspectives, it would be most appropriate to advertise for members rather than relying on 'word of mouth' recommendations or simply using the core group that developed the initial proposal. Advertising can be done through the trust intranet or newsletter, or perhaps by direct approaches to heads of clinical units to disseminate information about the CEC and invitations for applications. A personal approach to people who attended the initial meeting, if one was held, may target those with an interest in joining the committee. For potential members from outside the trust you may wish to consider advertising through the local PCT (GPs and other primary care professionals), and relevant departments in the local University (ethics / philosophy / law). Some committees have found that recruiting lay members is a difficult process.

A discussion of issues to consider in appointing lay members is provided in Appendix A13.

Few CECs in the UK have interviewed for committee members but this may become more common as CECs become an accepted part of NHS organisations. CECs already established may wish to consider interviewing potential new members as current members reach the end of their tenure. Conducting interviews for CEC members requires some thought. Key considerations are:

- Who will conduct the interviews?
- What criteria are used to guide the interview process?
- Will the same procedure be used for initial membership of the committee and subsequent replacement when an individual member leaves the committee?

Criteria used by one committee in interviewing potential committee members is given in Appendix A9

• Promotion / advertising of CEC

In order to generate sufficient referrals to the CEC it must have a recognised profile within the trust. Consider advertising the work of the CEC:

- In the handbook for new staff
- In the trust newsletter
- On the intranet
- With the Patient Advisory and Liaison Service
- In leaflets placed around the hospital
- Local GP surgeries

• Meetings

Frequency of meetings

Most CECs meet once a month or once every two months but some meet only where a case has been brought for discussion or there is ongoing work such as drafting of guidelines or consideration of a policy.

When and Where

If members are attending in their own time then it will be necessary to choose a time when most can attend on a regular basis. If it will prove difficult to choose a generally convenient time and place for meetings of the committee, then the hub and spoke model described above may provide the necessary flexibility.

- ## Training and education

In order for the CEC to be seen to have authority, for its views to stand scrutiny and to merit referrals by members of staff, there should be sufficient ethics experience and knowledge within the committee. It is usually the case that one or two members will have some formal ethics education but to ask them to provide training for the other members of the committee could be seen as unduly onerous.

  - Will members themselves be responsible for their ethics education?
  - Will they receive financial support to attend workshops, buy books and if so what is the limit per member?
  - Consider ethics training sessions perhaps with an invited speaker / facilitator.

- ## Committee process – considerations about how the CEC functions

Process of ethical discussion

It is necessary for the CEC to be able to demonstrate to the trust that its decision-making process and the advice it gives can be justified. Therefore the CEC needs to have an explicit process for ethical discussion. This will ensure accountability and consistency of its decisions.

The following points are important in considering the process for ethical discussion:

  - Declaration of personal interests and views, such as membership of relevant interests groups e.g. Voluntary Euthanasia Society.
  - An explicit framework for the process of considering a case. An example of such a framework is set out in **Section C**.
  - A mechanism for ensuring that the relevant facts of the case are ascertained, including the views of all those who will be affected by the outcome.
  - The views of all members of the committee / group should be heard.
  - Members should be prepared to justify their views in the light of counterarguments.
  - Formally test the consensus view of the committee with counter-arguments in order to justify the final conclusion.
  - Clearly state the ethical reasoning behind individual and consensus views.
  - Identify the relevant legal and professional frameworks (See **Section D**).
  - If legal terms such as ‘battery’ are used in the deliberations of the committee legal advice may need to be sought to ensure correct usage of the terms when recorded in the minutes.
  - Minutes of meetings of the CEC may in some instances be disclosed to those outside the trust (see **Section F**). Discussion of an ongoing case forms part of the medical record of the patient. Therefore it is extremely important that the committee adopts measures to ensure that its deliberations and decisions are transparent, factually and legally accurate and can withstand scrutiny.

Referrals and documentation

  - Consider a pro forma for case referrals that sets out details of the person referring the case, the outline issues of the case and the advice sought.
  - Who will be able to refer cases to the CEC?
  - Is there a procedure to be followed if a member of the CEC is approached for informal ethics advice because of their position on the CEC?
  - Consider whether a rapid response service will be provided and if so the process to implement it.
  - What administrative systems are in place - drafting of minutes, filing records and disseminating information to members and those in the trust?

An example of a pro forma referral form is shown in Appendix A14

Confidentiality of committee

Consider the process to be put in place to ensure all members, and those attending meetings to present cases, are aware that they are under a duty of confidence. Members of the CEC who are healthcare professionals will have a professional, ethical and legal duty to maintain confidences of patients of the trust. Lay (non trust) members should be made aware that they too have a duty of confidence, and this may best be achieved by asking that they sign a confidentiality agreement on joining the CEC.

Confidentiality issues also arise in respect of drafting cases for discussion at CEC meetings and writing up of minutes of the meeting.

Cases for discussion

There should be sufficient anonymisation of those cases brought to the CEC for discussion. Care should be taken to ensure that no factors identifying a patient are included in the write up of the case to be circulated to members for discussion. If certain factors are relevant for the discussion then perhaps the Chair could be ‘key-holder’ of the information, to exercise his / her discretion to reveal it to the meeting if he / she considers that necessary.

Minutes of meetings

Where individual cases have been discussed, the minutes of the meeting should not contain information identifying the patient. Nor should they identify a member of the CEC who has expressed an opinion. You may wish to consider having a general summary of the meeting that can be distributed fairly widely and a confidential section of the minutes, which is only available to committee members. Remember that sections of the minutes relevant to a particular case will form part of that patient’s record if the patient is identifiable or if the case discussion had an impact on the patient’s management.

• Indemnity

In theory it may be possible for a member of a committee who is not a trust employee to be individually liable to legal action. Many trusts provide indemnity for non-employee members of the CEC. The contact details of CECs where this is the case can be obtained from the Network (admin@ethics-network.org.uk)

See Section F for more information about confidentiality and the legal liability of members.

Reading

Aulisio MP, Arnold RM, Younger SJ (eds) *Ethics consultation: From theory to practice*. Baltimore: Johns Hopkins University Press (2003).

Ehleben C M, Childs B H, Saltzman S L. What is it exactly that you do? A "snapshot" of an ethicist at work. *HEC Forum*. 1998;**10**(1):71-4.

Jiwani B. An introduction to health ethics committees. Provisional Health Ethics Network (2001).

Journal of Medical Ethics – Clinical Ethics Committees Supplement 2001, April, Vol 27, Supplement 1.

Komatsu G I, Goodman-Crews P, Cohn F, Young E W. Effect of ethics consultations on non beneficial life-sustaining treatments in the intensive care setting: a randomised controlled trial. *Journal of the American Medical Association*. 2003;**290**(9):1166-72.

Larcher V, Lask B. McCarthy J. M. Paediatrics at the cutting edge: Do we need ethics committees? *JME*1997;**23**:245-9.

Slowther A, Bunch C, Woolnough B, Hope T. Clinical Ethics Support in the UK: A review of the current position and likely development. 2001; London; The Nuffield Trust

Slowther A, Hope T. Clinical ethics committees: They can change clinical practice but need evaluation. *BMJ* 2000;**321**:649-650

The report of the American Society for Bioethics and Humanities, *Core Competencies for Health Care Ethics Consultation,* 1998

Watson AR. An ethics if clinical practice committee: should every hospital have one? *Proc Roy Coll Phys Edin* 1999;**29**:335-337

APPENDIX A1

A first hand account of the experience of ethics support in the United States

Dr Ainsley Newson, Imperial College, London

In May 2004, I undertook a one-month placement with a Department of Clinical Bioethics in a large not-for-profit hospital in the United States. Here, I had the opportunity to observe ethics consultations and to discuss the various approaches to providing clinical ethics support with a variety of professionals in this field.

The Department in which I worked has been established for over twenty years and was one of the first such units in the US. Three clinical ethicists are employed in the department full-time, with ancillary research and support staff. On average, the Department handles around five ethics consultations a week, in addition to ongoing work in policy, education and academic research. Ethics consultants rotate on service approximately every three weeks.

The consultants make decisions about a similar range of issues as do clinical ethics committees in the UK: DNR orders, medical futility, withdrawal of treatment, decision-making capacity, treatment refusals, compliance concerns and disagreements between patients/families and health professionals. Cases also arose, however, to illustrate the broad range of theoretical and practical skills required to undertake successful ethics consultation. For example:

- Should an ethics consultant become involved when a dying child’s family wants to undertake a loud and involved religious service at the bedside?
- What, on a practical level, should an ethics consultant do when a potentially manageable genetic condition is identified in a donor organ?
- How much knowledge of surgery and its attendant risks is required in order to ensure a patient is providing fully informed consent rather than mere acquiescence?
- Should patients with impaired mental capacity who have limited family support be denied access to risky surgery?
- Should parents who ‘want everything’ for their terminally ill newborn have access to a full range of treatments even if these are futile?
- How should the demands of agitated families be managed?

The largely theoretical nature of the discussion and debate on these topics in the literature and the lack of consensus on many ethical issues in health care are brought into stark reality when a decision has to be made.

The level of consultation the Department provides varies with the kind of issue at hand. Ethics consultants regularly provide advice to the health care team, facilitate at patient/family meetings, provide education or refer on to another service (such as the institutional ethics committee). In contrast to the majority of UK clinical ethics committees, Department members undertake a significant proportion of their consults directly with patients. Often, ethics consultants take on a role beyond that typically construed as ‘clinical ethics’; Bioethics is often paged by health care team when, for instance, the hospital ombudsman or the social work team are unavailable. Staff also perform research ethics consults: assisting with the creation of consent forms or deliberating on the sensitive ethical issues in a proposed trial.

The approach to ethics consultation is largely individual, although unusually complex or difficult problems are discussed amongst the team. Cases are reviewed at a fortnightly meeting, in collaboration with other clinical staff interested in bioethics and academic medical ethicists from nearby universities.

The Department is also supported by an institutional ethics committee. This committee, like the majority of those in the UK, tended to work at arm's length; generating and responding to hospital policy and considering more difficult cases, such as maternal-foetal relations.

The Department also provides regular ethics liaison services throughout the hospital, including twice-weekly rounds in Intensive Treatment Units. Bioethics staff also provide regular support to a number of clinical programs, notably those committees assessing candidates for organ transplantation, living donor transplants and pre-surgical consults for procedures such as deep brain stimulation for Parkinson's disease, or epilepsy surgery. This more 'proactive' or preventive approach to ethics consultation has three main aims:

1. To address specific ethical questions raised by patients, families, or the health care team;
2. To determine whether there are any ethical contra-indications;
3. To ensure the patient has the ability to judge the risks and benefits of the intervention and that the patient's values match with the desire for the intervention.

All ethics consultations (whether simple or complex) are logged using a written summary report. This contains all relevant patient information, the requestor's details, a description of the problem and a report of the processes used in resolving it. In many cases, the clinical ethicist will make a note in the patient's chart or electronic patient record reporting his / her view as to the most appropriate course of action.

During my visit, I was struck by the significant integration of Bioethics into the provision of standard clinical care. Clinical staff were very aware of the bioethics service, and demonstrated no hesitation in asking for advice. The Department's details were highly visible on all hospital paperwork and the availability of bioethics was well-publicised to patients. After-hours access to consultation was also possible.

My observations also indicated that the success or failure of an ethics consultation is easily determined by the approach taken. Ethics consultation will only rarely involve one particular issue. If a consultant immediately jumps to classifying a problem, then it is likely that the consultation will fail as this will limit the range of thinking that will be undertaken. Rather, it is important to think widely and creatively about any given scenario: approaching problems in clinical ethics is a very creative process. Further, the qualities of a good ethics consultant range far beyond mere theoretical knowledge. Consultants need to be able to engage with a wide variety of people, listen, facilitate and show empathy.

The minutiae of details discussed in a consultation can also be vital: one patient being assessed for epilepsy surgery told the consultant that she knew the risk of her surgery being successful was 60%. Yet, when asked how many people from a room of 100 would represent this percentage, she could not answer. What does this indicate about her understanding of the surgery? What impact might this have on her ability to provide informed consent, and what are the ethical implications?

US clinical ethics consultation is by no means a static discipline and several methodological issues are currently being debated. For example, there is increasing concern about the 'professionalisation' of ethics consultation and the kind of qualifications and training that should be required. Additionally, anonymous consultations sometimes occur, particularly where there is a disagreement within the clinical team.

Further Reading

Aulisio MP, Arnold RM, Younger SJ (eds) *Ethics consultation: From theory to practice*. Baltimore: Johns Hopkins University Press (2003).

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APPENDIX A2

Clinical Ethics Committees and Ethics Consultation in German Hospitals

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Clinical Ethics Committees (CECs) are new institutions of implementing clinical ethics in German hospitals and nursing homes. Most of the CECs are in hospitals that are members of the Protestant or Catholic Hospital Association, which recommended in 1997 the founding of CECs. There are CECs at only three University Hospitals: Hanover (2000), Erlangen (2002) and Mannheim (2004). Another three have ethics consultation without a CEC: Marburg, Ulm, Freiburg. There are some communal and confessional hospitals wich have active CEC or ethics consultation or other forms of ethical support (Hamburg, Hanover, Göttingen, Frankfurt and Nuremberg). Altogether there were 77 CECs in German hospitals in 2003.

In 2002 we posted a questionnaire with 13 items to medical directors and directors of nursing of all 36 German University Hospitals to find out why so few University hospitals have CECs.

We found, that the most relevant ethical issues in everyday clinical practice were limitation of treatment, informed consent and the conflict between beneficence and autonomy. Improvement of interdisciplinary teamwork, further education in ethics and improvement of guidelines have been identified in order to improve ethical professional performance. Additional support of their staff in ethical issues was mentioned by more directors of nursing than medical directors and also the regret about the low priority that ethical issues have in everyday patient care.

Five German University Hospitals are planning to establish a CEC, another two want to employ a clinical ethicist. There is high need for information about CECs in German university hospitals. Tasks, working methods and chances for further development of CECs are neither known nor used by the majority of German University Hospitals.

Literature

1. Deutscher Evangelischer Krankenhausverband, Katholischer Krankenhausverband Deutschlands. Ethik-Komitee im Krankenhaus. 1. Auflage (Hrsg.). Stuttgart Freiburg: Selbstverlag 1997.

2. Deutscher Evangelischer Krankenhausverband, Katholischer Krankenhausverband Deutschlands. Ethik-Komitee im Krankenhaus. Erfahrungsberichte zur Einrichtung von Klinischen Ethikkomitees. 1. Auflage (Hrsg.). Stuttgart Freiburg: Selbstverlag 1999.

3. Gerdes B, Richter G. Ethik-Konsultationsdienst nach dem Konzept von J.C. Fletcher an der University of Virginia. Charlottsville, USA. Ethik Med 1999; 11: 249-261.

4. Kettner M, May A. Landkarte Klinische Ethikkomitees in Deutschland. Unveröffentlichtes Manuskript, 2003.

5. Neitzge G. Ethik im Krankenhaus: Funktion und Aufgaben eines Klinischen Ethikkomitees. Ärzteblatt Baden-Württemberg 2003; 4: 175-178.

6. Reiter-Theil S. Ethik in der Klinik- Theorie und Praxis: Ziele, Aufgaben und Möglichkeiten des Ethik-Konsils. Ethik Med 1999; 11: 222-232.

7. Simon A. A Report from a Catholic hospital- Neu Maria-Hilf, Göttingen. HEC Forum 2001; 13: 232-241.

8. Simon A. Ethics Committees in Germany: An empirical survey of Christian Hospitals. HEC Forum 2001; 13: 225-231.

9. Wernstedt T. Strukturen der Medizinethik in Deutschland, Teil 1 und 2 in Bayr. Ärzteblatt 1/2004: 69 und 5/2005:313.

10. Vollmann J, Weidtmann A. Das Klinische Ethikkomitee des Erlanger Universitätsklinikums. Institutionalisierung – Arbeitsweise – Perspektiven. Ethik Med 2003; 15:229-238.

11. Vollmann J, Burchardi N, Weidtmann A. Klinische Ethikkomitees an deutschen Universitätskliniken. Eine Befragung aller Ärztlichen Direktoren und Pflegedirektoren. Dtsch Med Wochenschr 2004; 129:1237-1242.

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APPENDIX A3

Considerations for CECs in developing policy and guidelines

Does the CEC wish to have a role in developing policy and guidelines?

This is usually given as one of the core functions of a CEC and can be a way for the committee to influence practice on a trust wide level. However it can be very laborious and time consuming if a committee meets infrequently, and may leave little time for other functions that the committee members may see as more important. If policy and guideline development are to be part of the CEC's role then the committee needs to clarify how it will carry out this role.

Options:

1. The committee develops, or plays a significant role in developing, specific policies or guidelines which are accepted and ratified by the Trust Board, e.g. DNAR guidelines, consent policy.
2. The committee reviews existing hospital policies and comments on the ethical considerations of these policies.
3. The committee has input into the development of policies and guidelines drafted by other committees, e.g. resuscitation committee.
4. The committee identifies areas where there is a need for a policy or guideline and either develops this or instigates development by another more appropriate committee.

Each option has advantages and disadvantages and the exact role of the committee will depend on where it fits within the structure of the Trust.

General considerations

There are some general considerations which will be applicable to whatever role the committee takes in guideline and policy development.

1. Is the policy / guideline developed / considered by the whole committee or will sub-committees be used?
2. If the policy / guideline is primarily developed by another committee, what feedback will the CEC have on its input, and on the subsequent dissemination and evaluation of the policy / guideline?
3. If the policy / guideline is developed primarily by the CEC, how much consultation will there be with clinicians and other members of staff affected by the policy, what authority will the policy have and how will implementation and evaluation be achieved?

The process of policy/guideline development

1. Identify the objectives of the policy / guidelines and summarise these
2. Identify the underlying ethical principles that inform the policy / guideline
3. Consider the application of the principles in relevant specific cases in order to formulate recommended procedures that will form the core of the policy / guideline.
4. Consider any legal frameworks in which the policy / guideline must sit.
5. Consider similar guidelines drafted by other institutions such as professional bodies and other CECs in order to refine or enhance the policy / guideline.
6. Consult outside the committee.
7. Aim for clarity in the final document; clarity in the definition of terms, clarity in describing the underlying ethical principles and clarity in setting out procedural steps.

Useful sources of existing guidelines

BMA guidelines	http://www.bma.org.uk/ap.nsf/Content/Hubethics
GMC guidelines	http://www.gmc-uk.org

Examples of CECs that have developed guidelines on the following issues:

CPR/DNR guidelines	Wirral Hospitals NHS Trust Nottingham City Hospital NHS Trust Oxford Radcliffe Hospital NHS Trust Royal United Hospitals Bath NHS Trust St Mary's NHS Trust
Withdrawal and withholding of life sustaining treatment	St Mary's NHS Trust The Royal Hospitals NHS Trust, London Wirral Hospitals NHS Trust
Advance directives	Oxford Radcliffe Hospital NHS Trust Nottingham City Hospital NHS Trust Wirral Hospitals NHS Trust
Consent to treatment	Nottingham City Hospital NHS Trust Royal Hospitals NHS Trust, London
Presence of relatives at CPR attempts	Royal Hospitals NHS Trust, London
Retention of tissues and organs post mortem	Royal United Hospitals Bath NHS Trust
Blood transfusion in Jehovah's witnesses	Royal United Hospitals Bath NHS Trust
Clinical alert policy (for investigations on infectious patients)	Wirral Hospitals NHS Trust
Clinical confidentiality and the media	Royal Hospitals NHS Trust, London

APPENDIX A4

The Newcastle Upon Tyne Hospitals NHS Trust Clinical Ethics Advisory Group (CEAG) Living Wills (Advance Refusals of Treatment)

Stephen Louw
Newcastle Upon Tyne Hospitals NHS Trust Clinical Ethics Advisory Group

Introduction

The CEAG discussed 'Living Wills' over a series of 5 meetings and the key conclusions and recommendations are presented below.

Helpful input was received from the Chairs of Ethics Committees of other Trusts, namely Dr M K Benson – Oxford Radcliffe Hospitals NHS Trust, Dr A K Watson – Nottingham and Dr J Dawson – Wirrell Hospital.

