

## Snapshots of five clinical ethics committees in the UK

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### Abstract

*Each of the following papers gives an account of a different UK clinical ethics committee. The committees vary in the length of time they have been established, and also in the main focus of their work. The accounts discuss the development of the committees and some of the ethical problems that have been brought to them. The issues raised will be relevant for other National Health Service (NHS) trusts in the UK that wish to set up such a committee.*

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### The development of Peterborough Hospitals NHS Trust clinical ethics committee

#### DEVELOPMENT OF THE COMMITTEE

The first clinical ethics committee meeting at Peterborough Hospitals NHS Trust was held in September 1999. The concept of a clinical ethics committee was first raised the previous year independently by doctors, nurses and professions allied to medicine—Professions Allied to Medicine—(PAMS) within their own professional groups. It was then discussed collectively by the trust's clinical management board in response to recommendations within the clinical governance agenda.

As a result of this discussion it was proposed by the clinical management board, whose members are multiprofessional, that a practice development nurse should look into the background of such committees and submit a formal proposal to the board. A proposal supporting the need for, and viability of, an ethics committee that would provide a multidisciplinary forum for the discussion of ethical issues affecting the delivery of patient care in Peterborough Hospitals NHS Trust, was submitted and accepted by the clinical management boards in May 1999.

#### MEMBERSHIP

The practice development nurse who submitted the proposal was invited to configure the committee and recruit members. It was decided at the outset that the committee should be multidisciplinary and would comprise 15 to 20 members. Membership is as follows: two nurses, two PAMS, two lay members, a solicitor, a philosopher, a chaplain, two

to four doctors, a midwife, a representative from an ethnic minority and a general practitioner (GP). The aim was to have a broad representation of views, while keeping the committee manageable. Membership could be extended to include other areas of expertise required for a particular issue that the committee addressed. Although the committee met for the first time in September 1999, full membership was not achieved until June 2000.

The committee members were a group of people who were interested in ethics, but few had any formal training in ethics. One member had an MA in ethics and another had a postgraduate diploma in health care ethics and was currently studying for an MA in medical and health care ethics. The philosopher on the committee taught the master's programme of ethics at Northampton College University.

#### DEVELOPING THE AIMS OF THE COMMITTEE

The terms of reference of the committee were kept general rather than specific, as this was a new development, for which there were no specific guidelines. The committee decided that the main functions of the committee would be to educate and act as an ethics resource for trust staff. The committee would also undertake the provision of ethical advice on the development of institutional policies. It would also provide a forum for objective, interdisciplinary review of trust policies. The terms of reference were to be reviewed approximately one year after its formation. It was felt that as members became more knowledgeable about ethics, they would be able, in the future, to define the terms of reference of the committee more specifically.

The committee has had much discussion about whether it should be involved in case consultation. The consensus is that the committee is not yet well enough established for this, and that a significant number of staff might feel this would constitute interference in their clinical judgment.

Meetings are held monthly in the evening. Initially meetings were held alternately in the day and in the evening. However, membership attendance during the day was poor because of members' other commitments.

Funding to support the committee was secured in April 2000 from the Cambridgeshire and North-west Anglia Education and Training Consortium. The funding, for two years, supports the payment

of the philosopher for attending meetings, four hours of secretarial time each month and resource purchases such as the medical and nursing ethics journals and training costs for committee members.

#### ETHICAL ISSUES AROUND THE TRUST'S GUIDELINES AND POLICY

The committee has critiqued various hospital policies and guidelines from an ethical perspective as a method of self education. These have included the trust's advance directive and CPR policies, which include do-not-resuscitate orders. Comments and observations made by the ethics committee were sent to the resuscitation committee, and the ethics committee then discussed their response.

The trust's strategy has also been looked at in some depth. Comments have been sent to the chief executive suggesting ethical perspectives that the committee feels should be included in the forthcoming update of the strategy. One broad comment is whether it should be the trust strategy to promote the availability of complementary medicines to staff, which on the whole are not evidence-based, whilst advocating in the same strategy that the trust should strive to provide research and evidenced-based care. Another question raised is: if complementary care is being made available to staff, should it not also be offered to all patients. The ethical principles of equity and justice were used as arguments against the strategy, to promote such a stance.

