

Clinical Ethics Support in the UK: A review of the current position and likely development

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Foreword

In May 2000 the Nuffield Trust published *Policy Futures for UK Health*¹ and *Genetics and Health*.² both of these publications raised the issue of resolving conflicting values in health policy. The Nuffield Trust's deliberations had been informed by a paper commissioned from Martyn Evans³ as one of the ten technical papers which formed part of the consultation process culminating in the publication of *Policy Futures for UK Health*. Martyn's paper highlighted the competing values that are played out in modern health debates - the tension between individual choice and collectivism.

Clinical Ethics Support in the UK. A review of the current position and likely development takes a look at the current position of clinical ethics support and, drawing on international experience, considers what might be a sensible way forward for the UK in the short and medium term on ethical issues arising from clinical practice. The findings of this survey indicate a widespread view amongst senior health professionals that there is a need for some form of support on ethical issues arising from clinical practice and that these recommendations should be carefully considered by health authorities and trust boards, as well as by the Health Departments and Executives within the home countries.

John Wyn Owen, CB
London: December 2000

1. Dargie, C, *Policy Futures for UK Health*. 2000 Report. London: The Nuffield Trust (2000).
2. Zimmern, R, Cook, C, *Genetics and Health*. Policy issues for genetic science and their implications for health and health services. London: The Nuffield Trust (2000).
3. Evans, M., *Reconciling Conflicting Values in Health Policy*. London: The Nuffield Trust (1999).

Executive Summary

Introduction

1.1 This report describes the findings of an assessment of the current provision of clinical ethics support services in the UK. The research was carried out by the Oxford Centre for Ethics and Communication in Health Care Practice (Ethox) in collaboration with the Department of Educational Studies, both at the University of Oxford. The project was funded by the Nuffield Trust.

1.2 Clinical ethics support services were defined as the formal or informal provision of support to health professionals on ethical issues arising from their clinical practice. The definition was kept as broad as possible in order to obtain a comprehensive picture of the current situation without pre-judging what might constitute such a service. However, ethical issues relating to medical research were specifically excluded. The project's main focus was on clinical ethics support in the secondary and community care sector of the health service. Because of the more diverse structure of the provision of primary care services (primary care groups and trusts were not established at the beginning of the project), and the changing pattern of primary care, it was felt that a useful assessment of clinical ethics support in this area would be beyond the scope of this project. Where possible, within the framework of the studies, we attempted to obtain some idea of how clinical ethics support might be provided in primary care.

1.3 The project had the following objectives:

- i. To identify any ethics support services relating to clinical practice currently provided for health professionals working in the UK.
- ii. To investigate the perceived need for such a service among senior managers and clinicians within the health service.
- iii. To place the UK experience broadly within an international context.
- iv. To make recommendations on how clinical ethics support could be developed in the UK.

1.4 The project comprised a series of studies based on five key groups thought likely to be sources of clinical ethics support.

- i. NHS trusts.
- ii. Health authorities and health boards.
- iii. Local research ethics committees.
- iv. Professional organisations.
- v. University departments of medical ethics.

Method

1.5 A combination of methods was used in order to obtain both a comprehensive overview and a detailed description of some aspects of clinical ethics support. The conclusions and recommendations are based on insights gained from the following.

- i. Questionnaire responses from one or more key individuals (chief executive, chairman, medical director or director of nursing) in 99.8% of NHS trusts.
- ii. Questionnaire responses from one or more key individuals (chief executive, chairman, director of public health and director of primary care) in 99.2% of health authorities and health boards.
- iii. Questionnaire responses from 90% of chairmen of local research ethics committees.
- iv. Questionnaire responses from twenty one national professional organisations.
- v. Interviews with the chairmen of the twenty clinical ethics committees currently established in the UK.
- vi. Interviews with the chairmen of seven local research ethics committees that provide advice on ethical issues relating to clinical practice.
- vii. Correspondence with fifteen university departments of medical ethics.

1.6 In addition, information about clinical ethics support services in other countries was obtained by a combination of literature review, personal communication and observational visits.

Findings

The following paragraphs summarise evidence that is described in subsequent chapters. The numbers at the end of each section refer to those sections of the report that amplify the point most fully.

1.7 Perceived need for clinical ethics support

There is a widespread view among senior health professionals that there is a need for some form of support for health professionals on ethical issues arising from clinical practice.

(3.4.3,4.4.2,5.4.1.2,6.4.2)

1.8 Current provision of clinical ethics support in NHS trusts

Many acute, community and mental health trusts have identified some formal method of addressing ethical issues arising from clinical practice within the trust. These vary from specific services dedicated to the provision of clinical ethics support to the incorporation of ethics into existing trust structures. They include the following:

- i. Clinical ethics committees (CECs).
- ii. Ethicists.
- iii. Professional or management structures.
- iv. Committees or groups other than a CEC.

- v. Chaplaincy services.
- vi. Policies on ethical issues.
- vii. Advice or support from university departments of ethics.
- viii. Individuals with some special interest in ethics within trusts. (3.4.1)

1.9 Support for the development of clinical ethics services

There was strong support for the introduction of specific clinical ethics support, such as clinical ethics committees or ethicists, within NHS trusts. A clinical ethics committee was the most favoured model for this but some health professionals expressed concern about the feasibility of providing clinical ethics support in general, and clinical ethics committees in particular. Concerns included:

- i. The cost of setting up such a service.
- ii. The need for a rapid response to requests for advice in urgent clinical situations.
- iii. The establishment of yet another committee, thus increasing bureaucracy within the trust.
- iv. That the clinical autonomy of health professionals would be compromised. (3.4.3, 3.4.4)

1.10 Clinical ethics committees (CECs)

1.10.1 Twenty NHS trusts were identified that had established formal clinical ethics committees. The majority of these have been established within the past five years. Another twenty NHS trusts expressed an intent to establish a committee within the next twelve months. The impetus for establishing a clinical ethics committee was most commonly from concerned clinicians rather than as a result of managerial initiative. Committee membership is multidisciplinary and many committees have lay members. The chairman of most committees is a senior doctor. (3.4.1, 8.4.1)

1.10.2 There is a perceived need among clinical ethics committee chairmen for some formal education in ethics of the committee members. Such education should focus initially on identification and articulation of the morally relevant facts in a case, and the process of resolving moral disagreement. Specific knowledge of moral theories is not seen as essential for all members of the committee but may be desirable for some members at a later stage in the committee's development. Training in how to function effectively as a committee is also necessary. Very few clinical ethics committee members in the UK have had any specific ethics training. The main barriers to such education of committee members are:

- i. Funding.
- ii. Time commitment for members.
- iii. Lack of appropriate courses. (8.4.3)

1.10.3 There is a considerable divergence of views amongst the chairmen of clinical ethics committees as to the benefit of having an ethicist, or other philosopher, as a member of the clinical ethics committee. The experience of some committees is that an ethicist is not essential to the successful functioning of the committee. Others however have found an ethicist of great

value to the committee. If the committee does not have an ethicist then ethics education of the committee becomes even more important, (see 1.10.2) (8.4.2)

1.10.4 The terms of reference of the established CECs identify three main functions of the committees; support for individual clinicians; input into trust policy and guideline formation; and education of health professionals within the trust. Most committees have concentrated on guidelines and policy, although a few carry out individual case consultation as their main function. (8.4.6,8.4.9)

1.10.5 Education within the trust has not been undertaken to any great extent by most committees. Reasons for this include:

- i. Lack of financial resources.
- ii. Lack of time.
- iii. Lack of confidence in the committee's own knowledge and ability to provide ethics education for others. (8.4.12)

1.10.6 Raising the profile of the CECs within the trust is a priority if the committee is to function effectively. Few committees are well known within their trust and are therefore accessed only by a small group of clinicians. However, it is important that when a committee is first established, it develops credibility in one or two areas before expanding its services to the whole trust. (8.4.7)

1.10.7 If CECs, or other clinical ethics support services, are to develop in the UK, evaluation and audit of the service is essential. Only one of the clinical ethics committees so far established has carried out evaluation of its work. Reasons for this include:

- i. Difficulty in defining outcome measures.
- ii. Lack of clarity in the committee's aims.
- iii. Lack of financial resources. (8.4.8)

1.10.8 The relationship between CECs and clinical governance needs clarification. Most chairmen of established CECs viewed consideration of ethical issues as an integral part of providing high quality patient care and therefore of clinical governance. However, they also considered it to be important for the clinical ethics committee to be seen as separate from the monitoring process of clinical governance. (8.4.13)

1.11 Clinical ethics support in health authorities and boards

Several health authorities and health boards have begun to address the ethical issues around resource allocation and priority setting. There is a lack of consensus amongst health authorities on whether ethical issues relating to other areas of clinical practice are their concern, or whether they fall entirely within the remit of trusts. Even within the area of resource allocation there is no clear boundary between health authorities and trusts as to where the responsibility for ethical input lies. There is a recognised need for health authorities to provide ethics support to primary care groups and trusts on issues arising from clinical practice and resource allocation. (4.4.3,4.4.4)

1.12 Clinical ethics support by local research ethics committees

A number of local research ethics committees (LRECs) are being asked for, and are providing, advice on ethical issues related to clinical practice. Most of the committees that do provide advice do so infrequently, but the provision of such advice is outside their terms of reference. Some LREC chairmen expressed concern that their committee was not appropriately constituted to give such advice. Others felt that an extension of their role into clinical ethics would result in an unacceptable increase in workload for the committee. (5.4.1.1, 5.4.2.2, 5.4.2.3, 5.4.2.4)

1.13 Clinical ethics support by professional organisations

Many health professionals see their professional organisations as a source of ethics support on clinical issues. Several of the professional organisations produce guidelines on specific issues and some offer a telephone advice service. However, there is concern within some professional organisations that advice from a national body may be too generalised to be helpful in local circumstances and that professional organisations should act as a resource for more local support services. (6.4.1, 6.4.2)

1.14 Clinical ethics support by university departments of ethics

Few university departments of medical ethics provide regular clinical ethics advice to health professionals. Three units have formal links with their local NHS trust based around the trust's clinical ethics committee. Some individual academic ethicists are approached in their role as teachers of medical ethics. (7.4)

1.15 The international context

Clinical ethics support exists to varying degrees in other countries. Clinical ethics support has become widespread in health care institutions in North America for over twenty years. In Europe, several countries are now developing support services. Examples of clinical ethics support are also seen in Australia, New Zealand and South America. The different models of clinical ethics support include:

- i. Ethics committees.
- ii. Ethicists.
- iii. Ethics consultation groups.
- iv. Clinicians with ethics training.
- v. Combined research and clinical ethics committees.
- vi. Frameworks for consideration of ethical issues in practice.

To date there has been no rigorous evaluation of the effectiveness of such services in North America, Europe or Australia, and there are no nationally recognised standards for clinical ethics support. (9.4)

Conclusions

1.16 The findings of this project have shown that there is a perceived need for ethics support on issues relating to clinical care among a wide range of health professionals in the UK. Initiatives to provide clinical ethics support have developed in some NHS trusts, mainly in the last three to five years, and other trusts are planning such initiatives. It seems likely that clinical ethics support services will increase dramatically in the UK over the next ten years following the pattern seen in North America. Developments in Europe and Australia show similar trends.

1.17 In the UK a number of different models of providing clinical ethics support have developed within trusts, using both new and existing structures. It is not clear which model, or models, will be most appropriate for UK health care. The structure of support may vary depending on the particular circumstances of the individual trust but these services will share some common aims and needs. They must also demonstrate that they provide an effective service that is beneficial to both health professionals and to patient care. In order to facilitate the achievement of the highest possible ethical standards in patient care within the UK we recommend that the potential of clinical ethics support services be investigated further.

Recommendations

1.18 Individual clinical ethics support services in the UK have developed in isolation. A common feature of the clinical ethics committees is that they are unaware of other committees. There is a need to share information and experience among clinical ethics committees and other support services. The development of a national network of clinical ethics support services to provide information, education and support to developing initiatives, and to facilitate the sharing of experience between initiatives, would address this need. A national network has been established as part of this project, but further development and support will be required.

We recommend the further development of a national network of clinical ethics support services to share information, and provide education for clinical ethics support services in the UK.

1.19 In order to properly assess whether a particular model of clinical ethics support is effective in achieving its aims, adequate support must be given to the development of that model. This should include.

- Expertise to support and develop the service.
- Appropriate training for those involved.
- Administrative support.
- A recognised status for the service supported by the trust management.
- Protected time for those providing the service.

Prior to the recommendation of particular models of clinical ethics support as providing best practice, they must be rigorously evaluated in terms of process and outcome. Internal (local) evaluation is necessary to measure the effectiveness of the service against local aims and objectives. In addition, an independent external (national) evaluation is necessary in order to

provide a generalisable assessment that can be used to inform national guidelines and recommendations. This method of local and national evaluation has been used previously in the context of local initiatives that will have national implications. Therefore, an appropriate strategy would be to use external funding to support specific initiatives in order to develop models of best practice which could then be evaluated. A period of at least three years would be necessary to enable the service to develop to a stage where meaningful evaluation was possible.

We recommend that specific initiatives be established, that are designed to develop models of best practice appropriate to the roles of different trusts, including the new primary care trusts. A formal evaluation of these specific initiatives should be carried out, including a local evaluation by the trust or health authority in which the initiative takes place, and an independent national evaluation.

1.20 Local research ethics committees perform a specific function that is fundamentally different from that of a clinical ethics committee. Their training and expertise is confined to research ethics and they are decision making, rather than advisory, bodies. Their current workload would not allow them to provide a responsive clinical ethics support service.

We recommend that local research ethics committees do not take on the role of a clinical ethics support service in the UK.

Summary of recommendations

- 1. The further development of a national network of clinical ethics support services to share information, and provide education for clinical ethics support services in the UK.**
- 2. Specific initiatives that are designed to develop models of best practice appropriate to the roles of different trusts, including the new primary care trusts, should be established. A formal evaluation of these specific initiatives should be carried out, including a local internal evaluation by the trust or health authority in which the initiative takes place, and an independent national external evaluation.**
- 3. Local research ethics committees do not take on the role of a clinical ethics support service in the UK.**

SECTION I INTRODUCTION

CHAPTER 1

Background

In recent years there has been increasing debate in the UK about ethical issues that arise in various aspects of health care. Many factors have contributed to this debate among both health professionals and the wider community. The development of innovative but expensive treatments, an ageing population, and an increase in the prevalence of chronic diseases has led to difficult choices in allocation of limited resources. The mapping of the human genome and advances in assisted conception techniques offer new hope for treatment of genetic disorders but also raise ethical issues. Improved techniques to prolong life benefit many but lead to questions about the appropriateness of such treatment in certain circumstances. There is greater public awareness of ethical issues through media reporting and a greater demand for public accountability of health care professionals in this area. The recent enquiries into paediatric cardiac surgery at Bristol, and the removal of the organs of dead children at post mortem without parental consent at Alder Hey, have focused as much on the ethical integrity of clinicians and health care institutions, and on the process of making ethical decisions as they have on clinical competence. A questioning of clinicians' decisions in difficult ethical situations has led to an increased judicial involvement in medical decision making.

Within this framework of raised ethical awareness and demand for public accountability, how can individual health professionals and health care institutions ensure high ethical standards in all aspects of patient care? Some support for health professionals on ethical issues in clinical care already exists in the UK in the form of guidelines from national bodies and professional organisations.^{1 2} However, local services may be needed to provide support that is responsive and relevant to local circumstances. There is some evidence to suggest that such support services would be welcomed by clinicians.^{3 4}

One model of local clinical ethics support that has developed widely in North America over the past three decades is the clinical ethics committee (CEC). These committees, also called hospital or institutional ethics committees or health care ethics committees (HECs), are based in local hospitals or health care institutions and their objective is to provide advice and support on ethical issues relating to patient care.^{5 6} CECs have been a feature of health care in North America since 1971,⁷ and their number increased dramatically in the 1980s.⁸ In the United States (US) the impetus for the development of these committees has mainly been from government and the courts.^{9 10 11} In 1983 the President's Commission for the study of ethical problems in Medicine and Biomedical and Behavioural Research, in their report on deciding to forgo life sustaining treatment, recommended the setting up of ethics committees as a way of resolving ethical conflict.⁹ However, some committees were established because of concern by clinicians and hospital managers that there was a need for some form of clinical ethics support.¹² In the 1990s accreditation of health care institutions required that they had some means of addressing ethical issues. The Joint Commission on Accreditation of Healthcare

Organisations requires that in order to comply with accreditation standards a hospital addresses the ethical issues in providing patient care. The official handbook states that having a functioning, multidisciplinary ethics committee is recommended to meet this standard.¹³ Similarly in Canada, the Canadian Council on Health Facilities Accreditation stipulated in their guidelines in 1986 that:

'The facility shall address the need for policies on the following biomedical ethical subjects: informed consent; patient choice of treatment; refusal of treatment; accessibility of treatment; withholding of treatment; restraints; abortion and other issues related to biomedical ethics'.¹⁴

The guidelines stated further that this process may be facilitated by the creation of a multidisciplinary ethics committee. In some States in the US, ethics committees are legally mandatory.^{15 16} Prior to the project reported here, there was some evidence that CECs were also developing in Europe and Australia although they are less widespread than in North America.^{17 18}

Although there is much variation in the precise structure and function of CECs, both between and within individual countries, they share a broad consensus on their overall objectives and core functions. The functions of CECs can be grouped into three main areas:

- i. Provision of ethical input into guideline and policy formation in the institution.
- ii. Education on ethical issues of staff (and in some instances patients) within the institution.
- iii. Individual case consultation or review.