The group was assisted by Dr Anna Bachelor (Head, ITU services, RVI and NGH).

Documents that were tabled included:

- 'Advance Medical Directive', published by Staywell;
- The Voluntary Euthanasia Society's Living Will;
- The BMA's 'Physician Assisted Suicide Debating Pack', Section 8 dealing with 'Advance Statements about Medical Treatment'.

Key issues and Recommendations

1. Name of the document

It was agreed that the document should be called a 'Living Will', on the grounds that this has greater currency for the public, adequately expresses the purpose of the document and does not raise the expectation (as does 'Directive') that any related future decision by a doctor could be directed. However, in order to indicate the proper legal standing of a 'Living Will', the full title of any Trust document should include the phrase:

'Living Will (Advance Refusal of Treatment)'

2. Legal status

The legal standing of Living Wills derives from case law, such as *Re T* (1993), which allowed that advance refusals of treatment are legally binding if: (a) they are clearly established; (b) they are applicable to the current circumstances; and (c) they have been made without undue pressure.

3. Medical Ethics Principles

3.1 The key principle of medical ethics that supports the use of Living Wills is that of autonomy, implying self-rule. It should be recognised, however, that this principle, despite its standing in discussion in most Anglo-American literature, is not universally accepted as being predominant. We recognise that most people should not be thought of atomistically as disengaged from the social environments in which they are embedded. For patients this means that they are normally engaged in a context that might include family, friends, neighbours, non-professional and professional carers, along with their legal advisers, spiritual leaders and advocates.

Hence, in making judgements about Living Wills medical staff must endeavour to become acquainted with the broader context in which the document was conceived.

This thought reflects the statement in the Green Paper *Who Decides? Making Decisions on Behalf of Mentally Incapacitated Adults* (1997, London: HMSO), namely:

> 'The advance statement is not … to be seen in isolation, but against a background of doctor/patient dialogue and the involvement of other carers who might be able to give an insight as to what the patient would want in the particular circumstances of the case.'

3.2 Involving relatives and carers and indeed the patient (in so far as their competency will allow) in interpreting a Living Will is in keeping with the common law principle that, in the case of an adult who lacks capacity, the doctor must act in the patient's 'best interests'. The same document suggests that in determining 'best interests', attention should be paid to:

- The ascertainable past and present wishes of the person and factors they would have considered if they were able;
- Encouraging the full participation of the person concerned as far as this is possible;
- The views of all significant others, both family, friends and all those involved in the person's care;
- The need to make sure that the purpose of any treatment is achieved in the least restrictive manner possible.

These criteria have been taken up in the government's subsequent White Paper *Making Decisions*.

3.3 With these considerations in place, any decisions about Trust policy with respect to Living Wills should bear in mind the following underlying ethical and philosophical principles:

- Living Wills exist in order to foster the autonomous agency of individuals who cannot otherwise exercise capacity;
- The individual person, however, is embedded in a broad social context and patients (in particular those who lack capacity to make decisions about their treatment) must often depend to some extent on those around, both professional and non-professional, in order to exercise their agency;
- It follows that professionals must pay attention to the views of others involved in the care of their patients; but also professionals must not be prevented from encouraging the agency of patients under their care. Indeed, in seeking the holistic well-being of their patients, professionals should encourage them to take steps to enhance their autonomous agency; this is in keeping with the principle of beneficence;
- Meanwhile, the Trust must ensure both that the interests of the patients under its care are not compromised (the principle of non-maleficence), and that its staff are not compromised: neither through lack of training, nor through lack of appropriate support.

4. Applying the directives in a Living Will in clinical practice

In determining the best interests of a patient, where the patient has a Living Will, it will be appropriate for clinicians to consider whether or not the legal criteria for a valid Living Will (see 2 above) have been satisfied. In particular, clinicians need to consider whether the condition(s) anticipated in the Living Will are actually those that obtain. Experience of a condition could lead to a change of view over time – this might call into question the validity of a Living Will. While it is recognised that people usually grow to accept disability and may therefore seek to revoke the terms of a prior Living Will this acceptance of disability may not always occur and the Living Will may thus remain valid.

5. Should the Living Will document be offered to patients in hospital or should it be provided only on request?

The consensus in CEAG was that patients should be made generally aware of Living Wills, but they should not be actively offered to all patients who have contact with the Trust. This recommendation is made on the grounds that patients might feel that undue pressure is being brought to bear on them if the Living Will is actively promoted, breaching the principle of non-maleficence and potentially undermining the patient's trust in their health carers in hospital. Suitable and morally acceptable methods of raising awareness include the use of posters or pamphlets.

Ideally, Living Wills should be part of a patient's whole management. While involvement of the GP would be ideal in helping patients to complete their Living Wills, the Trust should be able to provide Living Wills and advice relating thereto if requested. Leaflets should be made available describing the purpose and implications of a Living Will. In giving advice to patients, there should be a general discussion about the patient's values and beliefs before particular and detailed decisions are made; it would appropriate for any such discussions to take place over several meetings and to involve other family members or carers at the patient's request. Therefore, giving such advice is likely to be time-consuming and staff will require proper training if in fact the Trust undertakes to provide such advice and support. Nevertheless, any clinician must be prepared to offer advice within the bounds of their competence, or to refer to an appropriately informed colleague, if a patient seeks their help. By these means the patient's autonomous decision-making, in relation to whether they wish to have a Living Will and to the nature of such a document, is enhanced. There is a need to provide information and choice. Appropriate and authentic choices are likely to be made in situations where there is not any immediate urgency. However, if the patient freely requests a Living Will in hospital, the request should be responded to.

6. Recording the existence of a Living Will and its distribution.

Provided that patients give their consent, the Trust has a duty to ensure that the existence and content of the Living Will is made known to key health personnel. Thus, a copy of the Living Will should be sent with the patient's Discharge Letter to the patient's GP. A copy of the Living Will should also be kept in the patient's hospital notes, with a prominent sticker inside the cover indicating that the notes contain a Living Will.

7. Safeguards

7.1 Safeguarding the patient's autonomy – should staff play an active advisory role?

Ideally independent advice should be available to patients in the Trust, but such advisors should be senior and suitably trained.

It was agreed that a comprehensive **leaflet** should be made available, along the lines of 'Advance Medical Directive' (published by Staywell), describing the nature, purpose and practicalities of a Living Will. The leaflet should include an exploration of values and beliefs to help the patient to make their decisions in the Living Will document.

Since patients are often fearful of hospitals and do not necessarily understand the limits of Do Not Resuscitate decisions, there should be a clear definition of terms in the leaflet and in the

Living Will document. The leaflet should make it plain that the hospital staff would act in the best interests of the patient.

7.2 Safeguarding the patient's autonomy - should family members or carers be involved in discussions relating to a Living Will?
Patients should be encouraged to discuss their Living Will with family members, to avoid future conflicts of opinion regarding the patient's intentions. This is based on the principle that it is in the patient's interests to ensure that their wishes would be respected in future.

Trust staff may be called upon to safeguard the patient's autonomy if s/he wishes to complete the form without support from their family. The patient should be given time for reflection and the patient should be encouraged to involve family when the patient feels that the time is right. It is felt important neither to be proscriptive nor prescriptive.

In patients with mild dementia, the situation may be made more difficult if the family is not there to provide a context to the patient's life-experience and preferences. Nonetheless, patients must be encouraged to decide for themselves who should be involved in drawing up their Living Wills.

7.3 Safeguarding the patient's autonomy – the role of the Trust's solicitor.
Owing to financial considerations, a conflict of interest might arise where the Trust Solicitor is called on to advise on the appropriateness of completing a Living Will. It was agreed that a patient could request a solicitor and should be assisted in so doing, but that the document should not refer to the "Trust" solicitor.

8. Would it be acceptable for a member of staff to witness the patient's signature?

In order to minimise the risk of undue influence, staff that witness a signature should not be those with day-to-day responsibility, but staff from another area who are at a distance from the patient. Clinicians might attach greater weight to the validity of a Living Will if there is evidence that it has been carefully considered and knowledge of the identity of the witness to the signature might provide such reassurances.

CEAG was uncertain whether the witness of the signature was in fact only required to confirm the patient's identity in signing or whether the witness was confirming the legitimacy of the process of drawing up the Living Will. This would raise the issue of the person's capacity to sign the Living Will and staff need to be made aware that they should seek expert advice if they have any doubts about the patient's capacity.
It seems that if a member of the hospital team were asked to witness a Living Will, there would be a stricter criterion as to what might be expected from the witness than if a lay person acted as a witness. Staff have a duty to ensure that the process is carried out in the proper and appropriate manner. A further consideration is the need to guard against litigation. The Trust should consider the question of the seniority of the member of staff witnessing the document, who will require appropriate skills in assessing capacity.

If the document were only offered on request there would be a lower likelihood of coercion by a person signing their names as witness, but it might be considered that under some circumstances a clinician might wish to initiate thoughts about a Living Will.

It should go without saying that all discussions about Living Wills should be clearly, contemporaneously and accurately recorded in the clinical notes.

9. The contents of the Living Will

9.1 The Preamble

It was agreed that the preamble should contain the following statements:

11.1.1 The Trust wishes to assure you and your carers that under all circumstances the health team will strive to provide what they consider to be the best treatment for you.
11.1.2 This document is to record aspects of treatment that you do not wish to have under specified circumstances.

9.2 A statement of beliefs

CEAG considered whether a statement of the patient's beliefs should be included in the Living Will. It was felt that caution should be exercised, since the Living Will is a legal document and requires precision; however, space for a free text statement of beliefs and values seems appropriate in case the patient wishes to record such beliefs and values – this would be similar to a standard practise pertaining to Last Will documents. In instances where staff are asked for help a patient with their Living Will, they should be alert to the possibility that a 'statement of beliefs' may be in conflict with some components of the remainder of the document.

10. Should there be an option stating: 'If there is a medically indicated treatment available, my preference would be not to refuse such treatment'.

CEAG members were divided in their views on this matter. It was recognised that an affirmative guidance such as this (as opposed to an advance refusal of treatment) may be more relevant in some clinical scenarios. On the other hand, it could raise unrealistic expectations that future treatments could be demanded, or, alternatively, could engender fear that clinicians might withhold appropriate treatment unless such demands are clearly stated.

11. The duration and validity of a Living Will.

CEAG came to the conclusion that there were no ethical grounds on which to recommend that a time limit should apply to a Living Will. It follows that a Living Will should remain valid until the patient wishes to change it. However, CEAG recommends that the Trust's information brochure should advise patients who sign a Living Will to review it from time to time. Since ordinary Wills make provision for codicils, they may well be appropriate in a Living Will as well.

12. Should a Living Will be deemed invalid if the patient develops dementia?

CEAG considers that no ethical grounds exist to regard cognitive disturbance as necessarily invalidating a Living Will.

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Acknowledgements: Membership of CEAG at the time of the above discussions included: Sir Miles Irving, Dr Julian Hughes, Dr Tom Shakespeare, Dr Jill Lothian, Dr Kath Mannix, Miss Clare Abley, Dr Anna Batchelor, Dr Andrew Cant, Dr Nick Plant, Dr Patrick Kestevan, Mrs Mary Midgley, Mr H Thomas, Ms Gill Finlay, Mrs L Simpson, Mr Steve Kirkup provided secretarial support.

The following further information produced by CEAG is available from the Network web site www.ethics-network.org.uk/Committee/functions/functions.htm

- Explanatory Notes for Patients
- Sample Form

Appendix A5

Issues to Consider when Setting Up a Case Consultation Service

Many clinical ethics committees (CEC) / groups provide ethics case consultation for clinicians within the trust. Case consultation may be undertaken by the whole committee, by a small consultation group, or by referral to an individual member of the committee who then consults with other members as appropriate.

Below we identify some issues that a CEC may wish to consider in providing a case consultation facility.

- Who can refer cases to the CEC?
- Process of referral
- Pro forma referral forms
- Ethical framework and critical reasoning
- Who attends the consultation?
- Writing up the case consultation
- Disseminating information

Who can refer cases to the CEC?

Generally the Terms of Reference of a CEC / group are not prescriptive about who can refer cases. Some clinicians may be reluctant to refer cases in the belief that the view expressed by the CEC may limit his / her clinical autonomy. It should be made clear that the CEC provides an opportunity for difficult ethical issues to be considered but the view of the committee does not bind the clinician to a particular course of action.

In general fewer nurses and allied healthcare professionals refer cases to a CEC. This may be because any matter for consultation is channelled through the lead clinician. But what if the nursing team are faced with an ethical dilemma that the consultant does not feel merits referral to the CEC? How will the CEC / consultation group deal with referrals when there is conflict in the health care team over the need to make a referral?

Will patients or their families be able to refer cases to the CEC, and will they be involved in the case discussion when referral is by a clinician?

Process of referral

The committee will need a clear process for considering an initial referral, deciding whether it is appropriate for the committee / consultation group to consider the case, gathering of relevant information, convening a consultation meeting, and documenting the discussion.

Pro forma referral forms

It is very useful for a committee to produce a standard form for all case referrals made to it. This should state the name of the referring healthcare professional and clinical details (but excluding identifying information such as name and hospital number).

An example of a pro-forma for case consultation referral is shown in Appendix A14

Ethical framework and critical reasoning

In case consultation the ethics committee / group is being asked to consider the ethical issues arising in a particular case. It should therefore follow some process to ensure that the ethical issues are addressed and the Chair should ensure that all members have an opportunity to contribute to the discussion.

See Section C for ethical frameworks and critical reasoning.

Who attends the meeting?

The committee will need to consider who should be involved in the case consultation. This will include members of the CEC / consultation group, members of the clinical team, patients and their family or informal carers. How extensive should this group be. There needs to be a balance between the need to involve those people who are directly affected by the discussion, and to avoid an unwieldy meeting or delay in providing support. This may differ depending on the urgency and nature of the case.

Writing up the case consultation

There should be documentation of the case discussion for the CEC, including clear reference to the ethical reasoning leading to the conclusion. This will ensure transparency of process and contribute to consistency of decision-making by comparison of case discussions as part of the review process of the CEC. It will also be valuable in terms of auditing the work of the CEC. It may be useful if a form is created for this purpose.

If the case has been considered by a rapid response team and there has not been a full meeting of the CEC then there will be no formal CEC minutes. When the full Committee next meets the case should be presented for discussion so that all members can learn from the experience and give their views.

The patient's notes should record the referral and the outline ethical advice given.

Disseminating information

The clinician / healthcare professional that referred the case to the committee should be provided with a write up of the case and the outline discussion (ideally in a standard format). This can be used by the health care team for ongoing education. The process of case consultation should include a review of the outcome of the case to both inform future case consultation and for evaluation of the service.

Appendix A6

Protocol for emergency referrals to a clinical ethics committee

Dr Jim Eccles, Leeds Teaching Hospitals Clinical Ethics Committee

Code of Conduct for the Leeds Teaching Hospitals Clinical Ethics Committee

Members of the Committee are expected to:

1. **Respect patient confidentiality.**
They are expected to act responsibly in handling oral or written communication about individual patients, and to take all reasonable precautions to protect patient confidentiality.

2. **Respect the rights of patients to be involved in decisions about their care.**
They should take account of the competence of patients to be involved in such decisions, and of the position of those close to the patient.

3. **Be honest and act with integrity.**
The best interests of individual patients should be their first concern, though they may also need to consider wider interests. If the individual responsibilities of committee members result in conflicts of interest, these should be acknowledged and taken into account in the work of the committee.

4. **Respect the views of other committee members, and colleagues.**
The committee will seek to achieve agreement, but differences of opinion should be acknowledged and recorded.

5. **Refer matters beyond the scope of the committee to the appropriate body.**
This may include medico-legal questions, and matters concerning the quality of clinical care, and appropriate advice should then be sought.

6. **Maintain awareness and understanding of clinical ethical issues.**
This should involve the pursuit of appropriate educational opportunities, with the encouragement and support of the Trust.

7. **Promote the awareness of ethical issues involved in the work of the Trust.**
This should include the sharing and mutual understanding of specific professional guidance on the ethical standards of clinical practice.

8. **Promote the fair and equitable treatment of patients and their carers.**
The committee should encourage the Trust and its staff to treat patients and their carers in a fair and equitable manner.

References:

Code of conduct for NHS Managers. Department of Health 2002.
Code of Professional Conduct. Nursing and Midwifery Council. 2002.
Good Medical Practice. General Medical Council. 2001.

Terms of Reference of Clinical Ethics Consultation Groups

1. Establishment of each group to be in response to a request for advice about an individual clinical case or cases within the Trust.

2. Requests for such advice to be made to the chair of the Committee, who will be responsible for co-coordinating the response.

3. If a full Committee meeting is imminent, then requests for advice may be presented to the full Committee, but more urgent requests may require a response before the next meeting.

4. The establishment of a Case Consultation Group will depend on the complexity of the presenting problem, the time required to establish the group and the agreement and participation of the referring clinician.

5. Requests for urgent clinical ethical advice may need to involve the early participation of individual members of the Committee, at the discretion of the chair of the Committee. Whenever a Clinical Ethics Case Consultation Group is established, the group should include the following participants, depending on the availability of Committee members:

  5.1 Chair, or member nominated to chair the group
  5.2 Clinician involved in Clinical Risk management
  5.3 Lay or Academic member of the Committee
  5.4 Where possible, CEC member from relevant medical specialty
  5.5 Where possible, CEC member from unrelated medical specialty

6. The work of each Case Consultation Group will be reported to the next meeting of the full Committee.

7. The Case Consultation Groups will be responsible directly to the Clinical Ethics Committee, and therefore to the Clinical Governance Action Group.

Jim Eccles
Leeds Teaching Hospitals Clinical Ethics Committee
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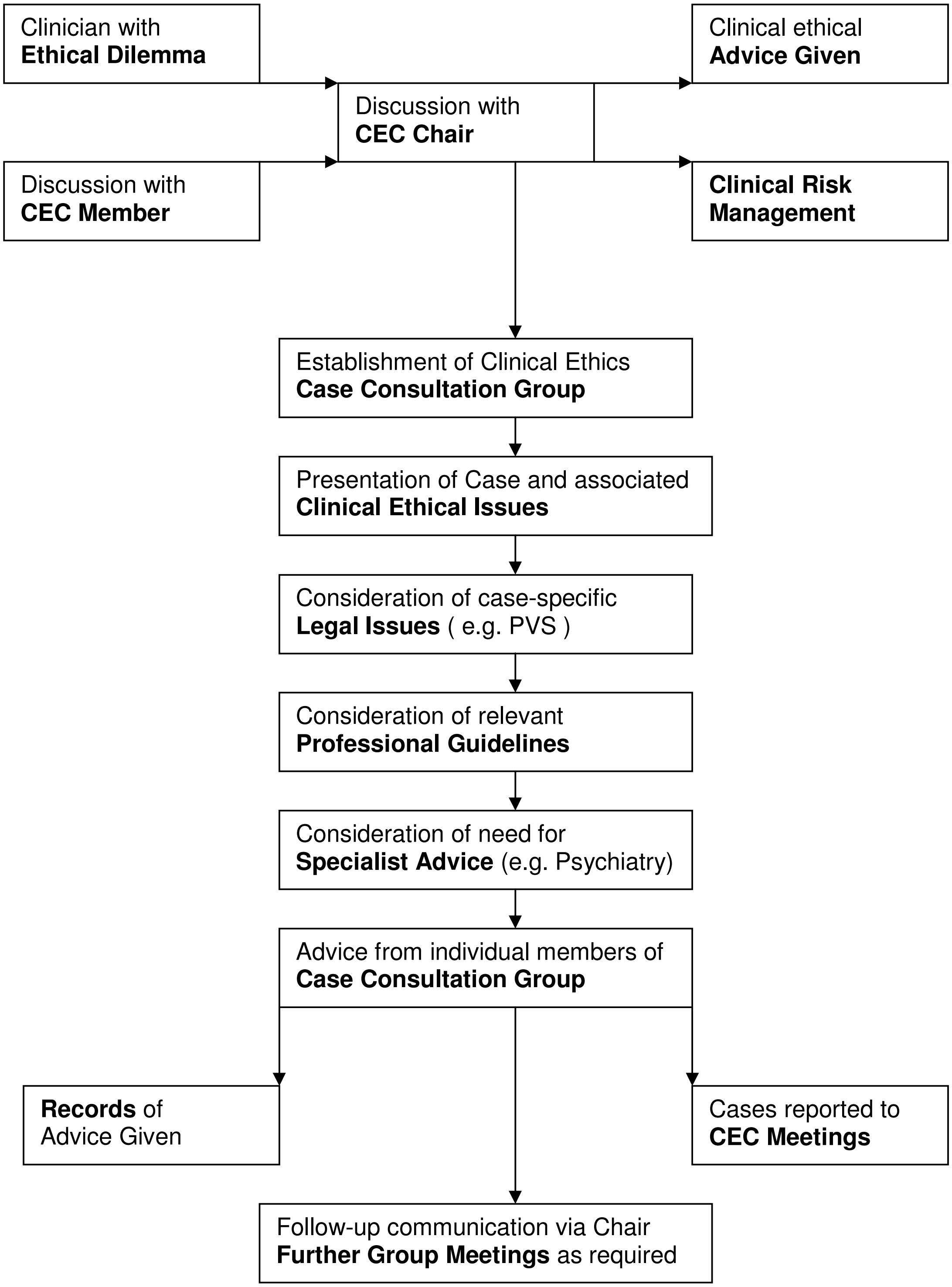
Clinical Ethics Committee Case Consultations Algorithm



APPENDIX A7

Report on findings from the UK Clinical Ethics Network Questionnaire, May 2003

Purpose of questionnaire and response rate

In January 2003 a seven page questionnaire was sent out to all Chairs of clinical ethics committees (CECs) / fora that were known to the Network (as a result of the work Anne Slowther carried out for the Nuffield Trust Report, December 2000 and through Ethox training programmes). The purpose of the questionnaire was to find out how CECs are operating - their structure and the range of work that is carried out by them. With this information the Network will be in a position to provide relevant support.