#### RESPONDING TO SPECIFIC CONCERNS OF TRUST STAFF ON ETHICAL ISSUES

Eight months after its formation the committee moved from its learning stage into its active stage. The clinical management board asked the committee to look at the issues surrounding media intervention in patient care and to make recommendations if appropriate. The request was as a result of concern among trust staff that the setting of priorities in surgical waiting lists was being influenced by pressure from the local media. The committee invited the communication manager to the committee meeting to discuss the issue.

The discussion centred on a case in which some staff felt that a patient had received care because the patient's case had received media attention. However, a broader discussion of equity among patients ensued. Committee members raised, as examples, the issue of patients who call consultants' secretaries frequently, or who persistently visit their general practitioner (GP). In some cases such patients have their appointments brought forward at the expense of other less "demanding" patients. However, the time taken by staff in resisting such demands could be even more unjust to other patients because it might mean their treatment was delayed even more.

In some situations there was a conflict between providing the treatment being demanded and the best care that could be delivered.

The conclusion of the discussion was that patients have a right to be treated justly, but not to make demands for better treatment than could be

given to all patients in a similar clinical situation. However, the greater good was sometimes achieved by meeting the demands of the occasional patient. The communication manager said only 20% of press coverage of the trust was in fact negative.

Confidentiality of patient information in the context of media coverage was also discussed. The conclusion from this discussion was that unless a patient gave specific permission no information could be given to the media.

The ethical discussions have been full and lively and some changes to the trust's media and patient complaint policies and distribution of those policies have been recommended. We currently await the clinical management board's response to our recommendations.

The committee feels that this request has been an important milestone in the development and acceptance of the committee within the trust. It has since been asked to advise on ethical aspects of admissions to intensive care.

#### RAISING THE PROFILE OF THE COMMITTEE

A year after the establishment of the committee we feel ready to advertise our existence more broadly. Members are accepting numerous invitations to talk about the activities of the committee at various trust meetings and educational events, and the committee is provisionally planning a regional ethics educational workshop.

Evaluation of the committee is essential, but will, we believe, be premature until the committee has been in existence for two years or more. We hope by then there will be information from other committees in the UK about how they have evaluated their effectiveness. The past year has seen the committee form, grow and plan for the future, in which its overall aim is to contribute to the provision of high quality care within Peterborough Hospitals.

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### **A clinical ethics committee in a district general hospital**

#### INTRODUCTION

It became apparent in the early 1990s that our hospital had no forum for debating the increasing range and complexity of ethical dilemmas faced in routine clinical practice. By analogy some consultants felt that if ethics committees were needed to review research ethics why not clinical ethics committees too? There is less consensus in clinical ethics than in research ethics, and many clinical ethical dilemmas are arguably more complex than those in research. Consequently a group of interested clinicians introduced the concept of a clinical ethics committee to the consultant medical board. While some consultants felt there was no need for such a forum, most supported the initiative. Acknowledging the dearth of experience in the United Kingdom<sup>1-3</sup> a group of 17 interested people was recruited after consultation with the medical board

*Table 1 Inaugural membership*

6 clinicians	
2 physicians	
1 general surgeon	
1 psychiatrist	
1 obstetrician	
1 paediatrician/neonatologist	
3 Members of the nursing profession	
1 chief nurse	
1 midwife/midwifery manager	
1 oncology ward sister	
Head physiotherapist	
Principal pharmacist	
Radiology services manager	
Hospital chaplain	
General practitioner	
3 lay members:	
	A senior police officer
	A personnel director
	An executive of a public company

chairman and the prospective clinical ethics committee chairman and began work, taking advice from ethicists at our local university and medical school.

#### SETTING, MEMBERSHIP AND ROLE

The Wirral Hospital is a 1250-bed hospital providing secondary care services to a population of 360,000. It is physically located with, but managerially distinct from, the regional oncology centre. The inaugural committee was multidisciplinary (see table). We were keen to recruit assertive lay members. The elected chairman was a senior clinician with extensive management experience and a longstanding interest in ethics dating from the London Medical Group in the 1970s. We felt it important to have a chairman of sufficient standing to have the confidence of both management and senior clinical staff. The elected vice-chairman was a paediatrician with an MSc in health care ethics and is chairman of the local research ethics committee.

