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CLINICAL ETHICS COMMITTEES IN THE UNITED KINGDOM: TOWARDS EVALUATION

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Abstract

In the United Kingdom there is a growing conviction that CECs have an important role to play in helping health care professionals address ethical dilemmas. For example, the Royal College of Physicians, the Nuffield Trust and the unofficial Clinical Ethics Network, which has received financial support from the Department of Health, commend the use of CECs in the UK. The growth of such committees has been influenced by the legal and policy support they have received in the United States. However, there is increasing concern about both the benefits and the quality of work produced by CECs. In addition, despite the rapid increase in the number of CECs in the UK, outside of the United States they remain under-researched and no formal mechanism exists to assess their performance. As a result we know little about the structure, function, impact and effectiveness of CECs. We are currently conducting a research project funded by the Wellcome Trust that seeks to interrogate the competing claims regarding the benefits and disbenefits of CECs. This initial account of our research provides a detailed analysis of theoretical issues that surround the development and use of CECs and points towards the questions that lie at the heart of the social science strand of our project.

THE DEVELOPMENT OF CLINICAL ETHICS COMMITTEES IN THE UNITED STATES

Hospital Ethics Committees (HECs) intended to help health care professionals address the dilemmas that arise in clinical care have existed in the United States since the early 1970s.² HECs generally perform one or more of three functions: individual case consultations; education of health care professionals, committee members or the wider community; and policy formation.³ HECs are also increasingly playing a role in conflict resolution between clinicians, patients and their relatives.⁴ In the US, HECs initially arose as a result of the desire of health care professionals to find a resource to help them address dilemmas arising within clinical care. As Hoffman notes:

The motivation for establishing most of these committees was internal – nurses, social workers, and physicians searching for a better way to think about and handle cases involving life-sustaining treatment, initiated the formation of the committees. The stated purpose of the committees was to protect the interests of patients, especially those patients who could not speak for themselves.⁵

These grassroots initiatives soon received support from a number of legal and policy developments that encouraged the establishment of additional committees. In this respect it is widely acknowledged that HECs in the US received support from three key sources:⁶ the judgement in the case of Karen Quinlan in 1976;⁷ the report of the President's Commission, 'Deciding to Forego Life-sustaining Treatment' published in 1983;⁸ and the 'Baby Doe' Guidelines of 1984.⁹

The case of Karen Quinlan was the initial legal impetus in encouraging the development of, and the authority given to, HECs in the United States.¹⁰ In this case a court was asked to

authorise discontinuation of life-support from a young woman diagnosed as being in a persistent (now permanent) vegetative state. The court noted that:

Physicians, by virtue of their responsibility for medical judgments are, partly by choice and partly by default, charged with the responsibility of making ethical judgments which we are sometimes ill-equipped to make ... there is little or no dialogue in this whole process.¹¹

The court suggested that the dilemmas confronting those caring for Karen were immensely difficult – as indeed they were.¹² In particular, it was said that ‘... it would be more appropriate to provide a regular forum for more input and dialogue in individual situations and to allow the responsibility of these judgments to be shared.’¹³ The court noted that ethics committees already existed in a number of hospitals,¹⁴ and commended their development and the opportunity for recognition of ‘additional views and diverse knowledge’ which they could offer.¹⁵ However, the *Quinlan* court went further than this, straying into much more controversial territory, when it suggested that effectively their deliberations and decisions could be determinative of the lawfulness of the conclusion reached, saying:

... a practice of applying to a court to confirm such decisions would generally be inappropriate, not only because it would be a gratuitous encroachment upon the medical professional's field of competence, but because it would be impossibly cumbersome.¹⁶

It was perhaps as a reaction to this judgement that an early indication of controversy that would come to surround the use of hospital ethics committees emerged in a case heard one year after *Quinlan*, when a US court reached a diametrically opposed conclusion about the role for HECs. In the case of *Superintendent of Belchertown State Hospital v Saikewicz*, it was categorically stated that:

Questions of life and death seem to us to require the process of detached but passionate investigation and decision that forms the ideal on which the judicial branch of government was created. Achieving this idea is our responsibility ... and not to be entrusted to any other group purporting to represent the ‘morality and conscience of our society’, no matter how highly motivated or impressively constituted.¹⁷

Nonetheless, in cases subsequent to *Quinlan* and *Saikewicz*, and in the face of sometimes agonising and life-threatening situations, some courts have continued to advocate decision-making by ethics committees. For example, in the poignant case of *Re AC*,¹⁸ which involved the decision whether or not to perform a non-consensual caesarean section on a terminally ill young woman in a desperate attempt to save her foetus, the court said:

We observe ... that it would be far better if judges were not called to patients' bedsides and required to make quick decisions on issues of life and death. Because judgment in such a case involves complex medical and ethical issues as well as the application of legal principles, we would urge the establishment – through legislation or otherwise – of another tribunal to make these decisions, with limited opportunity for judicial review.¹⁹

In 1991 the Joint Commission on Accreditation of Healthcare Organisations (JCAHO) issued a policy statement that required healthcare organisations in the US to ‘have a defined mechanism for addressing ethical issues in patient care’ in order for them to receive accreditation.²⁰ This requirement gave further impetus to efforts to develop hospital ethics committees and similar services (e.g. individual ethics consultants) in the US.²¹ As Fletcher and Hoffman stress JCAHO's recommendations were very general and provided no guidance on the form or role of such ethics services. Furthermore, they express concern that efforts to

evaluate and standardise the work of ethics services was not undertaken prior to recommending their establishment. Hence they argue:

... before granting ethics committees additional authority, there is a need for more research on their performance and a period of experimentation with quality standards governing membership and operations.²²

Similarly, Povar – writing in the year that JCAHO's recommendations were issued – noted that around fifteen years after the emergence of hospital ethics committees in the US there was still no agreement on how to evaluate their success.²³ Hoffmann also expresses concern that methods of evaluating ethics services have not developed alongside the growth of the services themselves. As she says:

The fact that some legislatures and courts, and a powerful body like JCAHO, appear to have wholeheartedly embraced these committees is truly surprising, given the paucity of data on their impact or effectiveness. These efforts to mandate or encourage the widespread establishment and use of ethics committees seem to ignore some of their risks.²⁴

More recently, arguably the most substantial work conducted to improve the quality of clinical ethics resources in the US was published by the American Society for Bioethics and Humanities: *Core Competencies for Health Ethics Consultation*.²⁵ Despite its importance, this report is purely advisory. The document outlined the minimum training requirements and skills for those providing clinical ethics advice, but considered the evaluation of ethics services to be beyond its scope.²⁶ However, the report does acknowledge that it 'attaches great importance to evaluation' and goes on to explain that the evaluation of '...ethics consultation is needed in three areas: the competencies of those who do ethics consultation, the process of consultation itself, and the outcomes of consultation'.²⁷

THE MOVE TO EVALUATION IN THE UNITED STATES

Despite the judicial and policy support that is afforded to ethics committees in hospitals in the US it has been argued that such bodies 'can pose a danger...'.²⁸ In fact, a number of studies of HECs in the US have questioned the need for their existence, as well as challenging their effectiveness, quality and impact.²⁹ In this respect, commentators have sought to calculate the benefits and disbenefits of clinical ethics committees (or consultation) by means of empirically based outcome and process studies. These studies include projects to determine whether: service users are happy with the outcomes or procedures they experienced (satisfaction);³⁰ the service has had a positive impact on appropriate treatment withdrawal;³¹ the service performs a sufficient number of ethical tasks to be deemed successful;³² the structure and procedures followed by the committee are sound;³³ and whether clinical ethics resources are able to resolve conflicts and promote consensus.³⁴ Some of these studies can provide useful information and advice for committees and those interested in their performance. However, for a number of reasons the value of their findings is moot.

It is, of course, important that service users approve any resources that are employed to address ethical conflicts in health care institutions. This is an important element in increasing public and institutional confidence in clinical decisions. It is, therefore, sometimes assumed that the provision of ethics advice can be measured for its success (or failure) solely on the basis of consumer (or provider) satisfaction. However, utilising satisfaction primarily to determine the value of ethics services can be problematic. This is because, as studies that report different levels of satisfaction between patients and medical staff show,³⁵ satisfaction is a subjective measure that need not be related to service quality. Also inadequate is research that equates the *quantity* of interventions performed by a

committee with service *quality*,³⁶ or which endeavours to ascertain the value of ethics services by abstractly recording their possible impact on the withdrawal of 'non-beneficial' treatment.³⁷ These approaches tend to overlook the case details that give rise to ethical conflicts. Only by attending to such details is it possible to assess the workings and quality of an ethics service.

UK ETHICAL PROVISION: GROWTH OF CLINICAL ETHICS COMMITTEES IN THE UK

As in the US, many of the early CECs in the UK began as grassroots initiatives. It is possible, however, that these committees will, in time, also be spurred by national regulation of some kind and perhaps by the type of judicial support witnessed in the US.³⁸ Indeed, those who support the use of CECs in the UK have already begun to suggest how they may have benefited particular cases. For example, in her commentary on the *Ms B* case,³⁹ Slowther suggested that:

Had the NHS trust caring for Ms B had a clinical ethics committee, it could have provided a neutral forum for clarification and discussion of the issues which may have led to a resolution without the need to apply to the High Court for a decision.
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This case involved the decision whether or not to remove – at the patient's request – life-sustaining ventilation. This suggestion that CECs in the United Kingdom could potentially act as a way of avoiding – even usurping – the role of the law in reaching decisions which bring about the death of an individual echoes the views of some commentators, and even some courts, in the United States. Clinical ethics committees in the UK may, in time, come to be afforded a role within clinical decision-making that makes them increasingly powerful. Thus, as critics in the US have suggested, there is an urgent need to assess their value before (and not after) they are given more power via institutionalisation and possibly regulation. Importantly, such evaluation needs to be performed in a manner that genuinely seeks to assess the benefits and disbenefits of clinical ethics committees and does not merely seek to rubber stamp their existence.

There has been increasing debate in the UK in the area of clinical ethics. Technological advances such as the mapping of the human genome and developments in the area of assisted reproduction and prolongation of life are exemplary of medical interventions that raise a number of ethical issues and concerns. Recent well documented and publicised inquiries into the practices in hospitals throughout the UK in respect of removal and retention of children's organs, such as those at Alder Hey Children's Hospital in Liverpool⁴¹ and the paediatric cardiac surgery enquiry at Bristol Royal Infirmary,⁴² as well as the report of the review of the way in which clinical research was conducted in the 1990s at North Staffordshire Hospital NHS Trust,⁴³ highlight the importance of legal and ethical scrutiny of decision making in clinical care at all levels.