Fifty-three questionnaires were distributed. A letter of reminder was sent out mid March. Thirty-eight questionnaires were received back (a response rate of 72%). This is a pleasing response rate and provides the Network with a good base of information from a range of CECs.

Updating information about Committees

Of the thirty-eight CECs that responded to the questionnaire three informed the Network that the Committee was no longer active.

Therefore we know that 35 CECs are active and we have up to date details for our database and relevant information useful for the website. The information in this report therefore relates to the 35 active CECs who responded to the questionnaire.

However we know there are other active CECs although they have not responded to the questionnaire. We shall be contacting CECs from whom we did not receive a response in order to find out if they are still active and, if so, to update our information.

Occasionally Ethox becomes aware of new CECs (where contact is made to find out about training workshops) although the CEC has not heard of the Network. The profile of the Network should be enhanced so that CECs are aware of the Network and can benefit from it. We hope to achieve this with the introduction of the Network website.

Contacting CECs

Those who have responded to the questionnaire have provided the Network with the most appropriate contact point whose address and email will be put on the website to facilitate ease and speed of communication between Committees.

Composition of CECs and the support they provide

The largest CEC has 26 members, the smallest 6 members (although this CEC has only recently been formed). On average, the number of members of a CEC is 13.

The majority of CECs have legal, religious and lay representation:

- 21 Committees have a legal member
- 26 Committees have religious representation
- 29 Committees have lay representation

Medical members of CECs outnumber nursing members by 2:1.

Meetings

Of the 35 CECs who responded, just under half have meetings every month, 7 have meetings quarterly and 5 meet bi-monthly. In most cases meetings are of between one and a half hours and two hours duration.

Interestingly, 24 of 35 CECs indicated that the majority of members attended the meetings. This is despite the fact that only a small minority of CECs pay for members' expenses to attend meetings, or their time in attending. We can conclude from this that committee members feel that they are fulfilling a worthwhile function.

Functions of CECs

Twenty-three CECs replied that they frequently provide ethical support to individual clinicians. However formal ethics case consultation is unusual[11]. This suggests that those responding to the questionnaire are indicating informal advice or retrospective review of cases. It would be useful to explore in more detail what is the range of ethical support.

Nineteen CECs state that they frequently contribute to Trust policies and guidelines. It would be useful if the expertise generated could be available for other committees and the website will indicate where CECs have contributed to particular policies / guidelines (www.ethics-network.org.uk/Committee/functions/functions.htm)

Only thirteen CECs stated that they frequently provide ethics education within the Trust.

Interpreting national guidelines is done infrequently by most CECs – only seven indicated that this is a function they performed frequently.

Risk management, eligibility of foreign nationals for NHS treatment and police access to patient records were indicated as other issues that CECs have become involved in. It is relevant to ask what is / should be the ambit of involvement in issues that are not exclusively clinical ethics. Should CECs become involved in ethical issues relating to management or 'organisational ethics' ?

Ethical issues that CECs are most frequently asked to advise on are withholding and withdrawing treatment, consent and DNR orders.

- 17 CECs frequently deal with withholding and withdrawing treatment
- 16 CECs frequently deal with issues of consent
- 12 CECs frequently deal with DNR orders

Other areas that arise with reasonable frequency are advance directives, capacity and refusal of treatment.

However in response to the question – 'which area of clinical practice do you find creates the greatest ethical difficulties for your Committee', those areas identified tended to be those that are not dealt with frequently by Committees – genetic testing, assisted reproduction, accident and emergency, intensive care, and NHS targets.

A question for discussion is whether the Network should provide education and training in those areas that frequently arise before CECs, or should it concentrate on developing training for those issues that CECs indicate cause greatest ethical difficulty even though they may arise infrequently?

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[11] Slowther A, Bunch C, Woolnough B, Hope T. Clinical Ethics Support in the UK: A review of the current position and likely development. 2001; London; The Nuffield Trust

Financial and other support for CECs

Twenty-nine CECs indicated that they have administrative support – mostly minute taking, distribution of papers and arranging meetings (six do not receive administrative support).

Nineteen committees receive some financial help from the Trust (four receive funding from other sources e.g. profit from an annual ethics forum).

In only two Committees are members paid for their time, and in only eight are members' expenses covered.

There were only 18 positive responses to the question 'are non Trust members of your Committee indemnified?'. Nine said that they were not and eight did not respond to this question. This leaves lay members of Committees potentially liable and is an area of concern that the Network will be addressing.

Ethics training

Training of members of CECs has improved since the Nuffield Trust survey. Twenty-four CECs have at least one member with a qualification in ethics and twenty-six CECs indicated that one or more members have attended a non-Ethox training course. Just under half of positive responses stated that Committees receive expenses for training of their members – it would be useful to identify the form this training takes.

It is worth considering whether there should be a minimum standard of ethics training of an ethics committee as a whole and any minimum standards of training for individual members (as is the case with LRECs).

Communication between Committees

Twenty-two Committees replied that they have contacted / collaborated with other Committees and where they have done so collaboration is reasonably frequent – twelve stating that they have collaborated two or more times a year. The outcome has been positive – Chairs have reported a useful validation of advice.

Of those CECs that have not communicated with others six felt it was unnecessary and one was concerned with issues of confidentiality.

In order to encourage dialogue between CECs it should be clear who to contact and how to do so – the website will make this information readily available.

Points for further discussion

- Should members of CECs receive expenses / payment?
- Indemnity of non Trust members
- Function of CECs – should they become involved with organisational ethics?
- How much should CECs be involved in formal case consultation?
- Training and education – should the network concentrate on those areas that frequently arise before CECs, or those issues that CECs indicate cause greatest ethical difficulty even though they may arise infrequently? Should there be specific training for case consultation?
- Should there be a minimum standard of ethics training for an ethics committee as a whole and/or any minimum standards of training for individual members?

Appendix A8

Role of a clinical ethicist

Professor Michael Parker, Professor of Bioethics, The Ethox Centre, University of Oxford

It is not uncommon for clinical ethics committees to include amongst their membership an academic ethicist, or to have links with academics working on ethical issues and based in a local university department of philosophy, law, theology or medicine. In some settings, even where there is not in fact an ethics committee, academic ethicists have developed good relationships with clinicians and other health professionals and have been willing to provide input into the discussion of cases. Many of the leading academics involved in research and teaching in medical ethics 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 ethical problems through.

In recent years, one or two academic ethicists have developed closer relationships with clinical practice and have begun to practice what might be called the role of a 'clinical ethicist'. As it has with ethics committees, this work has taken the form of support and advice rather than decision-making. It is as yet relatively uncommon for this work to be funded through the trust itself but in one or two cases some such funding has been available. What might a clinical ethicist do? To a great extent this will depend upon the needs of the particular clinical setting and upon the skills and experience of the ethicist. At the Oxford Radcliffe Hospitals Trust (ORHT) clinical ethics support mirrors to some extent the roles taken on by clinical ethics committees. That is, as an ethicist I have some educational role, some input into cases and some input into the development of policy. My role as the ethicist at ORHT takes something like the following form:

1. Supporting the clinical ethics committee.

I am a member of the clinical ethics committee, providing ethics input and helping to set the agenda. My relatively close relationship with the clinical setting means that I am able to identify and act as a collecting point for ethical issues and cases that might be suitable for discussion at the ethics committee. The availability of an ethicist makes it possible for the clinical ethics committee to provide relatively timely and flexible responses to health professionals. The clinical work of the ethicist can also act as a useful indicator of areas of practice in which there might be the need for policy development or education.

2. Case consultation

I run 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 group of doctors, counsellors and nurses. I also run a similar discussion group for the cardiology genetics team. In addition to these regular sessions, I provide ad hoc support in any clinical areas that wants it. In many cases the team simply wants someone who can facilitate a one-off discussion about a particularly problematic issue. In some cases this leads on (as in genetics) to a more long-term involvement. In addition to genetics and cardiology, I have provided ethics support in Intensive care, to the resuscitation team, prenatal testing, the Women's Centre, Neuro ITU, the Retained Organs Group, Paediatrics, among others. In many cases the ethical issues can be resolved locally, in others I am able to act as a link person encouraging access to the clinical ethics committee.

3. Education

The long-term input of an ethicist into a clinical team, in addition to helping 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, I have encouraged and participated in the educational activities of the committee. For example, running one hour open training sessions on ethical issues for members of trust staff on issues such as consent, confidentiality and so on.

4. Policy and guidance

In many cases, difficult ethical issues arising in practice 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 and to think through the ethical implications of new policy initiatives and changes in practice. Similarly, with policy and guidelines developed externally (whether nationally or at the level of the trust) the ethicist can help clinical teams to consider the ethical implications.

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APPENDIX A9

Steps on the Road to a new Clinical Ethics Committee

Graham Behr and Jon Ruddock, Central and North West London Mental Health NHS Trust

1. A **core group** of three clinicians (two consultant psychiatrists and one senior nurse) drove the process (and each other) from the outset.

2. **Experience of established CECs** was obtained by joining a local Acute trust CEC and visiting other CECs.

3. Core group attended **training** events through ETHOX and Imperial College, London.

4. Liaison with other **new CECs** was established (via ETHOX) and details of their functioning obtained (for example their remit, composition, process of selection, administration, and issues of liability and accountability).

5. The core group decided on **local priorities** to shape the remit of our CEC.

6. Discussions were then opened with the **Medical Director**

7. This was followed by a presentation of the proposal to the **Trust-wide consultant meeting** to sound out the reception such a committee might have, elicit concerns and involve consultants from the outset to avoid their being alienated.

8. Further discussions took place with the **Chief Executive** preparing the way for a formal proposal to the Trust Board.

9. Then followed a formal proposal **submitted to the Trust Board** with opportunity for the Board to put questions directly to the core group.

10. Following Board approval further meeting were held with the Chief executive to discuss particularly the composition of the CEC and begin seeking an **independent chair** (whom the Chief Executive subsequently appointed in consultation with the core group).

11. The core group then selected both the **special members** (lay person, religious representative, philosopher, lawyer etc.) as well as **clinicians** from within the Trust.

12. The ‘special’ members were selected by informal process; whomever the core group felt would do the job best was approached. However, for reasons of equity, a more formal process was adopted for clinicians. Explicit **criteria** were developed to judge suitability (Document 1), a Trust-wide **advert** was sent out on e-mail (Document 2) and applicants were **short listed** and **interviewed** by telephone. This process resulted in 24 applications and 10 interviewees for the four clinician places on the committee.

13. The Trust Secretary prepared **contracts assuring confidentiality and indemnity** which were completed by members before clinical discussions were embarked upon.

14. The CEC then **invited referrals** via Trust wide e-mail (Document 3). A pilot site was given priority for fear the CEC would be unable to meet the demand from the whole

Trust initially. However, this turned out to be unnecessary (referrals have come in at a steady rate of about 1/month.)

15. The **core group continued to meet** between the monthly CEC meetings. This was both to iron out administrative issues (see pitfalls) and to develop a way of synthesising the discussions from the meeting into a format that was concise and helpful for the referrer, as well as forming the basis for a potential educational database.

Pitfalls

1. Having both a **budget and an identified person for administration** is essential from the outset. Vast amounts of clinician time were spent on administrative tasks and having this agreed from the outset would have smoothed the development of a functioning committee greatly.

2. The process, from conception to fruition, took two years in this instance. Clearly it need not take that long but the sorely tested **patience** of the core group was repaid by having a CEC which was acceptable to all stakeholders and whose composition allowed it to function effectively.

Document 1: Criteria for Clinical Members of the CEC

Criteria to enable short listing and interviewing

- Interest in the subject of medical ethics
- An ability to work in a group
- A commitment to the group

Other considerations

- To broaden range of clinical background
- To broaden geographical representation
- Prioritise bringing special knowledge/ability/experience

Process

- Circulate ‘Expression of interest’ (EOI) form with core group contact details
- Consider possibility of being on co-optee list
- ‘EOI’ form has core members details for queries

Shortlist on basis of EOI then interview

Interview questions

1. Blurb about high interest and basis on which we are choosing
2. Clarify whether applicant is close to clinical decision making?
3. Would you be able to commit to a monthly meeting (e.g. every first Wednesday of the month 5.00- 6.30pm)?
4. What roles might this committee fulfil?
5. What case that you have encountered might such a committee usefully deal with in your view?

Document 2: Advertisement for Applicants for Members of the Clinical Ethics Committee

- Should I divulge those details to his family?
- Did she really consent to treatment as an informal patient?
- At what point is my patient's suicidality his responsibility rather than mine?
- Why should I treat this patient; she wants treatment but has been unable to make use of anything offered?
- How much of a threat must this patient pose before I feel we should withdraw treatment?
- She says she chooses to live in squalor but is that a real choice she's made?

These are the kinds of questions clinicians face every day in mental health. We often make them by consensus or by invoking a 'senior' opinion. Increasingly, however, clinicians across all disciplines and specialities are making use of clinical ethics committees to assist with decision making in complex challenging cases. There are currently over fifty such committees in the UK. This month CNWL has become the first mental health trust to establish such a committee.

The committee will comprise a chair (external), lay person, service user, lawyer, ethicist, faith representative and a number of clinicians.

If you are a clinician and:

- **have an interest in ethics**
- **have expertise in ethics or some related field that would enrich the discussions**
- **are willing to commit to a monthly meeting from 5.00 until 6.30pm for at least one year**

…. Consider applying to be a member of this committee!

In addition to the above criteria we will endeavour to represent clinicians from different disciplines and geographical parts of the trust.

Please note that this offer applies equally to employees of local authorities who are working within CNWL Trust structures.

If you are interested please send the following details to Dr Graham Behr

1. Name
2. Job
3. Site
4. Description of knowledge, skills or interest which would enhance the work of the committee

If there are more applicants than places available (four places available), a transparent selection process will be undertaken using the above criteria.

CLOSING DATE FOR APPLICATIONS IS FRIDAY 5 SEPTEMBER 2003

Document 3: Advertisement of Clinical Ethics Committee

CNWL now has a Clinical Ethics Committee (CEC), the purpose of which is to assist clinicians in making vexing clinical ethical decisions by reviewing them from an ethical perspective. Some examples might be:

- At what point is my patient's suicidality his responsibility rather than mine?
- How much of a threat must this patient pose before I feel we should withdraw treatment?
- She says she chooses to live in squalor but is that a real choice she's made?

These are the kinds of questions clinicians face every day in mental health. We often make them by consensus or by invoking a 'senior' opinion. Increasingly, however, clinicians across all disciplines and specialties are making use of clinical ethics committees to assist with decision-making in complex challenging cases. There are currently over fifty such committees in the UK. This month CNWL has become the first mental health trust to establish such a committee.

The committee comprises of a chair (external), layperson, service user, lawyer, ethicist, faith representative and a number of clinicians who represent different disciplines and geographical parts of the trust.

The committee has begun to take on both casework and policy-related work. In an attempt to broaden the base of referral sources and increase access to the CEC, we are formally inviting referrals from all clinical professionals. However, to help us gauge the prospective volume of referrals, for the first month referrals are to be invited from one directorate. We would strongly advise that the service user's care team is informed that the case is being discussed by the CEC, and that their contributions are encouraged.

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APPENDIX A10

Example Terms of Reference

A: Draft Terms of reference, membership and Modus Operandi for the Sheffield Teaching Hospitals NHS Trust, Clinical Ethics Group

The meeting will be called the STH Clinical Ethics Group (CEG)

1) Purpose

The purpose of the CEG is to:

a) Provide a forum for discussion on clinical ethical issues within STH
b) Raise the general awareness of clinical ethical problems within STH
c) Provide advice and guidance to the STH Trust Board, CMB and Directorates on ethical issues to facilitate the development of standards and policies, and improve the quality of care.
d) Provide 'real time support to individual clinicians / practitioners.
e) To assist the education of STHT staff (including Group members) in Ethical matters

The CEG **will not**:

- Provide legal advice
- Undertake risk management
- Provide advice on research matters
- Consider any issue not primarily of an ethical nature

The CEG will be advisory and <u>not</u> executive.

Collaboration with others in Sheffield (notably the Sheffield Children's Hospital) is essential.

2) Membership principles

The Chair will be appointed by the Group and serve for a term of three years at the end of which the filling of the position will be reviewed. There will be a Vice Chair appointed by the group, who will serve as above.

Members will serve for a period of three years. which may be renewable. Places shall be made available to new members where members retire from the group. Where no new members are ready to join the group, periods of service may be renewed. NB: care will be taken to ensure that periods of service are staggered to avoid significant problems of retirement from the group

The CEG will be quorate, when either the Chair or Vice Chair and 5 members are present

- Membership of the CEG. Membership will be limited to 12 – 15 individuals. There is a requirement to cross-reference with the Patients Council. CEG membership should be broadly acceptable to clinicians/practitioners.
- Members should be 'recruited' on the basis of reputation, performance, skill and knowledge.
- Lay representation is necessary, but specific pressure group representation should be avoided.
- Members should be clear that they are present for their personal attributes (see second bullet point above) and not as representatives of any given body, group, profession or organisation.
- Co-option of members in addition to a core membership for specific issues will take place as required.

- Members will be willing to participate in ethical educational activities, including links with other Ethics Groups and the UK Clinical Ethics Network

3) Place within the Trust infrastructure

CEG is a formally constituted group, ratified by the Clinical Management Board and Trust Board.

The CEG will prepare a summary report on the activities of the Group on an annual basis and will submit the report to the Clinical management Board.

4) Meetings

a) There will be a formal agenda, issued not later than seven working days before each meeting. Agenda items / papers to be submitted to the Chair net less than ten working days before each meeting. Items of urgent business arising after this time will be accommodated with the agreement of the meeting.

b) Notes of the meeting will be taken, recording key discussion points, actions agreed and any advice / guidance agreed by the group. Notes will be issued to members not later than 14 working days following meetings.

c) Meetings will take place initially at a frequency of every six weeks (to be reviewed in the light of experience).

These Terms of Reference to be reviewed at least every three years.

Paul Gerrish
Sheffield Teaching Hospitals NHS Trust, Clinical Ethics Group
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B: Great Ormond Street Hospital for Children NHS Trust Clinical Ethics Committee (formerly Clinical Ethics Forum) Terms of Reference

Authority

The Committee will operate under the authority of the Trust Board.

Membership

The membership of the Committee is multidisciplinary. Initially members will be invited or canvassed. The balance of membership will be reviewed by the Committee.