A junior doctor was added to the inaugural group. A psychiatrist, because of pressure of time in his role as medical director, was replaced by a consultant in palliative care. An intensive care anaesthetist subsequently joined the committee. We decided against having legal representation, but the trust solicitors have been consulted, as appropriate, over several issues. We have been helped by the fact that the trust chairman, a solicitor, has a strong interest in ethics and has attended the committee as an observer. The committee reports to the trust board and also to the medical board (all local hospital consultants).

We expected to be asked to consider dilemmas involving individual patients. In fact our major role has been in advising on the ethical aspects of policies produced elsewhere in the trust or instigated by the committee itself. We have used working groups which have reported back to the full committee. Educational activities have so far been self directed but we are beginning to address the education of junior doctors and other professionals. We have not formally undertaken individual case review, al-

though committee members, especially the chairman, have been informally consulted over such cases.

#### SPECIFIC ISSUES

The clinical ethics committee has been pivotal in the development of trust policies, including the "do not resuscitate policy", patient confidentiality in relation to the hospital computer information system, a contract for patients admitted with alcohol misuse and the local application of the British Medical Association's (BMA) guidelines for withholding and withdrawing medical treatment. We have also debated the eligibility of patients for renal replacement therapy, and issues around late termination of pregnancy.

The most recent dilemma discussed was the increasing number of requests from clinicians for a specific blood test, the CD4 lymphocyte subset, as a surrogate marker for HIV infection. It appeared that clinicians, when faced with the personal and practical difficulties of discussing HIV testing with patients, were bypassing these by requesting CD4 measurement instead. The test was also being requested by clinicians as part of a range of tests for patients with undiagnosed prolonged infections and wasting diseases, again without appropriate information being given to the patients.

The laboratory personnel were uneasy with this practice and felt it conflicted with their professional responsibility to perform investigations as requested. Their advice was that a low CD4 count was a specific indicator of HIV infection and thus the committee felt that doing the test without appropriate counselling of patients was unjustified. Also the CD4 measurement was not sufficiently sensitive to exclude HIV infection confidently. There was a danger, therefore that a normal result might be falsely reassuring. The request for the CD4 test without counselling was held to be an infringement of the patient's rights. It was also considered to be an infringement of the rights of the laboratory staff, who had a duty to uphold good medical practice and ensure adherence to guidelines. In other immunodeficiency states where HIV infection was not strongly suspected, other lymphocyte markers or tests for immunodeficiency could be done without infringing the patient's rights or compromising the laboratory staff.

The committee advised, therefore, that the laboratory staff could refuse to do the CD4 measurement unless the requesting clinician had given appropriate information to the patient.

As a result the consultant haematologists will now not sanction the CD4 test without the specific consent required.

#### CHALLENGES

While the committee has been generally welcomed, the greatest difficulties encountered have related to perceived threat to individual clinicians when dilemmas have been presented to the committee by other professionals in their clinical team. These difficulties have not yet been resolved. Perhaps the

most valuable role of clinical ethics committees is to emphasise the difficulties inherent in clinical ethical dilemmas, not just provide simple answers.<sup>4</sup>

Another challenge has been to persuade professionals of the importance of involving patients and families in decision making. This was highlighted when we debated the hospital's "do not resuscitate policy". Some committee members, and other clinicians involved in devising the policy, were reluctant to involve patients and families fully in the information disclosure necessary to make "do not resuscitate" decisions. Debate in committee succeeded in developing a policy which emphasised that patients should be involved in making such decisions, unless there were exceptional grounds for not doing so. Recent media publicity has vindicated the committee's stance.

In discussing withholding and withdrawing medical treatment in incompetent patients, we recognised that doctors might leave themselves vulnerable legally, despite making ethically justifiable decisions. After preparing local modification of the BMA document on this issue, we sought trust legal advice. This was necessarily defensive in pointing out that doctors might leave themselves vulnerable to charges of attempted murder or manslaughter if withholding or withdrawing such treatment, and recommended an approach in favour of continuing treatment. This approach could require doctors to act against the best interests of their patients in starting or continuing treatment that might prolong suffering. The committee was charged with producing, and did produce, advice which steered a middle road between protection of the trust and doctors, and a regard for patients' best interests.