In practice many committees spend most of their time on guideline formation and do very little case consultation.^{19 17} Education is generally seen as an important role for the committee but this function is often ignored because of lack of resources, both financial and human.^{20 21}

In North America, ethics consultation services provided by individual ethics consultants or teams have also developed, sometimes in association with a CEC and sometimes separately.^{22 23} In some parts of the US there has been a tendency in recent years to move away from individual ethicists providing consultation to a system of small groups providing the service, often facilitated by an ethicist or ethics centre. This avoids the potential problem of bringing only one moral viewpoint to the case, but maintains the advantage of responsiveness to evolving situations. There are no nationally recognised qualifications or job descriptions for the role of ethicist or ethics consultant, and until recently there has been no attempt to specify the skills required for ethics consultation. In 1998 The American Society for Bioethics and Humanities published a document setting out recommendations for core competencies necessary for ethics consultation.²⁴ This made it clear that a knowledge of ethical theory was not sufficient to provide a support service to clinicians for difficult ethical problems in patient care. A recent study carried out at the National Institutes of Health in Maryland USA has looked at trigger factors for clinicians requesting ethics consultation. The results suggest that conflicts and other emotionally charged concerns are more common triggers for requests than cognitively based concerns.²⁵ The authors of this research conclude that conflict resolution may be an important skill for ethics consultants or consultation teams.

Since the early 1980s there has been much discussion in the North American literature about clinical ethics committees, their legal standing, their relationship to clinicians and to ethicists, their effectiveness and the ethical probity of their decision making.^{26 27 28 29} However, there has been little written about their effectiveness. The methodology for the assessment of clinical

ethics support services is poorly developed. A few studies have tackled this issue, primarily focusing on process rather than outcome measures.^{30 31 32} In 1996 Philips wrote that there were few published studies on the process and outcome of ethics consultations, and a lack of consensus on their role in clinical medicine.³³ The lack of evaluation of these services is also a problem in Europe and Australia.

In the UK, both local research ethics committees (LRECs) and multi-centre research ethics committees (MRECs) are well established and regulated by the Department of Health. In contrast, there is no central guidance with respect to CECs and, prior to this report, no clear idea as to how far they had developed within the UK. There had been published reports on six different CECs,^{34 35 36 37} and anecdotal evidence suggested that there were other CECs developing within the UK as well as other methods of clinical ethics support. This report describes a detailed assessment of the current position of clinical ethics support services in the UK, informed by experience from other countries.

CHAPTER 2

Approach to the project

This report describes a series of related studies undertaken by the Ethox Centre (Oxford Centre for Ethics and Communication in Health Care Practice) between February 1999 and July 2000, with support from the Department of Educational Studies, both at the University of Oxford. The project was funded by the Nuffield Trust.

2.1 Aims of the studies

The central aim of the studies was to assess the current provision of ethics support on issues relating to clinical practice for health professionals in the UK and to place this in an international context. The purposes of such an assessment include informing policy makers in their consideration of how ethics support can best be provided in clinical practice, and providing a resource for future evaluation and research in this area.

The studies had four specific objectives:

1. To identify and assess any ethics support services relating to clinical practice currently provided for health professionals working in the UK.
2. To investigate the perceived need for such a service among senior managers and clinicians within the health service.
3. To investigate the position of ethics support for health professionals in other European countries, North America and Australia, in order to place the UK experience in an international context.
4. To make recommendations on how clinical ethics support could be effectively developed in the UK.

2.2 Overview of method

The studies used a combination of methods in order to obtain both a comprehensive overview and a detailed description of some aspects of clinical ethics support. We carried out seven related studies overall and these will be the subject of chapters 3 to 8. In addition, information about clinical ethics support services in other countries was obtained by a combination of literature review, personal communication and observational visits.

Methods used

- i. Questionnaires were sent to senior managers and clinical personnel in all NHS trusts and health authorities/health boards in the UK.
- ii. Questionnaires were sent to the chairmen of all local research ethics committees (LRECs) in the UK.

- iii. Questionnaires were sent to the senior officer of professional organisations in the area of health care.
- iv. Written requests for information were sent to senior members of university departments of medical ethics.
- v. Interviews were carried out with the chairmen of all clinical ethics committees identified in the NHS trust survey.
- vi. Interviews were carried out with a sample of LREC chairmen identified in the LREC survey.
- vii. Written requests for information about resource allocation/priority setting committees was requested from those health authorities identified as having such a committee in the questionnaire survey.

SECTION II STUDIES

CHAPTER 3

Clinical ethics support in NHS trusts

3.1 Summary

Clinical ethics support services are developing in NHS trusts within the UK. Eighty-four trusts (18%) reported some form of formal support for health professionals on ethical issues relating to clinical practice. These vary from specific services dedicated to the provision of clinical ethics support, to the incorporation of ethics into existing trust structures such as a clinical governance committees or professional advisory committees. Twenty trusts (4%) have established a clinical ethics committee and a further twenty trusts are in the process of establishing such a committee. Most of the established committees have developed within the last five years. All committees are multidisciplinary, and 70% have a senior doctor as the chairman. Fewer than half of the committees have any funding or administrative support. Most committees have concentrated on providing ethical input into policy and guideline formation, but eight committees have engaged in case consultation on ethical issues arising from individual cases. All committee chairmen recognised the potential role of the committee in educating the health professionals in the trust but few committees had developed their educational role in any significant way. The need for training of ethics committee members, and a support network for existing and developing committees were seen as priorities for the effective development of clinical ethics committees by committee chairmen. There was a perceived need for the provision of a clinical ethics support service by senior clinicians and managers in NHS trusts, with the majority favouring a clinical ethics committee. The importance of raising ethical awareness across the trust was emphasised by those completing the questionnaire. The responses also included suggestions on how a support service, or ethics committee, could be developed, together with concerns about the potential problems of such a service.

3.2 Introduction

In order to establish the current level of provision of clinical ethics support for health professionals in NHS trusts, a questionnaire was devised and administered to senior managers and clinicians in all trusts. The questionnaire also sought the views of health professionals on the need for an ethics support service and the form that this should take. This chapter describes the questionnaire survey and provides an analysis of the results.

3.3 Method

A questionnaire was designed and piloted in ten NHS trusts. The questionnaire was then administered to key post holders in all NHS trusts within the UK. This included acute trusts, community trusts (primary care trusts in Scotland), mental health trusts, health and social

services trusts in Northern Ireland, and ambulance trusts. Primary care trusts and primary care groups (England and Wales) were not in existence when the study was designed and so were not included. The key postholders were defined as the medical director, the director of nursing, the chief executive and the chairman of the trust. By targeting these individuals, we obtained the views of both managers and clinicians.

Initially all NHS trusts, and the postholders for each target group, were identified using the Medical Directory. The names of those selected as study subjects were recorded. Ambulance trusts do not have directors of nursing or in some cases do not have medical directors. If an ambulance trust had no medical director then a questionnaire was sent to the director of operations in addition to the chief executive and the chairman. For some trusts, one or more posts were vacant at the time of the questionnaire survey.

All subjects were sent a brief questionnaire accompanied by a letter explaining the nature of the study, the fact that the study focus was on clinical ethics and excluded information about research ethics, and that our aim was to obtain the views of more than one person in the trust rather than seeking an institutional response. If there was no response to the initial letter then up to two postal reminders were sent. For trusts where no postholders replied a further telephone request was made to the medical director. Between the initial questionnaire mailing and the first reminder there was a change in NHS trusts with some trusts merging and new trusts forming. Therefore, following the first reminder a confirmatory check was made to ensure the database included all current trusts using the NHSE website (England), the Welsh Office, Management Executive of the NHS in Scotland website and the Northern Ireland NHS website. trusts that no longer existed were removed from the database, new trusts were added and questionnaires were sent to the appropriate personnel.

The questionnaire contained four questions covering the following:

1. The existence of any formal support service for health professionals within the trust relating to ethical issues relevant to clinical care.
2. The existence of any informal mechanisms for providing such support.
3. The views of those respondents, whose trust had no formal service, on the desirability of such a service.
4. The views of the respondents on what form such a service should take.

Space was provided for general comments.

For those trusts where one or more individuals reported the presence of a clinical ethics committee or ethicist, this was verified by further personal telephone and/or written communication with the responder.

3.4 Results

A total of 1784 questionnaires were sent to postholders in 456 NHS trusts active from the 1st of April 1999 (see figure 1 for a breakdown of trusts). A reply was received from one or more postholder in all but one NHS trust (99.8% of trusts), and from 1,273 (71%) individual postholders (figure 2).

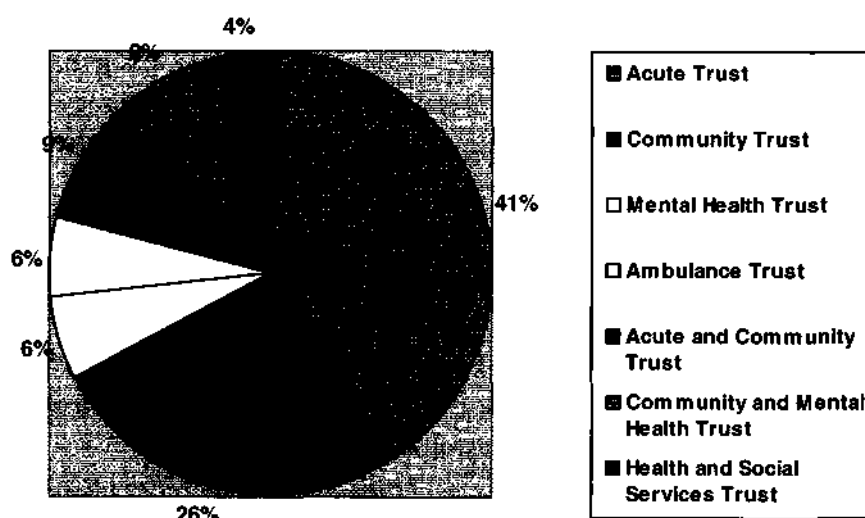


Figure 1 Types of NHS Trust active at April 1st 2000

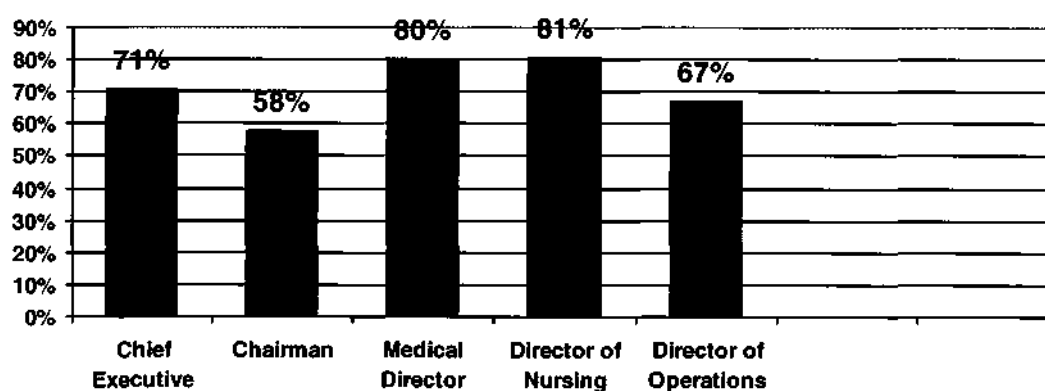


Figure 2 Response rate for different postholders

3.4.1 The provision of formal clinical ethics support services within NHS Trusts

Of the 456 NHS trusts active on April 1st 2000, 84 (18%) identified some formal method of addressing ethical issues arising from clinical practice within the trust. These methods varied from specific services dedicated to the provision of clinical ethics support, to the incorporation of ethics into existing trust structures such as a clinical governance committees or professional advisory committees (figure 3).

Twenty trusts (4.4%) had an established clinical ethics committee and in a further twenty trusts there was an intention to establish a clinical ethics committee in the next 12 months.

A more detailed breakdown of the formal support services described is given in appendix 1.

Ten trusts reported access to an ethicist. Follow up telephone enquiry showed that there were different roles for the ethicist (table 1).

Only one of the ethicists with a remit to give individual advice to health professionals within the trust was funded by the trust. The other two were members of a university department with allocated time, funded by the university, for ethics consultation in the trust.

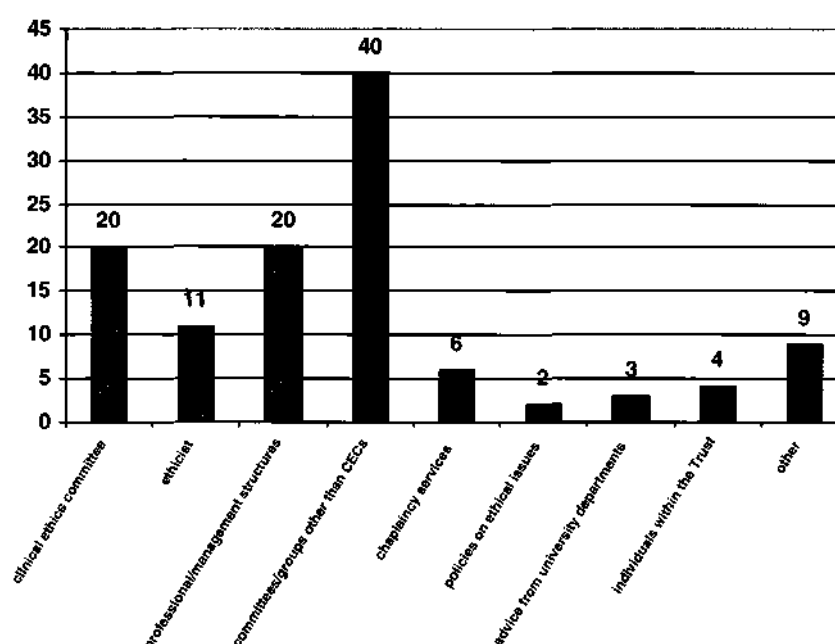


Figure 3 Types of formal clinical ethics support service in NHS Trusts

Table 1 Reported descriptions of access to an ethicist (N= 10)

| Type of access | Number of Trusts reporting such access |
|---|--|
| Medical ethicist member of ethics committee | 4 |
| Medical ethicist on ethics committee with remit to give individual advice to clinicians | 3 |
| Philosopher on ethics committee | 1 |
| Member of staff with MA in medical ethics | 2 |

3.4.2 The provision of informal clinical ethics support within NHS Trusts

At least one responder from 390 trusts (86%) reported some form of informal support for ethical issues for health professionals within the trust. The responses indicated that a wide range of informal support mechanisms are currently used (table 2.) Some trusts reported more than one form of support.

Table 2 Examples of informal clinical ethics support within NHS Trusts N=456

| Type of support | Number of Trusts reporting such support |
|--|---|
| Clinical directors | 192 |
| Other clinical colleagues | 103 |
| Clinical governance structures | 10 |
| Chaplain | 67 |
| Advice from chairman of research ethics committee or clinical ethics committee | 59 |
| Access to University departments of ethics | 10 |
| Clinical supervision | 28 |

A more detailed breakdown of informal support mechanisms is given in appendix 2.