The Committee includes at least one representative from medical, surgical, academic, nursing, social work and other paramedical specialties. It also includes representatives from Chaplaincy and a general practitioner. Lay members have been recommended and elected by the Committee and include those with specific ethical expertise and a representative of the local health authority. Academic representation is provided by a representative of the Institute of Child Health. It is hoped that the Committee will include a lawyer, though the latter will not be acting in a professional capacity.

The Chair and Committee have powers to co-opt individuals with expertise necessary for the discussion of particular issues.

From the experience of other groups, it would seem that membership should be limited to approximately 20. A quorum would consist of at least one representative from each professional group. plus at least two lay members and Chair or Vice-chair. The membership should generally be for three years, reviewable after that time.

Chair

The Chair should serve for a period not less than three years. The post should be open to all health care professionals or lay representatives.

Vice-Chair

The Vice-Chair should serve for a period of not less than three years. The post should be open to all disciplines. Either the Chair or Vice-Chair should be a lay member. The Committee should be a sub-committee of the Trust Board.

Aims and Objectives

- To provide a forum for the confidential, multidisciplinary discussion and analysis of matters of ethical concern arising from clinical practice at the GOS Trust and to provide, where appropriate, an informed, reasoned and justifiable opinion on such matters.
- To contribute to the integrated development of standards, guidelines and policies directed at enhancing good ethical practice and improving, patient care.
- To advise on and develop institutional ethics policies and to evaluate their outcome, and to contribute to other policies which have a significant ethical impact.
- To educate health care professionals in all disciplines in the principles required for good ethical practice and develop methods for the evaluation of the process.
- To initiate and support research, in collaboration with the Research Ethics Committee and Institute of Child Health, in the health care ethics field.
- To contribute an informed, reasoned view on matters of ethical concern arising from paediatric practice to the wider national and international communities and to provide a paediatric perspective on ethical issues of national importance.
- Although discussion on the ethical principles which individual cases might raise is important, it is not to be regarded as the key focus of the Committee.

- The role of the Committee is advisory and educational, rather than prescriptive, and there would be no compulsion for individual cases to be discussed by it. However, the Committee would be responsive to the need to discuss particular issues as they arose.

Teaching and Training

To be effective, members of the Committee will need to develop ethical expertise in a comparable fashion to members of the Research Ethics Committee by:

- Becoming more familiar with principles, concepts and theory.
- Studying relevant cases, legislation and policies.
- Having, input from invited individuals with appropriate expertise.
- Attending conferences etc. on health care ethics.
- Having access to and discussing relevant literature.

There is sufficient expertise within the currently proposed membership of the Committee to oversee this process.

The Committee would have an important wider role in teaching and training on ethical issues within the Hospital and the Institute. It is envisaged that close co-operation with the Research Ethics Committee, in the areas of teaching and training and research and development would take place. It would support and develop the long-term strategy of linking research ethics and clinical ethics by an integrated Department of Ethics.

Evaluation

The Committee will seek to audit its activities and develop a technique for assessment of its function. The Committee will submit an annual report to the Trust Board which will include aspects of audit and performance evaluation.

Frequency of Meetings

The Committee will meet monthly, or as required.

Administration

Administrative support for the Committee is provided by the Research & Development Office

Dr Richard Trompeter
Great Ormond Street Hospital for Children NHS Trust CEC
TROMPR@gosh.nhs.uk

C: Royal United Hospital NHS Trust, Bath Clinical Ethics Committee Terms of Reference

This is an informal group committed to helping to advise on problems of an ethical nature arising in a hospital setting. The members include ethicists from an academic institution, clinicians (doctors and nurses), a psychologist, solicitor and a cleric. Membership will lapse if a member fails to attend three consecutive meetings of the Committee.

Members of the group, who will be known within the hospital, can be contacted at any time by staff who feel that the opinion of group members may help to resolve particular difficulties. We would hope to receive enquiries relating to clinical ethical problems rather than to clinical competence, professional discipline or resource allocation. Enquiries outside our remit will, with the enquirers permission, be referred to the relevant person or group.

Once a member is contacted and the nature of the problem established, further members will be contacted as thought necessary. Members' views will be summarised by the Chair before issue.

The enquirer and patient involved will normally remain anonymous during discussions and when records are kept. It is accepted that this will not always be possible particularly if a meeting with the patient or relatives is thought to be of benefit. But no such meetings will take place without the explicit consent of the patient (or the relative if the patient is not competent). No identifying details will be kept in the records of the ethics committee. However, with the consent of those involved, a note about the consultation may be put in the patient's hospital records.

Records of all discussions will be kept on a pro-forma.

A regular audit of our work will be produced.

The group will meet quarterly. Some of these meetings will be open to members of the hospital staff. The group will be chaired by one of its members elected by the group for two years in the first instance. No person will act as Chair for longer than four consecutive years.

The group will consider a wider educational role, and there may be occasions on which it feels that written guidelines should be produced.

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APPENDIX A11

An example of a proposal to a trust board for the setting up of a Clinical Ethics Committee

Graham Behr, Jo Emmanuel and Jon Ruddock, Central and North West London Mental Health NHS Trust

Introduction

Public expectations of health care, and public criticism of health care professionals has increased over the past few years. The demand for greater public accountability in health care decision making means that health care professionals will need to justify both the clinical and ethical reasons for their decisions both to their patients and to society. Judicial involvement in medical decision making has also increased, often in cases where competing moral values need to be weighed against each other.

Much of the debate about how best to help mentally ill clients centres on the degree to which clinicians should intervene paternalistically (i.e. make choices on people's behalf) to safeguard the best interests of those clients who may have a reduced ability to make treatment decisions. The Mental Health Act 1983, associated commentaries and Code of Practice provide a framework to help clinicians faced with these decisions. However there are many facets of the care of people with mental illness that are not covered by the above mentioned guides, which present ethical dilemmas.

Furthermore some of the most difficult treatment decisions involve withholding or withdrawing treatment from people who want treatment but for whom clinicians feel treatment is conferring no good or may even have unwanted or unhelpful effects. In some cases clients and clinicians can agree together that 'not treating' is the best option. However, in a substantial number where agreement cannot be reached there is a risk of suicidal or violent behaviour. Clinicians, and also their managers, are anxious in the current political climate to minimise the likelihood of a resulting 'serious untoward incident' occurring.

Professionals also face decisions about withdrawing treatment when the patient is so threatening or violent that the treatment required can not be given without compromising the safety of the clinicians or other service users. This creates difficult management decisions within the Trust, and has led to differences of opinion between clinicians and managers.

These are the kinds of examples in every day mental health practice which require principles to guide us rather than purely senior opinion or group consensus.

The transition from a model of ethical paternalism to one of respect for autonomy and clinician/client partnership means that clinicians have to reassess the value systems used in their clinical decision making. Policies which guide the actions of clinicians must similarly be based on sound ethical principles.

In addition, the introduction of medical ethics into the undergraduate curriculum for medical students means that clinical teachers need to have an understanding of medical ethics, as applied to psychiatric practice.

Within this framework of raised ethical awareness and demand for public accountability, how can individual health professionals and Trusts ensure high ethical standards in all aspects of patient care? Some guidance already exists at a national level through DoH and GMC, but local resources need to be developed to provide support that is both responsive and relevant to local circumstances.

The way in which many Trusts deal with this challenge is by invoking the assistance of a Clinical Ethics Committee (CEC). The proposal for the development of a CEC in CNWL, recently highlighted in the NHS Clinical Governance Support Team Accelerated Service Improvement Program Evaluation Report (2002), arose from work undertaken following the Protected Time Initiative, held in North Westminster in 2001.

The national governing body of clinical ethics committees, ETHOX is not aware of any Mental Health Trust which has yet developed a dedicated CEC. It is our view that in a Trust the size of CNWL, the volume and complexity of clinical issues merits this.

Remit of a CEC

The CNWL CEC will have as its primary remit, the support of decision making by clinicians within an ethical framework. It may also extend its role to providing support for Trust policy development and education for Trust employees

1. Clinical management

CECs do not have the same executive decision making powers as Research Ethics Committees. Rather their function is to enable the professionals involved in any given decision to look at the situation from many viewpoints, and as such make better informed and considered decisions about their own cases. The responsibility for the decision remains with the clinicians bringing the case for consideration. There is no onus on a clinician to discuss cases in the CEC; it is available as a facility to be used at clinicians' discretion. It is recommended that a decision to bring a case be agreed by the relevant team though any member of the team may initiate this.

2. Input into policy development

Some examples of this (which might be pertinent to a Mental Health Trust) are: Advance directives, rights and duties of relatives, confidentiality, consent to participate in undergraduate education, withholding and withdrawing of treatment, use of restraining techniques, possession of illicit drugs, the abuse of the service by members of the public.

3. Education

We would wish to assist in the education of clinicians and students. Initially this may take place by the involvement of clinicians who sit on the committee and those who bring cases as well as by dissemination of the summarised debates of the committee.

Structure

Membership of Clinical Ethics Committee

Members should have:

Interest in the subject of medical ethics
An ability to work in a group
A commitment to the group
Some personal experience which would be useful to the group (clinical / service user / lawyer etc)

The committee will comprise:

- Professional ethicist
- Legal professional
- Clergyman
- Service user
- Non-executive member of the Trust Board
- Administrator
- Four other Trust clinicians
- Chair
- Core group (three Trust employees) to initiate and drive the process

The non-executive member of the Trust Board will be appointed by the Board.

The chair and the core group will be responsible for recruiting the other members of the committee and reviewing that membership on an annual basis.

All members of the CEC will be legally indemnified from prosecution by the Trust.

The role and responsibility of the chair

The chair will be recruited and appointed by the Chief Executive and will not be a Trust employee or member of the Board. This will reduce the likelihood of conflict of interest arising.

The chair is likely to become the ‘public face‘ of the committee and, as such it is crucial that they have broad acceptability to clinicians bringing cases.

The role of the chair would have particular requirements:

- To summarise ethical debate
- To clarify strands of argument
- To separate administration/managerial discussion from clinical discussion
- To ensure the discussion’s primary focus is on ethical considerations
- To frame conclusions in a way which is helpful to clinicians

The chair has the right to co-opt additional members to provide specialist expertise.

Accountability and reporting of proceedings

- The CEC will be constituted as a subcommittee of the CNWL Clinical Governance committee.
- The discussions of each meeting will be summarised and anonymised so that :
    They may be tabled at meetings of the clinical governance committee
    They may be accessed by clinicians as an educational tool

- The detail of the discussion will remain privy to the participants. The committee would divulge information to management only when there was a clear breach of the law
- An audit tool is currently being designed to determine the usefulness to clinicians of the committee.

- The CEC will continue to link with ETHOX, other CECs and other relevant organizations. In this way, the committee will continue to learn about ways of working which best support clinical decision-making.

Resource Implications

There are four areas with resource requirements:

1. Administration

Administration is required for: accurate minute-taking, telephone and email liaison with group members, clinicians and outside organizations, maintenance of a database, arranging training and education, carrying out audit, dissemination of information Trust-wide, input into Intranet etc.. It is expected that 4 sessions per week are required.

2. Education and Training

Although some members will have training in medical ethics, a basic level of knowledge for all members will assist the effectiveness of the CEC. This might best take the form of an annual training day, with initial training upon the commencement of the committee. Costs would involve the trainer/facilitator of such days. Access to key literature may also involve a small cost.

3. Honorarium payment to members

The chair will receive an honorary payment.
Trust employees would be expected to participate in this committee voluntarily. However, whilst our sense is that we are unlikely to have to pay for the services of other participants at this time, such payment may be required in the future.

4. Sundries

To include coffee facilities, possible remuneration of transport costs for any unemployed members, and other minor expenses as they arise.

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APPENDIX A12

An example of a workshop outline used by one NHS trust

Oxfordshire Mental Healthcare NHS Trust

CLINICAL ETHICS SUPPORT
A CONSULTATION WORKSHOP

THURSDAY 18 MARCH 2004 BETWEEN 9.30 AM – 2.30 PM
ROOM DG117, LITTLEMORE MENTAL HEALTH CENTRE

ALL STAFF WELCOME

Aim: To outline an action plan to provide clinical ethics support for the Trust

***Method*:** **Stage 1** – Discussion of two clinical cases which raise a range of eithical issues and promote discussion of these issues within specific contexts

Stage 2 – Clarification of a spectrum of kinds of situations and issues where ethics support could be helpful.

Stage 3 – Discussion of the ways in which ethics support could be provided, taking into account existing models of support in other Trusts.

Stage 4 – Develop the first steps of an action plan for the Trust.

Programme: Please See Separate Sheet

Facilitators Tony Hope, Professor of Medical Ethics, University of Oxford and Honorary Consultant Psychiatrist
Jacinta Tan, Welcome Trust Research Fellow in Ethics and Honorary Consultant Child and Adolescent Psychiatrist
Anne Stewart, Consultant Child and Adolescent Psychiatrist, Highfield Unit

To apply: To apply please complete the slip on the invitation letter and return to the OHSS Training Team, Littlemore Mental Health Centre or by E mail to the OHSS Training Dept. mail box or by fax on 01865 (2)23349. Enquiries to the OHSS Training Team telephone 01865 (2)23354

Oxfordshire Mental Healthcare NHS Trust

CLINICAL ETHICS SUPPORT
A CONSULTATION WORKSHOP

THURSDAY 18 MARCH 2004 BETWEEN 9.30 AM – 2.30 PM
ROOM DG117, LITTLEMORE MENTAL HEALTH CENTRE

All Clinical Staff Welcome

Programme

10.00 am **Coffee**

10.15 am Introduction to the workshop

10.20 am Ethical issues in practice – Presentation of 2 case vignettes

10.30 am Small Group Discussion – Ethical issues arising from one of the two cases.

10.50 am Plenary Discussion

11.20 am Small Group Discussion – Identification of ethical issues that arise in your area of work and what ethical support might be helpful.

11.45 am Plenary Discussion – General discussion of the range of issues and contexts across the Trust where support might be helpful.

12.30 pm **Lunch**

1.00 pm Models of Clinical Ethics Support – Presentation and discussion of different models for clinical ethics support.

1.30 pm Formulation of an action plan and way forward

2.30 pm Close

APPENDIX A13

Issues to consider when appointing lay members

Dr Paul Gerrish, Clinical Ethics Group, Sheffield Teaching Hospitals NHS Trust

Appointment of lay members to Clinical Ethics Group

Appointment of lay representatives is sometimes regarded as an important aspect of membership of a Clinical Ethics Group (CEG) and also in line with the current approach of the NHS for greater lay or patient involvement. Identifying and appointing lay appointments is not always easy and the following is aimed at giving some guidance to the process. There is no standard solution and each CEG will need to consider what is appropriate for the local situation; however it is important to identify a clear strategy at the outset.

Does the Trust already have a lay appointment process?

Most NHS Trusts now have started to have lay / patient involvement in the management structure e.g. of Directorates and there may well may a process that has been used locally before, although this may need to be significantly adapted as the needs of the CEG may vary from previous appointments.

What is meant by lay?

There should be clear agreement at the outset of what is meant by a lay member, what is his/her function and what he / she is expected to contribute. The expected contribution is certainly something prospective candidates will raise, as there will often be some concern as to what they can contribute. The definition of "lay" is not as simple as it may appear but needs early definition as this will need to be used in both job specification and short listing. One aspect that is easy to define is the person should not be an employee of the Trust but what about an ex-employee? Is a nurse who has not practiced for significant time "lay"? Is somebody who has been an LREC lay member for 10 years still a lay representative?

How many appointments?

In what may be considered a potentially intimidating environment there is much to be said for having at least two lay members to minimise any effects of isolation.

Routes for obtaining applicants?

The appropriate route for obtaining applicants will be very much dependant on what has been agreed as a "lay" representative. There may well be many people who already are involved within the local Trust in some format. The advantage of this route is that the members may well be a known quantity but the disadvantage is that they may already represent particular constituencies, it also may exclude excellent candidates to which ethics may be applicable but who are less interested in other aspects of voluntary involvement. In any approach adopted the Trust will need to be reassured it meets equal opportunity issues and formal advertisement and appointments in open competition for the posts has much to commend it. An advert in the public notice section of the appropriate local paper will often produce a number of good quality candidates, especially if this coincides with a small piece that papers are often happy to run about wider community involvement in difficult ethical decisions.

Advert example

> *As part of the Trust's Patient and Public involvement strategy and action plan we are looking to appoint members of the public as lay representatives to the Clinical Ethics Group. This group is a recently formed group to advise ad support the Trust and it's staff on ethical issues.*
>
> *We are looking for somebody who has a broad interest in ethical issues and who will be able to provide a balanced view from a lay perspective. Clinical qualifications or experience re not required but good team working is important for this innovative and challenging appointment. Applicants would be required to attend monthly meetings, usually in the evenings. Training and support will be provided. Although the post is voluntary reasonable related travel expenses will be paid.*

The advert should contain a clear contact point for interested individuals to make enquiries and the information pack sent to individuals should contain a detailed description of what the CEG is, who is on it and broadly what its functions are; this is best written by the CEG.

The practicalities of the applications

The appointment procedure should follow the standard approach for most NHS appointments; this will have the advantage of meeting equal opportunity requirements. A detailed job description along with a detailed personal specification will help ensure that short listed candidates are suitable; the personal specification can also form the basis for the assessment criteria at interview. Categories such as team working, communication, conceptual thought etc. may offer opportunities to explore the skills which a CEG may require.

The appointment process

It should be remembered through the whole process these are volunteers and everything should be done to make the process as stress free as possible.

Many Trusts will be happy for the CEG to handle the process, often with a personnel representative present to ensure that procedures are followed. Following short listing, which should involve as many of the CEG as possible it is useful to invite the short listed candidates to an informal meeting with perhaps two members of the CEG to find out more detail about what Clinical Ethics is and how this works. Most will not know how or what a CEG is. A short presentation of what a CEG is, how they are developing, who the members are, how it functions, the national picture etc. if useful, as this will provide a framework for questions and discussion. It is important to state any downside to the CEG at this time e.g. work may be spasmodic, it may be embryonic etc. and what it is **not** e.g. research ethics.

The interview process needs some thought and planning, a traditional interview panel is probably not appropriate as this may seem intimidating and may not offer an opportunity to easily explore important areas. An alternative model is of three “mini” interviews each perhaps of 20 minutes, with perhaps 2 CEG members for each interview and the candidates rotating around with relevant gaps. One interview may cover traditional areas such as experience, CV etc. and the other two each deal with an ethical discussion, the scenarios being given to the candidates on arrival.

Example Scenarios

1. Mr Z made a written advanced directive 5 years ago. He suffers from a chronic chest disease and the advanced statement provides that if he is admitted in respiratory failure he must not be ventilated. The advanced directive is placed in his notes.

   Mr Z is brought into A&E in respiratory failure and is intermittently confused due to low oxygen levels in his blood. He says that he wants “everything done” in order to save him. The doctor in charge of his care decides to ventilate him.

   Q1. What are the relevant ethical issues to consider?
   Q2. Can the doctor justify treating the patient?

2. Mr J is a 55 year old man with advanced lung cancer. He has had chemotherapy to which he initially responded, but has relapsed. In discussions with his consultant Mr J expresses a belief that he may respond to further treatment. The consensus amongst the medical team is that Mr J has only a few weeks left to live and that should he suffer a cardiac arrest whilst on the ward any attempts to resuscitate him would be futile. Mr J says he wants everything done to him including resuscitation.

   Q1. Should Mr J be resuscitated in the event of a cardiac arrest?

Q2. What are the ethical issues and what other things could the medical team do to help this patient?

After the decision is made it is important to feedback to unsuccessful candidates, again remembering these are volunteers.

Post appointment practicalities

References will need to be taken up and candidates will also need to be warned that many Trusts will require clearance by Criminal Records Bureau. The candidates will need to be offered some form of contract which should include an agreement in relation to confidentiality and this will also mean that they will usually have appropriate indemnity for Trust employees (even of a voluntary nature). Initially a contract of a year may be useful as this allows both sides to avoid long term unsuitable appointments. They may also need Occupational Health clearance and should be provided with the standard ID and access to library resources etc. It may be helpful to explain that the pace of NHS personnel departments in processing these practicalities may not be what is experienced in the private sector. It is important to make lay members feel part of the Trust, especially as many existing CEG members may well be senior experienced members of the organisation.

