



# BUILDING CLINICAL ETHICS CAPACITY

Final Report of the Developing Clinical Ethics Capacity in  
NSW Partnership Project

**September 2014**

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# CONTENTS

## GLOSSARY

<b>SECTION 1</b> .....	<b>6</b>
1.1 EXECUTIVE SUMMARY .....	6
1.2 KEY RECOMMENDATIONS .....	12
1.3 DISCUSSION OF RECOMMENDATIONS .....	13
<b>SECTION 2 - BACKGROUND</b> .....	<b>21</b>
2.1 INTRODUCTION .....	21
2.2 BACKGROUND - CLINICAL ETHICS SUPPORT .....	23
<b>SECTION 3 – LITERATURE REVIEW</b> .....	<b>27</b>
3.1 OVERVIEW.....	27
3.2 CLINICAL ETHICS SUPPORT – DESCRIPTION OF THE LITERATURE.....	28
3.3 CLINICAL ETHICS SUPPORT SERVICES: FUNCTIONS, APPROACHES, MODELS .....	33
3.4 EVALUATION OF CLINICAL ETHICS SUPPORT SERVICES .....	45
3.5 DISCUSSION .....	59
3.6 CONCLUSION.....	65
<b>SECTION 4 - METHOD</b> .....	<b>67</b>
4.1 INTRODUCTION .....	67
4.2 THEORETICAL FRAMEWORK.....	67
<b>SECTION 5 – CLINICIAN SURVEY</b> .....	<b>70</b>
5.1 AIM .....	70
5.2 METHODS .....	70
5.3 RESULTS.....	73
5.4 DISCUSSION .....	82
5.5 CONCLUSION.....	84
<b>SECTION 6 - INTERVIEW STUDY</b> .....	<b>86</b>
6.1 AIMS.....	86
6.2 METHOD.....	86
6.3 RESULTS.....	87
6.4 DISCUSSION .....	105
6.5 CONCLUSION.....	106
<b>APPENDIX 1</b> .....	<b>107</b>
<b>REFERENCES</b> .....	<b>112</b>

## Glossary

ABSH	American Society for Bioethics and Humanities
AHEC	Australian Health Ethics Committee
CEC	Clinical Ethics Committees
CI	Confidence Interval
EC	Ethics Consultation
HEB	Health Ethics Branch of NSW Health
JCB	Joint Centre for Bioethics (JCB)
LHD	Local Health District
MCD	Moral Case Deliberation
NHMRC	National Health and Medicine Research Council
NICU	Neo-natal Intensive Care Unit
NSW	New South Wales
OR	Odds Ratio
PHO	Public Health Organisation
STD	Sexually Transmitted Disease
TRC	Termination Review Committee
UKCEN	United Kingdom Clinical Ethics Network
UNESCO	United Nations Educational, Scientific and Cultural Organisation

# Section 1

## 1.1 Executive Summary

### Background

Clinical ethics support services are an established feature of health care in the US and Canada and are becoming so in the UK, France, Belgium and elsewhere in Europe. They are yet to be widely established in NSW or elsewhere Australia. Clinical ethics support typically involves the provision of expert ethics input into clinical education, policy development and the care of individual patients, particularly where this involves value, rather than clinical, or scientific, conflict. Ethics support is generally provided by an individual consultant, an ethics committee or some combination of the two. In its case consultation function, expert support is intended to clarify the values that are in tension and through promoting open and inclusive discussion, facilitate consensus on the appropriate next steps. Internationally, the guidance and recommendations issued by a support service on a particular case are, in most cases, advisory and not binding.

Advocates argue that clinical ethics support is necessary because contemporary clinical work takes place in a technologically, socially and ethically complex environment. The medical encounter has become far more open to scrutiny and is accountable to a more diverse public holding often quite different interests, ideas and values. In a more pluralist society, professional training, professional codes and institutional policies aren't sufficient to establish ethical practices and procedures or resolve the ethical dilemmas that arise in the care of individual patients. The ethics *expertise* provided by an ethicist or a panel of ethically trained clinicians is necessary to astutely appraise the values and arguments and generate consensus. Without such expertise the *ethicality* of practices cannot be assured.

Clinical ethics support is intended to promote ethically sound clinical and organisational practices and decision-making and thereby contribute to health organisation and system quality improvement.

The under-developed state of clinical ethics support in Australia and NSW prompted NSW Health, in partnership with the Centre of Values Ethics and Law in Medicine and the Centre for Health Law and Governance, to ask:

1. Do changes to the environment in which clinical practice occurs mean there is a need to change the way we deal with ethical dilemmas?
2. Is more formalised support for clinicians, when making difficult and possibly controversial ethical decisions, desirable or warranted?
3. If it is agreed that clinical ethics support should be enhanced, what model is most appropriate for local conditions?

The project described in this report was undertaken to consider these questions. It should be noted, however, that rather than look at ethical 'dilemmas' *per se* we looked at ethics in everyday clinical work and how the ethical issues that arise are generally managed.

## Method

Our study used standard social science methods. We have drawn upon the empirical work (e.g. surveys, randomised controlled trials) of earlier investigators to establish some of the basic descriptive features of ethics support services such as prevalence, types, and functions and to determine what is known about their performance. Our own empirical work included an ethnographic study of ethics 'as practiced', interviews and a survey to establish the views, experiences, attitudes and practices of clinicians regarding ethics support.

A survey was conducted with a convenience sample of 104 clinicians from two tertiary hospitals (Hospital 1 & Hospital 2). The survey asked clinicians about the frequency and types of ethical issues they faced, their actions in dealing with these issues, their perception of the adequacy of current ethics support mechanisms and their preferences for ethics support. The second component of this study was a qualitative study involving in-depth interviews with clinicians from a third tertiary hospital (Hospital 3), which focused on clinicians' experiences with, and preferences for, formal clinical ethics support. Details of the ethnography have not been included in this report because of concerns regarding the sensitivity of the findings and the potential for identification of the staff and patients involved.

## Findings

### *From the literature*

The growth of clinical ethics support internationally has been a grassroots development, although there is increasing interest in the capacity of ethics to contribute to organisational and system level quality improvement. In most countries clinical ethics services are not mandatory and not closely regulated. The ad hoc growth of ethics support services has prompted concern for the quality of the services they provide, particularly case consultation. There has been limited empirical research of ethics support services to date and the quality and value of support services is largely untested. Empirical studies of clinical ethics services are mostly descriptive, showing increasing prevalence and wide variation in approaches, models and process. A small number of evaluation studies have been undertaken and have shown positive results on outcomes such as clinician satisfaction and cost. However, methodological concerns, particularly regarding the validity of the outcomes used to assess *ethical* support, limit the conclusions that can be drawn from these studies or the extent to which these research findings can be generalised to other settings.

Although empirical work on clinical ethics support services is relatively limited, there is a growing literature on clinical ethics support – general expositions of approaches, accounts of establishing and operating a service, commentaries, discussions, and advocacy for ethics support. The quality of ethics support is the central issue. 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 provide expertise (or at least competence) in ethical analysis, and be independent from organisational imperatives, while at the same time being sufficiently institutionally integrated that it is credible, sustainable and influential.

We sum up this convergence as – ethics support needs to be *powered*: epistemically powered by ethical and legal expertise and institutionally powered by a clear and accepted role within

individual organisation. Experience internationally suggests that without expertise the ethical quality of any support provided is doubtful. And unless integrated and resourced it is difficult for clinical ethics services 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, where institutionalisation has resulted from the sustained advocacy of a small core of clinicians and academics.

There is clearly growing interest for clinical ethics support internationally but there is also still considerable uncertainty about how best to go about providing ethics support. 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. The empirical work done in this project, which involved talking to and surveying a sample of NSW clinicians about how they currently manage the ethical issues they face and whether ethics support is desirable and warranted, is an important initial step in advancing clinical ethics support for NSW clinicians.

#### *From our studies*

The interviews showed that ethics was not generally an explicit feature of discussions about patient treatment and care. Decisions and issues of moral importance were frequently faced by clinical staff with ethical tensions or concerns arising in the context of patient care generally being 'tacitly' managed. Clinicians were always 'doing' ethics, balancing benefits and harms, and considering patient preferences in terms of limitations of available resources. This ethical work was often not explicit, or reflective, but was recognised as an important and inevitable feature of patient care. While disagreements frequently occurred, intractable value conflict between clinicians and patients and families and between clinicians themselves was uncommon, and in most cases, value differences were resolved through iterative discussion eventually leading to consensus. But while overt conflict was infrequent, health professionals commonly experienced moral disquiet or uncertainty about particular clinical decisions or practices. Whether this disquiet was acted on, or not, depended on a series of factors, such as the individual's role in the particular case, their seniority, their degree of moral certitude, and their willingness to challenge majority opinion. Importantly, however, most saw the ethical climate of their hospital as *mostly right*. The law and regulations, professional practices and the policies and procedures combined with the commitment to best practice and patient centred care usually produced good outcomes. But it was also broadly recognised that this was not always the case, that error and conflict was an inevitable feature of contemporary health care and that things could always be done better. While all clinicians saw ethics as a core feature of their practice, they did not always recognise the moral importance and fragility of their practices and in many instances had difficulty disentangling ethical disquiet from legal concerns. Many clinicians were unaware of the concept of clinical ethics support but most were receptive to the idea.

At a more abstract level, the main concepts and themes to emerge from the qualitative data were: Value Plurality, Routine Moral Labour, Special Moral Labour, Settled Morality, Optimising and Satisficing, Ethical Auto-Pilot. What was clear from the qualitative data was that clinical ethics is *part of the fabric, not worn on the sleeve*. Both clauses are intended to reflect or connote the implicit *doing* of clinical ethics in everyday clinical work. The second clause is also used to reflect some of the ambivalence about having ethics as an explicit feature of clinical discussion.



The majority of clinicians we surveyed reported frequently experiencing ethical and legal concern or uncertainty, with patient choice and autonomy appearing as the most frequent ethically troubling issues. The most commonly reported response to uncertainty or concern is to talk to colleagues – an action that most clinicians found to be helpful and reassuring. But while most clinicians were satisfied with the ethical environment of their hospital and department, the majority also recognised that care could be improved, that conflict and disagreement was not always resolved satisfactorily, that ethical issues and ethical disagreement were not always thought through or articulated (particularly by more junior or non-medical members of healthcare teams) and that there would be merit in having clinical ethics support services to educate, guide and assist staff in managing the ethical issues that arise in the design and delivery of health care.

The survey data triangulated with the qualitative data supported the findings that most clinicians perceive themselves to be ethically engaged and working in an environment that is *ethically* mostly right. Again, most clinicians reported frequently encountering situations of ethical and legal uncertainty and concern and generally relied upon each other for ethics support. Uncertainty and concern were generally managed through discussion and only infrequently result in intractable conflict and distress. The clinicians who participated in this study indicated that their hospitals and departments generally allowed for inclusive discussion of ethical issues, but that some issues and practices were often not discussed and that ethical concerns and uncertainty were often not voiced – particularly by junior and non-medical staff. Most clinicians expressed support for the provision of expert ethics support to assist them dealing with the ethical issues raised by patient care, with a preference for clinical ethics support services being ethically expert, independent and advisory and providing both education and case consultation.

## Conclusions

Returning to our opening questions:

*First, does the changing environment in which clinical practice occurs mean there is a need to change the way we deal with ethical dilemmas?*

There is a cogent sociological argument for need: increased social plurality and complexity and a blurring of the boundary between the internal and external morality of medicine add to ethical complexity. Expertly navigating this complexity (even being aware of it) is beyond the training of most busy clinicians.

There is considerable potential for formal clinical ethics support services to improve the ethical quality of clinical practices and patient care – minimising conflict, distress and uncertainty and promoting open, inclusive and constructive discussion on professional, organisational and system values.

*Second, is more formalised support for clinicians when making difficult and possibly controversial ethical decisions desirable or warranted?*

Our findings support the notion that ethics is an irreducible part of healthcare – be that at the clinical interface or in the design and delivery of health care services. For the most part, these ethical aspects of care are dealt with in the process of standard clinical practice – and

generally appear to be managed appropriately most of the time - but they may also be the source of disquiet (often), distress (occasionally) or conflict (infrequently).

It is difficult to draw explicit conclusions regarding the degree to which the provision of formal ethics support is warranted given that our research was exploring perceptions of something (clinical ethics services or resources) that currently do not exist in any meaningful way in most health care settings in NSW and relied heavily upon health professionals own accounts of the adequacy of their management of the ethical aspects of health care.

There are, however, a number of reasons to believe that the formalisation of ethics support is warranted. First, ethics is very much a part of the fabric (or culture) of the health system and of clinical practice and is broadly recognised as a critically important facet of care. Supporting the 'ethics of healthcare', therefore, particularly where this is highly valued by health practitioners, patients and the community, and where it is challenged by pressures on the entire health care system, would seem, in-and-of itself, to be highly desirable. Second, healthcare is becoming increasingly complex, increasingly dependent upon multiple disciplines and multiple professionals and increasingly required to serve a community characterised by enormous cultural, social and moral diversity – creating greater possibility for error, miscommunication and conflict. Third, while health care in Australia is generally of very high quality, it is inevitable that problems will arise in regards to decision-making, the competent delivery of health care, communication and consent – problems that may pose a significant cost to the health system and to the community (AIHW, 2012) and problems that may arguably be ameliorated or better managed with clinical ethics support. Fourth, while scientific and medical progress has increased the scope and capacity of medicine, it remains true that no medical system is able to meet all needs – meaning both that some people will not receive the care they desire and that choices will inevitably be made between different populations. It is crucial, therefore, that these choices are explicitly justified and that processes are in place to manage the concerns or conflicts that may result from these choices. Fifth, the role of clinical ethics in promoting quality improvement within healthcare institutions is increasingly acknowledged by government through national accreditation standards and already recognised in the ACHS EQuIP 5 National Accreditation Standards (esp 3.1.2) – which should be interpreted as requiring that health services have explicit structures and processes for dealing with ethical issues that arise in clinical practice. The role of clinical ethics in health care has also been recognised internationally, with both 'bottom-up' and 'top-down' support for clinical ethics and for the establishment of clinical ethics support services and clinical ethics networks emerging in Europe, the United States, the United Kingdom, New Zealand and elsewhere. Sixth, our findings indicate that many clinicians do have concerns about the ethics of clinical practices and decisions and believe that access to expert ethics support would be helpful. And finally, as the literature makes clear, while most health professionals are sensitised to the ethical issues that emerge in the design and delivery of health care and from their own work, some are not, and there are occasions where issues of moral importance are overlooked, are not addressed or are poorly managed and that this may be a source of considerable moral distress (Downie and Macnaughton, 2007; Kalvermark et al, 2004; Oberle and Hughes, 2001).

*Third, if it is agreed that clinical ethics support should be enhanced, what model is most appropriate for local conditions?*

Ethics support services have proliferated overseas but, for the most part, their value remains to be empirically demonstrated. Uneven experience, equivocal evidence and continuing

debate make identifying a best practice model of ethics support difficult. The lack of evidence probably reflects the methodological and philosophical challenges involved in determining the outcome measures of value and in designing studies that would enable the assessment of the effectiveness of clinical ethics support services. The merit and limitations of different outcome measures, including costs of care, patient/carer satisfaction, treatment decisions, resuscitation orders, and service utilisation, remain a matter of intense debate. The lack of 'hard' evidence to demonstrate the value of clinical ethics support is problematic because such evidence inevitably builds support both for the resourcing and integration of ethics support services into healthcare systems and for the valuing and utilisation of such services where they exist. But while the absence of conclusive data is a challenge to the development and resourcing of clinical ethics support services, it is not an argument against it – both because good data is rarely available for interventions that largely do not exist, or are yet to be translated into practice, and because, lack of evidence is not equivalent to 'evidence of lack' (i.e. things that are of great social, moral or cultural significance, may have no 'proven value', but this may be a consequence of the methodological difficulties of studying them, rather than a consequence of them genuinely being of no value). Indeed many complex interventions that have been extensively supported and integrated into health systems worldwide, like multidisciplinary teams, clinical governance, infection control teams, research ethics, and processes for advance care planning, have received this support in the absence of good quality evidence regarding their utility.

The international experience suggests that in order for clinical ethics support to be sustainable, meaningful and accessible it needs to be institutionalised – formally integrated into the health care system. In the United States this has been achieved as a consequence of a legislative mandate whereas in the United Kingdom and in (parts of) Europe, the partial institutionalisation of ethics support has been achieved through the advocacy and leadership of clinicians and ethicists. This has involved a sustained attempt to raise awareness of the value of ethics support among clinicians and policy makers as well as to coordinate development and raise standards. We believe that a similar commitment to advocacy and leadership will be necessary to build ethics capacity in NSW and that unless clinical ethics services receive institutional and government support then efforts to provide clinical ethics support will simply not be sustainable.

Although there is no consensus on the best model of ethics support at the institutional level, it is clear that there needs to be a *structure* for ethics capacity building, like that of the 'hub and spokes' model, that incorporates the principles of integration, independence and quality, that provides for both local presence and central expert capacity, and that maximises the possibility of sustainability and rigour. While this model raises considerable practical challenges and requires the commitment of both hospitals/LHDs and the Ministry, we believe that this provides the best structure for the delivery of clinical ethics support services in NSW.

*Declaration of interest:* In our recommendations we note the benefits of building upon existing alliances and existing expertise and of creating ongoing collaborations between healthcare/clinical services and academic centres of excellence. While this raises the possibility of ongoing engagement with, and support for the two Centres at the University of Sydney who conducted this research (Centre for Values, Ethics and Law in Medicine and Centre for Health Law, Ethics and Clinical Governance), this is not the intention of our recommendations.

## 1.2 Key Recommendations

1. NSW Health should actively support system-wide development of high-quality clinical ethics support services in NSW.
2. Building clinical ethics capacity will necessitate the establishment of a clinical ethics infrastructure. A structure similar in shape and logic to the 'Hub and Spokes' model is most appropriate as it maximises scope, rigour, efficiency and sustainability and reduces unnecessary duplication.
3. All LHD/PHO/hospitals should review their current means for supporting clinical ethics and consider whether their organisation may benefit from the establishment of local infrastructure/mechanisms for supporting clinical ethics (ie a 'spoke'), including establishment of a clinical ethics service and employment of a clinical ethics expert who could coordinate clinical ethics support within the LHD/PHO/hospital and contribute to the hub and to the state-wide clinical ethics network. Where clinical ethics support services are established it is crucial that these are integrated, institutionalised, have a clear role, structure and reporting responsibility and yet remain independent.
4. Use the *Building Clinical Ethics Capacity Report* and the current NSW Health Policy Directive (PD2006\_027)
5. Develop and disseminate a detailed and comprehensive guide for LHD/PHO wishing to establish a clinical ethics support service. This guide should include specific advice on: models of delivery, membership, competencies and training, appropriate functions, processes and general operating procedures, evaluation and reporting.
6. Further develop the Clinical Ethics Resource website and consider other means of electronic delivery of ethics support.
7. Support education in Clinical Ethics and Health Law for health professionals in NSW through a range of different mechanisms including; establishment of a Fellowship in Clinical Ethics, support for existing short-courses and educational programs in ethics and health law, strengthening of the NSW clinical ethics forum and continued development and dissemination of *Ethics and Health Law News*.
8. Develop user-friendly, practical resources for clinical ethics and health law for all health professionals in NSW.
9. Encourage broad capacity building in clinical ethics through education, presence and engagement such that systems are not so dependent upon 'champions' but at the same time creating 'champions' through institutional support for clinical ethics services and through the establishment of a program of ethics research and scholarship. This could include the creation of clinical ethics PhD, MD and Masters Fellowships, scholarships and secondments (whereby departments are provided with reimbursement to replace/relieve staff who are pursuing short clinical ethics projects).