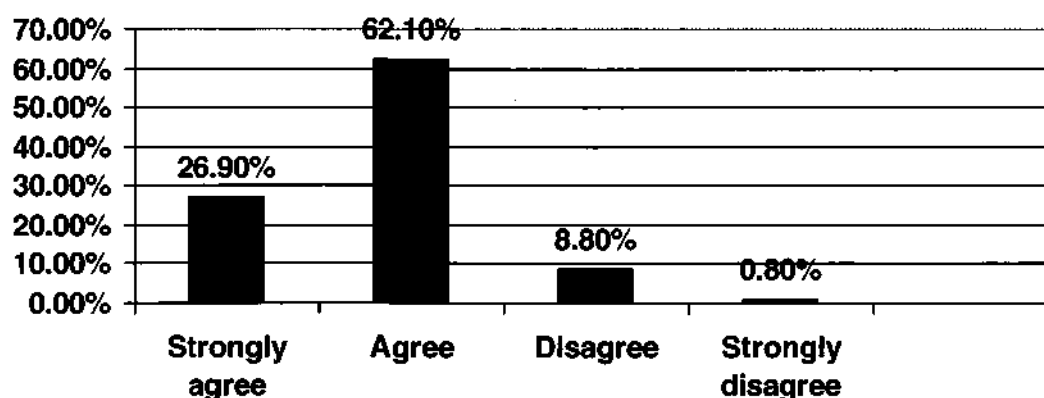


Figure 4 Perceived need for clinical ethics support

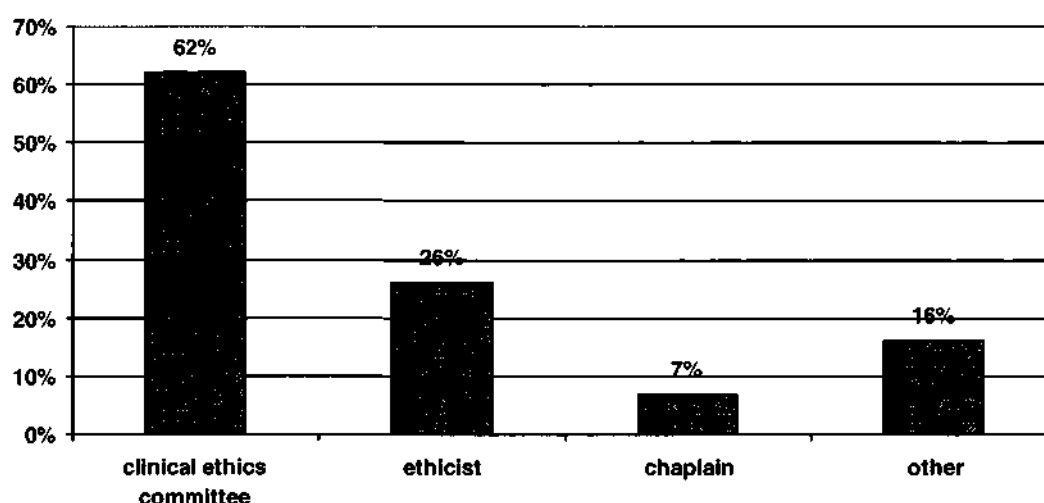


Figure 5 Suggested form of clinical ethics support service

3.4.3 Perceived need for clinical ethics support among respondents in NHS Trusts

Of the 1,273 trust questionnaire responders, 650 (51%) representing 365 (80%) of all trusts answered the question relating to a perceived need for a clinical ethics support service within their trust. The majority of respondents agreed a support service within the trust for health professionals on ethical issues in clinical medicine would be desirable (figure 4).

Those who responded were asked what form in their opinion an ethics support service should take. Their replies indicated that a clinical ethics committee was the favoured choice although other models were suggested. Some respondents favoured some combination of ethics committee, ethicist and chaplain (figure 5). A list of other suggested models is given in appendix 3.

3.4.4 Comments on clinical ethics support services in NHS Trusts

The questionnaire provided space for respondents to make free comments. Two hundred and eight respondents made use of this facility. The majority of comments indicated a recognition of the need for a mechanism to raise awareness of ethical issues within the trust, to provide a

forum for discussion of difficult clinical and ethical issues relating to patient care, and in some circumstances to provide more specific support and advice. The following examples illustrate some of these views.

"I feel very strongly that there are circumstances in practice, and our relationships with patients and their families, which could be handled better if we had access to individuals or processes which support ethically based decision making" Chief Executive

"Sadly lacking. We devote much time to research ethics committees but do not support clinicians with a 'service' ethics committee. Often the question becomes a legal one in my experience when in truth it is not." Medical Director

"Clinical ethics must become a part of clinical decision making and ethical principles must be shared and common to clinicians and managers i.e. both need to understand and share the same framework" Medical Director

Several respondents had had positive experiences of ethics support in the US and felt that there was a place for it in this country.

However, just under 20% of respondents who made comments expressed a clear opinion that any form of clinical ethics support was unnecessary within individual NHS trusts. They felt that ethical decisions were an intrinsic part of a clinician's work and support from senior colleagues was more appropriate than external mechanisms. There was a concern that by having a separate 'service', ethical decisions would be "removed from the local environment" and "delegated to a committee". Others felt that the multidisciplinary team framework was an effective forum for resolving ethical issues. Some respondents suggested that support should be regional or national if required and that current regulatory bodies or professional organisations were an adequate source of advice.

The following quotes illustrate their views:

"I am somewhat alarmed at the growth of quasi formal/regulatory committees and much prefer sensible informed decisions between colleagues." Medical Director

"We have no mechanism to advise on ethical issues. We don't need more committees. This can be dealt with by clinicians in the relevant clinical team, through NICE, Royal Colleges and other national guidelines and clinical governance structures." Chairman

Those respondents who supported the need for some form of ethics support had various views on how this could or should be achieved. A number of comments highlighted the importance of raising ethical awareness within the trust by education and a philosophy of openness. One respondent commented that there needs to be a cultural shift within the trust to

incorporate ethical issues as a fundamental principle of clinical governance. Clinical governance was seen as an important factor in this area by about 10% of those responders who made comments. Some felt that clinical governance made an ethics support service an essential activity and that such a service demonstrated a commitment to quality. Others felt that clinical governance would incorporate ethical issues and therefore there would be no need to develop a separate service.

Several respondents commented on the form an ethics support service should take. There was concern that an individual trust may not provide enough work for a committee or ethicist and that a regional service would be more appropriate. Small groups or named individuals within the trust were seen as preferable to a committee by some responders. Others suggested an extended role for clinical supervision as an appropriate mechanism. Possible difficulties and barriers to an ethics support service were highlighted. The most frequently mentioned were cost and the need for a service to be responsive to acute situations.

CHAPTER 4

Clinical ethics support in health authorities

4.1 Summary

Eighteen health authorities or health boards reported the provision of a committee or forum for addressing resource allocation or priority setting within the authority/board. A further forty-one health authorities/boards reported some other form of ethics support service for health professionals within the authority/board, including access to a university department of ethics and individual support from the director of public health. There was support for clinical ethics support services in health authorities/boards, in particular to provide support for emerging primary care groups and trusts.

4.2 Introduction

In order to explore the current provision of ethics support for health professionals within health authorities (health boards in Scotland) on issues around clinical practice, a postal questionnaire was administered to managers and senior clinicians in all UK health authorities/boards. This questionnaire asked responders whether there was any formal clinical ethics support within their health authority or health board. The questionnaire also asked for respondent's views on the need for an ethics support service within the health authority/board, and if the future development of primary care groups would influence such a need.

4.3 Method

A questionnaire was designed and piloted in five health authorities. The final questionnaire was administered to key postholders in all health authorities and health boards in the UK. The key postholders were defined as the chief executive, chairman, director of public health and, if applicable, director of primary care services. As in the trust questionnaires, the aim was to obtain the views of both clinical and non clinical senior managers.

Initially all health authorities/boards, and the postholders for each target group, were identified using the Medical Directory. The names of those selected as study subjects were recorded. For some authorities/boards one or more posts were vacant at the time of the questionnaire survey. All subjects were sent a brief questionnaire accompanied by a letter explaining the nature of the study, the fact that the study focus was on clinical ethics and excluded information about research ethics, and that we wished to obtain the views of more than one person in the health authority/board rather than obtain an institution response. Two postal reminders were sent. For those health authorities/boards where no postholders replied a further telephone request was made to the director of public health.

The questionnaire contained four questions that covered the following areas:

1. Whether the health authority/board had any formal mechanisms for providing ethics support on issues relating to clinical practice.

2. Whether the health authority/board received requests for clinical ethics support from health professionals.
3. Whether the respondents believed that there was a need for clinical ethics support within the health authority/board.
4. Whether the respondents thought that the health authority/board should have a role in providing clinical ethics support for primary care groups.

Space was provided for comments on any of these issues.

4.4 Results

Questionnaires were sent to 302 individuals in all 124 health authorities/boards in the UK. Responses were obtained from 238 individuals (79%) with at least one response from all but one health authority/board (99.2%).

4.4.1 Provision of formal ethics support services

Of the 238 individual respondents, 110 (46%), representing 59 (48%) health authorities/boards stated that there was a formal support service for ethical issues relating to clinical practice within the authority/board. A resource allocation committee or priorities forum was the most common with 18 health authorities/boards reporting such a model (figure 6).

One or more respondent from 80 health authorities/boards (64%) reported that the authority received requests for advice on ethical issues relating to clinical practice.

4.4.2 Views of respondents on the desirability of a clinical ethics support service

One or more respondent from 90 health authorities/boards (72%) thought a clinical ethics support service would be helpful in their health authority/board. There was no difference between managers and clinicians on this point (table 3).

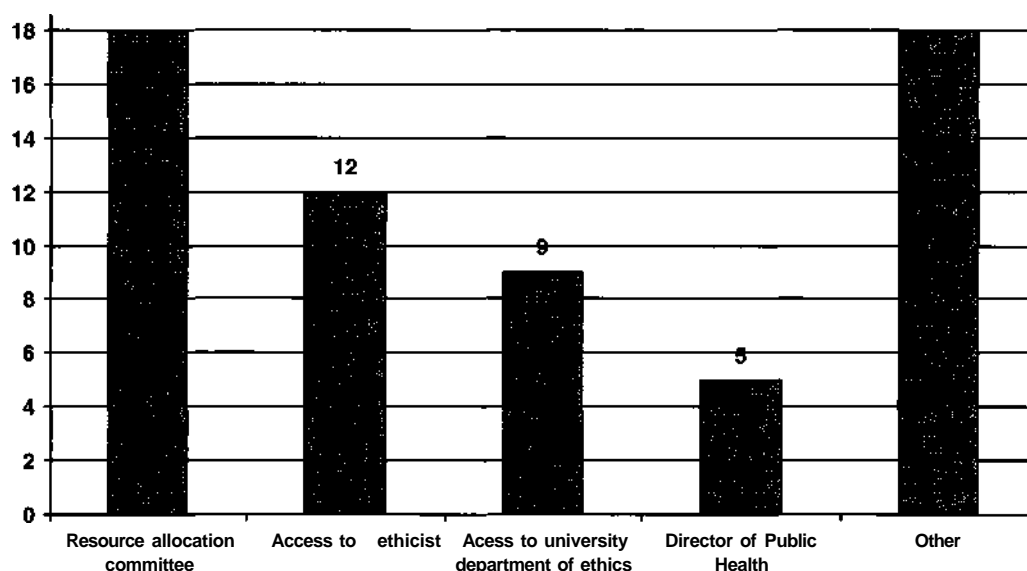


Figure 6 Number of health authorities/boards with a formal model of ethics support

Table 3 Respondents who thought that a clinical ethics support service would be helpful in the health authority/board

| Postholder | Chief Executive | Director of Public Health | Director of Primary Care |
|-------------------|-----------------|---------------------------|--------------------------|
| Response rate (%) | 47% | 55% | 53% |

4.4.3 Provision of clinical ethics support to primary care groups

Of the 238 individual respondents, 200 (84%) representing 120 (97%) of all health authorities/boards, thought that the health authority had a role to play in providing support or advice to primary care groups on ethical issues relating to clinical practice and/or resource allocation.

4.4.4 Comments on clinical ethics support in health authorities/boards

The questionnaire provided an opportunity for comments, and 56 individual responders made use of this opportunity. The majority of those who commented identified ethical issues relating to clinical practice as important and were in favour of some form of support service.

"Essential part of Health Authority infrastructure which will increase in relevance through the drive on equality and commission for health improvement"

Chief Executive

The main focus of ethics support was thought to be in the area of priority setting by several of the respondents and some health authorities were currently considering a framework for this. There was concern that a single health authority would not need a full time service and that a regional service/committee may be better. One respondent suggested a service should include services other than health services.

"...7 do think it would be useful to have this for the local health economy i.e. shared with local trusts, GPs, the voluntary sector, social services etc."

Director of Public Health

Just over 20% of respondents thought that there was no need for an ethics support service on clinical issues within health authorities and some suggested that the local research ethics committee was adequate for dealing with the small number of problems that arose. Others suggested that this was an issue for service providers such as trusts and general practitioners, and not a matter for the health authority.

"The ethics of individual clinical situations are not our business."

Chief Executive

"Almost all clinical work takes place in NHS trusts or in General Practice and professionals would look to their own organisations or the BMA/Royal Colleges for clinical advice."

Chief Executive

CHAPTER 5

The role of local research ethics committees in clinical ethics support

5.1 Summary

Some health professionals see local research ethics committees (LRECs) as a source of advice on ethical issues arising in clinical practice. Provision of advice on clinical ethical issues is not within the current terms of reference of research ethics committees in the UK. This study found that just under 50% of all LRECs have been asked for advice on clinical ethical issues and 25% of LRECs have given advice. The frequency with which advice is requested is low in most LRECs although three LRECs receive more than ten requests per year. Many of the requests are about innovative treatments and the use of drugs for unlicensed indications. There is a concern among some chairmen of LRECs that the LREC may not be appropriately constituted or trained to deal with clinical ethical issues. However, 77% of LREC chairmen thought that there was a need for support on clinical ethical issues for health professionals in the institutions that referred research proposals to them.

5.2 Introduction

In order to explore other sources of clinical ethics support for health professionals outside their employing institutions, we investigated the possibility that local research ethics committees (LRECs) were being used for advice on clinical as well as research ethics issues. This activity is not within the terms of reference of research ethics committees in the UK. In our questionnaire survey of NHS trusts, initial data showed that at least one respondent from each of 300 trusts thought that the trust had access to an ethics committee for advice on clinical ethics issues. On further investigation in all except twenty trusts the respondents were referring to a LREC. The most likely explanation for this finding is that respondents had mis-read the questionnaire and had not confined their answers to clinical rather than research ethics. However, some responders may have either assumed that LRECs dealt with clinical ethics issues, or had direct experience of using an LREC for such advice. To investigate this further, we carried out a questionnaire survey of the chairmen of all local research ethics committees in the UK, followed by telephone interviews with a purposive sample of chairmen of those committees who reported giving ethics advice on clinical issues.

5.3 Method

5.3.1 Questionnaire

A questionnaire was designed and piloted with the chairmen of ten LRECs. The final questionnaire was sent to the chairmen of all LRECs in the UK. LRECs were identified using the LREC database held at King's College, London. The initial questionnaire was sent with an

accompanying letter explaining the nature of the study and specifying that the questionnaire related to requests for advice on ethical issues in clinical practice and not relating to research ethics. Two postal reminders were sent.

The questionnaire covered the following areas:

1. Did the committee receive requests for advice on ethical issues relating to clinical practice, and if so did the committee give advice on these issues?
2. Would the committee be prepared to give advice on ethical issues relating to clinical practice?
3. Did the chairman of the committee receive requests for advice on clinical ethics issues because of his/her position as chairman?
4. The views of each chairman on the desirability of a clinical ethics support service for health professionals.

5.3.2 Interviews

A sample of LREC chairmen was identified. The sample was chosen purposively from those chairmen who had indicated in their questionnaire response that their committee gave advice on ethical issues relating to clinical practice. The sample was chosen to include those committees that rarely gave advice (less than 5 times a year) and those that gave advice more frequently (more than five times a year); and those committees that were health authority based and those that were based in an individual NHS trust. Twenty committees were identified and a letter was sent to the chairman explaining the nature of the study and the fact that the interview would be recorded and transcribed. A consent form was included for the chairman to complete and return if he or she wished to take part in the study. The topic guide for the interviews covered the following areas.

1. The number of requests for advice on clinical issues.
2. How such requests present to the committee.
3. Any formal procedures for dealing with such requests?
4. What issues are covered by the requests?
5. The views of the chairmen on the current arrangements for dealing with clinical ethics issues.
6. The views of the chairmen on clinical ethics committees.

The interviews were recorded and transcribed. The transcripts of the interviews were analysed for factual information such as the types of issues covered and the number of requests, and also to identify themes around the relationship of LRECs and clinical ethics support. The opinion of the Oxford & Anglia multi-centre research ethics committee was sought on the ethics of the interview study.

5.4 Results

5.4.1 Questionnaire results

Questionnaires were sent to the chairmen of 231 LRECs. Responses were obtained from 208 chairmen (90%).

5.4.1.1 *Requests to LRECs for advice on ethical issues related to clinical practice*

The responses indicated that LRECs are being approached for advice on ethical issues relating to clinical practice and that some LRECs are giving advice, or would be prepared to give advice on these issues (table 4).

Thus 90 respondents (43%), representing 38% of all LRECs, either have given, or would be prepared to give, advice on ethical issues relating to clinical practice.

The frequency of requests for ethics advice on clinically related issues varied between committees (table 5); 136 respondents (65%) had been asked for advice personally in their role as chairman of the LREC.

5.4.1.2 *Views of LREC chairmen on the need for clinical ethics support services*

Of the 208 LREC chairmen who responded to the questionnaire, 177 (85%) thought that there was a need for ethics support on clinical issues within the NHS organisations that referred research proposals to the LREC.