The educational challenge has been to persuade staff, particularly the junior medical staff, that ethical issues carry as much weight as purely didactic clinical teaching. Medical trainees are more set upon gaining factual clinical knowledge than debating the ethical issues surrounding them.

#### CONCLUSIONS AND OBSERVATIONS

The committee is still learning and developing. We have yet to achieve universal acceptance among clinicians and need to develop our educational role. We expect to become more involved in resource issues, and probably in individual case review. There are undoubtedly further challenges, but we believe that clinical ethics committees will play a pivotal role in delivering clinical governance and in mediating partnership between clinicians and patients.

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#### The ethics of clinical practice committee in Nottingham

Recognition by the medical director and members of the medical staff committee that ethical problems were playing an increasing role in clinical practice led to the formation of the committee at the City Hospital in June 1994. The title of ethics of clinical practice committee (ECPC) was chosen to emphasise its multidisciplinary nature; there was representation of medical and nursing staff from within the hospital and a hospital chaplain represented a multi-faith religious centre in the hospital. There are currently twenty-two representatives, eight of whom are from outside the hospital, including a professor of social studies, a senior lecturer in law, a deputy director of public health and three general practitioners (two retired).

The terms of reference for the committee are shown in the table.<sup>5</sup> Minutes are circulated to all consultant staff and to the hospital nursing forum. The committee meets monthly and in 1999 was expanded to represent both the City and University Hospitals in Nottingham as it is hoped to develop common policies in the new spirit of cooperation between trusts.

#### CASE DISCUSSION

In 1994 the committee discussed a problem of treatment for a patient with metastatic cancer, which was referred by the department of clinical oncology. The patient had been informed by medical relatives that there was a newer treatment, by injection, as opposed to the standard irradiation therapy. Injection therapy was very costly but apparently more effective. However, the use of the new treatment would soon exhaust the department's budget if it was available to all relevant patients. Guidance was sought from the clinical unit on the following five questions.

(1) If patients ask about treatments available for their disease should they be told of treatments that are available elsewhere but not in our department?

Committee members thought patients should be given as much information about treatment options as was available to the medical staff involved in their care. The availability of the treatment and its considered effectiveness should also be discussed fully with the patient.

*Table 1 Terms of reference for ethics of clinical practice committee*

General ethical issues arising from established policies in connection with patient treatment and care.
Ethical issues associated with new initiatives in patient treatment and care.
Items of ethical import concerning individual patients.
Advice on moral conflict issues where the clinician or other professional asks for such assistance.
Issues of conflict between the wishes ++of the purchaser and provider in terms of patient care.

(2) If the patient requests an expensive treatment do we provide that treatment for this one patient knowing that the treatment could not be afforded for other patients who could benefit from it?

Member felt that patients should be offered treatments that were considered to be of proven benefit for their symptoms. The question was whether the new injection treatment had been shown in properly controlled trials to be superior to the current treatment that was available. There needed to be an agreed policy within the department as it was recognised that directorates needed to keep within their budget allocations as well as considering the needs of all patients they treated.

(3) Should we offer to treat this patient as a National Health Service (NHS) patient if he were to pay for the cost of the drug alone but not for the full cost of being treated privately?

It was considered by the committee to be highly unethical for a patient to pay for the cost of the drug alone and to receive the remainder of his treatment as an NHS patient. Private and NHS treatment should always be kept strictly separate. The committee felt the ability to pay should not determine who receives a specific treatment within the NHS.

(4) Should we advise this patient to try and obtain the treatment from another centre in the UK?

A few centres are offering the treatment that this patient requested but those centres use various selection processes. The committee advised that patients should be informed of centres in the UK for this particular treatment if that information was requested. The possibility of referral from the patient's health authority within NHS funding would have to be considered. If the patient was too ill to travel and the treatment was essential, the general practitioner (GP) fundholder or health authority should be approached for funding for the treatment.

(5) Should we offer to treat the patient as a private patient?