### 1.3 Discussion of Recommendations

NSW Health should actively support system-wide development of high quality clinical ethics support services in NSW. International experience indicates that this will necessarily require leadership, coordination and support. Importantly, we believe that NSW has the opportunity to push forward the ‘promising but unproven’ status of clinical ethics support by implementing a concurrent program of research aimed at evaluating support.

Our specific recommendations are organised along three axes: structure, institutionalisation and capacity building. While we consistently refer to *ethics* expertise and capacity, this should be regarded as shorthand for *ethics and health law*.

#### Structure

Building ethics capacity necessitates developing a clinical ethics infrastructure. We propose a structure similar in shape and logic to the ‘hub and spokes’ model as this maximises scope, rigour, efficiency and sustainability and reduces unnecessary duplication.

The development of a network of clinical ethics services requires the concurrent development of the structural centre, or ‘hub’, and the network of locally embedded ethics services or ‘spokes’. Each of these requires a clear mission, strategic plan and the human and material resources to undertake a mid- to long-term program of capacity building. The hub will provide the leadership, infrastructure and administrative support so consistently identified as crucial for effective clinical ethics support. The hub will also be responsible for drawing together academic, clinical, legal and regulatory expertise available through the hub and spokes to develop common policy, jointly organised educational programs, in-service and coordinate the network of ethics services – guiding their development and ensuring their sustainability through support and through the rotation of Clinical Ethics Fellows and students. The spokes, in turn, will provide the ‘presence’ of clinical ethics and ensure that it has both local relevance and ‘buy-in’ of the Local Health District (LHD)/Public Health Organisation (PHO) – each of which has also been noted to be necessary for optimising the success of clinical ethics services. And collectively, those engaged within the hub and at each of the spokes will develop professional education programs for clinical ethics, design research projects that can be conducted across LHDs and across the state, and develop resources that may assist health professionals negotiate the difficult ethical and legal issues raised by practice.

*Importantly*, while we believe that it is imperative that a clinical ethics network be established that creates linkages between LHD/PHO/hospitals in order to optimise the sharing of policies, resources and expertise, this does not require that each LHD/PHO/hospital establish or support the same type (or model) of clinical ethics service. Indeed it is inevitable that different hospitals or healthcare providers will need different types of clinical ethics support and that the mechanism for clinical ethics support adopted at each site will depend in large measure upon the type and function of the health service, the needs of the population they serve and the local capacity to support a clinical ethics service. Thus, some healthcare providers will simply require access to a clinical ethics service whereas other healthcare providers will need, and be able to support, a much more elaborate clinical ethics service, which is tasked with providing education, assistance with development of models of care, retrospective case review and contemporaneous case consultation, particularly in situations of conflict.

### ***Developing the Hub***

We believe the hub can most efficiently emerge from building on existing relationships, arrangements and materials to create a *powered* centre of clinical ethical and legal expertise. The creation and consolidation of alliances between NSW Health, LHDs and academic centres of expertise in clinical ethics and health law could expedite creation of both the hub and its network of spokes and enrich and facilitate the development of educational programs in clinical ethics for health professionals across the state – reducing duplication of effort and maximising efficiency and utility. Exactly where the hub is located and how it relates to each of its collaborative organisations and to NSW Ministry pillar agencies, including the Agency for Clinical Innovation and the Clinical Excellence Commission, will need to be carefully considered, but is less of an issue than the principle of collaborative expertise and service delivery.

While the hub should be able to draw upon the expertise available through the NSW Clinical Ethics Advisory Panel (CEAP) and through the existing support of experts in ethics and health law who work in LHDs and academic centres throughout NSW, it will not be able to function effectively without substantial infrastructure, administrative and staff-salary support. Drawing from international experience, there are at least two ways in which the hub may be funded – either it could be funded ‘centrally’ by NSW Health or it could be funded by LHD/PHO/hospitals through payment of an annual ‘membership fee’. While the latter model has worked effectively in Ontario, given that local institutions or LHDs will also be responsible for supporting the employment of a clinical ethics position/co-ordinator within their own institution/LHD, it may be more realistic to expect that the hub be supported centrally (perhaps through enhancement funding).

### ***Developing the Spokes***

The creation of the network of ethics services (‘spokes’) will require both institutional support from each LHD/PHO (in order for a clinical ethics services to be established and appropriately resourced within each LHD/PHO) and uniform adoption of the ‘Hub and Spokes’ model by each LHD/PHO, so that each ‘spoke’ does not collapse under the weight of expectation and is supported in using resources developed by the hub and by other locally constituted spokes. But while the development of clinical ethics capacity in NSW requires acknowledgement of the structural advantages of the Hub and Spokes’ model, it does not require that each hospital/LHD establish or support the same local model for supporting clinical ethics as the model adopted at each site will vary depending upon the characteristics of the institution and of their user population, and the local capacity to provide a clinical ethics service. The development of the spokes, as with the hub, should draw on existing relationships and alliances.

In support of the development of the spokes, it would be desirable to:

- Build on the current NSW Health Policy Directive (PD2006\_027 Clinical Ethics Processes in NSW Health) and on this Report to create a strong argument in favour of all LHD/PHO/hospitals reviewing their current mechanisms for ethics support.
- Encourage all LHD/PHO/hospitals to review their current means of supporting clinical ethics and consider whether their organisation might benefit from the establishment of local infrastructure/mechanisms for supporting clinical ethics (a spoke), including employment of a clinical ethics expert who could coordinate clinical ethics within the LHD

and contribute to the hub and state clinical ethics network. This review could be done in conjunction with established Clinical Governance Units and/or Research Ethics Committees.

- Accept that it is unlikely that all LHD/PHOs will agree to establish clinical ethics services in the first instance and that it may be necessary to commence by implementing a pilot ‘hub and spokes’ strategy involving a small number of selected urban, rural and regional PHOs as the ‘spokes’.
- Draft and publish a detailed and comprehensive guide for LHD/PHOs wishing to establish a clinical ethics support service. This guide should include specific advice on: models of delivery, membership, competencies and training, appropriate functions, processes and general operating procedures, evaluation and reporting. Issues such the role of patients and due process may need particular attention.
- Further develop the Clinical Ethics Resource website (<http://clinicaethics.info/>) and consider other means of electronic delivery of ethics support. Targeted efforts are needed to:
  - Monitor the usage and visitation on the Resource using Google analytics;
  - Prepare and implement marketing strategies to advertise the Resource and increase its penetration into the minds and practice of NSW health professionals;
  - Develop the Resource materials further so that they are useful across digital formats as Apps, digital handbooks or electronic resources;
  - Ensure the Resource is included in the education and training materials for clinical ethics support services;
  - Continue to update and improve the quality of the Resource contents by adding more guidance on key areas of uncertainty as raised by the project. This could include FAQs pages and ethico-legal ‘fact packs’ on areas that suffer from heightened fears of litigation e.g. end-of-life decisions, resource allocation and termination of pregnancy. This process could adopt similar strategies to the ‘myth busting’ approaches being used by the Ministry in the implementation of the Advance Care Planning Framework;
- Support education in Clinical Ethics and Health Law for health professionals in NSW. This could/should take different forms including:
  - Support for formal academic training in clinical ethics and health law through, for example, creation of Fellowships in Clinical Ethics (like that offered by the Joint Centre for Bioethics in Toronto, Canada) or schemes to support continuing professional education in clinical ethics
  - Support for established short courses in clinical ethics and health law
  - Revision and strengthening of the NSW clinical ethics forum (by the hub)
  - Development of a structured program in clinical ethics and health law by the hub for local delivery by the spokes.
  - Continuing support for Ethics and Health Law News (<http://ehln.org/>) but making this available to all those involved in health care design and delivery via the Intranet and Outlook Email services across all LHDs.

## **Institutionalisation**

It is clear from overseas experience and from our own data that clinical ethics support needs to be effectively *integrated* into both the wider healthcare system as well as into individual LHD/PHOs. There are two ways in which integration will be achieved. The first is by making clinical ethics visible, local and personal – establishing clinical ethics within each LHD/PHO and employing people with the necessary expertise to coordinate clinical ethics at the local level (spoke) and to contribute to the central organisation of clinical ethics throughout the state (the hub). The second is by giving ethics support services a legitimate, formalised and readily discernible role over and above the typical triad of education, policy review and ethics consultation.

There are a number of different roles that clinical ethics services could take on within LHD/PHOs in order to increase both their value and their integration into standard clinical practice and healthcare delivery.

Clinical ethics services could, for example, be allocated a clear role where conflict arises at the end-of-life – ameliorating conflict and providing patients, their families and the health professionals caring for them an alternative means for resolving conflict than the courts. Clinical ethics services could also develop processes and policies for decision-making regarding high-cost drugs, and could be centrally involved in such decisions - decisions that are currently made by CEOs and/or hospital drug committees in the absence of clear principles or structures for decision-making. And following the logic of bodies like the PBAC and research ethics committees, both now accepted components of the system for drug subsidisation and research respectively, clinical ethics services could also take on the role of *ethical review* of:

- clinical variance,
- clinical (surgical and medical) innovations, and/or
- policies and procedures introduced by Local Health District (LHD), hospitals or departments/divisions that are felt to have important ethico-legal implications e.g. age-based rationing criteria for access to dialysis, policies regarding resuscitation of ‘grey-zone’ newborn, consent processes for genetic testing, or access criteria for fertility services.

With regards the review of clinical variance and medical and surgical innovations, while many LHDs have structures for the review of some forms of clinical variance and innovative practice, there is considerable variation in these processes and rigorous mechanisms generally do not exist for review of medical innovations/practice variation. While ethical review of identified clinical variance and innovations should (arguably) be mandatory, in the first instance ethical review of policies and processes could be voluntary, which may encourage considered ethical reflection, provide time for the ‘up-skilling’ of clinical ethics services, and promote the view that ethics is more to do with dialogue and with reflection on ‘what we should do’, than with governance.

While this raises substantial practical, political and cultural challenges, it is our view that institutionalising and formalising the role of ethics support by embedding ethical review as a routine part of its function will ensure the sustainability of clinical ethics services and, more importantly, ultimately contribute to fostering an ethical culture and climate of ethical enquiry. Establishing systems for ethical review of clinical care, institutional and departmental policies and practices will also have the additional advantages of encouraging ethical



reflection on clinical care and contributing to the standardisation of care for all patients in NSW.

## **Capacity Building**

The development of clinical ethics services in NSW faces considerable challenges, in part, because while there is no shortage of interest and enthusiasm, there are few people who have the requisite expertise necessary to develop, drive and sustain these services.

Developing clinical ethics capacity will therefore need a mid- to long-term program of leadership, coordination and support, education and research. We have reversed the usual ordering of research and development to emphasise that priority should be given to developing ethics support services. But development of clinical ethics services should also include continuing research to build an evidence base to show what models of ethics support work in which settings.

## ***Leadership***

Overseas experience has shown that the success of clinical ethics support often depends on the energy of 'champions'. While this is understandable it is also highly unstable.

In our view this characteristic of clinical ethics services should be addressed by:

- Encouraging broad capacity building through education, presence and engagement such that systems are not so dependent upon champions, but at the same time,
- 'Creating' champions through institutional support for clinical ethics services and through the establishment of a program of ethics research and scholarship. This could include the creation of clinical ethics PhD, MD and Masters Fellowships, scholarships and secondments (whereby departments are provided with reimbursement to replace/relieve staff who are pursuing short (<2-3 months) clinical ethics projects, and encouraging working clinicians to take these up.

## ***Coordination and Support***

Above all, capacity building in clinical ethics requires that such services are visible, meaningful and stable, and are supported both by the institution and by the clinical community. These, in turn, require structure (see above).

## ***Education***

Clinical ethics education is essential both to the creation of clinical ethics services and to their role. A range of strategies should be considered.

- Development of resources for all health professionals in NSW which provide user-friendly, practical resources for clinical ethics and health law. This could take the form of Apps, handbooks or electronic resources.
- Employ the Clinical Ethics Resource website (<http://clinicaethics.info/>) as the primary source of education materials on clinical ethics, health law and Ministerial policy. As stated above this would require continual updating and improvement of the quality of the Resource contents by adding more guidance on key areas of uncertainty with materials such as FAQ pages and ethico-legal 'fact packs', following on from strategies developed by the Ministry in the implementation of the Advance Care Planning Framework;
- Support education in Clinical Ethics and Health Law for health professionals in NSW. This could/should take different forms including:

- Support for formal academic training in clinical ethics and health law, through, for example, creation of Fellowships in Clinical Ethics (like that offered by the Joint Centre for Bioethics in Toronto, Canada) or schemes to support continuing professional education in clinical ethics
- Development of, or support for, established short courses in clinical ethics and health law
- Revise and strengthen the NSW clinical ethics forum
- Development of a structured program in clinical ethics and health law by the Hub for local delivery by the Spokes.
- Continuing support for Ethics and Health Law News (<http://ehln.org/>) but making this available to all those involved in health care design and delivery via the Intranet and Outlook Email services across all LHDs.

### **Research**

Should a decision be made to support the establishment of organised clinical ethics services in NSW efforts need to be made to build in research capacity at every point of such services. This will have three distinct benefits – it will enable evaluation of clinical ethics services; it will strengthen the very culture of ethical inquiry and ethical practice within the health service; and it will provide opportunities to increase understandings of issues of ethical and legal importance in the design and delivery of health care. Support for professional and post-graduate research, and for participation of clinicians in short-term research projects (perhaps through funded secondments), in particular, is likely, just as it is in any other area of practice, to promote local interest in, and support for, clinical ethics, and encouraging the development of a culture of critical, but respectful, ethical enquiry.

It is crucial that ongoing research into clinical ethics is conducted in order to establish what is necessary for clinical ethics services to work. Through critical examination of the international experience of clinical ethics and through the study of the views and experience of NSW health professionals, this project has facilitated the development of a tentative ‘theory’ of formal clinical ethics support. That is that:

providing formal clinical ethics support (expertise) produces a more ethically sound clinical process and decisions because ethics expertise clarifies and gives voice to all the values at stake,

and that;

To be active and sustainable a clinical ethics support service must be: visible, accessible, understood and trusted - qualities that require the service be; clear in purpose; fully integrated into the life of the organisation; adequately resourced; appropriately constituted and competent; accountable (transparent and assessable) and; independent.

Further research, including further case studies, is necessary to develop this tentative theory, and should logically be conducted concurrently with the development and delivery of clinical ethics services. Some of the questions that such research could explore include; To what extent are the qualities listed above present or absent in the cases of existing ethics

committees or past ethics committees; and how do these qualities interact and influence whether a clinical ethics support services is active and 'sustainable'?

Ongoing evaluative research of clinical ethics services should be a core component of the development of clinical ethics services in NSW given the nascent development of clinical ethics in NSW, the relative paucity of high quality evidence around clinical ethics internationally, and the general inadequacy of existing measures of the effectiveness of ethics support.

# Section 2 - Background

*Unfortunately, the relationship between quality health care and ethical health care is not commonly recognized (Nelson et al. 2010).*

## 2.1 Introduction

The Clinical Ethics Capacity Building Project is the latest initiative in a process undertaken by NSW Health to establish whether hospital-based clinical staff in NSW would benefit from greater access to formal ethics support for managing ethical issues in clinical practice. Contrary to the above quote, NSW Health has long recognised the role ethics plays in the quality of care in the State's public hospitals.

In 2003, citing "a growing sense that it is timely to consider whether patients and health care professionals would benefit from enhanced access to clinical ethics support" the Health Ethics Branch of NSW Health (HEB) drafted and released a discussion paper. Titled 'Improving Clinical Ethics Support' the paper was distributed among stakeholders with an invitation to provide feedback on the issues discussed. The relevant issues were canvassed in the paper by posing three 'fundamental' questions:

1. Does a changing environment in which clinical practice occurs mean there is a need to change the way we deal with ethical dilemmas?
2. Is more formalised support for clinicians when making difficult and possibly controversial ethical decisions desirable or warranted?
3. If it is agreed that clinical ethics support should be enhanced, what model is most appropriate for local conditions?

In 2004 HEB reviewed and reported on stakeholder response to the discussion paper. The discussion paper drew 26 responses from among the Area Health Service CEOs, directors of clinical services and CECs (response rate not given). The responses showed a general, if qualified, backing for more formal clinical ethics support. Formal support was seen by most respondents as potentially helpful in clinical decision making, improving clinicians' ethical skills and ensuring proper process. This backing for more formal support was qualified by the concern that an ethics support service (particularly an 'ethics committee') should not undermine clinician authority or otherwise interfere in the clinician-patient relationship. The responses identified the major challenges in establishing or sustaining clinical ethics services: the lack of local 'ethics expertise', the need for local champions, uncertainty among clinicians about the role and/or usefulness of clinical ethics services, the need for a clinical ethics service to fit within other institutional governance arrangements, the need for support among the executive of an institution and the need for resources.

On our interpretation, the responses to the discussion paper broadly showed agreement that some form of clinical ethical *support* is desirable as long as clinician *authority* isn't undermined. Presumably encouraged by the feedback, the HEB formulated a number of recommendations:

- develop a policy to guide clinical ethics consultations,
- create opportunities for ethics training and education for clinical staff;

- establish a network between centres interested in clinical ethics.

In 2006, NSW Health released a policy directive 'Clinical Ethics Processes in NSW Health'. The directive describes the circumstances under which NSW Public Health Organisations (PHOs) are to refer issues to the NSW Health Clinical Ethics Advisory Panel (CEAP). The directive also gives detailed advice for PHOs to follow in establishing a clinical ethics support service should they decide one is necessary. Guidance is predominantly focussed on case consultation. While the directive makes it clear that clinical ethics support services are not mandatory for NSW Health PHOs, where they are established they must follow the directive's guidelines (these guidelines will be discussed further below).

Following the release of the policy directive the Research and Ethics Branch (formerly HEB) consulted with senior 'key personnel' from the various area health services within NSW to gain feedback on the directive. Similar to the feedback on the earlier discussion paper, there was common acknowledgement that there may be some value in improving clinical ethics support. Again as previously, there was some suspicion expressed about such support where it involves 'centralising' authority and enhancing the authority of experts at the expense of clinicians (although these comments were made regarding the CEAP). There was an apparent preference for improving support via collegiate networks. It was also expressed that creating an 'ethics culture' might be preferable to support that centralises expertise and authority.

