

# CLINICAL ETHICS SUPPORT LITERATURE REVIEW



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# Introduction

This literature review was conducted as part of a University of Sydney research project commissioned by NSW Health. It provides a comprehensive summary of published international literature on clinical ethics support and clinical ethics support services for the period 2000 to 2012.

Clinical ethics support typically involves the provision of expert ethics input into clinical education, policy development and the care of individual patients. It is intended to promote ethically sound clinical and organisational practices and decision-making, thereby contributing to health organisation and system quality improvement.

NSW public health organisations are encouraged to review this document and use it as a resource for local decision-making about providing clinical ethics support. Additional clinical ethics resources are available on the NSW Health internet site: (<http://www.health.nsw.gov.au/clinicaethics/Pages/clinical-ethics-resources.aspx>).

## Acknowledgements

This literature review was prepared by Dr Evan Doran, Dr Jennifer Fleming, Associate Professor Ian Kerridge and Professor Cameron Stewart from the Centre for Values, Ethics and Law in Medicine at the University of Sydney. The Ministry of Health gratefully acknowledges the work of these academics in undertaking this research.

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## Overview

### Literature Review — Key Points

- The literature is predominantly descriptive, expository and/or instructive.
- The literature confirms the increasing prevalence of ethics support services internationally.
- Of the three typical functions policy development, education, case consultation the last has received the most critical and scholarly attention.
- Descriptive studies show that the structure, function and process of support services vary considerably between organisations.
- Evaluation of support services has been limited and the most appropriate set of measures and outcomes is subject to debate.
- Consensus on best practice model of ethics support is yet to emerge but there is consensus that regardless of model support requires a set of core competencies in ethics knowledge and practical skills and should reflect traits such as patience and compassion.
- Despite their growth, ethics support services appear to be underutilised related to a number of factors such as poor institutional support.
- Although there is a range of views on how best to deliver ethics support, there is a convergence on the need for ethics support to involve *independent* but *integrated* ethical expertise.
- We sum up this convergence as — ethics support needs to be *powered*: epistemically powered by ethics and legal expertise and institutionally powered by a clear and accepted role within individual organisations and the system and thereby access to resources.

“...the rapid proliferation of hospital ethics committees and ethics consultation services suggests that the worries of academics within the field of bioethics about the legitimacy of clinical ethics and ethics consultation are not impeding others from providing these services.” (Agich 2009)

The above quote illustrates a major theme of the literature — the proliferation of ethics support services has possibly outstripped our understanding of how best to go about it. There is something of a ‘suck it and see’ disposition among many advocates for support; a sense of urgency to get the *good idea* of ethics support up and running. Admirable as it may be, enthusiasm notwithstanding, the growth of clinical ethics support does not itself demonstrate any improvement in the quality (or ethicality) of patient care nor give a clear imperative to set up ethics support. The rationale for promoting ethics support needs to include more grounds than ‘just because others are doing it’. As we will see, for a number of reasons the evidence for the

effectiveness of ethics support is limited and many questions remain. Lack of evidence, however, does not mean abandoning a *good idea*. As Australia’s Productivity Commissioner recently observed in relation to (and support of) evidence based policy “All policy effectively is experimentation. But that does not mean flying blind — we still need a good rationale or a good theory” (Banks 2009). Seen as policy innovation, the work associated with this project seeks to develop a ‘good rationale’ for clinical ethics.

## Scope of the review

There is now a considerable size literature providing guidance on how to establish and operate a clinical ethics support service or 'program'. We do not attempt to comprehensively and critically review the various 'how to' approaches to ethics support. The focus of the review is on reports and empirical studies of clinical ethics support services. We do not review the extensive and rapidly growing empirical, theoretical and normative literature on clinical ethics in general.

The reviewed literature largely consists of peer-review journal articles published after 2000. This period has been chosen because it post dates the publication of two major statements regarding what is believed essential for the competent provision of clinical ethics services published by Bioethics Consultation Task Force on Standards for Bioethics Consultation in the United States (Aulisio et al 2000) and by the UK Clinical Ethics Network in United Kingdom (Larcher 2010). The major evaluation studies of ethics support services to date were conducted prior to 2000. Given that they are still considered the strongest evidence available, we have included these studies.

## Literature Search

Electronic databases (Pub Med, Medline, Google Scholar) were searched for English language papers published from 1990 – 2012 inclusive. In various combinations the following terms were used as search terms for articles: advice, ethics, clinical, committees, consultants, consultations, support, and services. The titles and abstracts of electronically identified articles were reviewed. Articles deemed potentially relevant were retrieved for further scrutiny. Articles that did not have ethics support as their focus were excluded. The reference lists of relevant articles were used to identify other potentially relevant articles. The articles were categorised according to whether the article was descriptive or empirical. Empirical papers were further categorised by the primary unit of analysis – support service or clinician.

## Clinical Ethics Support – Description of the Literature

As a relatively recent development involving the transition of a largely theoretical discipline (medical or clinical ethics) into a practical intervention (ethics support services), the literature is predominantly descriptive with relatively few empirical studies. Most of the literature is expository and/or instructive such as essays on the historical development of ethics support services, reports of establishing and operating a particular service, accounts of the experiences of clinical ethicists or ethics committees, position papers on core competencies, practical guidance for establishing a support services, advocacy for a particular model of service delivery and finally critiques of current approaches. We look at this disparate literature first to establish how it believed ethics support should be done and draw this together to identify a number of key themes (Prevalence, Quality, Facilitation, Expertise, Institutionalisation, Integration) regarding the rationale(s) for ethic support services, the types of support advocated for and the recommendations made for establishing and operating a support service. We then take a closer look at a small number of empirical studies that have systematically observed ethical support services to explore how it is done. These are predominantly descriptive but also include a small number of evaluation studies.

### Increasing prevalence of ethics support services internationally

The growing literature of reports on the history, structure and function of ethics committees confirms that hospital ethics committees are growing in number. The proliferation of formal clinical ethics 'support' initiatives, earliest and most widely in the United States has become a truly international development. Clinics support is now undertaken (or anticipated to be) in the United Kingdom, France, Belgium, Netherlands, Germany, Italy, Switzerland, Croatia, Lithuania, Bulgaria, Israel, Japan and other countries (Slowther et al 2001a, Wenger et al 2002, Hurst et al 2008, Frokovic and Gosic 2006, Guerier 2006, Hurst et al 2007,

Akabayashi et al 2008, Bankuaskaite and Jakusovaite 2008, Fukuyama et al 2008, Fournier et al 2009, Gaudine et al 2010, Alecksendrova 2010, Louhiala et al 2011).

Clinical ethics support is clearly well established in the English-speaking nations of the North. The results of a national survey by Fox and colleagues indicated that 80% of general hospitals had an ethics consultation service (Fox et al 2007). In Canada, a survey by Gaudine and colleagues found in 2008 that 85% of hospitals had an ethics committee compared to 58% in 1989 and 18% in 1984 (Gaudine et al 2010). A recent survey of clinical ethics committees in the UK showed the number of identified committees to have risen from 20 in 2001 to 82 in 2010 (Slowther et al 2012). In addition to the burgeoning number of services internationally, clinical ethics consultation is developing as a subject of professional and scholarly discourse. A conference series – *International Conference on Clinical Ethics and Consultation* held its 2012 (the eighth) meeting in Sao Paulo Brazil. Previous meetings have crossed the world having been held in Taiwan, Croatia, United States and the Netherlands.

The steady increase and spread of ethics support services is often taken to indicate a growing perception of need for ethics assistance among clinicians themselves i.e. that the development starts 'bottom-up' (Slowther et al 2012).

### A 'grass roots' phenomenon

The advent and spread of formal clinical ethics support is often described as a grassroots phenomenon. Increased social complexity and therefore greater ethical complexity appears to be an axiom of arguments for formal clinical ethics support. The fact that the growth in support services is largely ad hoc and uncoordinated is also argued to show that clinicians recognise that being 'ethical' in a more complex clinical environment is not straightforward and at least occasionally assistance is required (Agich 2005, Williamson,

McLean 2009, Larcher et al 2010). Given that only a few nations have made clinical ethics support (virtually) mandatory (e.g. United States and Belgium), the more recent initiatives in Canada, Scandinavia, the United Kingdom, Europe and Asia do appear to have largely emerged organically, from the 'bottom up' (Larcher 2010).

It should be noted that there has only been limited attempts to empirically establish the perception of 'need' for ethics support among clinicians; in most discussions clinician need is implicitly assumed (Dauwerse et al 2011). Often the studies cited as showing need, have involved surveys of service managers or chairs of existing ethics committees (e.g. Slowther et al 2001, Whitehead et al 2009, Slowther et al 2012) rather than clinicians. It is not exactly clear from the existing literature that the 'grassroots' agitation for ethics support includes clinicians as much their managers and ethicists. It seems clear that there has been a considerable push by advocates to have clinical ethics support services more widely established. Clinical ethics 'networks' have been established in Europe, the European Clinical Ethics Network (Fournier et al 2009) and in the UK, the United Kingdom Clinical Ethics Network (UKCEN) in an attempt to harness and further develop clinical ethics support services. The networks bring together isolated individual committees and consultants to collectively promote ethics support. The development of clinical ethics networks shows something of the social movement aspect of clinical ethics. The UKCEN, for example, has been established with express purpose of generating sufficient 'critical mass' to 'embed' clinical ethics as a core element of health care (Slowther 2008).

Likewise, a recent report into the role of clinical ethics in New Zealand supported by the Health Quality and Safety Commission (NZ) (Macdonald and Worthington, 2012) established that, compared with other countries, New Zealand had less access to formal clinical ethics advice and that what was necessary was to establish and promote a National Clinical Ethics Network that would support the development and sustainable delivery of clinical ethics services within all District Health Boards, hospitals and primary care services.

The 'bottom-up' development of ethics support may still describe how many services are established. There is, however, also a parallel movement which, if not 'top-down', is operating

from somewhere around the middle to more widely establish clinical ethics services.

## Ethics support is increasingly encouraged

If not mandated for from the 'top down', ethics support services are increasingly being encouraged. In the US ethics consultation has been supported by the courts and a major President's Commission (Aulisio et al 2000). In the US, the presence of some mechanism for addressing clinical ethical issues within health care institutions has been a requirement since 1992 (Fox et al 2010). The body responsible for hospital accreditation the Joint Commission on Accreditation of Health Care, recommends a multi-disciplinary ethics committee. In some US states (e.g. Maryland) this requirement has been passed into law (Slowther 2004). In Canada, the Canadian Council on Hospital Accreditation also recommends an ethics committee. In the UK bodies such as the Royal of College Physicians and the Nuffield Trust have made declarations in support for ethics support services, albeit with some caveats about performance given the limited evidence (Williamson 2008). The UK government partly funds the UKCEN. The Netherlands government provides financial support for the European Clinical Ethics Network. The supra-national agency the United Nations Educational, Scientific and Cultural Organisation (UNESCO) has strongly endorsed the development of bioethics committees, including hospital ethics committees, as 'ideal platforms' for ensuring human rights, such as those related to genetic data (UNECISO 2008).