If the patient were to be accepted as a private patient then this would require appropriate referral from the GP or other medical person.

#### FURTHER COMMENTS

The above case shows the close relationship between ethical and legal issues. The legal expert on the committee subsequently reported on the issue of the patient being treated as an NHS patient and paying for the cost of the drug alone without any handling or administrative charges. The suggestion was that it would not be illegal to enter into such an agreement but it would be risky to do so on the basis of mixed liability. A proper contract would need to be drawn up with the patient, and this would probably need specialist legal advice. If one supplied the drug to the patient on this basis then one could not force the patient to pay if he/she then refused. Such an arrangement appeared to be outside the spirit of the NHS and there did not

appear to be a case precedent or reference in the published literature in this area.

It is interesting to note that the subject of rationing of health care due to limited resources has been the focus of attention for the committee on a number of occasions.<sup>6</sup> The director of public health is a member of the ECPC. In 1997 there was increased pressure upon public health directors to sanction expensive individual packages of care at a time of major cash restraints with the purchaser/provider split. Inequalities of health care delivery had also been exacerbated in some instances by the issue of general practice fundholding. The ECPC also discussed the setting up of a forum in Oxford as a means of providing advice on rationing decisions in health care.<sup>7</sup>

#### A SECOND CASE DISCUSSION

The question of whether a patient with advanced cancer should pay for an expensive drug not available on the NHS while being treated in an NHS hospital arose once more, in 1999. The drug in question was licensed and may have had limited benefit in prolonging the patient's life. However, the drug was still regarded as of marginal benefit (it was assumed that any drug of proven efficacy would have been funded and made available to all NHS patients). Five years after the first case discussion members expressed some uncertainty about whether the principle of respecting the autonomy of the fully-informed patient, who wants to try every last avenue of treatment at whatever expense, overrode the principle of justice, with patients on an NHS ward receiving differential access to treatment.

Members are increasingly aware that there are examples of supplementation of state provision by private care within the NHS. There are also examples of patients commencing care in the private sector and then being admitted to NHS facilities with complications. Oncology patients having private treatment outside the NHS are an example of such a group of patients. It was felt that so long as there is no direct intermingling of patients receiving private and NHS care on the same ward, then some of the ethical dilemmas are avoided but it still raised the overall problem of equity of access.

On this occasion there was a 50/50 split in the viewpoints of members of the ECPC, with many of the doctors stating that the patient should be allowed to spend his own money on a drug even if it is only of marginal benefit. Many of the nursing staff felt such action was fundamentally against the principles of the NHS. Others pointed out that the core question may not be one of the patient's right to choose a treatment believed to be of marginal benefit, but whether the NHS or any other entity has a duty to make this treatment available. The NHS provides its services essentially on the basis of citizenship: by living in the country and paying taxes people are entitled to receive its services. The essence of citizenship is that like cases are treated alike and access and entitlement to treatment does not link to ability to pay. Patients using a particular

service should be treated equally in relation to their clinical needs. This is the only morally legitimate way to proceed.

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### **To test or not to test: that was the question: the first challenge for a novice clinical ethics group**

Two years ago a clinical ethics advisory group (CEAG) was established at the James Paget Hospital. It has adopted a "bootstrap" approach to its development and slowly determined its role and activity. The membership includes consultants, nurses, the hospital chaplain, a speech therapist and a lay person. Recruitment of a GP has been unsuccessful as attendance at the meetings does not carry remuneration. Meetings are held bimonthly or more frequently as the need arises.

The group has debated local case studies in order to develop skills in the analysis and management of ethical issues. Outside educational courses have also been attended. Links with the faculty of law at the University of East Anglia have been established.

The CEAG determined that it should be an independent body and act only in an advisory capacity. The first substantial case where its advice was sought is presented.