In our interpretation, the above ad hoc qualitative work showed quite conditional support for clinical ethics support. Among the senior health service personnel consulted there appeared to be more enthusiasm for generating a 'culture of ethics inquiry' than there was for providing a case consultation service – support and advice regarding a current ethically difficult case (further described below). This preference seems to be related to the perception that, in the case of a centralised ethics committee at least, clinician autonomy might somehow be undermined.

Given the informants were drawn from senior health service managers rather than clinicians, this important early qualitative study could only ever partially answer the three 'fundamental' questions initially posed by the HEB. Hearing what clinicians have to say is clearly crucial to establishing whether clinical ethical support for clinicians is warranted and desired and, assuming it is, what form support should take. As we argue in the literature review, equivocal evidence of benefit and the fragility of formal support services also provide good reasons for looking more closely at what clinicians perceive regarding want and need. Some understanding of the beliefs, attitudes and practices of clinicians will be essential for developing practical and valued clinical ethical support.

The empirical research described in this report was undertaken to explore the need and desirability for enhanced clinical ethics support among clinicians. The research was primarily an exercise in getting close to clinicians and talking to them directly about clinical ethics and observing how 'clinical ethics' features in the daily clinical practice. In the following sections we: briefly describe the development clinical ethics support services, review the major empirical studies of clinical ethics support services and present our primary research methods and findings.

## 2.2 Background - Clinical Ethics Support

### Background – Key Points

- Clinicians operate in a technologically advanced, socially complex and ethically fraught environment.
- Clinical ethics support services are increasingly prevalent internationally.
- Growth is largely organic as clinicians themselves have established their own ethical capacity or resources, such as ethics committees.
- Although the evidence of impact is limited, establishing support services is increasingly encouraged by governments and NGOs such as medical professional organisations.
- The growth in ethics support services raises the issues of service quality and appropriate governance.
- There is consensus that ethical support services, regardless of model, require a set of core competencies in knowledge, skills and character.

*“(W)herever healthcare is provided we believe that there will be a need for formal ethics support which is both timely and informed.”* (Royal College of Physicians 2005)

*“Clinical ethics consultation has always sounded like a good idea, at least in theory, to most of us in the healthcare field.”* (Davis 2006)

*Clinical ethics* is the explicit consideration of moral and ethical issues that arise in the context of patient care (McClimans 2011). In one sense clinical ethics is simply an inflection of medical ethics, the self conscious reflection on ethics that is as least as old as Western medicine itself (Zussman 1997). It has long been recognised that ethical deliberation is intrinsic to the practice of medicine and that practitioners therefore develop a capacity for it – their ‘practical wisdom’ (Aristotle 1976). The moral questions faced in caring for patients have traditionally been interpreted and solved with reference to the internal morality of medicine, the values and norms intrinsic to medicine (ten Have and Lelie 1998). In a more contemporary sense, clinical ethics is the recent and emerging field of theory and practice concerned with enhancing the ‘ethicality’ of clinical practice (Pellegrino 1988, Mclean 2009). The main thrust of contemporary clinical ethics, which might be regarded as a ‘movement’, has been to take the ‘practical wisdom’ out from behind the screen of the intimacy of the medical encounter and into the light of public scrutiny with reference to the ‘external morality’ of medicine – the values and norms of the wider community.

Health professionals have always frequently encountered ethically and legally complex clinical situations and by tradition have kept their own counsel (drawing on their practical wisdom) or turning to their trusted colleagues for wisdom and guidance. The clinical ethics support movement is predicated on the belief that the contemporary clinical environment is so

technologically and socially complex that reliance on one's own wisdom or the wisdom of colleagues although valuable and practical, is itself no longer sufficient (Gill et al 2004, Williamson et al 2007). The first quote above illustrates some of the weight behind the movement. The quote from the UK's Royal College of Physicians reflects the firm conviction among many in the medical and public health community that 'ethics' is something that health professionals need support with. The second quote is used to illustrate that, firm conviction notwithstanding, there is considerable uncertainty about how this 'good idea' can be put to use.

'Formal' clinical ethics support is generally used to refer to a clinical ethics consultant or a clinical ethics committee (also referred to using other titles such as Hospital Ethics Committee or an Ethics Forum). As will be described below, consultants and committees may perform a number of functions, most typically – education, policy development and case consultation. Case consultation is by far the function that has created most interest and debate and is generally considered the most potentially valuable. A clinical ethics consultation involves a consultant or a committee helping to identify, analyse, and resolve the ethical issues involved in a specific clinical case and in doing so improving the process and outcomes of patient care (Dubler et al 2009). Resolving conflict over the care of a patient without recourse to courts of law was the initial impetus for the development of clinical ethics support (Agich 2009).

Many commentators (e.g. Cranford and Doudera 1984, Rosner 1985, Rubin and Zoloth 2004) trace formal clinical ethics consultation to the early 1970s when the Karen Ann Quinlan case involving the decision to withdrawal ventilation support from a comatose patient prompted the Courts to suggest that clinical ethics committees be established to offer guidance. While the guidance envisaged by the court appears to be more concerned with the clinical than ethical aspects, Rubin and Zoloth argue the significance of the Quinlan case lies in the court considering that medical decision-making might be enhanced with a break from reliance on the individual doctor's expertise and inclusion of input from other interested parties (2004, 219). The case perhaps marks the moment that medical ethics become a more 'public affair' (Pellegrino 1988); the internal morality of medicine giving way to external morality. The Quinlan case and a later series of Baby Doe cases (also involving the withdrawal of life supporting interventions) in the United States established and gave momentum to the idea of ethics committees. The use of clinical ethics supports services has been led by the USA. More recently, the UK too has seen a proliferation of clinical ethics committees (Whitehead et al 2009, Slowther et al 2012).

Advocates for clinical ethics support point to the technological and social changes that are believed to have increased the ethical complexities and challenges in clinical settings (Aulisio, 2000, Agich 2005, Larcher et al 2010). Advances in critical care, reproductive medicine, fetal medicine, genetic testing have given rise to new ethical and legal dilemmas around issues such as withdrawing/withholding care, patient autonomy, consent and resource allocation. Just as they always have, intimate transactions between patients and clinicians remain central to clinical practice. But the clinician-patient encounter is held to now occur in a more pluralistic social context – an increased diversity of identities and values (Aulisio et al 2000, Irvine et al 2003). It's a social context that is accustomed to democracy and populated by better educated and frequently assertive 'consumers' (Pellegrino 1988).

The value diversity of the social world is reflected in the clinical setting and compounded by differences between the health professions, institutional and systemic imperatives (Aulisio et al 2000). As a number of authors (e.g. Zussman 1997, Royal College of Physicians 2005) have



noted, clinical relationships have changed: medicine has lost some of its authority e.g. paternalism is yielding to 'partnership' and shared decision-making; nursing is more professionalised and nurses more confident and assertive. The medical encounter is increasingly crowded with competing interests and influences. Clinical transactions usually involve 'third party payers' such as governments or private insurers making clinical work increasingly subject to scrutiny from these and related institutions. Advances in medical science and technologies have dramatically expanded what we can do in treating and caring for patients often blurring important boundaries (e.g. between life and death) and creating unprecedented choices. The ethical issues that arise as a result are not confined to the clinic, but often attract intense scrutiny from the media, from religious authorities and from the law, and clinical decisions (such as a decision to discontinue treatment) can become the focus of far-ranging public debates, access of same-sex couples to fertility treatment for example.

In this (sociological) explanation, a more complex clinical environment is assumed to lead to a more fraught moral climate. The possible consequences of this more difficult and uncertain environment are increased ethical conflict with its negative impact on staff morale, productivity patient care overall (Nelson et al 2010). To date there has only been limited attempts to empirically demonstrate any such increases. The commonly stated or implied aims of support services include: minimising the distress and conflict that clinicians and patients experience when faced with ethically difficult clinical decisions (Yen and Schneiderman 1999); improving the quality of patient care (Slowther 2008); controlling health care costs; reducing complaints; reducing litigation and the costs associated with it; reducing the fear of litigation; increasing trust in health care professions and institutions; creating better decision-making processes; facilitating decision-making where there is disagreement; creating a greater focus on patient-centred outcomes; reducing the frequency of intractable or unresolved disputes; improving staff morale, developing policies and practices that reduce risks to healthcare organisations, and promoting greater understanding of ethics (Nelson et al 2010).

One possible consequence of (putatively) greater ethical complexity is that clinicians may experience 'moral distress' the potential or actual threat to the moral agency and integrity of an individual clinician (Epstein and Hamric 2009, Hamric 2012). An increasing number of studies have been undertaken to examine the prevalence of moral distress and identify the possible emotional consequences such as anger and frustration and related occupational consequences such as job satisfaction, staff 'burnout' and turnover and quality of care in general (Schwenzer and Wang 2006, Schluter et al 2008, Chiu 2008, Pendry 2007, Pauly 2012). It has been argued that over the long term moral distress can lead clinicians to become desensitised to the moral dimensions of their work possibly resulting in significant ethical issues not being recognised or even overlooked (Hamric et al 2012). The ethical 'environment' or 'climate' of a unit and its impact on moral distress has also attracted research attention (McDaniel 2006, 2010).

In sum, it's an axiom of the ethics support literature that greater cultural and value diversity has made clinical decision making more ethically uncertain and difficult (Irvine et al 2003, Royal College of Physicians 2005, Dorries et al 2011). Waning medical paternalism, heightened patient autonomy, technological advances, increased consumerism and legalism have complicated the medical encounter. It is no longer sufficient to rely on 'practical wisdom' or the informal processes that rest on it, such as seeking 'wise counsel' from colleagues (Gill et al 2004); nor is it sufficient to rely on codes of ethics that enshrine traditional values. Rather, clinical practice nowadays needs to be able to draw on specialised

knowledge and training in ethics to supplement or guide deliberation and decision-making in the clinic. This is what is generally referred to as ‘formal clinical ethics support’.

It is important to note that as well as questioning the usefulness of current approaches for delivering these ethics support services some observers question (at least rhetorically) the very need for formal clinical ethics support services at all (See Williamson 2008). The limited and equivocal evidence of benefit ethics support services and their commonly encountered fate – chronic underuse, make such questions unavoidable. The push (perhaps proselytising) for clinical ethics support, i.e. clinical ethics as a ‘movement’, has sociological interest in its own right. We don’t pursue this at length in this report. Although we keep the debates around clinical ethics support in mind, our study proceeds on the broad assumption that support for managing clinical ethics issues is at the very least a *good idea*.

*“Doctors and other healthcare professionals are seldom widely educated in ethics, and no matter the length of their experience, they are by no means guaranteed to have “ethical perspicacity” (Sokol 2005)*

A more ethically complex clinical environment, it follows, is more susceptible to conflict involving values. The clinical ethics movement appears to be most exercised by the potential for value conflict between clinicians and patients, rather than say conflict between clinicians or between patient and their families. Arguably, the main normative claim for clinical ethics support is for enhancing the ethical quality of care by promoting patient autonomy – ensuring that patients have the right to pursue their own idea of what is good (Zussman1997, Aulisio et 2000, McLean 2008, 2009, UNESCO 2008, Larcher et al 2010).

In large part, ethics support involves putting value differences into the ‘language of ethics’ and is so doing provides a productive way of expressing and understanding conflicting views (Reiter-Theil 2001).

*“How logical the statement seems that “just as institutional review boards help educate investigators about ethical norms in research, institutional ethics committees can help educate health care professionals about moral issues and conflicts that arise in clinical practice and about acceptable ways to resolve them” (Robertson in quoted in Rosner 1985).*

Almost universally, support is seen in terms of edification i.e. providing ethics expertise and teaching to improve the moral reasoning (and reflexivity) of clinicians and (to a lesser and more controversial degree) patients and their families. Providing support is typically envisaged as some formal support ‘mechanism’ such as an ethics consultant or committee that is appropriately skilled and accountable. As we will show in the literature review there is less agreement on how best to provide this kind of support.

# Section 3 – Literature Review

## 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.

### 3.1 Overview

*“...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. Admiration for seat of your pants 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 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. This general literature is obviously relevant to any study of clinical ethics support and has been briefly discussed in the Background.

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.

### **3.2 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 ethics support it is believed ethics support *ought* to 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. As discussed in the Background, 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. US and Belgium), the more recent initiatives in Canada, the United Kingdom, Scandinavia, 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 commissioned 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 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 of 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 be 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.

### **3.3 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 3.1) 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 3.1

#### **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, 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 3.2) is wide ranging and requires targeted recruitment of suitable members or 'co-opting' relevant expertise as required. The values required of a committee (Box 3.3) are described as 'aspirations' to be acquired over time similar to professional development.

### Box 3.2

#### **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 3.3

#### 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 3.1). 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 3.1

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 and 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 multi-disciplinary 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 3.2 below 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.



Table 3.2

<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.				
Skill Area	Individual/At Least One Group Member Needs	Every Team Member Needs	Every Committee Member Needs	Individual/at least one member can access
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, including	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 recognize 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

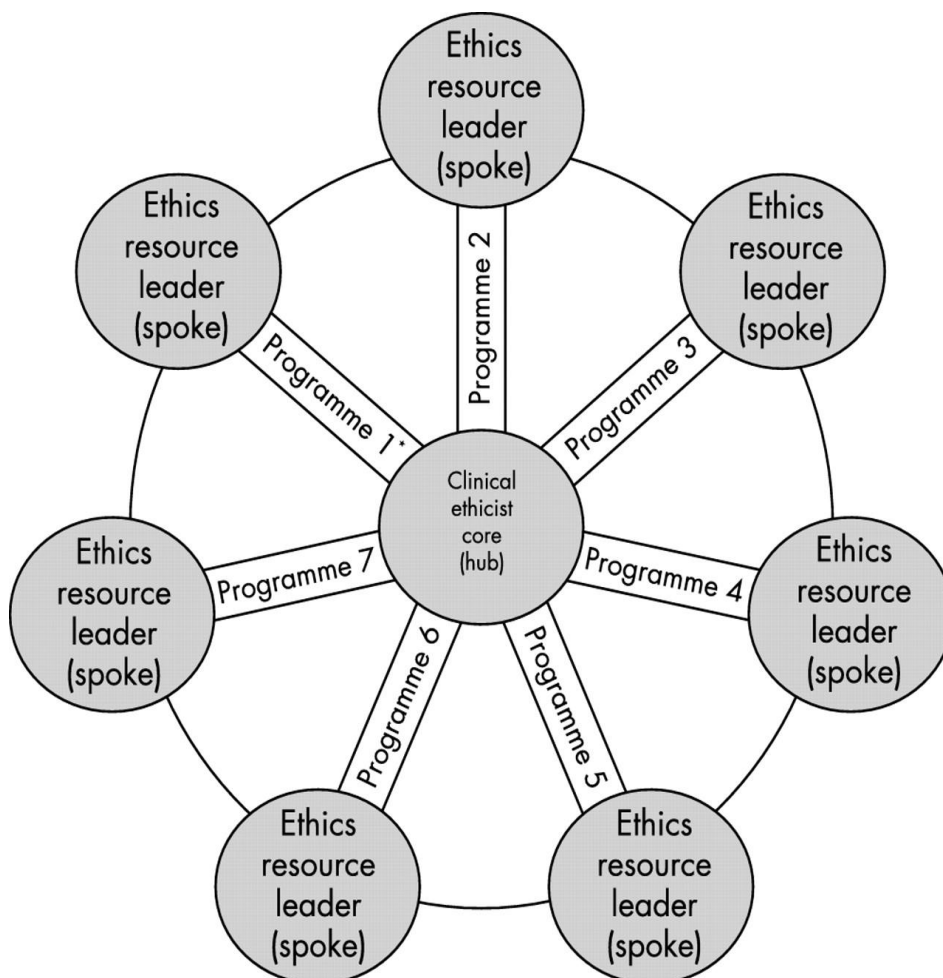
### Moral Case Deliberation

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.

Figure 1 (reproduced from MacRae et al 2005)



*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 <http://www.jointcentreforbioethics.ca/> )

### **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 organization are consistent with the accepted ethical standards, norms, or expectations for the organization and its staff. (Fox et al 2010). Drawing on theoretical developments in disciplines such as organizational 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 sometimes 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 3.3 below shows a comparison between the traditional and IntegratedEthics models with the latter clearly offered as a more system oriented.

Table 3.3

Traditional Ethics Committee Model	Integrated Ethics Model
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

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.

### 3.4 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 3.1 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 3.4) show that the majority of ethics support service provide all three of the core functions of education, policy review and development and consultation but may predominantly 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.

**Table 3.4 - Descriptive Studies of Ethics Support Services**

AUTHOR(S) YEAR, LOCATION	METHODS AND SAMPLE	VARIABLES & 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.	120 (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.	18% 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.

AUTHOR(S) YEAR, LOCATION	METHODS AND SAMPLE	VARIABLES & OUTCOMES of INTEREST	RESULTS and RECOMMENDATIONS
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 & 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 recognize 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 organizational 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.



AUTHOR(S) YEAR, LOCATION	METHODS AND SAMPLE	VARIABLES & OUTCOMES of INTEREST	RESULTS and RECOMMENDATIONS
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.	70% 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.	46% 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.

AUTHOR(S) YEAR, LOCATION	METHODS AND SAMPLE	VARIABLES & OUTCOMES of INTEREST	RESULTS and RECOMMENDATIONS
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.

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 3.5) 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 3.5 - Descriptive Studies of Clinician - Support Service Interaction**

AUTHOR(S) YEAR, LOCATION	METHODS AND SAMPLE	VARIABLES & 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.

AUTHOR(S) YEAR, LOCATION	METHODS AND SAMPLE	VARIABLES & OUTCOMES of INTEREST	RESULTS and RECOMMENDATIONS
Royal College of Physicians 2005, UK	Survey of senior specialist registrars.	Use of ethical support.	78% 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. 94% reported seeking support from senior colleagues; 47.9% referred to written literature and 32.8% to existing ethical policies. Thirty-four percent 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.

AUTHOR(S) YEAR, LOCATION	METHODS AND SAMPLE	VARIABLES & OUTCOMES of INTEREST	RESULTS and RECOMMENDATIONS
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.
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 organization, 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 3.6 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 nonbeneficial 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 3.6 - Evaluation Studies of Support Services**

AUTHOR(S) YEAR, LOCATION	METHODS AND SAMPLE	VARIABLES & 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.



AUTHOR(S) YEAR, LOCATION	METHODS AND SAMPLE	VARIABLES & OUTCOMES of INTEREST	RESULTS and RECOMMENDATIONS
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 percent 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	90% 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.

AUTHOR(S) YEAR, LOCATION	METHODS AND SAMPLE	VARIABLES & OUTCOMES of INTEREST	RESULTS and RECOMMENDATIONS
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.

### 3.5 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 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 quality and effectiveness 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 organizational 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 recognized 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 clinician’s to act in the best interest 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 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 organizational 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 organizational 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.

## **3.6 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 a 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. The empirical work of this project is an important initial step in advancing clinical ethics support for NSW clinicians.