In New Zealand, the clinical ethics report enlisted by the Health Quality and Safety Commission (NZ) has made a series of recommendations designed to support access to clinical ethics services throughout New Zealand (Macdonald and Worthington, 2012). These included;

- That comprehensive clinical ethics support should be available wherever health care is provided in New Zealand,
- That a Clinical Ethics Network should be established with the express purpose of fostering the development of clinical ethics support services in New Zealand,
- That Clinical Ethics Advisory Groups (CEAG) should be established wherever the need for clinical ethics support was greatest,
- That standards for CEAGs be established to



ensure their competence, utility, support, authority, impact and sustainability, and

- That to ensure the long-term viability of the Clinical Ethics Network and CEAGs they be adequately resourced and that their 'location' within the institution, their reporting mechanisms and their political independence be clearly established.

## Clinical Ethics Support in Australia

There is little information to gauge the degree to which clinical ethics support has penetrated the Australian health care system. Concern about the increased ethical complexity of clinical care underlies a number of important initiatives in Australia. At a national level, the Australian Health Ethics Committee (AHEC) has been established to provide the NHMRC with advice and guidance on ethical issues. At a state level, the NSW Ministry of Health has produced guidelines and policy directives relating to specific issues such as not-for-resuscitation, organ donation and use of human tissue, decision-making at the end-of-life, and advanced care directives. There have also been initiatives in continuing professional development (e.g. Guillemin *et al.* 2009). As yet there have been no systematic attempts to measure the use of, or satisfaction with, these resources or other initiatives.

There are few published studies of the prevalence and operation of clinical ethics support services in Australia. In the mid 1990s McNeil and colleagues surveyed all public and private Australian hospitals and estimated that 120 (10%) had a clinical ethics committee (McNeil 2001). Most reported fulfilling a policy development or educational role, but few reported input into actual patient management (McNeil *et al.* 2001). The accuracy of the 10% prevalence estimate is questionable, partly because survey respondents may have confused clinical ethics committees with research ethics committees (McNeil 2001).

There are two published reports that describe specific clinical ethics support services in Australia. Gill *et al.* (2004) describes a service at the John Hunter Hospital in Newcastle, and Gold *et al.* (2011) describes a clinical ethics committee that has been operating since 2005 at the Royal Hospital for Children in Melbourne. Both reports are positive in their assessment of these services and argue for wider adoption ethics committees. Clinical ethics support services are also available at several

hospitals in Sydney, including the Sydney Children's Hospital, the Royal Hospital for Women, Royal Prince Alfred Hospital, and St Vincent's Hospital. There is also a service in Brisbane at Prince Alfred Hospital. It is likely that others operate in public and private hospitals around the country, however the exact number is still unknown (Gold *et al.* 2011). We can find no published reports of systematic, evaluative research of these services.

It is safe to assume that in Australia the majority of clinical cases that raise difficult ethical issues are managed by the clinicians directly involved, or by organisational groupings, such as departments of clinical governance or patient advocacy services, whose brief is not explicitly an 'ethical' one. That is, the development of clinical ethics support services in Australia has to date been largely ad hoc and uncoordinated. It is possible that ethics support in Australia is currently similar to how it was in the UK in the 2000s prior to the sustained advocacy for ethics committees gained traction (this issue will be discussed further below). If the development has been ad hoc, then it is likely that existing ethics support services reflect a similar variation in type, function and process that resulted from the 'laissez faire' development of services in other nations such as the UK.

The development of clinical ethics support services in NSW certainly fits the UK picture circa 2000; an ad hoc, uncoordinated and sparse growth. The few committees that do exist are local grass roots initiatives. Anecdotal evidence indicates considerable variation in constitution, processes and activity. There is a limited degree of networking, largely sustained by the efforts of NSW Ministry of Health and Centre for Values, Ethics and Law in Medicine. As this very project demonstrates, there is incipient but sincere interest in expanding capacity in clinical ethics within NSW public health organisations (hospitals). The current institutional status of existing clinical ethics support services such as ethics committees would appear to be that they are on the periphery of attempts to promote quality health care in NSW.

Just as we don't know the exact number and details of existing services, we don't know much about the quality and effectiveness of the service they provide. How useful they are to the clinicians who use them, to their organisation and to what extent they enhance the ethical quality of patient care isn't known. This is noted not to gratuitously

impugn the performance of existing committees, only to point out that we don't know much at all about the committees that have emerged. Given that case consultation (where this function is provided by a support service) gives a committee or a consultant close, possibly decisive, influence on a decision about patient care, the quality of a consultation becomes important. Issues such as due process and the extent to which it is observed by existing committees are of particular concern. A lack of certainty about what the ad hoc development of ethics support services has meant for the quality of patient care has been the prime driver of efforts internationally to more closely regulate ethics support services. We will return to these issues below. For now we just want to highlight that *governance* for quality and effectiveness has important implications for building capacity.

If NSW's current stage of development of formal ethics services is somewhat lagging behind nations such as Canada, the UK and the US this is not necessarily a bad thing. The forceful push overseas to more fully integrate ethics support in to the system overlooks (to an extent at least) some of the uncertainties about the effectiveness of ethics support services in favour of getting support services up and running. As has been pointed out for the UK, where the institutionalisation of ethics support is some way off:

“There is still time, therefore, to consider what functions are being, or should be, performed by such committees, as well as to evaluate any problems which might arise from their nature and structure.”  
(McLean 2008)

Similarly NSW (and other states) has time to consider what it wants from ethics support and to design the structure and functions of support services accordingly. In the following, we describe some of the functions and models of ethics support services and attempt to show the broad areas of agreement on what clinical ethics *should* involve.

## THREE

# Clinical Ethics Support Services: Functions, Approaches, Models

There are three main functions typically associated with clinical ethics support — education, policy development and case consultation (Singer et al 1990, Blake 1992) with the emphasis a given service places on a particular function varying (Mills 2006). Of these three “canonical” functions, case consultation, the ‘driving force’ of clinical ethical infrastructure (Mills 2005 57) has received the most scholarly attention. More recently attention has started to be given to a fourth function, providing assistance with organisational ethics i.e. working through the ethical issues involved in areas such as management and resource allocation and quality improvement (Dorries et al 2011, McLimans et al 2012). This development reflects the rise in a ‘systems’ approach (fully integrating clinical ethics into the institution and wider health care apparatus) advocated for by some of the field’s most influential scholars and practitioners (Singer et al 2001, MacCrae et al 2008, Fox et al 2010). The systems approach will be discussed further below.

The relative neglect of education and policy development in the literature means there are few detailed descriptions and recommendations for the educative role of ethics support services (Chidwick et al 2010). In most discussions, description of a service’s educational activity is limited to enumerating the types of ethics teaching activities that are commonly undertaken such as presenting a case or an issue at Grand Rounds or conducting in-service training sessions for clinical staff. An exception to this is the educational method called ‘moral case deliberation’ (described further below). The policy development function of ethics services is also not usually discussed at length, more typically it is limited to stating that an ethicist or committee frequently provide input into their institution’s policies and guidelines. The neglect of the policy has recently been noted elsewhere (Frolic et al 2012). Exceptions to this are the descriptions of policy work by Ells (2006) and McDonald et al (2008). Despite these articles, the policy work of most support services remains is opaque and something of a ‘black box’ issue (Frolic et al 2012).

Evaluation of the process and impact of educational activities and policy development functions ethics support services does not appear to have been systematically undertaken. Recent work by Frolic and colleagues seeks to redress the policy development knowledge gap, arguing that the policy review function is a distinctive practice requiring its own metrics, which the authors have developed (Frolic et al 2012).

In contrast to the education and policy functions, case consultation has been the subject of considerable debate and also significant attempts at reaching consensus on what best practice might look like. In the following section we briefly discuss some of the main issues around the provision of clinical ethics support, particularly case consultation.

## Consultation should be facilitation

Clinical ethics support services have tended to lean towards one of two approaches the *authoritative* or the *pure facilitation* both of which have been argued to be inadequate (Aulisio et al 2000, American Society for Bioethics and Humanities 2009). In the authoritative approach the ethicist becomes the central figure in the deliberation; the expert making decisions and issuing binding recommendations. The authoritative model sees the consultant (whether a committee or an individual) assume decision-making authority and thereby (at least potentially) usurps the authority of the patient and the clinical team. In the pure facilitation approach, the ethicist’s role is to broker consensus. A focus only on consensus however can similarly compromise patient autonomy, where ‘consensus’ e.g. between clinicians and patient’s family overrides the wishes of the patient and thereby diminishes patient self-determination (Aulisio et al 2000, American Society for Bioethics and Humanities 2009). A third and most widely adopted approach is ‘ethics facilitation’ — where consultation involves clarifying the value uncertainty or conflict involved and facilitating consensus:

*“...agreement by all involved parties, whether that agreement concerns the substantively morally optimal solution or, more typically, who should be allowed to make the decision.”*  
(Aulisio et al 2000).

Most ethics services offering case consultation assume a non-directive, facilitative role in consultations (American Society for Bioethics and Humanities 2009).

The authoritative status of a consultant's support, whether it is advisory or more prescriptive, has important legal implications for the composition of committee and for 'due process'. While only a few services have attained legal or quasi-legal status, even advisory deliberations can attain considerable authority (McLean 2007). Attention to formal justice and due process is considered particularly important given that many requests for consultation arise because of conflict, often over withdrawing or withholding life sustaining care (McLean 2007).

### **Ethics consultation requires ethical expertise**

**“[CECs] are not just a forum for discussing the facts of a particular case and the normative values that surround it but must also have critical teeth to allow them to dissect flawed reasoning that may be used (perhaps inadvertently) either to support bad practice or to prevent much-needed developments within clinical practice.”** (Williamson 2008, 359)

Since the advent of ethics supports services there has been considerable debate on the role of expertise, specifically but crudely, whether it is bioethical experts or clinicians (with an interest or perhaps some training in ethics) who should be providing ethics consultations (Agich 2009). The expertise debate involves a number of important philosophical questions; an important one being whether the provision of ethics expertise, despite best intentions, ultimately undermines the democratic values underlying consultation. In the approach of Steinkamp and colleagues, drawing on the work of Habermas' discourse theory of ethics, it is argued that the dialogue between the expert

ethicist and clinicians is a democratic means of reaching consensus on the moral norms at hand (Steinkamp 2008). The expertise of the ethicist complements and enhances the moral competence of the non-ethicists, clinicians (and patients) involved in a consultation (Steinkamp et al 2003, 2008). For some critics, providing ethics expertise immediately presents a dilemma, by definition the knowledge of the expert is inescapably elevated above the knowledge of the non-expert; regardless of discourse, democracy will be undermined (Schofield 2008).

