Evaluation of clinical ethics support needs and service provision at a tertiary hospital in New Zealand

Libby Dai

A thesis submitted for the degree of Bachelor of Medical Science (Honours) at the University of Otago, Wellington, New Zealand

April 2013
Preliminaries
Abstract
Doctors often face ethical challenges in the course of clinical practice. Clinical ethics advisory services (CESS) provide a mechanism for supporting doctors facing these ethical dilemmas. In New Zealand, CESSs are relatively new and have emerged as a clinician-led initiative. This is an exciting time for CESSs in New Zealand, as their availability increases and their systems become increasingly formalised and integrated into the health care system.

This thesis is the first in New Zealand to explore the clinical ethics needs of doctors and to evaluate how their clinical ethics needs could be most effectively met. The Capital and Coast District Health Board (CCDHB), comprising a major tertiary hospital and its satellite hospital, is used as a case study. Doctors at CCDHB have had access to a clinical ethics support service since 2010, when the CCDHB Clinical Ethics Advisory Group (CCDHB CEAG) was established. Many of the findings of the research would be applicable to CESSs throughout New Zealand.

I developed a methodology to understand the clinical ethics needs of senior doctors at CCDHB and to evaluate how their needs could be better met. In-depth, semi-structured interviews were conducted with 14 senior doctors. The data were analysed using an iterative inductive strategy combining conceptual and normative analysis. My analysis draws on the current international literature of clinical ethics support, as well as my experience as a clinical medical student and my period of observation of the CCDHB Clinical Ethics Advisory Group.

This study found that in the absence of formal services, doctors use ad hoc strategies of peer consultation to manage ethical issues. Not all doctors were equally able to access informal support, particularly junior doctors. Many participants were unaware that formal clinical ethics support was available to them and most did not know how formal ethics support worked. Some participants felt that to seek case consultation was to abrogate clinical responsibility and thought that doctors should be able to manage ethical issues themselves. Participants identified a need for improved strategies for clinically relevant ethics education.

This study identifies five key recommendations to enhance clinical ethics support at Capital and Coast District Health Board:

1. CCDHB CEAG should formalise its activities, particularly case consultation, using a procedural justice model.
2. CCDHB CEAG should involve clinicians in the process of case consultation to increase user trust and to take advantage of case consultation’s educative value.
3. CCDHB CEAG should allow patients and their families and advocates the option of being involved in the process of case consultation, to ensure that patients feel that their perspectives have been adequately taken into account.

4. CCDHB CEAG should conduct monitoring and evaluation of its service to ensure that it achieves and maintains clinical relevance and normative robustness.

5. CCDHB CEAG should actively disseminate accurate and appropriate information about its aims and processes to all users and potential users to enhance trust in their service and to clarify misunderstandings about their role.
Acknowledgements

I would like to thank the many people who have helped and supported me in writing this thesis.

Angela Ballantyne, my primary supervisor, has been a tremendous source of support and encouragement. Being able to draw on her wisdom throughout the many challenging learning experiences of this thesis has been invaluable.

I would also like to thank Alastair MacDonald, my secondary supervisor, whose enthusiasm was essential in getting this research project off the ground. His passion for strengthening clinical ethics research and practice in New Zealand has been infectious.

I would like to thank everyone in the Department of Primary Health Care and General Practice at the University of Otago Wellington, for providing such a welcoming and supportive environment in which to learn and conduct research. In particular, I would like to thank Rachel Tester for her technological support and for being such a great office buddy to bounce ideas off; Maria Stubbe for her invaluable insights into research strategies; Sue Pullon, whose guidance and support helped me negotiate the challenges of this year; and Ben Gray, whose door always seemed to be open when I had questions.

I also owe a debt of gratitude to the CCDHB Clinical Ethics Advisory Group, for allowing me to observe and learn from them. Their generosity in providing voluntary ethics support for their peers is admirable and I wish them the best for their service going into the future.

This thesis would not have been possible without the love and support of my family. In particular, I would like to thank my mother for her help at the 11th hour with proofreading this document and her words of encouragement throughout the research process. I would also like to thank my wonderful friends for their fantastic support.
# Table of contents

## Preliminaries

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abstract</td>
<td>iii</td>
</tr>
<tr>
<td>Acknowledgements</td>
<td>v</td>
</tr>
<tr>
<td>Table of contents</td>
<td>vi</td>
</tr>
<tr>
<td>List of tables</td>
<td>ix</td>
</tr>
<tr>
<td>List of figures</td>
<td>x</td>
</tr>
<tr>
<td>List of abbreviations</td>
<td>xi</td>
</tr>
</tbody>
</table>

## Part 1: Context

### Chapter 1: Introduction and background

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.1 Introduction</td>
<td>2</td>
</tr>
<tr>
<td>1.2 Background</td>
<td>4</td>
</tr>
</tbody>
</table>

### Chapter 2: Literature review

| Section                                                         | Page |
|                                                               | 12   |
| 2.1 International literature on doctors’ views on clinical ethics support | 12   |
| 2.2 New Zealand literature on clinical ethics support          | 15   |

## Part 2: Empirical research

### Chapter 3: Methodology

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>3.1 Overview</td>
<td>18</td>
</tr>
<tr>
<td>3.2 Ethics Approval</td>
<td>18</td>
</tr>
<tr>
<td>3.3 Study design</td>
<td>18</td>
</tr>
<tr>
<td>3.4 Interview template development</td>
<td>20</td>
</tr>
<tr>
<td>3.5 Recruitment</td>
<td>20</td>
</tr>
<tr>
<td>3.6 Participants</td>
<td>21</td>
</tr>
</tbody>
</table>
3.7 Data set
3.8 Data Collection
3.9 Analysis

Chapter 4: Empirical research in ethics
4.1 Combining empirical and normative analysis
4.2 Applicability to this research
4.3 Generating an iterative and inductive methodology

Chapter 5: Results
5.1 Outline and notes on the text
5.2 Current ethical practice of participants
5.3 Theoretical issues in the provision of clinical ethics support
5.4 Practical issues in the provision of clinical ethics support
5.5 Conclusion

Part 3: Analysis
Chapter 6: Formal ethics support
6.1 Overview
6.2 Formal vs. ad hoc sources of ethics support
6.3 The need for formal ethics support

Chapter 7: Procedural justice
7.1 What do we mean by justice in clinical ethics?
7.2 Criteria to achieve procedural justice
Chapter 8: Clinical ethics education

8.1 Overview

8.2 Clinical ethics education: contextualising the issue

8.3 Clinician perceptions of ethical training

8.4 Participant assessments of ethical competency

8.5 CESSs as ethics training providers

8.6 A participatory approach to case consultation

Chapter 9: Summary and conclusion

Addenda

References

Appendix 1: Regulation of medical ethics in New Zealand

Appendix 2: Specialities of potential participants

Appendix 3: Interview template

Appendix 4: Participant information sheet

Appendix 5: Extended results
List of tables

Table 1 Specialities of participants 21

Table 2 Specialities of potential participants contacted 75
List of figures

Fig. 1 Grounded moral analysis 25

Fig. 2 Iterative inductive empirical and normative process 27
<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>CEAG</td>
<td>Clinical ethics advisory group</td>
</tr>
<tr>
<td>CESS</td>
<td>Clinical ethics support service</td>
</tr>
<tr>
<td>CCDHB</td>
<td>Capital and Coast District Health Board</td>
</tr>
<tr>
<td>CCDHB CEAG</td>
<td>Capital and Coast District Health Board clinical ethics advisory group</td>
</tr>
<tr>
<td>DHB</td>
<td>District Health Board</td>
</tr>
<tr>
<td>HDC</td>
<td>Health and Disability Commission/Health and Disability Commissioner</td>
</tr>
<tr>
<td>HDCA</td>
<td>Health and Disability Commissioner Act 1994</td>
</tr>
<tr>
<td>HDEC</td>
<td>Health and Disability Ethics Committee</td>
</tr>
<tr>
<td>HIV/AIDS</td>
<td>Human immunodeficiency virus/acquired immunodeficiency syndrome</td>
</tr>
<tr>
<td>HPCAA</td>
<td>Health Practitioners Competence Assurance Act 2003</td>
</tr>
<tr>
<td>HQSC</td>
<td>Health Quality and Safety Commission</td>
</tr>
<tr>
<td>JCB</td>
<td>Joint Center for Bioethics</td>
</tr>
<tr>
<td>MCNZ</td>
<td>Medical Council of New Zealand</td>
</tr>
<tr>
<td>MDT</td>
<td>Multi-disciplinary team</td>
</tr>
<tr>
<td>NZCEN</td>
<td>New Zealand Clinical Ethics Network</td>
</tr>
<tr>
<td>NZMA</td>
<td>New Zealand Medical Association</td>
</tr>
<tr>
<td>UKCEN</td>
<td>United Kingdom Clinical Ethics Network</td>
</tr>
<tr>
<td>WHO</td>
<td>World Health Organisation</td>
</tr>
</tbody>
</table>
Part 1: Context
Chapter 1: Introduction and background

1.1 Introduction

Clinical ethics support has been defined by the Ethox Centre as “the provision of advice and support on ethical issues arising from clinical practice and patient care within a healthcare organisation.” (Slowther, Johnston, Goodall, & Hope, 2004a) Throughout the world, clinical ethics support services (CESSs) have become increasingly prevalent in and integrated into healthcare delivery. Several models have emerged for the delivery of this support, ranging from formally trained clinical ethicists who work as professional consultants; to hospital ethics committees comprising membership from clinical and lay backgrounds. Often lay members of hospital ethics committees bring expertise in law, philosophy or religion, or offer specific cultural input.

Given their relatively recent advent, establishing and optimising CESSs have been topics widely discussed in the literature. (Dubler, Webber, & Swiderski, 2009; Godkin, Faith, Upshur, Macrae, & Tracy, 2005; Reiter-Theil & Agich, 2008; Slowther, Johnston, Goodall, & Hope, 2004b) The focus of this research has increasingly shifted away from ‘should CESSs be available?’ to ‘how should we deliver clinical ethics support?’

The “evolving process” (Newson, 2009) of service development has thrown up theoretical and practical challenges to ensuring services are able to meet the complex and changing needs of patients and clinicians in busy health care settings. A tenuous picture of what constitutes best practice in clinical ethics support is beginning to emerge: 2010 saw a world first when the conference, Best Practices in Clinical Ethics Consultation and Decision-Making was convened in London. (Terry & Sanders, 2011)

New Zealand has lagged slightly behind the United States, Europe and the United Kingdom in the uptake of CESSs. Only 7 of the 20 District Health Boards (DHBs) in New Zealand have CESSs available, and the majority of these have been established only since 2008. Perhaps because of this, there has been little New Zealand research into clinical ethics support.

This study is the first of its kind in New Zealand to explore the clinical ethics needs of doctors. Using qualitative techniques of in-depth interviewing and a normative analysis informed by current literature, my research investigates what New Zealand doctors need from a CESS and how understanding these needs can improve service design. This thesis is divided into three parts. The first part, made up of chapters 1 and 2, describes the context of this research, outlining the development of CESSs and reviewing existing literature on doctors’ perceptions of the services. The second part, chapters 3-5, explains the development of my original research strategy and
presents an overview of the results of my research. The third part, chapters 6-9, is an analysis of my findings and their relevance to ethical practice in New Zealand.

Capital and Coast District Health Board’s Clinical Ethics Advisory Group (CCDHB CEAG) provides a local case study of clinical ethics support. I have interviewed doctors at the CCDHB to assess what their clinical ethics support needs are and what their perceptions are of CESSs. In addition I have drawn on international literature. The successes and pitfalls of CESSs globally can be important learning points for those seeking to establish and improve services in New Zealand.

Ultimately, any service designed to support clinicians can only be effective if it has a good understanding of their needs and expectations. With this research I am able to offer a series of recommendations to ensure the CCDHB CEAG is accessible, practicable and helpful to clinicians. With an improved understanding of what doctors at CCDHB want and need in clinical ethics support, services like the CEAG can continue to develop and strengthen, enhancing ethical practice New Zealand-wide.
1.2 Background
Clinical ethics is defined as “the systematic, critical, reasoned evaluation and justification of right and wrong, good and evil in clinical practice, and the study of the kinds of persons healthcare professionals ought or ought not strive to become”. (Sulmasy, 2001) As a discipline, it has only been defined within the last few decades. (Jonsen, Siegler, & Winslade, 1986) However, this belies a long history of normative thought and practice in the healing professions. As such, any discussion about clinical ethics is best contextualised by an understanding the role ethics has played, explicitly and implicitly, in determining how health care is delivered.

This background chapter is divided into seven sections.

Firstly, a history of medical ethics and the ethics of research with human subjects will be covered briefly, which frames the emergence of clinical ethics as a discipline in its own right. The second section describes the advent of CESSs, looking at the US and the UK as particular case studies.

The third section will introduce the New Zealand context, describing a history of regulation of medical ethics in New Zealand. The fourth section describes the current state of CESSs in New Zealand. The fifth section covers the development of the New Zealand clinical ethics network that is currently underway.

The sixth section describes the CCDHB CEAG, the CESS that is used as a case study for this research.

1.2.1 Medical ethics and the ethics of research with human subjects
The concept of medical ethics is integral to the notion of medicine as a profession. Indeed, one of the oldest and most enduring examples of a code of conduct, the Hippocratic Oath, served the dual purpose of establishing a vocational body of medical practitioners and of delineating the standard of behaviour that those practitioners should adhere to in order to be worthy of the title of doctor. From the Hippocratic Oath to Ishaq ibn Ali Al-Ruhawi’s Adab al-Tabib (Conduct of a Physician), from Formula Comitis Archiatrorum to Thomas Percival’s Medical Ethics, the medical profession has a long tradition of normative standards of practice.

In large part, the role of monitoring practitioners’ adherence to these principles was regarded as the responsibility of the medical profession as a collective. This culture of complete internal regulation relied heavily on the trust of patients and the important sense of a social contract between clinicians and the rest of society. Individual professional guilds established their own internal codes of practice, such as the American Medical Association Code of Ethics, first written in 1847. (American Medical Association, 2012) Globally, there was little statutory oversight of
medical ethics beyond preventing criminal behaviour: the Western medical profession was largely afforded the privilege of self-regulation. (Campbell, Gillett, & Jones, 2005)

During the 20th century a series of horrific examples of unethical medical research initiated a move away from self-regulation and the development of codes written by those outside of medicine – including the Nuremberg Code, Declaration of Geneva and a year later, the International Code of Medical Ethics and Declaration of Helsinki (Annas & Grodin, 2008; Ashcroft, 2008) These new codes were significant for the fact that they established a universal standard of ethical conduct in medical practice. Importantly, the Declaration of Helsinki went a step further than the preceding codes by not only addressing the responsibilities of clinicians but also asserting the rights of patients for the first time. (Ashcroft, 2008) This signalled the beginning of what would become a growing movement away from medical paternalism into a more patient-centred era, where the input of both lay people and statutory regulation would become more prominent features of the landscape of medical ethics.

The second half of the 20th century saw the emergence of bioethics as an academic discipline in its own right, as a discipline that spanned medicine and the biological sciences, public policy and jurisprudence, and philosophy and theology.

1.2.2 Clinical ethics and CESSs

This section will describe the emergence and current design of CESSs in the United States, United Kingdom and Canada. This provides background context to the discussion of the still emerging CESSs in New Zealand.

Ethical challenges are an inevitable part of the practice of medicine, a vocation that serves people when they are vulnerable. As a result, doctors and other health professionals may face ethical questions almost daily. All doctors in the course of clinical practice encounter situations in which it can be challenging to ascertain the right thing to do. With the advent of ever more advanced medical technologies, what can be achieved medically is ever expanding, but often this makes the question of what should be done harder to answer.

Ethical reasoning is now recognised as an important component of the medical curriculum in many countries. The aim is to equip trainee doctors with the skills they will need to address ethical challenges inevitably encountered in practice. Increasingly, it is being recognised that it is equally crucial to provide mechanisms to address ethical issues not just to trainees, but also to qualified health practitioners. A study by Kälvemark et al conducted in 2003 found that moral distress was experienced at higher rates by clinicians who felt they did not have adequate support structures in place to help them work through ethical concerns. They, and others, have suggested that the onus is
on healthcare organisations to ensure support services are available to staff. (Kälvemark, Höglund, Hansson, Westerholm, & Arnetz, 2004; Pinnock & Crosthwaite, 2004; Tallis et al., 2005) CESSs have developed in response to the recognition that health care staff often need guidance and assistance in resolving ethical issues in clinical practice.

CESSs first began to emerge internationally in the 1970s, driven by a variety of factors that differed from country to country. (Fox, Myers, & Pearlman, 2007; Keating, 2006; Slowther et al., 2004b) Support services differ greatly in their composition and structure, but share a common purpose of providing education, advice and guidance to clinicians facing ethical challenges. The role these services play in their respective health care environments today, in large part, reflects the driving factors behind their formation.

In the United States, for example, a number of high profile court cases provided the impetus for changes in hospital and government policy to improve the way ethical issues were handled in health care. Among the most famous of these cases was that of Karen Ann Quinlan. (“In Re Quinlan, 70 N.J. 10 355 A.2d 647,” 1976) In 1976, Karen Ann’s father, Joseph Quinlan, appealed to the Supreme Court of New Jersey to allow him and his wife to turn off the ventilator that was keeping their daughter alive, against the wishes of the medical team treating her. Twenty-two-year-old Karen Ann had been in a persistent vegetative state for about a year after losing consciousness while intoxicated. The intensive care technologies keeping her alive had only been relatively recently developed, and many doctors at the time were reluctant to allow patients to die as they believed they had a professional obligation to sustain life where possible.

The Court found in Quinlan’s favour. But amidst concern that this action would lead to widespread litigation against healthcare providers by patients and their families who disagreed with their doctors’ management plans, they recommended the formation of an alternative avenue of recourse for these kinds of cases. (“In Re Quinlan, 70 N.J. 10 355 A.2d 647,” 1976) Healthcare organisations must have an internal CESS to be eligible for Joint Commission accreditation. The Joint Commission is an independent, non-profit health care provider accreditation organisation. In most states of the US, hospitals need Joint Commission accreditation to gain access to Medicare and Medicaid funding, creating an indirect legislative imperative to have institutional ethics support available. (Joint Commission, 2011) There is no stipulation in legislation as to what form these support services should take.

In the UK, CESSs emerged at a grass-roots level, driven by clinician perception of the need for increased support and training in ethics. (Slowther et al., 2004b) Early committees were informal and made up largely of clinicians and lay people who would offer their time on a voluntary basis. In recognition of the need for educational and administrative support for these groups, the United
Kingdom Clinical Ethics Network (UKCEN) was formed in 2001. They identify three primary aims: “to promote the development of ethics support in clinical practice in the UK, to promote a high level of ethical debate in clinical practice [and] to facilitate communication between all UK clinical ethics committees”. (“UKCEN: Clinical Ethics Network,” accessed 2 March 2013)

Many CESSs formed in the context of close alliances between health care providers and academic centres for bioethics. In Canada, for example, the Joint Centre for Bioethics (JCB) developed in a partnership between the University of Toronto and four hospitals in the Toronto area. (Keating, 2006) Over the subsequent decade, the collaboration has grown to include 15 organisations, including a range of health care providers and scientific institutions. The JCB employs a network of vocationally trained clinical ethicists who provide advisory services to local health care organisations and, in addition, is a hub for bioethics research and education. In addition to ethicists, the partnership includes a range of health professionals and academics. (Upshur, 2011) Similarly, many major universities have developed clinical ethics infrastructures and systems in parallel with local health care organisations, particularly those with medical faculties.

The model for ethics support in Toronto, and in much of North America, differs from the advisory committee model that prevails in the UK. The ethicists employed at the JCB to deliver support services are formally trained in clinical ethics, with core competencies including conflict resolution. Many of those who receive ethical training already have a health care qualification; those who do not receive training in key clinical competencies. They are available on-call for consultation by phone or at the bedside, and their service extends beyond an advisory role to actively facilitating mediation where required. (Anstey K, personal communication, 12 April 2012)

Throughout much of the rest of Canada, the availability and structure of CESSs is variable, although there is a trend towards increasing availability and formalisation. A 2008 survey of Canadian Hospitals of over 100 beds found that 85% of them had access to a CESS as compared to 58% in 1989 and 18% in 1984. (Gaudine, Thorne, LeFort, & Lamb, 2009) Many of these services are delivered by clinically trained ethical consultants, although the clinical ethics committee model is still widely used.

1.2.3 Regulation of medical ethics in New Zealand

This section outlines a brief history and the current status of regulation of medical ethics in New Zealand. A more comprehensive overview is included in appendix 1 for readers unfamiliar with this area.

