

Education and debate

Development of clinical ethics committees

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Support for dealing with ethical issues in clinical practice should be an integral part of patient care

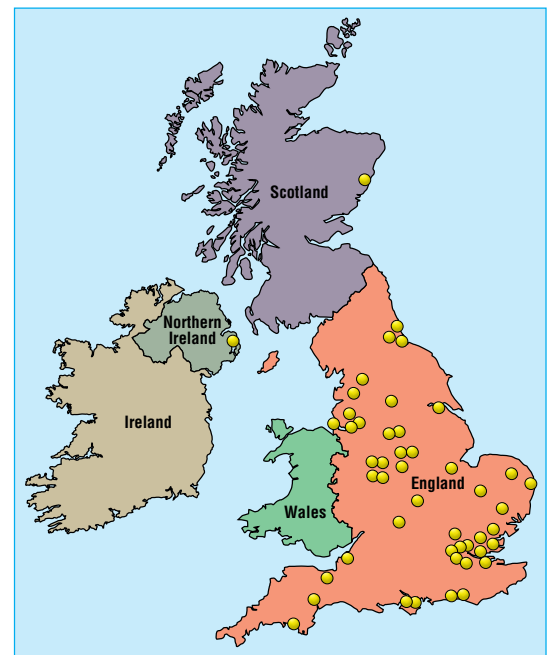
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Clinical practice raises a wide variety of ethical issues that can be difficult for individual doctors to resolve. Some NHS trusts have established clinical ethics committees to provide ethical support. These committees had largely worked alone until a meeting of committee representatives in January 2001 led to the development of the UK Clinical Ethics Network. The principal aims of the network are to promote the development of clinical ethics support in the United Kingdom, to encourage a high level of ethical debate in clinical practice, and to facilitate sharing of best practice between clinical ethics committees (box 1).¹ We consider the emergence of clinical ethics support in the context of similar development in other countries.

What is clinical ethics support?

Clinical ethics support can be described as the provision of support and advice to health professionals and patients on ethical issues arising from clinical practice or patient care. The support can take different forms, but in the United Kingdom the most common model is a committee or group sitting within an NHS trust, usually an acute trust. These committees are multidisciplinary and include lay members. Issues are referred to the committee by clinicians and managers, and some committees are now being approached by local general practitioners. Few committees include patients or their families directly in committee discussions.

The number of trusts with clinical ethics committees is increasing. In 2001 the Nuffield Trust published a survey of all NHS trusts that identified 20 clinical



Distribution of clinical ethics committees in United Kingdom

ethics committees.² A questionnaire survey conducted by the UK Clinical Ethics Network early in 2003 showed that 60 of the 315 acute NHS trusts had a clinical ethics committee (fig).³ We are unaware of any committees in primary care trusts, although two regional committees cover acute and primary care.

Functions of clinical ethics committees

The work of clinical ethics committees falls into three broad areas: providing ethics input into trust policy and guidelines around patient care, facilitating ethics education of health professionals within the trust, and giving advice to clinicians on individual cases (box 2).² The degree to which the committees engage in each of the functions varies, but there are examples of innovative work in all three areas. For example, some committees are involving patients in developing policies on cardiopulmonary resuscitation, using role play to help clinicians explore ethical dilemmas arising in their work, and developing a system of on-call support for case consultation. As committees become established and recognised, the scope of their work increases and they get more requests for advice from trust staff.

Box 1: Objectives of UK Clinical Ethics Network

- To offer support and advice to developing and established clinical ethics groups
- To provide networking facilities including a network newsletter, electronic mailing, and a network website
- To facilitate training for members of clinical ethics groups
- To support regional initiatives
- To organise an annual conference
- To produce a database of useful and relevant information for clinical ethics groups
- To establish links with clinical ethics groups internationally

Comparison with other countries

The development of clinical ethics committee in the United Kingdom was largely clinician led. The committees arose because clinicians were identifying difficult issues on which they felt that they needed ethics support and advice.²⁻⁵ Some countries have had a more top down approach, with committees (often called institutional or hospital ethics committees) forming in response to government recommendation or requirements of regulatory authorities.⁶ Many hospitals in North America also have ethics consultants, who provide individual support to clinicians, patients, and their families.⁷⁻⁸ Clinical ethics support is less widespread in continental Europe. However, all major hospitals in Norway are now required to have an ethics committee,⁹ and institutional ethics committees have been a feature of hospitals and nursing homes in the Netherlands for many years.¹⁰

Does ethics support make a difference?