Debates notwithstanding, the majority of advocates for clinical ethics support see ethics expertise as a necessary but not sufficient element of ethics support. Ethics expertise isn't the only expertise required of a committee or consultant. The questions an ethics service may be consulted on may not be primarily ethical questions but instead administrative or professional questions. There has long been concern that 'ethics per se' doesn't feature in much of the work of an ethics service:

**... “ethics” per se does not have a primary role in committee discussions of concrete cases. It is commonly said that clarifying the facts and fostering communication comprise upwards of 80 to 90 percent of their work.**

(Murray 1988 quoted in Williamson 2008)

Ethics consultations do appear to be often triggered more by conflict than by cognitively based concerns (Du Val et al 2004) a fact that has seen many authors call for ethics service to be competent at mediation and conflict resolution as well as ethical analysis (Agich 2009, Reiter-Theil 2001). Of course, if an ethics support service isn't primarily focused on ethics then it is arguably misnamed and risks only incidentally contributing to improving the *ethical* quality of care. To some clinical ethicists, the role of the 'ethicist' is decidedly not about improving communication or mediation but about clarifying moral perspectives and providing normative guidance (Rubin and Zoloth 2004). This inevitably requires expertise.

The lack of expertise and the shadow this casts on the 'ethical quality' of the support that a service (consultant or committee) provides continues to be a source of concern. Williamson (2008) argues

that ethical expertise i.e. the possession of the set of philosophical skills necessary to identify sound premises and arguments, is essential if an ethics support service is about crafting *ethical* outcomes.

The 'distinctive ethical remit' of an ethic support service is to examine arguments, identify flawed reasoning, false premises and determine what *is*, not simply what is thought to be, right and wrong (Williamson 2008). McLean (2009) argues that without ethical expertise it's hard to see how an ethics service can account for the ethics of a situation "*after all, ethics is not just common sense. It is an intellectual discipline requiring discrete skill and understanding*" (McLean 2009, 81). The need ethics support to reflect ethical skills and understanding has prompted the development and promulgation of a set of core competencies for ethics consultation.

## Core Competencies

In 1998 the US Bioethics Taskforce (Aulisio et al 2000) provided a well developed set of 'core competencies' that they argued were necessary for ethics support services. Ten years later in the UK, the UK Clinical Ethics Network (with The Ethox Centre, University of Oxford) has developed its own set of core competencies drawing on the earlier US Bioethics Task Force's work (Larcher et al 2010). Both of these guidelines resulted from lengthy and extensive consultation with scholars and those working in and around clinical ethics.

The core competencies focus on the knowledge, skills and character traits that any service (consultant or committee) must have to adequately perform as an ethical service. Given that they are the most recent and build on the work of US Bioethics Task Force, below we reproduce the core competencies set out by Larcher et al (2010).

The skills required (Box 1) are argued to be necessary to ensure that that a support service follows due process and is able to provide clinicians with guidance for "the moral dilemmas of real life situations" rather than in engage in abstract theoretical discussion.

### Box 1: Skills required of Clinical Ethics Committees

#### 1 Ethical assessment skills comprise the ability to:

- identify and discuss the nature of the moral conflict and the need for consultation
- elicit and understand the moral beliefs and values of all parties
- analyse moral uncertainty and conflict
- explain the ethical dimension of a case to those involved and to others
- formulate and justify morally acceptable solutions.

#### 2 Operational and procedural skills

- Facilitation, of both case consultation discussions and CEC meetings.\*
- Mediation and negotiation of conflict resolution in situations of emotional distress.\*

#### 3 Interpersonal skills

- Communication skills\* e.g. active listening, clarity, non-verbal communication.
- Advocacy skills to enable articulation of the views of those who find it difficult to express themselves.\*
- Non-judgementalism and awareness of power imbalances.

\*Advanced skill expected of chair, vice-chair or senior committee member involved in acute or retrospective case consultations.

Reproduced from Larcher et al 2010

The knowledge required (Box 2) is wide ranging and requires targeted recruitment of suitable members or 'co-opting' relevant expertise as required. The values required of a committee (Box 3) are described as 'aspirations' to be acquired over time similar to professional development.

### Box 2: Knowledge required of clinical ethics committees

- 1 Basic concepts of ethical theory and principle and the application and practice of moral reasoning. (Advanced knowledge of ethical theory and moral reasoning required by at least one committee member and the lead member of any case consultation group.)
- 2 Knowledge of the position of the CEC in the hospital framework and links to clinical and legal governance.
- 3 Relevant knowledge of clinical terms and disease processes.
- 4 Cultural context of patient and staff population and of local community.
- 5 Relevant professional codes of ethics, e.g. General Medical Council and General Nursing Council.
- 6 Relevant healthcare and statute law, including UK human rights legislation.
- 7 Local/national government.

Reproduced from Larcher et al 2010

### Box 3: Personal characteristics and values important for ethics consultations

- Tolerance, patience and compassion
- Honesty, fair mindedness, self-knowledge and reflection
- Courage
- Prudence, humility
- Integrity

The possession of these values enables:

- disparate views to be held in difficult situations
- recognition of personal limitations and development of relationships based on trust and respect
- recognition of power imbalances between individuals and how to address them
- voices of the weak and vulnerable to be heard and dissenting
- views to be put to those in authority, involving the skill of advocacy
- individuals not to go beyond their level of competency and/or
- to acknowledge conflicts between personal moral views and their role in consultation
- pursuit of ethically relevant options when it might be convenient to do otherwise
- sensitivity to changing circumstances that have ethical impact.

Reproduced from Larcher et al 2010

There has been some criticism of the core competencies. Gillon (2010) for example, suggests the core competencies and the value 'aspirations' advocated for by Larcher et al are 'exceedingly ambitious' and cautions against regulating to achieve them. As will be discussed below, other commentators are unsure that articulating a set of core competencies will itself advance the ethical expertise that is necessary for good quality ethics support. Evidence from the US and the UK suggests considerable variation in the extent to which the

ethics support services that have been established reflect the core competencies and thus are adequately ethically skilled. Nevertheless, standards have been articulated and there is a rough consensus on what base elements are necessary for sound ethical support. In the Discussion section we will cover some additional issues, such 'due process' that are important in considering ethics support. In the following section we describe the main models of 'competent' service delivery.

## Models of Ethics Support Services

“The ethics consultation team is ideally composed of individuals who bring a balance of the knowledge and skills requisite for effectively providing ethics consultation services. Although it is an open and empirical question whether such skills and knowledge are best delivered by teams or individual ethics consultants, it is certainly evident that both formats are thriving in a wide variety of healthcare settings.” Agich 2009

As the above quote indicates there is considerable uncertainty about how best to deliver ethics support (as consultation); via an individual ethicist or a committee or some alternative. There has not to date been any systematic empirical comparison of the available models and most commentators acknowledge that any particular model of support has strengths and weaknesses. The first ABSH Bioethics Taskforce and the UKCEN statements on competencies (described above) were neutral on the question of what model of delivery should be preferred. The second ABSH Task Force has been

more forthright and recommends that a service not rely on any single model but should employ all three depending on the nature of the particular consultation task.

In what follows we provide a brief overview of the various models. This is not intended as an exhaustive exposition and comparison. The original source materials themselves provide detailed information and should be referred to for more exposition and explanation of each model.

In the UK, UKCEN and Ethox have developed a comprehensive guide for establishing a clinical ethics service (Slowther et al (2004). The guide usefully identifies five models of clinical ethics support with their relative strengths and weakness (see Table 1). Of the five models two currently dominate: the ‘ethicist’ model of an individual (or small team) with specialist training in ethics is consulted as needed, much like specialist medical consultants. The main alternative model is the ‘clinical ethics committee’ a multi-disciplinary group convened on a regular basis, much like a research ethics committee. The individual ethicist model has become more prevalent in the United States and Canada; the committee model appears to be favoured in the UK, Europe and elsewhere (Larcher et al. 2010).

**Table 1: Clinical ethics support models**

Model	Strengths	Weaknesses
Committee	<ul style="list-style-type: none"> <li>■ Part of institutional structure — may have more influence.</li> <li>■ Multi-disciplinary — provides different perspectives and wide discussion.</li> <li>■ Relatively easy to set up.</li> </ul>	<ul style="list-style-type: none"> <li>■ May be seen as management tool rather source of support.</li> <li>■ Slow response.</li> <li>■ Potentially intimidating for a clinician.</li> <li>■ Large group may be unwieldy.</li> </ul>
Sub-committee	<ul style="list-style-type: none"> <li>■ Flexible.</li> <li>■ Quick Response.</li> <li>■ Efficient way to develop policy and guidelines.</li> <li>■ Can engage in consultation as necessary.</li> </ul>	<ul style="list-style-type: none"> <li>■ Fewer members, fewer views.</li> </ul>
Case consultation groups	<ul style="list-style-type: none"> <li>■ Quick response to individual cases.</li> <li>■ Answers immediate needs for ethics support.</li> <li>■ Less intimidating than full committee.</li> <li>■ Members develop expertise in case consultation.</li> </ul>	<ul style="list-style-type: none"> <li>■ Burden on CEC members.</li> <li>■ Fewer members, fewer views.</li> <li>■ Inadequate review.</li> </ul>
Hub and spokes model	<ul style="list-style-type: none"> <li>■ Flexible.</li> <li>■ Quick, informal response.</li> <li>■ Easy access.</li> <li>■ Developing expertise.</li> <li>■ ‘Ear to the ground’ — able to identify ethical issues that might otherwise be missed.</li> </ul>	<ul style="list-style-type: none"> <li>■ Inadequate review of spoke deliberations.</li> <li>■ Difficulty of ensuring sufficient level of ethics expertise in all clinical areas.</li> <li>■ Individual leads may provide a limited view of the issues.</li> </ul>
Ethicist model	<ul style="list-style-type: none"> <li>■ A readily available source of ethics expertise.</li> </ul>	

Reproduced from Slowther et al 2004



Ethics consultants are widely employed throughout the US and Canada, have been advocated for in the UK as a means of redressing the current underutilisation of available ethics support (Sokol 2005, Whitehead et al 2009, Doyal and Doyal 2009). The advantages of the consultant model are argued to be the flexibility and responsiveness (Aulisio 2000, Slowther et al 2001a). The main weakness of the lone ethicist is that consultation involves the perspective of a single individual model rather than the multiple views of a team or committee. Other limitations include onerous workload and professional isolation. Covering all three of the main functions of an ethics support service necessitates that the individual consultant holds or obtains high level ethical skills and a familiarity with clinical practice.

The committee model of ethics support would appear to be the most widely adopted model internationally. The multidisciplinary constitution of the committee is generally considered to be its main strength (ABSH 2009). A multiplicity of views overcomes some of the weaknesses of the single ethicist model, particularly in providing a degree of good procedural practice. In a situation involving conflicting substantive moral principles, there may be no 'right' answer and therefore the best, most 'rational' decision will be more closely approximated by relying on procedural principles. Good procedure, i.e. all relevant voices are heard and considered is best delivered by a committee (Doyal and Doyal 2009). On the negative side, other observers see the 'strength in numbers' advantage of a committee as also resulting in a "diffusion of responsibility" that can undermine the effectiveness a consultation (Agich and Youngner 1991).