Table 4 LREC responses to requests for advice on ethical issues relating to clinical practice (N=208)

| | Number of committees | |
|--|----------------------|-------|
| Committee has received requests for clinical ethics advice | 88 | (42%) |
| Committee has given clinical ethics advice in response to a request | 52 | (25%) |
| Committee has not been asked but would be prepared to give clinical ethics advice if asked | 38 | (18%) |

Table 5 Frequency of requests for advice on ethical issues relating to clinical practice to LREC

| Frequency of request | Number of committees receiving requests for advice (n=88) | Number of committees providing advice (n=52) |
|------------------------|---|--|
| Less than one per year | 24 | 17 |
| 1 to 5 per year | 53 | 32 |
| 5 to 10 per year | 7 | 3 |
| More than 10 per year | 3 | 0 |
| Don't know | 1 | 0 |

5.4.2 **Interview results**

One chairman had retired, one did not wish to take part in the study and one sent a copy of the LREC's annual report for our information. Eight chairmen (40%) agreed to take part in the interview study. Problems were experienced in arranging interviews with those chairmen who had given consent to take part. This was mainly because our point of contact was the LREC administrator who did not always have easy access to the chairman. Interviews were recorded with seven of the eight LREC chairmen who gave consent to be interviewed. An eighth interview was terminated very soon after commencing as the interviewee was called away. Further attempts to arrange an interview were unsuccessful. Chairmen of four health authority based

LRECs and three trust based LRECs were interviewed. The range of frequency of requests on ethical issues relating to clinical practice ranged from two per year to twenty-four per year.

5.4.2.1 Process of dealing with requests

Requests for advice on ethical issues relating to non-research matters came to the committee either as a direct request to the committee through the administrator or more informally through the chair of the committee. None of the committees represented in the interviews had any formal mechanism for dealing with such requests. The committee chairman, or in some cases the committee administrator, decided if the request should be discussed by the committee. Several of the requests were dealt with by the chairman personally. The administrator of the committee that received between twenty and thirty requests per year would sometimes give advice on issues where there was a clear precedent. In addition to 'formal' requests for advice, the medical chairmen were also approached for informal advice and reassurance on an *ad hoc* basis.

Replies to the requests could be either verbal or written. If the committee had considered the issue the reply was given in writing. If the chairman had dealt with the request without referral to the committee the reply could be verbal or written depending on the circumstances. There was no clear procedure for documenting requests and responses on these issues. One of the trust based committees had made it clear in their Standing Orders that the committee would be prepared to answer queries of a general ethical nature. However, the other committees do not advertise their willingness to deal with such requests.

5.4.2.2 Types of request

Many of the requests were on the borderline between research and audit. Other general areas covered by the requests include:

- Innovative treatment.
- Unlicensed use of a drug.
- The use of patient videos for training purposes in children with severe abnormalities.
- The need for counselling prior to hepatitis screening.

5.4.2.3 The suitability of LRECs to give advice on non-research issues

The chairmen were asked if they thought that the current arrangements for dealing with queries on ethical issues relating to clinical practice were satisfactory or could be improved. The general belief was that the current arrangements for their particular committee worked well. However, there were reservations about an extension of this role. Concerns raised included increasing workload and the fact that the committee was not appropriately constituted to consider issues relating to clinical practice.

"We are set up to do reviews of research proposals and not set up to go and do normal clinical stuff. I think I would want to go and review what the constitution of the committee was and the structure of the committee to make best use of it"

5.4.2.4 Views of LREC chairmen on clinical ethics committees

The concept of a clinical ethics committee was discussed and the chairmen were asked their opinion on such a model. The general view was that a clinical ethics committee was not a good idea, although ethics support and advice in the area of clinical practice was important. There was concern about developing yet another committee in each trust, although one chairman raised the idea of a district wide clinical ethics committee.

"... there is obviously an advantage in having a district wide committee where these sorts of issues could be dealt with, ... perhaps a clinical ethics committee could make decisions if you like on principles, although the implementation would be in an individual trust situation!"

Another concern was that a committee was too cumbersome to deal with ethical issues relating to clinical practice and that it would not be responsive to the urgency of some clinical situations.

"I'm slightly concerned about the idea that it's going to be a committee that you have to go and sort of put a submission to the committee. The world is too fast, too fluid for that to be really practical"

5.4.2.5 Other possible models for clinical ethics support

Other models of providing ethics support on clinical issues were suggested by the LREC chairmen.

One committee clearly had developed a combined role within the structure of the LREC and was actively involved in providing clinical ethics advice and also in commenting on the ethical aspects of hospital policies (3). The committee had advertised its clinical ethics services within the trust but had not developed any formal processes for provision of clinical ethics support or evaluation.

One suggestion was for a district or county-wide service providing access to an individual or group of people with training and expertise in ethics. Contact could be by telephone or email, but would need to be responsive to the unpredictable nature of clinical medicine.

A third suggestion was that the clinical governance committee/board in a trust should be responsible for providing ethics input into trust policies but that the LREC could be used for advice by the clinical governance committee.

"Whereas what you could do is have an ethical policy, or as much as possible, that was drawn up by the clinical governance board that then bounced particular issues to the research ethics committee if it needed another group of people to ask a question!"

CHAPTER 6

The role of professional organisations in clinical ethics support

6.1 Summary

Professional organisations are a source of ethics support for health professionals. Models of support include guidelines, educational sessions and telephone advice. Several organisations have an ethics committee that develops guidelines on specific issues. Of the senior officers of professional organisations who responded to the questionnaire survey, 70% thought that the clinical ethics support provided for their members should be improved.

6.2 Introduction

In order to investigate the advice and support on clinical issues available to health professionals from their own national organisations, a questionnaire survey was carried out among senior personnel in these organisations.

6.3 Method

A questionnaire was designed and piloted in four professional organisations. The final questionnaire was administered to the president or chairman of all the Royal Colleges and all the regional faculties of the Royal College of General Practitioners. National professional organisations representing medical, nursing and other clinical professionals were identified from the Medical Directory and a questionnaire was sent to the senior officer of the organisation. A list of the organisations identified is given in appendix 4.

The questionnaire covered the following areas:

1. The existence and nature of any support service for the organisation's members on ethical issues relating to clinical practice.
2. The views of the responder on whether ethics support services for members should be improved within the organisation.

6.4 Results

A total of forty-six questionnaires was sent (twenty one to national organisations). The response rate was 87% (40/46) for all those contacted, 95% (20/21) for the national organisations.

6.4.1 Presence of a formal mechanism for ethics support within the organisation

Of the respondents, 57% (23/40) stated that the organisation had some form of clinical ethics support for members (table 6).

Table 6 Types of formal support on ethical issues in clinical practice provided by professional organisations (N=40)

| Type of support | Number of organisations with such support |
|--------------------|---|
| Ethics committee | 15 |
| Written guidelines | 14 |
| Telephone advice | 11 |
| Education | 7 |
| Other | 7 |

6.4.2 Views of respondents on clinical ethics support provision within the organisation

The respondents were asked if support for their members on ethical issues relating to clinical practice should be improved within the organisation. Of the forty respondents, 28 (70%) agreed that the service should be improved, 10 (24%) disagreed and 2 (6%) did not know.

The questionnaire provided an opportunity for comments. Twenty respondents made further comments. The general view was that clinical ethics is becoming an increasingly important issue for health professionals. Most of those who commented thought that local support was needed although some suggested that current national bodies such as the GMC and BMA were sufficient. Medical defence organisations were also suggested as a source of support.

"Increasingly ethical dilemmas are being faced by health care professionals and often there does not appear to be any mechanism for addressing these issues within trusts etc."

"Increasingly important.....We should be aiming at a senior clinical person or team in every trust to whom clinicians can turn for advice and support. This will need promotion by professional bodies!"

CHAPTER 7

Role of university departments of medical ethics

7.1 Summary

Health professionals occasionally approach members of university departments of medical ethics for advice on clinical ethical issues. Three university departments provide specific support to a trust with a clinical ethics committee. Most departments are involved more with education than clinical ethics support.

7.2 Introduction

One possible source of clinical ethics support for health professionals, especially those working in trusts with close proximity to a university, is a department of medical ethics, or departments involved in undergraduate teaching of medical ethics. Some of the questionnaire survey respondents had mentioned having access to an ethicist or a department of ethics as a formal mechanism of ethic support. In order to investigate this we sought information from university departments of medical ethics.

7.3 Method

We identified individuals from the Association of Health Care and Medical Ethics Teachers (AHMET) database obtained from the Centre for Biomedical Ethics at the University of Birmingham; and the heads of other departments that we knew to exist but that were not part of the AHMET database. A letter was sent to these individuals explaining the nature of the study and requesting their help in obtaining information about the department's involvement with ethical issues involving patient care at their local NHS Trusts. The following information was requested:

1. Did they, or their colleagues, receive requests for ethics advice on issues relating to clinical practice by health professionals in their area?
2. If so, what broad areas did these issues cover?

7.4 Results

Of the eighteen individuals approached we received responses from fifteen (83%), eleven written responses, and four verbal responses. Ten of the fifteen respondents (67%) stated that they were approached by clinicians for advice on ethical issues relating to patient care. Five respondents (36%) received requests at least once a month and five respondents received requests infrequently, or were unable to specify how frequently they received requests. Four of the respondents who received requests at least once a month were involved with trust clinical ethics committees and the fifth responder was a member of an advisory committee on ethics to an assisted conception unit. Information on an association with a clinical ethics committee was not available for the other respondents.

7.4.1 Issues covered by requests for ethics advice

The requests from clinicians covered a variety of issues, including:

- Withdrawal of treatment.
- Patient refusal of life-saving treatment.
- Conflict between health clinicians and family over management decisions for children.
- Resource allocation issues.
- Confidentiality.
- Sibling donation of organs in children.
- Issues around neonatal intensive care.
- Inter-professional conflict.

CHAPTER 8

Interviews with chairmen of established clinical ethics committees

8.1 Summary

Twenty established clinical ethics committees (CECs) were identified in the questionnaire survey. A semi-structured interview was carried out with the chairman of all of these committees. This interview covered the history and functioning of each committee. Although the CECs had developed independently of each other they had many similarities in terms of process and structure. The CECs were multi-disciplinary but usually had a senior doctor as chairman. Most of the CECs had developed in the past five years and the impetus for development was usually from clinicians concerned about difficult ethical issues in their clinical practice. The functions of the CECs as stated in their terms of reference fell into three broad areas: ethical input into guidelines and policy, education of staff in the institution, and individual case review or consultation. Most committees concentrated on guideline and policy development but eight committees were actively engaged in individual case consultation. Education of trust staff was seen as an important function but difficult to realise. Only eight committees received any funding.

There was a broad consensus among the CEC chairmen on several issues. All agreed that the role of the CEC was advisory and not prescriptive. Education and training of CEC members was thought to be very important for the effective functioning of the committee. The status of the CEC within the trust, and the profile of the CEC among trust staff was seen as crucial if the committee was to have influence on clinical practice. Financial and administrative support was seen as crucial for further development of CECs. Evaluation of CECs was seen as necessary but difficult to carry out. The need for a support network to provide information and sharing of experiences between committees was identified by all chairmen.

8.2 Introduction

The questionnaire survey of NHS trusts identified twenty CECs. In order to explore in more detail the role and development of the clinical ethics committees identified in the questionnaire survey, interviews were conducted with the chairmen of all twenty committees.

8.3 Method

The names and contact details of all chairmen were obtained from the individual who had originally identified the committee in the questionnaire. The chairmen were approached by letter explaining the nature of the study and asking their agreement to take part in an interview about the clinical ethics committee that they chaired. The letter set out the general areas that the interview would cover, and specified that, if they agreed, the interview would be recorded. It was

made clear in the letter that no identifying material from the interview would be used without their consent.

A topic guide was developed covering the following areas:

1. The structure of the committee (membership, terms of reference, experience/expertise of members, training).
2. The functions of the committee (case consultation, policy development, education).
3. The development of the committee (reason for development, profile of the committee within the trust, achievements, problems).
4. The views of the chairmen on future development of the committee.

The interview was piloted with three chairmen of clinical ethics committees and some of the specific topics revised in the light of these interviews. Interviews were then conducted with the chairmen of all clinical ethics committees. The interviews varied in length from 30 and 60 minutes, and were recorded and then transcribed. Three of the interviews were not recorded for technical reasons but detailed contemporaneous notes were taken for these interviews.

The interview transcripts were analysed to obtain both factual data, e.g. membership, frequency of meetings, and to identify themes relating to the specific topic areas.

8.4 Results

The chairmen of all twenty identified CECs were interviewed. Most of the committees were in acute trusts but the two longest established committees were in a community based mental health and learning disabilities trust and a long stay mental health trust (figure 7).

Most of the committees were established because of concern by clinicians about difficult cases that they had encountered, or because clinicians had attended a course or presentation on ethics. Two committees developed from a research ethics base when it became clear that here was a need to consider ethical issues arising in the trust that did not relate to research. One committee was established on the initiative of the trust board and one on the initiative of the health authority Chief Medical Officer.

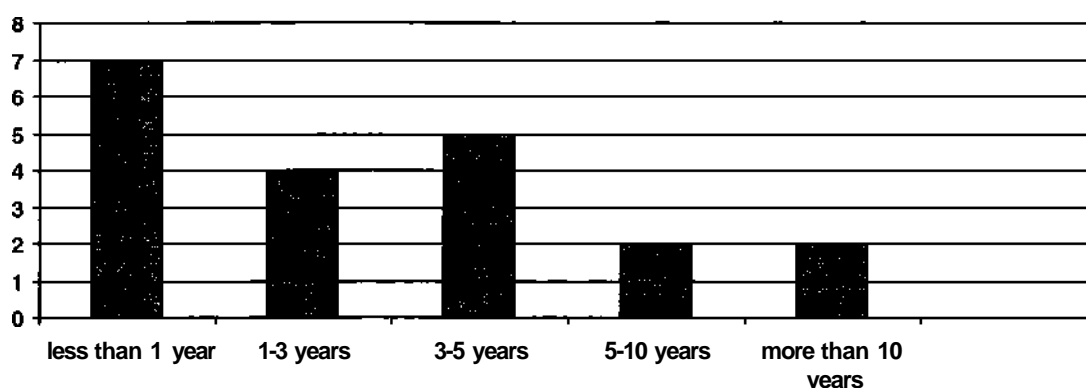


Figure 7 Length of time clinical ethics committees have been established

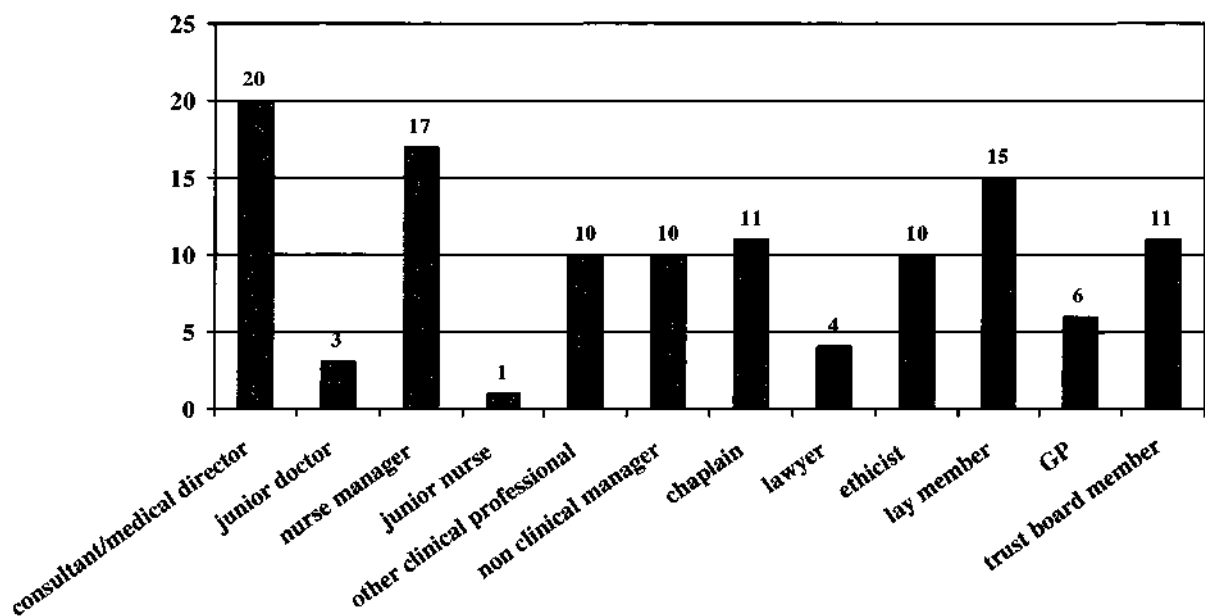


Figure 8 Membership of clinical ethics committees (number of committees with representation from the following groups)

8.4.1 Structure of committees

The committee structure and membership varied between committees. One committee was based mainly on the membership of the local research ethics committee with one or two extra members (2). All committees were multidisciplinary but the mix of disciplines and the presence of lay members differed between committees (figure 8).