Travel and support expense should be offered and it is important to consider a budget to offer some training e.g. the Ethox workshop.

Involvement in meetings

A mentor for lay members may be useful initially to ensure that they settle in and the chair of the meeting has a responsibility to ensure that any technical medical terms are tactfully explained to ensure that the lay members have adequate factual knowledge to contribute to the discussion. During the first year it is useful to have some of review to assess how the appointments are progressing.

Lay appointments by open application may seem daunting but there are also significant rewards providing the process is handled carefully. There are many lay members who can make an important contribution, often offering a well thought challenging viewpoint on difficult subjects.

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APPENDIX A14

Pro Forma Referrals Form

Royal United Hospital, Bath, Clinical Ethics Committee

Reference:

Proforma for Clinical Ethics Committee Records

Note these records are being kept solely for the purpose of statistical recording and audit of the committee's work

Name of Committee Member

Date and time of contact(s):

Source of Enquiry: (e.g. doctor (grade), nurse (grade), other health professional (position, grade), patient, relative)

Relationship of enquirer to patient:

Nature of problem: (Note enquirer may remain anonymous)

Names of other members of Committee contacted:

Referral:
If enquiry referred elsewhere (with permission of enquirer) state to whom, and fill in outcome (below), when known

Outcome(s) with date(s):

Was enquirer happy with outcome?:

Other comments:

Please make 2 copies of this form, one to be retained by you and one forwarded to Chair of the Committee

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B. UK CLINICAL ETHICS NETWORK

Introduction

In January 2001, 20 representatives of clinical ethics committees in NHS trusts met to discuss the future development of clinical ethics committees (CECs), and other forms of clinical ethics support, in the UK. This meeting prompted the development of the UK Clinical Ethics Network. The Network provides information and support for those involved in setting up CECs and for established CECs.

UK Clinical Ethics Network – who's who:

The Network Committee
Chair - Dr Alan Watson, Director of the Children and Young People's Kidney Unit at Nottingham City Hospital.

Vice Chair - Dr Stephen Louw, Clinical Director for General Medicine and Care of the Elderly Services at the Freeman Hospital in Newcastle upon Tyne.

The 11 other Network Committee members are chairs and representatives of CECs from across the UK covering a wide range of clinical specialities.

The remit of the Network Committee is to consider the aims, objectives and future development of the Network. It holds an annual general meeting for all members of the Network.

Network Support Project: Run by the Ethox Centre, University of Oxford
Dr Anne Slowther is supervising the development of the Network Support Project. Anne is a GP and clinical research fellow at Ethox.

Carolyn Johnston trained as a lawyer and is the Network Support Project Officer. She teaches medical law and ethics at Kingston University in addition to her work at Ethox.

Jane Goodall is the Network Support Project coordinator, designer and administrator of the Network web site.

The objectives of the UK Clinical Ethics Network are to:

- Offer support and advice to developing and established clinical ethics groups
- Provide networking facilities including a newsletter, electronic mailing and network website
- Facilitate training for members of clinical ethics groups
- Support regional initiatives
- Organise an annual conference
- Produce a database of useful and relevant information for clinical ethics groups
- Establish links with clinical ethics groups internationally

Support the Network can offer:

Newsletter

The Network newsletter is distributed three times a year to Chairs of CECs known to the Network and to individual members (where details have been supplied). Topical issues are dealt with on an occasional basis and have included Assisted Conception (Spring 2003), processes adopted by CECs and the Data Protection Act 1998 (Autumn 2003) and the Human Tissue Bill / Organ donation (Summer 2004). The newsletter is archived online at www.ethics-network.org.uk/reading/reading.htm

Network facilitation

The Network facilitates the sharing of information between clinical ethics committees through the electronic database of members. This often takes the form of an enquiry for information from a clinical ethics committee. The Network circulates this request to all members of the Network by email. Replies are collated and, together with additional information on the subject identified and summarised by the support team, form a brief discussion document that is sent to the requesting CEC and all CECs who responded to the request. Some of these summaries are published in the Network Newsletter.

Topics that have arisen for discussion / clarification include;

- Rationing of services due to lack of staff
- Ethical scrutiny of management decisions
- Developing a framework for ethical discussions
- Patients access to minutes of CEC meetings
- Medical student interaction with patients
- Committee membership and terms of office
- Service users sitting on mental health CECs
- Use of drugs of porcine origin
- Neonatal circumcision for religious reasons
- Developing a Do Not Attempt Resuscitation policy
- Case Consultation and Access to Minutes
- Electronic Tagging of Vulnerable Patients

Annual conference

Since 2001 the Network has organised a conference on clinical ethics in conjunction with an individual host CEC. The aim of the conference is to stimulate interest and discussion in clinical ethics and focuses on examples of the work of clinical ethics committees in the UK. Practical consideration of case studies has been a major part of the conference. The fourth annual conference, held in London in May 2004, focussed on end of life issues and included a European perspective with presentations from Germany and the Netherlands. The 2005 conference, to be held in Newcastle, will look at the issues of resource allocation.

Website

The Network website was launched in September 2003. The aim of the website is to provide relevant information that is easily accessible for CEC members, clinicians and patients.

It provides:

- Contact details for all CECs known to the Network and, where relevant, topics that the CEC has frequently considered and whether it has drafted / provided input into trust policy or guidelines
- Worked through hypothetical case studies
- Ethical and legal discussion of topical issues including Consent and Refusal of Treatment, Patient Confidentiality, End of Life issues and Resource Allocation

- Examples of frameworks for ethical discussion
- Links to national guidelines and a glossary of terms
- Commentaries and perspectives on ethical issues
- An ‘International Page’ that provides information about CECs abroad, international perspectives on clinical ethics, and details of courses and conferences held outside the UK.
- Details of courses and conferences in the UK
- Suggested reading to enable further research

Enquiries for further information about the Network have come from Norway, the Netherlands, Germany and North America. Several UK enquiries have been made requiring information and advice on setting up a clinical ethics committee.

Training for CECs

The Network Support Project provides support and information for those involved in establishing CECs. This includes presentations to trusts thinking of setting up a committee, or to a recently established committee. The Network website advertises courses that provide training relevant for CEC members. The Ethox team runs workshops that can be tailored to the requirements of an individual CEC.

Projects that involve the Network

Two projects concerned with Clinical Ethics Committees have been funded by a grant from the Department of Health to the Ethox Foundation. These projects are run in close collaboration with the UK Clinical Ethics Network.

1. Network Support Project

This project is to facilitate the development of a national network for clinical ethics committees in the UK. The project is funded from December 2002 for two years. It has spearheaded the ongoing development of the Network and has enabled the website and production of this Guide.

2. Education and Training Project

This project is to explore the education and training needs of members of clinical ethics committees (CECs) and to develop a range of teaching materials for them. The project runs from April 2003 to March 2005. As part of this project, pilot workshops were held on the following topics in 2004

- Ethics and genetics
- Ethics and the vulnerable patient
- Ethics and resource allocation

Teaching materials will be prepared for members of CECs to pursue independently.

Contacting the Network

The Network can be contacted at:

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Telephone: +44 (0) 1865 226936

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Web site: http://www.ethics-network.org.uk

Reading

Slowther A, Johnston C, Goodall J and Hope T. Development of clinical ethics committees. *BMJ* 2004;**328**:950 - 952

Slowther A, Bunch C, Woolnough B, Hope T. Clinical Ethics Support in the UK: A review of the current position and likely development. 2001; The Nuffield Trust, London.

Blackburn, S. 2001. Ethics: a very short introduction. Oxford University Press

C. ETHICAL FRAMEWORKS

Introduction

If a clinical ethics committee (CEC) is to provide support on ethical issues relating to clinical practice, and to facilitate discussion of the ethical dimension of clinical problems, members of a CEC will require an understanding of the moral theories and ethical frameworks that have informed the development of medical ethics. Although not all CEC members are expected to be experts in ethics (indeed one advantage of an ethics committee is that its members bring a variety of different expertise and experience to bear on a particular issue), they will need to justify their claim to be providing ethics support and advice over and above that which could be obtained from any other committee or informal group. In this section we provide a brief introduction to some of the key moral theories and ethical frameworks that have had an important influence on health care practice, particularly in Western medicine. The section concludes with one example of a practical framework for approaching an ethical dilemma.

Definitions

Moral philosophy

'Moral philosophy is the attempt to achieve a systematic understanding of the nature of morality and what it requires of us - in Socrates' words, of "how we ought to live," and why'[12].

Morality

Morality is usually construed as meaning what is right and wrong.

'The term morality refers to social conventions about right and wrong human conduct that are so widely shared that they form a stable (although usually incomplete) communal consensus, whereas ethics is a general term referring to both morality and ethical theory'[13].

Nevertheless, the words 'ethics' and 'morality' are often used interchangeably.

Ethics

'Ethics is a generic term for various ways of understanding and examining the moral life'[14].

'Ethics requires us to go beyond 'I' and 'you' to the universal law, the universalisable judgment, the standpoint of the impartial spectator or ideal observer, or whatever we choose to call it'[15].

Normative and Descriptive Ethics

Normative ethics is a systematic theory that tells us how one ought to live. An approach to ethics that is *normative* is one that presents standards of right or good action. An example would be deontological theory - 'do not kill, 'do not lie'.

Descriptive ethics reports on how people act, or what they believe, and is not committed to any particular normative ethical system.

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[12] James Rachels, *The Elements of Moral Philosophy*, 2nd edition, McGraw Hill 1993, Chapter 1.
[13] Beauchamp and Childress, *Principles of Biomedical Ethics,* 4th edition, Oxford University Press, page 5.
[14] Beauchamp and Childress, *Principles of Biomedical Ethics, 5*th edition, Oxford University Press, page 1.
[15] Peter Singer, *Practical Ethics*, 2nd edition, Cambridge University Press, 1993, page 12

Medical ethics / Healthcare ethics

These terms could simply be used to refer to ethical thinking in the healthcare setting.

Codes of Professional Ethics

Formal codes of medical, nursing and research ethics have been created, reflecting the application of ethical thinking to the issues arising in the relevant healthcare environment. Examples include the GMC 'Withholding and withdrawing medical treatment'. Ethical behaviour in this context may be understood as behaviour conforming to the relevant professional code of ethics.

Ethical Theory

We may feel instinctively that a certain conclusion to a problem is 'fair' or 'unfair', but what criteria do we use to make such judgments? There are different ethical theories that can be applied to a problem to elucidate our thinking, but even so the results may not fit with our moral intuition.

There are several types of normative ethical theory including consequentialism, deontology - such as Kantianism - and virtue ethics. They can be applied in several **procedures** of ethical analysis, such as in analysis of cases (casuistry) and in different **settings** such as in a range of ‘communitarian ethics’: for example, a feminist approach or a social class based approach.

Moral or ethical theory may consider the application of rules or the consequences of actions.
Deontological theory - what one MUST do, based on duties and obligations
Teleological theory - the purpose or consequences of the moral acts

Consequentialist Theory

This is one sub class of teleological moral theory. According to consequentialist accounts of morality the moral value of an act, rule or policy is to be found in its consequences, not in intentions or motives. Utilitarianism is the most influential consequentialist theory. Jeremy Bentham in the late 18th century and John Stuart Mill in the 19th century formulated this way of thinking. Such ‘hedonistic’ utilitarians argue that the principle to judge our moral thinking is utility, that is, the maximisation of happiness, in the sense of pleasure and the minimisation of suffering, in the sense of pain. In any situation the morally right thing to do is the action that promotes the greatest happiness for the greatest number of people.

However pain and pleasure are not the only criteria that later utilitarians have used to evaluate the consequences of actions, rules or policies. Welfare-utilitarians consider the contribution to, or lessening of, human welfare. Preference-utilitarians seek to establish and satisfy human preferences.

Some key issues:

- Calculate net benefit

The net benefit or dis-benefit is found by balancing the happiness and unhappiness resulting from an act or policy. If one then seeks the greatest happiness of the greatest number that may be taken to justify overriding individual unhappiness in the interests of the happiness of the greatest number

- Difficulty in calculating consequences

This theory requires that the consequences of acts or policies must be calculated. However in many situations one cannot predict consequences with any certainty and therefore consequentialism is probabilistic, one forecasts the consequences to the best of one's ability. Ethics committees using consequentialist criteria necessarily operate in an area of uncertainty.

- Act and rule utilitarianism

Bentham tended to deal with the consequences of **acts**. However, '**rule** utilitariansim' justifies certain rules on utilitarian grounds. For example, one might justify the general rule 'do not lie' on the utilitarian ground that lying produces more bad consequences than good consequences overall.

Deontological Theory

A criticism of consequentialist theory is that it is so concerned with **ends** that it may overlook the moral importance of **means** - the ways in which the ends or goals are achieved.

Deontological theory uses rules rather than consequences to justify an action or policy.

The best-known deontological theory is that of Immanuel Kant in the 18th century. 'Kantianism' is a modern term, referring to a Kant-like emphasis on duties and rules. Kant defended rules such as 'do not lie', 'keep promises', 'do not kill' on what he claimed were rational grounds. Rules should comply with the *categorical imperative.* The categorical imperative holds that:

- Moral rules should be universalisable i.e. applied to all rational, moral members of the community rather than to just some
- All persons should be treated never simply as means but also always as ends in themselves
- Members of the moral community should take a hand in making the laws as well as living by them

Many modern *Kantians,* as opposed to Kant himself, are not absolutist in their application of moral rules or laws, whilst nevertheless stressing the importance of generally living by moral rules or laws.

Virtue ethics

Virtue ethics is the name given to a modern revival and revision of Aristotle's ethical thinking. Aristotle's ethics, while not generally thought of as consequentialist, is certainly teleological. For him, the telos, or purpose, of a human life is to live according to reason. This leads to 'happiness' in the sense of human flourishing. This flourishing is achieved by the habitual practice of moral and intellectual excellences, or 'virtues'.

For Aristotle, the excellences are of two types. A moral virtue is an excellence of character, a 'mean' between two vices. One of Aristotle's virtues is courage, a mean between recklessness and cowardice, which are vices. Modern virtue ethics sets itself the task of discerning the virtues for our time. In a healthcare setting what virtues would we like doctors, nurses, etc. to possess - self-control, truthfulness, generosity, compassion, discernment, integrity?

Aristotle also identified a second type of excellences, intellectual virtues, which constitute a preference for truth over falsehood and for clarity over muddle, both in pure reason and in practical affairs. Both the moral and intellectual virtues are, for Aristotle, the expression of reason.

Casuistry

Casuistry, or case based reasoning, does not focus on rules and theories but rather on practical decision-making in particular cases based on precedent. So first the particular features of a case would be identified, and then a comparison would be made with other similar cases and prior experiences, attempting to determine not only the similarities but also the differences.

So if a clinical ethics committee were asked to consider whether it was ethical for a clinician to breach his / her duty of confidence, the committee would identify key factors, like the health risks to others if information was not disclosed. It would then make a comparison with other similar cases, identifying the relative risks of non-disclosure.

Casuistry should not be divorced from consequentialism, deontology, or virtue ethics but complement them.

The Four Principles

Beauchamp and Childress' Four Principles approach is one of the most widely used frameworks and offers a broad consideration of medical ethics issues generally, not just for use in a clinical setting.

The Four Principles provide a general guide and leave considerable room for judgement in specific cases.

Respect for autonomy: respecting the decision-making capacities of autonomous persons; enabling individuals to make reasoned informed choices.

Beneficence: balancing benefits of treatment against the risks and costs; the healthcare professional should act in a way that benefits the patient.

Non maleficence: avoiding causing harm; the healthcare professional should not harm the patient. Most treatment involves some harm, even if minimal, but the harm should not be disproportionate to the benefits of the treatment.

Justice: respect for justice takes several forms:

- Distribution of a fair share of benefits
- Legal justice - doing what the law says
- Rights based justice, which deals in the language, and perhaps the rhetoric, of claimed human rights, and hence goes beyond, though it includes, legal rights.

These principles are prima facie – that is, each to be followed unless it conflicts with one or more of the others - and non-hierarchical i.e. one is not ranked higher than another. In recent years however, respect for patient autonomy has assumed great significance in the context of patient choice, underpinned by the requirement to provide the patient with sufficient information to put him / her in a position to choose.

The 'Four Principles' are intended as an aid to balance judgement, not a substitute for it.

We would like to thank Don Hill, Co-ordinator of Postgraduate Education, The Ethox Centre, University of Oxford for his assistance in producing this section.

The following is a practical clinical ethics framework that may be useful for a clinical ethics committee to work through in discussion of a case

1. What are the relevant clinical and other facts (e.g. family dynamics, GP support availability)?

2. What would constitute an appropriate decision-making process?
   - Who is to be held responsible?
   - When does the decision have to be made?
   - Who should be involved?
   - What are the procedural rules e.g. confidentiality?

3. List the available options

4. What are the morally significant features of each option e.g.
   - What does the patient want to happen?
   - Is the patient competent?
   - If the patient is not competent, what is in his or her 'best interests'?
   - What are the foreseeable consequences of each option?

5. What does the law / guidance say about each of these options?

6. For each realistic option, identify the moral arguments in favour and against.

7. Choose an option based on your judgment of the relative merits of these arguments using the following tools.
   - Are there any key terms the meaning of which needs to be agreed e.g. 'best interest', 'person'?
   - Are the arguments valid?
   - Consider the foreseeable consequences (local and more broad)
   - Do the options 'respect persons'?
   - What would be the implications of this decision applied as a general rule?
   - How does this case compare with other cases?

8. Identify the strongest counter-argument to the option you have chosen.

9. Can you rebut this argument? What are your reasons?

10. Make a decision

11. Review this decision in the light of what actually happens, and learn from it.

Further discussion of approaches to ethical decision-making can be found in Appendix C1

Reading

Beauchamp T, Childress J. 2001. Principles of Biomedical Ethics. 5th edition Oxford University Press ISBN 0-19-514332-9

BMA . 2004. Medical Ethics Today. London, BMA Books

Boyd, K.M., Higgs, R., Pinching, A.J., (1997) The New Dictionary of Medical Ethics BMJ Publishing Group, London

Campell A, Gillett G, Jones G. 2001. Medical Ethics. 3rd edition Oxford University Press

Gillon, R., (1986) Philosophical Medical Ethics Chichester, Wiley

Glover, J., (1997) Causing Death and Saving Lives Harmondsworth, Penguin

Hope T (2004) Medical Ethics A Very Short Introduction Oxford University Press

Hope T, Savulescu J, Hendrick J 2003 Medical ethics and the law, the core curriculum. Churchill Livingston Chapters 1-3

Mautner, T., ed. (1997) Penguin Dictionary of Philosophy Penguin Books

Parker M, Dickenson D. 2001. The Cambridge medical ethics workbook: case studies, commentaries and activities. Cambridge University Press.

Parker M, Hope T. Ways of Thinking About Ethics. Medicine 2000;28:10:2-5

Rachels J. 1995. The elements of moral philosophy. 2nd edition Mc Graw Hill

Singer, P., ed. (1986) Applied Ethics (e.g. vi, J. Harris, The Survival Lottery) Oxford University Press

Singer, P., ed. (1991) A Companion to Ethics (e.g. Essays 10, 14, 20, 21 and 22) Oxford, Blackwell

Warburton, N., (1999) Philosophy, the Basics Routedge. 3rd Edition. Introduction and Chapter 2.

Warburton, N., (1998) Philosophy, the Classics Routledge. Chapters 1, 2, 11, and 14.

D. PROFESSIONAL GUIDELINES, LAW AND ETHICS

Introduction

The role of an ethics committee or group is to provide support and advice on the ethical issues involved in clinical practice, at the level of both individual cases and organisational policy. Thus the focus of a committee's discussion must be on the ethical considerations raised rather than on, for example, risk management issues. However, ethics committees, like clinicians and the institutions in which they work, must be aware of the legal and professional frameworks that govern health care practice, and their advice should be situated in the context of legal and professional guidance. In section C we have discussed briefly some moral theories and ethical frameworks that will inform a discussion of ethical issues presenting to an ethics committee. In this section we give a brief description of the legal framework in the UK, with particular reference to health care law, and an introduction to sources of professional guidance relevant to health care. We illustrate how an ethics committee may use ethics, law and professional guidance to inform a discussion by using an example case study that might be brought to an ethics committee.