The late 1980s to early 2000s in New Zealand saw a shift from an almost entirely self-regulated medical profession to a health system with an external regulatory framework with considerable lay
input. The Cartwright Report of 1988 recommended widespread and radical reform of the health sector and led to changes in legislation and the formation of several independent, government-funded bodies to promote and uphold the rights of patients and human research participants. (Cartwright, 1988)

One such body is the Office of the Health and Disability Commissioner, established under the Health and Disability Commissioner Act (HDCA) 1994. The Commissioner’s Office provided a new mechanism by which consumers with grievances with respect to the quality of the services they had received from a health practitioner could lay complaints and seek redress. The Commissioner was also charged with overseeing the development of the Code of Health and Disability Services Consumers’ Rights, which passed into law in 1996. For the first time, the rights of patients and the obligations of individuals and organisations providing health care in New Zealand were codified.

Since its formation in 1914, the Medical Council of New Zealand (MCNZ) has been the statutory body responsible for enforcing standards of conduct and competency of doctors, a role reaffirmed under section 118 of the Health Practitioners Competence Assurance Act (HPCAA) in 2003. The MCNZ developed Good Medical Practice (Medical Council of New Zealand, 2008) as a benchmark of professional conduct. With regards to ethics, Good Medical Practice confirms the historical role that the New Zealand Medical Association (NZMA) has had in developing and updating the Code of Ethics for New Zealand doctors. (New Zealand Medical Association, 2008)

1.2.4 CESSs in New Zealand

The recent emergence of CESSs in New Zealand has largely been driven by grass roots movements by clinicians, in part with the intent to counter the New Zealand regulatory focus on clinical misconduct.

Legislation and clinician support services play different and complementary roles in enhancing ethical medical practice in New Zealand. The emphasis of New Zealand’s regulatory framework is very much on protecting the rights of the patient from clinician misconduct, rather than on supporting clinicians to make ethically-sound decisions, and consequently, the main mechanism by which the Health and Disability Commission (HDC) exert its influence is through the complaints process. (“Health and Disability Commissioner - About Us,” 2009) It is important to note that the HDC was not designed to provide a mechanism by which health and disability care providers could seek specific prospective advice when they encounter ethically complex cases. In fact, until relatively recently, no formal bodies providing this advisory and support role for clinicians have existed in this country, in contrast to the increasing prevalence of such bodies overseas.
As such, the New Zealand system has been ill-equipped to deal with instances in which a clinician intends to act ethically but is faced with a dilemma in which he or she is uncertain of what an ethical course of action would be. As Tim Dare points out, the HDC and the courts recommend doctors engage in “broad consultation in difficult clinical situations”, but do not offer mechanisms by which this should occur. (Dare, 2010)

The development of clinical ethics advisory services in New Zealand has been largely driven by clinicians concerned about the dearth of support in area. The first formal CESS was launched at Auckland Hospital in 1997, two years after the need for the service was suggested by the Medical Advisory Group. The founding Auckland Hospital Clinical Ethics Committee was comprised of three clinicians and three non-clinicians, including one lay member, a lawyer. Tasked with acting as a “sounding board for clinicians with ethical dilemmas”, the Committee accepted referrals from clinicians, and after consideration of the ethical issues, offered non-binding advice on a course of action. (Auckland District Health Board Clinical Ethics Advisory Group, 2012)

It is of note that the original Committee chose not to appoint an ethicist as a permanent member of their group because they “feared that this could lead to protracted, and unproductive discussions”. (Pinnock & Crosthwaite, 2004, pg 2) However, within 12 months of their establishment the value of having formal ethical input became apparent, and an ethicist was appointed to the group with approval from the Medical Advisory Committee. The paper does not elaborate further on why the views of the group changed.

As of April 2013, seven of the twenty DHBs in New Zealand had a CESS available for clinicians. The most prevalent model is that of a committee-style advisory group composed predominantly of clinicians. The majority of these groups have been established within the last two years, and the extent to which their members have been trained in ethics varies. The clinical ethics environment in New Zealand is currently in a state of rapid change.

1.2.5 The New Zealand Clinical Ethics Network

In July 2012, the Health Quality and Safety Commission (HQSC) offered a grant to support the establishment of a New Zealand Clinical Ethics Network. The Commission had set aside a funding stream to provide grants for projects that they judged would “improve patient safety, foster quality improvement and/or improve consumer engagement” in a grant allocation scheme called Quality and Safety Challenge 2012. (“Health Quality & Safety Commission | Clinical ethics network (Capital & Coast DHB),” accessed 20 February 2013)

The proposal that was awarded the funding highlighted the challenges facing clinical ethics in New Zealand. It identified that where CESSs exist, they were isolated and poorly resourced. The lack of
guidance at a national level had meant service development had been haphazard and often dependent on the goodwill of their membership to continue to function and no mechanism existed for sharing expertise and resources. (MacDonald & Worthington, 2012)

MacDonald and Worthington’s HQSC submission proposed the formation of a New Zealand Clinical Ethics Network Secretariat, which would coordinate the activities of the network. The functions of the Network would include:

- Facilitating information and resource sharing between local CEAGs;
- Developing a guide for the development of clinical ethics support in areas where this support had not yet been set up, including providing recommendations for cultural and vocational diversity of membership;
- Creating a means to co-opt specific expertise between groups on an urgent, case-by-case basis;
- Establishing a curriculum of core competencies for ethics support services;
- Introducing best practice guidelines for the provision of ethics support;
- Promoting research into areas of ethical importance and developing a base of resources for reference; and
- Organising a national conference to promote development of relationships between members of ethics support service members to encourage the dissemination of information about advancements in the field of clinical ethics. (MacDonald & Worthington, 2012)

The centralisation of resources and expertise goes some way towards addressing the fact that New Zealand largely lacks formally trained clinical ethics personnel. In addition, the network structure supports newly established CESSs, particularly in geographically isolated areas.

The HQSC proposal highlighted the importance of tailoring the provision of clinical ethics support to local needs. In order for this to be achieved, it is necessary to accurately describe and quantify these needs. To date, there is little New Zealand data on these needs. My study addresses this gap in the literature by interviewing senior doctors at Wellington Hospital, a major tertiary hospital, to assess their clinical ethics support needs. The CCDHB CEAG provides a case study of a CESS for this research.

1.2.6 The CCDHB CEAG
In this section I describe the establishment, role and function of the CEAG at CCDHB in order to provide background to the interview data presented in this thesis. CCDHB CEAG was established in 2010. The case for establishing a clinical ethics committee was brought to the Senior Medical
Staff forum in 2006 and CCDHB Clinical Ethics Advisory Group became operational in February 2010.

The Terms of Reference identifies two central purposes of the CEAG:

- *To provide a consultative, advisory and supportive mechanism to assist healthcare professionals to make informed ethical decisions in their management of patients.*
- *To facilitate education in the area of ethics and to foster a culture of ethical awareness at C&C DHB so as to equip healthcare professionals with the means to approach ethical problems and conflicts in clinical practice.* (“Terms of Reference - Capital and Coast District Health Board Clinical Ethics Advisory Group,” 2011)

Their major function is a case-consultation service. This service is for clinicians who encounter specific ethical challenges within the course of their practice. If a clinician requires ethical advice on an urgent basis, the CEAG can convene a meeting or teleconference within a timeframe of 24-48 hours. In all other cases, referrals are considered at a regularly scheduled monthly meeting.

The case consultation process begins with the referring clinician meeting the CEAG in a confidential setting to provide relevant clinical and ethical details of the case. Patients and their families are not involved with CEAG process and often are not aware that the case has been referred to the CEAG for consideration. The CEAG then has a closed session in which they discuss possible approaches to managing the ethical issues. CEAG members have access to patient medical records to acquire further background information if necessary. The CEAG provides a formal opinion in writing. The advice provided by the CEAG is consultative only and no recommendations are binding.

Other activities of the CEAG include ethics training days for members of the CEAG themselves and professional development sessions in ethics for a range of health professionals run by MacDonald, the current CEAG chair. The CEAG has also, on several occasions, presented to the Medical Grand Round. (Macdonald et al., 2010) The CEAG also offers ethical input into the development and review of CCDHB policy and guidelines.

Recruitment of new members occurs by word-of-mouth and expressions of interest. Members of the CEAG are appointed subject to the approval of the Director of the Clinical Governance Executive. At present, most members are clinicians. The current membership have limited formal training in clinical ethics.
Chapter 2: Literature review

This chapter outlines the existing literature on doctors’ perceptions of CESSs. Section 2.1 will look at the international literature, drawing on studies from the United States and Europe to describe clinical ethics support perceptions and needs of doctors.

Section 2.2 will address the one New Zealand study that has been published on clinical ethics support. This details the early experiences of New Zealand’s first formal CESS, the Auckland Hospital Clinical Ethics Advisory Group.

2.1 International literature on doctors’ views on clinical ethics support

There is a growing body of international literature investigating how clinical ethics support is perceived by doctors and how these perceptions impact on the rates at which they access CESSs. The literature also surveys the reasons clinical ethics support is sought. (Davies & Hudson, 1999; DuVal, Clarridge, Gensler, & Danis, 2004; Førde, Pedersen, & Akre, 2008; Kadioğlu, Can, Öner Yalçın, & Kadioğlu, 2011; McClung, Kamer, DeLuca, & Barber, 1996; Orlowski, Hein, Christensen, Meinke, & Sincich, 2006; Perkins & Saathoff, 1988)

Most of these studies used questionnaires or other fixed-format information gathering strategies such as interviews using templates. (DuVal et al., 2004; Kadioğlu et al., 2011; McClung et al., 1996; Orlowski et al., 2006; Perkins & Saathoff, 1988) Qualitative techniques such as in-depth interviewing have also been used as a research strategy. (Davies & Hudson, 1999; Førde et al., 2008)

Several studies sought the views of doctors who had referred cases for clinical ethics consultation on how useful they perceived the referrals to have been, (Førde et al., 2008; McClung et al., 1996; Perkins & Saathoff, 1988) while other studies looked at a broader cross-section of the medical population, recruiting doctors irrespective of whether or not they had accessed clinical ethics consultation. (Davies & Hudson, 1999; DuVal et al., 2004; Kadioğlu et al., 2011) Orlowski et al’s study took the interesting approach of deliberately recruiting two study populations: one group of doctors who had chosen to access clinical ethics consultation and another who had not, to compare the rationales behind access behaviours. (Orlowski et al., 2006)

Broadly speaking, the studies found that the majority of doctors perceive clinical ethics consultation to be a useful service to have access to. A number of different reasons were cited by participants but there were three major themes that ran across the studies: a) that case consultation increases clinician confidence in decisions made; b) that case consultation teaches clinicians how to better manage ethical issues; and c) that case consultation aids in resolution of conflict and helps achieve ethical resolution.
The first major theme was that seeking clinical ethics consultation increased doctors’ confidence in the decision-making process. Perkins and Saathoff, for example, found that 93% of participants felt that the referral process had increased their confidence in the management approach that they had finally settled on. (Perkins & Saathoff, 1988) Potential reasons for this increase in confidence were suggested in the findings of other studies. Orlowski et al found that the majority of participants who used clinical ethics consultation services agreed that it “helps the family to have an outside objective review [and] strengthens the patient’s or family’s confidence in the thoroughness of the doctor’s review of options.”

Participants in Kadioğlu et al’s study also stated that a major reason for seeking ethics consultation was the perception that it would increase the trust of the patients and their families. Interestingly, another significant driver behind the sense of security that is derived from seeking ethics consultation came from a more defensive standpoint: another major reason cited was that in case of “any judicial problem, my receiving ethics consultation is considered as a factor in my favor [sic].” (Kadioğlu et al., 2011)

Førde et al’s study revealed that a strong driver behind seeking ethics consultation was the desire to have external analysis or validation of their clinical approach. The implication was that the ethics consultation service, by virtue of being removed from the immediacy of the clinical situation, was able to provide an objective appraisal of ethical practice. (Førde et al., 2008)

A second major theme emerging from the international literature suggested a benefit of accessing clinical ethics consultation was its value as an ethics teaching tool for clinicians, both in managing the case at hand, and in learning to manage future ethical issues. McClung et al found that 96% of the doctors in their study who had accessed case consultation found that it had clarified their ethical thinking. (McClung et al., 1996) Perkins and Saathoff’s findings were only slightly less impressive, with 89% of participants stating the same benefit. (Perkins & Saathoff, 1988) Participants in Forde et al’s study felt that the educational value of case consultation was greatest when they perceived consultation to have offered them tools for managing ethical issues beyond the immediate case referral. (Førde et al., 2008) DuVal et al’s findings reiterated this point: participants indicated that the “instructive value” extended beyond the immediate case. (DuVal et al., 2004)

Resolving conflict and improving outcomes were a third key benefit of accessing ethics support. This was also noted across several studies. (DuVal et al., 2004; Førde et al., 2008; McClung et al., 1996; Orlowski et al., 2006; Perkins & Saathoff, 1988) 85% of doctors participating in McClung et al’s research, for example, found that clinical ethics consultation was medically beneficial. (McClung et al., 1996) Orlowski et al commented that an advantage of the case consultation was
that it seemed to facilitate the communication required to resolve ethical conflict. This reinforced an interesting finding from McClung et al.’s study. The researchers here compared the perceptions of doctors seeking case consultation with the perceptions of the patients whose cases had been referred. There was a significant discrepancy, with only 65% of patients and their families perceiving consultation to have been useful as compared to 96% of doctors. Where patients were dissatisfied, the majority cited poor communication as the most significant factor behind their assessment of the service. (McClung et al., 1996) This finding indicates the importance of ethics support services effectively facilitating communication.

The literature suggested four major themes as to why doctors opt not to access ethics consultation. These were that a) doctors perceived ethical decision-making as their own responsibility; b) doctors felt that they were sufficiently proficient at managing ethical issues (and are potentially overestimating their proficiency) c) doctors feel that ethics support is too time-consuming; and d) doctors were concerned that the providers of clinical ethics consultations might lack the necessary expertise.

Davies and Hudson’s study was a significant outlier amongst the other studies in that it was the only one in which the vast majority of participants felt that ethics consultation was unhelpful. 10 of their 12 participants stated that they would not use consultation services and described them as unhelpful. The main reason was that these doctors perceived referral of cases for consultation to be an abdication of clinical responsibility and suggested that it undermined the doctor-patient relationship to make such a referral. (Davies & Hudson, 1999)

The idea of ethics being a doctor’s responsibility was echoed in Orlowski et al.’s study. These researchers found that one of the most significant differences between doctors who did and those who did not access CESSs was what they perceived their own role to be in ethical decision-making. Participants who did not use consultation services were more likely to feel that resolving ethics issues was their own responsibility, whereas those who used ethics consultation were more likely to feel that ethics decision-making is a shared responsibility. (Orlowski et al., 2006)

The second major reason doctors did not access ethics support was that they perceived themselves to be sufficiently competent to manage ethical issues themselves. This was a finding in both Orlowski et al and in DuVal et al’s studies. (DuVal et al., 2004; Orlowski et al., 2006)

Interestingly, DuVal et al also found that, paradoxically, the doctors least likely to access ethics support were the doctors who had had the least training in ethics. They were also the most confident in their own ethical abilities. This suggests that where clinicians have had very little access to training, they may have poorer insight into their own areas for potential development.
Kadioğlu et al also indicated that a lack of awareness may have been behind one of their more surprising findings. In their study of Turkish doctors’ perceptions of clinical ethics support, they found that despite the fact that 90% of their participants stated they would like to have access to clinical ethics consultation, 80% stated that they have never encountered an ethical difficulty in the course of their practice. The authors indicated that this finding was indicative of the fact that ethics is not an overarching medical curriculum requirement in Turkey and that some doctors qualify without having taken a course in ethics. They stated this “draws attention to the fact that Turkey is currently faced with a lack of medical ethics awareness and possible incompetency in the country’s undergraduate programs.”

The third major reason identifiable in the literature why doctors do not access clinical ethics support is the practical consideration of time restrictions. Duval et al and Førde et al both found that this was perceived as a significant barrier to accessing ethics support in the busy lives of clinicians. (DuVal et al., 2004; Førde et al., 2008)

A fourth perception that led to doctors’ aversions to seeking clinical ethics consultation was a concern that those providing the service do not have sufficient clinical knowledge or are too far removed from clinical practice to be able to contribute to clinical decision-making. (Førde et al., 2008; Orlowski et al., 2006) Orlowski et al found this aversion to be particularly true of surgeons, who were much less likely to access clinical ethics consultation where they perceived clinical ethics service providers were unable to “grasp the full picture from the outside.” (Orlowski et al., 2006)

A review of the literature suggests there are some areas of strong concordance in what doctors perceive to be the benefits and disadvantages of having CESSs available. That most of the themes are replicated in more than one study suggests the validity of the findings. Davies and Hudson’s study may indeed be the exception that proves the rule. It is of note that it is one of the older studies, published in 1999, and that they only recruited doctors who were heads of their respective clinical departments. (Davies & Hudson, 1999) While it is true that senior doctors may play a significant role in shaping the mindset of the departments they lead, it is also true that in the evolution of departmental culture over time, younger clinicians coming up through the ranks change collective mindsets. It is possible that this study captured a snapshot that illustrates how rapidly the tide has shifted towards a greater recognition of the potential value of increasing availability of clinical ethics support.

2.2 New Zealand literature on clinical ethics support

The only New Zealand research on CESSs published to date is Pinnock and Crosthwaite’s 2004 review of Auckland Hospital’s Clinical Ethics Advisory Group (Auckland CEAG). (Pinnock &
This paper reports on the findings of two different studies conducted by the Auckland CEAG as a means of evaluating how effective the advisory group was perceived to be. The first was a survey of clinicians who had referred cases to the Auckland CEAG to gauge their perceptions on the usefulness of the service. All but one participants offered positive feedback. It is interesting to note that the study found that even clinicians who disagreed with the opinion of the committee found the service useful. This suggests that clinicians were not simply finding value in the consultation process when it reinforced their own opinions. They acknowledged the very small size of the group prevented strong conclusions from being drawn from their research. Ideally, it would be useful to have evaluations of a service conducted independently of the service itself, particularly given the small size of New Zealand’s medical community.

In the second study, doctors and nurses working at Auckland Hospital were surveyed to assess awareness amongst staff of Auckland’s CEAG and staff perceptions of the Auckland CEAG’s usefulness. The response rates were not high, achieving only 40% amongst doctors and 44% amongst nurses. Of these, however, a majority felt there was a role for an ethics committee, though only 67% of doctors and 60% of nurses who responded were aware that the committee was already in existence. This reflects the ongoing challenge of increasing staff awareness of the ethics committee as a resource. In addition, even staff who were aware of the committee and thought it was valuable as a concept did not refer cases to the ethics committees, reflecting barriers to accessing the service beyond lack of awareness.

In summary, CESSs are increasingly well developed and well researched in many parts of the world, particularly North America and Europe. By contrast, CESSs have been late to emerge in NZ and there is very little local literature on the subject –and no qualitative literature. My study analyses for the first time, using qualitative techniques, the clinical ethics support needs of a sample of New Zealand doctors.
Part 2: Empirical research
Chapter 3: Methodology

3.1 Overview
This was a qualitative study, in which I conducted in-depth, semi-structured interviews with senior doctors working for CCDHB. The interviews explore the clinical ethics support needs of the participants and strategies for meeting these needs; in particular, the role of CEAG is as a model for the delivery of clinical ethics support. Fourteen interviews were conducted between December 2011 and April 2012, and the data was analysed using an inductive thematic analytical process.

3.2 Ethics Approval
The New Zealand Central Regional Ethics Committee approved the study, under expedited review, on 14th September 2011 (CEN/11/EXP/073). Ngai Tahu Research Consultation Committee were consulted regarding the impact of this study on Maori and how the study could be optimised to better meet the needs of Maori. They recommended gathering ethnicity data on participants, which was done by including the 2006 Census question on ethnicity as an addendum to the interview template. Locality assessment was approved from Dr Geoff Robinson, the Chief Medical Officer of the CCDHB, on behalf of the DHB on 26th October 2011.

3.3 Study design
Recruitment was restricted to senior doctors. The research was conducted for a BMedSci degree and as such needed to be completed within a year. Given the limited time available, it was necessary to limit the scope to a single professional group to be able to generate meaningful data. As a senior medical student I have particular insights into the culture of medicine and familiarity with the clinical environment doctors work in. Although without constraints on time and resources it would have been valuable to include other professional groups in the study, this recruitment strategy was focused to allowing more in-depth data to be collected at the expense of breadth.

Within the medical hierarchy, the responsibility for making major clinical decisions lies with the consultant who heads a given clinical team. Due to their seniority in knowledge and experience, they are accountable for the actions of the more junior members of their team. As such, the culture of ethical behaviours in a team is often shaped by the most senior clinician. As a purposive sampling strategy, this seemed most likely to achieve what Patton described as “information-rich cases for in depth study”. (Patton, 2002, pg 46)

Doctors from a range of specialities were recruited in order to gain perspective on whether the ethics support needs differed between specialities or if there were significant differences in the way ethical issues and ethics support services were approached by different specialities. CEAG aims to
serve all health professionals across the DHB, and as such it was appropriate to seek representation from as wide a range of specialities as would be able to access the service.