The terms of reference of some committees allowed for other people to be co-opted on to the committee for discussion of specific issues.

The chairman of the committee was a senior doctor in fourteen of the committees, a nurse in three of the committees and a trust board member in a further three committees.

One theme arising from the interviews was the issue of the professional status of the chairman of the committee. It was generally thought that the chairman did not need to be a doctor and that the position could be held by another health professional or a lay person. However, there was a view that the chairman needed to be someone with authority and respect within the trust in order that the committee was perceived as important by employees of the trust. The support of the medical staff was seen as essential for the useful functioning of the committee and resistance from them as a potential barrier to the committee's effectiveness. There was therefore a widespread view that, for pragmatic reasons, the chairman should be a senior doctor at least during the early development of the committee.

"Not for the actual decisions that are made or whatever. I think it's when something like this is being set up, I think it's important that it's somebody that's got a fairly high profile within the hospital."

"If you are starting I think it matters a lot. Once you are running I don't think it matters a fig and I personally, if a nurse in the Trust had done an MA in ethics or

something and was running it, it wouldn't bother me. I think she would find it a much more uphill battle than I will."

However, two long standing committees in mental health trusts have nurses as their chairmen and have not experienced any problems. One acute trust has a nurse chair, and although she experienced some initial opposition this had been overcome fairly quickly.

"There was some opposition that I, as a nurse, was leading it. But it was viewed that it was very much to be multi-disciplinary and because of its nature that we didn't want someone that was a medic"

8.4.2 The role of an ethicist on a clinical ethics committee

The views of the chairmen on the need for an ethicist or philosopher on the committee were sought. A wide spectrum of views were expressed. Some thought that an ethicist, or someone with a qualification in ethics was essential to the effective functioning of a clinical ethics committee.

"I think that the idea of having a committee like this without appropriate expertise all round is absurd."

"I think that support from someone who can cut through all this and say, It's like this' and draw out what the issues are in that way is invaluable to the deliberations on that kind of committee!"

Others thought that it was more important to have clear thinking, articulate people with an interest in ethics and an ability to place the issues in a practical context. One chairman expressed concern about bringing in someone from outside the trust who would not have practical experience of the trust.

"Philosophers are interesting to listen to but don't suggest practical solutions!"

"I think many of the people with expertise in this area are theoreticians rather than practitioners."

8.4.3 Training for committee members

The need for all members of the ethics committee to have some training in ethics was also discussed. All chairmen thought that some training for committee members was desirable but pointed out barriers to achieving this aim. The two main barriers identified were funding and lack of suitable courses. Six committees had arranged training for their members which ranged from paying for some members to attend a specific course to having 'in house' training by the committee's ethicist. The training was usually organised when the committee was initially

established but no programme of updating members or training new members had been instituted by any of the committees.

The content of ethics training was discussed by some chairmen and two main approaches were identified; training in ethical theory and training in the process of ethical deliberation. Committees with ethicists were more likely to receive education around moral theories and principles, and specific issues such as consent or confidentiality. However some chairmen thought that education aimed at improving critical ethical thinking, and learning to work through issues as a group, was at least as important as a detailed knowledge of ethical theories.

"An initial introduction for members may be useful; a short two day course may be helpful in that at least people can reflect on the approach to medical ethical problems. But one should stress again that an effective committee may be one that actually develops its own expertise as it goes along."

One committee commissioned training for all members in the process of ethical decision making and found this training extremely helpful.

"We didn't get ethics training let's be clear about that. What we got was a procedure, a community of enquiry, ...I can see the contribution intelligent articulate professional people are making without knowing the words and the terms, without any kind of background ethical theory. I think probably it isn't necessary. It would be very nice and interesting and we would perhaps be even better, but I think you can run a very successful committee without it!"

8.4.4 Funding and administrative support

Only eight committees had access to any funding. Of those committees that had funding the amount and the specified use of the funding varied (some committees had funding for more than one purpose) (table 7). Sources of funding included the trust board, education and training budgets, specific grants and local research ethics committee funding.

Except where specific funding had been allocated, administrative support for the committee was usually provided by the chairman's secretary, and in at least one case the chairman wrote the minutes of committee meetings.

Table 7 Funding available for clinical ethics committees

| Type of funding | For education/training | For an ethicist | Administrative |
|---|------------------------|-----------------|----------------|
| Number of committees with access to funding | 5 | 2 | 4 |

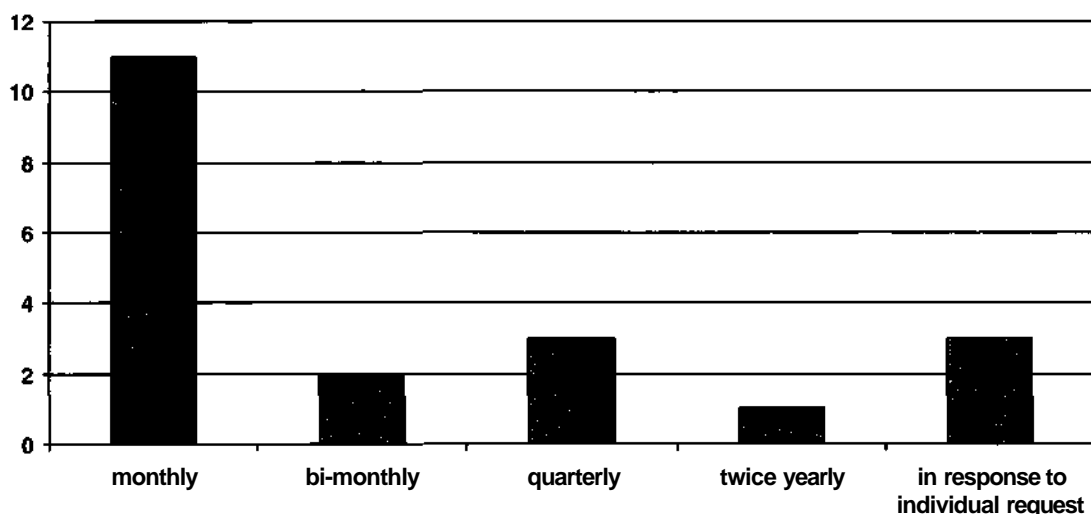


Figure 9 Frequency of meetings by committee

8.4.5 Process of committees

The frequency with which the committees met showed wide variation. The two long established committees, which were also the only two committees in mental health trusts, met only in response to requests arising from individual cases. Most committees met monthly (figure 9).

All committees had the support of the trust board and were incorporated into the trust management structure in various ways (table 10).

Table 8 Position of CEC within trust management structure

| Position in Trust | Official Trust Committee | Reports to Clinical Governance committee | Reports to medical advisory committee | Sub committee of Trust Professional Advisory group |
|----------------------|--------------------------|--|---------------------------------------|--|
| Number of committees | 8 | 5 | 2 | 1 |

8.4.6 Terms of reference

Thirteen of the committees provided written terms of reference as part of the study. One committee had no written terms of reference. Written terms of reference varied from a simple statement of the aims of the committee and a list of membership, to more detailed documents setting out procedures for accessing the committee, education of committee members, and accountability. Table 9 lists the main points covered in the terms of reference.

8.4.7 Profile of the committee within the Trust

A concern that most committee chairmen expressed was the lack of awareness of the committee among health professionals within the trust. This was seen as a considerable barrier to the effective functioning of the committee. If health professionals were unaware of the committee they would not bring cases or issues to the committee for advice or support.

Table 9 Terms of reference of clinical ethics committees

| Area covered by terms of reference | Number of committees |
|--|----------------------|
| Committee is a forum for discussion of ethical dilemmas | 6 |
| Provides support for individual clinicians | 11 |
| Has input into guidelines and trust policy | 11 |
| Provides education for health professionals in trust | 8 |
| Gives advice to trust board | 6 |
| Contributes to wider national and international debates | 1 |
| Committee is advisory in nature | 11 |
| Committee can co-opt other members as necessary | 4 |
| Guidance is provided for access to the committee | 2 |
| Annual report /evaluation is part of the committees duties | 8 |

"The weakness of that is that I would be willing to bet that 99% of the organisation don't know it exists. Therefore it's very difficult to ask somebody you don't know."

Various methods of raising the profile of the committee were suggested including placing information in the trust's various newsletters, dissemination via the 'cascade system' of information dissemination within the trust, and the trust intranet. However, several chairmen, while agreeing that the committee needed to be well known within the trust, highlighted the danger of a committee raising its profile without first establishing its reputation as a worthwhile enterprise.

"One of the things a lot of us felt strongly about was that we didn't want to spend a lot of time publicising ourselves ... until we had generated some policies that seemed to make sense to people."

"My own feeling is that we are going to have to take a while to develop our internal integrity, and make people feel comfortable with the role that they are actually playing, and perhaps even begin to understand that role, and then we can go and talk to others"

8.4.8 Evaluation of the committee

Only one committee had undertaken any formal evaluation of its work. This involved an assessment of the process of the committee using questionnaires administered to the members of the committee. There was also an external assessment carried out of 'user satisfaction' by an independent assessor. Comments were generally favourable but users of the committee comprised a small section of the trust. The chairmen of other committees were aware of the importance of evaluation but had concerns about how this should be carried out. These included:

- Difficulty in defining outcome measures.
- Lack of clarity in the aims of the committee.
- iii. Lack of financial resources.

In addition, many committees were in the early stages of development and it was thought that evaluation would not be helpful at this stage.

8.4.9 Functions of the committee

All the committee chairmen defined their committee's role in terms of guideline development and policy formation, education and individual case discussion although the emphasis on a particular function varied between committees. Most committees found that their main function was in the development of trust guidelines and policy. However some committees were involved in individual case consultation and all committee chairmen acknowledged that there was an important role for the committee in facilitating ethics education within the trust.

8.4.10 Guideline and policy development

The role of committees in guideline and policy development covered three main areas.

1. The consideration of existing, or developing, hospital policies and advising on the ethical issues arising from them.
2. Identifying areas of concern where a policy or set of guidelines may be required, and having input into their subsequent development.
3. Development of guidelines on ethical issues by the committee for consideration and ratification by the trust board.

A range of subjects have been considered by the committees in relation to trust policy and guideline development. The majority of acute trust committees considered 'do not resuscitate' guidelines as their first task. Guidelines considered by the committees include:

- Do not resuscitate (DNR) guidelines.
- Consent policy.
- Advance Directives.
- Rights and duties of relatives.
- Confidentiality.
- Consent to participate in undergraduate education.
- Withholding and withdrawing of treatment.
- Guidelines relating to HIV.
- Policy for dealing with the media.
- Commercial use of tissue.
- Consent for DNA testing.
- Total parenteral nutrition.
- Use of restraints.
- Elective ventilation.
- Possession of illicit drugs.
- Abuse of the service by members of the public (ambulance trust).

8.4.11 Case consultation

Most committees used retrospective case discussion as a form of self education for the committee members. Several of the chairmen commented that issues arising from individual cases often highlighted a need for the development of a policy or guidelines. Eight committees have engaged in discussion of active cases and provided advice and support in these cases. The

Table 10 Models of case consultation used by CECs

| Type of model | Number of committees using model |
|---|----------------------------------|
| Committee discusses cases retrospectively | 20 |
| Committee considers active cases | 8 |
| Individual members of committee provide case consultation | 2 |
| Ethicist on committee also carries out case consultation | 3 |

frequency of requests for advice on individual cases is low (usually less than two per year) although one committee in an acute trust had received thirteen requests over the two years that it had been functioning. A feature of this committee is that it is able to provide a response to requests made directly to individual members of the committee (usually the chair) between committee meetings. Another committee in an acute trust has recently been established with the intention that its prime function is case consultation. This committee will be able to respond to requests on individual cases, again by direct contact with members of the committee, as required, outside normal meetings.

Three acute trusts have an ethicist on the committee who also gives individual advice and support to individuals and care teams within the trust. These ethicists are attached to university departments and are not funded by the trust. One trust has funding for an ethicist from sources outside the trust.

The various approaches to case consultation by the clinical ethics committees are summarised in table 10.

Some examples of the type of cases considered include:

- Confidentiality around HIV testing.
- Refusal of life saving treatment.
- Refusal of spouse to give permission for life saving treatment because of patient's previously stated views.
- Request from relatives not to divulge distressing information to a person with learning disability.
- Use of restraint to allow appropriate treatment.
- Relatives requesting information about patients.
- Conflict between medical team and parents over the use of CPR for severely disabled children.
- Withdrawal of treatment.

8.4.12 Education of health professionals

There was a recognition among committee chairmen of the importance of education on ethical issues for all health professionals within the trust, and that one role of the committee may be to initiate or facilitate such education. Education was seen as one way of raising the profile of both the committee and clinical ethics in general across the trust.

"We intend, when we feel ready, to do a grand round or the equivalent so that people are aware that we are there to help and advise where necessary!"

"I actually think that is a good idea. One of the issues for us is that ethics is like death, you actually don't think about it until you need to!"

However, few of the committees were actively involved in education in a regular or structured manner. There were various reasons for this, most commonly lack of resources (time and money) and a lack of confidence among ethics committee members in their ability to educate others when they were still learning.

"We talked for some time about the importance and the need for developing training programmes within the Trust which incorporate ethical and legal matters. However, we are so under resourced."

"I don't think we have fully explored our educational role but education takes time for members."

"We've got quite a steep learning curve before we reach that plateau."

Models of educational activity that had been tried include:

- Grand rounds.
- Seminars or workshops on specific issues.
- Educational document on consent.
- Ethics slot in post-graduate seminar programme.
- Teaching of specific groups by individual members of the committee.

8.4.13 Clinical ethics committees and clinical governance

The chairmen were asked how they saw the ethics committee fitting in with clinical governance. Two main themes arose from the replies. First, that clinical ethics is part of clinical governance in so far as good clinical practice includes good ethical practice. Thus for a trust to ensure high quality clinical care it needs to consider the ethical issues. Second, that the clinical ethics committee should be seen as separate from the managerial and monitoring aspects of clinical governance. It was thought that the committee's role was to facilitate good ethical practice, but not to be seen as a clinical governance watchdog.

"I see ethics as being part of the whole aspect of clinical governance."

"I think it's very important that ethics committees are independent because if they are seen to be somehow doing what a trust says then they no longer serve the best interest of the patient!"

"I think it needs to be seen to be functioning with, but not simply as part of clinical governance. I think ethical issues arise out of properly applied clinical

governance clearly. But the way you approached an issue, a clinical quality issue as opposed to any ethical issues is totally different and I think the spread of influence is totally different"

The requirement of the clinical ethics committee to evaluate its work in the context of clinical governance was raised. One committee chairman commented that the ethics committee would also be accountable within the clinical governance frameworks by producing an annual report and being subject to audit and evaluation.

8.4.14 Potential hindrances to the effective functioning of clinical ethics committees

All chairmen felt that clinical ethics committees could potentially offer a model for raising ethical standards of patient care in NHS trusts. However, several obstacles were identified that could impede their successful development and their effectiveness. These included:

- Resources (financial and human).
- Availability of training for members.
- Appropriate expertise on the committee.
- Reluctance of clinicians (particularly doctors) to recognise and use the committee.
- Difficulties in raising the profile of the committee.

SECTION III INTERNATIONAL PERSPECTIVE

CHAPTER 9

The international perspective

9.1 Summary

Clinical ethics committees (CECs) have been a feature of North American health care for the past two decades. In more recent years, CECs have begun to develop in many European countries, and also in Australia. Although there are many differences in CECs both between countries and within individual countries, they share some core objectives and functions. Most CECs are multi disciplinary but patient or lay participation is not universal. The advisory nature of the CEC and its role as a forum for ethical discussion are common features across national boundaries. The need for training of CEC members is widely acknowledged to be of prime importance and a range of training initiatives is found in different countries. Raising the profile of the committee within the host health care institution is identified as a problem, even in North America where CECs have been established for some considerable time. Evaluation of CECs is necessary but there have been few evaluative studies to date. Ethics committee networks provide a popular and valuable source of support and education for members of CECs, and others interested in health care ethics. These are most common in North America.

Ethics consultation is a function of CECs but often committees do not have a very active consultation service. In North America, ethics consultation is often provided by individual ethicists or small groups of individuals who may be members of a CEC. There are also models of ethics consultation services without a CEC in Germany. There are no nationally or internationally recognised qualifications or training programmes for ethics consultation.

9.2 Introduction

The experience of other health care systems, in providing support for clinicians on ethical issues in patient care could help to inform the development of such services in the UK. Successful models of support, or experience of problems in particular areas, may be relevant to the NHS, although it will be necessary to take into account significant differences between the different health care systems and legal systems. CECs, also called hospital or health care ethics committees (HECs), have been a feature of hospitals and health care institutions in North America for many years.²² CECs and other ethics support services are less well developed in Europe and Australia. In order to place the position in the UK in an international perspective we examined models of clinical ethics support in several other countries. The aim of this study was not to obtain a comprehensive overview of the situation in other countries but to obtain the views of opinion leaders active in the area of clinical ethics and to look in more detail at a number of models of clinical ethics support.