*“To incorporate medical ethics into clinical practice, it must first be understood and valued by health care professionals” Tweedale 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. Clinicians in NSW PHOs already have a number of ethics sources such as guidelines and policies to draw on. A relevant and important first question to ask is – *do NSW PHO*

*clinicians perceive the need for additional ethics support?* This question presupposes the importance of understanding the beliefs, attitudes and practices of clinicians regarding their clinical practices and ethics. In the following sections we describe our fieldwork where we observed, talked to and surveyed a sample of NSW clinicians asking how they currently manage the ethical issues they face and whether ethics support is desirable and warranted.

# Section 4 - Method

## 4.1 Introduction

Clinical ethics (and clinical ethics support) can be approached from a number of disciplinary perspectives – philosophy, medical, epidemiological, social sciences and humanities, psychology. This study approaches clinical ethics support services (the ‘capacity’ to be built) firstly as a health service intervention and secondly as a sociological development. In this report our primary interest is practical.

In its most abstract form clinical ethics support is a complex intervention intended to be, as evaluation researchers such as Ray Pawson would put it, a ‘fresh input’ into the system introduced in the hope that it will bring change or restore balance et al (2004, 4).

We consider what is known about ethic support services as an intervention and draw on our research with clinicians to describe how ethics currently features in daily clinical routine and what kind of support they might prefer. The sociological analysis is not fully developed in this report but will be presented in reports prepared for academic audiences/peer-review journals.

To recapitulate; the original research proposal stated: this 2 year project will use *qualitative* and *quantitative* methods to determine:

- The kinds of ethical and issues that arise in the context of patient care in NSW;
- How much ethical discussion happens now in clinical practice, of what kind, and between whom;
- Potential entry points for normalising or ‘routinising’ clinical ethics discussion in daily practice;
- Situations where prospective ethics review might be warranted;
- The degree to which clinical ethics resources are desired and needed by health professionals and health systems; and
- The range of clinical ethics resources that could/should usefully be made available within the NSW health system.

In the remainder Section 5 we briefly outline the theoretical framework guiding the qualitative and quantitative research methods used.

## 4.2 Theoretical Framework

The epistemological framework for this study is ‘realism’ – drawing on both the ‘subtle realism’ of Hammersley (Hammersley 1992, Hammersley and Atkinson 2007) and ‘critical realism’ advocated by Sayer (2002) and Danermark et al (2003). The ‘realism’ refers to treating the objects of study as real independent, knowable phenomena. The ‘subtle’ or ‘critical’ acknowledges that our observations are concept dependent – our cultural, professional, scientific assumptions colour what we see. This important to note given that much of this report is taken up with an *interpretation* of what clinicians’ told us about clinical ethics i.e. how they interpret things.

In the realist approach – people’s perceptions are real in their consequences; we act on what we believe the situation to be. Methodologically we need to understand how clinicians understand the situations they find themselves in. The situations that clinicians encounter may involve any number of social structures, arrangements and relationships. Talking to people and listening to their descriptions and explanations can show ‘real’ social arrangements - defensive medicine because of fear of litigation, for example. The belief that you could be sued (well noted in the literature and observable in our data) regardless that statistics suggest the likelihood is actually low is related to some established social ‘facts’ such as the increasing interaction of health and law and associated areas like insurance.

Our study uses standard social science methods. We draw on the empirical work (e.g. surveys, RCTs) of earlier investigators to establish some of the basic descriptive features of ethics support services such as prevalence, types, functions and to determine what is known about their performance. Our own empirical work includes ethnography, interviews and a survey used to establish the views, experiences, attitudes and practices of clinicians regarding ethics support. More detail on these methods is given below.

The approach taken can be categorised as *empirical* or *descriptive* ethics. We empirically explore but do not normatively appraise the clinical practices and decisions that we have observed. Our approach roughly follows the position described in the quote below by ten Have and Lelie – our task is to describe not evaluate:

*“Descriptive ethics is geography; it maps the moral domain; it can explain how clinicians and their patients behave in moral situations. But it does not tell us how actors ought to behave or what kinds of decisions are morally justified.”* Ten Have and Lelie (1998)

## **Qualitative Data**

Our data is primarily clinicians’ accounts of how they manage the ethical issues they encounter. Accounts are people’s descriptions, explanations and justifications of events, ranging from the mundane to the dramatic (Orbuch 1997). In their accounts events and experiences will be described, typically in the form of (more or less coherent and complete) narratives. Narratives of events and experiences are where meanings are observed. We can see in their accounts how people interpret and make sense of the world and their experience of it. In their accounts, people demonstrate their knowledge of ‘ideal’ behaviours and talk about themselves as legitimate actors with reference to the socially constructed moral order. In sum, accounts show us people’s beliefs about how the world is and how it should be and their reasons for acting in it.

Our qualitative analysis involves categorising what clinicians said about what *is* and *ought* to be, identifying the degree of convergence and divergence on what is and ought and extracting ‘themes’. The intention, not at this point fully realised (see note below) is to develop a sociological explanation for our observations. Accounts should give us a plausible description of the situation and we can largely take it as how that individual understands a situation. They could be wrong, they could be lying but they must give a plausible account which can be compared with other accounts.

*“Separating the question of the truth or falsity of people’s accounts from the analysis of those accounts as social phenomena allows us to treat participants’ knowledge as both resource and topic, and to do so in a principled way” (Hammersley & Atkinson 2007, 99)*

You put together a story from all the stories people have put together for you. You do not end up with a value free collection of facts but you do get a glimpse of the ideas, values and interests at play in a given situation.

### **Quantitative data**

The survey data is primarily clinicians responses to fixed-choice questions about the type of issues faced, how these are managed, how often and openly ethics is discussed and preferences for different types of ethics support. Descriptive statistics are used. In addition to putting numbers against specific features of everyday ethics (e.g. type of ethical issues) the survey data are used to explore some of the findings that emerged from our qualitative research.

# Section 5 – Clinician Survey

## 5.1 Aim

The survey is intended to establish: the range and frequency of clinical ethical issues; the various means used by clinicians to address these issues; and the perceived adequacy of the processes and resources available to them. The survey also looks at clinician satisfaction with the ethics of their hospital and department.

The survey design was informed by our qualitative data and sought to gather descriptive data about the ethical, professional, organisational and contextual issues identified in the interviews and ethnography (not included in this Report because of the sensitivity of the issues identified and the potential for identification of the staff and patients involved). The qualitative study identified that clinicians saw the ethical environment of their hospital as as 'mostly right', but highlighted issues about the extent of frequent and open discussion about the ethics of a case or issue. The survey seeks to quantitatively explore some of the features and concepts emerging as significant from the qualitative findings.

## 5.2 Methods

Design: cross-sectional survey using a self-complete questionnaire.

Sample: a convenience sample of clinicians at (medical, nursing/midwifery allied health staff) at two tertiary hospitals: Hospital 1 and Hospital 2.

### *Instrument development*

The content of the questionnaire was developed using the team's developing understanding of the relevant issues based on our qualitative data and on similar surveys in the published peer-reviewed literature.

The questionnaire was reviewed by a small number of clinicians 'experts' for face validity. The questionnaire was then distributed to six clinicians who volunteered to complete the questionnaire and provide comments and suggestions.

### *Instrument content*

The questionnaire included both closed questions with pre-determined response options and open-ended response items. The instrument was intended to be as brief as possible requiring a maximum of 15 - 20 minutes on average to complete.

In addition to drawing on the results emerging from the qualitative study, the questionnaire content was informed by a review of clinical ethics related surveys published in the literature, particularly: McDaniel 1997, Hui et al 2008, DuVal et al 2004, Hurst et al 2005, 2007, Schwenzer and Wang 2006, Forde and Aasland 2008, Saarni et al 2008.

The key questions asked by the survey data are:

- How common is it to experience ethical/legal ethical uncertainty or concern?

- What issues/situations are associated with ethical difficulties?
- What are the most common ways of dealing with ethical difficulties?
- What is the perceived adequacy of current ways of dealing with ethical difficulties?
- How often are ethical issues discussed?
- Is open discussion of ethical issues common?
- How do clinicians evaluate the ethical environment of their unit (conceived as openness)?
- How do clinicians evaluate the ethical environment of their hospital?
- Do clinicians indicate a need for clinical ethical support?
- What types of support are most preferred?
- Are there differences between medical and nursing staff, junior and senior staff, between a public and private hospital?

The questionnaire is reproduced in Appendix 1. The opening questions (A1 and A2) asked about the frequency thinking or being concerned about the ethical and legal implications of clinical work. We distinguished between thinking about and being uncertain or concerned about one's own actions and uncertainty and concern about own actions and the actions of others. The response options were chosen as idiomatic expressions of difference in frequency. Although it is not possible to tell the precise numeric difference or distance between occasionally and rarely – we presume that most respondents would interpret 'occasionally' as referring to event occurring more than rarely.

Question A3 lists a number of situations drawn from the literature and from discussions with clinicians believed to be ethically and legally sensitive. Respondents are asked whether they have experienced uncertainty or concern at these situations in the last 12 months. Questions A4 and A5 ask for the frequency of experiencing concern about specific aspects of patient care, such as patient choice and aggressive treatment. The rationale for A5 was to explore what it was about a situation that caused uncertainty and ethical concern. Many of the statements are conjunctions. This was partly done to avoid proliferating categories. This was to give some complexity to each kind of cause but without proliferating categories. For example - it's not just about the type of information being given but how it's being given. Questions A6 – A8 ask about actions in response to ethical concern. A9 and A10 ask about the frequency and focus of ethics related discussions among the team.

We did not believe that the available scales on ethics environment were suitable (partly because of content and partly because of length) and therefore we developed our own focussing on the individual's satisfaction with the ethical environment of their hospital and department. At the hospital level, satisfaction is operationalised in statements about ethics at the hospital and congruence with the individual's values. At the department level, satisfaction is operationalised through statements about the openness and frequency (routine) of ethical discussion.

A11 is a set of eight positively worded declarative statements about ethics at the respondent's hospital. The items were generated using the literature (Forde and Asland 2008). Using Likert style response options, the respondent is asked to agree or disagree with each statement. The eight items are intended to perform as a uni-dimensional scale to show the individual's degree of satisfaction with the 'ethical climate' of their hospital. Each response is scored and a total score across the items is calculated. A higher score is interpreted as showing greater satisfaction. Scores were divided in to three equal strata (7 – 13 = **1** Low satisfaction; 14 – 20 = **2** Moderate Satisfaction; 21 – 28 = **3** High Satisfaction). To

be deemed highly satisfied an individual would have agreed or strongly agreed to most positively worded items.

A13 is also is a set of eight positively worded declarative statements about ethics within the respondent's department. The items are a scale used to estimate the respondent's satisfaction with the ethical climate of their department following the procedure described above.

Questions A12, A14, A15 are open-ended item asking how care and ethics could be improved at their hospital and within their department.

In Section B of the questionnaire, respondents were asked about existing and preferred means of ethics support. In Section C, respondents were asked for some basic personal and professional information.

#### *Other survey materials*

Distribution of the questionnaire was accompanied by an e-mail from the relevant Clinical Director and outlining the study, the aim of the survey and providing researcher details.

#### *Data management*

Electronic and pen and paper responses were directly entered into SPSS Version 16 for analysis.

#### *Data Analysis*

Conventional descriptive statistics are used to summarise the data. Further analysis centred on the differences by gender, age, profession and hospital. Associations were explored using Pearson chi square analyses and odds ratios with their 95% confidence intervals. In some analyses age was dichotomised into younger 21-40 years and older 41+ years; and profession into medical and non-medical. Frequencies and proportions are shown with percentages rounded. Odds ratios are used to show statistically significant associations. Only statistically significant associations are reported

#### *Survey Administration*

The survey was available as an online questionnaire or a pen-and-paper questionnaire. We followed advice from staff members on how best to distribute the survey and reach clinicians within that unit. The survey distribution modes were an on-line questionnaire distributed by email and a pen-and paper survey.

The on-line survey was distributed by electronic mail. An invitation to participate and a link to the online survey was e-mailed to potential respondents via Clinical Directors. The email contained a brief description of the survey from the research team, an assurance of anonymity, and an estimate of the time commitment involved. We asked for the surveys to be completed within 2-3 weeks. To participate in the survey the email recipient was directed to press a hyperlink, this took the participant directly to the questionnaire. Reminder e-mail was sent at two weeks following initial mail-out to encourage non-responders to complete the survey.

The pen and paper questionnaire was distributed by several pathways: personal handout of the questionnaire by the Clinical Support officer; a distribution of the questionnaires by the Nursing Unit Manager; and an on-the-spot administration of the questionnaire by ED at a



prearranged meeting. One planned distribution, attaching the questionnaire to a payslip, was unable to be undertaken.

### 5.3 Results

A total of 104 clinicians from two hospitals completed the survey. The units that participated were Birthing Services/Fetal Medicine at Hospital 1, Haematology and Radiation Oncology at Hospital 2. Respondent characteristics are given in Table 5.1

#### *Response rate*

It is not possible to establish how many clinicians received or sighted the email invitation to complete the survey and this precludes calculating a meaningful response rate. Similarly, we do not know how many staff were made aware that the pen and paper survey was available, again precluding an estimation of response.

Table 5.1

<b>Respondent Characteristics (N= 104*)</b>	
<b>Age</b>	
Mean	43 (SE 1.46) Range 21-70+ years
<b>Gender</b>	
	81 Female 17 Male
<b>Occupation</b>	
Medical	32
Nursing	45
Allied Health	21
<b>Area of employment</b>	
Oncology & Palliative care	31
Midwifery	23
Haematology	23
O&G	10
Other	5
<b>Years in Profession</b>	
Mean	16.5 (SE 1.17) Range 1 – 40+ years

\*6 respondents did not provide this data

#### **How common is it to experience ethical/legal ethical uncertainty or concern?**

Respondents were asked about the frequency of being in a situation where they will think about the ethical implications or experience uncertainty or concern about what is the right thing to do (Table 5.2). Over half (58, 55.2%) of respondents reported often thinking about the ethical implications of their decisions, a much smaller (12.4%) proportion reported often being uncertain or concerned. Combining often and occasionally 94 (89.5%) of respondents indicated that they often to occasionally thinking about ethical implications; 62 (59.1%) reported often to occasionally being concerned about what is the right thing to do; and 74 (70.5%) are often to occasionally concerned about the actions of others.

Respondents were asked about the frequency of thinking about or being uncertain or concerned about the legal implications of their decisions (also Table 5.2). Less than half (44, 41.9%) report often thinking about the legal implications of their decisions, much smaller proportion reported often being uncertain or concerned. Combining often and occasionally 78 (74.3%) of respondents indicated that they often to occasionally think about legal implications; 46 (43.8%) reported often to occasionally being concerned about what is the right thing to do; and 57 (54.3%) are often to occasionally concerned about the actions of others.

Table 5.2

<b>How often do you face a clinical situation where...</b>	<b>Often N (%)</b>	<b>Occasionally</b>	<b>Rarely</b>	<b>Never</b>
<b><i>Ethical</i></b>				
you will think about the ethical implications of your clinical decisions	58 (55.2)	36 (34.3)	9 (8.6)	0
you are uncertain or concerned about what is ethically the right thing to do	13 (12.4)	49 (46.7)	41 (39)	1 (1)
you are uncertain or concerned about the ethics of the decisions and actions of others	13 (12.4)	61 (58.1)	29 (27.6)	1 (1)
<b><i>Legal</i></b>				
you will think about the legal implications of your clinical decisions	44 (41.9)	34 (32.4)	18 (17.1)	8 (7.6)
you are uncertain or concerned about what is legally the right thing to do?	12 (11.4)	34 (32.4)	47 (44.8)	12 (11.4)
you are uncertain or concerned whether what others are doing is legally right?	8 (7.6)	49 (46.7)	40 (38.1)	8 (7.6)

### **What situations are associated with ethical difficulties?**

Respondents were given a list of situations and asked whether they had experienced either or both ethical or legal uncertainty/concern related to the particular relevant situation (Table 5.3). The results show that experiencing *both* ethical and legal uncertainty was most commonly reported category for each situation.

Table 5.3

In the last 12 months did you experience uncertainty or concern related to the following situations	Yes Ethically	Yes Legally	Both	Neither	Not relevant to me
	N (%)				
A patient refusing recommended treatment	25 (23)	3 (3)	39 (37)	25 (23.8)	12 (11)
A patient requesting treatment outside of hospital guidelines	14 (13)	3 (3)	32 (30)	33 (31.4)	21 (20)
A patient requesting treatment of borderline necessity or benefit	29 (28)	5 (5)	24 (23)	26 (25)	20 (19)
The handling of a medical error or incident	9 (9)	8 (8)	36 (34)	39 (37)	11 (10)
A family request to withhold information from a patient	9 (9)	0	21 (20)	51 (49)	23 (22)
A patient request to withhold information from his/her family	20 (19)	1 (1)	15 (14)	49 (47)	18 (17)
Staff withholding information from a patient and/or family	3 (23)	1(1)	15 (14)	60 (57)	22 (22)
Ordering/participating in aggressive treatment of terminally ill patient	25 (24)	0	15 (14)	24 (23)	40 (38)
Disagreement among staff about care or treatment	25 (24)	1 (1)	35 (33)	26 (25)	16 (15)
Carrying out an Advanced Directive	5 (5)	0	7 (7)	44 (42)	47 (45)
Carrying out a Do Not Resuscitate order	3 (3)	0	8 (8)	43 (41)	50 (48)
Making the decision to withdraw or withhold treatment	7 (7)	0	18 (17)	33 (31)	45 (43)
A request for late termination of pregnancy	7 (7)	1 (1)	10 (10)	24 (23)	62 (59)

For each situation considerable proportions of respondents indicated that the situation wasn't relevant to them. Table 6.4 combines those reporting experiencing ethical and/or legal concern related to the given situations that *relevant* to them and ranks them highest to lowest. Two situations showed a statistically significant difference by age. Younger respondents (21-40 years) were more likely to report one or both ethical and legal concern at a patient refusing recommended treatment (86% versus 61%; OR 3.9, 95%CI 1.4 -11.5). Younger respondents were less likely to report ethical or legal concern at carrying out an advance directive (8% versus 35%; OR 0.2, 95%CI 0.3 – 0.9).

Table 5.4 Proportion of Respondent Reporting Uncertainty or Concern in *relevant situations*

<b>In the last 12 months did you experience uncertainty or concern related to the following situations?</b>	<b>Yes Ethically/Legally/Both</b>
A patient refusing recommended treatment	72.8%
Disagreement among staff about care or treatment	70.1%
A patient requesting treatment of borderline necessity or benefit	69.0%
Ordering/participating in aggressive treatment of terminally ill patient	62.5%
A patient requesting treatment outside of hospital guidelines	59.7%
The handling of a medical error or incident	57.6%
Making the decision to withdraw or withhold treatment	43.1%
A request for late termination of pregnancy	42.8%
A patient request to withhold information from his/her family	42.3%
A family request to withhold information from a patient	37.0%
Staff withholding information from a patient and/or family	24.0%
Carrying out an Advanced Directive	21.4%
Carrying out a Do Not Resuscitate order	20.3%

Respondents were asked indicate the frequency of specific causes for their ethical concern or uncertainty (Table 5.5). The three most frequently cited causes were whether the patient is receiving the treatment they really want (63, 60%), the quality of what information the patient is being given and how (59%) and whether treatment is too aggressive. There were no statistically significant differences by gender, age, profession or hospital.