Relationship between Law and Ethics

"It would not be correct to say that every moral obligation involves a legal duty; but every legal duty is founded on a moral obligation."[16]

For example, the law on informed consent gives effect to ethical principle of respect for autonomy, and the current development of a Mental Capacity Bill in the UK highlights the need to enable patients to make treatment decisions for themselves.

Law and ethics are both **normative**, that is they are concerned with a minimum standard of behaviour that may be considered acceptable or unacceptable by the relevant society.

Nevertheless there are clear differences. Compliance with legal rules is **mandatory** and a failure to comply may result in penalties. By comparison ethics could be seen as **aspirational** – it attempts to articulate a framework for reflection. Whilst this may affect the way that a person acts as a result of such reflection it is by no means necessary that it would or even that it should produce the same action by all people in specific cases.

Law is more specific in its terminology and application. Legislation, i.e., an Act of Parliament, and case law will state what should happen if a certain set of circumstances are fulfilled. Although law does not always offer clear answers there is a set framework for discussion.

For example the legal framework for human reproductive technology is set out in the Human Fertilisation and Embryology Act 1990 and the nuances of its application have been considered by the courts. Court cases have shown how the law is to be applied, although there have been many difficult areas of interpretation, e.g. the meaning of 'embryo' etc.

The moral and ethical considerations are much more difficult to pin down. Not only do individuals possess different moral perspectives, but also ethical considerations may conflict. In the debate over 'saviour siblings', for example, the issues of parental choice and autonomy may conflict with the benefits to society overall; acting beneficently towards the future children created and issues of justice.

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[16] Lord Chief Justice Coleridge R v Instan [1893] 1 QB at 453

Ethics committees are not a substitute for consideration of legal issues. If there is concern about the legal position in a clinical case, or if there is serious conflict between clinicians and patients or their relatives, a legal opinion should be sought and, if appropriate, a referral made to court. The court may take into account the view of a clinical ethics committee (CEC), but it is not constrained by it. Nevertheless an ethical dimension is increasingly assuming greater prominence in the deliberations of the court. In the Nationwide Organ Group Litigation[17] case the court was supplied with a consideration of the ethical issues arising from the retention of organs from dead children without the parents' consent.

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[17] A B and Others v Leeds Teaching Hospital NHS Trust, Cardiff and Vale NHS Trust [2004] EWHC 644, (2004) 77 B.M.L.R. 145

The Legal Framework in the UK

There are two strands to UK law, statute and case law, both of which have a bearing on health care. Within the UK, Scotland and Northern Ireland have their own legal system so it is important to be clear about which law applies in particular circumstances. While there are often similarities between the different jurisdictions, there may also be significant differences. For example, in Scotland it is possible for a person to appoint a welfare attorney to make decisions about medical treatment for that person in the event that he / she becomes incompetent (Adults with Incapacity (Scotland) Act 2000) but this, as yet, is not possible in England.

Statute

Statutes or Acts of Parliament can only be overturned by a further Act of Parliament. The Courts may interpret statute in particular cases, but they cannot overrule it. Major Parliamentary legislation usually follows widespread consultation and includes several stages, culminating in a Bill that is put before Parliament. There are several statutes that have relevance for health care and we list a range in **Appendix D1**. The Human Rights Act 1998 is likely to have an increasing impact on health care in the UK.

Case law (common law)

Case law is a body of law built up by judicial consideration of cases over many years. It is also known as common law. A court must follow any previous ruling of the court on the same matter – this is known as the doctrine of precedent. However, a court hearing a matter may consider that the issues are sufficiently different from a previously decided case not to bind it and in that respect it can make 'new' law. Higher courts are not bound by decisions of lower courts, so for example the House of Lords, the highest national court, is not bound by decisions of the Court of Appeal.

A number of high profile medical cases have been heard in recent years, for example, assisting suicide[18], refusal of medical treatment by a competent patient[19], use of frozen embryos created by IVF[20].

Many of the medical cases that come before a Court involve treatment of a patient who lacks capacity to make a decision regarding his / her own treatment. In England currently no one (including the Court) can consent to treatment on behalf of an incompetent adult. Thus, when there is disagreement over treatment of an incompetent adult the Court is asked to make a declaration that the proposed treatment, or treatment withdrawal, is in the patient's best interests. In the case of children the Court may, in some circumstances, give, or withhold, consent to treatment for a child.

A declaration of the Court **must** be sought about the best interests of the patient in some areas of medical practice e.g. removal of artificial nutrition / hydration from patients in permanent vegetative state, non therapeutic sterilisation of mentally handicapped adult patients, neonatal circumcision for religious reasons where parents disagree.

A list of some of the key cases in English law relevant to health care can be found in Appendix D2

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[18] R (on the application of Pretty) v DPP, [2001] UKHL 61, [2002] 1 A.C. 800
[19] Re B (Consent to Treatment: Capacity), [2002] EWHC 429, [2002] 2 All E.R. 449
[20] Evans v Amicus Healthcare Ltd & Ors [2004] EWCA (Civ) 727

Guidance for Health Professionals in the UK

A range of organisations, including professional organisations, regulatory bodies and government departments, provide guidance for health professionals on ethical issues relating to clinical practice. Below we describe the type of guidance provided by some of these organisations. A detailed list of guidance can be found in Section E.

General Medical Council (GMC)

The General Medical Council is a statutory body. Its purpose is to protect the public by maintaining a register of doctors who are competent and fit to practise medicine. There are about 200,000 doctors on the medical register. The GMC handles complaints about doctors' performance.

The general responsibilities and ethical standards of a doctor are summarised in 14 key principles, called the duties of a doctor.

The General Medical Council has built upon these principles by issuing guidance on the general aspects of good medical practice and specific areas, including guidance on **confidentiality**, **consent** and **withholding and withdrawing life-prolonging treatment**[21].

> *"This guidance describes the principles of good medical practice and standards of competence, care and conduct expected of doctors in all aspects of their professional work. Serious or persistent failures to meet these standards may put a doctor's registration at risk'*[22].

Although guidance produced by the GMC creates no statutory legal obligation, it does carry weight in law and the Courts have recognised the importance of such guidance. In the case of W v Egdell[23] the Court of Appeal referred to and applied the (then) current GMC guidelines on confidentiality. However, the Courts may also question GMC guidance.

British Medical Association (BMA)

The British Medical Association is a professional association of doctors, representing their interests and providing services for its 128,000 members. Almost 80% of UK practising doctors are members.

The BMA has a medical ethics department that answers individual ethical enquiries from doctors, and produces guidelines and books on ethical issues. It also provides the secretariat to the Medical Ethics Committee (MEC) of the BMA. The MEC comprises 18 members, including doctors, philosophers, lawyers, theologians and lay people, thus providing expertise from diverse fields. The MEC debates *'issues of principle in medical ethics, medical law, and ethical matters concerning the relationship between the medical profession, the public and the state*[24]*'.*

The BMA produces a number of publications on a wide variety of topics, such as consent and refusal of treatment and patient access to health records. These publications highlight the ethical issues but do not have force of law but, as with GMC guidance, may be taken into account by the Court in specific cases.

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[21] The lawfulness of this Guidance has been considered by the court in R (on the application of Burke) v GMC [2004] EWHC 1879 (Admin). In October 2004 the GMC stated it would appeal this decision.

[22] GMC, Ethical Guidance http://www.gmc-uk.org/standards/default.htm

[23] W v Edgell [1990] Ch. 359, [1990] 2 W.L.R. 471

[24] http://www.bma.org.uk/ap.nsf/content/hubmedicalethicscommittee

Nursing and Midwifery Council

'The Nursing and Midwifery Council is an organisation set up by Parliament to protect the public by ensuring that nurses and midwives provide high standards of care to their patients and clients.'
http://www.nmc-uk.org/nmc/main/about/$aboutUsMain

It sets standards for education and practice, provides advice for nurses and midwives and considers allegations of misconduct. It has published a range of documents on standards and guidance for nurses on issues including a Code of Professional Conduct: Standards for conduct, performance and ethics.

Royal Colleges

Many of the Royal Colleges and Healthcare Professional Organisations provide guidance to their members on ethical issue relating to practice. Some Royal Colleges have an ethics committee that considers ethical policy and guidelines on specific issues. In general, these organisations do not provide advice on individual cases.

Department of Health (DH) http://www.dh.gov.uk/Home/fs/en

The Department of Health is responsible for setting health and social care policy, and providing guidance on healthcare issues in England.

Relevant documents can be accessed from the Department web site.

Links to DH guidance on specific issues such as consent can be found on the Network website www.ethics-network.org.uk

Appendix D3 provides information about the National Institute of Clinical Excellence

Ethics, law, and professional guidance in case consultation

Below we use a case scenario to illustrate how a CEC will use ethical principles, professional guidance, and knowledge of relevant law in providing support and advice to health professionals.

Consent to Medical Treatment, Confidentiality and Teenage Patients

Dr Jennings, a consultant gynaecologist at an NHS trust, approaches the chair of the trust's clinical ethics committee requesting the advice of the ethics committee on the following case. She has just seen a 15 year old girl (pseudonym Mary) in her gynaecology out patient clinic who has been referred by her GP for termination of pregnancy. Mary is 9 weeks pregnant. She has had the same boyfriend for the past 12 months and he is believed to be the father of the baby. Mary was extremely upset when seen in clinic. She had been using the oral contraceptive pill on a regular basis and was shocked that she had become pregnant. She said that she did not really agree with abortion but that after talking it through with her boyfriend she had decided that she would not be able to go through with the pregnancy and bring up a baby. A factor in her decision was the likely reaction of her mother to the news that she was pregnant, and she stated clearly that she did not want her mother to know anything about the pregnancy or the abortion. Mary's father had left home when Mary was two and she had no contact with him. She had no brothers or sisters, and no other close relatives. Dr Jennings is unhappy about performing a termination without informing Mary's mother. She thinks it is important for Mary's mother to know in case there are problems after Mary is discharged, and she is concerned that Mary will have no emotional support in her distressed state. She has contacted Mary's GP who said that he would not be prepared to breach Mary's confidentiality by telling her mother.

Ethical Issues

Respecting autonomy

A key principle of medical ethics is that of respecting a person's decisions about his/ her own health care. A person who understands all the relevant information about his/her medical problem, possible treatments and consequences of not having treatment, should be able to make a decision about what treatment to have, if any. This principle would also confer a duty on a doctor to respect a patient's confidentiality and not divulge information about her to another person without her consent. The important consideration here is whether a patient is competent to make a decision about the particular treatment or particular breach of confidence. Thus, if Mary understands the nature of the treatment required, and the potential consequences of not telling her mother, and is clear that she does not want her mother to be told, the principle of respect for autonomy dictates that her confidentiality must be respected.

Consequences of the decision

While the principle of respect for autonomy is crucially important, there may be other ethical considerations that argue against respecting an individual's autonomous decision in a particular case. It is possible that complying with a patient's request for confidentiality might have harmful consequences for the patient him/her self (best interests and non maleficence conflicting with respect for autonomy), or for others. A careful assessment of the likely consequences of breaching Mary's confidentiality, and the consequences of not breaching it, will need to be made but the risk of harm as a result of not breaching her confidentiality would need to be significant to justify overriding her autonomy by telling her mother.

Beneficence

Consideration of beneficence, or acting in Mary's best interests, has a wider implication than simply assessing consequences of different courses of action. If Mary's autonomous request for confidentiality is respected, the principle of beneficence would still require that the health professionals involved in her care did all that they could to ensure a good outcome to the process for Mary. For example, they could try and identify someone in whom Mary would confide and who could offer support to her, if not a relative or friend then professional support such as a youth worker.

Legal Issues

In English law a patient is a minor until 18 years of age. In Scotland the age limit is 16.

The Family Law Reform Act 1969 in England and Wales provides a person who is 16 or 17 years old with a statutory right to consent to medical treatment. Section 8, provides that:

Consent of a minor who is 16 years and over to any surgical medical or dental treatment is as effective as if an adult

If a minor aged 16 or 17 has given effective consent then there is no necessity to obtain consent from a parent. (Consent to certain procedures, such as organ donation and non- therapeutic research, is not covered by this provision).

A person who is below 16 years old may consent to medical treatment provided that they have 'sufficient intelligence and understanding to appreciate the information and advice about treatment and what it involves'. This is a statement of common (case) law. The issue was considered in detail by the case of Gillick v West Norfolk and Wisbech AHA[25]. This case dealt with the issue of a teenage girl consenting to receive contraceptive advice independently of the consent and knowledge of her parents.

While the issue in Gillick judgement was whether a child under the age of 16 years could consent to treatment, the case also raises the question; in what circumstances may the duty of confidentiality owed to a teenage patient be breached? As the law recognises a duty of confidentiality to adults by health care professionals[26], it seems to follow that this duty would also apply to children who were competent to consent to treatment without requiring parental consent.

This issue has recently been considered by the Department of Health in the context of teenage girls seeking termination of pregnancy without parental knowledge[27].

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[25] Gillick v West Norfolk and Wisbech Area Health Authority [1985] 3 All ER 402 (HL).

[26] W v Edgell [1990] Ch.359, [1990] 2 W.L.R. 471

[27] Publication of revised guidance for health professionals on the provision of contraceptive services for under 16s.
http://www.dh.gov.uk/PublicationsAndStatistics/PressReleases/PressReleasesNotices/fs/en?CONTENT_ID=4086804&chk=gId6AB

Professional Guidelines

GMC

Confidentiality: Protecting and providing information

April 2004

http://www.gmc-uk.org/standards/secret.htm

The GMC has issued extensive guidelines on confidentiality, laying out the general principle that confidentiality should only be breached if there is a risk of serious harm as a consequence of maintaining confidentiality.

Disclosures to protect the patient or others

Paragraph 27

"Disclosure of personal information without consent may be justified in the public interest where failure to do so may expose the patient or others to risk of death or serious harm".

This principle holds true whether the patient is an adult or a competent minor, as set out in the joint guidance on confidentiality and people under 18 published in 1994.

Guidance issued jointly by the BMA, GMSC, HEA, Brook Advisory Centres, FPA and RCGP January 1994

http://www.bma.org.uk/ap.nsf/Content/Confidentiality+and+people+under+16

Confidentiality & people under 16

Exceptional Circumstances

> *"Although respect for confidentiality is an essential element of doctor-patient relationships, no patient, adult or minor, has an absolute right to complete confidentiality in all circumstances. Confidentiality must be balanced against society's interests in protecting vulnerable people from serious harm. Thus, in rare cases for example, a breach of confidentiality may be justified if the patient's silence puts others at risk and the doctor cannot persuade the patient to make a voluntary disclosure."*

Department of Health guidance

http://www.dh.gov.uk/PublicationsAndStatistics/PressReleases/PressReleasesNotices/fs/en?CONTENT_ID=4086804&chk=gId6AB

In 2004, the Department of Health published revised guidance for health professionals on the provision of contraceptive services for under 16s entitled **Publication of revised guidance for health professionals on the provision of contraceptive services for under 16s.**

"The new guidance highlights for the first time that where a request for contraception is made by a person under the age of 16, doctors and other health professionals should establish a rapport with the young person and give the young person the time and support to make an informed choice.

They should do this by discussing:

- *The emotional and physical implications of sexual activity, including the risks of pregnancy and sexually transmitted infections;*
- *Whether the relationship is mutually agreed or whether there may be coercion or abuse;*
- *The benefits of informing their GP and encouraging discussion with a parent of carer. Any refusal should be respected. In the case of abortion, where the young*

woman is competent to consent but cannot be persuaded to involve a parent, every effort should be made to help them find another adult to provide support, for example another family member or specialist youth worker.
- *Any additional counselling or support needs."*

The Ethics Case Consultation Process

When a clinical ethics committee considers a case referral such as that brought by Dr Jennings in the case described on page D6, its discussion will be informed by consideration of the ethical principles involved in the case, the legal framework and professional guidance on the issue. Working within the structure of general legal and professional guidance, the ethical issues in this particular case will need to be considered carefully before appropriate advice and support can be offered to Dr Jennings. As we have illustrated, it is important for a clinical ethics committee to have knowledge of the relevant law and professional guidance, if it exists, when considering an issue, to guide the ethical discussion but not to pre-empt it.

Reading

Tonks A, McCall Smith A, Smith R. The BMJ’s ethics committee is open for business. *BMJ* 2001;**322**:1263 –1264

Mc Call Smith A, Tonks A, Smith R. An ethics committee for the BMJ. *BMJ* 2000; **321**: 720

Hope, T, Savulescu J, Hendrick J. 2003 Medical ethics and law, the core curriculum.
Chapter 4 – An introduction to law. Churchill Livingstone

APPENDIX D1

Some Statutes Relevant for Healthcare

It is important to bear in mind that the passing of a new Act of parliament will change the law.

Human Tissue Bill
http://www.parliament.the-stationery-office.co.uk/pa/cm200304/cmbills/009/2004009.htm

Mental Capacity Bill
http://www.publications.parliament.uk/pa/cm200304/cmbills/120/2004120.htm

Abortion Act 1967
The Abortion (Amendment) (Wales) Regulations 2002
http://www.wales-legislation.hmso.gov.uk/legislation/wales/wsi2002/20022879e.htm

The Abortion (Amendment) (England) Regulations 2002
http://www.legislation.hmso.gov.uk/si/si2002/20020887.htm

The Abortion (Scotland) Regulations 1991
http://www.legislation.hmso.gov.uk/si/si1991/Uksi_19910460_en_1.htm

Mental Health Act 1983
Not available electronically

Guidance for Access to Health Records Requests under the Data Protection Act 1998
http://www.dh.gov.uk/assetRoot/04/03/51/94/04035194.pdf

Data Protection Act 1998
http://www.hmso.gov.uk/acts/acts1998/19980029.htm

Human Fertilisation and Embryology Act 1990
http://www.hmso.gov.uk/acts/acts1990/Ukpga_19900037_en_1.htm

The Children Act 1989
http://www.hmso.gov.uk/acts/acts1989/Ukpga_19890041_en_1.htm

Adults with Incapacity (Scotland) Act 2000
http://www.scotland-legislation.hmso.gov.uk/legislation/scotland/acts2000/20000004.htm

Mental Health (Care and Treatment) (Scotland) Act 2003
http://www.scotland-legislation.hmso.gov.uk/legislation/scotland/acts2003/20030013.htm

Community Care and Health (Scotland) Act 2002
http://www.scotland-legislation.hmso.gov.uk/legislation/scotland/acts2002/20020005.htm

Freedom of Information (Scotland) Act 2002
http://www.scotland-legislation.hmso.gov.uk/legislation/scotland/acts2002/20020013.htm

Regulation of Care (Scotland) Act 2001
http://www.scotland-legislation.hmso.gov.uk/legislation/scotland/acts2001/20010008.htm

Mental Health (Public Safety and Appeals) (Scotland) Act 1999
http://www.scotland-legislation.hmso.gov.uk/legislation/scotland/acts1999/19990001.htm

The Health and Social Care Act 2001 (Commencement No. 6) (Wales) Order 2004
http://www.wales-legislation.hmso.gov.uk/legislation/wales/wsi2004/20040103e.htm

The Health and Social Care (Community Health and Standards) Act 2003 Commencement (No. 2) (Wales) Order 2004
http://www.wales-legislation.hmso.gov.uk/legislation/wales/wsi2004/20040873e.htm

The Health and Social Care Act 2001 (Commencement No. 7) (Wales) Order 2004
http://www.wales-legislation.hmso.gov.uk/legislation/wales/wsi2004/20041754e.htm

Health and Personal Social Services Act (Northern Ireland) 2001
http://www.northernireland-legislation.hmso.gov.uk/legislation/northernireland/acts/acts2001/20010003.htm

APPENDIX D2

Some Cases Relevant to Healthcare

Below we list some key cases where the courts have considered important issues of medical law.