The ethics sub-committee seems to be a fairly common approach to case consultation taken by many full ethics committees, particularly in the US (Fox et al 2007). A small number of members of the larger committee undertake the consultation work thereby allowing for a more timely response to a request for advice than is possible for the full committee. A quicker response comes at the cost of the greater range of views offered by a multidisciplinary committee.

Increasingly, those engaged in ethics consultations advocate for a support service to combine all three models in order to maximise the strengths and minimise the weaknesses of each (ABSH 2009, Fox et al 2010). Fox et al (2010) recommended that rather than rely exclusively on one model, all three should be available with the consultation task itself determining which model is utilised e.g. whether a full committee or an individual ethics consultant is used to address and issue or respond to a request for support. Table 2 overpage lists the type and level of knowledge required within each of the three main models and helps show why a combination of models might be advantageous over a single model approach.

### **Moral Case Deliberation**

Moral Case Deliberation (MCD) is a specific form of clinical ethics support that has developed (with government support) in the Netherlands (Molewijk et al 2011). Within a MCD event, a multidisciplinary group of healthcare professionals meets to deliberate systematically on a moral case from their own practice. The meetings are facilitated by a specifically trained MCD facilitator following a structured conversation method. The aim is to create a 'learning environment' where experiential knowledge is collectively constructed (Wiedema et al 2011). There are number other 'dialogical' approaches to supporting clinicians and improving ethical decision making for example 'ethics rounds' (Svantesson et al 2008, DeRenzo et al 2006).

### **The Hub and Spokes model**

A more recent innovation for providing ethics support is the 'Hub and Spokes' strategy developed by the Joint Centre for Bioethics (JCB) at the University of Toronto, Canada in conjunction with 10 affiliated hospitals (MacRae et al 2005). The basic idea of the strategy (developed from business and organisational ideas) is to provide decentralised resources, the 'Spokes', coordinated by the centralised 'Hub'. The hub provides the bioethics expertise and leadership to the spokes; clinicians and others organised along professional or departmental lines throughout the organisation who act as a local ethics resource.



**Table 2: Skills for ethics consultation**

<b>Skills for Ethics Consultation</b>				
Ethics consultants must have a variety of “basic” skills, which are used in straightforward cases, and “advanced” skills, which may be required in more complex cases.				
<b>Skill Area</b>	<b>Individual/at least one group member needs</b>	<b>Every team member needs</b>	<b>Every committee member needs</b>	<b>Individual/at least one member can access</b>
1. Skills necessary to identify the nature of the value uncertainty or conflict that underlies the need for ethics consultation	Advanced	Basic	Basic	Not Required (NR)
2. Skills necessary to analyse the value uncertainty or conflict	Advanced	Basic	Basic	NR
3. The ability to facilitate formal and informal meetings	Advanced	Basic	NR	NR
4. The ability to build moral consensus	Advanced	Basic	Basic	NR
5. The ability to utilize institutional structures and resources to facilitate the implementation of the chosen option	Advanced	Basic	NR	NR
6. The ability to access relevant ethics literature, policies, guidelines, and standards	Advanced	Basic	NR	NR
7. The ability to document consults and elicit feedback regarding the process of consultation so that the process can be evaluated	Advanced	Basic	NR	NR
8. The ability to listen well and to communicate interest, respect, support, and empathy to involved parties	Advanced	Basic	Basic	NR
9. The ability to educate involved parties regarding the ethical dimensions of the case	Advanced	Basic	NR	NR
10. The ability to elicit the moral views of the involved parties	Advanced	Basic	NR	NR
11. The ability to represent the views of the involved parties to others	Advanced	Basic	NR	NR
12. The ability to enable the involved parties to communicate effectively and be heard by other parties	Advanced	Basic	NR	NR
13. The ability to recognise and attend to various relational barriers to communication	Advanced	Basic	Basic	NR
14. Ability to effectively run an ethics consultation service	Advanced	NR	NR	NR
15. QI and evaluative skills	Basic	NR	NR	Advanced
16. Ability to communicate and collaborate effectively with other responsible individuals, departments, or divisions within the institution	Advanced	Basic	NR	NR

Adapted from ABSH 2009

While it is encouraging that healthcare organisations are turning their eye towards ethics, placing a clinical bioethicist and/or ethics committee as the “ethical centre” of an organisation, without an overall cultural commitment to ethics within/from the organisation, may not be effective or sustainable.

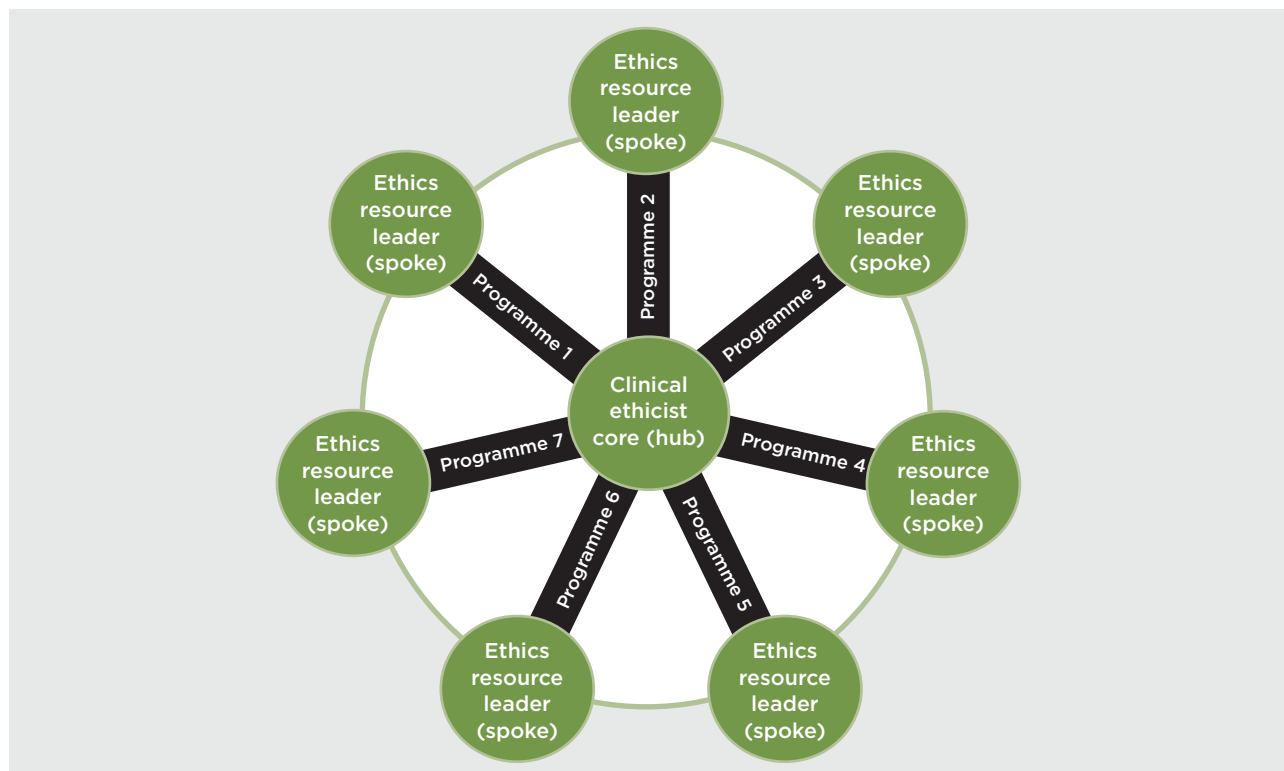
MacCrae et al 2005

The Hub and Spokes strategy is about creating an ethics infrastructure. The goal of the Hub and Spokes strategy is for ethics support services to become (over time) fully integrated into the life of the organisation it serves: *“The greatest strength of the Hub and Spokes Strategy is its power to integrate ethics services into an organisation”* (MacRae 2005). The Hub and Spokes are intended to foster an ethical climate where the responsibility to be ethically engaged and aware is recognised from “those in the boardroom to those at the bedside” (MacRae et al 2005, 257). The core innovation of the strategy is that builds capacity through ethical expertise ‘radiating’ from the Hub, through the Spokes and to the clinical and general staff

(MacRae 2005). This diffusion of knowledge and skills is intended to overcome some of the limitations of the typical static model of ethics support where expertise remains concentrated in the individual consultant or committee. The Spokes reach out to all parts of the organisation generating ethics awareness and competence and thereby minimising the perennial challenges of workload, peer support and isolation facing the lone ethicist (or committee). The strategy establishes an infrastructure of relationships within an organisation which serves to both formalise previously implicit responsibilities and generate a commitment (or ‘buy-in’) to ethics at all levels; this helps address the problem of poor sustainability and limited accountability of traditional models of support.

The JCB’s experience of implementing the Hub and Spokes model has been described in detail in a number of peer-review papers (Godkin et al 2005, MacRae et al 2005) but there hasn’t to date been any published evaluation of the performance of strategy. It should also be noted that JCB model appears to be unusually well resourced by comparison to most ethics support services. In 2011 the JCB hub was staffed by two trained bioethicists (1.8 FTE total) plus clerical support (see [www.jointcentreforbioethics.ca/](http://www.jointcentreforbioethics.ca/) )

Figure 1: Hub and spokes model



Reproduced from MacRae et al 2005

## The 'evolution' of ethics support

[W]e believe their ('ethics support services') objective should expand from reacting to isolated clinical ethics cases, to the broader goal of enhancing quality of care by focusing on the context of the ethics issue. Nelson et al 2010

As described above, detailed and comprehensive guides for providing ethics support (e.g. the updated ABSH 'core competencies' and the UKCEN's similar set of competencies) exist but some uncertainty remains on what model is likely to be most useful to an organisation. There appears to be an emerging consensus on the benefits of combining models (e.g. ethics committee complemented by a sub-team and/or individual ethicist). A more significant development in thinking on providing clinical ethics support is the rise of a 'systems' approach with its emphasis on the *quality improvement, context and prevention*.

Calls for ethics support to be better and more comprehensively integrated into its parent organisation and wider system have been made for some time. In 2001 three eminent medical ethicists identified the need and challenge of integrating ethics into the quality improvement culture of health organisations (Singer, Pellegrino and Siegler 2001). While ethics support services have proliferated, the 'systems' approach to clinical ethics remains to be widely embraced (MacRae et al 2008). There are, however, a number of well-developed frameworks for implementing systems thinking in ethics support (Fox et al 2010, MacCrae et al 2008, Nelson et al 2010). All posit the mutual dependence of quality care and ethical principles; ethics quality means that practices throughout an organisation are consistent with the accepted ethical standards, norms, or expectations for the organisation and its staff (Fox et al 2010). Drawing on theoretical developments in disciplines such as organisational studies and social, cognitive, and cultural psychology, all share a commitment to ethics services having a more proactive role in the continuous *quality improvement* effort of the organisation and system within which it operates.