Table 5.5

<b>How often would your ethical concern or uncertainty be about...</b>	<b>Often/Occasionally N (%)</b>
The treatments and care being given and whether this is what the patient really wants	63 (60%)
The information that is being given to a patient and how it's being given	62 (59%)
The treatments given and whether this is too aggressive for a particular patient	59 (56%)
Being restricted by resources in providing the care or treatment you believe a patient needs	57 (54%)
Patient preferences and whether choice is being respected	52 (49%)
Being restricted by hospital rules or guidelines in providing the care or treatment you believe a patient needs	39 (37%)
Personal values of other clinical staff inappropriately influencing patient care	27 (26%)
The appropriateness and quality of care generally	22 (21%)

### What are the most common ways of dealing with ethical difficulties?

Respondents were asked what they do when they are uncertain or concerned about the ethical implications of a clinical situation (Table 5.6). Most respondents (96, 91.4%) indicated they would ask for the opinions of colleagues, around two-thirds indicated they would raise the issue in a group forum (68, 64.8%) and consult a relevant guideline (64, 61.0%). There were no statistically significant differences by gender, age, profession or hospital.

Table 5.6

<b>What would you do if you were uncertain or concerned about the ethical implications of a clinical situation*</b>	<b>N (%)</b>
Ask for the opinions of colleagues	96 (91.4)
Raise the issue at handover or ward meeting or other group forum	68 (64.8)
Consult and follow relevant guidelines or protocol	64 (61.0)
Meet with the patient/family and allow them decide	39 (37.1)
Consult with a Clinical Ethics Committee or other source of ethics expertise	29 (27.6)
Discuss with partner or close friend	23 (21.9)

### What is the perceived adequacy of current ways of dealing with ethical difficulties?

Respondents were asked - How often is what you usually do not helpful in addressing your uncertainty or concern? A total of 69 (66%) respondents reported Never or Rarely 18 (17%) reported Occasionally and 4 (4%) reported Always.

### How do clinicians evaluate the ethical environment of their hospital?

Respondents were asked to agree or disagree with set of statements about their *hospital* and the congruence with personal, professional and community values (see Table 5.7). A large majority of respondents agreed to strongly agreed with the positive statements and disagreed with the single negative statement ('This hospital is too ready to accede to external political demands').

Table 5.7

<b>Statement</b>	<b>Strongly Agree</b>	<b>Agree</b>	<b>Disagree</b>	<b>Strongly Disagree</b>
The policies and procedures of this hospital are generally ethically appropriate	19 (18.1%)	76 (72.4%)	5 (4.8%)	-
The interests of this hospital are rarely put before the interests of the patient	14 (13.3%)	55 (52.4%)	27 (25.7%)	2 (1.9%)
Patients at this hospital are generally treated equally	23 (21.9%)	67 (63.8%)	8 (7.6%)	1 (1.0%)
The values upheld at this hospital mostly reflect my professional values	14 (13.3%)	79 (75.2%)	5 (4.8%)	1 (1.0%)
The values upheld at this hospital mostly reflect my personal values	12 (11.4%)	78 (74.3%)	8 (7.6%)	1 (1.0%)
My conscience is rarely troubled by the care patients receive at this hospital	9 (8.6%)	79 (75.2%)	10 (9.5%)	1 (1.0%)
The values upheld at this hospital mostly reflect values of the community	10 (9.5%)	71 (67.6%)	16 (15.2%)	-
This hospital is too ready to accede to external political demands	4 (3.8%)	43 (41%)	42 (40%)	3 (2.9%)

The ethical environment of the hospital was also explored by scaling the above statements and estimating the individual's satisfaction with the ethics of their hospital (see Methods above). The scale was evaluated using Cronbach's Alpha. The alpha score (with the item 8 removed) was 0.87 strongly indicating 'unidimensionality' i.e. each item is 'tapping into' the same underlying latent variable – degree of satisfaction. This allows for a valid summary score to be calculated.

Each response is scored and a total score across the items is calculated. A higher score is interpreted as showing satisfaction. Scores were divided in to three equal strata (7 – 13 = **1** Low satisfaction; 14 – 20 = **2** Moderate Satisfaction; 21 – 28 = **3** High Satisfaction). To be deemed highly satisfied an individual would have agreed or strongly agreed to most positively worded items.

Table 5.9

<b>Satisfaction Score</b>	<b>N</b>	<b>%</b>
High satisfaction	65	61.9
Moderate satisfaction	33	31.4
Low satisfaction	1	1.0

Table 6.9 shows that almost two-thirds of respondents indicated being highly satisfied with the ethical environment of their hospital. There were no statistically significant differences between medical and non-medical respondents or by hospital.

**How do clinicians evaluate the ethical environment of their unit? How often are ethical issues discussed? Is open discussion of ethical issues common?**

These questions were explored using a set of items about the openness of the clinicians' department (Table 5.10). Respondents were asked to indicate their agreement with a set of statements about their *department*.

Table 5.10

<b>Statement</b>	<b>Strongly Agree</b>	<b>Agree</b>	<b>Disagree</b>	<b>Strongly Disagree</b>
When an ethical issue arises it will be openly discussed	24 (22.9)	67 (63.8)	7 (6.7)	-
If I am concerned that a patient's best interest isn't being met I am able to air my view	23 (21.9)	68 (64.8)	6 (5.7)	1(1.0)
Ethical issues are usually handled appropriately	18 (17.1)	77 (73.3)	3 (2.9)	
Ethical issues are often overlooked	1 (1.0)	14 (13.3)	73 (69.5)	9 (8.6)
We talk about ethics as much as is necessary	8 (7.6)	72 (68.6)	17 (16.2)	-
We could handle ethics issues better than we currently do	2 (1.9)	47 (44.8)	47 (44.8)	-
If an ethical issues arises all staff are able to voice their view	9 (8.6)	67 (63.8)	19 (18.1)	1 (1.0)
There should be more discussion of the ethical aspects of our clinical practices	11 (10.5)	54 (51.4)	29 (27.6)	1 (1.0)

The ethical environment of the department was also explored by 'scaling' the above statements and estimating the individual's satisfaction with the ethics of their department (operationalised as the openness of process see Methods above). The scale was evaluated using Cronbach's Alpha (0.82) strongly indicating 'unidimensionality' i.e. each item is 'tapping into' the same underlying latent variable – degree of satisfaction. This allows for a valid summary score to be calculated. Table 5.11 shows the results of the scoring, almost one quarter of respondents were categorised as being highly satisfied and three quarters were categorised as moderately satisfied. There were no statistically significant differences between medical and non-medical respondents or by hospital.

Table 5.11

<b>Satisfaction Score</b>	<b>N (%)</b>
High satisfaction	22 (22.4)
Moderate satisfaction	74 (75.5)
Low satisfaction	2 (2.0)

**Open-ended questions**

We asked respondents a number of open-ended questions about their hospital and department. Forty respondents provided responses to the question: *Are there one or two particular aspects of patient care in your area of clinical practice that you think raise ethical issues?* Responses were compared and categorised into the following: (N=13) aggressive treatment at end-of-life (Hospital 2 respondents); (N=10) late termination of pregnancy (Hospital 1 respondents); (N=6) equity issues (such as patient access to unfunded drugs).

Other aspects identified as raising issues included: clinician disagreement; patient refusing recommended treatment; resuscitation of <24 week infant. Box 5.1 provides examples of categorised responses.

Box 5.1

<b><i>Are there one or two particular aspects of patient care in your area of clinical practice that you think raise ethical issues?</i></b>
<b>Aggressive treatment at end-of-life</b> <i>"Treatment of patients who express their desire to cease treatment to frontline staff but then agree to proceed after convince/coerced by medical staff."</i>
<b>Termination of pregnancy</b> <i>"Termination of pregnancy; maternal versus fetal rights."</i>
<b>Patient confidentiality</b> <i>"Older patient's family not wanting the patient to know they have cancer."</i>
<b>Equity</b> <i>"Lack of patient equity re availability of support services, particularly community based palliative care"</i>
<b>Other</b> <i>"The use of new or advanced technology is a definite benefit when treatment is of radical intent. However when it is used for palliation just because the technology is available, I find the practice questionable."</i>

Forty-two respondents provided responses to the question: *If you could improve how care is delivered at your hospital where would you start?* Responses were compared and categorised into the following: quality of care (N=13); more staff/resources (N=12); align hospital values with community values (N= 5); more beds (N=4). Other improvements included: better communication between departments; pay increase for nurses and changing key hospital appointments. Box 5.2 provides examples of categorised responses.

Box 5.2

<b><i>If you could improve how care is delivered at your hospital where would you start?</i></b>
<b>Quality</b> <i>"More collaborative practice - the women and families voice being heard. Less internal politicking and corridor gossiping."</i>
<b>Staff/Resources</b> <i>"Funding for more staff to deliver timely care and assess appropriateness of that care to particular case"</i>
<b>Align hospital values with community values</b> <i>"Suggest that the Hospital accept the standards acceptable to the general community when in conflict to its own ethical framework"</i>
<b>Other</b> <i>"Change communication style between departments,</i>

Twenty-nine respondents provided responses to the question: *If you could improve ethics within your department where would you start?* Responses were compared and categorised into the following: integrating ethics into regular meetings such as handovers and grand rounds (N= 12); providing access to ethics expertise such as an ethicist (N= 5); more inclusive discussions (N=4); ethics education (N=4). Other improvements included: treating public and private patients equally, greater accountability and implementing NFR orders earlier. Box 5.3 provides examples of categorised responses.



Box 5.3

<b>If you could improve ethics <i>within your department</i> where would you start?</b>
<b>Integrating ethics into regular meetings</b> <i>“Raise its profile, try to look at best practice and formalise ethics through ethics meetings and discussions”</i>
<b>Providing access to ethics expertise</b> <i>“An external well informed voice to consult”</i>
<b>More inclusive discussions</b> <i>“Allow those other than medical officers a chance to put forward an opinion as to whether treatment is ethical”</i>
<b>Ethics education</b> <i>“Basic training and education around ethical issues as they relate to our subspecialty”</i>
<b>Other</b> <i>“By being able to treat public and private patients the same”</i>

**Do clinicians indicate a need for clinical ethical support?**

Respondents were asked whether they believed that clinicians are usually comfortable in handling the more common clinical situations involving substantial ethical issues 71 (67.6%) reported Yes, 9 (8.6%) and 17 (16.2%) Don’t know. Respondents were asked “Are there some ethically complex or challenging situations where more support might be helpful? A total of 72 (68.65%) answered Yes, these respondents were then asked to identify what they felt might be helpful.

**What types of support are most preferred?**

Table 5.12 shows what types of support would be most helpful. The three most commonly preferred types of support were protocols and guidelines (44, 41.9%), having ethics or legal issues covered in routine clinical meetings (42, 40.0%) and having an ethics or legal expert available for advice (39, 37.1%).

Table 5.12

<b>If Yes what do think might be helpful?</b>	<b>N (%)</b>
Having protocols/guidelines in place that outline appropriate responses to ethical/legal issues	44 (41.9%)
Having ethical/legal issues as a routine element of grand rounds or morbidity and mortality meetings	42 (40.0%)
Having an individual ethics and/or legal expert available for advice	41 (39.0%)
More ‘in-service’ training or education on the ethics and law of patient care	39 (37.1%)
Having regular educational seminars on ethics and law	37 (35.2%)
Having a member(s) of the clinical team trained in ethics who can provide ethical advice when needed	37 (35.2%)
Having an advisory group (made of clinicians, lawyers, ethicists, patient representative)	34 (32.4%)
Having an internet based resource (storing relevant literature, case studies, policies etc.)	33 (31.4%)

## 5.4 Discussion

The majority of clinicians we surveyed reported frequently being in a situation where they experience ethical and legal concern or uncertainty regarding their own decision or the decisions of colleagues. In most cases patient choice and autonomy appearing as the most frequently ethically troubling issues. The most commonly reported response to uncertainty or concern is to talk to colleagues an action considered by most to be helpful in most instances. While the majority clinicians indicated being satisfied with the ethical environment of their hospital and department, the majority also felt that they would benefit from support in handling the ethical issues that arise.

The results show that experiencing both ethical and legal uncertainty was the most commonly reported category for each situation. This may indicate some support for the idea that ethical and legal implications of decisions are closely associated.

Most respondents reported that they often think about the ethical and legal implications of their own decisions or the decisions of their colleague and on many occasions are uncertain or concerned about what is the right thing to do. Taken together, the responses to these questions suggest ethics is a relatively active aspect of clinical decisions. There is a fairly high risk of 'social desirability' bias with such questions, of course. Clinician's may think they *should* be thinking about ethics and occasionally being concerned and have answered accordingly (this bias is discussed further below). The picture that emerges from these questions is clinicians being frequently prompted to some degree of moral deliberation as they make their decisions. There was no difference in reports of the frequency of ethical disquiet between medical and non-medical staff. They equally frequently encounter ethical concerns but possibly of different kinds.

The types of clinical situations reported as causing uncertainty or concern reflects the findings of other studies of clinicians and everyday clinical ethics. A substantial proportion of respondents indicated experiencing ethical or legal uncertainty/concern in particular ethically fraught situations such as end-of life care issues such as 'overtreatment' and 'futility' (Schwenzer and Yang 2006, Saarni 2008, Tapper et al 2010), disagreement among staff (Hurst et al 2007) inadequate staffing (Schwenzer and Yang 2006).

Of the five most commonly reported situations of uncertainty or concern: 1) a patient refusing recommended treatment, 2) disagreement among staff, 3) a patient requesting a treatment of uncertain value, 4) aggressive treatment of terminally ill patient and 5) a patient requesting treatment outside of hospital guidelines; three (1,3,5) are directly related to managing patient choice. Other studies have found autonomy and patient's rights to be a central ethical concern of clinicians (Du Val et al 2001, 2004, Hui 2008). The second highest situation identified as reporting uncertainty or concern was disagreement among staff, a concern identified in studies by Hurst et al (2007). Over half of respondents indicated that the handling of a medical error or incident caused them concern, an issue also reported in other studies (Forde and Aasland 2008). Patient privacy and confidentiality were also issues of concern for respondents. Comparatively few clinicians reported uncertainty and concern at carrying out Advance Directives or Do Not Resuscitate orders possibly reflecting the confidence imparted from the various policies and guidelines that have been developed around these issues.

The issue of patient choice was also prominent in the specific causes clinicians reported for their ethical concern or uncertainty. The most commonly reported cause for concern was whether the treatment and care a patient is receiving is really what the patient wants; the second highest concern about the information a patient is being given and how. Both are related to patient choice and autonomy. Choice and autonomy are also implicated in concern for patient preferences being respected and staff inappropriately influencing care identified by over half of respondents. Almost two-thirds of respondents reported aggressive treatment as a cause for concern which is related to beneficence. Guidelines and policies were a concern for around 40% of respondents. Relatively small proportions reported concern at staff being non-judgmental or at the overall appropriateness and quality of care.

The results also reflect the findings of other studies (Du Val et al 2004, Slowther et al 2001) that show when they are uncertain or concerned about the ethical implications of a clinical situation clinicians talk to their colleagues. Raising an issue of concern at a group forum was also commonly reported as was consulting a relevant guideline. These actions were generally considered helpful.

Respondents were asked to agree or disagree with set of statements about their *hospital* and the congruence with personal, professional and community values. A large majority of respondents agreed or strongly agreed with the positive statements and disagreed with the single negative statement ('This hospital is too ready to accede to external political demands'). The statements declared that the policies and procedures were ethically appropriate, that patients' interests generally have priority and the values upheld at the respondent's hospital mostly reflected the respondent's personal and professional values. The responses to these statements, taken individually or collectively (i.e. as a scale score) indicate a general satisfaction with the hospital's ethical climate.

Similarly, the responses to statements about their *department* indicate a general satisfaction with the ethical climate. Ethical issues are not generally overlooked, are attended to appropriately, openly and inclusively. The majority indicated that if they do have an ethical concern they are able to raise this with their colleagues. Again, the responses to these statements, taken individually or collectively suggest a general satisfaction with the ethical climate at the department level.

Most respondents believe that clinicians generally comfortable dealing with the ethical issues they face but over two-thirds also believe that there are some ethically challenging situations where support might be helpful. Protocols and guidelines, having ethics as a part of routine in meetings and having an ethics or legal expert available for advice appeared to be most preferred. An ethics committee was among the least preferred options.

The responses also show some receptiveness among the majority of clinicians to the idea of more ethics support being available. The question is hypothetical and again it is possible that a type desirability bias – respondents were saying either what they thought we wanted to hear or a wish list bias, respondents were making a costless 'well if you're giving it away' judgement. Nonetheless, two-thirds of respondents reported a range of types of support preferred with similar size proportions indicating ethics guidelines, ethics discussion, ethics expertise and ethics training.

## **Limitations**

This is a small, non-randomly selected sample with only a proportion of clinical staff from each unit participating. Generalisation of the statistical results to other clinicians is not claimed but was not the main aim of the survey; the survey was intended to collect descriptive data and extend the reach of the emerging findings of our qualitative work. The administration of this survey wasn't entirely successful. Of the six units we had hoped to distribute the questionnaire, only four participated. A number reasons, such as staff personnel key to the distribution unexpectedly becoming unavailable during the fieldwork phase.

Clearly, in a survey where we confine people's response to researcher determined options, a lot of detail is missed. We don't know how keenly clinicians feel the ethical concern they reported or how much or little this impacts morale and performance.

There is a possibility of 'social desirability' bias (respondents anticipate the most socially appropriate response) influencing the survey results. Respondents were asked questions and to agree to statements about their own ethics e.g. that they are thinking about ethics and may have read this as what should be done and answered the most 'appropriate' or ideal response. It's not possible to deny this possibility however, if clinician behaviour does not always conform to the ideal, there's no reason to think that people don't generally do as they say.

The questionnaire itself appeared to perform well. There was only limited missing data, the scales were internally consistent and many respondents provided qualitative data via the open-ended questions. Both the content and the presentation of the questionnaire will be developed further. But we have a basically sound instrument that with some modifications could be administered a wider and more robustly sampled population of clinicians.

The survey and the interview study (discussed in Section 8) draw data from clinicians working in a small number of specialties in three urban based hospitals. The data then cannot with confidence be used to infer to other specialties and other hospitals. The survey sample is not representative; it is limited in its capacity for statistical generalisability by the non-random sampling and the low response. However, to restate the point made above, it was not our intention to achieve statistical generalisability with the survey. The goal of the survey was to enable us to further establish the prevalence and distribution of the descriptive factors of interest such as the kinds of situations that are considered ethically challenging and to explore some of the factors that had emerged as relevant in the interviews and observations.

## **5.5 Conclusion**

The majority of clinicians we surveyed reported frequently being in a situation where they experience ethical and legal concern or uncertainty regarding their own decision or the decisions of colleagues. In most cases patient choice and autonomy appeared as the most frequently ethically troubling issues. The most commonly reported response to uncertainty or concern is to talk to colleagues an action considered by most to be helpful in most instances. While the majority clinicians indicated being satisfied with the ethical environment of their hospital and department, the majority also felt that they would benefit from support in handling the ethical issues that arise.