Additionally decisions about the provision of health care have been subject to increasing scrutiny following the passing of the Human Rights Act 1998. The impact of this Act on health care delivery seems likely to be most acute in respect of the process which informs and shapes delivery of health care. Although it is anticipated that patients and others will increasingly seek to use human rights as a platform for challenging individual health care decisions, the major impact on health care is likely to be an intense scrutiny of the principles which underpin the decisions of those delivering the care, the process by which decisions are reached and the quality of these decisions. It is therefore arguable that the quality and structure of ethico-legal governance is, or will become, as significant as clinical and financial audit.

Despite a rapid increase in their numbers, however, UK CECs remain unregulated and under-researched. In the absence of any nationally recognised standards for clinical ethics support, increasing activity in the area of ethical guidance within the NHS has seen the development of an unofficial network of clinical ethics committees, known as the UK Clinical Ethics Network. The Network currently comprises more than 80 committees across the UK.

The UK Clinical Ethics Network was established under the auspices of the Oxford Centre for Ethics and Communication in Health Care Practice (Ethox) in 2001.⁴⁴ The expressed aim of the Clinical Ethics Network is 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.'⁴⁵ It is surely unobjectionable that we encourage proper ethical debate, but whether this will emerge from ethics committees themselves is less than clear. Indeed, perhaps the most significant aspect of this self-imposed remit is its apparently uncritical assumption that such committees should be *promoted*. This is despite the fact that key architects of the network have also concluded that:

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 ... It is therefore important that any services have clearly stated objectives, and that there is a rigorous evaluation of both process and outcome during their development.⁴⁶

The soundness of promoting such committees when such fundamental gaps in knowledge about their role and their effectiveness exist is questionable, yet the UK Clinical Ethics Network received public monies from the Department of Health to allow its formation and achieve its aims. Slowther and Hope accept that 'evaluation is needed to determine whether these committees are influencing clinical practice ...'.⁴⁷ We would add that, whether or not they actually do influence practice, a root and branch analysis of their constitution, function and performance is also required that is open to the possibility that CECs could create more problems than they solve within clinical environments.

As in North America, a number of publications debating the need for and format of CECs in the UK have begun to emerge.⁴⁸ Research conducted into CECs in the UK has, however, generally been limited to small-scale studies that describe the background, role and functions of individual committees.⁴⁹ Although research conducted by Szeremeta *et al.* provides an insight into the development, membership, aims and ethical issues arising in five UK CECs,⁵⁰ to date only one large scale study has begun the task of examining the position of clinical ethics committees throughout the UK.⁵¹ The most significant effort to determine the nature and provision of clinical ethics support in the UK is that conducted by the Ethox team, yet the study did not seek to evaluate the value or performance of such committees.⁵² Rather it aimed to identify the provision of ethics services in the UK, to determine whether clinicians and health managers thought there was a need for such resources and to make recommendations regarding the future development of ethics services.⁵³

More recently, the use of clinical ethics committees in the United Kingdom has received support from the Royal College of Physicians (RCP) and the Nuffield Trust. In *Ethics in Practice* the working party of the RCP cautiously accept the use of CECs and make recommendations for their assessment and use. However, they also point to concerns over the manner in which such committees are assessed:

The problem with all such studies is the assumption that the outcome, measured as mortality or length of stay or therapeutic interventions, is important. The goals of ethics consultation are surely broader even than conflict resolution, valuable as this may be.⁵⁴

The recent report from the Nuffield Council on Bioethics – *Report on Critical Care Decisions in Fetal and Neonatal Medicine: Ethical Issues*, published in November 2006⁵⁵ – recommends that the most difficult decisions in neonatal medicine, which could easily mean life or death for a given child, should be reviewed by clinical ethics committees. The report says:

There is a perception that the courts are being asked to resolve a growing (though still small) number of disputes. In most (but not all cases) the courts are asked to decide where a dispute arises between those responsible for a baby. We consider that there is a role for a forum to assist parents and professionals making these difficult decisions even when there is no dispute. *We therefore recommend that NHS trusts should explore ways to ensure that all neonatal intensive care units have rapid access to a clinical ethics committee, available to families and staff.* Such committees can play a crucial role in resolving the different views held by parties in dispute, and in developing local guidelines appropriate for the community served by the neonatal intensive care unit.⁵⁶ (original emphasis)

ISSUES FOR CLINICAL ETHICS PROVISION IN THE UK

Support from such austere bodies (even if not unequivocal) suggests that, as in the United States, clinical ethics committees in the UK are gradually gaining greater status. However, this endorsement of ethical review by committee comes without any evidence from within the UK as to the efficacy of such committees. As the Royal College of Physicians has stated '[j]ustifying adequate resourcing for ethics support nationally and locally requires evidence of effectiveness.'⁵⁷ This evidence is, to date, absent. Nonetheless, Beylerveld *et al.* argue that there is a perceived need for health care institutions to calm the anxieties created by a string of high profile legal cases and suggest that this makes the 'institutionalization of CECs (perhaps even by law) ... almost inevitable'.⁵⁸

Given the growing body of literature from the United States that questions the quality of clinical ethics committee and their value, the development of CECs in the UK without preparatory assessment is arguably unwise.⁵⁹ Yet for one commentator at least, their value is not in doubt. Indeed he goes further, claiming that:

Resistance to the creation of CECs risks ... the appearance of self serving. Such resistance is particularly ironic in a country where the professional reputation of doctors has recently come under attack for poor ethicolegal practice. There is no reason any longer to tolerate a double standard where rigorous regulation of clinical activity is confined only to research. A high standard of clinical care is essential, whatever the context of its delivery. Properly organised and functioning CECs can help to ensure such a standard through the active involvement of clinicians themselves.⁶⁰