In particular, participants were recruited from both medical and surgical specialities and from both adult and paediatric medicine. Orlowsk et al in 2006 researched factors leading clinicians to use or not use clinical ethics consultation services, with sub-analysis by speciality. They found that surgeons were much less likely than other clinicians to use services if they perceived the clinical ethics service not to have expertise in their own area of practice. (Orlowski et al., 2006) This indicated the importance of including both surgical and non-surgical specialities in the sample, particularly as the CCDHB CEAG in 2012 has no member with a surgical background.

Lyren and Ford identified significant differences in approach to ethical decision-making necessary in paediatrics as opposed to adult medicine. They emphasise the differing nature of the doctor-patient relationship in a paediatric setting, and suggest for this reason that paediatric ethics can be regarded as a separate competency from adult ethics consultation.(Lyren & Ford, 2007) Some centres have for this reason developed separate clinical ethics consultation services.(Mercurio, 2011) The CCDHB CEAG serves both adult and paediatric patient populations, so it was important to consider the needs of clinicians working with both groups.

Within the parameters outlined above, the intention was to achieve as much heterogeneity within the sample as possible. Recruitment was therefore limited to a maximum of three participants per speciality, with preference given to the first to indicate interest in participating, in order to ensure a breadth of specialities were able to be represented.

One-on-one, in-depth, semi-structured interviews have advantages over other techniques for a number of reasons. Interviewing clinicians in a confidential one-on-one setting allows them to be candid in their responses. These interviews often covered distressing personal experiences or circumstances where participants had been uncertain or vulnerable in their own practice. In addition, some clinicians described situations in which they had been concerned about the practice of a peer. It would have been difficult to have gathered this depth and intimacy of information in a group setting. This is particularly so given that Wellington Hospital, a 434 bed hospital, is of a small enough size that most senior clinicians know one another.

The richness of data gained through in-depth interviewing was greater than that available through surveying, which is a technique that has been widely used to gather information on clinician perspectives of CESSs.(DuVal et al., 2004; Fox et al., 2007; Kadioğlu et al., 2011) A distinct advantage was that it allowed data collection to be participant led, so that novel themes emerged beyond the interview template.
3.4 **Interview template development**

The questions were designed to encourage clinicians to draw on their own experiences of facing ethically challenging clinical situations to illustrate instances in which they felt well supported and to demonstrate how support could be optimised. The template was developed based on the major themes to emerge in the literature review and was revised during data collection to reflect emergent themes.

The interview was divided into four domains of inquiry:

1. The clinician’s role and the nature of the ethical challenges they encounter within that role.
2. The clinician’s approach to making ethically challenging clinical decisions. Clinicians were asked to outline the strategies and services that they use to make these decisions and describe the process of being taught or developing this approach. They were then invited to discuss whether they felt that the training and support that they had received was adequate.
3. Different models of ethics support and how they felt their needs in terms of ethics support could be better met. Clinicians were encouraged to comment not just on their personal needs in their current practice but on the needs of their colleagues and peers on a local and national level.
4. The utility of CEAG as a model for the provision of ethics support, with reference to the structure and the function of the group. Clinicians who had referred cases to the CEAG were asked to give feedback on the process and the outcome.

The template provided a series of open questions to begin discussion in each of these focus areas. A combination of open and closed follow-up questions was used as appropriate to (a) elicit further elaboration and (b) clarify ambiguous responses.

3.5 **Recruitment**

Initial contact with 90 potential participants was made via email. An invitation to participate in the study and the participant information sheet was emailed to senior doctors, using their work CCDHB email addresses, accessed from the CCDHB website. ("Capital and Coast District Health Board,” 2012) A list of specialities contacted is included in appendix 2.

Four participants expressed interest in being involved in the study prior to the recruitment email being sent out. Alastair MacDonald, chair of the CCDHB CEAG and my secondary supervisor contacted senior peers who he felt would be able to offer an interesting perspective for the study to inform them it was taking place. His position as CEAG chair and a senior physician meant he was in a good position to identify individuals who would have unique insights into the culture of clinical ethics decision-making at the CCDHB. Liamputtong described this method as “intensity
sampling”, where particularly rich cases are selected for the depth of information they will offer. (Liamputtong, 2009) MacDonald passed on the names of those doctors who were interested in the study to me; I then emailed them the participant information sheet and consent form. Clinicians who had been informed of the study by MacDonald and did not wish to be involved were not known to me. As such, they may have been sent the general recruitment email subsequently.

Recognising the potential for this group to hold or express different views from other clinicians at the DHB due to their relationship with MacDonald, I analysed these interviews as a separate sub-group initially. A specific concern was that the clinicians recruited through this strategy might be more likely to express views in favour of the CEAG.

Participants were offered a light morning tea consisting of a hot beverage and a cake or slice to thank them for their involvement. This was felt to be sufficient to express gratitude, without providing undue inducement.

### 3.6 Participants

*Table 1: Specialities of participants*

<table>
<thead>
<tr>
<th>Specialities of participants (in alphabetical order)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Endocrinology</td>
</tr>
<tr>
<td>Endocrinology and older adult medicine</td>
</tr>
<tr>
<td>General medicine and infectious disease</td>
</tr>
<tr>
<td>Intensive care</td>
</tr>
<tr>
<td>Paediatrics</td>
</tr>
<tr>
<td>Paediatrics/neonatology</td>
</tr>
<tr>
<td>Paediatrics/neonatology</td>
</tr>
<tr>
<td>Neurosurgery</td>
</tr>
<tr>
<td>Neurosurgery</td>
</tr>
<tr>
<td>Obstetrics and gynaecology</td>
</tr>
<tr>
<td>Older adult medicine and palliative care</td>
</tr>
<tr>
<td>Orthopaedic surgery</td>
</tr>
<tr>
<td>Psychiatry</td>
</tr>
<tr>
<td>Renal medicine</td>
</tr>
</tbody>
</table>

### 3.7 Data set

Recruitment was terminated when data saturation was achieved. Data saturation is achieved when one has sufficient interviews to get “a reliable sense of thematic exhaustion and variability within [a] data set”. (Guest, Bunce, & Johnson, 2006) The complexity of the data was such that saturation could not be determined by the absence of new information in each subsequent interview. Rather, saturation was achieved when no new broad overarching themes were being revealed by each
subsequent interview. Clear themes were evident by the sixth interview. By the tenth interview, it seemed that thematic saturation was established. By the fourteenth interview I was satisfied that no new overarching themes were emerging. Another consideration for cessation of further recruitment was appropriate variability in the data set to achieve heterogeneity. A spectrum of perspectives on clinical ethics needs and CESSs was apparent from early in the data collection process; even within the first six interviews it was clear that the sampling method had achieved appropriate variability.

3.8 Data Collection

All interviews were audio-recorded with the consent of participants. Limited hand-written notes were also taken during the interviews.

Fourteen one-on-one, semi-structured interviews were conducted. These ranged in duration from forty minutes to two hours. All participants gave written informed consent. The interview template provided a loose guideline to steer the interview, included as appendix 3.

Participants were given the option of volunteering which ethic group they belonged to. They were also asked if they were New Zealand trained and if they had worked overseas.

In recognition of the fact that it was an iterative process, clinicians were encouraged at the conclusion of the interview to give feedback on how the interview went and what recommendations they could offer for future interviews. Feedback was incorporated into the template where appropriate or was used to develop the process of future interviews.

Interviews were transcribed and analysed concurrently with the process of recruiting and conducting subsequent interviews.

3.9 Analysis

The initial study design was to perform a simple inductive thematic analysis, but elements of grounded theory came into the design as the course of each interview evolved in the light of the themes that emerged in preceding interviews.

Key themes were identified during the initial interviews and, where necessary changes were made to the relevant sections of the question template to reflect the emerging themes.

The flexibility of the interview template was valuable in allowing ideas that had emerged in previous interviews to be raised for discussion by subsequent participants. For example, after the first interview, the participant questioned some of the assumptions that had been inherent in the template. The template had been framed with the assumption that doctors would be aware of the existence of the CCDHB CEAG and would therefore already have had an opportunity to have
formed a view on them. The template was revised after interview 1, to include a discussion of the current form and function of the CEAG for clinicians unfamiliar with it, and a description of other models for provision of ethics support that exist elsewhere. This approach provided the groundwork for participants to evaluate which services had potential to make a contribution to their clinical practice.

In addition to adapting the interview process in response to explicit feedback, participants were asked to reflect on themes that had emerged in earlier interviews. An example of this occurred when several participants expressed the opinion that there were characteristic differences in approaching ethical challenges between specialties. Discussion was encouraged on what these differences were and what the participants’ perspectives were on why these differences might exist, within these and subsequent interviews.

Participants were encouraged to reflect not just on their own practice, but on prevailing cultures of ethical decision-making at a departmental and institutional level and the attitudes of their peers to ethics and ethics consultation.

Data was not analysed separately by stated ethnicity, but ethnicity and culture of healthcare providers as it related to ethical decision-making was discussed by several participants. None of the participants was of Maori descent. It was of value to note that many of the participants had trained or worked overseas. Those who had done so contrasted their experiences working and training in different healthcare systems with their experiences in New Zealand healthcare.
Chapter 4: Empirical research in ethics

4.1 Combining empirical and normative analysis

The research I have conducted of the clinical ethics support needs of doctors at Wellington Hospital draws on both the empirical data collected in this study and normative principles derived from the literature of clinical ethics support. This chapter addresses the challenges and benefits of combining descriptive and normative techniques in ethics research. I argue that the use of empirical data in ethics is not only valid but essential to ensure that the field continues to grow in relevance.

The use of empirical data to inform normative claims is something that has been an issue of contention in the literature. (Dunn, Sheehan, Hope, & Parker, 2012; Hurst, 2010; Pellegrino, 1995; Rehmann-Sutter, Porz, & Scully, 2012; Reiter-Theil, 2012) Criticisms have been levelled from both the social scientists whose methods have been widely adopted by empirical ethicists and from moral philosophers who feel Hume’s classic is/ought distinction is being undermined by empirical ethics researchers. Hurst states that the primary concern of social scientists is that proponents of empirical ethics have “imported methodological tools from empirical disciplines, but too often [have] not imported the standards to which researchers in these disciplines are held.” (Hurst, 2010)

Conversely, Pellegrino argues that empirical ethicists “cannot extrapolate from the ‘is’ to the ‘ought’ without destroying normative ethics. They cannot establish what is morally acceptable or reprehensible or what would be a morally defensible public policy.” (Pellegrino, 1995)

Sulmasy, however, suggests that clinical ethics has a twofold agenda: a) of research – to address the “ethical questions that arise in clinical settings”, and b) of practice – to “grapple with ethical issues” in those clinical settings. (Sulmasy, 2001) Practice and theory must necessarily inform one another and empirical research is an important tool to move our understanding of clinical ethics forward.

So while it is difficult, combining empirical and normative material is an essential pursuit for bioethics.

Dunn et al propose a methodology in which sociological and philosophical techniques are combined in an inductive and iterative analytical process, to overcome some of the criticisms of empirical ethics. (Dunn et al., 2012) They argue that the challenges inherent in drawing on the empirical to make normative claims do not render empirical ethics an oxymoron. Rather, they suggest that empirical ethics requires different methodologies of empirical research than those traditionally employed in purely descriptive fields like sociology.
Dunn et al describe three methodologies for empirical ethics research, one of which, “grounded moral analysis”, is particularly applicable in the context of this research. It draws heavily on both the sociological method of grounded theory research and on traditional philosophical approaches to normative analysis to create grounded norms that can be used to adapt practice. The diagram below, taken from Dunn’s paper, describes this process.

![Diagram of grounded moral analysis](image)

*Fig. 1 Grounded moral analysis (Dunn et al., 2012)*

Dunn et al highlight that one of the strengths of this methodology is that the research process is not divided, with a normative analytical phase is secondarily superimposed over a descriptive phase. In grounded theory analysis, a hypothesis is drawn from the data. Where a hypothesis is intended to have both normative and descriptive components, it is important that “conceptual and normative analysis [proceed] contemporaneously alongside data collection and analysis”. (Dunn et al., 2012) As such, as the researcher builds up an understanding of the experiences and practices of research participants, the process of gathering data is altered to better capture the emerging picture.

### 4.2 Applicability to my research

When evaluating the need for clinical ethics support at CCDHB and determining an effective way to deliver that support, the use of empirical data is not only acceptable, it is essential. Although it is a normative field, for clinical ethics to be relevant and useful it must be applicable in a practical way. This was made clear by the aversion that study participants expressed to ethics support being provided by those out of touch with the realities of clinical practice. Holm identified the imperative of engaging healthcare professionals in the dialogue of ethical decision-making. “If we want to influence the ethical decision-making of healthcare professionals and patients we need to understand their way of looking at the ethical world if we are to engage them in any kind of
reasonable discussion.” (Holm, 2005) Holm’s comment indicates that in order to develop practice, practitioners must be included in the dialogue, not least to ensure that recommendations have real-world applications.

However, a description of clinicians’ assessments of what they want or perceive themselves to need is only one dimension of appraising the need for clinical ethics support. The analysis that follows does not take their assessments of their needs at face value, but appraises these perceptions in light of the literature – normative and empirical – and on my own experience of both studying and working in the clinical environment of CCDHB and on my period observing the CCDHB CEAG. This was important for two reasons: 1) most of the participants had little experience or familiarity with clinical ethics support systems and what they do; and 2) the fact that self-appraisal, though useful, is an inherently limited means of accurately assessing need. (Davis et al., 2006; Overeem et al., 2012)

Interpreting participants’ assessments of their clinical ethics needs beyond description alone is particularly important given Du Val et al’s research suggesting that clinicians with the least training in ethics are also the least likely to perceive a need for ethics support. (DuVal et al., 2004) This highlights that self-assessment of abilities or needs without a tool to independently guide analysis may overestimate strengths of existing practice and by extension, underestimate perception of needs.
4.3 Generating an iterative and inductive methodology

Here I will describe the methodology for data collection and analysis for this project, which is based on Dunn et al grounded moral analysis.

![Diagram](image)

Fig. 2 Iterative inductive empirical and normative process of this study, adapted from Dunn et al. Both normative and conceptual analyses of data occur simultaneously, at once describing and critiquing norms of practice.

This diagram demonstrates the features of this research strategy. Importantly, both normative and inductive thematic analyses at each point during the data collection process were used to modify the approach to collection of subsequent data. Continuous analysis of collected data using both normative and sociological frameworks allowed the data collection process to evolve, incorporating features of action research, where the researcher specifically invited participants to comment on philosophical issues around the topic of discussion and emergent trends from preceding interviews. Participants did not simply describe their ethical practice, but were pushed to engage in analysis of ethical practice across the institution.

Further, different possible modes of clinical ethics support were described to participants, who were invited to comment on potential benefits and disadvantages of CESSs to their practice. In this way, participants were not merely asked to report their a priori understanding and thoughts, but were invited to participate in normative discussion that helped form what Dunn et al term a “practice-orientated normative argument” – an active process of description and evaluation that can be used to adapt practice. (Dunn et al., 2012) As such, the process of data collection and analysis has allowed the development of a theory of practice that informs a series of recommendations for how practice could be further enhanced.
Chapter 5: Results

5.1 Outline and notes on the text

This section outlines the major themes derived from the data. This chapter is organised according to the three central themes: (1) current ethical practice of participants; (2) theoretical considerations in the provision of clinical ethics support; and (3) practical considerations in the provision of clinical ethics support.

The data emerging from the interviews were rich and varied. The results represented here are an overview of some important themes. A more comprehensive version of this results section is included in appendix 5. As this research is the first empirical qualitative study to explore the ethics support needs of doctors in New Zealand, the comprehensive results represent an important resource for further work in clinical ethics. In this chapter I have categorised and sorted participants’ views according to key themes, while in the following chapter I have analysed and interpreted these results in light of the broader clinical ethics literature.

To preserve anonymity, participants have been allocated a number at random to which their quotations are linked for internal consistency. Square brackets indicate where edits have been made for clarity.

Only one of the participants was female. Identifying this participant by gender in the results and discussion would have undermined her anonymity. For this reason, where her quotations have been included, the pronouns he and his have been substituted for she and her.

5.2 Current ethical practice of participants

During the interviews, participants described the resources and strategies they currently use to help them solve ethical problems. The five key themes emerging in this section are:

   a. Participants’ prior experience with the CEAG
   b. Ethical issues encountered by participants
   c. Participant approaches to managing ethical dilemmas in practice
   d. Ethics training and education
   e. Barriers to accessing ethical support

Participants’ prior experiences with the CEAG

Participants had had varying experience with the CEAG prior to being interviewed. Two of the participants had referred a case to the CEAG (3 and 14) and four others had been peripherally
involved in such cases. (2, 6, 7 and 13). Participant 12 sits on the CEAG as a clinical representative. Most of the remaining participants had not heard of the CEAG. Even amongst the clinicians who were aware of the CEAG, most did not have a clear understanding of its functions or how to access it.

**Ethical issues encountered by participants**

As was expected, participants described encountering a wide range of ethical challenges, many of which were specific to their specialist area of medicine. These included situations of disagreement or conflict, either between patients or family members and treating clinicians, or within clinical teams. Precedent-setting cases, in which clinicians were managing situations that had not been encountered before but might be required to manage again, were another major source of ethical uncertainty.

**Participant approaches to managing ethical dilemmas in practice**

All participants used similar strategies in their approach to ethically challenging scenarios, many emphasising the importance of effective communication in resolving ethical dilemmas. Most felt the most ethically challenging cases were those unresolved by dialogue alone.

All participants relied heavily on informal systems of ad hoc consultation with a range of colleagues to manage ethical issues. They highlighted the importance of multidisciplinary team discussion to ensure that all facets of a patient’s care were adequately considered.

**Ethics training and education**

All participants felt that ethical competence was a core component of clinical competence, but they had differing opinions on how this is attained. Several indicated the model of clinical ethical education in the undergraduate programs was unhelpful because ethical principles were divorced from clinical realities.

Most participants suggested that ethics is learned experientially: that by taking responsibility for patient care, by observing the practice of senior peers and by changing one’s own practice reflectively in response to one’s mistakes, ethics is developed through clinical practice.

Two participants added the cautionary note that the expectation that clinicians can acquire ethical competence by osmosis may be flawed. “You learn it at the coalface . . . but you can always learn the wrong things from experiences.” (6) Participant 4 pointed out that when trainees adopt norms of practice without scrutiny or external oversight, poor practice and culture may be perpetuated.
**Barriers to accessing ethics support**

Participants described a range of barriers to accessing ethics support, which included isolation (particularly amongst junior staff) and a medical culture inhibiting both help-seeking behaviours and constructive criticism.

A theme that recurred throughout the interviews was that challenging ethical decisions were much harder to make when unsupported. Participant 12 stated that the medical system is not well-set up to identify and help staff members who do not have informal peer support networks in place to manage challenging clinical situations.

Participants noted that junior staff, in addition to facing the inherent disadvantage of being less experienced, came up against cultural and systemic barriers to being able to seek adequate support in managing ethical concerns. “…going cap in hand to your boss and asking for advice on things like this is often perceived as a sign of weakness.” (9)

Interestingly, though most participants felt well-supported and comfortable about seeking ethics support from peers, they recognised that there were other groups of professionals less willing or able to do so. Several emphasised that while their own departmental culture fostered advice-seeking behaviours, other departments were less supportive.

Many clinicians emphasized that the culture of medicine makes it very difficult to raise concerns about the practice of peers – particularly senior peers – and that this can be a barrier to dialogue about ethical issues. “In medicine we’re not very good at criticizing people. . . The more senior the person gets, the harder it is...” (11)

5.3 **Theoretical issues in the provision of clinical ethics support**

In addition to talking about what they actually did when faced with an ethical problem, participants also theorised about what sorts of additional ethics support would be useful. Their views on this point have been organised into four themes:

- Ethical and clinical responsibility
- Accountability for decision-making
- Ethics support services as a moral authority
- External provision of ethics support

**Ethical decision-making: a clinical responsibility**

The perception of where ethical responsibility lies was a significant point of difference that shaped participants’ views of clinical ethics support. On the one hand, some argued that ethical decision-making is a clinical responsibility that should not be abrogated. Others contended that ethics
support has the potential to enhance ethical decision-making and thus is a mark of responsible practice.

Most clinicians expressed the view that clinical ethics is a core competency for any doctor. Some felt that to “outsource” ethical decision-making to a CESS is to remove the decision-making role from the individual who a) has a professional obligation to fulfil that role and b) is in the best position to make that decision, by virtue of their expertise in their field of practice.