#### **CASE REPORT**

A health care worker sustained a needlestick injury during a surgical procedure on a patient who was potentially at risk of HIV infection. The health care worker had followed the protocol for universal precautions and, following the injury, sought to follow the recommendations laid down by the trust. A starter pack for postexposure prophylaxis against potential HIV infection was provided. However, the health care worker was reluctant to begin treatment because of previous drug sensitivities, the complexity of the treatment and the other possible side effects. The health care worker asked whether the treatment would be necessary if the patient was found to be HIV negative. Following recovery from the general anaesthetic, the patient was seen and counselled by a health advisor. Unfortunately, consent for HIV testing was refused on the grounds that the patient felt unable to cope if there was a positive diagnosis. The plight of the health care worker was explained to the patient who felt it was unfair that he should have to be tested because of the needlestick injury. It was noted that a sample of the patient's serum had been saved prior to the surgical procedure for cross matching.

The consultant in genito-urinary medicine (GUM), who was also a member of the CEAG, was asked to become involved. He met with the patient, who again declined to consent to testing. He suggested that the opinion of the CEAG be sought. As prophylaxis needed to be taken within 48 hours

of the injury, an emergency meeting of the CEAG was called on the evening of the event, some four to five hours after the needlestick injury.

Prior to this advice was also sought from the General Medical Council and legal experts.

The General Medical Council has produced guidelines on HIV testing in exceptional circumstances. In situations where prophylactic treatment is available, an existing blood sample taken for other purposes may be tested. However, this could then be challenged in the courts or be the subject of a complaint to the employer and the General Medical Council. This would then require the hospital staff to justify their action.<sup>8</sup>

Legal advice suggested there was no right or wrong decision in testing or not testing, as long as the case had been discussed with peers and employers.

Discussions were also held with other genito-urinary physicians at local, regional and national level. They were sympathetic to the plight of the health care worker, but they all considered these were not the sort of exceptional circumstances that would justify testing without consent.

#### **THE FIRST CEAG MEETING**

Five members of the CEAG, including the GUM physician, met at very short notice to discuss the case. The problem was identified as whether or not the clinicians could test a blood sample of a patient for HIV without consent when a health care worker had suffered a needlestick injury. A structured approach was taken and the facts of the case were examined. The individuals involved were identified as:

- The healthcare worker
- The patient
- The partners and family of both the health care worker and the patient
- Other patients that the health care worker might become involved with, who could then be at risk of cross infection

The right of the patient not to be tested without consent was considered, as well as the right of the health care worker to know the HIV status of the patient. The main discussion focused on the utilitarian argument of weighing the consequences of each course of action. The argument in favour of not testing was based on the distress a test would cause the patient. The argument in favour of testing was that the uncertainty of infection would cause considerable psychological stress to the health care worker and could put other members of the health care worker's family at risk. In addition, the worker might have to be restricted in clinical activity thereby affecting the delivery of care to other patients (for example, cancelled operating lists, clinics etc). Significant career effects might also occur. The potential physical harm from the prophylactic drugs was also taken into account. Most of the members of the meeting could person-

ally identify with an equivalent situation that they might encounter in their own everyday practice.

The committee concluded that the balance of arguments supported the blood testing without the patient's consent. However, as there was some time before a final decision needed to be taken, it was agreed to reconsider the issues at a larger meeting of the CEAG the next morning. This would also allow time for further counselling of the patient.

#### THE SECOND CEAG MEETING

At the second meeting, seven members reviewed both the case and the outcome of the first meeting. Two members who were present at the first meeting were unable to attend. In the subsequent debate the rights of the patient were seen as paramount. There was an opinion that all health care workers must subordinate their own rights to those of their patients. The decision on prophylaxis was for the health care workers to take as they were aware of the risks they took in the course of their work. The utilitarian arguments were seen as less persuasive in this context. The consensus view of the meeting was that testing without the patient's consent should not take place.

#### THE SUBSEQUENT EVENTS

As no testing took place, the health care worker took the prophylactic medication, became unwell and developed a rash. The worker felt aggrieved at a perceived lack of support from the CEAG.

#### THE LESSONS LEARNT

At the next bimonthly CEAG meeting, there was a review of the case consultation and various points emerged.