The survey data (triangulated with the qualitative data) support the findings that most clinicians perceive themselves to be ethically engaged and working in an environment that is *ethically* mostly right. Many reported frequently encountering situations of ethical and legal uncertainty and concern and generally relying on each for ethics support. Uncertainty and concern are managed through discussion and only infrequently result in conflict and distress. The clinicians indicated their hospital and department as generally allowing for inclusive discussion of ethical issues but that some issues and practices wouldn't be discussed. Ethical concern and uncertainty are not always voiced. Most clinicians indicated a qualified interest in having more support dealing with ethical issues made available to them. Preferences converged on support being ethically expert, independent and advisory. Support should be available for education as well as case consultation.

In the following section, we describe the results of an interview study undertaken to further explore clinicians' preferences for ethics support.

# Section 6 - Interview Study

## Clinician Perspectives of Clinical Ethics Consultation

### 6.1 Aims

To investigate clinician views of and experiences with clinical ethics support focusing on:

- What are possible triggers (& barriers) for accessing a clinical ethics consultation support service?
- What are the preferred attributes and model(s) of clinical ethics support?

### 6.2 Method

Semi structured interviews were conducted with a convenience sample of clinicians at the Hospital 3 a large tertiary referral hospital.

The clinicians were asked a set of open-ended questions about their views on and in some cases their experiences with clinical ethics consultations. Interviews primarily focused on identifying: the possible triggers for seeking clinical ethics support; the barriers and enablers in accessing support; and the key attributes/preferences for clinical ethics support.

Additionally the study included the piloting of a brief online survey, administered post interview, with all participants. It is anticipated that this survey tool will be applied in future research exploring clinician views and experiences with clinical ethics support services.

#### ***Sample***

A total of 23 interviews were conducted with medical and allied health staff across a number of specialist areas: emergency medicine, neonatal and adult intensive care, anaesthetics, neuro-psychiatry & psychiatry, neurology & neurosurgery, paediatric oncology and surgery, palliative care, paediatric oncology, general medicine and surgery.

Interviewees were identified by the site sponsor or by 'snowballing' - where participants identified and approached other clinicians who may wish to participate. The site sponsor made initial contact to clinicians who have/have not sought a clinical ethics consultation.

#### ***Data Management and analysis***

The interviews were audio taped and transcribed. Transcribed data was imported in to N-Vivo 9 for analysis. Analysis involved listening to audio-recordings and reviewing written transcriptions for categories and themes relevant to: triggers, barriers, attributes and preferred models and mechanisms of clinical ethics consultation. As all interview data is potentially identifiable, transcriptions were coded and where possible identifiable information removed. All data has been securely stored on a password protected computer. Data collection was completed in March 2012.

## 6.3 Results

### Triggers for Seeking Clinical Ethics Consultation

Table 6.1 summarises the broad range of triggers identified by interview participants that have (or would potentially) lead them to seek clinical ethics consultation. It is worth noting that many of the triggers identified by interview participants are multifaceted, complex and not mutually exclusive.

Table 6.1 Triggers for Seeking Clinical Ethics Consultation

<b>Summary of Triggers (actual and potential) identified by clinicians for seeking clinical ethics consultation</b>
<ul style="list-style-type: none"><li>• Conflict resolution (inter/intra-professional, interactions with complex family, patient or surrogate decision makers)</li><li>• Addressing Uncertainty</li><li>• Consensus</li><li>• Emotional Triggers</li><li>• Specific Ethical Issues<ul style="list-style-type: none"><li>○ Withdrawal or Withholding treatment</li><li>○ Ethico-Legal Interface<ul style="list-style-type: none"><li>▪ Advance Care Directives &amp; Care Plans</li><li>▪ Guardianship &amp; Substitute Decision Making</li><li>▪ Complaints involving legal entities (HCCC)</li></ul></li><li>○ Resource Allocation &amp; Futility</li><li>○ End of Life</li><li>○ Choice (Patient Autonomy)</li><li>○ Quality of Life</li><li>○ Capacity Assessment (including mental health)</li><li>○ Specific Paediatric &amp; Adolescent Health</li><li>○ Emerging or Novel Technologies</li></ul></li></ul>

### Conflict Resolution & Emotional Charged Concerns

Conflict and other potentially emotionally charged concerns, may trigger consultation by individual clinicians.

*“The most complex cases I’ve been involved with, that’s been where ourselves and family and patient are in conflict about a particular treatment decision.” Interviewee 01*

*“I think particularly in circumstances where there may be some disagreement between myself as a doctor and the patient or the patient’s relatives...say someone has a neurological event, a major stroke, an elderly patient and the family want everything done and it’s – seems inappropriate. You discuss it with family members and there seems to be an impasse as to how actively you should treat this patient. And I think where there is a disagreement which can’t be resolved, then having someone who is seen to be separate...” Interviewee 12*

A number of emotional triggers were identified by interview respondents, including dealing with distressed families, staff (moral) distress in dealing with limited resources, “drama” and “anxiety” experienced by an individual or team.

*“They’re very distressed, they’re pressured. There are factors that they may misinterpret, saying look, if this person stays, we’re going to get hammered as a clinical team because our length of stays are getting too long. This patient is going to cost us too much, those sort of issues.” Interviewee 14*

*“ If there’s no drama related to it, then I think generally people will maybe leave those ethical issues unexplored. But if there is drama related to it I think having a collaborative and team approach to management of those decisions rather than feeling like all the clinical decision making sits on your shoulders is a very helpful way of ensuring your longevity in the profession.” Interviewee 01*

*“I support the other thing which crossed my mind was the importance of recognizing how- it came up the other night in that discussion – how distressing some of these things, cases are, for staff. And that’s a component of it that has to be handled sensitively.” Interviewee 14*

*“I’ve got to say that my experience was driven out of my own anxiety in relation to a particular case but equally I think by having the cases like that or those sort of sentinel cases it – it increases your awareness of the types of issues at play and other less troubling situations. I would assume that more often than not it comes from people’s anxiety around particular cases that drives them to seek an ethics consult, rather than oh, this is an interesting ethical issue...” Interviewee 01*

## **Uncertainty and Seeking Consensus**

Navigating through uncertainties about the right thing to do and seeking consensus featured among interview participants as (potential and actual) triggers for seeking clinical ethics consultation, often to complement the valued support provided by their senior and experienced colleagues.

*“ What’s been helpful is that one of my senior and experienced colleagues has been willing to take the time to look at a situation that I’m concerned about, or that I have doubts about, I have **uncertainties** about, what **the right thing is to do** and to spend that time that’s required to understand that as fully as they can from their perspective which is inevitably going to be different is some ways from mine.... I think that clinicians have to be open to their own uncertainties in order to – I mean, that’s the first step to asking for assistance. So having insight into the fact that you’re not always right and can’t always be right, is really important and being able to lay out situations where I’m very confident, I’m reasonably confident, I don’t know is a really important skill I think. “ Interviewee 05*

*“So, we do talk a lot about these things. When would we like access to an ethics consultant or panel or whatever? I guess the times that we really would like access to ethics is when we feel that an outcome is inevitable, death is inevitable, and that we should be withdrawing care and we can get absolutely no agreement from parents to*



*do that. And I don't know whether we're needing ethical, legal or both sort of advice, at that point.* " Interviewee 20

*"The other option of course was to take it to Guardianship and ask for a public guardian to be appointed. But, that's a very – to me a very antagonising and hostile thing. And that maybe the solution but like I think that someone with an interest in, background in ethics and the right personality traits might have been able to reach a **consensus** view - bring the family more involved without necessarily going down that path."* Interviewee 22

*"And, interestingly, from the ethics point of view, it came back that well, yes, that would be a reasonable thing to support him... and really our main issue was we actually had various views in the medical side of things and the line that was taken, was that there wasn't a medical consensus, therefore treatment would continue. It was extremely helpful, I think. If we hadn't sought his help, it may have been that, well, I'm not sure, we may have floundered a bit."* Interviewee 19

### **Reassurance**

A few interview participants identified that clinical ethics support, in addition to support from their peers, may provide reassurance to clinicians that their decided course of action in dealing with complex decision would not be perceived as unreasonable, particularly if it came under scrutiny.

*"I definitely felt a relief. I guess you need reassurance that what you think is being done in good faith is in fact the right thing. So I had no doubt about the intentions of everybody involved, but I had a lot of doubt about how it would be perceived from outside looking in. And so that, the reassurance I got (plus from other colleagues), in relation to what was happening –should it come under further scrutiny that I was acting as part of an institution not as a maverick person on my own. So I guess that was where the reassurance came, that it was not unreasonable, the course that was being undertaken."* Interviewee 01 (IS)

*"Certainly I would feel that one of the things about ethics is that it makes you feel much more confident within yourself and it helps if there's any doubts."* Interviewee 12

*"So you will only go back if you thought that it was a positive experience. Now, how do you determine what is a positive experience? I think clinicians – because we've all got hard heads – I think what we want is, I guess, input in the decision, maybe I'm talking generally but – so you will approach an ethicist or an ethical sub-committee for advice but generally when you go there, most clinicians will have an idea what they think is the right thing to do."* Interviewee 06

### **Ethico-legal Triggers**

Many interview participants identified a range of ethico-legal triggers (actual and potential). Ethico-legal issues of concern, namely withdrawal and with-holding of treatment, advance care directives, specific paediatric issues, guardianship legislation and substitute decision making along with handling complaints procedures were among key issues identified by interview participants.

*“Well it’s interesting. More and more patients are coming with them (advanced directives). But some of them come – have them, but we don’t have a copy. Some of them come with their copy but they don’t want to follow what’s written in the document. Some, they come and then the staff don’t even notice that they’re in the notes. So there’s actually extremely complex situation. And sometimes some of the patients – like some of the forms are kind of tick box kind of forms. When you actually talk to the patient, you don’t necessarily get a good feeling that what’s written on the form is necessarily reflected in what the person actually want.” Interviewee 20*

*So I think – so I think it would – so from my perspective a useful thing for a clinical ethics group would be to say, okay the last 20 patients that came into the ED with advanced care directives, let’s just pull all their notes and see what happened and review it and see how we would could improve things...” Interviewee 19*

*“I think anybody who could have intervened in the HCCC process to mediate some improved understanding with the family that had brought the complaint would have been good. And I guess the problem is that by the time it’s a quasi-legal process in the HCCC, you become uncertain about what flexibility, what freedom you have to go around the HCCC process and try to sort it out less formally. I don’t know. Basically, I think that in the particular case that I was involved in, had there been a knowledgeable person who had been trusted by the family who could have sat down and said, “This is what happened and this is why,” I think it would never have been a complaint. Surely this situation didn’t have to end as it did. Whereas in fact it did, and all they needed was someone knowledgeable and trustworthy to say, “Yes, that’s the case.” Interviewee 12*

The role of clinical ethics support in providing advice, updates and clarification on changes in legislative requirements and complex ethico legal issues (including support to alleviate fears of legal reprisal(s) in failing to continue clinical intervention) was acknowledged.

*“Part of it is just keeping abreast of the law, 'cause there are changes in legislation and stuff that we don't necessarily know about, but certainly, there have been individual cases in which I have phoned for a bit of advice.” Interviewee 04*

*“Another reason I think we should have ethics (committees / support) is I think people do a lot of things that are unethical because they think that they’re illegal not to. So we have a lot of continuing intervention with people because we fear the law can’t sue us or the family sues us for not actually doing something. Some sort of concept if in fact you only can get sued for not doing something versus you can’t be sued for doing something.” Interviewee 11*

The following excerpts also highlight that clinicians recognise a close interface between many of the ethical and legal complexities faced in clinical practice across multiple disciplines.

*“I suspect there will be times when all you’re looking at is an ethical decision and there will be times where you’ll be looking at – all you’re looking at is a legal decision, which may not be where this – but lots of times they’ll be both of those things. So I think you do need – you’ll need that expertise, I think.” Interviewee 06*

*“I would say that a big part of consulting ethics ‘cause of the legal ramifications and so are extremely important – the Jehovah’s Witness who needs to have a blood transfusion, that sort of – 100 different scenarios with different conditions but that sort of dilemma where potential litigation – as I say when people disagree, when families disagree that often leads to a lot of ill feeling and I think the value of having an independent assessment is tremendously important in terms of medico legal outcomes.” Interviewee 12*

*“And then the question, and then this becomes quite difficult and I think a lot of paediatric type ethical dilemmas become a mismatch of child protection issues, legal issues and ethical issue. And in this circumstance the question is, is a 15 year old able to make the decision and not to have therapy, and the ethical problems that if you don’t give him the therapy then potentially he will die of the disease. By law, he’s probably not able to make that decision, but then by the practicalities of trying to make someone have chemotherapy at 15; it’s easier at five or six or seven or eight, much harder when they are 15 or 16...” Interviewee 03*

Specific ethical issues such as the withdrawal and withholding of treatment, end of life decision making, patient autonomy and choice, capacity assessment, quality of life and resource allocation were also identified by interview participants as (potential and actual) triggers for seeking clinical ethics consultation.

*“And I think clearly a lot of doctors don’t have a very good understanding about some of the ethical legal issues, particularly around **withdrawal of treatment**, I think, is probably one of the most difficult areas and is a bit muddled at times.” Interviewee 06*

*“The sort of situation where an ethics group would have been very good...I had a patient...who had severe anorexia nervosa and really the options were to intubate her in ICU and feed her with the risk that it might kill her...versus being on the ward which we didn’t think would work and she’d die. So here we say, how do you make that decision? Her partner was a druggie and her mother was sort of [and] didn’t have much to do with her for many years. So [in] that situation an ethics team would have been very good...” Interviewee 20*

Overall, participants acknowledged that clinical practice is by nature complicated by many ethical dilemmas and they would not necessarily request formal clinical ethics consultation.

*“I guess (in the ED) we’re increasingly being involved in complex family situations...which often involves...ethical questions about responsibility and I guess **capacity to make decisions**...and some of those get reasonably complicated. And we have a cohort of people who frequently present here with those things which I think is probably a little bit easier for us to sort out than some of the complicated ethical questions that I’m not sure that a committee could really help us with that at times. Sometimes there’s various other people that could get involved with that.” Interviewee 23*

Many of the triggers identified by participants mirror those identified by Du Val et al (2001). who reported the most common triggers that led to consultation as: (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 [4].

## Barriers to Seeking Clinical Ethics Consultation

The following table (Table 7.2) summaries the range of reasons why clinicians would not seek a clinical ethics consultation (particularly a service that involved a Committee model).

Table 6.2: Perceived Barriers to Seeking Clinical Ethics Consultation

Summary of Perceived Barriers Identified By Clinicians in Seeking Clinical Ethics Consultation
<ul style="list-style-type: none"><li>• Personal &amp; Professional Reasons</li><li>• Not an issue, too hard or at odds with beliefs</li><li>• Clinician are trained to be autonomous decision makers &amp; not to acknowledge uncertainty</li><li>• Fear(s) of relinquishing their responsibility as the treating clinician</li><li>• Too removed, bureaucratic, legalistic, disciplinary or punitive</li><li>• Difficult to access, time consuming - need for relevance &amp; timely (rapid) response</li></ul>

Some interviewees speculated on why their colleagues might be reluctant to use an ethics support service, some identified time and effort as barriers.

*“I think people like doctors are trained to be autonomous... fear of the unknown perhaps and it’s time consuming.” Interviewee 11*

*“I think the biggest challenge that we have is that we (in the ED) don’t often have a lot of time to delve into the depths and the background and to get to know a patient really well and their family situation and all the other things that go into making complex ethical decisions.” Interviewee 22*

*“I suppose it probably goes without saying but a bureaucratic approach to that. Whether people doing that were essentially seeking a managers approach - not clinicians within the service who would be perceived, whether it’s their personal intention or not would be perceived as perhaps two or three steps removed from the realities of clinical practice.” Interviewee 14*

*“Too Hard I mean, what would be the barrier to that. Well, some people don't see, won't see these things as dilemmas, so therefore it's not an issue for them. Some people have very strongly held religious beliefs that override anything else. Some people recognise it's difficult, but almost find the decision too hard to make and therefore don't. But it's one of these sort of things that you can't change people's thinking about it unless you sort of continually put it in their face.” Interviewee 04*

Others saw that consultations could be used politically.

*“I think as a treating clinician you do take on the responsibility fairly seriously. But I think if it was used as a – not as a way of seeking assistance, but more to try and use the committee more to enforce one view over another, I think that would have to be thought about.... “I suppose if it became a necessary part so that, for instance, how would I feel if I’m looking after a patient but then the nursing staff [or] nursing*

*manager suggested 'I don't agree with what you're doing and I want this referred to the ethics committee'. If there's a committee available it could be used perhaps in that way where – **would that be palatable to me? No.**" Interviewee 12*

*"Although the way the system works it's usually one clinician who is in control. So if a physician thought a surgeon should operate and a surgeon said no, I don't think I should operate or I'm not going to operate because of the patient has carcinoma of the prostate **and limited life expectancy** and something like that. Yes, and then the next step is some difference between the members of the same team. So nursing staff or allied health or the treating doctors or, yeah. I mean, **not to use the committee in a disciplinary role**, to be advisory rather than resolving professional differences"*  
Interviewee 14

Barriers identified by interview participants included perceptions by clinicians that clinical ethics consultation (particularly a Committee model) could be too removed, disciplinary or punitive, bureaucratic or managerially influenced. Personal cognitive concerns, time pressures, and the fact that clinicians are trained to be autonomous decision makers and the person responsible for decision making also featured as barriers to seeking support. Acknowledging uncertainty and fears of relinquishing their responsibility as the treating clinician, along with the realities of time restraints in demanding clinical areas were also identified as potential barriers.

A number of the barriers identified by interview participants in this study reflect those identified in the literature. As suggested in the literature, reasons for clinicians choosing to utilize or not a clinical ethics consultation service are likely to both personal and professional (McLean 2008). The value placed in shared-decision making (Orlowski 2006) and the willingness to expose one's uncertainty (Sokol 2008) can influence the decision to seek support. Clinicians can find consultations difficult to access, the process time consuming and intimidating and the outcomes unhelpful, they may fear loss of autonomy or fear of retaliation (Du Val et al 2004, Slowther al 2004, Slowther et al 2009, Gaudine et al 2011). Forde reported that barriers included the medical culture's conflict aversion and its anxiety of being judged by outsiders and that committees were perceived as a court by some of the clinician (Forde et al 2008). Other reasons for underutilisation include clinicians not being aware that a clinical ethics support exists and fear that involvement of clinical ethics support will worsen the situation or not receive institutional support (Doyal 2009).

## ***Preferred Attributes and Models of Clinical Ethics Consultation***

Table 6.3 summarises the preferred attributes and models of clinical ethics consultation identified by interview participants.