Participant 2 suggested that the role of the doctor as the ultimate decision-maker did not preclude the involvement of a CESS, but rather imposed parameters on it. “An ethicist . . . can help define the problem but at the end of the day it’s still going to be a clinician’s decision.” (2)

Participant 10 pointed out that doctors are expected to attain such a broad range of competencies that they cannot possibly be expert in all of them. “If you’re a Jack-of-all-trades, you tend to miss the finer details.” (10) He argued that the multidisciplinary team model of medicine depended on a range of professionals with complementary skill sets to provide optimal patient care.

Participant 3, one of the clinicians who had taken a case to the CEAG, did not feel that referral to an external ethics support service required relinquishing clinical autonomy. “My experience of it was it actually helped me to see the situation from a slightly different perspective . . . I found it empowering . . . rather than stripping me of my clinical autonomy.” (3)

**Accountability for ethical decisions**

Participant 8 suggested the advisory nature of CEAG opinions deflects accountability for decisions they helped to make. “I mean, the final question is, who would be responsible for this decision if something goes wrong?” (8)

Many participants felt that it was clear that accountability remains with the referring clinician. Some, however, emphasised the importance of referrers being aware that they can decide against using the advice of the CEAG. “I don’t think that an ethical opinion could then take over the custody of the patient . . . things would have gone too far, if that was the case.” (9)

**Ethics support services as a moral authority**

Some participants expressed concern that a CESS may be making unreasonable claims to moral authority by offering to solve clinical ethical problems.

Participant 8 stated that there was no reason the CEAG should be any better at making ethical decisions than a well-trained, experienced group of health care professionals from a range of
backgrounds. “...If we cannot come to the conclusion all together, who else could come back and tell us, ‘Oh, this is exactly the way to go.’?” (8)

**Ethics support provided by an external body**

For participants, one of the most significant differences between ad-hoc support systems and using a formal ethics support service was that formal support is *external* to the group of people involved in patient care.

Several participants felt that the value of the CEAG was that it could provide an objective sounding board in challenging cases, noting that at times maintaining perspective was difficult when one was closely involved. Participant 4 argued that seeking an objective ethical opinion was a sign of appropriate, reflective practice.

Conversely, other participants expressed concern that an external ethics advisory group would be out-of-touch with the specific clinical realities that contextualise ethical decisions in medicine. Participant 5 stated that “if you’re working in a very specialised area of practice, the ethics of what you’re dealing with rotates extremely strongly around knowledge around the topic or the clinical area with which you’re grappling.” (5)

### 5.4 Practical issues in the provision of clinical ethics support

The final major topic of discussion focused on a series of practical considerations that should be built into the design of a useful and efficient CESS. Participants’ comments have been categorized according to the following four themes:

a. Timeliness
b. Stakeholder involvement
c. Capacity building
d. Ethical education

**Timeliness in case consultation**

The timeliness of service provision was an issue that came to the fore when participants were discussing pragmatic concerns about delivering external ethics support.

Several participants pointed out that the urgency of many ethical decisions was such that it was simply not possible to expect a decision to wait for review by an external body.

Participants held varied views on the value of retrospective case consultation. Participant 4 said he was wary of examining decisions through a “retrospectoscope” (4). He felt there was nothing to be
gained by judging clinicians acting in a messy clinical environment from the sterile environment of a deliberative forum.

Participant 2, conversely, indicated that the aim of the retrospective review was not to judge what could have been done differently, but rather to help the clinical team to develop an approach that could be used in future.

Participant 5 felt case consultations could be of more use in precedent setting cases or cases that had an impact beyond an immediate clinical situation. “[An ethics committee is] a slow bloody organisation. For individuals it’s too slow. . . Where you’re dealing with policy and larger picture things, I think that’s where it works really well.” (5)

**Clinician involvement in external ethical deliberation**

Many participants indicated that their concern about external ethics consultation services was the perception that clinicians were shut out from the process of ethical deliberation.

Participant 7 said he felt concerned with the lack of transparency when he was involved in referring a case to the CEAG. “I presented my case, but then the rest of the stuff was held behind closed doors. And you want to be involved in that discussion . . . it shouldn’t be a secretive –which it isn’t –but that's what it feels like.” (7)

Several participants emphasized that any model for ethics support must involve clinicians in the process if it was to be accepted. Participant 1 pointed out that when clinicians were not involved, they did not learn from the consultation process. “I think discussions, which are iterative, would be a lot better.” (1)

**Ethics as a core clinical competency and enhancing ethics capacity**

Most participants felt that the most useful activity of an ethics support service would be to enhance ethical capacity of the clinical workforce. Many felt that services should help clinicians to attain a degree of ethical fluency such that external ethical consultation would be required only in exceptional circumstances.

Participant 1 suggested that a CESS should foster ethics capacity throughout the hospital, devolving the responsibility from the top of the hierarchy throughout the health workforce. “How would you support ethical decision-making and ethical clinical governance? Rather than having a central committee, my prejudices are, you need to distribute it… which is more of a network than a committee.” (1)
Providing meaningful ethical education

Participants offered their perspectives on the role a CESS might play in providing or supporting ethics education. Key ideas were that ethics education needed to be practical and integrated into the workplace and that it needed to break down medical cultural barriers to open ethical discourse.

Participants stressed that ethical education must be pragmatic and clinically relevant. Some suggested using existing structures by which clinicians keep their practice up-to-date. “Having an ethicist as part of a panel is actually quite helpful, like the Grand Round... people who come from a different angle having a dialogue.” (13)

Participants had a range of ideas on how to foster ethical development of trainee clinicians. Many participants talked about concepts like mentorship and ensuring that the culture of practice was open to ethical dialogue, though they acknowledged the existing barriers to this.

5.5 Conclusion

In summary, clinicians had a broad spectrum of views about the value of clinical ethic support services. There was, however, consensus on the importance of clinical ethics competence to the medical profession. Interestingly, where clinicians felt that they would have to devolve ethical responsibility to a CEAG, they were less likely to perceive it as a positive thing. However, clinicians who felt that the availability of ethics support services either protected or enhanced their ethical autonomy were more likely to perceive ethics support to be of value.

The practical considerations in the provision of clinical ethics support are indicative of the environment in which doctors have to make ethical decisions: they are often under stress and time pressure and they know that they will bear responsibility for all outcomes. Participants take their ethical responsibilities as doctors seriously and want to feel better equipped to manage them, but support services must work in with the pace and complexity of clinical realities.
Part 3: Analysis
Chapter 6: Formal ethics support

6.1 Overview of analysis chapters
This section of the thesis will explore the clinical ethics support needs of doctors at CCDHB, with particular reference to where their needs are not currently being adequately met. In quantifying the clinical ethics needs of doctors, this section will also begin to examine how a formal CESS might meet those needs.

The analytical part of this thesis is broken up into three major areas, each of which will be addressed in a separate chapter. Chapter six addresses the distinction between ad hoc and formal ethics support. I discuss the fact that in the absence of formal services, participants in this study developed informal and ad hoc means of managing ethical challenges. I argue that irrespective of the presence of ad hoc services, there is still a place for formal CESSs. They offer an independent neutral forum which, in the presence of conflict, protects the interests of all stakeholders. Further, I argue that even in the absence of conflict it is important to have a forum available for impartial and just deliberation on ethical issues.

Chapter seven addresses the importance of procedural justice as a clinical ethics need. Having established the utility of a formal and independent ethical forum, I will analyse the features that give this forum value in enhancing ethical practice.

Chapter eight will examine a third clinical ethics need: the importance of continuing medical education in ethics that is both clinically relevant and normatively sound. I argue that where a procedural justice model is used for case consultation, a CESS is an effective provider of ethical education.

6.2 Formal vs. ad hoc sources of ethics support
In this section I demonstrate that ad-hoc and formal ethics support systems can be complementary and highlight the advantages of having a formal service available to clinicians, even those who already have ad hoc systems available to them.

Formal CESSs have only been available to clinicians in Wellington since 2010, but all participants had at some stage used informal mechanisms, such as peer consultation, to help resolve ethical issues. Some participants seemed to assume that formal CESSs were intended to serve as a substitute for these, and found this problematic, arguing that the mechanisms of a formal CESS were too unwieldy to be used for the multitude of day-to-day ethical issues faced.

However, CESSs are not positioning themselves as a substitute for clinician competence in managing ethical issues.
The analogy Participant 6 used is a helpful one to explain the relationship between ad hoc services and formal clinical ethics support. As he put it, doctors should not need a haematologist to interpret their patients’ blood results on a day-to-day basis, but it is important they recognise and refer cases requiring a haematologist’s expertise. Likewise, the role of a CESS is to assist in the management of only those ethical issues that are beyond the scope of the referring clinician’s expertise. The analogy could be extended further; once a referring clinician has learned the significance of a given pattern of blood results, the next time they see this pattern they may be better equipped to identify and manage it. The CESS has a similar role to any other specialist service in the hospital: to aid lead clinicians in the management of patients for whom decision-making considerations span more than one area of expertise. It is not a substitute for ethical competence in clinicians; rather, it allows clinicians to be realistic about the limitations of their ethical competence, and provides a) an immediate means to manage issues outside the clinician’s competence and b) a mechanism to enhance clinician competence for managing future ethical issues.

The UK Royal College of Physicians’ working party on Ethics in Practice noted that the profession has long relied on discussion within professional relationships as the primary mechanism for ethics support, but state that in the context of increasing complexity and frequency of ethical concerns the availability of formal ethical support in all health care environments is imperative.

Medical practitioners are encountering ethical uncertainties and even dilemmas in their daily practice with increasing frequency. This has many causes: advances in medical technology; developments in the law; more intense scrutiny of and challenge to medical decision-making by patients, the public, the media, politicians and regulatory bodies; the breakdown of consensus in a culturally diverse society; and the emergence of a multiplicity of guidelines and advisory bodies. (Tallis et al., 2005, ix)

They go on to state that the provision of “timely, comprehensive ethics support should no longer be left to chance or be dependent on the enthusiasm of individuals”. (Tallis et al., 2005, xi)

This is significant for the assertion that it is not sufficient for a CESS to be built on good will and enthusiasm alone. Ethics support services carry the same mandate as any other health service provision: to be reliable, consistent and accountable. While in many areas – CCDHB being no exception – CESSs have needed the enthusiasm of volunteers to provide services in their nascent phase, it is important that noble intentions are justified by rigorous evaluation. The grass-roots emergence of ethics support in New Zealand has mirrored the early years of clinical ethics support in the UK, where individual trusts haphazardly established isolated ethics support services. The important next step is to introduce infrastructure to support and enhance the quality of these emerging services, as the UKCEN has done.
Implicit within the stated need for formal clinical ethics support is the assumption that formal services must offer something over and above what informal peer consultation can offer. There must be a demonstrable benefit of using the system over informal mechanisms to justify the change in practice. Study participants raised three major criticisms of the CEAG that they felt demonstrated it would be no better able to offer ethical support than their existing informal mechanisms:

1. They highlighted that referring a case for consultation to the CEAG is a more laborious mechanism to access than a quick corridor consult; it requires a greater investment of time and energy on the part of both the clinicians accessing the service and those volunteering to provide it.

2. The training of CEAG members in ethics is not necessarily greater than the senior colleagues that a doctor in need might otherwise consult, at least at present.

3. Despite their diverse clinical backgrounds, members of the CEAG may not necessarily have the specific clinical expertise necessary to grasp the intricacies of the cases referred to them, as not all specialities are represented.

There are two things that a CESS should be able to offer clinicians that informal systems cannot. The first is a just, independent process of resolving ethical dilemmas that uses validated mechanisms of ethical deliberation. The second is an opportunity for education and professional development in managing ethical issues. These two features will be examined in the following discussion. I discuss them in turn in the following two chapters.

### 6.3 The need for formal ethics support

This section will address how CESSs can aid doctors in making decisions by providing a just, independent process to weigh up ethical considerations in practice.

First, it must be emphasised that participants in my study recognise the importance of shared decision-making. In proposing an independent forum for clinical ethics support provision, I do not mean to imply that doctors are not taking patient wishes or other ethical considerations into account in routine decision-making. However the two cases described below are illustrative of the importance of having an independent forum for ethical decision-making – a need which could be met by an ethics support service. The specifics of the cases have been altered slightly to protect anonymity, but the essence of the ethical dilemma that lay at their core has been preserved.

The first case was that of a family struggling to decide on a treatment course for a family member rendered unable to make his own decisions by severe illness. The family was split into two groups,
each of whom wanted different courses of action. The clinical team were exasperated by the conflict, which they felt was fuelled by misunderstandings and ignorance. The terms the participant used to describe the particular case were telling; the family was “dysfunctional”, the parents were “extremely aggressive”, the demands were “not appropriate”. The participant framed the ethical conflict as a battle of reason against ignorance.

While it is possible that the family were indeed belligerent and unreasonable, this story demonstrates an important point about the contexts in which ethical decisions are made in healthcare environments. Often these decisions are made in situations of high emotion, conflict and communication breakdown. It is important that differing perspectives are not interpreted as necessarily irrational perspectives. When patients and their families are put into the broad class of ‘difficult’, it can be all too easy to diminish their concerns as less valid and their input into negotiation and discussion as less valuable. Fiester argued that once a patient has been saddled with the label of ‘difficult’, this becomes an unstated justification to end dialogue, where it should indicate the imperative, or even the moral obligation, of fostering dialogue. (Fiester, 2012)

The scenario presented in this case, where neither party feels heard and each party feels the other is wrongheaded in their thinking, was widely recognised by participants as a common ethical dilemma. Many of the participants concurred with the view expressed by Fiester that communication is the key to working towards resolution but equally pointed out that by the time conflict has escalated to that level, damage has been done to the doctor-patient relationship such that neutral dialogue is close to impossible.

_We rely on the trust of the family to do the best for the patient. And once you lose that, then your entire relationship breaks down. They don’t trust the nurses, they don’t trust the doctors, and you can’t look after people in that environment. I think in some cases the best thing to do is just to take them away from this and send them to another ICU where you can start to rebuild that trust._ (4)

The participant who offered this view was not realistically suggesting that cases in which conflict occurs could be feasibly sent to another ICU. But the notion of starting afresh that Participant 4 proposes is an important one. A CESS has the value of being independent from the conflict in scenarios like this, and thus has the potential to provide a forum in which stakeholders in the decision-making process can share their perspectives and deliberate.

The second case illustrating the need for an independent forum for clinical ethics support was that of a clinical team and a family struggling to decide whether to continue life-prolonging measures for a patient in a semi-conscious state. The patient had fought a long battle with illness, and death
within the following week or so was inevitable. The patient’s condition was such that nutrition could only be provided using invasive means, which was felt to be causing distress to the patient. The clinicians and the family were weighing up whether to continue to provide nutrition and accept the potential suffering that this might cause, or to remove the source of nutrition and accept that this had the potential to curtail the patient’s life.

The family and the clinicians felt that the best course of action was not to continue with invasive nutrition. However, despite the consensus, they requested an ethical case consultation on the matter. The CEAG convened an urgent sub-group, which included a specialist not involved in the case whose clinical expertise was co-opted for the deliberations. After a deliberation process, they provided the opinion that the course of action decided on by the clinicians and the family was ethically sound.

This case stood out for the fact that an ethics consultation was sought even after the treating team and the family were able to agree on a course of action. This demonstrates a very important point: that ethical conflict can exist in the absence of interpersonal conflict – just as interpersonal conflict is not always an indicator that values are in conflict. This is worth highlighting because of the extent to which some participants in this study seemed to rely on interpersonal conflict as a proxy marker for an ethical dilemma. Where this is occurring there is a real risk of not recognising ethical dilemmas that are not red-flagged by conflict. Daniels points out the risk of “[ignoring] underlying ethical disagreements because we think the decisions are technical and involve no value judgments”. (Daniels, 2004) This is all the more important a consideration where ethical issues may be missed simply because there are no frank disagreements.

What motivated the clinicians and the family members of this patient to seek the support of the CEAG was that they needed the decision they had made to have the legitimacy of a fair, independent process. The responsibility of deciding whether or not a person receives life-prolonging treatment is something that no family member or clinician takes lightly. Having made a decision, knowing that the decision has been rigorously reviewed and deliberated on by an independent expert committee is reassuring.

This case illustrates that even in instances where all stakeholders want the same outcome and have achieved a consensus about a course of action, there is still a need for an independent forum for ethical deliberation. This reinforces the legitimacy of decision-making outcomes by ensuring there is a robust system to give all facets of a case due consideration. This is particularly important in light of the fact that the ethics decision-making processes that most participants use are informal ones learned by observing peers or developed ad hoc in what one participant described as the “baptism by fire” of entering clinical practice. (9) These informal processes are not necessarily
wrong or unjust, but as Agich argues, without accountability for ethical practice – whether internal or external – quality cannot be assured. (Agich, 2009)

The value of a formal CESS in this situation is thus twofold. Firstly, in clinical scenarios where ethical uncertainty exists, an external ethical consultation service can provide both a forum in which the process of ethical deliberation can take place; and a framework for ethical reasoning. Secondly, the framework provides what Participant 4 described as a benchmark for “external validation and appraisal” of existing practice, which clinicians can use to reflect on their own practice and potentially use to strengthen their own practice in future.
Chapter 7: Procedural justice

Here I argue that procedural justice is essential to legitimize the process of ethical deliberation provided by the CEAG. The first section of this chapter discusses how ethically justifiable decisions are made. The second section draws on Daniels’ account of procedural justice to establish three criteria critical to be met to achieve procedural justice in clinical ethics support: 1) stakeholder involvement in ethical deliberation; 2) transparency and publicity of CEAG procedures; and 3) monitoring and evaluation of clinical ethics service provision.

7.1 What do we mean by justice in clinical ethics?

This section will examine how ethically justifiable decisions are made and will define procedural justice as a consideration in making ethically justifiable decisions in the New Zealand health care setting. I contend that three features are necessary: patient and clinician involvement in the deliberation process; transparency and publicity of processes; and monitoring and evaluation built into service design.

It is clear that irrespective of their views on CESSs, all participants in this study agreed on the importance of ethical clinical practice. Participants consistently stated that they wanted to make the right decisions for their patients.

This begs the question of how “right” decisions are made. I would argue that it is the process of clinical ethics support provision that gives value to its outcomes. For decisions to be fair the process by which they are made must stand up to scrutiny.

Participants in this study identified many instances in which ethical principles seem to suggest different courses of action, or instances in which different stakeholders in a decision-making process hold different ethical principles to be of value. In fact, instances of value conflict – whether between the patient and the doctor, or within the health care team – were most frequently cited by participants as the most ethically challenging situations and were the situations in which they were most likely to seek external help with ethical decision-making.

In the New Zealand health care setting, practitioners have a mandate to provide patient-centred care. (New Zealand Medical Association, 2008) In settings of value conflict, given the unequal distribution of power in the doctor-patient relationship, the onus should be on the medical profession to ensure the patient’s perspective is adequately taken into account. This generates an obligation on the profession to ensure that when doctors and patients disagree on ethical principles that will impact on a patient’s management, there is a mechanism to objectively balance competing or differing interests.
Procedural justice describes a mechanism that strives to promote “moral legitimacy for outcomes” in instances where there is no “consensus on substantive principles” of ethical import. (Daniels, 2004) Procedural justice involves acknowledging the plurality of ethical perspectives and having a framework to gather information on differing considerations, and to deliberate on apparently competing ethical values and practical considerations to endeavour to ensure that balanced and fair decisions are made. It depends on the creation of a forum for ethical discussion that affords all stakeholders the opportunity to put forth their perspectives for consideration.

### 7.2 Criteria to achieve procedural justice

Daniels has developed an account of just process for the purposes of making resource allocation decisions in health care (Daniels, 2004) and his framework has been used by WHO, for example, in making resource allocation decisions for antiretroviral therapy for HIV/AIDS on a global scale. The framework draws on a Rawlsian theory of justice and emphasises the deliberative nature of the process to better achieve fair outcomes. He highlighted four criteria necessary to ensure the system is able to account for differences of opinions while working towards just outcomes. The following text outlining the four conditions is taken directly from his account:

- **Relevance Condition:** Stakeholders affected by these decisions must agree that the rationales rest on reasons, principles and evidence they view as relevant to making fair decisions about priorities. Community and stakeholder participation and voice must vary in an appropriate way with institutional context.

- **Publicity Condition:** The process must be transparent and involve publicly available rationales for the priorities that are set. People have a basic interest in knowing the grounds for decisions that fundamentally affect their wellbeing.

- **Revisability and Appeals Condition:** The process allows for revisiting and revising decisions in light of new evidence and arguments, and allows for an appeals process that protects those who have legitimate reasons for being an exception to policies adopted.

- **Enforcement or Regulation Condition:** There is a mechanism in place that assures the previous three conditions are met. (Daniels, 2004, ii)

Daniels’ account of just process is a valuable starting point for a discussion about fair process that could be used in the provision of clinical ethics support. However, in adapting Daniels’ account to the clinical ethics support setting, distinctions between the uses of these frameworks must be made.