1. The complexity and unusual nature of the case had been a serious challenge to the CEAG and had revealed weaknesses in its operation. No formal plan had been established for the management of emergency ethical dilemmas. Organisation of the emergency meetings was difficult and documentation of the discussions was therefore limited. The time available was very limited for considered debate.
2. The leadership of the CEAG was not clear during this episode because the chairman was on leave.
3. The GUM clinician acted in his capacity both as a consultant providing clinical advice on the case and as a CEAG member in debating the ethical issues. It was later agreed that this could lead to a conflict of interest.
4. The two meetings had come to different conclusions based on two different approaches to the problem (utilitarian and deontological). Those who attended both meetings found their opinions changed as the debate developed. This demonstrated that there was no method for the resolution of such disagreement within the CEAG, beyond consideration of a further debate.

5. The health care worker had expected an executive decision for testing and had misunderstood the advisory role of the group. This showed that the role of the CEAG was unclear in the minds of hospital staff. Many staff still perceived the role of the ethics committee as being to make difficult decisions.
6. The CEAG had not established a mechanism for formal discussions with any of the parties, during the assessment of the ethical situation. However, most of the committee was agreed that their presence during a meeting would constrain debate. There was no mechanism either for formally debriefing the parties afterwards about the decisions that the CEAG had reached.
7. The visceral response of most clinicians ("test") was in stark contrast to the opinion of the GUM specialists nationally ("don't test"). The CEAG were disappointed that the GMC guidelines and advice from other national bodies failed to give direction and support in this area of conflict. It was difficult to see where a developing ethics group could go to obtain such support.

#### CONCLUSION

It was unfortunate that such a difficult case was the first real test of the CEAG. As a result of this episode the group is looking at its operational policy and the way in which it presents itself to the rest of the trust's staff. The issue of a lack of national guidance and support on difficult ethical issues should be debated. Perhaps a national or regional ethics advisory group may be required for help with issues where a local group feel out of their depth.

#### Acknowledgements

This paper has been a case study in which there was substantial contribution from all members of the CEAG. The authors have merely written the report.

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#### The clinical ethics committee at St Mary's

The clinical ethics committee (CEC) at St Mary's was established by the trust medical advisory committee (TMAC) in 1997. It was inspired by the Imperial College Medical School (ICMS) course in medical ethics that several members of the TMAC attended. The only stipulation of TMAC was that the chairman should be a trust consultant and that the professor of medical ethics at ICMS should be a member of the committee.

The CEC was developed following the model published by Henry J Silverman in 1994, describing how such a committee had been established then revitalised in Maryland and New Jersey.<sup>9</sup> An account of three UK ethics committees was also helpful.<sup>3</sup> Members were selected because of their

Table 1 *Original membership of the committee*

Consultant physicians	2
Nurses	6
Professor of medical ethics	1
Reader in medical ethics	1
Physiotherapist	1
Paediatric social worker	1
Medical student	1
Lay member	1
Hospital chaplain	1

enthusiasm for clinical ethics and not as representatives of their discipline or department. However, the committee membership was similar to those of other hospitals on which we had modelled ourselves.

Since then, there have been some changes in membership. The vice-chairman is now a senior nurse and the chaplain currently fulfils the role of secretary. The trust does not provide secretarial facilities. Since the advent of clinical governance the committee, while still reporting regularly to TMAC, also reports to the clinical quality steering group. This group is responsible for the circulation of any guidelines that the CEC produces and for communication with the trust board.

#### ETHICS CASE CONSULTATION: THE CHOSEN FOCUS OF THE COMMITTEE

The committee has chosen to focus on assisting the clinical staff of the trust in the management of cases when difficult ethical issues arise. The modus operandi is that requests for a clinical opinion come either directly from a consultant to the committee chairman, or through the usual request path for a specialist consultant opinion. The patient is then seen at the earliest opportunity by any clinical member of the CEC, who then summarises the case. The summary is circulated to those members of the CEC who are available, or who may have specialist knowledge relevant to the case, for example palliative care. The chairman is contacted, or in his absence the vice-chairman, who decides whether an opinion can be offered immediately or whether an emergency committee meeting should be called. The opinion of the member of the CEC who sees the patient is always written in the case notes and the case is always discussed at the next meeting of the CEC. If the opinion of the committee differs from that originally entered in the case notes, then the amended opinion is also documented in the notes.