Capacity

Re C (adult: refusal of treatment) [1994] 1 WLR 290, [1994] 1 All ER 819.
Re T (Adult: Refusal of Treatment) [1992] 4 All ER 649
R (on the application of S) v Collins and Others [1998] EWHC Admin 490 (and use of the Mental Health Act 1983)
Gillick v West Norfolk & Wisbech AHA [1986] AC 112 (minors)
Re W [1993] 1 FLR 1(minors and refusal of treatment)
Re R [1992] 1 FLR 190 (minors and refusal of treatment)

Negligence

Bolam v Friern Hospital Management Committee [1957] 1 WLR 582
Bolitho v City and Hackney HA (1993) 13 BMLR 111 (CA)
Penney v East Kent HA [2000] Lloyd's Rep Med 41 (CA)
Pearce v United Bristol Healthcare NHS Trust [1996] EWCA Civ 702

Best Interests – children

Re C (HIV test) [1999] 2 FLR 1004
Glass v UK (Application no. 61827/00)
Portsmouth NHS Trust v Wyatt [2004] EWHC 2247 (Fam)

Best Interests – adults

Re F (mental patient: sterilisation) [1990] 2 AC 1
Simms v An NHS Trust [2002] EWHC 2734 (Fam)
Re A (Male sterilisation) [200] 1 FLR 549

End of Life Issues

Airedale NHS Trust v Bland [1993] 1 All ER 821
Pretty v United Kingdom (2346/02) [
B v An NHS Hospital Trust [2002] EWHC 429 (Fam)

Right to Medical Treatment

R v North West Lancashire Health Authority ex p A and others *[2000] 1 WLR 977*
R (on the application of Watts) v Secretary of State for Health [2004] EWCA Civ 166

Advance Decisions

HE v A Hospital NHS Trust [2003] EWHC 1017
R (on the application of Burke) v GMC [2004] EWHC 1879 (Admin)

This is not a definitive list – a comprehensive and up to date search can be made using websites such as:
Westlaw UK (subscription) http://www.westlaw.co.uk/
British and Irish Legal Information Institute http://www.bailii.org/
European Court of Human Rights http://www.echr.coe.int/

APPENDIX D3

National Institute of Clinical Excellence

NICE is part of the NHS. It is the independent organisation responsible for providing national guidance on treatments and care for those using the NHS in England and Wales. Its guidance is for healthcare professionals and patients and their carers, to help them make decisions about treatment and healthcare. NICE produces guidance in three areas of health:

- The use of new and existing medicines and other treatments within the NHS in England and Wales - technology appraisals
- The appropriate treatment and care of patients with specific diseases and conditions within the NHS in England and Wales - clinical guidelines
- Whether interventional procedures used for diagnosis or treatment are safe enough and work well enough for routine use - interventional procedures.

NICE guidance has relevance for the allocation of resources. Many clinical ethics committees will not become involved in issues of resource allocation but will rather focus on the ethics of **clinical** practice at the individual patient level. Indeed it is worth considering the Terms of Reference of the clinical ethics committee to see if the ethics of resource allocation comes within its remit. Nevertheless, as CECs develop increasingly within PCTs, awareness of NICE guidance will be valuable.

E. EXAMPLES OF PROFESSIONAL GUIDELINES

British Medical Association (BMA)

The following guidelines have been published by the British Medical Association. All the guidelines are available on their web site, www.bma.org.uk, free of charge.

The Law and Ethics of Abortion, BMA Views

www.bma.org.uk/ap.nsf/Content/abortion
March 1997
Revised December 1999

- Legal considerations
- Conscientious objections clause
- Ethical considerations
- Consent
- Confidentiality

Access to Health Records by Patients

www.bma.org.uk/ap.nsf/Content/accesshealthrecords
Revised December 2002

- Legal rights of access to health records and information
- Rights under the Data Protection Act 1998
- Applications for access
- Information which cannot be disclosed
- Access to records of deceased patients
- BMA advice on record keeping

Access to Medical Report Act (1988)

www.bma.org.uk/ap.nsf/Content/accessmedreps
December 1988
Revised September 1995

- Consent
- Individual's rights
- Seeing the report
- Amendments
- Delayed access
- Withholding of information

Medical treatment for adults with Incapacity – guidance on ethical and medico-legal issues in Scotland

www.bma.org.uk/ap.nsf/Content/adults+with+incapacity+-+scotland
2nd Edition October 2002

- Adults with Incapacity (Scotland) Act
- Assessment of capacity
- Adults with capacity
- Certificate of incapacity
- Proxy decision making
- General authority to treat

- Mental Health (Scotland) Act
- Special safeguards

Advance Statements – BMA Views

www.bma.org.uk/ap.nsf/Content/advancestatements
November 1992
Revised May 1995

- What is an advance statement?
- Legal scope of an advance statement
- Assistance with drafting
- Healthcare advocates and proxy decision makers
- Doctors' responsibilities

Advance Statements about Medical Treatment – Code of Practice

www.bma.org.uk/ap.nsf/Content/codeofpractice
April 1995

- Making treatment choices
- Drafting
- Implementation

Decisions Relating to Cardiopulmonary Resuscitation

www.bma.org.uk/ap.nsf/Content/cardioresus

- Presumption in favour of attempting resuscitation
- Essential aspects of decision making
- Information to patients
- Competent adults
- Incapacitated adults
- Children and young people
- Involving people close to the patient
- Refusal of treatment
- When is it appropriate to consider making a DNAR order?
- Responsibility for decision making
- Effects on others

Confidentiality and Disclosure of Health Information

www.bma.org.uk/ap.nsf/Content/Confidentiality+and+disclosure+of+health+information
October 1999

- Disclosure with consent
- Disclosure without consent in the subject's vital interests
- Obligatory disclosure
- Other disclosures and their safeguards
- Disclosure in the public interest
- Examples of disclosure in the public interest
- Safeguards

Confidentiality and People Under 16

www.bma.org.uk/ap.nsf/Content/Confidentiality+and+people+under+16
January 1994

- Teenage sexual activity
- Reasons for concern
- The legal position
- Consulting another doctor
- Confidentiality
- Immature patients
- Exceptional circumstances
- Breach of confidentiality

End of Life Decisions – Views of the BMA

www.bma.org.uk/ap.nsf/Content/End+of+life+decisions+-+June+2000
June 2000

- Refusal of treatment
- Euthanasia
- Physician-assisted suicide
- Withholding and withdrawing life prolonging medical treatment
- Advance statements

Parental Responsibility – Guidance form the Ethics Department

www.bma.org.uk/ap.nsf/Content/Parental
February 2004

- What is parental responsibility?
- Who possesses parental responsibility?
- Consent from people with parental responsibility
- What are the limits to parental responsibility?
- What happens when people with parental responsibility disagree?
- Some common questions relating to parental responsibility
- Parental responsibility and Human Rights
- Competent children and the limits to parental responsibility

Treatment Decisions for People in Persistent Vegetative State

www.bma.org.uk/ap.nsf/Content/Treatment+decisions+for+patients+in+persistent+vegetative+state
Revised June 1996

- Defining PVS
- Misdiagnosis
- Initial assessment and treatment
- Diagnosis
- Review of treatment options
- Views of the patient
- Views of people close to the patient
- Views of healthcare professionals
- Conscientious_objection
- The legal position
- Use of tissue
- Research on PVS
- Pregnant PVS patients

General Medical Council (GMC)

The following guidelines have been published by the General Medical Council. All the guidelines are available on their web site, www.gmc-uk.org, free of charge.

Seeking Patients' Consent: the Ethical Considerations

www.gmc-uk.org/standards/consent.htm
November 1998

- Consent to investigation and treatment
- Providing sufficient information
- Presenting information to patients
- Ensuring voluntary decision making
- Establishing capacity to make consent
- 'Best Interests' principle
- Applying to the court
- Forms of consent

Confidentiality: Protecting and Providing Information

www.gmc-uk.org/standards/secret.htm
April 2004

- Patients' right to confidentiality
- Sharing information with patients
- Disclosure of information
- Frequently asked questions

Withholding and Withdrawing Life Pro-longing Treatments: Good Practice in Decision-making

www.gmc-uk.org/standards/whwd.htm
August 2002

- Guiding principles
- Good practice framework
- Areas for special consideration

Antenatal Testing for HIV

http://www.gmc-uk.org/standards/antenatal.htm
November 2002

Priorities and Choices

http://www.gmc-uk.org/standards/priorities_and_choices.htm
July 2000

- The duties of care
- The provision of services
- The role and responsibility of doctors
- Quantity or Quality?

Management in Healthcare – the Role of Doctors

http://www.gmc-uk.org/standards/manage.htm

May 1999

- Managers' responsibilities - what takes priority when they conflict?
- When are doctors held accountable for management decisions
- Protecting patients from serious harm
- Dealing with colleagues - the role of managers
- Public health
- Occupational health
- Standards of practice
- Management practice
- Honesty in financial matters
- A short selection of publications for doctors in management

Department of Health (DH)

The following guidelines have been published by the Department of Health. All the guidelines are available as pdf documents on their web site, www.dh.gov.uk, free of charge.

Seeking Consent Working with Children

http://www.dh.gov.uk/assetRoot/04/06/72/04/04067204.pdf
November 2001

- Who can give consent?
- Seeking consent
- Consent to treatment for mental disorder

Seeking Consent Working with Older People

http://www.dh.gov.uk/assetRoot/04/06/70/20/04067020.pdf
November 2001

- Seeking consent: people with capacity
- When adults lack capacity
- Withdrawing and withholding life-prolonging treatment

Seeking Consent Working with People with Learning Disabilities

http://www.dh.gov.uk/assetRoot/04/06/70/19/04067019.pdf
November 2001

- Seeking consent: people with capacity
- When adults lack capacity
- Withdrawing and withholding life-prolonging treatment

The Use of Human Organs and Tissue. An Interim Statement.

http://www.dh.gov.uk/assetRoot/04/05/47/79/04054779.pdf
April 2003

- Organs and tissues taken in the future
- Existing stored organs and tissues
- Genetics research
- Disposal of tissue

The Import and Export of Human Body Parts and Tissue for Non-therapeutic Uses. A Code of Practice.

http://www.dh.gov.uk/assetRoot/04/07/71/12/04077112.pdf

Royal Colleges and Societies

The following guidelines are available on the Royal Colleges and Societies web sites free of charge.

Royal College of General Practitioners

Confidentiality – Examining the principle of medical confidentiality
www.rcgp.org.uk/rcgp/corporate/position/confidentiality/confidentiality.doc
November 2000

- Confidentiality
- Implied consent
- Explicit consent

Royal College of Midwives

Maternal choice and caesarean section
http://www.rcm.org.uk/files/info/documents/261101123720%2D132%2D2%2Epdf

Umbilical cord blood collection
http://www.rcm.org.uk/files/info/documents/261101122934%2D131%2D2%2Epdf

Enforced caesarean sections and consent to treatment
http://www.rcm.org.uk/files/info/documents/190602120845%2D163%2D1%2Edoc

Royal College of Nurses

Confidentiality – RCN guidance for occupational health nurses
http://www.rcn.org.uk/publications/pdf/confidentiality.pdf

Royal College of Obstetrics and Gynaecology

A consideration of the law and ethics in relation to court-authorised obstetric intervention
www.rcog.org.uk/guidelines.asp?PageID=109&GuidelineID=33
April 1994

- Good practice
- United Kingdom law
- Consent
- Refusal of consent
- Possible exception to right to refuse consent
- Court-authorised caesarean section – United Kingdom
- The Infant Life Preservation Act (1929)
- Professional ethics

Confidentiality and disclosure of health information: RCOG Ethics Committee comments on a BMA document
http://www.rcog.org.uk/guidelines.asp?PageID=109&GuidelineID=36
October 2000

Royal College of Ophthalmologists

Guidance on the retrieval of human eyes used in transplantation and research
http://www.rcophth.ac.uk/scientific/docs/OcularTissueAndTransplantation_.pdf
1998

- Consent
- Donor medical assessment
- Acknowledgement of eye donation

Royal College of Paediatrics and Child Health

The British Paediatric Surveillance Unit (BPSU) and patient confidentiality
www.rcpch.ac.uk/publications/BPSU/Ethics_Advice_summary_May_2001.pdf
2001

- The BPSU mechanism
- Maintaining confidentiality in BPSU investigations
- Ethical consent for BPSU studies

Responsibilities of doctors in child protection cases with regard to confidentiality
http://www.rcpch.ac.uk/publications/recent_publications/Confidentiality.pdf

Royal College of Physicians

Guidelines on the practice of ethics committees in medical research involving human subjects
www.rcplondon.ac.uk/pubs/brochures/pub%5Fprint%5Fgpecmr.htm
Third Edition 1996

Royal College of Psychiatrists

Good psychiatric practice
www.rcpsych.ac.uk/publications/cr/council/cr83.pdf
2002

- The trusting relationship
- Consent to treatment
- Confidentiality

Good practice guide on confidentiality
www.rcpsych.ac.uk/publications/cr/council/cr85.pdf
2001

- Keeping patients informed
- Consultant responsibility with respect to other professionals in multi-disciplinary teams
- Disclosure
- Situations with dual obligations
- Provision of reports
- Requests for case notes
- Child and adolescent issues
- Issues arising in relation to people with learning disabilities and people with dementia
- Security and secondary use of patient information

Royal College of Surgeons of England

Code of practice for the surgical management of Jehovah's Witnesses
www.rcseng.ac.uk/services/publications/publications/pdf/witness.pdf
2002

- Ethical considerations
- Legal and consent issues
- Preoperative considerations

- Surgical techniques

Good surgical practice
www.rcseng.ac.uk/services/publications/publications/pdf/gsp2002.pdf
2002

- Good clinical care
- Maintaining good surgical practice
- Teaching, training and supervising
- Relationship with patients

Nursing and Midwifery Council

Code of professional conduct
http://www.nmc-uk.org/nmc/main/publications/codeOfProfessionalConduct.pdf

Guidelines for mental health and learning disabilities nursing
http://www.nmc-uk.org/nmc/main/publications/guidelinesForMh.pdf

UKCC position statement on the covert administration of medicines
http://www.nmc-uk.org/nmc/main/publications/covertAdministrationOfMedicines.pdf

F. LEGAL ISSUES AND CLINICAL ETHICS COMMITTEES

Introduction

A clinical ethics committee (CEC) sits within the framework of the institution (NHS trust or private hospital) and carries out its functions with the approval, and within the control, of the trust. Many CECs report directly to the trust Board while others report to one of the other committees within the trust management structure, for example the clinical governance committee. In any event, the trust will be responsible for the conduct of the CEC to external scrutiny. The trust will be concerned therefore to ensure that the CEC has adequate processes in place to address issues such as confidentiality (of individual patient information and information relating to the trust), and to ensure that the advice and support provided by the CEC is consistent and ethically informed. In this section we consider some areas where the law may have an impact on the work carried out by a CEC, including:

- Legal liability of a CEC and of individual members of a CEC
- Patients' notes and referrals to a CECs
- Action taken by the healthcare professional following a case referral to a CEC

Legal liability of the members of a CEC

Relevant issues for consideration include:

- The extent to which individual members as opposed to the CEC itself, can be legally liable - for what and to whom?
- The extent to which a member of a CEC represents the view of the trust, and/or its own views and/or the individual views of its members

As Judith Hendrick commented in 2001,
'…*the vulnerability of committee members to legal action is difficult to assess with certainty."* [28]

In the United States, where CECs have been a feature of hospitals for the past 30 years, there have been no occasions to our knowledge when an ethics committee, or an individual ethicist, has been held legally liable for the advice that they have given. However, there is increasing concern that this will not continue to be the case, and concerns about legal liability have in part driven the debate about developing standards for ethics consultation. The potential for legal action is most likely to arise where a CEC has been asked for prospective advice concerning the care of a patient, for example whether it is ethical to withhold treatment from a patient. The patient, or his / her relatives, may argue that the view of the CEC was inappropriately persuasive, coercive and/or **negligent**. If perceived to be exercising its functions as part of the NHS, which is a public body, then a CEC could find its decisions and processes open to **judicial review**. However, the most likely action taken against a CEC would be a negligence claim.

Negligence of the CEC

In order for an action in negligence to succeed, three conditions must be met.

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[28] Hendrick J. Legal aspects of clinical ethics committees. Journal of Medical Ethics. 2001;27 supp 1:i50-53.

- **The claimant must establish that he/she was owed a duty of care**

Certainly the doctor with clinical care of the patient who refers the case for consideration to the CEC owes a duty of care to the patient. The hospital or trust also owes a duty of care to all patients for whom it is providing health care, including the establishment of systems necessary for the safe operation of the trust. A clinical ethics committee too may be considered to owe a duty to the patient, and the patient's relatives if acting as part of the *health care* team.

- **There must be a breach of the established duty**

In establishing a breach of duty it is necessary to demonstrate that the required standard of care has not been met. Unlike research ethics committees, CECs are presently unregulated so it may be difficult to determine the standard by which a CEC should be judged. Essentially there would be a breach of the duty if the CEC fell below a standard required by the common law, established with reference to current case law precedents.

- **There must be a causal link between the duty of care and some legally recognised form of harm**

For a claimant to succeed it must have been **foreseeable** that the breach of duty suffered would cause, and has caused, some legally recognised form of harm. Forseeability is judged upon whether the type of harm suffered could reasonably have been predicted. In this context a claimant may argue that the clinician would have acted differently without the advice of the CEC and accordingly that the involvement of the CEC has led to foreseeable but avoidable harm.

There are some difficulties in applying the conditions of a negligence action to the work of CECs as they currently stand in the UK. Firstly, there is no requirement to refer a case or an issue to a CEC (in contrast to the position in some States in North America). Secondly, even if there is a referral, the role of a CEC is seen as advisory and supportive rather than decisive. Only in situations where a health professional was required to follow the advice of a CEC could it be clearly demonstrated that a breach of duty on the part of the CEC had directly led to the ensuing harm. The legal position would be much less clear when, as is the case in the UK, a health professional is held responsible for the standard of their own actions and decisions, and can ignore the advice of a CEC.

Negligence of the trust

Whilst a trust need not have a CEC to demonstrate that it has systems and processes of a reasonable standard, appropriately organised CEC's may facilitate clinical management and play an active part in clinical training supportive of best practice in relation to patient care. However, if the clinical ethics support provided by the CEC fell far short of what could reasonably be expected i.e. no-one on the committee had any ethics training, then the trust could be said to have breached its direct duty and be liable in negligence.

Unreasonableness of CEC view

The role of a CEC in advising trusts on policy and guidelines, or in providing advice on individual cases, may be scrutinised by a judicial review of trust policy or treatment decisions. The advice of a CEC could be challenged on the grounds that it acted unreasonably or took into account irrelevant considerations. The Human Rights Act 1998 and case law developments related to treatment decisions suggests that health organisations will increasingly face challenges about the fairness of decisions which may be perceived as adversely affecting the rights of individual patients or patients' relatives.

Points for a CEC to consider

- In order for a CEC to show that it is acting reasonably it is essential that the processes by which it operates are **open** and **transparent**. It should also be able to demonstrate that the manner in which it comes to a decision is **informed and**

consistent i.e. like cases are considered in like fashion and any deviation can be explained on relevant grounds.

- A CEC will need to demonstrate that its members have sufficient knowledge of ethics to enable ethical issues to be identified and informed ethical debate to take place. Different levels of knowledge and skills may be required for different committee functions, for example case consultation may require specific skills that are less important in advising on policy and guidelines. This raises the question of appropriate training for CEC members.
- It is important that CECs have clear terms of reference about the extent to which individuals represent, and may act independently, of the committee. For example what happens if a member is approached by a clinician for advice on an urgent ethical dilemma? When is advice informal and when is it seen as having the authority of the committee?
- CEC's should be aware of, and be able to access, relevant national guidelines, for example GMC guidance on confidentiality. They will also need to be aware of, and have access to information about, relevant law. While they should not be seen as providers of legal advice, they should know when legal advice is likely to be required in specific cases.
- It is important for the committee to establish proper **criteria for membership**. There should be a transparent process by which members are selected, and continue to be part of the committee. Members who are not employed by the trust will need to undergo an appropriate checking procedure before appointment akin to that applied in relation to the selection and appointment of Non-Executive Directors.

Legal indemnity

There is a statutory exemption that covers liability for negligence for trust employees, for acts and omissions carried out in the course of their employment. Thus, in the event of a CEC being sued for negligence, trust employees would have indemnity from personal liability. This would not apply to those members of a CEC not employed by the trust. Thus we would recommend that a trust makes arrangements to provide indemnity for CEC members who are not employed by the trust for their work as members of the CEC.