Table 6.3 Preferred Attributes & Characteristics for Clinical Ethics Consultation

<b>Summary of Attributes &amp; Characteristics and values important for clinical ethics consultation</b>
<ul style="list-style-type: none"> <li>• Facilitator and Advise</li> <li>• Credibility and Trust               <ul style="list-style-type: none"> <li>○ (inc. integrity, fair mindedness, self knowledge, insightful, preference for clinician)</li> </ul> </li> <li>• Communication and Interpersonal Skills               <ul style="list-style-type: none"> <li>○ (to facilitate discussion, reflection and education)</li> </ul> </li> <li>• Knowledge and Experience               <ul style="list-style-type: none"> <li>○ (An understanding and up-to-date knowledge of ethical frameworks and health law)</li> </ul> </li> <li>• Accessible and Timely               <ul style="list-style-type: none"> <li>○ (flexible, approachable, informal, available for rapid response or informal discussion)</li> </ul> </li> <li>• Independent and Impartial               <ul style="list-style-type: none"> <li>○ (non judgmental, “aware of power imbalances” and at “arms length to clinical governance” )</li> </ul> </li> <li>• Routinise Ethical Discussion               <ul style="list-style-type: none"> <li>○ (a “safe” environment for “privileged” discussion &amp; reflection)</li> </ul> </li> <li>• Education Imperative to Advance Knowledge &amp; Understanding               <ul style="list-style-type: none"> <li>○ (mortality and morbidity meetings and case conferences; grand rounds, training and education forums )</li> </ul> </li> <li>• Encourage Reflective Practice               <ul style="list-style-type: none"> <li>○ (including reviews of complex cases and recurrent issues and clinician initiated research/audits)</li> </ul> </li> <li>• Accountability &amp; Reporting mechanisms               <ul style="list-style-type: none"> <li>○ (within the medical record) to ensure a level of “privileged” consultation while being transparent &amp; accountable)</li> </ul> </li> <li>• IT Initiatives to ensure timeliness &amp; accessibility               <ul style="list-style-type: none"> <li>○ (such as anonymous web based queries, blog or FAQ, access to a NSW teleconference Rapid Response Panel)</li> </ul> </li> </ul>

### **Clinical Ethics Facilitation**

Facilitation was identified by the majority of interview participants as a pivotal role of a viable clinical ethics consultation service. Participants consistently identified that, whether speaking as individuals or as members of (multidisciplinary) clinical teams, a clinical ethics support service (whether as an individual consultant, panel or group, or committee) would be worthwhile if it focused on facilitating open discussion and reflection, acting in an advisory capacity as opposed to mediator, arbiter or expert decision maker.

*“I would say a **facilitator rather an arbiter**, because I think the risk is that there’s a lot for teams to gain from struggling through something and reaching an outcome. And to see it as arbitration, I think, assumes that they’re stuck and all efforts to resolve that have failed. And I think if we’d reached a point where all our efforts had not achieved any clarification or – that would be further down the track, I think, if you see what I mean. I think if you do that too early, it prevents people from problem solving as a team.” Interviewee 14*

*“I think it’s very much an **advisory role** to facilitate making decisions. I mean, I guess I see it as being two main components.... One is having them talk to us periodically about changes in legislation, which we often are not abreast of, and the other issue is being available to discuss individual cases and very, very occasionally actually to become directly involved in them. It’s more advisory, I would have thought, than anything else.” Interviewee 04*

*“How to communicate more effectively with families and patients in distress...and I suppose I think that a facilitator that helped with those tasks that people are struggling with, rather than arbitration, would be more appropriate.” Interviewee 14*

### **Independent & Impartial Relationship**

Many interview participants recognized the challenge in striking a balance between ensuring a viable and sustainable clinical ethics consultation service that is supported, recognized and legitimized by the institution while working independently and at arm’s length from institutional clinical governance.

*“Realistically, you should keep them (clinical governance) completely as far apart as you possibly can. Yeah. I mean, one can certainly see that they do legitimately overlap, but I think historically, the role of governance and its practice would undermine the way a really effective ethics consulting process would work, if they were seen to be too closely associated.” Interviewee 04*

*“That’s how things work well. So if you want to put the resources into something, then things stay connected to each other. You can’t do things in isolation or they’ll just fall over. So clinicians may not see the logic of it, but if you want to be able to drive a process, you have to drive it from a number of levels, including from the top.” Interviewee 11*

Some interview participants identified that reporting a clinical ethics consultation, within the medical record would provide accountability to the organisation while respecting the discussion as privileged and confidential discussion within the clinical setting. A few interview participants also acknowledged the clinical and educational value in providing a note in the medical record, indicating that a clinical ethics consultation (informal or formal) had occurred would be helpful to the clinical team and management.

*“I would think the outcomes of it should be in the patient’s notes, because if its’ going to be a useful meeting, it will help inform management and plans for the patient, and help everybody be working from the same page. If (clinical ethics support) it’s too remote, then people won’t know necessarily what the outcomes were, if you work*

*from shift to shift. Or it could be seen as a discussion that's happened up on top of the mountain."* Interviewee 14

*"Now I think there's a case for a recording of the fact that the person has brought that problem to attention and sought assistance and something has come of it. What the details of that are, probably shouldn't be routinely reported to a third party, but, what could be reported to a third party is yes, this situation has occurred. So basically saying, the clinical ethics confirms that this clinician has brought a particular problem to our attention on this date, and that's been dealt with."* Interviewee 05

*"Perhaps the reporting would simply be what the outcomes were of the discussion and the decisions that were made, rather than the issues that were aired. At the end of the year, perhaps a general report on the nature of the problems that have been dealt with, or the nature of problems have been brought to attention, that certainly could be an issue. But I don't think there's a case for any more routine reporting than that."* Interviewee 14

*"It's only if there are extraordinary circumstances that the details would need to come to light. But short of that, it remains privileged information, because that clinician has fulfilled their responsibilities in attempting to do their best for this particular patient, or this particular problem..."* Interviewee 05

*"Maybe if there is a degree of anonymity there that would be more freely entered into."* Interviewee 07

There was a preference for only minimal information to be documented on the specifics of the discussion, respecting the perceived need for individual clinician anonymity and the desire for "privileged" discussion whilst would allowing professional responsibilities to be met in terms of accountability to the institution.

## **Trust & Credibility**

Many interview participants identified that trust and credibility are two important attributes for a viable clinical ethics support service.

*"Trust and credibility are two issues, I think. Trust is very important because I suppose...people need to feel that they can talk about their concerns without feeling that they're going to get into trouble or they're going to be criticised or that...the problem or concerns are going to be taken elsewhere."* Interviewee 14

*"Well I think what makes it attractive, so they do need to have a trusted clinician, that they know, that's involved. Not necessarily that it's that person who then provides the advice, or actually does the consultation, but I do think there needs to be a lead that everybody knows this is our - this is where we go to with these sort of issues. We trust this person."* Interviewee 02

Many interviewees would prefer to consult an experienced, respected and familiar *clinician – a partner, part of the organisation, part of the struggle...*



*“Well, I think they, in order to manage a clinical team, need to respect the role of all the different team players. That’s important. I think they need to be experienced clinicians, senior respected clinicians. I think they obviously need to approach it like any sort of facilitation, with an open mind about what some of the issues might be. And I think they need to be a partner – well I support it goes without saying, in a big sense, part of the organisation, part of the struggle they’re placed with, trying to sort this out”. Interviewee 14*

*“It doesn’t have to be a doctor, but – but a health practitioner with – with good clinical experience, and the educational background, who’s senior enough and respected enough for people to sort of at least listen to their opinions, because we’ve got some very senior experienced clinicians in the area.” Interviewee 21*

*“I mean, part of the readiness to consult people is that you know them and encounter them in various different ways.” Interviewee 04*

*“To have a rapport and understanding and for the person to know you and to be – have had that contact in the past and to – it’s certainly much more comfortable dealing with someone that you know, for instance, compared with dealing with guardianship where you never meet the people although you might talk to them on the phone on numerous occasions where it’s just not the same connection I think.” Interviewee 12*

For some interviewees it was important that clinical ethics support was provided by a fellow clinician.

*“They need to be a clinician themselves, an experienced clinician. I think if you are having one ethics consultant to the hospital, I know I personally would prefer it to be somebody who was a medical professional. And medical could be seen as a bit broad, but they would have to have patient – patient experience.” Interviewee 21*

Accessibility and rapport were seen as important characteristics and may be directly linked to clinician preferences for support from those with clinical experience and understanding.

*“Well I think **accessibility and timeliness**, they’re two very important functions, because...some of the issues really need to be dealt with very quickly and if they’re not, the clinicians will just lose faith and go back to whatever they were depending on in the past.” Interviewee 02*

*“So they have to be **approachable**, they have to be experienced. They have to be up to date, they have to - I mean, I think coming along to educational meetings and things so that they’re - we continually interact with them clinically and --- And so I think somebody who has potentially been in a similar situation and can understand what it might be like is a bit more beneficial.” Interviewee 04*

Knowledge and experience in clinical ethics were considered important attributes. Having an extensive understanding and up to date applied knowledge of clinical ethics and health law (including changes in legislation) was also considered important.

*“Well, I think – I suspect there will be times when all you’re looking at is an ethical decision and there will be times where you’ll be looking at – all you’re looking at is a legal decision....– but lots of times they’ll be both of those things. So I think you do need that expertise.” Interviewee 06*

*“I guess they do need to be conversant with ethical frameworks; or at least if you had a panel, someone who was familiar with those – very familiar with ethical discussions and ethical principles, but not necessarily come in with an ethical rule book.” Interviewee 12*

*“ I suppose, they have to have the time, because they have to be used to dealing with – good with dealing with groups, not upset by conflict, they’d have to obviously have a good grounding in ethics... I think working in the area is probably more important than anything and I don’t even know that you have to have-necessarily qualifications in ethics or specific training, or I suppose if it’s going to get you to a point where you can do that sort of work faster.... just working on so much that they’re very expert” Interviewee 20*

Communication and interpersonal skills were also seen as important, with many interviewees suggesting that it was important for provider(s) of clinical ethics support to have a combination of attributes and skills.

*“Well, so apart from good communicator and knowledgeable, really good interpersonal skills, because when they come in, they’re dealing with some distressed staff. They’re very complex decisions. And – and sometimes family, depending on what the – which – what their role was. And so they need to be able to actually take on that angst and – and help to – to sort of settle things down, keep things clear. So it’s sort of an ability to – they have to be good problem solvers.” Interviewee 21*

*“So I think you clearly need someone with the right sort of personality traits and conversation style and someone who was I think had the right approach to that. I think they need some (probably) training or experience in ethics. I think to me that would be important. I think to have some credibility to it, and I don’t think they necessarily need to have any particular clinical experience or come from a particular clinical background. I think having an understanding of ethics would be more important and their style and personality and the way they approached it would be more important. But certainly they have to have a willingness to get involved and talk to all the parties and collate all that which some people are quite good at just getting into difficult situations and communicating and drawing out people’s concerns and listening and being supportive.” Interviewee 22*

Overall, interview participants identified that in order to be credible and to be utilised, clinical ethics consultation services must provide an advisory service (as opposed to providing arbitration, mediation or acting as the decision maker). As an advisor or facilitator, the pivotal role of a viable clinical ethics consultation service is to assist clinicians (as individuals or often as member(s) of a clinical team) to openly communicate and navigate through the complexity of the situation to a point of moral acceptance or consensus in what is the best interests of the patient.

## A Safe Space

Facilitating a “safe” space for open communication and “privileged” discussion within the clinical setting was seen by a number of interview participants as a key responsibility of a support service, particularly in ‘time critical’ areas such as an emergency department.

*“A **space** for people to reflect and think. And in the hurly-burly of clinical practice, sometimes that isn’t there, particularly when you have patients whose care involves multiple clinical teams, it’s sometimes unclear who has the final responsibility for a patient, or who’s the decision maker. It’s very hard to get people together and say, “Okay, can we just think about this case for a while and just maybe get a second opinion on a clinical matter? Or to think about – think about it in such a way that we can get an agreed way forward.” It might even be identifying our areas of disagreement that we need assistance with. But I think that space and opportunity for reflection is one of the most critical things.” Interviewee 14*

## Education and Knowledge

Facilitating reflective practice, including retrospective reviews of complex cases and discussion recurrent issues (e.g. dealing with advance directives) were identified by those in emergency medicine as the most beneficial role of clinical ethics support rather than case consultation at the actual time of dealing with a complex case.

*“So I think it would – so from my perspective a useful thing for a clinical ethics group would be to say, okay the last 20 patients that came into the ED with advanced care directives, let’s just pull all their notes and see what happened and review it and see how we would - - - “Yeah, and reflect on it and maybe then that will help to refine the process. Yeah, I think so. I think that’s – and then having a clinical ethics person involved with that would be a really useful kind of thing. So it’s – that’s not an individual case but like a cumulative – and it might be the same with the adolescent...” Interviewee 19*

*“I suppose a lot of our issues in the ED...because they happen seven days a week, 24 hours a day, I think what would be helpful from a clinical ethics service is not...those scenarios [but for] the really complex ones it’s good to be able to access them for the individual case...the tools and the communication and the training and the ability to reflect on the cases with a group and go through the case and have a clinical ethics expert involved with the review...so from an ED perspective, I think they’re probably more likely – they’re going to be retrospective based.” Interviewee 17*

Placing an emphasis on clinical ethics educational activities to assist clinicians in handling ethical dilemmas on their own was recognised by a number of interview participants.

*“One thing - I think it’s very useful to have a clinical ethics service that actually provides education so that we don’t have to reinvent the wheel or be in the situation yourself, so I think there should be some sort of discussion or education so you actually know what you’re looking at so to speak and you think about an issue much more broadly and all the ethical complications of it.” Interviewee 11*

*“I mean, I think the person could be potentially very busy simply just educating people. I mean, there’s a constant flow of new people coming through, just in the educational process, quite apart from the consultative process.” Interviewee 04*

Encouraging regular, open discussions of ethically complex issues was identified as an important way of assisting clinicians, particularly junior medical staff to “normalising” responses to ethically complex issues, including formulating departmental strategies and guidelines.

*“I think that if there were people who were developing this conversation about clinical ethics with people right from the time that they enter the institution... that ties in with the sorts of regular discussions of ethical issues mediated, or chaired, or what have you, by someone with a clinical ethics background.” Interviewee 14*

*“And if that were a routine, that at some stage of each month or each six months, or each year, there is going to be a discussion about clinical ethics, then that normalises the whole issue, brings it out into the public arena and stops people who were interns or residents from thinking well, this is a terrible situation, I don’t know what to do, and everybody else seems so competent, I can’t really talk to them about it. But I can see that, you know, after a year or two you would have basically formulated your departmental default strategy and perhaps have some written guidelines behind it.” Interviewee 12*

A number of interview participants suggested that in encouraging multidisciplinary small groups at a local level to facilitate clinical ethics discussion and reflection of different perspectives.

*“I think in the real world you’d want a support group that actually has different viewpoints.” Interviewee 11*

*“I think there may be individual cases that came up that would be well served by discussing at a broader forum, so this was the issue, this was the ethical dilemma, this was the advice. Have people experienced similar situations...” Interviewee 12*

*“Well I think the morbidity and mortality meetings, they’re mandated, and at the moment, they’re almost always focused on clinical problems, and I don’t see why they shouldn’t be focused on clinical ethical problems as well.” Interviewee 05*

*“We have mortality morbidity meetings where we go through all the deaths in the last quarter of kids at this Hospital, to have a representative from a clinical ethics committee at those meetings to just tease out some of the ethical issues that are at play or were never really identified but just to say look, here’s a situation where there’s a potential conundrum here would be very useful. So having a presence within the staff development quality assurance field as well, not just at the patient delivery level, would be very helpful.” Interviewee 01*

For some interviewees, mortality and morbidity meetings are not considered to be an appropriate forum for discussing the ethics of case.

*“I think it has to be a completely separate thing because M&M meetings, I don’t know, maybe other people have different experiences, but they’re just a joke. I think that’s really sad. I mean to think that for goodness sakes, if someone dies or has a serious problem, we should at least pay a bit of respect and be honest about it and that doesn’t happen in my experience.” Interviewee 10*

### **Interface with existing “liaison” consultation support**

A few interviewees suggested that in developing clinical ethics support, it may be worth considering the similarities of clinical ethics consultation and the “liaison” consultative work provided by specialist disciplines such as Palliative Care and Psychiatry.

*“Obviously there’s a huge interface about end of life decision making between clinical ethics and palliative care. So it’s a – they’re sort of natural bedfellows in a way and I’ve developed an interest in clinical ethics as a result of the exposure that I have had to both paediatric and adult cases that have been – had particularly tricky ethical issues.” Interviewee 01*

*“See the interesting thing of course, is liaison psychiatry often almost offers that (clinical ethics) service in a way, because we go through at the whole hospital and we’re dealing with really difficult decision making.” Interviewee 21*

*“Given the nature of the sort of psychiatry work in a general hospital; we’re often working around cases where there are all sorts of complex clinical issues to deal with. And some of those are where it’s felt as if we really needed additional clinical opinion or some guidance around complex legal or ethical matters that might arise during the course of these patients’, a family’s involvement.” Interviewee 14*

A few interview participants highlighted the unique nature of ethico-legal dilemmas faced by clinicians in delivering optimal care to paediatric and adolescent patients. These interviewees also recommended the need for cohesion in facilitating support and that the distinction between providing support for paediatric/adolescent and adult would be an important consideration in developing clinic ethics support services.

*“So, yes there are ethical considerations, but in paediatrics there are frequent child protection issues or legal issues and I think if they are not represented on any committee (or other support) you design, you’re going to have to go to various places to actually get the answers, and even then I’m not entirely sure we got the answers to be honest. In the end it worked out okay, but I just, I guess, I felt as a clinician, not so much let down, but as I said, I felt let down because there really was no cohesion in coming up with the decision, really.” Interviewee 03*

*“We’ve got child protection paediatricians and things so when there is complex things about that, they can often help guide some stuff there. And they’re probably more-closer to legal than ethical questions. Although I think they’re probably ethical but mostly what’s been answered is a legal question about can this person agree or consent to something like this which I think is ethical. But the way the system works would make it a legal question.” Interviewee 22*

## Preferred Models

Table 6.4: Preferred Models of Clinical Ethics Consultation

Summary of Preferred Models & Relationships identified by clinicians as important for Clinical Ethics Consultation
<ul style="list-style-type: none"><li>• Multidisciplinary group, panel or committee.</li><li>• Individual clinical ethics consultant(s) supported by a panel or committee.</li><li>• State-wide pool of clinical ethicists or those with knowledge and experience</li><li>• Rapid Response Team (via teleconferencing)</li><li>• A bank of people skilled in thinking about clinical ethics problems</li><li>• Local expertise/champions within departments</li><li>• Engaging existing similar consulting services (e.g. palliative care, psychiatry)</li><li>• Build on academic affiliations to strengthen clinical ethics education and training for clinicians</li><li>• Relationship to Community -Regional Support</li></ul>

A number of interview participants identified their preference for an advisory panel or a multidisciplinary group of (clinically experienced) trusted local champions to ensure independent, accessible, credible, flexible and timely (often informal) advice.