#### CASE EXAMPLES

##### *Advance directives*

Soon after the committee was established it was asked to give an opinion on the withholding of hydration and nutrition from a patient who was resident overseas and who had been admitted with a severe intracerebral haemorrhage that rendered the patient unconscious, although the patient was still breathing spontaneously and there was no indication for neurosurgery. The patient had

written an advance directive (AD) that was legally valid in the jurisdiction in which she was resident. The AD had been written five years previously after the death of a friend following a severe stroke, and the patient's clinical condition corresponded exactly to that stipulated in the AD. The directive stated that the patient did not want hydration, nutrition or any life-prolonging therapy in these circumstances.

This was the first time that a patient who had written an AD was being managed in the trust. If the AD was followed then the unconscious patient would be transferred to a ward with no intravenous line or nasogastric tube inserted. All nutrition, hydration and life-sustaining treatment would be withheld, in a patient who was not necessarily irreversibly close to death. The patient's spouse and children, who were anxious that the AD was complied with, had accompanied the patient from overseas. The consultant in intensive care asked the CEC for guidance on how the patient should be managed.

The CEC members were unanimous in supporting adherence to the AD. They thought the patient's condition corresponded to one of the situations specified in the AD, that the AD had not been written under duress and that there was no strong reason to suggest that the patient had changed her opinion since writing the AD. However, the committee thought the opinion of an English court should be sought as a matter of urgency. The CEC's opinion was written in the hospital notes and communicated to the patient's family, who appeared much relieved by it. However, while an application to the court was being prepared the patient died.

Subsequent to this case the CEC has been asked to advise on another case of an overseas patient who suffered a severe stroke while in the UK and who had an advance directive. In this case the AD did not clearly apply to the patient's clinical state and the CEC did not advise compliance with the AD. The patient recovered sufficiently to be flown home.

#### GIVING ADVICE IN EMERGENCIES

The ability of the CEC to respond in an emergency is illustrated by the case of a patient with an imminently life-threatening condition who was refusing treatment which would be life-saving, on the grounds that he had suffered a reaction to previous treatment. The treatment needed to be given within a few hours or the patient would suffer irreversible brain damage. The patient's disease had resulted in moderate hypoxia but he did not appear confused. The consultant caring for the patient asked the advice of the CEC on whether it would be ethical to treat the patient against his will. The chairman and the other consultant physician on the committee were on annual leave so the vice-chairman, a senior nurse, consulted with the professor of medical ethics. They felt that the degree of hypoxia was enough to lead to a degree of confusion that would impair decision making capacity in the patient. They



established that the patient had not been given information about the consequences of refusing treatment before the hypoxia had developed. Therefore, their advice was that it would be ethical to treat the patient against his wishes, on the assumption that if the patient was not hypoxic he would consent to life-saving treatment, even if there was a risk of a reaction to the treatment. The treatment was given, the patient had a moderate reaction but survived. Following recovery the patient expressed gratitude that his wishes had been overruled. The ethics advice was available to the clinicians within two hours of being sought.

#### COMMITTEE ADVICE TO TRUST MEMBERS

Apart from helping with the management of cases, the CEC has advised various members of the trust on a variety of subjects including the following:

The ethical issues raised by limb transplantation. The ethical problems involved in the treatment of staff and students in the accident and emergency department.

The ethical issues around providing prophylactic treatment for staff members who receive needle-stick injuries, but not for partners of HIV-positive patients after intercourse.

When such subjects are discussed, the member of staff who has requested the advice is invited to attend the committee meeting and take part in the debate.

#### GUIDELINE DEVELOPMENT BY THE COMMITTEE

The CEC has produced three documents or guidelines for the trust staff: guidelines on the management of patients in a persistent vegetative state; guidelines on the withholding and withdrawing of treatment in adult patients who are not dying and

who have not written an advance directive, and the committee has contributed to the development of a pro-forma to be kept in the hospital case notes, for patients who are not for cardiopulmonary resuscitation (CPR).

There has been no audit of the CEC's contribution to patient management but there is a perception within the trust that the staff are better informed on the problems of managing incompetent patients. There are now fewer requests for guidance on these issues than there have been over the last two years. The CEC recognises that appropriate audit is essential to the proper functioning of a clinical ethics committee but there is currently no consensus in the committee as to how this should be carried out.

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