It may well be that Doyal is correct to recognise a need for systematic review of the clinical as well as the research domain, but he does not explain why it is that ethics committees are the appropriate vehicle for this. It is also important to consider the implications for the quality of ethical work in clinical care of encouraging the 'active involvement' of clinicians in the way Doyal suggests.⁶¹

Moreover, it is unclear whether such committees would exist for doctors, for patients or for both. Currently in the UK insufficient attention has been focussed on considering the extent to which patients and/or their families use, or might want access to, clinical ethics services. Slowther *et al.*, however, have noted that their study found that 'few committees include patients or their families directly in committee discussions.'⁶² The absence of information about the impact on patients and their families in the UK mimics the initial failure in the US

to consider the impact of HECs on patients. In the US, however, this deficit was later redressed in a number of studies.⁶³ However, moves to consider the interests of patients and ensure that these were considered by committees raised concerns about the ethical standing of committees given their apparent 'double identity'.⁶⁴ In other words, there remains a possible problem whichever way these committees develop; they may exist to serve the healthcare team and the hospital, which may be inimical to paying serious attention to the views of patients, or they may prioritise patients' expectations at the expense of healthcare professionals. Resolution of this potential tension is surely important before the existence and role of these committees is set in stone.

As CECs spread and develop in the UK it is also important to determine the extent to which they are actually engaging in ethics *per se*. As Fleetwood *et al.* have noted in the *Quinlan* case ethics committees were used to 'confirm the prognosis' rather than to ethically appraise the case.⁶⁵ Further, Craig and May have recently suggested that many of the empirical studies that have assessed clinical ethics committees and consultation in the US often failed to engage with the apparent *ethical* remit of such services.⁶⁶

It is important, therefore, that ethics committees, and efforts to determine their value and quality, engage with ethical language. Ethical work and its evaluation cannot be undertaken without examining ethical tools and methods. Yet reference to ethical terms is often scarce in social science based assessments of ethics committees. It is, of course, true that efforts to identify and monitor the characteristics of a 'good' ethical decision are highly problematic. Hence, there is a trend to give emphasis to a procedural approach to evaluating the performance of clinical ethics committees.⁶⁷ Such studies variously interrogate the procedures, structure and functions (education, consultation and policy advice) of committees. While these are important issues if such committees are not to be vulnerable to the charge that they are 'a due process wasteland'⁶⁸ – given that attention to fundamental rights (even procedural ones) is an inherent aspect of ethical behaviour – if they are truly to be described as 'ethics' committees, they must be able to 'do ethics'.⁶⁹ Unlike many other commentaries on CECs, our research supplements consideration of these indicators by contextualising the work of committees within an ethical (and legal) analysis.

Users (medical staff and presumably the public) must have faith in these new organisations. Yet it remains unclear how clinical ethics services will win – and justify – this trust. Without clarity on this issue there is a risk that clinical ethics committees will be viewed as bureaucratic white elephants that foster derision rather than confidence. Alternatively, they may simply become an untested, poorly evaluated but grudgingly tolerated part of the delivery of healthcare. For example, a survey of doctors in Tampa, Florida suggested that some doctors simply do not use the ethical services available.⁷⁰ Those who do, 'do so because they believe in shared decision making'.⁷¹ Those who do not 'tend to believe that it is their responsibility to resolve issues with patients and their families'.⁷² Whether widely used or not, it is important that ethics committees are seen to provide 'ethically defensible results'.⁷³ As Campbell has said:

... ethics committees themselves should not be exempt from the sustained and planned scrutiny of clinical governance. Do they provide a service that meets national standards of professional ethical consultancy? How do they audit their own performance? And what measures are they taking to remedy deficiencies in their own procedures? If – to return one last time to the maritime image of governance – they see themselves as part of the good ship NHS as it tries to chart its somewhat perilous voyage, we need to know that they are professional and trustworthy members of the crew.⁷⁴

Finally it is important to identify and understand the extent to which CECs are aware of, and able appropriately to utilise, legal rules, as well as being clear about the extent to which legal questions influence, or are reflected in, the CEC's decisions. This is of particular significance given the incorporation of the European Convention on Human Rights into UK law following the enactment of the Human Rights Act 1998. Amongst other things, this legislation requires that individuals (or practices) are 'judged' by an impartial and appropriately constituted tribunal.⁷⁵ Whether or not – as currently constituted – CECs can meet this requirement is one additional and important issue being explored in this research.

CONCLUSION: QUESTIONS FOR FUTURE RESEARCH

Ethical (and legal) dilemmas will continue to arise in healthcare practice and delivery and it is important that their resolution is informed, appropriate, principled and accountable. At present, there seems to be considerable enthusiasm (in some quarters at least) for addressing such questions by relying on CECs. However, no solid empirical or theoretical basis exists to support this approach. As Van der Kloot Meijburg and ter Meulen presciently said, before embarking on a particular path:

....a *strategic plan* is needed....Ethics committees should not come into being simply because someone, one day, decided that it was a "good thing" to have one, or because there happened to be some ethical emergency that needed acute attention. This approach is analogous to running before one has learned to walk.⁷⁶ (original emphasis)

To help elucidate whether clinical ethics committees actually offer a suitable vehicle with which to address the ethical issues within clinical care a range of fundamental questions must be addressed. Our study aims to help advance knowledge in this area. The approach we are employing juxtaposes stakeholder engagement (through a multistranded social science study) and detailed ethico-legal analysis. In this way we aim to ensure that ethics and law remain at the heart of both our theoretical examinations and the questions within our social science study.