In a systems approach ethics support moves 'upstream' to address systemic and structural

elements that produce value conflict rather than remain only at the level of the particulars of the issue or case at hand. This encourages a more proactive and preventative form of ethics support (Fox et al 2010, MacCrae et al 2008, Nelson et al 2010). The approach is some time labelled 'preventive ethics'.

Clinical ethics that is geared at systems change is not as focused on the crisis situations as it is on the overall context of these situations...As clinical ethics becomes more systems focused, interventions (e.g. consultation or educational sessions) are seen as opportunities to understand the "root cause" of a problem or behaviour and to suggest changes or alternative systems models that will reduce rather than create ethical difficulties for clinicians and patients (MacCrae et al 2008)

The 'root causes' will involve local clinical practices and dynamics but will also involve broader systemic elements such as the organisation's business model. There are 'levels' of ethics and these interact to produce the ethics of an organisation; too often ethics services are 'reactive' (responding to and focussing on the particulars of a case) and fail to account for these levels (Fox et al 2010).

In the 'clinical microsystems framework' approach (Nelson et al 2010) the levels are micro and macro systems. Larger systems (or macrosystems) are composed of smaller systems (micro-systems) which produce quality, safety, and cost outcomes at the front line of care. The outcomes of the macrosystem depend on the outcomes of its constituent microsystems. Ethics issues and difficulties are recurring expressions of problematic systemic structures and processes within and between microsystems and the interactions between the microsystems and macrosystem (Nelson et al 2010). In the 'IntegratedEthics' of Fox et al (2010) the need to recognise levels is illustrated using an iceberg analogy; at the tip of the iceberg are ethically problematic decisions and practices; below these are the organisational systems and process that inform decisions and practices; and below these are the organisations

ethical and environment and culture which though values and norms “almost imperceptibly” shape ethics practices. The upshot of these approaches is that clinical ethics support needs to take into account the systemic origins of many ethics issues that arise in patient care. Table 3 below shows a comparison between the traditional and ‘IntegratedEthics’ models with the latter clearly offered as a more system oriented.

The ‘systems’ approach represents a theoretically well developed approach to how clinical ethics support should be designed and implemented. While the many challenges of providing valued and valuable ethics support are not instantly overcome with this approach, they are at least explicitly addressed. In the following sections we review the literature on what is reported about how ethics currently is implemented.

**Table 3: Ethics models**

<b>Traditional Ethics Committee Model</b>	<b>Integrated Ethics Model</b>
Isolated Committee	Integrated Program
Narrowly focused	Comprehensive
Purpose vague	Purpose clear
Functions based on tradition	Functions derived from purpose
One-size-fits-all structure	Structures tailored to functions
<i>Ad hoc</i> approach	Clear standards
Reactive	Proactive
Case-based	Systems-oriented
No performance metrics	Clear performance metrics

Reproduced from Fox et al 2010

## Evaluation of Clinical Ethics Support Services

The proliferation of initiatives in clinical ethics support has seen a rapidly growing literature but this has not been accompanied by extensive empirical research and evaluation. Empirical studies of clinical ethics support services are overwhelmingly descriptive with only a few attempting systematic evaluation. Table 4 summarises the main empirical studies of clinical ethics services since 2000.

### Descriptive Studies of Ethics Support Services

Most studies of ethics support services have sought to establish the prevalence of support services their type, structure, composition, main functions, activities and processes. What these studies mostly show is the diversity of ethics support services in their goals, functions and models of support. These studies (see Table 4) show that the majority of ethics support service provide all three of the core functions of education, policy review and development and consultation but predominantly may focus on one function e.g. policy development; some services are provided by a single ethicist, some by committees, others employ both; with regards to consultations, many issue non-binding recommendations, a small number issue binding recommendations and some do not make any recommendations at all; most ethics committees are multidisciplinary but vary in their membership mix and their mode of recruitment; some committees have members with formal ethics training, many do not; legal expertise is represented on some committee but not on others; some committees actively educate their members, others do not or are unable to; some services involve patients and families directly in their deliberative process and allow them to refer to the service, in many support is primarily if not exclusively for clinicians; some committees have adopted systematic means of documenting their activities, others do not appear to bother; some services undertake to evaluate their activities, many do not.

Descriptive studies of clinical ethics services show variation in the goals and processes of clinical ethics services. Diversity is often attributed to the ad hoc, grass roots development of support services and the lack of regulatory oversight and coordination.

One important common finding is the low rates of referral of case to support services. In the most recent data for the US, Fox et al (2007) the median number for the year prior to the survey was 3. In the UK, Slowther et al (2012) found half of the committees they survey had between 1-5 consultations in the previous year. Another relatively recent study of clinical ethics services in the United Kingdom led the researchers to conclude “*At the moment, the stark reality about CECs in the UK is that clinicians are not using them.*” (Whitehead et al 2009). The issue of underutilisation will be discussed further below.

### Descriptive Studies of Clinician – Ethics Support Service Interaction

A small number of studies have focussed on the interaction between a service and clinicians (see Table 5). Studies have looked at the types of ethical issues (variously referred to as *inter alia* – problems, dilemmas, difficulties) that clinicians face; what issues that prompt clinicians to seek ethical support; what enables or impedes access to support; clinician perception of the adequacy of ethics support available to them and their preferences for types of ethics support. Studies such as DuVal et al (2001, 2004) and the Royal College of Physicians (2005) show ethics consultations are mostly requested for acute situations such as: end-of-life issues, ‘futility’, and withdrawal or withholding of life-sustaining treatment and abortion. Other frequently occurring issues include disagreement among clinicians, professional conduct; truth-telling and confidentiality; justice issues. A common and important finding is that clinicians continue to rely on each other as a source of support when facing an ethical issue. Dilemmas about end-of-life decisions and patient autonomy were often

referred for consultation, while dilemmas about justice, such as lack of insurance or limited resources, were rarely referred (Du Val 2004).

Many of these studies have investigated why clinicians do or do not seek ethics support. Clinicians tend to seek support for conflict resolution, reassurance about a decision, clarification of issues, new insights on a case and emotional support (Du Val et al 2001). Clinicians with ethics training appear to be more likely to request ethics support (Du Val et al 2004, Hurst et

al 2007). Clinicians often do not seek support because consultations are difficult to access, the process is time consuming and intimidating and the outcomes unhelpful, they may fear being scrutinised, fear loss of autonomy, they may even fear retaliation (Slowther et al 2001, Du Val et al 2004, Forde et al 2008, Gaudine et al 2011). Other possible reasons for underutilisation include clinicians not being aware that a clinical support service exists, fear that a committee will worsen the situation (Gaudine et al 2011) and placing a low value in shared decision making (Orlowski 2006).

**Table 4: Descriptive Studies of Ethics Support Services**

Author(s) Year, Location	Methods and Sample	Variables and Outcomes of Interest	Results and Recommendations
McGee 2001, US	Quantitative – national (random sample) survey of EC chairpersons.	Prevalence, structure, functions.	High prevalence. Clinicians predominate. 86% of EC provide clinical ethics consultation, all contribute to policy development. Clinician request only in some institutions. Only 5% issue binding recommendations. Autonomy main ethical issue. Not an evaluation of performance.
McNeill et al 2001, Aust	Quantitative – national survey of hospital administrators.	Prevalence, committee activity.	One hundred and twenty (10%) had a clinical ethics committee (accuracy of the 10% estimate is questionable, partly because survey respondents may have confused clinical ethics committees with research ethics committees). Survey was conducted in 1994 this is a critical review of the survey data. Not an evaluation of performance.
Slowther et al 2001, UK	Quantitative – survey of senior administration and clinical staff of NHS Trusts. Qualitative – interviews with chairpersons of CECs (N = 20).	Prevalence, structure, function, perceived need for support EC development.	Eighteen per cent of UK NHS Trust had formal ethics support service. Number of ECs growing, 89% see a need for EC, EC should be advisory. CECs should offer support not issue decisions. Not an evaluation of performance.
Slowther et al 2004, UK	Quantitative – survey of CECs.	Composition, function, activity, training and funding.	Limited role in consultation and educational support mostly input into policies and guidelines. Not an evaluation of performance.
Slowther 2011, UK	Postal/electronic questionnaire survey to the chairs of all 82 clinical ethics services registered with the UK Clinical Ethics Network in July 2010.	Composition, structure and function, process of case consultation, institutional support and evaluation.	Clinical ethics services in the UK are increasing as is their involvement in case consultation. Significant variation in committee processes. Further qualitative research recommended on the function and role of committees in their institution. Not an evaluation of performance.
Godkin et al 2005, Canada	Retrospective case study of ethics services records.	Structure, activities, resources.	Lone ethicist model dominates; considerable variability in structure, activity resources and reporting. Wide variation in consultation rate (2 – 250 per year). Not an evaluation of performance.
Milmore 2006, US	Quantitative – survey of EC chairperson or spokesperson.	Structure, composition, function, degree of activity.	Composition of EC dominated by administration and medicine few with bioethics training and struggling for credibility. Half of ECs have low activity. Draws a link between the two and call a more inclusive committee. Not an evaluation of performance but does see low activity linked to composition.
Fox et al 2007, US	Descriptive study – 56 item phone or questionnaire survey of the “best informant” within each hospital in the US. Random sample of 600 U.S. general hospitals, stratified by bed size.	Prevalence, practitioners, and processes of ethics consultation in U.S. hospitals.	Ethics consultation services (ECSs) were found in 81% of all general hospitals in the U.S., and in 100% of hospitals with more than 400 beds. The median number of consults by ECSs in the year prior to survey was 3. Most individuals performing ethics consultation were physicians (34%), nurses (31%), social workers (11%), or chaplains (10%). Only 41% had formal supervised training in ethics consultation. Consultation practices varied widely both within and between ECSs. For example, 65% of ECSs always made recommendations, whereas 6% never did. These findings highlight a need to clarify standards for ethics consultation practices. Not an evaluation of performance.
Frewer and Fahr 2007, Germany	Quantitative – survey of members of CECs.	Opinions on clinical ethics meetings and confidentiality.	CEC members “convinced” that clinical ethics consultation is an appropriate and useful means for quality assurance in daily medical practice. Not an evaluation of performance.