Firstly, and most importantly, the function of policy setting and ethics consultation are different. The process defined by Daniels was one designed to make decisions that will directly result in
specific actions. The role of a CESS, by contrast, is purely *advisory* with no decision-making powers. As such, the revisability and appeals condition does not apply in this context.

Secondly, Daniels’ account is designed for making decisions that have broad-reaching implications and innumerable stakeholders. In the clinical ethics setting, most decisions will have comparatively few stakeholders and so the requirement to include them in decision making is, if anything, stronger in the case of clinical ethics.

Thirdly, Daniels’ account of fair process is specific to the situation of making resource allocation decisions. Clearly, the kinds of ethical dilemmas that will be encountered by a CESS will cover a greater breadth of ethical issues than resource allocation alone.

In light of these considerations, I have revised Daniel’s four criteria to apply to fair process in clinical ethics support. Commentary on the importance of these features and some practical considerations in their implementation are drawn from the findings of this study and other literature.

A. *Stakeholder involvement in deliberation process:* This includes involving clinicians and patients (and their families or advocates) in both the initial fact-finding discussion and the process of ethical deliberation. I contend that at the very least stakeholders should all have the opportunity to independently present their perspectives. Optimally, they should be engaged in the process of finding resolution of the ethical issue so that they can feel that they have been given the opportunity to have their say and can buy into the outcome. For clinicians, involvement in the process of working towards a solution will equip them with strategies for resolving future ethical dilemmas.

B. *Transparency and publicity of processes:* This entails the CESS taking a proactive approach to publicising the procedures that they use to aid clinicians and patients in resolving ethical dilemmas. This includes but is not limited to: a) making information available to stakeholders on how they can access the service; b) having and communicating clear ground rules for the deliberation process; and c) where a particular model of ethics decision-making (such as principlism)\(^1\) is used, making this explicit and inviting stakeholders to offer differing views.

---

\(^1\) Beauchamp and Childress’ Four Principles account of principlism is widely used as a framework for clinical ethics case consultation. Two other commonly used frameworks are Jonsen and Toulmin’s account of casuistry, and varying accounts of narrative ethics, perhaps best exemplified by Hunter. (Jecker, 2008; Nicholas & Gillett, 1997)
C. Monitoring and evaluation built into service design: On-going monitoring and evaluation is an important mechanism for accountability and is important to attain legitimacy for the service and gain the trust of users.

Each of these conditions of fair process in case consultation will be considered separately in greater depth in the following discussion.

7.2.1 Stakeholder involvement
There are two dimensions to stakeholder involvement that merit separate discussion. The first is the involvement of patients and their families and advocates. The second is the involvement of clinicians. In this section, a justification for the involvement of each of these two major groups of stakeholders will be addressed in turn, incorporating suggestions about how involving stakeholders might take place.

There are two stages at which stakeholders can be involved in case consultation: the fact-gathering stage and deliberation stage. The CEAG does not currently include patients in either stage. In fact, many patients are not even informed that their case has been referred to the CEAG, let alone given the opportunity to present their perspectives.

Clinicians are given the opportunity to present the case that they refer, but the deliberation session is closed to them also.

Patient involvement
For clinical ethics support in the context of case consultation to be just, patients must be allowed to represent their own interests directly and in a safe, neutral environment. If they are unable to represent their own interests, a member of their family, or another representative should have the opportunity to do this on their behalf. New Zealand’s health care system places strong emphasis on the primacy of patient-centred health care delivery. Any organisation that has the power to influence the way decisions are made about a patient’s care must ensure that the patient’s interests are adequately represented in the process. This remains true irrespective of whether they function in a purely advisory capacity or they can compel mandatory care decisions.

There are two reasons why patient involvement is important. The first is that in order for the deliberation to be just, the parties deliberating must have access to complete and accurate information, which is best achieved through patient input. The second is that to achieve better patient-centred care, it is optimal to involve patients in making their own health care decisions.

The importance of full information to just process is described by Daniels, who emphasises that the first step in making ethical decisions is to “undertake a careful, comprehensive gathering of
relevant evidence that bears on the empirical background to the various ethical issues at stake”.

(Daniels, 2004) In his keynote speech on at the Best Practices in Clinical Ethics Consultation and Decision-Making conference in 2012, Diekema emphasised the importance of hearing the patient’s perspective, stating that “good ethics decision-making requires getting good facts, not ‘filtered’ facts”. (Terry & Sanders, 2011) This highlights the fact that even with the best intentions, a health care professional is not able to capture and report a patient’s view as accurately as the patient could in expressing this view themselves. In the interests of ensuring that deliberation takes place with the best and most complete information, it is necessary to hear patients’ views.

It could be argued that for the CESS to get accurate information, the patient could be offered an opportunity to share their views without being privy to the subsequent discussion and deliberation process. This model is used by some ethics consultation services for various reasons. Some services have expressed that they do not want to “expose patients to a potentially adversarial environment”. Others have suggested that patients are excluded to “protect them from potential harm arising from a detailed yet speculative discussion”. (Fournier et al., 2009) I would argue that it is diminishing to patients to suggest that they are unable to have input into decision-making processes on the off-chance that involvement will be distressing or harmful, particularly given that they will have to bear the consequences of that decision-making. It is true that there may be a risk of distress to the patient by being involved in deliberations, but this is at most a reason not to compel patients to participate. It is certainly not a reason to deny them the opportunity altogether.

As such, I would recommend that clinical ethics consultation services have staggered levels of patient involvement and that it is left largely at the patient’s discretion to determine the extent they wish to be involved. If it is their preference not to be involved, there should be a mechanism available to gather information on their perspectives before deliberation, for example by having a single CEAG member speak with them in an environment of their choosing – perhaps at the bedside. If they want to be involved in the full deliberation process, I would suggest that the onus falls on the CESS to set and maintain ground rules such that the environment is as un-adversarial as possible. This would serve the purpose of minimising harm to patients and would likely benefit the process of rational deliberation in general.

Yen and Schneiderman found that in instances where patients and their families were dissatisfied with ethics consultation processes the reason they cited was consistently that they were not adequately involved in the decision-making process. (Yen & Scheiderman, 1999) The right of the patient to have their “needs, values, and beliefs” taken into account in service provision is protected under Right 1(3) of the Code of Health and Disability Services Consumer’s Rights. (Office of the Health and Disability Commissioner, 1996) Given New Zealand’s diverse cultural,
religious and ethnic population, it is not valid to assume that it is possible, even with broad representation on a committee, that the patient’s unique perspective will be represented adequately without their direct input. Furthermore, the NZMA Code of Ethics for the New Zealand Medical Profession states that “doctors should ensure that patients are involved, within the limits of their capacities, in understanding the nature of their problems, the range of possible solutions, as well as the likely benefits, risks, and costs, and should assist them in making informed choices”. (New Zealand Medical Association, 2008)

The obligation of New Zealand doctors to involve patients to the extent of their capacity and willingness is enshrined in our codes of ethical practice. The kinds of cases that are referred for case consultation often involve dilemmas that are thornier than the run-of-the-mill cases and the imperative of protecting the right of patient involvement in these cases, where the stakes are potentially higher, becomes all the more important. In addition, I would argue that most doctors want to make patient-centred health care decisions. Where this process is challenged by conflict or misunderstanding, the availability of a mechanism to support patients to voice and negotiate their interests in a neutral setting is critical to aiding doctors to achieve that end.

_Clinician involvement_

I argue that clinician involvement in clinical ethics consultation processes has two main benefits. The first is that clinician involvement makes the process of ethical deliberation transparent and accountable, promoting clinician trust in the procedures and, as such, their buy-in to the outcomes. The second benefit is that where clinicians are given the opportunity to be involved in deliberation, it becomes an educative experience that equips them with the knowledge and skills to better address ethical issues in practice in the future. I will discuss this first point here, but the second point – that case consultation with clinician involvement has educational value – befits its own discussion and is addressed in chapter 8, “Ethics education as a clinical ethics need”.

Involving clinicians in case consultation is an important way to address the concerns expressed by multiple participants in this study about the chain of accountability in ethical decision-making where clinical ethics consultation is sought. Some participants felt concerned that they would be liable for decisions made because of clinical ethics input if they followed advice, even if they disagreed with that advice. Even where they recognised that the opinion of a clinical ethics consultation is advisory in nature, they reported feeling that having requested a consultation it would be difficult to justify not taking the advice offered.

The way that clinicians framed the issue of referring a case without being privy to deliberation was that they were in a position of relinquishing autonomy over decision-making while retaining accountability for outcomes. Participants recognise that they are accountable to their patients for
their clinical decisions irrespective of how the decision was made. As such, it is important for them to feel adequately involved in the process because they will have to wear the outcome.

7.2.2 Transparency and publicity of processes

Transparency underpins all of the other important features of clinical ethics consultation services in that even if a service achieves best practice in clinical ethics, unless it is perceived to do so, its efforts to provide support are completely undermined. This was demonstrated clearly by the fact that much of the wariness expressed about the CEAG by participants in this study was fuelled by misunderstandings about what the CEAG does or claims to do. Most participants, even those who had used the services, expressed confusion about how the ethics support services provided by the CEAG are delivered. Put simply, unless potential users understand and trust that a CESS is able to aid them in resolving clinical ethics dilemmas, they will remain potential users.

The lack of information available about the CEAG’s role and procedures has, if anything, undermined its ability to successfully provide clinical ethics support more than any other factor. Clinicians raising questions about the CEAG positioning itself as a moral authority or having the power to override clinical interests reflect the fact that the CEAG has not adequately communicated its intentions and function to the clinicians it aims to serve. It is clear from the CEAG’s Terms of Reference that the CEAG offers itself as “an advisory body only: it does not have any executive function in decision making”. Furthermore, “the CEAG’s recommendations are not binding and clinical decisions remain the responsibility of the treating healthcare professional(s)”. (“Terms of Reference - Capital and Coast District Health Board Clinical Ethics Advisory Group,” 2011) Concerns about the CEAG undermining clinical autonomy in patient care are unfounded, but the fact that they were raised at all indicates how little some clinicians at CCDHB know about the service. The features of just process I have described here are critical in ensuring that the CEAG is accountable for its practice and – equally importantly to gain the trust of users – is perceived to be accountable for its practice.

7.2.3 Monitoring and evaluation built into service design

Here I will discuss the importance of evaluation in ensuring quality and accountability and in building stakeholder trust. I compare three methods for evaluating CESSs: clinical outcome measures, stakeholder satisfaction, and process evaluation. I conclude that process evaluation is the most suitable evaluation method.

The value of a CESS as a mechanism to enhance reflective practice is contingent on its own robustness as an evidence-based resource. A challenge inherent in this is that what constitutes best practice in clinical ethics is an evolving concept. The last decade has seen a coming of age of clinical ethics along a trajectory that is moving from early iterative development to a stage where
services are subject to evaluation, and where best practice in clinical ethics is being established. (Dubler et al., 2009; Pearlman, Bottrell, Altemose, Foglia, & Fox, 2013; Pfäfflin, Kobert, & Reiter-Theil, 2009; Terry & Sanders, 2011; Williamson, 2007) In 2010, a conference in London was “the first of its kind dedicated to identifying best practices in clinical ethics consultation and decision-making”. (Terry & Sanders, 2011) However, rapid development of literature is a common feature of many medical fields and the demands of keeping up with a changing evidence base is not a reason not to strive for continual development.

Just as clinicians need the trust of their patients to achieve anything in medicine, clinical ethics consultation services depend on the trust of users – clinicians and patients alike – and this trust must be earned by demonstrating that their procedures stand up to external scrutiny. Medical culture places strong value on actions justified by evidence, but the end points of assessing the “rightness” of an ethical decision are difficult to define. The literature on evaluation of clinical ethics support has thrown up a wide range of potential measures for assessing whether CESSs are achieving their aims.

Many evaluations of CESSs have looked at the outcomes of clinical ethics consultation to weigh up how well services are contributing to ethical decision-making. (Dubler et al., 2009; Godkin et al., 2005; McClung et al., 1996; Pfäfflin et al., 2009) Both clinical endpoints (such as length of stay in hospital or patient mortality) and non-clinical endpoints (such as user satisfaction) have been used to determine the efficacy of clinical ethics support. (Orr, Morton, DeLeon, & Fals, 1996; Schneiderman et al., 2003)

I argue that clinical outcomes alone are not a good measure for assessing the efficacy of a CESS. CESSs pursue aims that, while they may be tangible, are not necessarily quantifiable. For example, it may be the “right decision” for one person to be offered life-prolonging measures while it would be equally “right” for another person to be allowed to die. What gives the decision its value of rightness is something unique to the case in question and unique to the individual patient concerned. To use clinical outcomes as a sole measure of efficacy is to run the risk of only taking technical considerations into account in decision-making, which Daniels warns against. (Daniels, 2004)

The use of stakeholder satisfaction to evaluate CESSs is closer to the mark. This method recognises that people affected by challenging ethical dilemmas need to feel that their input has been valued and that they have contributed to a resolution. But using stakeholder satisfaction as a sole measure of a successful outcome carries the implication that CESSs are aiming to ‘please’ the people. And while it is true that a good ethics support service may win the approval of those who use it, this must be regarded as a fortunate side effect rather than an end to pursue in its own right.
Interestingly, a study by Orr et al of patient and clinician evaluations of clinical ethics consultations found that satisfaction with consultation was not correlated with the perception that consultation had been helpful. (Orr et al., 1996) This finding was borne out in my research. Participant 3, a clinician who had referred a case to the CEAG, stated that even though he disagreed with the recommendations of the CEAG on a personal level, he was happy to accept the recommendation because he felt that the decision had been deliberated on in what he perceived to be a fair and appropriate way.

The fact that both clinicians and patients place value on a process of clinical ethics consultation rather than simply on whether the outcome was the one they wanted suggests that process evaluations could be a useful tool for appraising how well CESSs function.

Pfäfflin et al, in describing a mechanism they have developed to critically appraise the performance of clinical ethics consultation services, state

   ... we prefer to assess a kind of Rawlsian ‘‘procedural justice,’’ that is, whether the participants experienced the process of consultation as fair. The ethical dimension of ‘‘justice as fairness’’ includes all affected persons, even those who are absent. . . Justice as fairness opens the horizon because it appeals to the need to follow a fair process and include all interested persons in the consultation. (Pfäfflin et al., 2009)

Pfäfflin et al, after analysing a range of methods that have been used in the literature to evaluate clinical ethics consultation service, suggest that the way forward may be to develop a process evaluation tool. They propose drawing on multiple sources of information to gain a more complete picture of how CESSs are experienced by users and how they contribute to enhancing ethicality in health care organisations.

Ultimately, the debate on how to effectively evaluate the performance of a CESS is on-going. It is not a question that can be answered in the scope of this discussion. It is sufficient to emphasise the importance of monitoring and evaluation of CESSs to ensure their accountability and continuing quality improvement – to promote clinician trust in the services and, most importantly, to promote the interests of patients.

In summary, I have so far argued that a CESS must be just. Given the pluralistic nature of many countries, New Zealand especially, justice is best understood as procedural justice. I have presented an adapted version of Daniel’s account of fair process, one that is tailored to the clinical ethics context. I contend that fair process in a CESS relies on three features: patient and clinician involvement in the deliberation process; transparency and publicity of processes; and monitoring and evaluation built into service design.
Chapter 8: Clinical ethics education

8.1 Overview
This chapter discusses the second key area of need to be addressed by a CESS: education in managing ethical issues. For the purposes of this discussion I define ethics education as training in ethical reasoning and deliberation processes and managing ethical conflict.

The first section will address the broad issue of teaching medical ethics. Section 2 considers participants’ reflections on their ethical teaching during their medical training. Section 3 summarises participants’ assessments of ethical competency (both their own and their peers). And finally part 4 examines how case consultation could provide a forum of participatory education for clinicians that may be stronger than current didactic methods of ethics education.

I will argue that there are three benefits of using case consultation as a mechanism for medical ethics education. The first is the benefit for individual clinicians in building ethics capacity by providing a toolbox of clinically relevant approaches for managing ethical issues in practice. The second benefit is that case consultation provides an independent and validated standard of ethical best practice against which clinicians can evaluate their existing practice. The third is that where clinicians adapt the evidence-based models of managing ethics into their own practice, they strengthen ethical practice across the institution by a) modelling an effective approach to managing ethical concerns and by b) becoming sources of ethics support themselves – in what Participant 1 described as an ethical network.

8.2 Clinical ethics education: contextualising the issue
The challenge of teaching doctors clinical ethics has been a topic of contention in the literature in recent years. (Caldicott & Danis, 2009; Campbell, Chin, & Voo, 2007; Hafferty & Franks, 1994; Mills & Bryden, 2010; Myser, Kerridge, & Mitchell, 1995; Siegler, 2002) Perhaps the only point that is not disputed is that it is important that doctors learn to be ethical; there is disagreement in the literature about everything from aims to methods to outcomes of teaching ethics to medical students and medical trainees.

Because of this, it is important to define the parameters of this discussion. Firstly, I am not postulating that CESSs are in a position to “solve” the issue of teaching ethics to doctors. CESSs may have a part to play, as I will argue here, but they are only one of many factors in determining the ethical standards of doctors’ practice. The myriad of other factors, such as the culture of medicine and of institutions, the undergraduate clinical ethics curriculum and continuing medical education requirements in the field of ethics may be touched on in this discussion insofar as they define the context of clinical ethics consultation service as a tool for education.
Secondly, it is worth noting that the participants of this study are all senior doctors. As such, their comments on undergraduate medical training may not have particular bearing on the current undergraduate curriculum, which has undergone considerable evolution over the last few decades. (Hafferty, 1998; Mills & Bryden, 2010; Gray, personal communication, April 2012)\(^2\) I contend that although these perspectives might not reflect directly on current challenges in undergraduate training in New Zealand, they provide an important commentary on the culture of ethical decision-making at CCDHB and demonstrate a current need for education in ethics to be embedded in the clinical setting.

8.3 Clinician perceptions of ethical training

This subsection will address participant perspectives on ethics education and training. This will contextualise discussion in subsequent sections on how a CESS might contribute to filling the gaps that participants identify in current clinical ethics training practices.

A strong theme to emerge was that participants identified education in ethics as the area in which a CESS could be of greatest benefit.

It was evident that participants would value a service that helps them to make better decisions, rather than a service that makes decisions for them. Without exception, they identified ethical competency to be important and feel that it is a core skill for clinicians to be effective ethical decision-makers. Indeed, one of the main objections to the idea of a CESS was that some participants regarded it as shirking clinical responsibility to refer challenging cases. This demonstrates the importance of a service that focusses on equipping clinicians with the skills that they need to better manage ethical issues in their own practice.

An equally striking theme was the paucity of what participants judged to be effective ethics education. All clinicians described a similar experience of ethics training: if they had received any formal training at all, it was didactically taught undergraduate training that felt irrelevant to clinical practice. Participant 5 stated that undergraduate medical education was “detached from real life” and went on to comment “I think human nature is such that you only learn these things when you actually grapple with a problem. And sitting in a classroom having a pretend problem to grapple with is not the same thing”. (5)

After leaving medical school, the process of learning ethics in practice was described by clinicians as experiential: clinicians were expected to learn ethics by what was variously described (at the

\(^2\) Dr Ben Gray is the current convener of the Professional Skills, Attitudes and Ethics module of the clinical medical student curriculum at the University of Otago, Wellington.
more generous end of the spectrum) as “passive acquisition” (4) and (more starkly) as a “baptism by fire” (9).

What emerged from participants’ descriptions of ethical training were two conflicting messages. The first was that they would like to feel better equipped to manage ethical issues in practice, which would imply that they think further ethics education would be of value. The second message, which at face value seems slightly contradictory, is a perception that practical clinical ethics is something that can’t be formally taught. Participants expressed views that ethics is either something so inherent to human nature that it cannot (and perhaps need not) be learned, or that it is something that each clinician develops personally through the rigours of practice – as Participant 2 expressed it, “something that’s made up as one’s gone along.” (2) Participant 5 summed up this widely experienced scepticism of ethics education simply: “I don’t know how you’d teach that in a way that would be helpful.” (5)

This apparent contradiction is a reflection on the two models of ethical training that the participants had been exposed to, neither of which is meeting clinicians’ needs fully. The first was a formal medical school ethics curriculum, in which ethics was taught divorced from the practical realities of clinical medicine and thus did not feel applicable. The second is what Hafferty and Franks describe as the process of “moral enculturation”, where clinicians adopt the normative practice of the medical cultural environment they are immersed in. (Hafferty & Franks, 1994) It is clear that neither of these models of ethical training was perceived by participants to be adequately meeting their needs and this seemed to be influencing the scepticism of ethics education that the participants expressed.