9.3 Method

Leading individuals in the field of clinical ethics, and centres with an active programme of clinical ethics were identified by a review of published papers on the subject. Contact with these individuals or centres led to further individuals being identified and contacted. A member of the research team (TH) already had extensive contacts with individuals in this field, particularly in Europe. A member of the research team (AS) visited several centres (four in the US, two in Canada, three in Germany and one in the Netherlands). Written communication with a further eight centres in North America, Europe, Australia and South America provided further information.

9.4 Results

9.4.1 History, prevalence and regulation of clinical ethics support services.

In both the US and Canada CECs, also called institutional or hospital ethics committees (HECs) have been present since the early 1970s. During this time ethics consultation services have also developed with a corresponding increase in the number of ethicists and people with 'ethics expertise'. In 1980 1% of US hospitals had a CEC but by 1987 this figure had risen to 60%.⁸ In 1989 a survey of all hospitals in Maryland, District of Columbia and Virginia found that overall, 50% of all hospitals in these jurisdictions had established an ethics committee, with 89% of the hospitals in Maryland having such a committee. The higher number in Maryland may be because this is the only state in the US where legislation exists stating that hospitals should have a CEC.³⁸ In the 1990s, the US Joint Commission on Accreditation of Health Care Organisations made it a requirement of accreditation that a hospital addresses the ethical issues in providing patient care. Their handbook recommends that having a functioning, multidisciplinary ethics committee is recommended to meet this standard.¹³ It seems likely, therefore, that most hospitals in the US will now have some form of CEC. Similarly, in Canada CECs increased in number dramatically in the 1980s. Studies of all English speaking hospitals with over 300 beds showed a rise in the presence of a clinical ethics committee from 18% in 1984 to 58% in 1989.³⁹ The sharpest increase in the number of newly established CECs occurred in 1998, two years after the Canadian Council on Health Facilities Accreditation stipulated in their guidelines that facilities must address the need for policies in specific biomedical ethical subjects. The guidelines further stated that this may be facilitated by the creation of a multi-disciplinary ethics committee.¹⁴

In Europe, clinical ethics support services have been slower to develop and it is only in the last ten years that most European countries have begun to consider the need for such services. In the Netherlands CECs (called institutional ethics committees) are widely accepted in hospitals and nursing homes although the functions of the committees vary among institutions. Most hospitals originally had mixed committees covering research and clinical matters although now many of these have split into research ethics committees and institutional (clinical) ethics committees.⁴⁰ Nursing homes have generally only had institutional (clinical) ethics committees. The presence of mixed committees for research and clinical ethical issues is a feature of other European countries' development of ethics committees, for example Belgium and France.^{41 42} However, other countries have separate committees for research and clinical ethical issues as shown in table 11.

Table 11 Types of local ethics committees in some European countries

| Country | Research ethics committees | Mixed committees | Clinical ethics committees |
|-----------------|----------------------------|------------------|----------------------------|
| Belgium | No | Yes | No |
| France | Yes | Yes | Yes |
| Sweden | Yes | No | Yes |
| Norway | Yes | No | Yes |
| The Netherlands | Yes | Yes | Yes |
| Spain | Yes | No | Yes |
| Italy | Yes | No | Yes |
| Germany | Yes | No | Yes |
| Denmark | Yes | No | No |

Most European countries do not have legislation or other regulations governing CECs, although many countries have legislation on research ethics committees. The law in Belgium specifies that every hospital, or hospital group, should have an ethics committee that addresses research and clinical issues.⁴¹ In Spain, the National Institute of Health has issued an internal regulation covering the establishment of hospital ethics committees, and there is a system of accreditation of such committees. To date there are eighteen such accredited committees in Spain.⁴³ We are unaware of any comprehensive surveys of CECs in European countries so it is difficult to assess their prevalence. Ethics support services other than ethics committees have not been reported in European countries with the exception of Germany. In Germany there are several examples of clinical ethics support in individual cases being provided by ethicists or people with some training in ethics. The University of Freiburg has an ethics programme that combines ethics consultation with research in this area.⁴⁴ Germany also has some CECs, mainly in small hospitals that are part of the Christian Association of Hospitals.⁴⁵

In Australia, ethical support for clinicians is described as 'patchy' (Little M. personal communication). There are some independent ethics centres that provide ethics consultation services for clinicians but there is no published evidence on how frequently these centres are used by individual clinicians for advice on ethical issues relating to patient care. In 1991, McNeill and colleagues conducted a survey of all public and private hospitals in Australia in order to identify the ethical issues facing clinicians and the methods used to resolve them.¹⁸ This survey found that 14% of hospitals had a committee that considered both research and clinical ethical issues and 4% had established a separate clinical ethics committee. There is some anecdotal evidence to suggest that CECs have increased in number over the past ten years but there are no comprehensive data comparable with the 1991 survey.

9.4.2 The role of clinical ethics committees

Clinical ethics committees in North America have had longer to explore and define their role than most European or Australian committees. However, there is evidence, both written and verbal, to suggest that many of the issues that arise in considering the development of clinical ethics committees are common to all countries.

9.4.2.1 Committee membership

The importance of a multi-disciplinary membership of CECs is widely accepted, reflecting the view that these committees are fora for ethical debate that is enriched by the contribution of different moral and professional viewpoints. There is less agreement about the need for lay representation on these committees. In North America lay representation is usually advocated in published papers on the subject but in practice by no means all committees have lay members. In 1989 a Canadian survey of clinical ethics committees found that the composition of the committee always included physicians and nurses, and usually members of the management structure and clergy.³⁹ Patient/lay representatives were mentioned by less than 50% of respondents, the exact number not being reported in the survey. Acute care institutions appear less likely to specify patient or lay representation than intermediate or long term care institutions. Comparison of sample terms of reference of hospital ethics committees in Canada showed that those hospitals providing long term care were more likely to include community representation on their committee.⁴⁷ Lay representation is not a feature of clinical ethics committees in The Netherlands, and the legislation for ethics committees in Belgium does not include specific lay representation. However, Spanish clinical ethics committees do have lay members.⁴³

9.4.2.2 Functions of clinical ethics committees

The specific functions of CECs vary both between countries and within countries, depending on the objectives of the committee and its position within the health care institution. In some European countries, for example France, the functions of the committee may vary depending on its place in the broader health care context (is the committee a local or regional committee?).⁴² However, there are some basic similarities about the functions of CECs that are common to North America, Europe and Australia.

- Raising ethical awareness within the institution by education.
- Providing ethical input into departmental and institutional policy and guidelines.
- Providing advice and support in individual cases.

In addition, the advisory nature of the committee is seen as of paramount importance in all countries. The emphasis placed on each of these functions varies between committees, as does the method of achieving it.

9.4.2.3 Education of ethics committee members

Adequate training for members of CECs is recognised as a priority in both Europe and North America. Most accounts of developing committees describe an initial programme of self education of the committee, often facilitated by an ethicist member of the committee, or more formal, external training.⁴⁶ In North America there are centres for bioethics associated with universities or large hospitals that provide training for CEC members.⁴⁷ In addition, masters and doctoral courses in bioethics have been designed to cater for the needs of those members of CECs who wish to gain further experience and knowledge in this area. In the Netherlands, centres in Maastricht and The Hague offer training courses for members of CECs as well as courses tailored to the particular needs of a specific committee. The National Institute of Health

in Spain has established a publicly financed masters degree in bioethics for hospital professionals that aims to provide doctors and nurses with the appropriate skills to begin to establish ethics committees.⁴³ The Ministry of Welfare and Health in Norway has provided funding for a full time co-ordinator to facilitate the development and training of CECs in every major hospital in the country.⁴⁸

Facilities for provision of ethics education for clinical ethics committee members

- Training courses run by an associated bioethics centre.
- Training organised by an ethics committee network.
- Training organised by the committee using external experts.
- Masters courses in bioethics and health care ethics.

9.4.2.4 Profile of CECs within their institutions

The problem of ensuring that all health professionals (and patients) in the hospital or health care institution are aware of the presence of the CEC, and its core functions, has been difficult to address successfully. This is true even in North America where CECs have had much longer to establish themselves as a core structure within the institution. In 1990, Hoffman and colleagues found that in a survey of all staff in five hospitals with active CECs in Maryland USA, 35% of staff did not know of the existence of the committee.³⁸ In 1995, Kerridge et al surveyed a random sample of staff at a teaching hospital in New South Wales, Australia that had had a CEC since 1990. Of the responders, 36% were unaware of the CEC and only 6% were aware of the committee's policies and guidelines.⁴⁹ This problem was also highlighted anecdotally by several members of European CECs. There are several ways in which this problem is addressed. Many North American hospitals or ethics centres have information sheets for patients, and use staff newsletters to convey information about the CEC. Educational programmes for staff can also raise awareness of the CEC. One clinical ethics committee in Germany spent the year prior to its establishment discussing the concept of a CEC with all staff members in a series of departmental meetings. This same committee also runs a regular open forum for the discussion of ethical issues every three months. These sessions are open to staff, patients and relatives at the hospital.⁴⁵

9.4.2.5 Evaluation

Evaluation of CECs is recognised as important in theory but difficult in practice. Most North American evaluation has been in terms of process rather than outcome, and those studies that have considered outcome are usually user satisfaction studies.^{30 31 32 50} As CECs vary in their specific objectives and functions, comparative evaluation may be difficult. In Europe few CECs have been in place long enough for meaningful outcome evaluation. A project in Norway has evaluated the development of three CECs that were established as part of a feasibility study for the introduction of CECs in all hospitals.⁴⁸ The evaluation concentrated very much on the committee members, and whether the committees had achieved objectives in terms of numbers of seminars organised etc, rather than on the effect of the committee on health professionals and patients. There is widespread acknowledgement that further evaluation of CECs is needed.⁵¹

9.4.3 The role of ethics consultation services

Although case consultation is seen as one of the core functions of a CEC, in practice many committees do not provide a case consultation service and are more likely to concentrate on guideline and policy development.¹⁹ In North America other models of case consultation have been developed and may exist in conjunction with a CEC. In Europe and Australia specific case consultation services are less common. There are examples of ethicists providing case consultation in Germany and some ethics centres in Australia provide ethics consultation services for local hospitals.⁴⁴, (Little M. personal communication) The various models of case consultation service identified in this study are described below.

9.4.3.1 Consultation by committee

Some CECs provide case consultation by the whole committee and have a mechanism for convening a committee meeting at short notice for this purpose. Referrals to the committee may be screened by an individual such as the committee chairman, in order to identify inappropriate referrals, for example complaints or legal queries.

Advantages of case consultation by committee

- A diverse range of views and experience is brought to bear on the case so there is less likelihood of a particular bias occurring in the advice given.
- The process may be more transparent than if carried out by individuals or small groups.

Disadvantages of case consultation by committee

- A committee may be too cumbersome to react quickly enough to requests for consultation.
- A committee may not have anyone with appropriate training in moral reasoning or identification of moral values.
- Patients and their families, and also health professionals, may find it intimidating to appear before a committee to discuss their concerns. This issue was highlighted by a member of a children's hospital ethics committee in Canada.

9.4.3.2 Consultation by an ethicist

Some hospitals employ an ethicist to work as a member of the ethics committee and/or provide an ethics consultation service in individual cases. The term ethicist is not specific as ethicists may come from the fields of medicine, nursing, philosophy, social sciences, or theology.

Advantages of case consultation by an ethicist

- A more responsive service with an 'on call' capability.
- An ethicist has training in critical reasoning and identification of moral issues.

Disadvantages of case consultation by an ethicist

- The ethicist's own biases may influence the consultation.
- An ethicist may not have the clinical knowledge to place the facts and values of the case in context.
- If the ethicist is employed by the hospital there may be a conflict of interest between the need for objective advice and the policies of the institution.

9.4.3.3 *Consultation by a small group of individuals*

This model can take several forms:

- i. A sub-group of the clinical ethics committee.
- ii. Individuals from the clinical ethics committee led by an ethicist from an associated centre or employed by the hospital.
- iii. An ethics consultation service made up of individuals working in the hospital but not necessarily part of the ethics committee.

An example of the latter is the ethics consultation service in the University of Virginia School of Medicine. The ethics consultation service comprises twelve professionals working in the hospital including nurses, doctors, social workers and a chaplain. They provide an on-call rota working in pairs, although the pairs are not always the same two people. The 'consultants' undergo a training programme lasting six to twelve months and have weekly meetings to discuss cases and new issues. They report to the clinical ethics committee once a month but the committee usually only becomes involved in individual cases when the consultation has raised an issue that indicates a need for guidelines or education of staff.

9.4.3.4 *Ethics mentors*

This model is being investigated by a Catholic hospital in Vancouver (Murphy M. personal communication). Health professionals working in the hospital who express an interest in ethics are given training by the ethics centre and then act as mentors in their particular area of work. The mentors are available for advice and support on ethical issues at a local level. If a problem is considered too complex for the mentor alone to provide advice then a formal case consultation can be requested from the ethics committee or ethicist. The mentors can also facilitate education about ethical issues and implementation of guidelines and policies on ethical issues. As the number of mentors increases, it will be possible to ensure that a mentor is available in all departments or wards, and on all shifts, so that access to ethics support should be available to all health professionals at all times.

9.4.4 **Training and qualification for ethics consultation services**

The standard of training and competency required for someone providing an ethics consultation service is greater than that required of members of a CEC. In the US there has been a move to develop nationally accepted standards for ethics case consultation. In 1998, the American Society for Bioethics and the Humanities (ASBH) published a document, 'Core Competencies for Health Care Ethics Consultation'.²⁴ This was a report from a task force set up to consider issues around ethics case consultation including:

- The nature and goals of ethics consultation.
- The types of skills, knowledge and character traits that are important for conducting ethics consultation.
- The special obligations of ethics consultants and institutions.

The task force recommended that the core competencies for ethics consultation which it had developed should be used as voluntary guidelines by health care organisations and training programmes. However, certification of individuals for ethics case consultation, or accreditation of educational programmes, was rejected by the task force. This was because of the danger of introducing an authoritarian approach to ethical decision making, with ethics experts displacing patients and providers as the primary moral decision makers. The task force also highlighted the practical difficulties of accurately testing required competencies in view of the limited data available on the nature and effectiveness of ethics consultation at this time.

9.4.5 Ethics committee networks

A needs assessment survey of CECs in Toronto found that committees thought it was important to share knowledge and experience with other committees.²¹ One way of facilitating communication between ethics committees is by an ethics committee network. There are many such networks in both Canada and the US, but we are unaware of any in Europe and Australia. Like clinical ethics committees, the networks vary in both their structure and function, but their stated aims are similar

- i. To act as a resource on ethical issues for ethics committees and their members.
- ii. To facilitate communication and sharing of information between ethics committees.
- iii. To provide a programme of education for members of ethics committees, other health care professionals and members of the general public.

Some networks, for example the Medical Ethics Resource Network of Michigan, are open to anyone with an interest in ethics and not restricted to ethics committees or health care professionals.⁵² The more successful networks are often attached to a centre for ethics or a university department of bioethics that can provide some of the infrastructure and educational resources required for the network to achieve its aims.

SECTION IV CONCLUSION

CHAPTER 10

Issues arising

The previous chapters of this report have described the findings of a comprehensive survey of clinical ethics support in the UK and the experience of other countries in the development of such services. A number of issues have emerged from the various strands of the study which help to provide a clearer picture of both the potential benefits and difficulties of developing a clinical ethics support service in the UK. These issues will need to be considered in order that robust and appropriate recommendations can be made regarding the challenge of facilitating high quality ethical decision making in patient care. This chapter sets out the issues that will need to be considered.

10.1 The development of clinical ethics committees in NHS Trusts

Clinical ethics committees (CECs) are developing within UK NHS trusts and their number will almost certainly increase rapidly in the next few years. In addition to trusts that this survey shows are intending to set up a CEC in the near future, there has been interest expressed by other trusts since the completion of the survey. Several factors have influenced, and will continue to influence, the development of CECs.

1. Clinician based factors

Clinicians are increasingly aware that advances in medical science, while offering great benefits to patients also raise previously unconsidered ethical dilemmas. The transition from a model of medical paternalism to one of respect for individual autonomy and doctor/patient partnership means that clinicians are having to reassess the values systems used in their clinical decision making. The introduction of medical ethics into the undergraduate curriculum for medical students will raise awareness of ethical issues among tomorrow's doctors. This is likely to increase requests for advice on ethical issues; a parallel with the clinical situation of increased knowledge in an area leading to increased referrals for expert advice in that area.

2. Management based factors

The development of new, effective, but often expensive treatments, and an ageing population leading to increased prevalence of chronic diseases raises difficult decisions about priority setting and allocation of limited resources for health care managers. This survey has shown that several health authorities and health boards in the UK have established a priority setting or resource allocation committee to address these issues. The development of clinical governance has given managers the responsibility of both ensuring the provision of high quality health care, and of providing the support necessary for health care professionals to deliver high quality health care.