It is difficult to evaluate ethics support using a traditional outcomes based model,¹¹ although some US studies have used this approach. A recent study of ethics input in an intensive care unit showed positive outcomes in terms of a reduction in time spent on ventilators among patients who eventually died and in satisfaction of patients' families with the process of care.¹²

Although measuring specific outcomes of ethics support can be helpful, it ignores other dimensions of ethics support. An equally important aspect is the provision of an explicit and transparent process for engaging with the ethical dimension of clinical decision making. A model of ethics support that facilitates and informs a shared understanding of difficult ethical issues can support and reassure both clinicians and patients, without presupposing that there is an ethically correct outcome. Thus, a principal value of ethics support may lie in its contribution to the process of ethical decision making.

UK Clinical Ethics Network

The UK Clinical Ethics Network is now an important source of information and support for clinical ethics committees and for NHS trusts that are considering providing ethics support for their staff. The network

Summary points

About a fifth of NHS acute trusts have clinical ethics committees and their numbers are increasing

The aim of committees is to facilitate ethical decision making by doctors and hospital policy makers

A national clinical ethics network has been formed to facilitate and coordinate high quality ethics support

The network aims to promote good clinical ethics support throughout the United Kingdom

provides a regular newsletter, an annual conference, and educational workshops, and facilitates sharing of information and experience between committees.

The network has also recently launched a website. The site provides contact details for all clinical ethics committees known to the network, ethical and legal discussion, hypothetical cases, and links to national guidelines on ethical issues (www.ethics-network.org.uk). The aim is to provide relevant information that is easily accessible for members, clinicians, and patients. Since its launch, the website has had an average of 105 hits a week, of which 62% are returning visitors. The most common search terms are consent and refusal of treatment.

Future development

Clinical ethics support is now an established feature of many NHS trusts. It has the potential to become a valuable component of high quality health care, but for this to happen it will require support from trust boards, clinicians, and the medical ethics community. The increasing number of clinical ethics committees, and the increasing workload of established committees, suggests that health professionals in the United Kingdom are becoming more aware of the need to openly engage with the difficult ethical issues arising in their work and that ethics committees are seen as a valuable part of this process.

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Box 2: Issues considered by clinical ethics committees

- Withholding or withdrawing treatment
- Do not resuscitate orders
- Advance directives
- Consent
- Capacity
- Refusal of treatment
- Confidentiality
- Genetic testing
- Assisted reproduction
- Issues around intensive care
- Issues in emergency medicine

- 1 UK Clinical Ethics Network. About the network. www.ethics-network.org.uk/who.htm (accessed 6 Feb 2004).
- 2 Slowther A, Bunch C, Woolnough B, Hope T. *Clinical ethics support in the UK: a review of the current position and likely development*. London: Nuffield Trust, 2001.
- 3 UK Clinical Ethics Network. What are clinical ethics committees? www.ethics-network.org.uk/what.htm (accessed 6 Feb 2004).
- 4 Larcher V, Lask B, McCarthy J. Paediatrics at the cutting edge: do we need ethics committees? *J Med Ethics* 1997;23:245-9.
- 5 Slowther A, Underwood M. Is there a need for a clinical ethics support service in the UK? *J Med Ethics* 1998;24:207.
- 6 Joint Commission on Accreditation of Healthcare Organizations. *Comprehensive accreditation manual for hospitals, the official handbook*. Oakbrook Terrace IL: JCAHO, 1996:R1.
- 7 Ehleben CM, Childs BH, Saltzman SL. What is it exactly that you do? A "snapshot" of an ethicist at work. *HEC Forum* 1998;10(1):71-4.
- 8 La Puma J, Toulmin SE. Ethics consultants and ethics committees. *Arch Intern Med* 1989;149:1109-12.
- 9 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*. Brussels: Brussels University Library, 2000: 91-105.
- 10 Van der Kloot Meijburg H. Different profiles for the institutional ethics committees in the Netherlands. *HEC Forum* 1994;6:139-57.
- 11 Fox E, Arnold RM. Evaluating outcomes in ethics consultation research. *J Clin Ethics* 1996;7:127-38.
- 12 Schneiderman LJ, Gilmer T, Teetzel HD, Duggan DO, Blustein J, Cranford R, et al. Effect of ethics consultations on non-beneficial life-sustaining treatments in the intensive care setting: a randomised controlled trial. *JAMA* 2003;290:1166-72.