The obvious point to emphasise in respect of any indemnity afforded by the trust is that it will only extend to acts and omissions arising in the course of the committee members normal duties (as members of the CEC). Hence the importance of setting out the boundaries of the role of committee members, for instance in providing 'informal' ethics advice outside the committee

Several CECs have Trust indemnity for lay members of the committee. Contact details of these CECs can be obtained from the Network administrator.

Confidentiality and exceptions to duty of confidence

Members of a CEC will owe an ethical, professional and legal duty of confidentiality to patients and other third party non-healthcare professionals named within a patient's medical records except in limited circumstances where there is a duty to disclose these records, for example, in situations where the is a risk of a serious crime. Lay members are also under a legal duty of confidentiality in respect of their discussions of cases in CEC meetings. Lay members should be made aware of this obligation upon joining the committee and an undertaking of confidentiality should be signed.

Patients’ notes and referrals to CECs

CEC documents i.e. minutes, case write ups, agendas etc. are not public documents as such but) they may be disclosable as part of a court action if considered relevant to issues arising in the legal case.

If sufficient information is available for the patient to be identified then the case write up, or minutes of the meeting appertaining to that case, could be deemed part of the patient record. Accordingly, as far as possible facts identifying the patient – name and hospital number should not be used in the discussions of the CEC nor in writing up minutes of meetings. However, it may be impossible to anonymise a case sufficiently because of the unique nature of individual cases, and the likelihood that a case difficult enough to be brought to a CEC will be recognisable, even if it is anonymised. It is probably best to assume that discussions of active cases (rather than retrospective case discussion) are part of the patient’s record.

The provisions of the Data Protection Act 1998 (as amended by the Freedom of Information Act 2000) will come into play where a patient can be identified. CEC’s should therefore be aware of the patient’s rights to access records of the CEC meeting at which his/her case was discussed.[29] A helpful summary of frequently asked questions about accessing health records is available on the Department of Health website.

http://www.dh.gov.uk/PolicyAndGuidance/InformationPolicy/PatientConfidentialityAndCaldicottGuardians/AccessHealthRecordsFAQ/fs/en?CONTENT_ID=4039714&chk=iOJNGp

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[29] See **Appendix F1** for relevant issues of the Data Protection Act 1998

Action taken by the healthcare professional following a referral to CEC

It is important to note that presently there is no requirement for a clinician to refer a case to a CEC. The existence of a CEC within a trust does not impose an obligation to use it. Accordingly, the role of the CEC is consultative and not prescriptive. The CEC will consider the ethical issues that a particular case raises but will not tell the clinician what to do. Responsibility for the decision lies with the clinician who may use the ethical discussion, and comments of the committee, to inform or guide that decision. However, if the responsibility for the clinical decision is to lie with the referring clinician the committee has a duty to make this clear in its terms of reference. This is particularly important when the referring health professional is a junior member of trust staff.

In the event of a negligence claim being brought against a clinician when a CEC had been consulted, the court would need to establish if there had been a breach of a duty of care on the part of the clinician (see above re conditions for proving negligence). Failure to consult a CEC, or making a decision contrary to the advice of a CEC would not of itself be seen as falling below a minimum accepted standard of clinical practice. Nor would following the advice of a CEC be a defence against a negligence claim. However, if a CEC had been consulted about the case, the court may consider the process of consultation and the nature of the committee's advice or input, when considering whether the clinician had acted reasonably and whether the trust had appropriate systems in place to support provision of patient care. Thus a CEC's deliberations could come under scrutiny in a negligence claim against an individual clinician.

If a clinician, having consulted a CEC, decides to go against the advice of the CEC, they will need to document their reasons for their decision clearly in the patient's notes, as they would with any other clinical decision.

APPENDIX F1

Data Protection Act 1998

Below we summarise the main points of the Data Protection Act 1998 (DPA) which is relevant to data held on patients and used by the CEC in its discussions.

The DPA protects data held about individuals and regulates the use of that data.
- The Act covers ‘processing’ of personal data of a living individual from which he/she can be identified.
- Personal data includes health information and it also covers facts and opinions about an individual.
- 'Processing' is defined very widely and covers the obtaining and disclosing of data.
- Information about the health of an individual is termed ‘sensitive personal data’.
- A condition in Schedule 2 AND a condition in Schedule 3 of the Act must be satisfied in order that sensitive personal data is processed fairly and lawfully.

Schedule 2 condition 6: processing is necessary for the data controller (the trust) to pursue its legitimate interests i.e. provision of healthcare.

Generally if a clinician decides that a case should be referred to a CEC then it would be considered necessary for the provision of healthcare (the referring clinician would have to be able to justify this on a case by case basis).

Schedule 3 condition 8: processing is necessary for medical purposes (including the provision of care and treatment). Provision of care and treatment is wider than merely clinical care and so discussion of patient's health information at a CEC meeting would be covered by this condition.

Assuming both Schedules 2 and 3 conditions (as explained above) are satisfied then the patient is not required to give explicit consent for his / her health details to be considered by a clinical ethics committee.

However it is a requirement of the Data Protection Act that personal data should be processed fairly and lawfully.

'Fairly and lawfully'

Although the Act does not define 'lawful', it is taken to mean that the data controller must comply with all rules of law. Of particular relevance is the duty of confidentiality.

Anyone who receives information knowing / believing it to be confidential is under a duty of confidence. Therefore members of a CEC will receive health information about an individual whose case is to be considered at a committee meeting, under a duty of confidence (this is the case irrespective of whether they have signed a confidentiality agreement on joining the committee). This information will therefore have been processed lawfully.

In deciding whether information has been processed 'fairly' it is relevant to consider if the person from whom the data is obtained is deceived or misled as to the purposes for which the data is to be used. Where an individual's case is discussed at a meeting of the CEC and therefore his / her health information will be included in the minutes, then it may not be fair processing if the patient is not aware that such a record exists. Ideally the patient should be told that his / her health information will be discussed and the purpose of the discussion. The record of the discussion of the CEC forms part of the patient's medical record.

Can a patient whose case has been discussed at a CEC meeting see minutes of that meeting?

If the minutes do not contain patient identifiable information then the provisions of the DPA do not apply. However, the inclusion of information about the patient's age, religion etc and indeed specific medical information would mean that patient identifiable information is included in the minutes and the DPA will apply so long as the patient is alive. Even if information is anonymised, if its use affects treatment, for example if the clinician who brings the case to the CEC acts on the advice of the CEC in managing the patient, then it is considered personal data. A data subject, (a patient) has a 'right' to access his / her health data held by a data controller (although this may be denied in some circumstances).

What if an 'old' case is discussed by the CEC for teaching purposes?

If there is an abstract discussion of a case, by way of a teaching exercise, and it is clear this would not impact on the patient's care, then such a discussion would not form part of the patient's record. In these circumstances it may be considered unnecessary to seek the patient's consent or to tell the patient about the discussion. However in the event of the discussion revealing information that may be relevant to the patient's care then strictly there would be a duty to inform the patient.

Why is referral to a CEC different from a referral to another group e.g. dieticians, biologists, or referral to another clinician about how best to manage the patient's situation?

A patient would appreciate the need for discussion with other healthcare professionals about the management of his or her case but may not appreciate that a referral to a CEC may occur. Most patients are unaware of the existence or the function of CECs.
Accordingly unless informed that his / her case will be discussed at a CEC meeting the patient will remain ignorant of that fact. The question in this situation is whether this is ethically and / or legally appropriate. Whilst it could be implied that a patient will be aware that a clinician may discuss his or her case internally for educative reasons, arguably the sort of information sharing that is required with non-healthcare professionals at a CEC meeting suggests that a patient should be have a right to decide whether or not he / she is happy for the referral to be made.

http://www.informationcommissioner.gov.uk/eventual.aspx?id=34

http://www.dh.gov.uk/PolicyAndGuidance/OrganisationPolicy/RecordsManagement/DataProtectionAct1998Article/fs/en?CONTENT_ID=4000489&chk=VrXoGe

G. EXAMPLES OF PATIENT ORGANISATIONS

Alcohol Concern
Waterbridge House
32-36 Loman Street
London
SE1 0EE
Web site: www.alcoholconcern.org.uk

Alcohol Concern is the national agency on alcohol misuse.

Alzheimer's Society
Gordon House
10 Greencoat Place
London
SW1P 1PH
Tel: 020 7306 0606
Fax: 020 7306 0808
Web site: www.alzheimers.org.uk/index.htm

The Alzheimer's Society aims to maintain, promote and improve knowledge and understanding of dementia. They provide information and advice to carers and professionals about all forms of dementia, caring, legal and financial issues, social and health services and benefits.

British Heart Foundation
14 Fitzhardinge Street
London
W1H 6DH
Tel: 020 7935 0185
Web site: www.bhf.org.uk/index.asp

The British Heart Foundation provide support and information for people with heart disease, their families and carers. They also promote training and education into heart disease, and fund research into causes, prevention and treatment of heart disease.

British Lung Foundation
73-75 Goswell Road
London
EC1V 7ER
Tel: 020 7688 5555
Fax: 020 7688 5556
Web site: www.britishlungfoundation.org/index.asp

The British Lung Foundation provides support and advice for people with lung disease and their carers.

Carers UK
20-25 Glasshouse Yard
London
EC1A 4JT
Tel: 020 7490 8818
Fax: 020 7490 8824
Web site: www.carersonline.org.uk

Children's Heart Foundation
Tel: 020 7820 8517
Fax: 020 7735 8718
Web Site: www.childrens-heart-fed.org.uk
Free phone Helpline: 0808 808 5000 (9.30 am – 9.30 pm Monday to Friday)

A federation of local and national support groups for families of children with heart disorders in the UK and Ireland.

Depression Alliance
35 Westminster Bridge Road
London
SE1 7JB
Tel: 020 7633 0557
Web site: www.depressionalliance.org

DIPEx
41 Cornmarket Street
Oxford
OX1 3HA
Web site: www.dipex.org

DIPEx is an online database of patient experiences of health and illness, provides reliable information on treatment choices and information on where to find support.

Eating Disorders Association
103 Prince of Wales Road
Norwich
NR1 1DW
Tel: 0845 634 1414
Open 8.30am to 8.30pm Monday to Friday and 1.00pm to 4.30pm Saturdays

The Eating Disorders Association provide information, help and support in the UK on all aspects of eating disorders.

Epilepsy Action
New Anstey House
Gate Way Drive
Yeadon
Leeds
LS19 7XY
Tel: 0113 210 880
Fax: 0113 391 0300
Web site: www.epilepsy.org.uk/index.html

Epilepsy Action is a working name of the British Epilepsy Association. They provide comprehensive information on epilepsy and how to control it for people with epilepsy, their friends, family and carers. They also have a Helpline for anyone with queries about epilepsy or the group.

Hospital Information Service for Jehovah's Witnesses
IBSA House
The Ridgeway
London
NW7 1RN
Tel: 020 8906 2211
E-mail: his@wtbts.org.uk

Jehovah's Witnesses have developed a Hospital Liaison Committee Network to assist healthcare professionals in the treatment of Jehovah's Witnesses. They have a 24 hour contact number to provide advice and explain the Jehovah's Witness stance on certain forms of medical treatments.

Long-Term Medical Conditions Alliance (LMCA)
Unit 212
16 Baldwins Gardens
London
EC1N 7RJ
Tel: 020 7813 3637
Fax: 020 7813 3640
Website: www.lmca.org.uk

LMCA is the umbrella body for national voluntary organisations working to meet the needs of people with long-term health conditions.

The Mental Health Foundation
Foundation for People with Learning Disabilities
UK Office
7th Floor, 83 Victoria Street
London
SW1H 0HW.
Tel: 020 7802 0300
Web Site: www.connects.org.uk

The Migraine Trust
2nd Floor
55056 Russell Square
London
WC1B 4HP
Tel: 020 7436 1336
Fax: 020 7436 2880
Web site: www.migrainetrust.org
The Migraine Trust is the UK's leading medical research and patient support charity for the condition. The Trust is committed to supporting sufferers and their families by funding and promoting research, improving diagnosis and treatment, providing information and advice, and raising awareness of migraine as a significant public health problem.

Multiple Sclerosis Resource Centre
7 Peartree Business Centre
Peartree Road
Stanway
Colchester
CO3 5JN
National Helpline: 0800 783 0518 (8.30am – 5.30pm Mondays to Fridays)
Website: www.msrc.co.uk

Patients Association
PO Box 935
Harrow
Middlesex
HA1 3YJ
Help Line: 0845 4239111
Tel: 020 8423 9111
Fax: 020 8423 9119
Web site: http://www.patients-association.com/

The Patients Association offer useful information on healthcare in the UK, offering help and support for patients. The web site contains comments on healthcare issues and items in the news, as well as a Guide to Living Wills, how to access your own medical records and other useful advice.

Patient UK
Web Site: www.patient.co.uk

Patient UK provides free information for patients on health and disease, GP leaflets and a directory of patient support groups.

Voluntary Euthanasia Society
13 Prince of Wales Terrace
London
W8 5PG
Tel: 020 7937 7770
Fax: 020 7376 2648
Web site: www.ves.org.uk/index.htm

The Voluntary Euthanasia Society, VES, actively campaigns to change the law regarding euthanasia. They are the leading UK supplier of Living Wills and provide comprehensive information about the current law and the legal status of living wills.

H. READING LIST

Aulisio MP, Arnold RM, Younger SJ (eds) *Ethics consultation: From theory to practice*. Baltimore: Johns Hopkins University Press (2003).

Beauchamp T, Childress J. 2001. Principles of Biomedical Ethics. 5th edition Oxford University Press

Blackburn, S. 2001. Ethics: a very short introduction. Oxford University Press

BMA . 2004. Medical Ethics Today. London, BMA Books

Boyd, K.M., Higgs, R., Pinching, A.J., (1997) The New Dictionary of Medical Ethics BMJ Publishing Group, London

Campell A, Gillett G, Jones G. 2001. Medical Ethics. 3rd edition. Oxford University Press

Ehleben C M, Childs B H, Saltzman S L. What is it exactly that you do? A "snapshot" of an ethicist at work. *HEC Forum*. 1998;**10**(1):71-4.

Gillon, R., (1986) Philosophical Medical Ethics Chichester, Wiley

Glover, J., (1997) Causing Death and Saving Lives Harmondsworth, Penguin

Hope T (2004) Medical Ethics A Very Short Introduction Oxford University Press

Hope T, Savulescu J, Hendrick J 2003 Medical ethics and the law, the core curriculum. Churchill Livingston. Chapter 1

Jiwani B. An introduction to health ethics committees. Provisional Health Ethics Network (2001).

Journal of Medical Ethics – Clinical Ethics Committees Supplement 2001, April, Vol 27, Supplement 1.

Komatsu G I, Goodman-Crews P, Cohn F, Young E W. Effect of ethics consultations on non beneficial life-sustaining treatments in the intensive care setting: a randomised controlled trial. *Journal of the American Medical Association*. 2003;**290**(9):1166-72.

Larcher V, Lask B, McCarthy J. Paediatrics at the cutting edge: do we need clinical ethics committees? *JME*1997;**23**:245 - 249.

Mautner, T., ed. (1997) Penguin Dictionary of Philosophy Penguin Books

McCall Smith A, Tonks A, Smith R. An ethics committee for the BMJ. *BMJ* 2000; **321**: 720

Meslin E, Rayner C, Larcher V, Hope T, Savulescu J. Hospital Ethics Committees in the United Kingdom. *HEC Forum* 1996; **8**(5):301-315

Parker M, Dickenson D. 2001. The Cambridge medical ethics workbook: case studies, commentaries and activities. Cambridge University Press.

Parker M, Hope T. Ways of Thinking About Ethics. Medicine 2000;28:10:2-5

Rachels J. 1995. The elements of moral philosophy. 2nd edition Mc Graw Hill

Singer, P., ed. (1986) Applied Ethics (e.g. vi, J. Harris, The Survival Lottery) Oxford University Press

Singer, P., ed. (1991) A Companion to Ethics (e.g. Essays 10, 14, 20, 21 and 22) Oxford, Blackwell

Slowther A, Bunch C, Woolnough B, Hope T. Clinical Ethics Support in the UK: A review of the current position and likely development. 2001; London; The Nuffield Trust

Slowther A, Hope T. Clinical ethics committees: They can change clinical practice but need evaluation. *BMJ* 2000;**321**:649-650

Slowther A, Johnston C, Goodall J and Hope T. Development of clinical ethics committees. *BMJ* 2004;**328**:950 - 952

Slowther A, Underwood M. Is there a need for a clinical ethics support service in the UK? *JME*1998;**24**:207.

The Report of the American Society for Bioethics and Humanities, *Core Competencies for Health Care Ethics Consultation,* 1998

Tonks A, McCall Smith A, Smith R. The BMJ's ethics committee is open for business. *BMJ* 2001;**322**:1263 –1264

UK Clinical Ethics Network, Report on the Network Questionnaire, 2003

Warburton, N., (1999) Philosophy, the Basics Routedge. 3rd Edition. Introduction and Chapter 2.

Warburton, N., (1998) Philosophy, the Classics Routledge. Chapters 1, 2, 11, and 14.

Watson AR. An ethics if clinical practice committee: should every hospital have one? *Proc Roy Coll Phys Edin* 1999;**29**:335-337

I. Some Useful Web Sites

UK Clinical Ethics Network www.ethics-network.org.uk

This site offers additional information to the manual. The site contains the contact details of clinical ethics committees throughout the UK, categorised into the CECs geographical area and the issues the CEC commonly discuss. There is also information on Committee Functions, with examples of policies that have been formed by CECs and methods of case consultation.

The site also contains information on the most common issues faced by CECs, such as consent and confidentiality, with explanations of the legal position, professional guidelines, hypothetical case studies and suggested reading.

BioethicsWeb www.bioethicsweb.ac.uk/

A searchable catalogue of internet sites covering all areas of biomedical ethics. The recommended sites have been reviewed to ensure their suitability for this useful resource.

British Medical Association www.bma.org.uk/ap.nsf/Content/__Home_Public

As well as useful information about the many roles of the BMA, this site has extensive details of the activities of the BMA Ethics Committee, with the full documents of many of the ethical guidelines produced by the Committee.

Bulletin of Medical Ethics www.bullmedeth.info/index.html

An independent publication offering views on healthcare ethics issues in the news, both in the UK and abroad.

Cardiff Centre for Ethics, Law and Society www.ccels.cardiff.ac.uk/

This site is based at the Cardiff Law School and is a very useful resource for policy makers, and researchers with educational information, a comprehensive database of international useful links and articles.

Department of Health http://www.dh.gov.uk/PolicyAndGuidance/fs/en

This section of the website contains the publications by the Department of Health; nearly all the publications are available electronically and are categorised alphabetically into the subject area.

General Medical Council www.gmc-uk.org/

This site contains more general information about the GMC, but it also has a good section on ethical guidance. The full documents of the Guidance on Good Practice are available.

Human Fertilisation and Embryology Authority www.hfea.gov.uk/Home

The HFEA is the UK statutory body that regulates, licences and collects data on fertility treatment, IVF, donor insemination and human embryo research. The web site contains useful information about the Authority, patient information leaflets, code of practice and details of the HFEA publications.

The Internet Encyclopaedia of Philosophy www.iep.utm.edu/

A searchable encyclopaedia of philosophical theories and thinkers with a good section on ethical theory. The site covers approaches to ethical thinking including virtue theory, dentology, consequentialism and utilitarianism.

Journal of Medical Ethics http://jme.bmjjournals.com/

The official journal of the Institute of Medical Ethics. The web site contains a lot of useful resources, as well as original articles and case conferences the site also contains a supplement produced in 2001 dedicated to clinical ethics committees at http://jme.bmjjournals.com/content/vol27/suppl_1/ . There is also an archive of articles categorised by the main topic at http://jme.bmjjournals.com/collections/ making searching for specific subject areas simpler.

Provincial Health Ethics Network http://www.phen.ab.ca

The website of the Provincial Health Ethics Network (PHEN) for Alberta, Canada provides education and resources for developing and existing ethics support.