A criticism of an overly theory-based teaching approach – which is how participants described their undergraduate training – is that knowledge of ethics is separated artificially from use of ethics. The lack of applicability of the academic tools they were given is apparent in participants’ descriptions of beginning clinical practice and feeling so out of their depth. This is not to decry the usefulness of ethical theory in medical education. Participant 9’s comment – that one cannot learn to perform an operation from a textbook, but that the operation will make more sense if one has some book knowledge beforehand – could be equally taken to apply in ethics education. But it is clear that for clinicians to buy into ethical education, it must have demonstrable applicability to their own practice. Participants found undergraduate ethical education irrelevant because at that stage they had no clinical context to frame it; they had never had the experience of “waking up in the middle of the night and saying heck! I’ve buggered this one up!” (5)

Some participants also had concerns about the second element of ethical education – of moral enculturation. Participant 4 and 6 both expressed wariness that immersive experiential learning
without external oversight has potential to lead to ethical practice that lacks normative validity. As participant 6 reflected “you can always learn the wrong things from experiences.” (6) In addition, several participants identified elements of medical culture that inhibit ethical discourse. They added that the culture is perpetuated through generations of clinicians in the apprenticeship model of teaching practice, without adequate critical analysis of the validity of cultural norms.

The lack of suitable ethical training can leave junior doctors feeling isolated and out of their depth. Several described not feeling as if they had strategies for managing ethical issues until they were more senior. Several participants made the comment that they would not want junior staff coming through the system now to go through the same experiences of uncertainty and isolation, but added that they feel that the intransigence of medical culture perpetuates this challenge to junior staff.

I would argue that clinical ethics – by which I mean ethical reasoning and deliberation processes and managing ethical conflict – is a teachable skillset. Two criteria must be met. The first is that ethical education must be clinically contextualised and practically focussed in order to be applicable in a real-world setting. The second is that ethical education must be normatively robust. The fact that neither the formal nor informal systems of ethics education that participants experienced meet both criteria is not an indicator that ethics education is not possible. Rather, it indicates that there is a role for a model of continuing medical education in ethics that is both clinically pragmatic and intellectually rigorous.

8.4 Participant assessments of ethical competency

This section will address the observation that participants made differing assessments of their own ethical competence relative to their peers’ assessments and will discuss the significance of this both for practice and for ethics education.

An interesting theme to emerge from the data was the discrepancy between participants’ assessments of their own ethical competency as compared to colleagues in other departments. Most participants described feeling comfortable with their own standards of ethical practice and of the practice within their own department. However, many participants indicated that they felt ethical practice of other departments fell below par. This suggested that a consequence of the paucity of ethical training is that standards of ethical practice are likely to be variable amongst clinicians. Interestingly, criticisms were levelled by participants at the departments of other participants in the study – unbeknownst to each other – including at departments that participants self-assessed as having good ethical systems. Importantly, the discrepancy between self-assessment and peer assessment may indicate that poor standards of ethical practice are under-recognised.
In interpreting this disparity between self-assessment and assessments of colleagues, several issues need to be taken into consideration. The first is a potential methodological limitation. Despite the fact that one-on-one interviews with assurances of confidentiality can open up the scope of discussion, discussing areas of weakness in one’s practice is not easy. The fact that the interviewer was a medical student and the participants were all senior doctors – diametrically opposite ends of the medical hierarchy – could arguably have created a greater barrier to frank discussion in this area. However, the fact that participants were otherwise open in acknowledging the areas that they found difficult – in particular when they used illustrative cases to describe ethical issues they felt they could have handled better – suggested that reticence to discuss their own faults was not a major factor behind this disparity.

The second factor is that self-evaluation has been demonstrated to be a poor measure of clinician competence, with doctors being prone to over-rate their own abilities. (Barnsley et al., 2004; Davis et al., 2006; Overeem et al., 2012) A systematic review by Davis et al in 2006 examined the findings of 20 studies that compared self-assessments of physician competence with other observed measures of competence. Of these, 13 studies found no, little or even an inverse relationship between clinical assessments of competence and their competence as determined using independent measures. Of particular relevance is the fact that the physicians who performed most poorly at self-analysis were also those who were found to be a) the least competent and b) the most confident. (Davis et al., 2006)

A study by Overeem et al in 2012 compared evaluations by doctors themselves, peers from the same scope of practice, non-medical co-workers like nurses and social workers and patients to develop a valid multisource feedback tool. They found that while peer, co-worker and patient assessments correlated well and appeared to offer a broadly accurate measure of doctor performance, self-evaluation again proved an unreliable measure of clinician competence. (Overeem et al., 2012)

These studies were examining doctors’ abilities to self-assess on measures of clinical competence, but it is probable that the same phenomenon would be found regarding ethical competence. This is suggested by DuVal et al’s finding that doctors with the least training in ethics were the least likely to access formal ethics support, although the authors did not attempt to make an independent assessment of participants’ ethical competence. The authors commented that this finding indicates a wider need for education in ethics integrated into every level of training from the undergraduate curriculum to continuing medical education. (DuVal et al., 2004)
This finding has important implications in determining the goals of a clinical ethics service. While providing clinicians with support such as case consultation to manage clinical ethics issues is important, it is a service predicated on an assumption that doctors know an ethical issue when they see one. The challenge to a CESS whose function is geared purely towards case consultation is highlighted by participant 4, who described CESSs as “one of the things that you don’t think you need until you use it.” (4) This demonstrates the particular importance of gearing a CESS towards capacity building: a clinician needs to have attained a certain level of competence in ethics to gain insight into what they do not yet know.

In summary, participants want continuing medical education in ethics that is both clinically applied and academically rigorous.

8.5 CESSs as ethics training providers

For the reasons highlighted in the discussion above, I argue that training in managing ethical issues is both a necessary and feasible undertaking. This section will address how CESSs might meaningfully contribute to meeting this need for ethics education, as one part of a broader system of medical ethical education.

I contend that clinical ethics consultation provided by a CESS has the potential to fulfil both criteria as a mechanism for continuing medical education. I argue that the best way to achieve this is to use case consultation as a mechanism of participatory clinical ethics education.

The main mechanism by which the CEAG aims to perform its educative function is by providing seminars on key ethical topics for clinicians. I suggest that the CEAG might be selling itself short by not using its case consultation function as its main tool for enhancing clinical ethics capacity in the hospital. Seminars have the potential to be of great value in providing information about clinical ethics, but participants highlighted that didactic education strategies had been ineffective for them because they felt disengaged with hypothetical scenarios removed from clinical realities.

Case consultation, by contrast, has immediate clinical relevance. Several of the clinicians who had used the CEAG’s case consultation service – and some who had not – pointed out the educational value of case consultation with user involvement. When referrers participate in case consultation, the CESS a) models best practice in ethical reasoning and deliberation, b) offers clinicians specific skills for managing ethical conflict and c) provides feedback on clinicians’ existing strategies for managing ethical issues to enhance reflective practice.
8.6 A participatory approach to case consultation

This section will define what is meant by a participatory approach to case consultation and explain the merits of a participatory approach to maximise the value of case consultation by evolving it from an ethical trouble-shooting service to a means to equipping clinicians with the skills to better identify and manage ethical issues in future. A participatory approach to case consultation requires that the stakeholders involved in the decision-making process are present to observe and contribute to the process of ethical reasoning and deliberation (C/f Chapter 7, section 7.2.1 on “Stakeholder involvement”). Recall that under the current CEAG model, clinicians are not present for the deliberation phase. There are three benefits of using case consultation as a mechanism for medical ethics education.

The first strength of a participatory mechanism of case consultation is that referring clinicians have the opportunity not merely to have their problem resolved, but to observe and participate in the resolution process. Clinical ethics support is not a static resource, but a process that can be adapted to a range of situations and by seeing it modelled and experiencing how it works, they can see how it might be integrated into their own practice. Clinical relevance is a given because the cases referred are ones that clinicians are grappling with in real time. In this sense, a case consultation service is bringing ethical expertise into the clinical setting, rather than sitting as a clinical and ethical expert removed from the coalface of practice.

It is clear that participants want opportunities to discuss and debate ethical issues in practice; they value being exposed to different viewpoints and acknowledge that they have a lot to gain from the diverse and often complementary expertise and experiences of others. Participant 13 felt that one of the most valuable features of clinical ethics support would be witnessing – or better, participating in – ethical debate by those with experience and expertise in differing areas. He pointed out that observing the process that people use to approach problems that he did not ordinarily encounter was of great value to his own practice, particularly “people who come from a different angle having a dialogue” (13). Participant 12 emphasised the value of case consultation as a forum that brings together people of different expertise so that everyone can learn from one another’s strengths: “one person's problem is another person's bread and butter”. (12)

The second valuable feature of a CESS with a participatory structure is that it provides a means for clinicians to appraise their ethical practice. Structured case consultation can be a yardstick against which they can evaluate their own practice and feel reassured that the systems they have informally developed are valid and effective. Participant 4 indicated that the process of requesting formal ethical input is a sign of reflective practice and gives doctors the opportunity to a) validate the
strengths of their existing practice and b) identify weaknesses that they may not have had insight into.

In New Zealand, under the NZMA Code of Ethics, “doctors have a responsibility to participate in reviewing their own practice and that of others”. (New Zealand Medical Association, 2008) This obligation to improve practice is not limited to clinical development. Continuing medical education has a professional development element that includes ethics.

However, while in some countries centres are developing resources with which doctors and CESSs alike can appraise and strengthen their ethical practice (such as IntegratedEthics of the National Center for Ethics in Health Care in the US) there is no parallel structure or service in New Zealand. (Bottrell, Pearlman, Foglia, & Fox, 2013; Fox, Bottrell, Chanko, Foglia, & Pearlman, 2010; Pearlman et al., 2013) CESSs have the potential to fulfil this function, by maintaining and modelling up-to-date standards of ethical best practice and as such providing a means by which doctors may independently appraise their own practice.

The third benefit of CESSs using a participatory education model for clinical ethics is that it enhances ethical practice at an institutional level, so that even those who are not directly engaging with the service benefit from an institutional culture shift towards increasing ethical awareness. This benefit takes advantage of the process of moral enculturation by providing individual clinicians with the skills to discuss ethical issues at a higher level in their everyday practice. Where the predominant mechanism of learning ethical practice is moral enculturation, enhancing the practice of individuals – particularly senior individuals – is a means to changing the culture of an institution.

Participant 2 expressed the importance of clinicians being able to see an “effector arm” of a CESS, stating that such a service must “justify their on-going existence by demonstrating that they are actually changing practice”. (2) Where clinicians are active participants, learning from the process of consultation and deliberation, they are the effector arm of the service. The professional development referrers undergo through the process of case referral is the mechanism of “disseminating the results of [case consultation] discussions”. (2)

Where case consultation is closed off to clinician involvement, there is a risk that its utility is reduced to providing what Campbell describes as a “quandary ethics” (Campbell et al., 2007) resolution service. In fact, case consultation has the potential to be a mechanism to enhance ethical practice beyond a limited case-by-case basis. Involving clinicians in the process of case consultation turns it into a forum to model the use of ethical skills, provide a measure of ethical
best-practice and equip clinicians with approaches to ethical issues that can enhance practice throughout the hospital.

In summary, I have argued that further education in ethics is a clinical ethics need. I suggest that for doctors to feel engaged with ethics education they must perceive it to be clinically relevant and that it must offer useful ethical skills. I propose that when referring clinicians are able to participate in the case consultation process, CESSs are able to fulfill this need for relevant and robust clinical ethics education. This provides yet another reason why it is important to involve clinicians in the case consultation deliberation process.
Chapter 9: Summary and conclusion
An ethicist affiliated with the Auckland Clinical Ethics Advisory Group said in a 2010 article on clinical ethics support services in New Zealand, “No one thinks. . . Clinical Ethics Advisory Groups solve ethical dilemmas and no one thinks they do so alone. [emphasis added]” (Dare, 2010)
My research suggests the contrary: some doctors do think that CESSs are staking a claim to moral authority, and where this perception exists it is perhaps understandable that clinicians are wary of services.

Dare’s statement identifies an important challenge to CESSs in New Zealand by underscoring the fact that mutual misperceptions exist between clinical ethics support providers and the clinicians they serve. And where these misperceptions do exist, they undermine the ability of support services to meet doctors’ needs and enhance ethics practice in New Zealand. Empirical research, such as that undertaken for this thesis, serves a crucial role in clarifying what doctors think about CESSs so that misperceptions can be combated and services can be improved.

My interviews with senior doctors at CCDHB identified a diverse range of views on clinical ethics and clinical ethics support services. Most participants felt competent to manage ethical issues in practice, but some felt that their competence was hard-won and learned without support or guidance. All participants value ethical competence, but they differed in their perception of how ethical competence is attained. Some felt that ethics is either intrinsic or learned experientially, while others identified ethics as a teachable skill.

Many participants felt that formal CESSs had the potential to improve ethical practice, both on a case-by-case basis and by enhancing ethical practice across the CCDHB. By contrast, some participants felt that the availability of CESSs would lead to clinicians abrogating their ethical responsibilities, to the detriment of patients.

An analysis of participant perspectives on clinical ethics and CESSs suggested three key themes about clinical ethics support needs at CCDHB. Firstly, it is not enough for clinicians to depend exclusively on ad hoc mechanisms for clinical ethics support: formal CESSs can offer independent and accessible ethics support for all clinicians in a way that ad hoc systems cannot. Secondly, ethical deliberation by a CESS must use just procedures to ensure that their practices are normatively sound and that clinicians can buy into them. Thirdly, there is a need for formal continuing professional development in ethics beyond medical school; this could be effectively provided by a CESS if they adopt a participatory approach to case consultation.
My research suggests five key recommendations to begin the process of optimising the CEAG for the provision of clinical ethics support at CCDHB. I have summarised these below:

1. CCDHB CEAG should develop a formal and consistent set of procedures for their activities, particularly case consultation, using a procedural justice model.
2. CCDHB CEAG should involve clinicians in the deliberation process of case consultation, to increase their buy-in to clinical ethics consultation, to provide an appropriate chain of clinical accountability, and to take advantage of the educative opportunity that case consultation as an ethical forum provides.
3. CCDHB CEAG should allow patients and their families and advocates the option of being involved in the process of case consultation, to ensure that patients are given a voice and that their perspectives and values inform ethical deliberation.
4. CCDHB CEAG should conduct monitoring and evaluation of its service to ensure that it achieves and maintains clinical relevance and procedural validity.
5. CCDHB CEAG should actively disseminate accurate and appropriate information about its aims and processes to all users and potential users to enhance trust in their service and to clarify misunderstandings about their role.

In interpreting the findings of this research, it is important to look at the analysis in context. The CEAG is a new service that has been established without a precedent at CCDHB. The positive feedback they received from participants who had referred cases to them reflects that they are fulfilling an important niche. Their development is an iterative process: participants in this study and CEAG members alike point out that the function of the CEAG is likely to evolve and strengthen as the members become more knowledgeable and experienced in delivering clinical ethics support.

In addition, the CEAG’s services are provided on a voluntary basis with limited resources. As such, comparison with services overseas that have been mandated by law or otherwise have funding earmarked for their provision may appear unfavourable taken at face value. Much of the literature around best practice in clinical ethics has come from centres that are comparatively well-funded and have access to expertise and resources that are simply not available to clinicians in Wellington. (Godkin et al., 2005; Slowther et al., 2004b; Terry & Sanders, 2011)

CEAG has taken important first steps and my research provides guidance on how to move forward and strengthen the service.

This research is not without limitations. Like all qualitative research, breadth of information is sacrificed for depth. I was unable to include other health professionals in this study. If CESSs are
to cater to the needs of all clinicians, similar research must be conducted with other groups of health professionals. In addition, it became clear that the experiences of junior clinicians may be very different from those of senior clinicians. As such, my study was limited by sampling only senior doctors.

Furthermore, to an extent, participants in this study self-selected for involvement by expressing interest in being involved. The aim of qualitative research is not to achieve representativeness in the way that quantitative research should. It is possible that other doctors at CCDHB may hold different views about CESSs. There may be other clinical ethics needs and barriers to accessing support that this study was unable to reveal.

Although the research was conducted at CCDHB, some of the results are likely to be applicable more broadly. The arguments in favour of patient participants in CESSs draw upon principles of patient-centred medicine that apply throughout New Zealand. The misunderstanding about the aims of CESSs and the concerns relating to abrogation of moral responsibility are likely to be shared by clinicians in other hospitals. Given that there are only two medical schools in New Zealand, the experience of undergraduate medical ethics education and the need for on-going training in this area are likely to be widespread. My findings reinforce some of the conclusions of international studies in this area. This congruence allows CESSs in New Zealand relying on international data to do so with greater confidence. Significantly, many of the barriers to accessing clinical ethics support are the same. Misperceptions about services, lack of awareness about the existence of services and lack of insight into how ethics practice could be strengthened by services are common to both the international literature and this research. Effective international strategies developed by CESSs to reduce the impact of these barriers to accessing clinical ethics support may well translate into a New Zealand setting.

My research combining empirical and normative analysis strategies provides a strategy for further empirical research in clinical ethics and may be a useful guide to further research in this area. The qualitative data I have gathered may be able to inform future quantitative research. It should allow development of more targeted questionnaires to gain a greater breadth of information across institutions.

Priorities for future research in clinical ethics in New Zealand should include looking at junior doctors and other healthcare professionals. In particular, the clinical ethics support needs of junior doctors may differ from the needs of senior doctors, reflecting their relative position in the hospital hierarchy and their comparative inexperience. This befits further research into the clinical ethics support needs of more recent graduates to ensure they do not feel isolated and unsupported in their ethical practice.
Ensuring that New Zealand clinicians are ethically competent and well-supported in facing ethical challenges is imperative. It protects clinician well-being and enhances patient interests. The further development of CESSs in New Zealand, informed by research, can only bring us closer to achieving this end. The next step in strengthening CESSs is to bring them together to share their collective expertise, research and resources. The New Zealand Clinical Ethics Network currently under development will help the existing isolated and fragmented services to improve in capacity and quality. With any luck, clinicians nationwide will soon have access to effective clinical ethics support.
Addenda
References


and validation study of multisource feedback instruments. BMC health services research, 12(1), 80. doi:10.1186/1472-6963-12-80


Appendix 1: Regulation of medical ethics in New Zealand

This section provides a more comprehensive history of regulation of medical ethics in New Zealand and details of its current status.

New Zealand has had legislation governing standards of conduct for doctors since 1867. In that year, the Medical Practitioners Act created a national Medical Board authorised to oversee registration of the profession. The Medical Board had powers to discipline or exclude doctors on the grounds of professional misconduct. However, it was disestablished under revisions of the Act in 1869 and from this time until 1914, doctors could only be removed from the Register by the Registrar-General following conviction for felony or misdemeanour. Beyond this, the conduct of medical practitioners was not addressed in legislation. In 1914, further legislative changes saw the establishment of what would become known in 1924 as the Medical Council of New Zealand (MCNZ). The formation of the Council, composed entirely of doctors, marked the establishment of independent self-regulation by the medical profession, which continued largely unchanged until the late 1980s. (McLintock, 1996)

The late 1980s to early 2000s in New Zealand saw a shift from an almost entirely self-regulated medical profession to a health system with an external regulatory framework with considerable lay input. The driver for this change was the public and governmental response to what became known as the “Unfortunate Experiment” – a highly controversial study at National Women’s Hospital in which hundreds of women with cervical pathology were undertreated.

In 1987, a ministerial inquiry was launched following the malpractice allegations against the doctors responsible for the study. District Court Judge Silvia Cartwright’s subsequent report in 1988 found that existing systems from an institutional to national level were inadequate to protect the rights of patients. The report recommended widespread and radical reform of the health sector and led to changes in legislation and the formation of several independent, government-funded bodies to promote and uphold the rights of patients and human research participants. (Cartwright, 1988) Though the trigger for this overhaul of regulation had been local, the resultant change in medical culture and regulation was in keeping with the global trend away from paternalism towards a new culture of patient-centred health care. (Campbell et al., 2005)

One body that emerged following the Cartwright Report was the Office of the Health and Disability Commissioner, established under the Health and Disability Commissioner Act (HDCA) 1994. The Commissioner’s Office provided a new mechanism by which consumers with grievances with respect to the quality of the services they had received from a health practitioner could lay complaints and seek redress. The Commissioner was also charged with overseeing the
development of the Code of Health and Disability Services Consumers’ Rights, which passed into law in 1996. For the first time, the rights of patients and the obligations of individuals and organisations providing health care in New Zealand were codified.