*"I guess I'd have two or three people who are the clinical ethicists working - serving the whole area health service, people who are available by phone who, you know, frequently give seminars, lectures and tutorials who come to the M&M meetings, who occasionally come to sort of departmental meetings and who sort of really are available for issues, but kind of go around fertilising the ground - person at the time, which is really what it takes, I think, they're constantly feeding into the system so you change people's mind-set and sort of, by stealth almost, get them to think in different ways. I think that's the most effective way by miles." Interviewee 04*

*"I think having a person or maybe people who are experienced clinicians who have training, or interest in training in these areas, i.e. – well to me, it would be much preferable to putting this case to, yeah, some sort of ethics committee." Interviewee 13*

*"I become a little bit uneasy when people start talking about committees because then it becomes a little less flexible in terms of the committees tend to meet at certain times because there are different members involved and they're only able to get together at certain times. But I would see the role of the committee perhaps being there to provide support to an individual or to provide a framework for there being a number of individuals that you could contact. So if the individual consultant was not available because he was on leave or away at a conference or whatever, there would be someone else who was familiar with and part of the clinical ethics team – would be helpful. Also there may be some issues that need to be referred to a wider group." Interviewee 12*

*“So there would be some advantages in having such a committee and there would be elective issues, patients that don’t require urgent advice, maybe outpatient issues or there may be the clinician attached to the ethics committee would like a wider discussion or there are certain patients or relatives who I would anticipate would be more satisfied with a more formal process of ethical review. So that’s a rather long-winded way of saying I think you need both. I think you could work on a day to day basis contacting a single person but having a more formal committee there will be situations where that would be very helpful.” Interviewee 14*

A hybrid approach where local champions are supported by a core panel (perhaps reflecting the Hub & Spokes model) was also suggested

*“That’s a bit of a part-time job for them. Yes, I can certainly see that. You could have your, you know, your ethics specialist within your own department. Yes, yes, I can certainly see that. I mean, I think **there’s actually huge benefit though in having people that cross departments**, because I think it’s very easy to be quite narrow, you know, and get pigeon-holed.” Interviewee 04*

Some interview participants suggested that smaller groups could supplement a clinical ethics consultation structure via a state-wide panel or a bank of people skilled in thinking about clinical ethics problems. This model could potentially offer the flexibility of timely rapid consultations via teleconferencing if requested along with the opportunity for reporting back to a multidisciplinary panel or committee.

*“It depends on which level of the organisation you provide it at, **but if it’s state wide for example, and if you’ve got a pool of clinical ethicists who, on a roster, respond to queries**. Hopefully that wouldn’t be too onerous, but it would assist in, what I think is the biggest problem, which is actually getting over that hurdle of actually talking to someone about it, rather than just stewing on the problem. And so, **I would think a structure which was much more flexible than the average committee or board, would be the most useful**. In fact, I think it’s the only thing that would be usable. **I don’t think that there would be very much use for the sort of standard committee structure.**” Interviewee 12*

*“Yeah, I think you need a **rapid response team** that doesn’t necessarily have to be based in the hospital that you need that response from, because you know how many hospitals there are in New South Wales. I think you need people with knowledge rather than with a title. So that you need the people who can give you the right answers and I think in that circumstance there might not be many people in New South Wales who have that information, but if – why have – and I’ll tell you about another case in a minute – I have an ethical, ethical dilemma it would be nice to say, right, can we please get together the ethics and law, New South Wales committee, this is the situation, and you email it to a secretary or a PA, she can just send that to the rest of the group, you need a quorum, however many that is, and then they can, we can have a meeting, a teleconference meeting and we can have a plan soon after.” Interviewee 03*

*“So I guess that requires some sort of bank of people who are skilled in thinking about the clinical ethics problems, but a sufficient variety of them, and I guess that means that we’re going to be talking about either large clinician populations in large centres, rather than small ones. So that when I come up with a problem I can think oh yeah, well this would be a good one to ask X about. This one would be good to ask X about and so on and so forth. So in that very restricted area of I have a clinical ethics problem, what am I going to do with it, how am I going to deal with that, that’s the sort of structure that I would see as being helpful.” Interviewee 05*

A few interview participants acknowledged the value of further developing existing University affiliations to offer accessible clinical ethics education and training programs for clinicians.

*“And I think if the relationship between the district and the university is strengthened...every district should have a relationship with a university because they will have medical students that come to them, et cetera, every medical program has a health or ethics component to it.” Interviewee 02*

*“It’s [ethics] part of the curriculum, so I imagine that, you know, I see a role in the university and the district working together, if the university was willing, and I think it’s in their - it’s in our interests because we’ll obviously have experts in the area who are involved, it’s in their interests, because they are kept up to date with the types of issues that their graduates will face once they graduate and are working, and they’ve got real life examples to discuss, and case studies to discuss and they are educating their students. So I see it as a win-win really.” Interviewee 02*

A number of interview participants discussed the potential of exploring the contribution IT initiatives (including web-based discussion forum and tele-health conferencing) to supplement a clinical ethics consultation service.

*“...- we’ve got an intranet; we’ve got the capacity to set up a website for clinical ethics. So right from the start, you could have a situation where an intern says, “I’ve got this problem, I don’t know what to do and where to go.” If they were able to go to that website and write in the problem anonymously and say, “This is the problem I’m confronted with, can you help me?” Now that could be done anonymously to begin with; over a period of time it might evolve into a personal contract to try to sort out their problem, but it would be another way of providing support and assistance in that area for people who are really confronting some of the most difficult years of their professional careers.” Interviewee 12*

*“There are desktop tele-health, teleconference facilities that can be bought for three or four thousand dollars, every hospital in New South Wales has access, every hospital is linked via a tele-health network, so costs are not a big issue...if you had a committee of five or six, seven or eight,...for under \$50000 you can provide them with a tele-health desktop conferencing system and the person who may be at various hospitals can easily find a room like we have here that could then access that very easily.” Interviewee 03*



## 6.4 Discussion

Acknowledging the limited number of clinician participants interviewed, this study provides a snapshot of clinician views across a multidisciplinary sample of specialist areas at a tertiary referral teaching hospital in NSW. Many of the findings from our interview data mirrored those presented in the literature.

**Triggers** (potential and actual) in seeking clinical ethics support included the desire to resolve conflict, navigate through uncertainties about the right thing to do and to seek reassurance and (partial) consensus or at least moral acceptance in dealing with complex decisions (at the time or upon reflection). Ethico-legal concerns, including clarification of current legislative requirements and fears of legal reprisal(s) following complex clinical decisions, were identified by many participants as important triggers. The value in seeking clinical ethics support was often discussed as complementing the support provided by peers and experienced colleagues.

**Barriers** (potential and actual) identified by interview participants included perceptions by clinicians that clinical ethics consultation (particularly a Committee model) could be too removed, disciplinary /punitive, bureaucratic or managerially influenced. Personal cognitive concerns, time pressures, and the fact that clinicians are trained to be autonomous decision makers and fears of relinquishing their responsibility as the treating clinician were also identified as potential barriers.

**Attributes and preferences** of a viable clinical ethics support service that would be palatable to clinicians that were identified by interview participants were similar to those identified in recent other overseas studies (Larcher 2010; Whitehead 2009; Dauwerse 2011). A number of the characteristics identified by clinicians as important attributes of clinical ethics support could apply to different models of support (i.e. individual consultants, members of a clinical ethics advisory panel or committees).

Facilitation was identified as a pivotal role of clinical ethics support. Interview participants consistently identified that, whether speaking as individuals or as members of multidisciplinary clinical teams, a clinical ethics support service would be worthwhile if it focused on facilitating open discussion and reflection, acting in an advisory capacity in dealing with complex cases (prospectively and retrospectively). Facilitating clinician education and the acquisition of applied knowledge via clinical ethics training programs was acknowledged as important and achievable via developing existing University affiliations.

Additionally, to develop accessible clinical ethics consultation within NSW public hospitals there may be value in introducing a web based or teleconference forum to supplement onsite clinical ethics consultation services. Overseas experience with online forums suggests that an advantage of electronic communication is that it offers flexibility, ensures equal access to all clinicians and enables members to participate in discussion irrespective of time & place (Louhiala et al 2012). Electronic communication forums also allow experienced and high profile clinicians from around the state/country to function as members (given that face to face meetings on a regular basis are often impracticable).

Overall, the interview participants in this study saw the value of clinical ethics support in encouraging ethical discussion and reflective practice (implicit or explicit), particularly in relation to complex cases. Accepting that clinicians deal with ethical issues all the time within their daily practice, *as part of the fabric*, viable clinical ethics support services could play a vital role in routinising or normalising discussions and reflection about clinical ethics.

## 6.5 Conclusion

Facilitating education and applied knowledge of clinical ethics has been identified by interview participants in this study and elsewhere as one of the most significant contributions clinical ethics consultation can offer clinicians. Placing an emphasis on educational activities to assist clinicians in handling ethically complex cases on their own and improving the accessibility and responsiveness of ethics consultation when needed. Findings from this study suggest that consideration could be given to a number of initiatives that may support sustainable education and training programs for clinicians to engage in clinical ethics and reflective practice:

- Strengthening existing University affiliations.
- IT initiatives could be provided via the **Clinical Ethics Online Resource** launched earlier this year as part of this project.
- Program(s) to conduct clinician initiated audit activities and research studies. [Examples provided by interview participants included: Clinical Audits of Advance Directives and Advanced Care Plans in the ED; The Role of Mortality and Morbidity Meetings in providing the Space for Reflection of Clinical Ethics Issues & Education].
- Adapting components of the **Hub & Spokes Model, building capacity** through established and sustainable relationships between university and affiliated teaching hospital(s) (MacRae, 2005). As discussed elsewhere in this Report the model suggests that in order to build ethics capacity and sustain a demanding range of responsibilities clinical ethics consultation services an acceptable level of integration, sustainability, and accountability within a complex organisational structure.

# Appendix 1

ID Number (office use only)					



VELiM Centre for Values, Ethics & the Law in Medicine, University of Sydney

## Clinical Ethics – A brief survey of your experiences and opinions

Clinical Ethics refers to the ethical aspects of what clinicians “ought to do” in day to day clinical decision making and practice. Ethics is present in all aspects of patient care and ethical concerns can arise in both particular cases and over more general issues. We are interested in finding out:

- What clinicians in NSW hospitals identify as ethical concerns
- How clinicians respond to and deal with these ethical concerns
- How clinicians view the support available to them in addressing these concerns and what support do they consider would be helpful

The survey should take approximately 10 minutes to complete

*Your answers are confidential. Information from the survey is aggregated and shall not be reported, presented or published in any way that would permit identification of any individual. The project has been approved by the [redacted].*

A1	How often do you face a clinical situation where...	Often	Occasionally	Rarely	Never
	you will think about the ethical implications of your clinical decisions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	you are uncertain or concerned about what is ethically the right thing to do	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	you are uncertain or concerned about the ethics of the decisions and actions of others	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

A2	How often do you face a clinical situation where...	Often	Occasionally	Rarely	Never
	you will think about the legal implications of your clinical decisions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	you are uncertain or concerned about what is legally the right thing to do?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	you are uncertain or concerned whether what others are doing is legally right?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

A3	In the last 12 months did you experience uncertainty or concern related to the following situations	Yes Ethically	Yes Legally	Both	Neither	Not relevant to me
	A patient refusing recommended treatment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	A patient requesting treatment outside of hospital guidelines	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	A patient requesting treatment of borderline necessity or benefit	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	The handling of a medical error or incident	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	A family request to withhold information from a patient	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	A patient request to withhold information from his/her family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Staff withholding information from a patient and/or family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Ordering/participating in aggressive treatment of terminally ill patient	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Disagreement among staff about care or treatment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Carrying out an Advanced Directive	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Carrying out a Do Not Resuscitate order	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Making the decision to withdraw or withhold treatment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	A request for late termination of pregnancy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Other ( <i>please describe</i> )	<input type="checkbox"/>	<input type="checkbox"/>			
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A4	Are there one or two particular aspects of patient care in your area of clinical practice that you think raise ethical issues?

A5	How often would your ethical concern or uncertainty be about...	Often	Occasionally	Rarely	Never
	the treatments and care being given and whether this is what the patient really wants	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	the information that is being given to a patient and how it's being given	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	the treatments given and whether this is too aggressive for a particular patient	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	patient preferences and whether choice is being respected	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	personal values of other clinical staff inappropriately influencing patient care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	the appropriateness and quality of care generally	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	being restricted by hospital rules or guidelines in providing the care or treatment you believe a patient needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	being restricted by resources in providing the care or treatment you believe a patient needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Other reason ( <i>please describe</i> )	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

A6	What would you do if you were uncertain or concerned about the ethical implications of a clinical situation ( <i>Please identify as many responses as fit</i> )
<input type="checkbox"/>	Ask for the opinions of colleagues
<input type="checkbox"/>	Discuss with partner or close friend
<input type="checkbox"/>	Consult and follow relevant guidelines or protocol
<input type="checkbox"/>	Raise the issue at handover or ward meeting or other group forum
<input type="checkbox"/>	Meet with the patient/family and allow them decide
<input type="checkbox"/>	Consult with a Clinical Ethics Committee or other source of ethics expertise
<input type="checkbox"/>	Other – <i>please describe</i>

A7	How often is what you usually do <i>not</i> helpful in addressing your uncertainty or concern?
	Often <input type="checkbox"/> Occasionally <input type="checkbox"/> Rarely <input type="checkbox"/> Never <input type="checkbox"/>

A8	What would you do if you were uncertain or concerned about the legal implications of a clinical situation ( <i>Please identify as many responses as fit.</i> )
<input type="checkbox"/>	Talk to those involved
<input type="checkbox"/>	Raise the issue with a higher authority
<input type="checkbox"/>	Seek informal legal opinion (e.g. from professional association)
<input type="checkbox"/>	Raise the issue at handover, ward meeting or other forum
<input type="checkbox"/>	Other – <i>please describe</i>

A9	How often would the ethical aspects of your area of clinical practice be discussed among the team?
	Always <input type="checkbox"/> Often <input type="checkbox"/> Occasionally <input type="checkbox"/> Rarely <input type="checkbox"/>

A10	What is the focus of ethical discussion?
<input type="checkbox"/>	The issues in a particular current case
<input type="checkbox"/>	More general ethical issues
<input type="checkbox"/>	Other ( <i>please describe</i> )

A11	Please indicate your view on the following statements about your <i>hospital</i>			
<b>Statement</b>	<b>Strongly Agree</b>	<b>Agree</b>	<b>Disagree</b>	<b>Strongly Disagree</b>
The policies and procedures of this hospital are generally ethically appropriate	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The interests of this hospital are rarely put before the interests of the patient	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Patients at this hospital are generally treated equally	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The values upheld at this hospital mostly reflect my professional values	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The values upheld at this hospital mostly reflect my personal values	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My conscience is rarely troubled by the care patients receive at this hospital	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The values upheld at this hospital mostly reflect values of the community	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
This hospital is too ready to accede to external political demands	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

A12	If you could improve how care is delivered at your hospital where would you start?	
Is this also an issue of ethics?		Yes <input type="checkbox"/> No <input type="checkbox"/>

A13	Please indicate your view on the following statements about your <i>department</i>			
<b>Statement</b>	<b>Strongly Agree</b>	<b>Agree</b>	<b>Disagree</b>	<b>Strongly Disagree</b>
When an ethical issue arises it will be openly discussed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
If I am concerned that a patient's best interest isn't being met I am able to air my view	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Ethical issues are usually handled appropriately	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Ethical issues are often overlooked	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
We talk about ethics as much as is necessary	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
We could handle ethics issues better than we currently do	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
If an ethical issues arises all staff are able to voice their view	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
There should be more discussion of the ethical aspects of our clinical practices	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

A14	If you could improve ethics <i>within your department</i> where would you start?

A15	How would this suggestion improve ethics <i>within your department</i> ?

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<b>B</b>	Support for dealing with ethically complex or challenging situations
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B1	Do you believe that clinicians are usually comfortable in handling the more common clinical situations involving substantial ethical issues?		
	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Don't Know

B2	Are there some ethically complex or challenging situations where more support might be helpful?		
	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Don't Know

B3	If Yes to B2 what do think might be helpful? <i>(Choose as many as appropriate)</i>		
<input type="checkbox"/>	Having an advisory group (made of clinicians, lawyers, ethicists, patient representative)		
<input type="checkbox"/>	Having an individual ethics and/or legal expert available for advice		
<input type="checkbox"/>	Having regular educational seminars on ethics and law		
<input type="checkbox"/>	Having a member(s) of the clinical team trained in ethics who can provide ethical advice when needed		
<input type="checkbox"/>	Having an internet based resource (storing relevant literature, case studies, policies etc.)		
<input type="checkbox"/>	More 'in-service' training or education on the ethics and law of patient care		
<input type="checkbox"/>	Having ethical/legal issues as a routine element of grand rounds or morbidity and mortality meetings		
<input type="checkbox"/>	Having protocols/guidelines in place that outline appropriate responses to ethical/legal issues		
<input type="checkbox"/>	Other <i>(please briefly describe)</i>		

B4	What formal support for dealing with ethically complex situations is available at this hospital? <i>(Choose as many as appropriate)</i>		
<input type="checkbox"/>	Clinical Ethics Committee or Advisory Group	<input type="checkbox"/>	Chaplain/Pastoral Care
<input type="checkbox"/>	Clinical Ethics Consultant	<input type="checkbox"/>	Hospital Social Workers
<input type="checkbox"/>	Clinical Governance	<input type="checkbox"/>	Don't know
<input type="checkbox"/>	Policy/Guidelines	<input type="checkbox"/>	Other – <i>please describe</i>
<input type="checkbox"/>	Human Research Ethics Committee		

B5	If you have used one or more of the services listed below please indicate how helpful it was <i>(tick one box for each item)</i> 1 = Very helpful, 2 = Helpful, 3 = Neutral, 4 = Detrimental, 5 = Made things worse					
		<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
	Clinical Ethics Committee or Advisory Group	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Clinical Ethics Consultant	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Clinical Governance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Policy/Guidelines	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Human Research Ethics Committee	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Chaplain/Pastoral Care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Hospital Social Workers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Other <i>(as described in B4)</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

<b>C</b>	Professional Demographics
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Your Age	_____ years				
Your Gender	<input type="checkbox"/> Male	<input type="checkbox"/> Female			
Occupation	<input type="checkbox"/> Medical Staff	<input type="checkbox"/> VMO	<input type="checkbox"/> Nursing/Mid-wife	<input type="checkbox"/> Allied Health	<input type="checkbox"/> Other
Main area of employment (e.g. oncology, midwifery)					
Years since professional qualification	_____ years				

**Thank you for your time in completing this questionnaire.**

If you are willing to be contacted by the research team to talk more about ethics, please provide your email address in the box below. Alternatively email either: Evan Doran - [evan.doran@sydney.edu.au](mailto:evan.doran@sydney.edu.au) or Jenn Fleming [jennifer.fleming@sydney.edu.au](mailto:jennifer.fleming@sydney.edu.au), Centre for Values Ethics & the Law in Medicine, University of Sydney

Email address	
Preferred contact details	

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