Amongst the issues that it remains crucial to investigate from both a theoretical and empirical perspective are: the rationale for establishing CECs; whether committees are the most satisfactory way to address ethical issues; who should be able to seek advice from CECs; how the committees should be constituted in terms of members; whether qualifications or training in ethics and/or law are necessary, and if so what type of training in terms of content and length would be optimal and/or viable; whether national regulation and guidelines for CECs are desirable and, if so, the form these might take; how the legal liability of committees should be determined; and whether service users and providers are satisfied with the service they provide and receive.

It is also vital to determine whether members can: identify an ethical issue, distinguish such issues from any legal or professional/personal conflicts that may exist in a particular case; the extent to which ethical principles actually inform the decision-making of CECs; what ethical principles or frameworks are used; the issues committees consider; and how the committee goes about resolving conflicts. Similar questions need to be asked regarding the legal knowledge of committees and their use of case law and legislation.

Currently, in the UK questions such as these are theoretically and empirically under-researched. Thus we concur with Godkin *et al*/that, '[a]s the field of clinical ethics continues to grow and gain prominence, the need to attain knowledge about benchmarks, best practices, and measures of effectiveness becomes increasingly significant.'⁷⁷ Our research aims to add to that knowledge. It would be unfortunate if any move towards

institutionalisation of CECs were to occur without any real sense of their value. Indeed, this would mimic the situation that developed in the United States, where committees began small and increasingly expanded in authority – receiving legislative backing in some states – without proper evaluation. In the United Kingdom we still have the opportunity to give attention to questions concerning the value and functioning of ethics committees before they are institutionalised. Modern healthcare delivery is highly complex and it is plausible that in some areas at least there are serious ethical (and legal) issues raised by the offer of treatment. While legal questions often have relatively straightforward answers, ethical dilemmas are generally more complex. However, their impact on the provision of services, on those delivering and receiving them, is of great importance. This mandates serious consideration of whether or not the provision of formalised advice by a clinical ethics committee is able to enhance decision-making and to foster the principled approach to patient care that everyone surely desires.

NOTES

1. Institute of Law and Ethics in Medicine, University of Glasgow. The study 'Ethico-Legal Governance in Health Care' is funded by the Wellcome Trust (ref. 07446). Additional financial support was provided by NHS Grampian.
2. Cranford, RE.; Doudera, AE. The Emergence of Institutional Ethics Committees. In: Cranford, RE.; Doudera, AE., editors. *Institutional Ethics Committees and Health Care Decision Making*. Michigan: Health Administration Press; 1984. p. 5-21.
3. Dougherty, CJ. Clinical Ethics: Institutional Ethics Committees. In: Post, S., editor. *Encyclopedia of Bioethics*. Macmillan Reference; New York: 2004. p. 444-447. Slowther A, Hope T. Clinical ethics committees. *British Medical Journal*. 2000; 32:649-650. [PubMed: 10987750] Doyal L. Clinical ethics committees and the formulation of health care policy. *Journal of Medical Ethics*. 2001; 27(Suppl 1):i44-i49. [PubMed: 11314613]
4. Nelson RM, Shapiro RS. The role of an ethics committee in resolving conflict in the neonatal intensive care unit. *Journal of Law, Medicine & Ethics*. 1995; 23:27-32. [PubMed: 7627299]
5. Hoffman DE. Regulating Ethics Committees in Health Care Institutions – Is It Time? *Maryland Law Review*. 1991:746-797. 50. at p. 747. [PubMed: 11651206]
6. Fletcher JC, Hoffmann DE. Ethics Committees: Time to Experiment with Standards. *Annals of Internal Medicine*. 1994; 120(4):335-338. [PubMed: 8291827] Dougherty, CJ. Clinical Ethics: Institutional Ethics Committees. In: Post, S., editor. *Encyclopedia of Bioethics*. New York: Macmillan; 2004. p. 444-447.
7. Matter of Quinlan. p. 647355 A.2d
8. President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioural Research. *Deciding to Forego Life-Sustaining Treatment*. Washington, D.C.: US Government Printing Office; 1983.
9. Department of Health and Human Services. *Nondiscrimination on the Basis of Handicaps: Procedures and Guidelines Relating to Health Care for Handicapped Infants*. Federal Register. 1984:622-54.
10. Matter of Quinlan. p. 647355 A.2d
11. Matter of Quinlan. p. 668355 A.2d
12. Matter of Quinlan. p. 668355 A.2d
13. Matter of Quinlan. p. 668355 A.2d
14. cf Teel K. The Physician's Dilemma a Doctor's View: What The Law Should be. *Baylor Law Review*. 1975; 27(6)
15. Matter of Quinlan. p. 669355 A.2d
16. Matter of Quinlan. p. 669355 A.2d
17. *Superintendent of Belchertown State Hospital v Saikewicz*. 1977; 728:759. 373 Mass.
18. *Re AC*. p. 1235573 A.2d (D.C. 1990)
19. per Terry, J. at p.1237 n.2.