Author(s) Year, Location	Methods and Sample	Variables and Outcomes of Interest	Results and Recommendations
Swetz et al 2007, US	Retrospective review of ethical consults.	Issues subject to consultation.	Issues of communication, family conflict, and futility dominate consultations. Not an evaluation of performance.
Akabayashi et al 2008, Japan	Quantitative — surveys of medical organisational ECs (1998, 2003).	Prevalence, structure, function, activities and strategies of EC.	Increase in prevalence (25% to 50%) between 1998 and 2003. Protocol review and policy development predominant functions. Concludes that there has been an 'overall rise' in awareness of importance of ethical issues. Not an evaluation of performance.
McLean et al 2009, UK	Quantitative — survey of EC chairs.	Composition, function, competency.	Preferred skills basic knowledge of medical ethics, ethical principles, ethical frameworks, guidelines and debates; knowledge of medical law and current legal debates; governance, procedures and policies. Not an evaluation of performance.
Pederson et al 2009, Norway	Qualitative — interviews among Committee members.	Barriers to consultations.	Members recognise the need for clinical ethics support services, tendencies to evade moral disagreement, conflict, and 'outsiders' are common barriers to utilize a CEC in the hospitals. Recommend improving routines and procedures, clarifying profile and responsibilities, operating conditions, and developing organisational integration. Various strategies to meet these challenges on a local, regional or national level are provided.
Romano et al 2009, US	Quantitative — retrospective review of records.	Number of consults, reasons for consults.	A steady increase in number of consultations following introduction of mandatory consult policy. Speculates on positive impacts such as 'increased learning' — no data to support this though. Not an evaluation of performance.
Whitehead et al 2009, UK	Survey (on-line) of 30 CEC chairpersons.	Structure, function, activity of CEC, problems encountered; perceived need for CECs, explanations sought from respondents.	Seventy percent reported member with ethics training; 70% reported rapid consultation team; approx 50% reported low rates of consultations <3 per year. Explanations offered for low activity include lack of funding, support and inadequate publicising of CEC within hospital. Not an evaluation of performance.
Gaudine et al 2010, Canada	Quantitative — national survey hospitals (> 100 beds).	Structure, function and activity of CEC, problems encountered; perceived need for CEC.	The percentage of hospitals with CEC 85% (compared with 58% and 18% in 1989 and 1984). Wide variation in the size of committees and the composition of their membership has continued. CEC meetings have become more regularized and formalized and continue to be predominately advisory. 2008 shift in the priority of the activities of CEC to meeting ethics education needs and providing counseling and support with less emphasis on advising about policy and procedures. Not an evaluation of performance.
Kesselheim et al 2010, US	Quantitative — survey of paediatric clinical ethicists.	Number and nature of clinical ethics referrals across 46b paediatric hospitals in the US.	Forty-six per cent of hospitals had between six and ten referrals per year and 16% had more than 15 cases per year. Found inconsistent adherence among services to national consensus statements on standards for consultation.
Nelson et al 2010, US	Quantitative — national survey of rural hospital executives.	Prevalence, perceived need.	Prevalence declines with increasing rural remoteness. Advocates establishing a virtual ethics committee network to redress lack of availability of ethics assistance. Not an evaluation of performance.
Tapper et al 2010, US	Quantitative — retrospective review of ethical consultations.	Issues subject to consultation; consultation per admission, resource utilisation per consult.	The issues of patient code status, palliative v curative and end of life dominate. Consults in obstetrics, general medicine, and surgery were the most time-consuming. Not an evaluation of performance.
Moeller et al 2012, US	Quantitative — retrospective review of consultations.	Details of consults (e.g. reasons for consult) recommendations of EC; % of recommendations followed; consultation trends pre and post start of rival service.	Changes in the reasons for EC consults (e.g. from family opposition to withdrawing life saving treatment to doctor opposition) and changes to the recommendations (e.g. from initiate DNR to comfort care) observed post start of rival (palliative care) service. Not an evaluation of performance.



**Table 5: Descriptive Studies of Clinician — Support Service Interaction**

Author(s) Year, Location	Methods and Sample	Variables and Outcomes of Interest	Results and Recommendations
Larcher et al 1997, UK	Survey and Interviews with clinicians.	Issues faced, strategies and functions of clinical ethics support for paediatrics.	Value of clinical ethics support in the paediatrics setting. Four desirable functions of clinical ethics support: (a) consultation, but not prescription, on ethical issues including those which are case related; (b) participation in development of guidelines for good clinical practice; (c) education and (d) reflection on ethical issues away from the acute clinical setting.
Wood and Ellis 1999, UK	Survey of clinicians (N=89 of 136).	Knowledge and attitudes to hospital CEC.	Low awareness of CEC among clinicians; clinicians want education and support; clinician autonomy not undermined.
Du Val et al 2001, US	Quantitative — telephone survey of clinicians (mainly oncology and critical care specialists).	Triggers for consults.	Most common triggers that led to consultation relate to: (i) wanting help resolving a conflict; (ii) wanting assistance interacting with a difficult family, patient, or surrogate (iii) wanting help making a decision or planning care, and (iv) emotional triggers. End of life decision making, patient autonomy issues and conflict were of particular concern.
Duval et al 2004, US	Quantitative — national telephone survey of clinicians.	Ethical dilemmas and experience with consultations; satisfaction with resolution with and without consultation.	Most commonly reported dilemmas regarding end-of-life decision making, patient autonomy, justice, and conflict resolution. Most found consultations useful in dealing with future ethical dilemmas (72%), some hesitated to seek ethics consultation because they believed it was too time consuming (29%), might make the situation worse (15%), or that consultants were unqualified (11%). Recommends improved ethics education and greater access to consultation.
Royal College of Physicians 2005, UK	Survey of senior specialist registrars.	Use of ethical support.	Seventy-eight per cent encountered ethical dilemmas on a daily or weekly basis most frequently regarding consent, confidentiality, end of life decision-making, the role of relatives in decision-making and decision-making in incompetent patients. Ninety-four per cent reported seeking support from senior colleagues; 47.9% referred to written literature and 32.8% to existing ethical policies. Thirty-four per cent indicated they would value support from a CEC.
Orlowski et al 2006, US	Quantitative — survey of clinicians.	Decision to seek consultation.	Doctors who believe in shared decision making more likely to seek a consultations; doctors who see themselves as responsible for resolving issues and who believed they were proficient in ethics were less likely to seek a consultation.
Hurst et al 2007 Norway, Switzerland, Italy, UK	Quantitative — survey of clinicians.	Access to and use of ethics support services.	Only a minority (17.6%) reported having access to ethics consultation in individual cases. Ethical difficulties most often reported were uncertainty or impaired decision-making capacity (94.8%), disagreement among caregivers (81.2%) and limitation of treatment at the end of life (79.3%). Frequency of type ethical difficulties most frequently faced varied among countries.
Aleksandrova 2010, Bulgaria	Quantitative — survey of clinicians.	Issues/problems encountered; strategies for dealing with issues, attitudes to consultations.	Issues and problems encountered similar to clinicians in other countries. A generally positive attitude towards clinical ethics support.
Asai et al 2008, Japan	Qualitative — interviews with clinicians.	Expectations of consultations and preference for mode of support.	Clinicians value the advice, insights and emotional support from an external (but familiar with clinical area) source. Time, pride and low awareness may inhibit utilisation.
Forde et al 2008, Norway	Qualitative — interviews with eight clinicians who evaluated six committees' deliberations on 10 clinical cases.	Experiences with, perceived preferences for and obstacles to utilising a Committee.	A systematic approach to case consultations is vital. Procedures should be known. Clinicians want to be included in deliberations and a written report should be provided. Obstacles for utilizing CECs include: medical culture's conflict aversion and its anxiety of being judged by outsiders and the committees viewed as a 'court'.
Svantesson et al, 2008b	Qualitative — clinician interviews, 7 doctors, 11 nurses.	Experiences with and preferences for ethical discussion 'ethical rounds'	Positive and negative experiences reported. Good rounds included stimulation to broadened thinking, a sense of connecting, strengthened confidence to act, insight into moral responsibility and emotional relief. Negative experiences were associated with a sense of unconcern and alienation, as well as frustration with the lack of solutions and a sense of resignation that change is not possible.



Author(s) Year, Location	Methods and Sample	Variables and Outcomes of Interest	Results and Recommendations
Dauwerse et al 2011, Netherlands	Mixed methods: 2 focus groups, 2 questionnaires, and 17 interviews among board members and ethics support staff.	Perceived need for and willingness to seek ethics support.	Emphasis on creating a culture of dialogue about complex situations. Four main clusters of goals: 1) encouraging an ethical climate, 2) fostering an accountable and transparent organisation, 3) developing professionalism and a final goal, overarching the previous three, 4) good care.
Gaudine et al 2011, Canada	Interviews among thirty-four nurses, 10 nurse managers and 31 physicians working at four Canadian hospitals (as part of a larger study).	Barriers and facilitators to seeking an ethics consultation.	Barriers: not confident with result, lack of knowledge about the committee, lack of time, length or not timely process, belief that an individual should be able to manage, reactions from others, ineffective ethics consultations and lack of expertise. Facilitators: accepting one may need help, support within unit and hospital, knowing consultation would not sideline them.

## Evaluation of Ethics Support Services

Table 6 details the most frequently cited and discussed attempts to evaluate ethics consultations. All of these studies are now over ten years old. The absence of any similar follow up evaluative work is probably explained by the continuing debate around *how* to evaluate ethics support.

Two prospective studies by La Puma and colleagues (1988, 1992) collected descriptive information on consultations such as reason for consultation, the characteristics of the patients involved, the clinicians' satisfaction with the service and whether they would use it again. In both studies large majorities of clinicians found consultation helpful and nearly all indicated they would use the service on the future. Similar findings on the perceived helpfulness of consultations have been found in other studies of clinicians (Orr and Moon 1993, McLung et al 1996, Yen and Schneiderman 1999 not tabulated). In those studies that have compared clinician with patient satisfaction, patients have been found to be less satisfied with ethics consultation (McLung et al 1996, Yen and Schneiderman 1999).

A small number of studies have assessed clinical ethics support service using an experimental design. The most well known and well regarded are a series of studies by Schneiderman and colleagues looking at the impact of ethics consultation in intensive care settings (Schneiderman et al 2000, 2003). The Schneiderman et al trials were looking at ethics consultation to parents with 'value laden' treatment conflicts identified by clinicians. Two trials, a single centre and a multi-centre, were conducted with patients randomised to the intervention (offer of ethics consultation) or control (not offered). The findings were consistent in both trials — ethics consultation was associated with shorter stays, reduced use of services and less cost among those who did not survive to discharge.

There were no statistically significant difference between intervention and control difference for those who survived to discharge. It seems that the intervention of ethics consultation was beneficial to patients who did not survive to hospital discharge and was not harmful to patients who did survive. The author's main and oft cited conclusion was that consultations "were useful in reducing conflict that may have inappropriately prolonged non-beneficial or unwanted treatments in the ICU" (Schneiderman 2003).