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Role of next of kin in accessing health records of deceased relatives

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When potential benefits outweigh harms should clinical geneticists be given access to medical records of dead patients without relatives' consent?

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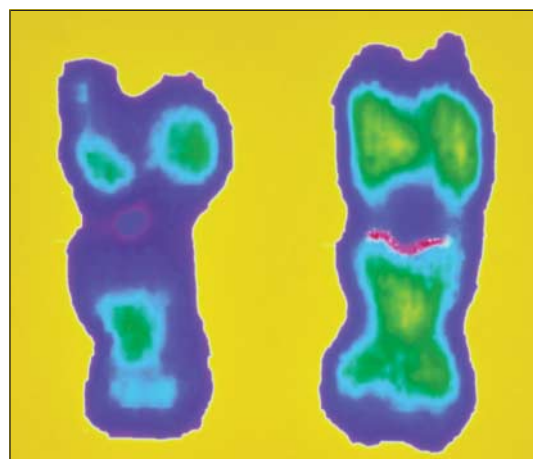
Family history is an important tool used by clinical geneticists to assess risk. Patients' recollection of family illnesses can sometimes be inaccurate or lack detail. Information obtained through medical records of the patient's relatives is therefore important. When relatives are alive, the person seeking genetic advice usually asks them for access to their medical records. However, access is more difficult if the relatives are dead. This difficulty is the result of a combination of a lack of clarity in the law and a wariness among hospital departments about releasing information in the light of recent public inquiries and means that hospital departments are often unwilling to allow access to the medical records of deceased patients without consent from their next of kin. We use a fictional case based on real experiences to illustrate the difficulties that this practice can cause in obtaining relevant information for diagnostic and surveillance management of relatives.

Case history

Anne Cole is 38 years old and has a family history of cancer. Her mother died of breast cancer at the age of 42 and her maternal grandmother developed breast cancer in her late 40s. Her maternal aunt died three years ago from an abdominal malignancy, aged 56. Ms Cole wants to know whether she is at increased risk of developing breast cancer and what measures she can take to prevent it or improve her prognosis should she develop it.

The clinical genetics team attempts to confirm the details of Ms Cole's family history through cancer registries, and from pathology reports by accessing hospital records. The maternal aunt is of particular concern, since if her abdominal malignancy was an ovarian carcinoma, the chances of a dominantly inherited predisposing gene mutation such as BRCA1 or 2 are increased.

The cancer registry confirms the diagnosis in Ms Cole's mother but has no details on her aunt. The hospital's histopathology department has details on the



Having only one BRCA1 gene on chromosome 17 (shown in red) increases the risk of breast or ovarian cancer

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aunt but refuses to disclose them until it has received a signed consent form from her next of kin authorising such access. Ms Cole does not know who is the next of kin of her aunt. She knows her aunt had a husband and three children but is not in touch with them, does not know their address, and feels it would be inappropriate for her to contact any one of them to seek consent. She asks the genetics department whether such information could be accessed without having to involve a third, possibly unrelated, person, who might find such an approach upsetting.

What is meant by next of kin?

The term next of kin, as used in everyday language, has no single definition. Although a dictionary might define next of kin as the nearest blood relative, many married people would regard their spouse as their next of kin. Others might wish to nominate a trusted close friend as next of kin.

These differences are further complicated by the fact that next of kin has no legal standing in relation to