20. JCAHO. Accreditation Manual for Hospitals. Oakbrook Terrace: JACHO; 1992.
21. Corsino BV. Bioethics Committees and JCAHO Patients' Rights Standards: A Question of Balance. *The Journal of Clinical Ethics*. 7(2):177–181. [PubMed: 8889893]
22. Fletcher JC, Hoffmann DE. Ethics Committees: Time to Experiment with Standards. *Annals of Internal Medicine*. 1994; 120(4):335–338. [PubMed: 8291827]
23. Povar GJ. Evaluating Ethics Committees: What do we mean by Success? *Maryland Law Review*. 1991; 50:904–919. 906. [PubMed: 11651210] Van Allen E, et al. Evaluating Ethics Committees. *Hastings Center Report*. 1989; 9(5):23–24. at p. 23. [PubMed: 2793436]
24. Hoffmann DE. Evaluating Ethics Committees: A View from the Outside. *Milbank Quarterly*. 1993; 71(4):677–701. at p. 679. [PubMed: 8246852]
25. American Society for Bioethics and Humanities. Core Competencies for Health Care Ethics Consultation. Glenview, IL: ASBH; 1998.
26. American Society for Bioethics and Humanities. Core Competencies for Health Care Ethics Consultation. Glenview, IL: ASBH; 1998. p. 27
27. American Society for Bioethics and Humanities. Core Competencies for Health Care Ethics Consultation. Glenview, IL: ASBH; 1998. p. 27
28. Hoffmann DE. Evaluating Ethics Committees: A View from the Outside. *Milbank Quarterly*. 71(4):763.
29. Lo B. Behind closed doors. Promises and pitfalls of ethics committees. *N Eng J Med*. 1987; 317:46–50. [PubMed: 3587312] La Puma J, Stocking C, Darling C, Siegler M. Community hospital ethics consultation: evaluation and comparison with a university hospital service. *The American Journal of Medicine*. 1992; 92:346–351. [PubMed: 1558080] Blake DC. The hospital ethics committee. Healthcare's moral conscience or white elephant? *Hastings Center Report*. 1992; 2:6–11. [PubMed: 1544801] Siegler M. Ethics committees: decisions by bureaucracy. 1986; 16:22–4. [PubMed: 3721844]
30. Orr RD. Evaluation of an Ethics Consultation Service: Patient and Family Perspectives. *American Journal of Medicine*. 1996; 101:135–141. [PubMed: 8757352] La Puma, et al. Community Hospital Ethics Consultation: Evaluation and Comparison with a University Hospital Service. *American Journal of Medicine*. 1992; 92:346–351. [PubMed: 1558080] McClung JA, et al. Evaluation of Medical Ethics Consultation Service: Opinions of Patients and Health Care Providers. 1996; 100:456–460. [PubMed: 8610734] Yen B, Schneiderman LJ. Impact of Pediatric Ethics Consultations on Patients, Families, Social Workers, and Physicians. *Journal of Perinatology*. 1999; 19(5):373–378. [PubMed: 10685260]
31. Schneiderman LJ. Impact of Ethics Consultations in the Intensive Care Setting: A Randomized, Controlled Trial. *Critical Care Medicine*. 2000; 28(12):3920–3924. [PubMed: 11153636] Schneiderman LJ. Effect of Ethics Consultations on Nonbeneficial Life-Sustaining Treatments in the Intensive Care Setting. *Journal of the American Medical Association*. 2003; 290(9):1166–1172. [PubMed: 12952998] Dowdy MD, et al. A Study of Proactive Ethics Consultation for Critically and Terminally ill Patients with Extended lengths of Stay. *Critical Care Medicine*. 1998; 26(2):252–259. [PubMed: 9468161]
32. Scheirton LS. Determinants of Hospital Ethics Committee Success. *HEC Forum*. 1992; 4(6):342–359. [PubMed: 10123219]
33. American Society for Bioethics and Humanities. Core Competencies for Health Care Ethics Consultation. Glenview, IL: ASBH; 1998. Slowther, A., et al. *Clinical Ethics Support in the UK: A Review of the Current Position and Likely Development*. London: Nuffield Trust; 2001. Guo L, Schick IC. The Impact of Committee Characteristics on the Success of Healthcare Ethics Committees. *HEC Forum*. 2003; 15(3):287–299. [PubMed: 14686101] Fletcher, JC. Standards for Evaluations of Ethics Consultation. In: Fletcher, JC.; Quist, N.; Jonsen, AR., editors. *Ethics Consultation in Health Care*. Michigan: Health Administration Press; 1989. p. 171-184. at p. 173ff
34. Orr RD, Leon DM. The Role of the Clinical Ethicist in Conflict Resolution. *Journal of Clinical Ethics*. 2000; 11(1):21–30. [PubMed: 10904887] Fletcher JC. Goals and Process of Ethics Consultation in Health Care. *Biolaw*. 1986; 2(2):S37–S47. Doyal L. Clinical Ethics Committees and the Formulation of Health Care Policy. *Journal of Medical Ethics*. 2001; 27(Suppl I):i44–i49. [PubMed: 11314613] Moreno JD. Ethics by Committee: The Moral Authority of Consensus. *Journal of Medicine and Philosophy*. 1988; 13:411–432. [PubMed: 3246580] Povar GJ. Evaluating