High ethical as well as clinical standards will be expected and managers will need to consider mechanisms to facilitate the achievement of these standards. Many managers in this survey identified clinical governance as an area where clinical ethics committees may contribute.

3. Society based factors

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.

10.2 The perceived need for clinical ethics support within the UK

The responses to the trust and health authority questionnaire surveys in this study demonstrate that there is a perceived need for some form of clinical ethics support among senior clinicians and managers within the UK NHS. Other studies have shown a similar perceived need among consultants and other health care staff.³⁴ The questionnaire surveys of other groups in this study show that health professionals are seeking advice on clinical ethical issues from various sources including professional organisations, university departments of ethics and local research ethics committees (LRECs).

The development of CECs and other ethics support services is also occurring in Europe, South America and Australia. Together with their well established presence in North America this would suggest that it is a global phenomenon. In the UK, we have the opportunity at this stage to develop these services in a coherent manner, and ensure that they are appropriately evaluated.

10.3 Other models of clinical ethics support in the UK

There are several potential models for providing clinical ethics support within NHS trusts in the UK. In this study, eighty-eight trusts reported some mechanism of providing clinical ethics support other than CECs. It is not possible to say from this study how active or effective these forms of support are, or whether it is just wishful thinking on the part of the respondents that these mechanisms could be used for ethics support. The findings raise the possibility that existing structures in trusts could be developed to provide support and guidance on ethical issues in clinical care. Health authorities and health boards have a role in providing clinical ethics support to primary care groups and trusts. They too will need to consider appropriate models of providing such support.

Local research ethics committees

LRECs are used by some clinicians as a source of clinical ethics support. In our survey, 25% of LRECs had given clinical ethics advice on request. The terms of reference of LRECs do not

currently permit them to consider clinical ethical issues, so those committees providing advice may not be indemnified in the event of a claim against them.⁵³ Interviews with the chairmen of some of these LRECs raised concerns about the use of an LREC for clinical ethics support. These included lack of time available in view of the high workload of LRECs in relation to research ethics submissions, and the fact that LRECs were not appropriately constituted in terms of expertise and training to provide this service. A fundamental concern is that LRECs give binding decisions on the submissions made to them, while it is universally acknowledged that CECs should be advisory in nature. It would be difficult for one committee to operate in an advisory capacity on some issues and as a decision making body on others. The difficulty of combining the two types of committee has been highlighted in the Netherlands where many combined committees have now split into a research ethics committee and an institutional ethics committee that addresses clinical issues.

Professional organisations

Professional organisations and national bodies such as the GMC are an important source of ethical guidance for health professionals. They offer a reference point on major ethical issues and compliance with these guidelines are normally considered favourably by the courts in any legal cases.^{54 55} However, national guidelines tend to be general and often need to be interpreted locally, for example the BMA guidelines on withdrawal and withholding of treatment advise that the guidelines are developed locally.² Many of the responders to the questionnaire surveys identified a need for a support service that was both responsive and relevant to local needs.

10.4 Important considerations for the development of CECs and other ethics support services

Whatever models of clinical ethics support are found to be most suitable, either for individual trusts and health authorities, or more generally within the health service, many of the issues identified in the interviews with chairmen of CECs will be relevant. Enough common themes were identified in both the interview study with UK CEC chairmen and in the analysis of the international context to enable a framework for future development in this area in the UK to be developed.

The key common themes are as follows:

1. Advisory role of CECs

A fundamental point arising from all the interviews with CEC chairmen was that CECs should be advisory, offering support but not issuing decisions. This is true of CECs in all other countries considered in this study.

2. Status within the trust or health authority

For the committee to be successful, it must have recognition and support from within the institution at all levels, including administrative and financial support. The CEC should be a

formal committee within the institutional structure but it is important that the CEC is seen as independent of management and not as a regulatory or disciplinary mechanism.

3. Training for CEC members

Many CEC chairmen identified the need for appropriate training or education of committee members as important. The areas identified as important in such education include basic moral theory, ethical analysis, critical thinking, and knowledge of national ethical and legal guidelines. There are models for training programmes for CEC members in other countries and these would be a useful starting point for the development of training that is appropriate to CECs and other support services in the UK. As a result of this study, the Ethox centre has developed a two-day course for newly developing CECs, and new members of established CECs. If CECs, and other support services, are to develop effectively in the UK such courses will need to be further developed.

4. Support networks for CECs

All committee chairmen commented that they were unaware of most other CECs. They believed that contact between CECs would be an important method of providing support and education for developing CECs. The sharing of experience and specific guidelines through some form of network would avoid each committee having to 'reinvent the wheel'. A network of UK clinical ethics committees was established in January 2000 in response to the expressed views of CEC chairmen in this study. The aim of the network is to provide information, support, and education for established and nascent CECs in the UK.

5. Defining the functions of the committee

Although most UK committees have concentrated on guidelines and policy formation, some committees see case consultation as their main function. Some degree of case review is essential to inform the debate around guideline and policy formation. This retrospective case review function will also be helpful to clinicians in their future work. However, active case consultation in response to requests regarding current cases will have different implications for the committee's workload and mode of functioning. The committee will need to be clear about the parameters of its role and in turn ensure that all staff are aware of what the committee does and does not do.

6. Education of health professionals by the CEC

Most UK CEC chairmen agree that education of health professionals within the institution, and raising awareness of ethical issues, are important but there are concerns about how a committee can provide this service. Similar problems were faced by CECs developing in North America. If CECs are to take a lead in ethics education among health care professionals they will need adequate resources, which will include financial resources and access to appropriate expertise.

10.5 Other models of ethics case consultation

Experience from North America and Germany suggests that ethics case consultation may be carried out using models other than a committee. Whatever model of case consultation is adopted by a health care institution, attention must be paid to the development of appropriate skills in those undertaking this role. The document on core competencies for health care ethics consultation produced by the American Society for Bioethics and Humanities provides a model for developing minimum standards in this area.

10.6 Evaluation of clinical ethics support services in the UK.

Several of the CECs in the UK are not yet clear about their exact role in the institution and there are concerns about how effective the committees are. Comments from the questionnaire surveys also raise concerns about the effectiveness of a clinical ethics support service, even among those who are very much in favour of raising ethical awareness in clinical practice. Although some evaluation of such services has taken place in North America and Europe, there has been little rigorous evaluation of outcomes with most research looking at process data such as satisfaction of health professionals and patients.^{30 31 50} In general, satisfaction is high among users of CECs but this accounts for only a small percentage of any professional group within the institution.³⁸ Longer term evaluative studies using outcome as well as process data are needed. It is therefore imperative that any service has clearly stated objectives, and that there is a rigorous evaluation of both process and outcome during their development.

CHAPTER 11

Conclusions and recommendations

11.1 Conclusions

11.1.2

Clinical ethics committees (CECs), and other forms of clinical ethics support, have begun to develop in the UK, and will almost certainly increase in number dramatically in the near future. A similar development is occurring in many European countries. These CECs and other support services vary between and within countries, in response to the particular requirements of their health care systems, but they share common objectives and core functions. These are broadly similar to those of North American clinical ethics support services, which have developed over the past two decades.

11.1.2

In the UK, this development has until now been mainly driven by the concerns of clinicians about difficult ethical decisions that they have encountered in clinical practice, in a 'bottom up' approach. Apart from those clinicians who have been motivated to initiate the development of a CEC, there is evidence of a perceived need for such services among senior clinicians and managers throughout NHS trusts and health authorities in the UK. In other countries, the impetus has come from managers, regional authorities and national governments. It is likely that with the advent of clinical governance in the UK, a 'top down' approach to the development of CECs may become more apparent in the future.

11.1.3

Isolation is a problem for CECs developing in the UK. Many committees are considering similar issues and policies independently and would benefit from a forum for sharing information in order to avoid reinventing the wheel. A national support network can provide this service, and in addition be active in the development of appropriate training for CEC members.

11.1.4

Although the clinical ethics committee is the most easily identified form of clinical ethics support, having been specifically established for this purpose, many NHS trusts reported other forms of clinical ethics support involving the use of existing committees or clinical support structures. It is not clear at this stage which is the most appropriate model, or range of models, for providing clinical ethics support to health professionals within the UK NHS.

For any clinical ethics support service to develop effectively it will need to be properly supported. This support will include:

- Appropriate expertise to support and develop the service.
- Appropriate training for those providing the service.
- Administrative support.
- A recognised status for the service supported by the trust management.
- Protected time for those providing the service.

11.1.5

Although clinical ethics support services are developing in the UK and elsewhere, and there is a strong belief in their utility, there has been no robust evaluation of these services either in the UK or in other countries. In order to justify supporting the development of CECs or other support service within the NHS, a continuing evaluation process will be necessary as with any other area of clinical practice. The evaluation would need to answer two questions:

1. Does the service meet its own objectives?
2. Does the service have an effect on practice?

11.1.6

Local research ethics committees (LRECs) are not an appropriate model for providing clinical ethic support. Their mode of operation does not sit easily with the advisory nature of clinical ethics support and the increased workload required if they performed a dual function would be prohibitive. This conclusion is supported by the experience of other countries.

11.2 Recommendations

Ethical dilemmas in health care are likely to increase in the future, both in frequency and complexity. There is evidence to suggest that there is a need for support for health professionals in this area and initiatives are already taking place to provide that support. In order to facilitate the achievement of the highest possible ethical standards in patient care within the UK we recommend that the current development of clinical ethics support services in the UK be supported and fully evaluated.

11.2.1 Individual clinical ethics support services in the UK have developed in isolation. A common feature of the clinical ethics committees is that they are unaware of other committees. There is a need to share information and experience among clinical ethics committees and other support services. The development of a national network of clinical ethics support services to provide information, education and support to developing initiatives, and to facilitate the sharing of experience between initiatives, would address this need. A national network has been established as part of this project, which has demonstrated the need and potential for such support, but further development will be required.

We recommend the further development of a national network of clinical ethics support services to share information, and provide education for clinical ethics support services in the UK.

11.2.2 In order to properly assess whether a model of clinical ethics support is effective in achieving its aims, adequate support should be given to the development of the model. This would include:

- Appropriate expertise to support and develop the service.
- Appropriate training for those involved.
- Administrative support.
- A recognised status for the service supported by the trust management.
- Protected time for those providing the service.

Before any particular model of clinical ethics support can be confidently supported rigorous evaluation of the various models will be necessary. Internal (local) evaluation is necessary to measure the effectiveness of the service against local aims and objectives. In addition, an independent external (national) evaluation is necessary in order to provide a generalisable assessment that can be used to inform national guidelines and recommendations. This method of local and national evaluation has been used previously in the context of local initiatives that will have national implications.⁵⁶ Therefore, an appropriate strategy would be to use external funding to support specific initiatives in order to develop models of best practice which could then be evaluated. A period of at least three years would be necessary to enable the service to develop to a stage where meaningful evaluation was possible.

We recommend that specific initiatives be established that are designed to develop models of best practice appropriate to the roles of different trusts, including the new primary care trusts. A formal evaluation of these specific initiatives should be carried out, including a local evaluation by the trust or health authority in which the initiative takes place, and an independent national evaluation.

11.2.3 Local research ethics committees perform a specific function that is fundamentally different from that of a clinical ethics committee. Their training and expertise is confined to research ethics and they are decision making, rather than advisory bodies. Their current workload would not allow them to provide a responsive clinical ethics support service.

We recommend that local research ethics committees do not take on the role of a clinical ethics support service in the UK.

Summary of recommendations

- 1. The further development of a national network of clinical ethics support services to share information, and provide education for clinical ethics support services in the UK.**
- 2. Specific initiatives that are designed to develop models of best practice appropriate to the roles of different trusts, including the new primary care trusts, should be established. A formal evaluation of these specific initiatives should be carried out, including a local internal evaluation by the trust or health authority in which the initiative takes place, and an independent national external evaluation.**
- 3. Local research ethics committees do not take on the role of a clinical ethics support service in the UK.**

References

- ¹ Seeking Patients' Consent: the ethical considerations. London. GMC, February 1999.
- ² British Medical Association. Withholding and withdrawing life-prolonging medical treatment. London, BMA, 1999.
- ³ Slowther A, Underwood M. Is there a need for a clinical ethics support service in the UK? *Journal of Medical Ethics*. 1998;24:207.
- ⁴ Larcher V, Lask B, McCarthy J. Paediatrics at the cutting edge: Do we need ethics committees? *Journal of Medical Ethics*. 1997;23:245-9.
- ⁵ Bartels D, Younger S, Levine J. Ethics committees: Living up to your potential. *AACN* 1994;5:313-23.
- ⁶ Iserson KV, Floyd BG, Markham JJ. The future functions of hospital ethics committees. *HEC Forum*. 1989;1:630-76.
- ⁷ Rosner F. Hospital medical ethics committees: A review of their development. *JAMA*. 1985;253:2693-7.
- ⁸ Gibson JM, Kushner TK. Will the 'Conscience of an Institution' become society's servant? *The Hastings Center report*. 1986;3:9-11.
- ⁹ President's Commission for the Study of Ethical Problems in Medicine and Biomedical and behavioural Research. Decisions to forgo life sustaining treatment: a report on the ethical, medical and legal issues in treatment decisions. Washington DC: US.G.P.O.; 1983.155-70, Appendix F.
- ¹⁰ In re Quinlan. 70 N.J. 10,335 A2d 647 (N.J.) cert denied, U.S. 922,50, L.Ed2d289,97 S Ct 319 (1976).
- ¹¹ Services and treatment for disabled infants; Model guidelines for health care providers to establish Infant Care Review Committees, Federal Register 50 (1985) 14873-901.
- ¹² Millspaugh D. From anonymity to respect: Lessons in the establishment of a bioethics forum. In Spicker S. Ed. The Healthcare ethics committee experience. United States. Krieger Publishing Company. 1998.
- ¹³ Joint Commission for Accreditation of Healthcare Organisations. 1996 Comprehensive Manual for Hospitals. Chicago: JCAHO, 1996:95-97.
- ¹⁴ Canadian Council on Hospital Accreditation. Guide to accreditation of Canadian health care facilities, 1986; CCHA Ottawa. Section 6.1.1.
- ¹⁵ Maryland Health-General Code annotated. Sections 19-370 to 19-374 F.
- ¹⁶ Admin. Code tit. 8, Section 43G-5.1 (16 March 1992), New Jersey Statutes Annotated. Section 2A:84A-22.10(1990).
- ¹⁷ Van der Kloot Meijburg H. Different profiles for the Institutional Ethics Committees in the Netherlands. *HEC Forum*. 1994;6:139-57.
- ¹⁸ McNeill PM, Walters JD, Webster I. Ethics decision-making in Australian hospitals. *Medical Journal of Australia*. 1994;161:487-8.
- ¹⁹ Blake DC. The Hospital Ethics Committee: Health Care's Moral Conscience or White Elephant. *Hastings Center report*. 1992;January-February:6-11.
- ²⁰ Slomka J. The ethics committee: Providing education for itself and others. *HEC Forum*. 1994;6:31-8.
- ²¹ AUatt P. Hospital ethics committee needs assessment. Report for the University of Toronto Joint Center for Bioethics. 1998.
- ²² Singer P, Pellegrino E, Seigler M. Ethics Committees and Consultants. *The Journal of Clinical Ethics*. 1990;1:263-7.
- ²³ Neff-Smidi M, Giles S, Spencer E, Fletcher J. Ethics program evaluation: The Virginia hospital ethics fellows example. *HEC Forum*. 1997;9(4):375-8.
- ²⁴ American Society for Bioethics and Humanities: Core Competencies for Health Care Ethics Consultation. United States. American Society for Bioethics and Humanities. 1988.
- ²⁵ DuVall G, Sartorius L, Clarridge B, Gensler G, Danis M. What triggers requests for ethics consultation? *Journal of Medical Ethics*. In press.
- ²⁶ Woolf SM. Ethics committees in the courts. *Hastings Center report*. 1986; June: 12-15.
- ²⁷ Fleetwood J, Arnold R, Baron R. Giving answers or raising questions: The problematic role of institutional ethics committees. *Journal of Medical Ethics*. 1989;15:137-32.
- ²⁸ Weir RF. Paediatric ethics committees: Ethical advisors or legal watchdogs? *Law, Medicine and Healthcare*. 1987;15:99-109.
- ²⁹ Fleetwood J, Unger S. Institutional ethics committees and the shield of immunity. *Annals of Internal Medicine*. 1994;120:320-5.
- ³⁰ La Puma J, Stocking CB, Silverstein MD, DiMartini A, Siegler M. An ethics consultation service in a teaching hospital. *JAMA*. 1988;260:808-11.
- ³¹ White JC, Dunn PM, Homer L. A practical instrument to evaluate ethics consultations. *HEC Forum*. 1997;9:228-46.
- ³² Lindon JL, Draugalis JR, Iserson KV, Coons SJ. Evaluation of a bioethics committee intervention: A limitation of medical treatment form. *HEC Forum*. 1996;8:145-56.
- ³³ Philips DF. Ethics consultation quality: Is evaluation feasible? *JAMA*. 1996;275:1866-7.
- ³⁴ Thornton JG, Lilford RJ. Clinical ethics committees. *BMJ*. 1995;311:667-9.
- ³⁵ Meslin E, Rayner C, Larcher V, Hope T, Savulescu J. Hospital Ethics Committees in the UK. *HEC Forum*. 1996;8:301-15.
- ³⁶ Watson A R. An Ethics of Clinical Practice Committee: Should every hospital have one? *Proc R Coll Physicians Edinb*. 1999;29:335-7.
- ³⁷ Wood K, Ellis S. A clinical ethics committee in a small health services Trust. *Journal of Medical Ethics*. 1999;25:420.
- ³⁸ Hoffmann DE. Does legislating hospital ethics committees make a difference? A study of hospital ethics committees in Maryland, the district of Columbia and Virginia. *Law, Medicine and Health Care*. 1991;19:105-19.
- ³⁹ Storch JL, Griener GG, Marshall DA, Olineck BA. Ethics committees in Canadian hospitals: Report of the 1989 survey. Healthcare management forum. 1990; winter:3-7.