The Schneiderman studies provide good quality empirical evidence on the impact of ethics consultations; carefully planned and conducted randomised controlled trials using intention-to-treat analyses. As a number of authors have pointed out, however, the studies do have a number of methodological limitations (Lo 2003, Chen and Chen 2008). Lo (2003) challenges the Schneiderman study on a number of grounds. Methodologically, he points to the lack of standardisation and the resulting difficulties with comparing and evaluating the impact of consultations. Chen and Chen (2008) argue that the Schneiderman trials are 'inevitably' problematic because the intervention (a consultation) is not standardised and not blinded. The form and content of an ethics consultation will vary by the contingencies attached to each specific case and by the differences in approach between institutions and individual consultants (Chen and Chen 2008). A lack of placebo controlled group and difficulties associated with standardising the intervention cast doubts of the validity of the results (Chen and Chen 2008). Lo (2003) also challenges the Schneiderman studies on the applicability of the results to other clinical environments. The trials were conducted in critical care units with established and experienced ethical consultants (Schneiderman et al do acknowledge that the generalisation of the results should be made with some caution).

**Table 6: Evaluation Studies of Support Services**

Author(s) Year, Location	Methods and Sample	Variables and Outcomes of Interest	Results and Recommendations
La Puma 1988, US	Mixed: Interviews & questionnaire. Physicians, patients and family of Fifty-one consultation requests between period July 1, 1986, and June 30, 1987.	Evaluate physician assisted ethics consult. Identify characteristics of patients as subject of consult, reasons for physician request and level of satisfaction.	The requesting physician sought assistance with withholding or withdrawing life-sustaining treatment in 49% of cases, with resuscitation issues in 37%, and with legal issues in 31%. Assistance with more than one issue was sought in 39 cases (76%). In 36 cases (71%), the requesting physician stated that the consultation was “very important” in patient management, in clarifying ethical issues, or in learning about medical ethics. Recommended: Ethics consultation performed by physician-ethicists provides useful, clinically acceptable assistance in a teaching hospital.
La Puma 1992, US	Qualitative — structured questionnaires. Data compared to previously reported university hospital data over 2 years (January 1, 1988, to December 31, 1989), prospectively evaluated a newly established ethics service.	3 aspects of ethics consultation: clinical questions asked; helpfulness and differences between consultations at a community teaching hospital versus a university hospital.	During the 2-year study, 104 consultation requests were received from 68 physicians in eight departments. Most frequent request(s): decision to forego life-sustaining treatment (74%), resolving disagreements (46%), and assessing patient competence (30%). Consultation “very helpful” or “helpful” in one or more aspects of patient care in 86% of cases, or in one or more aspects of physician education in 86% of cases. These data are similar to university hospital data.
McLung et al 1996, UK	Questionnaire — Physicians, nurses and patients or family members involved in 20 cases consultations during a 2-year period.	Satisfaction and perceived effectiveness of (3 person) CE consult by staff, patients and families.	Ninety-six per cent of physicians and 95% of nurses felt that the consult was helpful, compared with only 65% of the patient/family responses. Lack of communication between patients and staff was cited as a problem in all cases (where consult was deemed unhelpful by patients and family). Patients or family members and professional staff have different perceptions regarding the value of bioethics consultation. Recommend: earlier mobilization of consultative staff, rigorous training of consultants in techniques of conflict resolution, education of primary caregivers — on communication problems may be beneficial.
Yen and Schneiderman 1999, US	Interviews with medical staff and families involved in 35 retrospective cases	Satisfaction and perceived effectiveness by medical staff and families	Ninety per cent of medical staff interviewed saw consult as important and would recommend to others. Higher satisfaction with consult among medical staff than families
Schneiderman et al 2000, US	Prospective, randomized, controlled trial of ethics consultations in medical and paediatric ICUs at a university medical center — Seventy-four patients randomly assigned to an intervention (ethics consultation offered) or nonintervention (ethics consultation not offered) arm of the trial.	Effectiveness of clinical ethics consultation	No differences in overall mortality between the control patients and patients receiving ethics consultations. CECs were associated with reductions in ICU hospital days and life-sustaining treatments. Most participants viewed consults to be beneficial and seen as useful in resolving conflicts that may be inappropriately prolonging futile or unwanted treatments. Consults can help in difficult clinical decisions.
Schneiderman et al 2006, US	Multisite RCT among ICU patients.	Effectiveness of clinical ethics consultation. Time spent in ICU on ventilation among those who did v did not receive ethics consult.	The majority of healthcare providers and patients/surrogates agreed that ethics consultations in the intensive care unit were helpful in addressing treatment conflicts. Ethics consultations also reduce hospital costs without diminishing the quality of care. Hence, ethics consultations seem to be useful in resolving conflicts that may be inappropriately prolonging nonbeneficial or unwanted treatments at the end of life. Further research on whether ethics consultations are beneficial in other settings is needed.

## Discussion

The literature clearly demonstrates the increased interest in and prevalence of clinical ethics support services internationally. Given that most countries have not followed the United States and made clinical ethics support mandatory for health care organisations, growth appears to be a grass roots development. The literature is also clear that ethical support services typically function to assist with policy development, education and provide case consultation (and to a lesser extent research). Of these, consultation has received the most scholarly attention and is also the most developed in the terms having established approaches and models for service delivery.

There is broad consensus among scholars and practitioners in the field that a set of 'core competencies' is necessary for quality ethics support. How consultation is undertaken varies by underlying approach and the different models for delivering support that have evolved. The literature indicates that there is at least two major schools of thought about how the ethics expertise of a consultant or a committee should contribute to a case — *authoritative* and *facilitative*. The two most significant and commonly used guidelines for support services, the US Bioethics Taskforce core competencies (first and second versions) and the UKCEN's 'core competencies' advocate for the latter. Internationally, most ethics services (many of whom draw directly on the Bioethics Taskforce and UKCEN work) issue advice rather than binding recommendations.

The ad hoc growth in support services has seen considerable diversity in the functions and processes adopted by particular committees. The wide variation in practice has long prompted concerns about the quality of the ethics support being provided (Slowther 2008). Quality has been the main impetus for the 'core competency' work of the Bioethics Taskforce and UKCEN. While there is a broad consensus that an ethics support services needs to be competent and advisory, there is no agreed 'best practice' model of service delivery. Most empirical studies of clinical ethics

support are descriptive and are of limited value in showing effectiveness. The few trials that have been conducted have reported statistically significant positive impacts of ethics consultations on savings and user satisfaction. Although encouraging, the confidence in the validity of these results is undermined by several methodological weaknesses such as the validity of the outcomes used (e.g. cost effectiveness) to assess ethical support. A common finding of surveys of support services is a low rate of case consultation activity. It appears clinicians often don't seek ethics support when it is available.

Overall, on our reading of the literature ethics support services are promising if yet to be proven means of improving the ethical quality of patient care. There is clearly considerable potential for ethics support to, *inter alia*, minimise moral conflicts and distress, support patient autonomy and enhance operational efficiency and cost-effectiveness. In discussing some of the challenges of implementing ethics support services we believe the comment immediately below should be kept in mind.

**“Like democracy, ethics committees and ethics consultations are not a perfect system, but they are better than the alternative of having no ethics consultation process at all.”**

Somerville 2004

### The evaluation problem

Perhaps the most common observation in the clinical ethic support literature is that ethical support services have not yet undergone the evaluation of effectiveness that most other health service programs are routinely subject to. The quote below is used to again draw attention to some of the ambivalence about the usefulness of ethics support services.

“To date information on the benefits and disbenefits of clinical ethics committees is so scant that it should not be assumed that the best course would be to reform the way a particular committee works. Rather, committees must also allow for the possibility that the assessment process could recommend their temporary or permanent dissolution, rather than ways to hone their performance.”

Williamson 2007

Few commentators appear to be calling for permanent dissolution of ethics committees, all seem to agree however, on the urgent need for some systematic means of assessing the quality of an ethics service (regardless of model). Evaluation of performance is seen as important for service accountability (Craig and May 2006). A support service needs to show the merit of its input into difficult cases to gain the confidence and respect of the clinicians (and patients) it seeks to support (Williamson 2007). Confidence and respect are necessary for clinicians to use the support services that are available (UNESCO 2008). Accountability is also necessary to ensure that due process, particularly the rights of patients, is observed (Williamson 2007).

“If CECs cannot demonstrate that they can contribute to improvement in quality of patient care then it is legitimate to ask why have CECs at all?”

Dorries et al 2011

Again, few commentators on clinical ethics support services appear to seriously doubt their importance and utility but as most point out, health care has become a field dominated by questions of performance and cost effectiveness and ethics support needs to demonstrate its value to “justify adequate resourcing” (RCP 2005) and show that it does “not waste resources” (American Society for Bioethics and Humanities 2009).

Evaluating the quality of a clinical ethics services is an area of considerable uncertainty and debate. Major criticism has been voiced at evaluating clinical ethics services using outcome measures more suitable for standard clinical interventions. It's not

clear to some observers that quantitative measures, such as tallying the tasks performed by a service or calculating cost savings are appropriate for assessing the quality of a clinical ethics service (Mills et al 2005, Gordon 2007, Williamson 2007, McLean 2009, Pfafflin et al 2009). The number of consultations a service provides is clearly not a proxy for quality. One ethics committee may conduct a large number of consultations but be a little more than a ‘rubber stamp’; another committee may conduct fewer consultations but provide rigorous ethical analysis (Williamson 2007). While user satisfaction with an ethics service may be helpful in assessing service quality there are some difficulties with it. Williamson (2007) advises caution in using satisfaction because firstly it's validity as a measure of quality is suspect given its inherent subjectivity and that it is often the case that only clinicians and not patient who are asked.

Cost savings aren't particularly meaningful in the absence of estimates of the costs of a service and more importantly do not capture the ‘intangible benefits’ created by an ethics service (Mills et al 2005). An additional problem with using cost savings as an outcome is the loss of trust that could occur if clinicians (patients) come to perceive that cost is the primary objective (Mills et al 2005).

“If the “quality” or effectiveness of an outcome has any relationship to trust, as it should in healthcare-related activities, then quality will be eroded, as stakeholders understand that cost savings may be one of the reasons for initiating a consultation.’

Mills et al 2005

Williamson (2008) argues that many of the outcome measures used to assess the effectiveness of ethics support services aren't measuring ethics outcomes at all — measures such as user satisfaction lack ‘ethical content’. *“The authors of such studies fail to appreciate that these empirical outcome measures are not in fact measuring ethics on its own terms, but essentially miscast ethics as an empirical discipline”* (Williamson 2008, 359). The distinctive features of ethics support, particularly the qualitative and contingent nature of consultations, make measuring quality and performance using typical process and outcomes measures questionable (Gordon 2007, American Society for Bioethics and Humanities 2009). What's needed is

to measure ethics in its 'own terms' although how this is to be done remains an open question (Williamson et al 2007). There are a number of suggestions in the literature. Mills and colleagues argue for viewing the ethics knowledge of a support service as an intangible asset (its 'intellectual capital') that creates important but intangible benefits such as relieving 'moral distress' (although this intangible could possibly be measured by looking at more concrete outcomes such as staff retention rates (Mills et al 2006). Similarly, the second version of the ABSH core competencies points to the need for ethics consultations to be evaluated using 'soft' outcomes such as 'ethicality' the degree to which clinical practices conform to ethical standards (ABSH 2009).