The Health and Disability Commission (HDC) has had a hugely important role to play in ensuring ethical standards of medical practice are met and maintained in New Zealand. In particular, the HDC has provided an important avenue of recourse for patients concerned about standards of care and has strengthened the ability of patients to self-advocate. In large part the role of the Health and Disability Commission has been to redress the historical imbalance of power in the doctor-patient relationship. Their website describes their aspiration to be the champion of consumer rights. ("Health and Disability Commissioner - About Us," 2009)

Healthcare consumers or their advocates have the opportunity to raise complaints about standards of care that they have received and to seek redress. For the healthcare provider concerned, this may lead to changes in institution policy or practice, or education of the individual clinician(s) concerned, to ensure appropriate standards of care are achieved in future. If concerns are sufficiently serious, the complaint may be referred to the Director of Proceedings for disciplinary measures to take place or criminal charges to be laid. ("Health and Disability Commissioner - About Us," 2009)

Also in 1996, the New Zealand Health and Disability Advocacy Service was established. This was to effect Judge Cartwright’s recommendation that all health consumers have access to an advocate, independent of the government and health providers, to inform and empower them to ensure their rights are enacted. Health and disability advocates are now available free to all consumers of health and disability services in New Zealand, including advocates specialising in representing the interests of a number of minority groups such as the deaf community and the refugee and migrant communities. ("Background of the Advocacy Service,” 2009)

The Cartwright Report also recommended increased regulation of health research ethics. The New Zealand Public Health and Disability Act 2000 mandated the formation of seven Health and Disability Ethics Committees (HDECs) to provide independent ethical review of all research with human participants conducted in New Zealand. Prior to this, the ethical review of research was typically conducted by institutional ethics committees, if, indeed, any review took place.

2012 saw an overhaul of the HDEC system, following a Health Committee Inquiry in 2010 into the New Zealand research environment. The Health Committee’s report, submitted to the House of Representatives in June 2011, suggested a “simplifying and streamlining” of the ethics review process. ("Government Response to the Report of the Health Committee on its Inquiry into
improving New Zealand’s environment to support innovation through clinical trials,” 2012) As a consequence, the number of HDECs has been reduced from seven to four. Furthermore, the trigger point at which an ethics review by an HDEC is mandated has been raised, with a greater proportion of studies now being eligible for internal ethics review by the institutions conducting the research. (“Government Response to the Report of the Health Committee on its Inquiry into improving New Zealand’s environment to support innovation through clinical trials,” 2012)

Throughout the legislative changes of the 1990s and early 2000s, the Medical Council of New Zealand remained the statutory body responsible for enforcing standards both of clinical and cultural competency and the ethical conduct of doctors, a role reaffirmed under section 118 of the Health Practitioners Competence Assurance Act (HPCAA) 2003. The Council developed *Good Medical Practice* (Medical Council of New Zealand, 2008) as a benchmark of professional conduct. Since the passing of the HPCAA 2003, all doctors have been expected to familiarise themselves with and adhere to these standards of conduct to maintain their registration. *Good Medical Practice* is also used by the Health Practitioners’ Disciplinary Tribunal, the MCNZ’s Professional Conduct Committees and the Health and Disability Commissioner to determine acceptable standards of behaviour for doctors.

*Good Medical Practice* provides general information about expectations of professional conduct. It describes appropriate behaviour in a range of settings encountered in everyday clinical practice and informs doctors of their statutory responsibilities in delivering patient care. With regards to ethics, it confirms the historical role that the New Zealand Medical Association (NZMA) has had in developing and updating the Code of Ethics for New Zealand doctors. The NZMA is the peak representative body for the medical profession in New Zealand and it is a requirement of membership that practitioners adhere to the NZMA Code of Ethics. (New Zealand Medical Association, 2008)
# Appendix 2: Specialities of potential participants

*Table 2: Specialities of potential participants contacted*

<table>
<thead>
<tr>
<th>Specialities of potential participants contacted</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anaesthesia</td>
</tr>
<tr>
<td>Cardiology</td>
</tr>
<tr>
<td>Dermatology</td>
</tr>
<tr>
<td>Ear, Nose and Throat (ENT)</td>
</tr>
<tr>
<td>Endocrinology</td>
</tr>
<tr>
<td>Emergency Medicine</td>
</tr>
<tr>
<td>Gastroenterology</td>
</tr>
<tr>
<td>General Surgery</td>
</tr>
<tr>
<td>Infectious Disease</td>
</tr>
<tr>
<td>Intensive Care</td>
</tr>
<tr>
<td>Internal Medicine</td>
</tr>
<tr>
<td>Neurology</td>
</tr>
<tr>
<td>Neurosurgery</td>
</tr>
<tr>
<td>Obstetrics and Gynaecology</td>
</tr>
<tr>
<td>Oncology</td>
</tr>
<tr>
<td>Ophthalmology</td>
</tr>
<tr>
<td>Orthopaedics</td>
</tr>
<tr>
<td>Paediatric Surgery</td>
</tr>
<tr>
<td>Paediatrics/Neonatology</td>
</tr>
<tr>
<td>Palliative Care</td>
</tr>
<tr>
<td>Psychiatry</td>
</tr>
<tr>
<td>Radiology</td>
</tr>
<tr>
<td>Renal Medicine</td>
</tr>
<tr>
<td>Respiratory Medicine</td>
</tr>
<tr>
<td>Urology</td>
</tr>
<tr>
<td>Vascular Surgery</td>
</tr>
</tbody>
</table>
Appendix 3:  Interview template

The Role of Clinical Ethics Advisory Groups at the Capital and Coast District Health Board

I am looking at the way doctors make ethically challenging clinical decisions at the CCDHB. I am particularly interested in learning about the strategies and tools they use and how they learned or developed them. I would like to see if doctors feel they have received enough support and training in the way that they learned to deal with ethical challenges. I would also like to know if doctors feel that they would like more support in meeting ethical challenges in their current practice and if so, what form they think the support should take.

Questions about the role of the clinician

1. What is your role in the DHB?
2. What do you see as some of the ethical challenges of your role? Can you describe a case that you feel illustrates these challenges?

Questions about ethical decision making in the hospital

1. What strategies and approaches do you use to make decisions that are ethically challenging?
2. How did you learn to make decisions that were ethically challenging? Do you feel you had adequate training and support?
3. Who is involved in making these decisions and what is their role in the decision-making process?
4. Do you feel that you have the opportunity to discuss and work through ethically challenging clinical decisions? With whom? In what context or format?
5. Do you feel that you have the opportunity to debrief retrospectively on outcomes of ethically challenging clinical decisions? With whom? In what context or format?
6. What would be some aspects of a case that would make it challenging enough that you would seek support or external input in making your decision?
7. How do you think the culture or ethnicity of your patient influences your clinical ethical decision-making? Do you use different strategies or services for patients of different ethnicities? For example, the Whanau Care Services for Maori patients.

Questions about ethics support services:

A number of different forms of ethics support services have emerged over the past few years:

- On-call ethicists
- Ethicist input in MDT meetings
- Advisory groups to whom challenging cases can be referred for support and advice
- Further training and education for clinicians
- Protocols and guidelines provided by the health boards developed with the input of ethicists

1. Do you feel that clinical ethics support are a valuable service in theory and why?
2. If so, what form or format would be the most practicable and helpful for you practice?
3. In your clinical environment, do you feel it is practicable and helpful to seek the advice of a clinical ethics advisory group?
4. Do you feel that the current model of the CCDHB Clinical Ethics Advisory group is an effective model that could be applied to other DHBs around New Zealand and why or why not?
5. What do you think are the reasons clinical ethics advisory services are not widely available in many New Zealand hospitals? What do you think would need to change for there to be an increase in availability of these services?
6. What services do you think an effective clinical ethics support service should provide, if any? (Examples of what other services provide include case consultation on an urgent, acute and retrospective basis, education and advocacy of ethics in the area and contributing to the development of policy and guidelines within the organisations that they support.)
7. To whom do you think clinical ethics support services should be accountable?

**The CEAG**

The clinical ethics advisory group was set up in 2010. It has three roles according to its terms of reference:

- To provide a case consultation service on an urgent, acute or retrospective basis.
- To be involved in the development of CCDHB policy and guidelines.
- To promote ethical awareness. (Potential for the development of education and training.)

1. Have you sought the consultation services of the CCDHB Clinical Ethics Advisory Group? If so, could you describe the case/cases concerned?
2. How would you describe your experience taking a case to the CEAG? Were you satisfied with the outcome?
3. If you haven’t already, would you seek the advice of the CEAG? In what circumstances?
4. If not, what factors have lead you not to seek their advice?
5. What would you change to improve the accessibility of this service? (Including access issues specific to speciality.)
6. What would you change to improve the quality of this service? For example, what training or qualifications would you expect the CEAG to have as a group?

Demographic information

1. Which ethnic group do you belong to?
Appendix 4: Participant information sheet

The Role of Clinical Ethics Advisory Groups at the Capital and Coast District Health Board

Introduction:

You are invited to take part in a study looking how doctors at the CCDHB make ethically challenging decisions. We hope to interview doctors at the CCDHB about the ethical challenges they face in their job and the strategies and services they use to manage these challenges.

You are being invited to take part in this research because you are a doctor at the CCDHB.

Participation:

Your participation is entirely voluntary (your choice). You do not have to take part in this study. This will not affect your employment.

If you do agree to take part in the study, you are free to withdraw from the study at any time, without having to give a reason.

You don’t have to decide if you want to be involved in this study right now.

About the study:

We want to find out how doctors at the CCDHB make ethically challenging decisions and whether the Clinical Ethics Advisory Group is meeting the needs of doctors. This study will run from November 2011 until October 2012.

We would like to interview 8-12 consultants from a range of specialities working at the CCDHB. If you agree to take part, you will be asked to take part in one interview which will be a maximum of 1 hour 30 minutes long.

These interviews will take place in a private meeting room within Wellington or Kenepuru Hospitals. If you would prefer, we can use a meeting room in the Department of Primary Health Care and General Practice instead.

You may have a support person present for the interview if you wish. If you do not want to answer any of the questions in the interview you may say so and we will move onto the next question. If you want to stop the interview at any time you can do so and you do not have to give a reason.

The interview will be recorded and transcribed.
Benefits, risks and safety:

You may receive no benefit from involvement in this trial. This research may help changes to be made at the CCDHB to better support doctors in dealing with ethical challenges in their job.

There is no physical risk of being involved in this study.

There might be some risk of distress in talking about difficult situations you have faced in your work.

You will not be paid to be involved in this research. A coffee and a cake will be provided to thank you for your time.

General:

You can contact Libby Dai, the principal investigator, or Dr Angela Ballantyne, her supervisor if you would like to know more about the study.

If you have any comments or complaints about how the study is run, please contact Dr Angela Ballantyne.

If you have any queries or concerns regarding your rights as a participant in this study, you may wish to contact your professional organisation, NZMA.

Phone: (04) 472 4741
Postal address:
PO Box 156
Wellington 6140
Email: nzma@nzma.org.nz

Confidentiality:

No material that could personally identify you will be used in any reports on this study.

Only Libby Dai and Dr Angela Ballantyne will have access to the recordings and transcripts. You will not be identified in any publications of the study’s findings, but we would like to include your speciality and position. For example, “A consultant paediatrician said…” We would also like to gather ethnicity information, but you do not have to give this information if you don’t want to.

Recordings and transcripts will be kept on the password-protected computers of Libby Dai and Dr Angela Ballantyne. If paper copies of the transcripts are made, they will be kept in secure storage at the Department of Primary Health Care and General Practice.
The recordings and transcripts will be kept for 10 years and will be destroyed after this.

**Results:**

If you would like, a copy of the results will be sent to you before they are published. We will not have our final results to send out until the study finishes in November 2012.

We hope to publish our findings as a component of a BMedSc(Hons) thesis and in several medical and ethical journals.

**Statement of approval:**

This study has received ethical approval from the Central Regional Ethics Committee, ethics reference number CEN/11/EXP/073.

The CCDHB has given permission for this study to be carried out.

Please feel free to contact the researcher if you have any questions about this study.

**Principal investigator:**

Libby Dai  
BMedSc(Hons) Candidate  
c/- Department of Primary Health Care and General Practice  
Wellington School of Medicine and Health Sciences  
PO Box 7343  
Wellington  
daiel871@student.otago.ac.nz  
027 200 7465

**Primary Supervisor:**

Dr Angela Ballantyne  
Senior Lecturer  
Department of Primary Health Care and General Practice  
angela.ballantyne@otago.ac.nz  
021 071 6326
Appendix 5: Extended results

Outline and notes on the text
This section outlines the major themes derived from the data. This chapter is organised according to the three central themes: (1) current ethical practice of participants; (2) theoretical considerations in the provision of clinical ethics support; and (3) practical considerations in the provision of clinical ethics support.

The data emerging from the interviews were rich and varied. As this research is the first empirical qualitative study to explore the ethics support needs of doctors in New Zealand, the results will be described in some detail. These results represent an important resource for further work in clinical ethics and medical ethics teaching in New Zealand. In this chapter I have categorised and sorted participants’ views according to key themes. In the following chapter I will analyse these results and interpret them in light of the broader clinical ethics literature.

For the purposes of preserving anonymity to the greatest extent possible, participants are not named, but have been allocated a number at random to which their quotations are linked for internal consistency. Square brackets indicate where the transcripts have been edited by the researcher for clarity.

Only one of the participants was female. It was not intended to perform a sub-analysis by gender, and in any case this would not have been meaningful with only one female participant. In addition, as the identification of this participant by gender in the results and discussion would have undermined her anonymity and privacy, the pronouns he and his have been substituted for she and her, where her quotations have been included. In other words, all participants are referred to as he/his regardless of gender.

1. Current ethical practice of participants
During the interviews, participants described the resources and strategies they currently use to help them solve ethical problems. The five key themes emerging in this section are:

f. Participants’ prior experience with the CEAG
g. Ethical issues encountered by participants
h. Participant approaches to managing ethical dilemmas in practice
i. Ethics training and education
j. Barriers to accessing ethical support
Participants’ prior experiences with the CEAG
Participants had had varying experiences with the CEAG prior to being interviewed. Two of the participants had referred a case to the CEAG (3 and 14). Several of the participants (2, 6, 7 and 13) described being peripherally involved in cases that had been referred to the CEAG, including one who had been asked to provide specialist clinical input into a deliberation (6). Participant 12 sits on the CEAG as a clinical representative. Of the remainder, most participants had either not heard of the CEAG or had heard of it through MacDonald’s (Chair of the CEAG) 2011 Grand Round presentation in which a paediatric case consultation was discussed. Even amongst the clinicians who were aware of the existence of the CEAG, most did not have a clear understanding of its functions or how to access it.

Ethical issues encountered by participants
As was expected, participants described encountering a wide range of ethical challenges, many of which were specific to their specialist area of medicine. The most frequently cited general issues were:

- Disagreement between the treating team and the patient’s proxy decision-maker in cases where the patient has limited capacity to make autonomous decisions, such as in the paediatric or intensive care setting;
- Conflict in the doctor-patient relationship;
- Disagreements within a treating team on the best course of management for a patient;
- Making decisions where resource constraints are a significant factor in determining options;
- Making life-or-death decisions, particularly in instances when a surviving patient would be likely to have poor quality of life, or in instances where decision-making is time-pressured;
- Using novel treatment approaches;
- Managing the care of patients in cases that are socially controversial or where the clinician has strong personal views about management;
- Approaching potentially precedent-setting cases; and
- Trying to manage the impact of factors outside of the patient or the clinician’s control, such as a pharmaceutical company withdrawing a drug or funding allocations that limit patients’ access to certain treatments or support.

Participant approaches to managing ethical dilemmas in practice
This section addresses the strategies that participants used routinely to manage ethical issues in their practice.
All participants used similar strategies in their approach to ethically challenging scenarios. Most participants emphasised that effective communication with the patient was one of the most important tools in resolving ethical dilemmas. “Even a rarefied specialty like neurosurgery is immensely reliant on the fundamentals, which is: knowing your patient. There is no substitute.” (9) All highlighted that the majority of ethical issues could be resolved by having open dialogue with the patient and their families. Participant 2 stated “the first sort of approach is to try and clarify with the patient, the patient’s family, interested parties what the points of contention or dispute might be. And sometimes just talking through that process may itself sort things out.” (2)

Several participants indicated the obligation on clinicians to ensure effective communication occurs in the doctor-patient relationship. “I think with people you expect difference, or you find difference. It’s always incumbent upon you, as the health professional, to try and understand them, rather than have them understand you.” (12) However, most participants also went on to define the most ethically challenging cases as being those in which resolution has not been achieved with discussion alone.

All participants relied heavily on informal systems of ad hoc consultation with a range of colleagues to manage ethical issues. A typical approach in the first instance was to discuss cases with peers working at the same level in the same speciality. This consultation would take place either in a formal setting of a weekly departmental meeting or, if advice was needed on a more urgent basis, in corridor consultations or phone consultations. Several participants said that they felt lucky in their practice to have strong collegial relationships with their senior peers that made this consultation possible. Several participants also highlighted the importance of multidisciplinary team discussion to ensure that all of the facets of a patient’s care were adequately considered.

A strongly recurring theme was that the end-point of peer consultation is achieving a consensus of opinion on the best course of action; most participants emphasised this point. Some participants added that they would consider consulting more widely in circumstances where there was either general indecision or where even a single individual disagreed strongly with an otherwise unanimously agreed-upon approach. Several participants also suggested that many apparent ethical dilemmas are simply resolved with a wait-and-see approach. When asked to comment on how he resolves dilemmas where consensus is not achieved, Participant 1 replied “time will always sort them out”. (1)

**Ethics training and education**

All of the participants felt that ethical competence was a core component of clinical competence, but they had differing opinions on how ethical competence is attained. Most agreed that clinical ethics is primarily picked up passively during the clinical years, as trainees learn the culture of
medicine. Several indicated the model of clinical ethical education in the undergraduate programs was unhelpful because the ethical principles were divorced from clinical realities.

*If there had been any formal ethics training in my medical school, I would have probably died of boredom. Because it would have been completely detached from real life and I think human nature is such that you only learn these things when you actually grapple with a problem... I don’t know how you’d teach that in a way that would be helpful.* (5)

Most participants agreed that it was not until they were working in a clinical environment and facing ethical issues first hand that they began to appreciate the complexities and subtleties of trying to resolve ethical issues in practice. Participant 14 said of his undergraduate medical training

*It wasn’t part of my training that I particularly remember with a degree of certainty and fondness. But that also might better reflect my stage of life at the time, and relative youthfulness. And, you know, med students are young. And perhaps not ready for some of that stuff.* (14)

Participant 3 suggested that the reason existing models of teaching ethics are unhelpful is that didactic teaching strategies are not a suitable method for teaching ethical reasoning. “*I think unlike medical training where you, you know, learn the ten causes of clubbing or whatever, ethics is not something that you learn as such... I think inherently as you go through, you pick up ethical principles as you go.*” (3)

Participant 6 reiterated this idea, explaining that it is not possible to teach clinical ethics meaningfully in the undergraduate curriculum: “*that’s not a criticism of medical school though because I just don’t know how much you can learn until you’ve actually had to face the experience practically*. (6)

Participants differed in opinion on how ethics education takes place or could be provided for medical graduates. Most expressed the view that ethics is learned experientially: that by being immersed in medical culture, by being forced to take responsibility for patient care, by observing the practice of senior peers and by changing one’s own practice reflectively in response to one’s mistakes, ethics is developed through clinical practice. “*I suppose a lot of it is just learnt by being here, and being here long enough that you see people doing it. So it’s a passive acquisition, because you’re probably not aware you’re doing it.*” (4)

*I don’t think you’re ever taught. I think you just get placed in the situation and left to get on with it. It’s the old see one, do one, teach one. I haven’t ever been trained. You do pick up an awful lot just by watching people do it. . . You don’t really start doing it until you’re*
qualified. . . And even then, well, that is a baptism by fire... There was no training or support. You were just left. (9)

One participant disagreed with the view that ethics is a teachable skill. “Every person, even without having been trained in ethics formally, [has] got some idea about what is ethical, what is unethical. It's like a part of culture, and moral, open society.” (8)

Two participants agreed with the assessment that clinicians pick up a lot of their ethical skills in practice rather than by being taught, but they also added the cautionary note that the expectation that clinicians can acquire ethical competence by osmosis may be flawed. “You learn it at the coalface but then you also have opportunities to synthesise your experiences and learn the best you can. . . but you can always learn the wrong things from experiences.” (6) Participant 4 pointed out that the process of “passive acquisition” of ethics means that a clinician’s ethical mind-set is a product of the environment in which he or she trained.

I’m a product of this unit. I’ve been here ten years now, so I came as a registrar and trained here and got through as a consultant. So the colleagues I now work with, as equals, were the ones who trained me and they’re probably very much responsible for my ethical mind-set, I suppose, how I consider things. (4)

He said that while he feels in his case this has been an asset, he is aware that the practice of adopting the ethical norms of one’s working environment without scrutiny or external oversight might be a means by which poor practice and culture can be perpetuated.

**Barriers to accessing ethics support**

Participants described a range of barriers to accessing ethics support, which include isolation – particularly amongst junior staff – a medical culture inhibiting both help-seeking behaviours and constructive criticism, and some staff members not having insight into the fact that they might need support.