- ⁴⁰ Ter Meulen RHJ, van der Kloot Meijberg HH. Developing standards for clinical ethics committees: Lessons from the Netherlands, *Journal of Medical Ethics*. In press.
- ⁴¹ Carbonnelle S, Scmitz P. Ethical function in Belgian Hospital Ethics Committees: Historical overview. In Lebeer G, Moulin M. eds. *Ethical Function in Hospital Ethics Committees: Biomed 2 Working Papers*. Belgium. Universite Libre de Bruxelles. 2000.39-45.
- ⁴² Arnoux I. Specificities of French ethics committees. In Lebeer G, Moulin M. eds. *Ethical Function in Hospital Ethics Committees: Biomed 2 Working Papers*. Belgium. Universite Libre de Bruxelles. 2000.59-73.
- ⁴³ Sainz A. Spanish ethics committees. In Lebeer G, Moulin M. eds. *Ethical Function in Hospital Ethics Committees: Biomed 2 Working Papers*. Belgium. Universite Libre de Bruxelles. 2000.123-8.
- ⁴⁴ Reiter-Theil S. Ethics consultation on demand: concepts, practical experiences and a case study. *Journal of Medical Ethics*. 2000;26:198-204.
- ⁴⁵ Simon A. Support for ethical dilemmas in individual cases: Experiences from the hospital Neu-Mariahilf in Goettingen. *Journal of Medical Ethics*. In press.
- ⁴⁶ Christensen KT. Self education for hospital ethics committees. In Spicker S. Ed. *The Healthcare ethics committee experience*. United States. Krieger Publishing Company. 1998.
- ⁴⁷ Browne A, Sweeney VP, Norman M. Ethics committee education: Report on a Canadian project. *HEC Forum*. 1996;8:290-300.
- ⁴⁸ Ruyter KW. Ethics committees: The national situation in Norway. In Lebeer G, Moulin M. eds. *Ethical Function in Hospital Ethics Committees: Biomed 2 Working Papers*. Belgium. Universite Libre de Bruxelles. 2000.91-105.
- ⁴⁹ Kerridge IH, Pearson S, Rolfe IE. Determining the function of a hospital clinical ethics committee: Making ethics work. *Journal of Quality in Clinical Practice*. 1998;18:117-24.
- ⁵⁰ McClung JA, Kamer RS, DeLuca M, Barber HJ. Evaluation of a medical ethics consultation service: Opinions of patients and health care providers. *The American Journal of Medicine*. 1996;100:456-60.
- ⁵¹ Tulskey J A, Fox E. Evaluating ethics consultation: Framing the questions. *The Journal of Clinical Ethics*. 1996;7:109-15.
- ⁵² Medical Ethics Resource Network of Michigan. Wysiwyg://<http://office.chm.msu.edu.mern> accessed 12.09.00.
- ⁵³ Bendall C, McKenna & Co. Standard operating procedures for local research ethics committees. HMSO. 1994111:11-19.
- ⁵⁴ Airdale NHS Trust v Bland [1993] 1 All ER 821, (1993) 12 BMLR64 (HL).
- ⁵⁵ W v Edgell [1990] 1 All ER 835 (CA).
- ⁵⁶ www.npcrdc.man.ac.uk/Pages/Special/whatpc.htm accessed 28.10.00.

APPENDIX 1

Formal clinical ethics support in NHS trusts

Formal methods of clinical ethics support service reported by responders to trust questionnaires

Professional/Management structures 20

Includes

| | |
|--|----|
| Medical Director/Nursing Director/Professional Heads | 15 |
| Clinical supervision | 2 |
| Designated individuals | 2 |
| Clinical governance structures | 1 |

Committees/groups other than CEC 41

Includes

| | |
|---|----|
| Professional fora | 6 |
| Therapies board | 1 |
| Clinical governance committee/group | 12 |
| Clinical board/nursing board | 3 |
| Children's rights advisory forum | 1 |
| Clinical risk group | 1 |
| Professional/medical advisory committee | 10 |
| Mental health committee | 1 |
| New procedures committee | 1 |
| Confidentiality panel | 1 |
| Local paramedic steering group (Ambulance Trusts) | 2 |
| Ad hoc group | 2 |

University dept of ethics 3

Chaplaincy services 6

Policies on ethical issues 2

Includes

| | |
|------------------------------|---|
| Bereavement care policy | 1 |
| Expression of concern policy | 1 |

Individuals within Trust 4

Includes

| | |
|-------------------------------------|---|
| Trust solicitor | 1 |
| Ethics facilitators | 1 |
| Clinical effectiveness co-ordinator | 1 |
| Quality advisor | 1 |

Others 9

Includes

| | |
|---|---|
| Ethics forum/training days | 3 |
| Ethics facilitators | 1 |
| Joint committee with another trust | 1 |
| Subject specific ethics committee | 1 |
| Regular staff meetings | 1 |
| Access to a hospital based clinical ethics committee (Ambulance Trusts) | 2 |

Some trusts reported more than one form of support

APPENDIX 2

Informal clinical ethics support in NHS trusts

367 trusts (693 individual replies) reported some form of informal ethics support within the Trust. The table shows the types of informal support reported by individual responders. Many responders reported more than one type of support therefore the total numbers exceed the number of responses.

Informal clinical ethics support reported by individual responders to trust questionnaire

| | |
|---|--|
| Support from other clinicians | 513 |
| Medical Director | 165 |
| Other clinical colleagues | 159 |
| Director of Nursing | 98 |
| Clinical supervision | 39 |
| Senior clinical colleagues | 37 |
| Staff with expertise/interest in ethics | 21 |
| Research related support | |
| Advice from members of REC | 59 |
| Approach to LREC | 11 |
| R&D support | 77 |
| Other forms of support | |
| Non clinical management structures | 44 |
| Chaplain | 82 |
| Professional bodies/organisations/groups | 33 |
| Other hospital committees/groups | 32 |
| Advice from members of clinical ethics committee | 31 |
| Professional advisors/professional advisory committee | 29 |
| Education and practice development | 21 |
| Access to University Departments of ethics | 20 |
| Clinical governance | 17 |
| Legal advice | 13 |
| Multidisciplinary team discussions | 13 |
| 3 wise men | 10 |
| Ethics group / forum | 10 |
| Risk management structures | 8 |
| Staff counselling | 6 |
| Patients' advocate/patient bodies | 5 |
| Director of Public Health / HA | 3 |
| Teaching sessions | 3 |
| Networking | 3 |
| Ad hoc groups | 3 |
| Others | |
| Mentorship | Informal network of physicians and surgeons co-ordinated by audit head |
| Library | Mental Health Commission |
| Freedom of speech policy | Catholic doctors' guild / world federation of doctors |
| Named confidential contact | Informal religion and psychiatry group |
| Child protection officer | Non executive Board Members |
| IVF and psychiatry | |
| Palliative care team | |
| Access to professionals as required | |

APPENDIX 3

Suggested models of clinical ethics support services

A breakdown of the answers to question 4 in the trust questionnaire survey

Question 4

If a support service was developed in the trust, what form do you think it should take?

| | | |
|--|----------|-------------------------|
| Total responses | 642/1171 | (55%) of all responders |
| Ethics committee | 366 | (57%) |
| Ethicist | 156 | (24%) |
| Chaplain | 37 | (6%) |
| Other | 83 | (13%) |
| Other: | | |
| Clinical governance | 8 | |
| Access to external advice / expertise | 93 | |
| Ethics forum / support group | 5 | |
| Ethics education | 2 | |
| Identified individuals in Trust | 4 | |
| Clinical director/supervision | 5 | |
| Multidisciplinary approach | 2 | |
| Specific team (not committee) | 3 | |
| Enhanced chaplaincy service | 1 | |
| LREC | 1 | |
| Part of R&D | 1 | |
| Community Health Council | 1 | |
| Formalising current mechanisms | 2 | |
| 3 wise men | 1 | |
| Mix of formal and informal services | 1 | |
| Network of service | 1 | |
| Joint approach for small organisations | 1 | |
| Combination of suggested approaches | 2 | |

APPENDIX 4

Professional organisations identified for questionnaire survey

Royal College of Physicians
Royal College of Obstetricians and Gynaecologists
Royal College of Nursing
Royal College of General Practitioners (including regional faculties)
Royal College of Psychiatrists
Royal College of Midwives
Royal College of Surgeons
Royal College of Paediatrics and Child Health
Royal College of Ophthalmologists
Royal College of Radiologists
Royal College of Anaesthetists
Royal College of Physicians and Surgeons of Glasgow
Royal College of Surgeons of Edinburgh
British Association of Occupational Therapists
UKCC
General Medical Council
BMA
British Association of Medical Managers
British Dietetic Association
Chartered Society of Physiotherapy
Society of Chiropractors and Podiatrists

APPENDIX 5

Trust questionnaire

Clinical Ethics Support Services in the UK

(This questionnaire does not relate to research ethics)

1. Does your Trust have any mechanism of formal support or advice on ethical issues for health professionals working in the Trust? Yes ☐1 No ☐2
If Yes what form does this take (please circle all that apply)
Ethics committee 1 ethicist 2 other 3 (please specify)
.....
2. Are you aware of any informal mechanisms which provide support or advice on ethical issues within your Trust? Yes ☐1 No ☐2
If Yes what form does this take?
.....

These questions are for Trusts without a formal Clinical Ethics Support Service

3. Do you agree with the following statement: **An Ethics Support Service for health professionals within the Trust, on ethical issues in clinical medicine would be desirable.** (please circle)
Agree strongly 1 Agree 2 Disagree 3 Disagree strongly 4
4. If a support service was developed within the Trust, what form do you think it should take? (please circle all that apply)
Ethics committee 1 ethicist 2 other 3 (please specify)
.....

If you have any comments you would like to make about clinical ethics support services please use the following space.

.....

We would like to contact all Trusts that have, and some that do not have, Clinical Ethics Support Services. Please can you confirm your contact details, or let us have the details of an alternative contact person for the next stage of our research.

Name Telephone
Job Title Fax
Address email
.....
.....

Thank you for your help. Please return the questionnaire in the envelope provided.

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APPENDIX 6

Health authority questionnaire

Clinical Ethics Support Services in the UK

(This questionnaire does not apply to research ethics)

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1. Do you have any mechanism for providing support or advice on ethical issues that arise in your Health Authority? Yes ☐1 No ☐2
If **Yes** what form does this take? (please mark all that apply)
Ethicist ☐1
Clinical ethics committee ☐2
Resource allocation committee ☐3
Don't know ☐4
Other (please specify) ☐5
.....
2. Does your Health Authority receive requests for advice on ethical issues in clinical care from health professionals? Yes ☐1 No ☐2
3. Do you think that a clinical ethics support service would be helpful in your Health Authority? Yes ☐1 No ☐2
If you wish to comment on clinical ethics support in the Health Authority please do so below.
.....
.....
.....
4. Ethical issues may arise for Primary Care Groups (PCGs) both from resource allocation and clinical practice. Do you think the Health Authority has a role to play in providing support or advice on these issues? Yes ☐1 No ☐2

We would like to contact all Health Authorities that have, and some that do not have, Clinical Ethics Support Services. Please can you confirm your contact details, or let us have the details of an alternative contact person for the next stage of our research.

Name Telephone
Address Fax
..... email
..... Job title

Thank you for your help. Please return the questionnaire in the envelope provided.

APPENDIX 7

LREC questionnaire

Clinical Ethics Support Services in the UK Questionnaire for LREC Chairmen

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1. Has your committee been asked to consider requests for ethical advice on **clinical**, rather than **research**, issues? Yes ☐1 No ☐2
If **Yes**, has the committee provided ethical advice? Yes ☐1 No ☐2
If **No**, would the committee be prepared to offer advice if asked? Yes ☐1 No ☐2
2. Approximately how often does the committee receive requests for clinical ethics advice
Less than one a year ☐1
1-5 times per year ☐2
6-10 times per year ☐3
More than 10 a year ☐4
Not applicable ☐5
3. Are you personally (i.e. outside the committee) ever asked for ethical advice on clinical issues because of your position on the LREC? Yes ☐1 No ☐2
4. Do you think that there is a need for ethical support on clinical issues within the NHS organisations which refer to you for research ethics advice? Yes ☐1 No ☐2

We would like to contact Local research ethics committees that have provided Clinical Ethics Support Services about this work. Please can you confirm your contact details, or let us have the details of an alternative contact person for the next stage of our research.

Name Telephone
Address Fax
..... email
..... Job title

Thank you for your help. Please return the questionnaire in the envelope provided.

APPENDIX 8

Professional organisation questionnaire

Clinical Ethics Support Services in the UK

(This questionnaire does not apply to research ethics)

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1. Does your organisation have any form of support service dealing with ethical issues in clinical care (as opposed to research) for your members? Yes ☐1 No ☐2

If yes what form does this service take?

- Clinical ethics committee ☐1
Telephone advice service ☐2
Written guidelines ☐3
Education ☐4
Other (please specify) ☐5

2. Do you think existing clinical ethics support services for health professionals in your organisation should be improved? Yes ☐1 No ☐2

3. If you have any comments about the need for, or the provision of, clinical ethics support for health professionals please write them below.

.....
.....
.....
.....

We would like to contact all professional organisations that have, and some that do not have, Clinical Ethics Support Services. Please can you confirm your contact details, or let us have the details of an alternative contact person for the next stage of our research.

Name Telephone
Address Fax
..... email
..... Job title

Thank you for your help. Please return the questionnaire in the envelope provided.

APPENDIX 9

Topic guide for interviews with chairmen of clinical ethics committees

Section I

1. When was the committee set up?
2. How often does it meet?
3. How is it constituted? List of members status of chair (medical or lay)
4. From where does it get its authority? Trust Board, official hospital committee, health authority,
5. Does it have a written constitution or terms of reference? Copy if possible
6. Does it have any funding or administrative support?
7. Do any of the members have a qualification in ethics?
8. Is there a programme of ethics education for members of the committee?
9. If no to above how do the committee members receive education/training in ethics?

Section II

1. What function/s does the committee have? education, policy formation, case review/consultation
2. How is each function accomplished? formal structures or is each situation treated differently
3. Policy formation. How much authority would guidelines produced by the committee have and from where would they get their authority? What subjects have been considered by the committee?
4. Case consultation/review. How often, what subjects?
5. Education. What form does it take, what subjects covered?
6. Does the committee make decisions by consensus or voting?
7. How well do you think the committee is recognised within the Trust?
8. What other sources of ethics support would be used by clinicians within the Trust?

Section III

1. What were the circumstances which led to the development of the committee?
2. Was the impetus mainly from management or clinicians?
3. What, if any, have been the difficulties experienced so far with the committee?
4. What do you consider have been the committee's achievements?
5. How would you describe the purpose of the committee?
6. Do you think it is achieving its aims?

Section IV

1. How do you see the committee developing?
2. How do you see clinical ethics support developing?
3. What is needed to encourage it to flourish?
4. What are the potential hindrances to its flourishing?
5. What issues do you consider would be appropriate for a clinical ethics committee to address?
6. How do you see the ethics committee fitting in with clinical governance?

General Comments

APPENDIX 10

Topic guide for interviews with LREC chairmen

1. How many requests about ethical issues in clinical practice does the committee get per year?
2. How do they present?
 - To the chair
 - To other members of committee
 - As a formal request to the committee
3. Does the committee have a procedure for dealing with such requests?
4. Is a decision given?
5. Is advice given?
6. What sort of issues are involved in the requests?
7. Do you think that the current arrangements for dealing with these requests are satisfactory?
8. Some Trusts have established clinical ethics committees for ethical issues relating to clinical practice. What are your views on this development.