The current evidence on the effectiveness and quality of clinical ethics services established to date is limited and equivocal. The diversity of ethics support goals and methods make comparisons between services difficult and the question of appropriate criteria complicates evaluating effectiveness. Even accepting that outcomes such as satisfaction and reduction in non-beneficial treatment are valid indicators of quality, there is still only limited number of studies undertaken on which to judge quality and choose a best practice model.

The lack of evidence of effectiveness is also a function of the relatively recent development of ethics support services and the dearth of funding to support evaluation as well as the inherent difficulties in quantifying a case specific, qualitative exercise such as ethics consultation. It's been noted elsewhere that research ethics committees, a firmly established and integrated feature of health organisations, face similar challenges in demonstrating effectiveness, yet few would question their need or worth. Indeed, the attempts to impose the consistency in process and outcomes on research ethics committee of effectiveness has been rejected by some (Edwards et al 2004).

**"...incorporating a discipline that cannot easily be measured within the intensely audited field of governance will be a challenge."**  
(Williamson 2007)

Regardless of model used, the capacity of a support service to demonstrate the merit of its

services to clinicians, its organisation and perhaps to the wider health system needs to be carefully attended to.

## The underutilisation problem

It is widely acknowledged that there has been mixed success with establishing and maintaining support services. Some flourish, others 'fail to thrive' (Conrad 2006). The most reliable estimates of ethics support services in the UK (Slowther et al 2012) and in the US (Fox et al 2007) suggest fairly low rates of requests for consultations. While the UK has experienced a substantial increase in the number of NHS trusts with ethics committees since 2000, rates of referral remain low (Whitehead et al 2006). Failure to thrive can arise from a lack of clear purpose or lack of institutional support (Mills et al 2006). The absence of a clear position and role within an organisation may also see clinicians avoid using a support service.

**However, a committee that is not clearly part of the organisational structure of the hospital in which it sits risks being ignored. An alternative explanation for low referral rates to committees is that clinicians see no point in seeking advice from a group which has no recognised authority within the institution.** Dorries et al 2011

The barriers to a clinician utilising an ethics support service are likely to be both personal and professional (McLean 2009) with many clinicians having mixed feelings about CECs (Dorries 2003). Non-referral might reflect clinician reluctance to seek support because of factors such as fear of scrutiny, loss of authority or because they are not found to be helpful are not trusted or simply because clinicians aren't aware they exist (DeRenzo et al 2006, UNESCO 2008, Slowther et al 2012). No particular model (i.e. consultant, committee) appears to be any more likely to flourish or fail to thrive than any other.

Consultations make up only one function of a committee, of course, but they are arguably the main driver of clinical ethics programs. As already argued, rates of referral *per se* do not unambiguously demonstrate anything about the quality of services or the need for them within an organisation. High

or low activity could be a sign of success or failure. High activity could reflect success in that the service is accessible and clinicians (and patients) are consulting it. Conversely it could reflect failure that clinicians are not learning how to do ethics for themselves (Mills et al 2006); that is, fewer consultations may reflect the success of a service in raising the ethical competency of the clinicians it serves.

The low rates of consultation experienced by many services might indicate that what is being offered isn't seen as either 'desirable or warranted' by many clinicians. A low rate of referral could mean that clinicians do not perceive a need for ethics support. Neither the 'bottom-up' development nor increased prevalence of support services show how widely the 'need' for ethics support is shared among clinicians. With only a small number of studies attempting to empirically establish need among clinicians (Larcher 2007, Slowther 1998, Racine and Hayes 2006), need for formal clinical ethics support appears more implicitly assumed than systematically, empirically established (Williamson 2007, Dauwerse et al 2011). The lack of perceived need for ethics support does not itself indicate that clinicians and patients and overall quality of care would not benefit from support. As a relatively new development, many clinicians will be unaware of what ethics support is and how it might help. Additionally it's been shown that clinicians often fail to identify that a difficult issue or case has an ethical as well as a clinical component (McLean 2009).

## Patient involvement and due process

“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.”

Williamson 2007

Who is the ethics support service supporting — clinicians, patients, the public, the system? It's been pointed out that although the intention of ethics committees is to support clinicians' to act in the best interest of patients, by and large committees internationally serve health professionals (McLean 2007, Newson 2009).

The evidence to date suggests that many ethics support services do not directly involve the patients and their families in the consultation process (Williamson 2008). The involvement of patients and their families can vary from the patient (or family) being able to refer a case to a support service, to the patient being notified that a consultation has been requested and invited to participate in the deliberations, to the patient simply being notified that a consultation has been requested. There appears to be considerable variation between and within nations on what degree of involvement is extended to patients (Fournier et al 2009, Newson et al 2009). Even where the terms of reference of support service allows for direct involvement of patients, it appears that patients are often not routinely made aware of this.

Agich and Youngner (1991) have argued that patient access to ethics consultation “is complicated by ambiguity in the accepted understanding of what hospital ethics committees are all about” (1991, 17)'. These authors enumerated a set of questions they believed made the issue of patient involvement complex and contentious: how and when should a patient be made aware that an ethics consultation service exists; how and when should a patient be made aware of consultation request; should the patient's consent be sought; should patients be allowed to request a consultation or case review; should patients be allowed to attend a meeting where their case is discussed; should the patient be advised of the outcome of a consultation or case review. These questions are particularly important as they have implications for 'due process'.



## Due process

“The goal of the HEC should be to work for the good of the patient. But the pervasive nature of the law in medicine means that the implementation of decisions may often turn on legal considerations. How a clinician and/or institution weigh these legal factors is itself an ethical issue and underscores the difficulty in treating law and ethics as utterly separate and discrete entities in the practical world of HEC deliberation...”

De Ville and Hassler 2001

The importance of a consultation following appropriate procedural principles is well recognised (Doyal 2001, Slowther et al 2001, McLean 2008). When providing a case consultation an ethics support service may play a decisive role in the decisions regarding a patient’s care. Even if the consultant (or committee) issues non-binding advice this may still impact on subsequent actions, possibly involving conflict over life-and-death decisions (McLean 2007). In cases where a consultation involves a dispute between the patient (and family) and the clinical team, there is a need to ensure some degree of procedural fairness; all parties in a dispute have the right to a ‘fair hearing’. As has been discussed above, the evidence suggests that in many cases patients do not directly participate in (or are even aware of) a consultation related to their care. A lack of direct patient involvement in consultations could very well undermine a support service’s attempt to promote patient rights and autonomy (McLean 2007).

McLean (2008) in reviewing the evolution of ethics support services in the United States argues that the US experience shows an “all too easy move from and advice to authority and from commentary to decision making” (2008, 101). As ethics support services have developed in the US (and in other nations e.g. Belgium) there has been a creeping quasi-legal status attached to the deliberations of committees and consultants. The major concern for McLean is that given the ad hoc development of ethics support services and the variability in operating procedures, due process and formal justice may be overlooked (McLean 2008). The

implications of increased authority go beyond ensuring procedural fairness for patients. The legal liability of the consultant (or committee) issuing advice is also potentially heightened as authority increases (Hendrick 2001). The issue of patient involvement, due process and the legal status of the advice or recommendations that are issued in an ethics consultation will need to be addressed in establishing and promoting clinical ethics support services in NSW PHOs.

## Independence and trust – the challenge of integration

“In the final analysis, this is the major challenge for CECs. If they want to ‘do ethics’, they need to be equipped with ethical expertise. But even if this remains their only aspiration, the more they attend to the procedural rules which their very existence arguably demands, the more they may become legalized and less like ‘ethics’ committees. If ethics support services are to play (or continue to play) an important role in modern health-care delivery, this is an enigma that needs to be solved.” (McLean 2008)

While thinking on clinical ethics support has evolved towards a systems approach, greater integration brings its own challenges. Institutionalisation is required to ensure quality and due process but too institutionalised and you risk undermining rather than strengthening the service. Institutionalisation may require services to show outcomes (cost savings for example) that are of dubious or uncertain applicability to the quality of a service and thereby set them up to fail (Williamson 2007, Mills 2005). Similarly institutionalisation could see an ethics service being perceived by clinicians as being ‘regulatory’, part of risk management strategies and with a role akin to the ‘ethics police’ (Campbell 2001, Dorries et al 2011).

“There are clearly benefits for a committee in being part of the formal organisational structure of the institution, including increased impact on policy, greater recognition among staff, and more practical benefits such as provision of administrative support and funding. However, the more firmly the CEC is embedded in the organisational structure the more difficult it may be for it to maintain its ethical independence. (Dorries et al 2011)

UNESCO's published guidelines for ethics committee acknowledges that hospital ethics committees frequently serve the purpose of providing additional legal cover for their institution. They caution of the danger that this can pose where the committee becomes more concerned with the vulnerability than with protecting patients rights (UNESCO 2008). While more fully integrating a support service within the organisation and wider system poses a number challenges, there is, as we have discussed a growing consensus that the benefits of integration outweigh the risks.

## Advocacy

If the growth of clinical ethics services in the UK was a bottom-up, grass roots development it appears to be transforming into a more top-down development as awareness of clinical ethics support has arisen and financial support has followed (Williamson 2007, McLean 2007, 2009). The expansion in the UK is the result of advocacy and agitation. Advocacy for clinical ethics support in the UK has become well organised, recognised and funded primarily through the activities of UK Clinical Ethics Network (UKCEN) and the Ethox Centre. We believe that similar commitment to advocacy will be necessary to promote and coordinate the development of ethics support in NSW PHOs.



## Conclusion

Although there is a range of views on how best to deliver ethics support, there is a convergence on the need for ethics support to involve *independent* but *integrated* ethical expertise. Advocates argue clinical ethics support should reflect expertise (or at least competence) in ethical analysis, be independent from organisational imperatives but be sufficiently institutionally integrated to be a viable and influential service.

We sum up this convergence as — ethics support needs to be *powered*: epistemically powered by ethics and legal expertise and institutionally powered by a clear and accepted role within individual organisations and the system and thereby access to resources. Experience internationally suggests that without expertise the ethical quality of any support provided is doubtful. Without the latter it will be difficult to obtain and retain expertise or gain traction among the clinicians it seeks to support. The proliferation of ethics support services overseas is largely the result of institutionalising ethics support i.e. they are powered (plugged into the system if you like). Institutionalisation is more advanced in countries such as the US but is increasing in other countries such as the UK. The incipient institutionalisation achieved thus far in the UK has resulted from the sustained advocacy of a small core of clinicians and academics.

The absence of a best practice model coupled with evidence of underutilisation provides good grounds for advancing ethics support (and building ethics capacity generally) in an assertive but cautious fashion.

**“To incorporate medical ethics into clinical practice, it must first be understood and valued by health care professionals.”**

Tweeddale 2001

**“Clinical ethics support services... will be most useful if they are designed to match the ethical concerns of clinicians.”**

Hurst et al 2007a

The evidence suggests that clinical ethics support is unlikely to be viable where it is not valued and used.

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