- Ethics Committees: What do we Mean by Success? *Maryland Law Review*. 1991; 50:904–919. [PubMed: 11651210]
35. McClung JA, et al. Evaluation of Medical Ethics Consultation Service: Opinions of Patients and Health Care Providers. 1996; 100:456–460. [PubMed: 8610734] Yen B, Schneiderman LJ. Impact of Pediatric Ethics Consultations on Patients, Families, Social Workers, and Physicians. *Journal of Perinatology*. 1999; 19(5):373–378. [PubMed: 10685260]
 36. Scheirton LS. Determinants of Hospital Ethics Committee Success. *HEC Forum*. 1992; 4(6):342–359. [PubMed: 10123219]
 37. Schneidermann LJ. Impact of Ethics Consultations in the Intensive Care Setting: A Randomized, Controlled Trial. *Critical Care Medicine*. 2000; 28(12):3920–3924. [PubMed: 11153636]
Schneiderman LJ. Effect of Ethics Consultations on Nonbeneficial Life-Sustaining Treatments in the Intensive Care Setting. *Journal of the American Medical Association*. 2003; 290(9):1166–1172. [PubMed: 12952998]
 38. Beylerveld D, et al. Clinical Ethics Committees: Clinician Support or Crisis Management. *HEC Forum*. 2002; 14(1):13–25. at p. 17. [PubMed: 12001798]
 39. *Ms B v NHS Hospital Trust*. 2002. p. 14965 BMLR
 40. Slowther A. The Case of Ms B and the “Right to Die. *Journal of Medical Ethics*. 2002; 28:243. at p. 243. [PubMed: 12161579]
 41. The Royal Liverpool Children's Inquiry. London: The Stationery Office; 2001.
 42. Learning from Bristol: the report of the public inquiry into children's heart surgery at the Bristol Royal Infirmary 1984–1995. Cm 5207
 43. Review of the research framework in North Staffordshire Hospital NHS Trust. available at <http://www.doh.gov.uk/pdfs/northstaffs.pdf> (accessed on 23/02/2007)
 44. For more information about the work of this Centre, see <http://www.ethox.org.uk> and for information of the network see <http://www.ethics-network.org.uk/Committee/list.htm> (accessed on 16/02/2007)
 45. Slowther A, Johnston C, Goodall J, Hope T. Development of clinical ethics committees. *British Medical Journal*. 2004; 328:950–952. at p. 950. [PubMed: 15087349]
 46. Slowther A, Bunch C, Woolnough B, Hope T. Clinical ethics support services in the UK: an investigation of the current provision of ethics support to health professionals in the UK. *Journal of Medical Ethics*. 2001; 27(suppl I):i2–i8. at p. i.8. [PubMed: 11314606]
 47. Slowther A-M, Hope T. Clinical Ethics Committees: they can change clinical practice but need evaluation. *British Medical Journal*. Sep 16.2000 321:649–650. at p. 650. [PubMed: 10987750]
 48. McCall Smith A. Committee Ethics? Clinical Ethics Committees and their Introduction in the United Kingdom. *Journal of Law and Society*. 1990; 17(1):124–139. Larcher V, Lask B, McCarthy J. Paediatrics at the Cutting Edge: Do We Need Ethics Committees? *Journal of Medical Ethics*. 1997; 23:245–9. [PubMed: 9279747] Slowther A, Hill D, Mc Millan J. Clinical Ethics Committees: Opportunity or Threat? *HEC Forum*. 2002; 14(1):4–12. [PubMed: 12001801]
Slowther A, Underwood M. Is there a need for a clinical ethics supports service in the UK? *Journal of Medical Ethics*. 1998; 24:207. [PubMed: 9650117] Slowther A, Johnston C, Goodall J, Hope T. Development of Clinical Ethics Committees. *British Medical Journal*. 2004; 328:950–952. [PubMed: 15087349] Doyal L. Clinical Ethics Committees and the Formulation of Health Care Policy. *Journal of Medical Ethics*. 2001; 27(Suppl I):i44–i49. [PubMed: 11314613] Watson AR. An ethics of clinical practice committee: should every hospital have one? *HEC Forum*. 1996; 8:301–315. [PubMed: 10164105] Beylerveld B, Brownsword R, Wallace S. Clinical Ethics Committees: Clinical Support or Crisis Management? *HEC Forum*. 2002; 14(1):13–25. [PubMed: 12001798]
 49. Thornton JG, Lilford RJ. Clinical ethic committees. *British Medical Journal*. Sep 9.1995 311:667–669. [PubMed: 7549638] Slowther A, Johnston C, Goodall J, Hope T. Development of clinical ethics committees. *British Medical Journal*. 2004; 328:950–952. [PubMed: 15087349] Doyal L, Colvin B. The clinical ethics committee at Barts and the London Hospital Trust: rationale, achievements and difficulties. *HEC Forum*. 2002; 14(1):26–36. [PubMed: 12001799] Slowther A, McMillan J. The development of healthcare (clinical) ethics committees in the UK. *HEC Forum*. 2002; 14(1):1–3. Rudd P. The clinical ethics committee at the Royal united Hospital – Bath England. *HEC Forum*. 2002; 14(1):37–44. [PubMed: 12001800] Larcher V. Role of clinical ethics

- committees. *Arch Dis Child*. 1999; 81:104–106. [PubMed: 10490512] Melsin E, Rayner C, Larcher V, Hope T, Savulescu J. Hospital Ethics Committees in the UK. *HEC Forum*. 1996; 8:301–315. [PubMed: 10164105] Wood K, Ellis S. A Clinical Ethics Committee in a Small Health Services Trust. *Journal of Medical Ethics*. 1999; 25:420. [PubMed: 10536771]
50. Szeremeta M, Dawson J, Manning D, Watson A, Wright M, Notcutt W, Lancaster R. Snapshots of Five Clinical Ethics Committees in the UK. *Journal of Medical Ethics*. 2002; 27:i9–i17. [PubMed: 11314616]
 51. 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.
 52. 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. Slowther A, Johnston C, Goodall J, Hope T. Development of Clinical Ethics Committees. *British Medical Journal*. 2004; 328:950–952. [PubMed: 15087349] Slowther A, Hill D, Mc Millan J. Clinical Ethics Committees: Opportunity or Threat? *HEC Forum*. 2002; 14(1):4–12. [PubMed: 12001801]
 53. 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. p. 16
 54. Royal College of Physicians. Ethics in Practice: Background and Recommendations for Enhanced Support. London: Royal College of Physicians; 2005. p. 25
 55. London, November 2006.
 56. para 9.37 see also paragraphs 8.48–8.49.
 57. Royal College of Physicians. Ethics in Practice: Background and Recommendations for Enhanced Support. London: Royal College of Physicians; 2005. p. 25
 58. Beylerveld D, et al. Clinical Ethics Committees: Clinician Support or Crisis Management. *HEC Forum*. 2002; 14(1):13–25. at p. 17. [PubMed: 12001798]
 59. Anzia DJ, La Puma J. Quality Care and Clinical Ethics. *Quality Review Bulletin*. 1992; 18(1):21–23. [PubMed: 1549320] Brennan TA. Quality of Clinical Ethics Consultation. *Quality Review Bulletin*. 1992; 18(1):4–5. Siegler M. Defining the Goals of Ethics Consultations: A Necessary Step for Improving Quality. *Quality Review Bulletin*. 1992; 18(1):15–16. [PubMed: 1549318]
 60. Doyal L. Clinical Ethics Committees and the Formulation of Health Care Policy. *Journal of Medical Ethics*. 2001; 27(Suppl I):i.44–i.49. at p. i.49. [PubMed: 11314613]
 61. Benatar D. Bioethics and Health and Human Rights: A Critical View. *Journal of Medical Ethics*. 2006; 32:17–20. [PubMed: 16373517]
 62. Slowther A, Johnston C, Goodall J, Hope T. Development of Clinical Ethics Committees. *British Medical Journal*. Apr 17.2004 328:950–952. at p. 950. [PubMed: 15087349]
 63. Orr RD. Evaluation of an Ethics Consultation Service: Patient and Family Perspectives. *American Journal of Medicine*. 1996; 101:135–141. [PubMed: 8757352] McClung JA, et al. Evaluation of Medical Ethics Consultation Service: Opinions of Patients and health Care Providers. 1996; 100:456–460. [PubMed: 8610734] Yen B, Schneiderman. Impact of Pediatric Ethics Consultations on Patients, Families, Social Workers, and Physicians. *Journal of Perinatology*. 1999; 19(5):373–378. [PubMed: 10685260]
 64. Wolf SM. Due Process in Ethics Committee Case Review. *HEC Forum*. 1992; 4(2):83–96. at p. 85. [PubMed: 10119671]
 65. Fleetwood JE, Arnold RM, Baron RJ. Giving Answer or Raising Questions? The Problematic Role of Institutional Ethics Committees. *Journal of Medical Ethics*. 1989; 15:137–142. at p. 137. [PubMed: 2795627]
 66. Craig JM, May T. Evaluating the Outcomes of Ethics Consultation. *Journal of Clinical Ethics*. 17(2):168–180.
 67. Fletcher, JC. Standards for Evaluations of Ethics Consultation. In: Fletcher, JC.; Quist, N.; Jonsen, AR., editors. *Ethics Consultation in Health Care*. Michigan: Health Administration Press; 1989. p. 171–184. Doyal L. Clinical Ethics Committees and the Formulation of Health Care Policy. *Journal of Medical Ethics*. 2001; 27(Suppl I):i44–i49. [PubMed: 11314613]
 68. Wolf SM. Due Process in Ethics Committee Case Review. *H.E.C. Forum*. 1992; 4(2):83–96. at p. 84. [PubMed: 10119671]

69. Annas GJ. Ethics Committees: From Ethical Comfort to Ethical Cover. *Hastings Center Report*. May-Jun;1991 :18–21. For discussion on a related point,, see. [PubMed: 1885292]
70. Orlowksi JP, Hein S, Christensen JA, Meinke R, Sincich T. Why doctors use or do not use ethics consultation. *Journal of Medical Ethics*. 2006; 32:499–502. [PubMed: 16943327]
71. *Journal of Medical Ethics*. 2006; 32 at p. 501.
72. *Journal of Medical Ethics*. 2006; 32 at p. 501.
73. Povar GJ. Evaluating Ethics Committees: What do we mean by Success? *Maryland Law Review*. 1991; 50:904–919. at p. 907. [PubMed: 11651210]
74. Campbell AV. Clinical governance – watchword or buzzword? *Journal of Medical Ethics*. 2001; 27(Suppl I):i54–i56. at p. i.56. [PubMed: 11314615]
75. Article 6 states that ‘In the determination of his civil rights and obligations or of any criminal charge against him, everyone is entitled to a fair and public hearing within a reasonable time by an independent and impartial tribunal established by law.’
76. Van der Kloot Meijburg HH, ter Meulen RHJ. Developing Standards for Institutional Ethics Committees: Lessons from the Netherlands. *Journal of Medical Ethics*. 2001; 27(Suppl I):i36–i40. at p. i37. [PubMed: 11314611]
77. Godkin MD, et al. Project Examining Effectiveness in Clinical Ethics (PEECE): phase 1 – descriptive analysis of nine clinical ethics services. *Journal of Medical Ethics*. 2005; 31:505–512. at p. 511. [PubMed: 16131551]