Almost all clinicians described experiences of having made decisions that were ethically difficult or even distressing. They described the uncertainty of having to make decisions under pressure and the subsequent tension of trying to manage outcomes as decisions have played out. A theme that recurred throughout the interviews was that challenging ethical decisions are much harder to make when unsupported – irrespective of the form that that support takes. “I couldn't imagine trying to do this sort of stuff in isolation... that would be impossibly hard at times.” (9)

Participant 12 highlighted the importance of being supported in clinical decision-making, drawing on his own experiences of isolation as a junior physician. Shortly after qualifying he recalled
feeling so poorly supported that he was not coping. He stated that the system is not well-set up to identify and help staff members who do not have informal peer support networks in place to manage challenging clinical situations of whatever nature, which was why he felt his own struggle had not been identified.

Numerous times participants noted that junior staff, in addition to facing the inherent disadvantage of being less experienced, came up against cultural and systemic barriers to being able to seek adequate support in managing ethical concerns. “The problem... of course, is going cap in hand to your boss and asking for advice on things like this is often perceived as a sign of weakness. And if any progress is going to be made on that front, I think that’s one of those elements of the culture that needs to be broken down somewhat.” (9)

Interestingly, most participants identified other departments and groups of professionals in the hospital whom they perceived to be less supported or less able to access support. It was of note that although all participants stated that they felt comfortable to manage ethical issues within their practice and felt well-supported in their department, some indicated the same was not true for all of their colleagues. In particular, several emphasised that while their own departmental culture fostered advice-seeking behaviours, other departments were less supportive of this practice. Two participants went so far as to describe other departments as having environments that inhibited discussion of ethical challenges.

Some units are very dysfunctional and no doubt they have difficulties with making difficult ethical decisions, because they don’t have a consensus as a group... But I certainly know that if there was something I didn’t agree with that I could speak up and my voice would be heard by my colleagues. So, that makes a good environment to be in. (4)

We’re a much more collegial department than most other departments. In fact, we probably are the most collegial department, I would go so far to say. We don’t all agree, but at least we will agree to disagree, and continue to support each other. And I don't believe that that can be said for some of the other departments, which are quite... I would almost call them dysfunctional. (11)

Many clinicians emphasized that the culture of medicine makes it very difficult to raise concerns about the practice of a peer and that this can be a barrier to initiating dialogue about ethical issues. “I don’t think we’re very good at constructive criticism of either our team that are working for us or even if you’re a house surgeon, giving some constructive feedback to our registrar or consultant, you know, we don’t do that.” (3) In particular, several participants indicated that the
higher up in the medical hierarchy a colleague is, the harder it is to raise concerns, even for equally senior clinicians.

_In medicine we're not very good at criticizing people… You know, it's perhaps not too hard to criticize a medical student, because you don't have to deal with them very much. The more senior the person gets, the harder it is to be more direct with them about what their shortcomings might be, and where you think their room for improvement might be._ (11)

In addition, some of the participants suggested that the kind of people drawn into some specialities were by their nature not given to reflection on ethical concerns and that this may act as a factor reducing their likelihood of seeking advice from any source on ethical issues. Three participants – two physicians and a surgeon – indicated that this might be more true of the surgical specialities. This tendency was not described by these participants as being necessarily a disadvantage. Rather, they indicated that those who are less inclined to “ruminate” (6) on ethical issues would require a different format for the provision of support. “If everyone was reflective, nothing would happen. The best way to engage people who are less reflective is to have something available when they come against a problem... to get 'do-ers’ involved in that sort of process.” (6)

2. Theoretical issues in the provision of clinical ethics support

In addition to talking about what they actually did when faced with an ethical problem, participants also theorised about what sorts of additional ethics support would be useful. Their views on this point have been organised in the following way:

b. Ethical and clinical responsibility
d. Accountability for decision-making
e. External provision of ethics support
   i. Objectivity and external perspectives
   ii. External appraisal and validation of practice
   iii. Lack of clinical expertise
   iv. Diffusion of accountability

_Ethical decision-making: a clinical responsibility_

The perception of where ethical responsibility lies was a significant point of difference that shaped participants’ views of clinical ethics support. On the one hand, some argued that ethics is a core clinical competency and thus should not be outsourced. Others contended that ethics support has the potential to enhance ethical decision-making and thus is a mark of responsible practice.
Most clinicians expressed the view that clinical ethics is a core competency for any doctor. "Ethical issues come up every day... We make ethical decisions every day. It’s part of being a doctor." (5) Many felt that to “outsource” ethical decision-making to a CESS is to remove the decision-making role from the individual who a) has a professional obligation to fulfil that role and b) is in the best position to make that decision, by virtue of their expertise in their field of practice and the information they are privy to as the head of a clinical team.

Participant 9 suggested that it would be easy for clinicians to depend on an external service to whom they could refer their ethical decisions but that would be devolving clinical responsibility. “Would I actually be worth the money I’m paid, if I was unable to make the kind of decisions I now routinely make, without referring to someone else first?” (9)

Participant 5 spoke of all the inputs that go into making a decision, the intricacies of which would be lost on an external body. He suggested that making clinical decisions depends on specific knowledge that would be simply unavailable to a CESS and too complex to attempt to convey.

Participant 1 was among several participants to express concern that the use of external clinical ethics support is an abrogation of the responsibility of clinicians to make challenging management decisions. He further asserted that a CESS addresses the symptom of clinicians being unable to manage ethical concerns in practice without addressing the cause. “We need a clinical ethics committee is the answer. Well... what is the problem that that’s an answer to?” (1) He argued that the role of doctors includes the ability to integrate information from a range of sources to make decisions. This necessarily includes a good understanding of the patient’s desires and needs and consideration of societal and institutional factors like resource constraints. Considering the ethical implications of clinical decisions in the context of all these other factors is something he regards as a core clinical competency.

Participant 3, one of the clinicians who had taken a case to the CEAG, disagreed with the assessment of some of the other participants that referral to an external ethics support service was an abrogation of clinical responsibility or that it required relinquishing clinical autonomy.

My experience of it was it actually helped me to see the situation from a slightly different perspective and to be able to take on board that collective opinion which helped to resolve the conflict... So I found it empowering, I suppose, for want of a better word, rather than, rather than stripping me of my clinical autonomy. (3)

He compared it to any of the other situations in clinical practice where a clinician acknowledges that a decision requires the expertise of someone who has a different scope of practice, which
happens every day and is not regarded as being an abrogation of responsibility at all. In this context, the primary clinician retains responsibility for a patient’s care but makes management decisions in consultation with others.

Participant 2 suggested that the role of the doctor as the ultimate decision-maker did not preclude the involvement of CESSs in decision-making, but rather imposed parameters on it. “An ethicist is not in a position to say: this is what must be done now. An ethicist is in a position to say... these are the ethical principles at play here, this is the judgement you need to make... that can help define the problem but at the end of the day it’s still going to be a clinician’s decision.” (2) Couched in this way, a CESS was seen as providing just another of the many inputs that go into decision-making, rather than a service to which a clinician may hand over the responsibility of decision-making. This participant suggested that the “voice” of ethics is sometimes lost among competing interests in the complexity of practice and that a role for the CEAG may be in ensuring that ethical issues are given due weight, particularly when “the discussion reaches across more than one clinical area”. (2) He felt it would be of value to have an “institutional or national ethical body to clarify what they would regard as being the ethical imperatives”. (2)

He went on to talk about the importance of the clinical ethics advisory group having a clearly defined role in the decision-making process. He stated that external ethics consultation “helped the subsequent discussion. It wasn’t an end in itself.” He said that he went into the consultation process with a clear sense of what they were offering: that the advice “cannot be binding”, but is an opinion that can be taken into consideration. “It is not a legal kind of judgement with the weight of law, it’s not a clinical judgement... it informs both of those things... but only informs.”(2)

Participant 10 furthered the argument that the role of external ethics support is not to make decisions, but to contribute to decision-making. He pointed out that doctors are expected to attain such a broad range of competencies that they cannot possibly be expert in all of them. “If you’re a Jack-of-all-trades, you tend to miss the finer details.” (10) He argued that acknowledging this fact underpins the multidisciplinary team (MDT) model of medicine: a range of professionals with complimentary skill sets are needed to provide optimal patient care. He regarded the ethicist or ethics consultation service as a natural extension of the existing MDT model.

**Accountability for ethical decisions**

Following on from responsibility is the issue of who will be accountable for the impact of ethical decisions on patients.

Some participants pointed out that it may be difficult for a clinician to decide to go against the opinion of a CESS, having made the referral. Participant 8 highlighted that the fact that the advice
of the CEAG is framed as only an opinion means they defer accountability for decisions they helped to make. ‘It's like, ‘Yeah, I can provide you friendly advice, but I'm not obliged to do this. It's just basically you can take it, or you can throw it away.’ So there is no accountability in this situation. . . I mean, the final question is, who would be responsible for this decision if something goes wrong?’” (8)

Most participants, however, felt that it was clear that accountability remains with the clinician who leads the clinical team, just as it would have been had the clinician not decided to seek external ethical input. They did emphasise the importance of ensuring clinicians know they are able to decide against using the advice of the CEAG. “I don't think that an ethical opinion could then take over the custody of the patient... things would have gone too far, if that was the case.” (9)

Some participants expressed concern that distance from the cases could lead to a diminished sense of responsibility and a diffusion of accountability, both on the part of referrers and the CEAG. One participant suggested that the psychology of group decision-making is such that it might reduce the sense of clinical accountability of the clinician.

I don’t know how much of that is devolving responsibility, because there’s the whole psychological concept of decisions made in groups, you’re all individually less responsible for that. The sort of herd mentality of taking away difficult decisions by saying, well the committee decided to do this, rather than me as an individual. (4)

**Ethics support services as a moral authority**

Some participants expressed concern that a CESS may be making unreasonable claims to moral authority by offering to solve clinical ethical problems.

Participant 1 felt that the CEAG as a model of for ethics support is predicated on the notion that the ethical dilemmas of clinical practice could be solved if one simply identified and applied the right framework to any given problem. He asserted that the insoluble nature of many clinical dilemmas could not be better managed by an ethics support service than a clinician: “I’m not sure how much an ethics committee could help... A lot of ambiguities and differences and difficulties I’m prepared to live with.” (1) He also felt wary of any group purporting to have solutions to these apparently intractable ethical problems. “...they’ll come up with a decision with a framework that you might agree with or not agree with, or they’ll come up with advice so woolly that it’s not helpful.” (1)

This clinician was not the only one to express reservations about the CEAG that seemed to be based on the idea that the CEAG was positioning itself as a moral authority, whether by virtue of their status as an independent ethical body or by a claim to a superior normative framework.
Participant 8 said of the CEAG, “No, it’s a waste of someone’s time. I cannot imagine a situation when we really have to go and ask an ethicist what do we do in this situation.” He went on to state that there is no reason a clinical ethics advisory group should be any better at making effective ethical decisions than a well-trained, experienced group of health care professionals from a range of backgrounds; “…if we cannot come to the conclusion all together, who else could come back and tell us, ‘Oh, this is exactly the way to go.’”

Ethics support provided by an external body

For participants, one of the most significant differences between ad-hoc support systems and using a formal ethics support service was that formal support is external to the group of people involved in patient care. Participants had both positive and negative views about the implications of ethics support from an external body. Benefits identified were that an external opinion carried greater objectivity and that external input allowed reflective appraisal of practice against an independent measure. Disadvantages identified were that an external group might lack the expertise of specific clinical environments and that there might be a diffusion of responsibility when a case is referred externally.

Several participants suggested the advantage of external ethical consultation may lie in the objective perspective the CEAG has by virtue of its distance from the immediate clinical scenario. Participants expressed that at times they found it challenging to maintain perspective on difficult ethical decisions because of their proximity to the decision they are making. Participant 4 argued that seeking an objective opinion on one’s decision-making is a sign of appropriate, reflective practice.

I see them... as a sounding board, where you can just go and talk to someone who’s not directly involved with the case, who has no emotional involvement with the case, which is not always easy to do... There’s an emotional component that can cloud –maybe not cloud –but that informs your judgement. (4)

Another participant, Participant 3, pointed out that often individuals do not have insight into the way that their decision-making is shaped by their personal views. He had referred a case to the CEAG because of disagreement within his department over the management of a patient for whom he was primarily responsible. He found that the process of case consultation gave him insight into the extent to which his practice was being shaped by his personal beliefs.

I found it useful because I guess I’d come to it from a quite a different perspective than what the majority of the members of the [CEAG] came to it from... I think I realised that
many of my concerns were more about my prejudices than necessarily about the ethics of the situation per se. (3)

Another key benefit of having an external ethics support service identified by some clinicians is that it provides a means of having clinicians’ practice challenged and appraised externally. Within medicine, it is an oft-cited adage that the measure of competence is that one’s practice aligns with one’s peers. Participant 4 highlighted that there are many mechanisms for ensuring clinical practice is appropriate and up-to-date, but there is no obvious yardstick by which one can appraise one’s ethical practice. He expressed concerns that he held that within a single department of a single hospital it is easy to lose perspective on what he described as the “homogeneous” practice within his unit. He suggested that within his department, the fact that there are so few instances of clinicians having points of difference over ethical issues might be symptomatic of the fact that they have been enculturated through their training to think alike. “And in some ways that doesn’t reassure me, that worries me. Because it could mean we’re all wrong. It’s unlikely we’re all right.” (4)

This participant stated that the value of CESSs is that it provides a tool for clinicians to validate their own ethical practice externally and to safeguard against the complacency borne of habit.

Not all clinicians shared the view that having external ethical consultation – removed from the bedside – was an advantage. Other participants expressed concern that an external ethics advisory group would be out of touch with the specific clinical realities that contextualise each and every ethical decision a doctor makes. In large part this seemed to reflect a perception that clinical ethics support would be provided by academic ethicists without clinical experience or training; as one participant put it, “someone from the pointy towers of Dunedin or somewhere who’s got an ethics qualification”. (5) The concern on the part of some participants extended to include clinically trained ethics support providers who were unfamiliar with their speciality. Participant 5, a paediatrician, went on to state that “if you’re working in very specialised area of practice, the ethics of what you’re dealing with rotates extremely strongly around knowledge around the topic or the clinical area with which you’re grappling.” (5)

As an example, he described the process of making a decision about managing the care of a neonate born at 23 weeks gestation, which is at the cusp of viability for the Wellington Neonatal Intensive Care Unit. He explained that even familiarity with best practice and the literature on the subject is not enough; one needs a specific understanding of the capacity and performance of the unit in which one is operating. “They’d [the CESS] have to call in a whole lot of experts and to do it properly, they’d have to call in experts from your own department. In other words, my colleagues. So that where we have an ethical issue we tend to raise it with our colleagues, who are in a similar position, and we reach a consensus.” (5) For this reason, he suggested that existing
strategies of peer consultation are more effective ethical decision-making tools than external ethics support services.

3. Practical issues in the provision of clinical ethics support

The final major topic of discussion focused on a series of practical considerations that should be built into the design of a useful and efficient CESS. Participants’ comments have been categorized according to the following six themes:

   e. Timeliness
   f. Stakeholder involvement
   g. Protection of clinicians and institutions
   h. Capacity building
   i. Ethical education
   j. Conflict resolution

Timeliness in case consultation

The timeliness of service provision was an issue that came to the fore when participants were discussing pragmatic concerns about delivering external ethics support.

Several participants pointed out that the urgency of many ethical decisions is such that it is simply not possible to expect a decision to wait for review by an external body. “You know, we couldn’t afford to wait for a committee to pontificate on everything we deal with.” (5) They highlighted that ethical challenges can occur at any time of the day or night and that often decisions have to be made so quickly that external ethics consultation is unrealistic. Participant 9 suggested that there might be a role for retrospective case review, or for case consultation to take place once the situation has been stabilised.

It’s the… trying to make ethical decisions in the heat of battle, I think, it’d be difficult. So you know, whether you should be phoning someone when you're in full flow… you probably need to be phoning them the next day, to talk about the aftermath of something you've just done, rather than whether or not you should go for it (9)

However, two participants felt differently from Participant 9 on the usefulness of retrospective case consultation. Participant 4 said he was wary of examining decisions, particularly those made on an urgent basis, through a “retrospectoscope”. He indicated that all clinicians acting under that kind of pressure would have made the best decisions that they felt they were able to make under those circumstances. He pointed out that decisions made in the context of a calm meeting space with time to deliberate may well seem more logical or rational but there is nothing to be gained by
judging clinicians acting in a messy clinical environment by the yardstick of the objective decision made by a group of experts who are not stressed, exhausted and under immense time pressure.

Participant 2, conversely, had been involved in a case that had been taken to the CEAG retrospectively and felt that the experience had been valuable. He indicated that the aim of the retrospective review was not to ruminate on what could have been done differently, but rather to help the clinical team to develop an approach that could be used if a similar situation were to arise in future. He indicated that in cases where retrospective review of cases is performed, there must be mechanisms to disseminate the findings so that any recommendations for changes in practice can be enacted. “Consultation is a useful, on-going, prospective kind of tool. And ultimately [it] might help ethical decisions to be made, or decisions to be made by clinicians ethically. And then a retrospective approach is useful . . . So I don’t think it would need to be one or the other.” (2)

Participant 5 acknowledged that while he felt the clinical ethics advisory group has too long a turnaround time to be useful in individual case consultations, it could be of more use in precedent-setting cases or cases that have an impact beyond an immediate clinical situation.

[An ethics committee is] a slow bloody organisation. For individuals it’s too slow. I want to know at three in the morning you know? Who’s going to come help me at three in the morning? No, it’s no good . . . Where you’re dealing with policy and larger picture things, I think that’s where it works really well. (5)

Clinician involvement in external ethical deliberation
Many participants indicated that their concern about external ethics consultation services is the perception that clinicians are shut out from the process of ethical deliberation. This was of particular concern to clinicians because they pointed out that they remain responsible for clinical outcomes irrespective of the degree to which they have been involved in the deliberation process. As such, if they receive an ethical opinion without being involved in the discussion that leads to the opinion and they disagree, they are in a difficult position. As Participant 4 pointed out, “you’re not bound to take the advice of the ethics committee, but you probably have to justify it more if you went against them”. (4)

Participant 7 said he felt concerned with the lack of transparency of process in the case that he was involved in taking to the CEAG. He was not the lead referrer, but nonetheless felt the process lacked openness.

This one case I was involved with, I presented my case, but then the rest of the stuff was held behind closed doors. You know? And you want to be involved in that discussion.
You want to be involved in their deliberations, so that you feel that you've made your point to them, and you want to hear what they have to say if they don't agree about your point. . .

It might feel like a closed shop, where you put the input in and then they give you their answer. We don't know what's been discussed. . . it shouldn't be a secretive –which it isn’t—but that's what it feels like. (7)

Participant 3, who had been the referring clinician in the case he took to the CEAG, agreed on the importance of clinician involvement but felt that this was achieved well in his case. “I appreciated the opportunity to go along to the meeting and discuss the case directly with the committee; I thought that was essential. Rather than simply providing the material and getting back some sort of [report]. I found that process was engaging.” (3)

Several participants emphasised that any model for ethics support must involve clinicians in the process if it is to be accepted. Participant 1 stated that for this reason the ethics committee model is unsuccessful, because by design clinicians cannot be as involved as they want and need to be to benefit from the consultation process. “I think discussions, which are iterative, would be a lot better.” (1) He felt that ethics support services should instead focus on creating an environment which fosters and promotes ethical debate and heightens ethical awareness. “There isn’t a good ethical forum, I don’t think.” (1)

One participant disagreed with the view that clinicians should be involved in the deliberation process, stating that he would prefer to feel the opinion of the CESS had been reached without being unduly swayed by the referring clinician’s views. “I’d probably just want to say, ‘Here’s the case’, give them as many facts about it as I can provide, and allow them to go and ruminate on it without me necessarily trying to influence them. You know, I want their opinion, I don’t want my opinion. I already know my opinion.” (9)

**Protection of clinicians and institutions**

Some participants suggested that a benefit of the CEAG is in providing formal back-up for clinicians making challenging decisions. “I think the more that a formal body of that nature is involved in the process, the greater the safety for an individual clinician making a decision... I'd regard that as a support and a bonus.” (9) These participants were careful to draw the distinction between protecting clinicians by having an appropriate decision-making process in place and offering a tool that facilitates the practice of defensive medicine. Participant 9, who trained overseas, pointed out that New Zealand practitioners are lucky to work in an environment where litigation is a rarity and that this frees clinicians here to make better decisions if they have the
right tools. “I think it enables one to make the right decision, rather than the medicolegally appropriate decision. You can be courageous.” (9)

Participant 3 stated the importance of having a CESS that was able to be sufficiently objective that the needs of the patient were put before the needs of the clinician or the institution. He was concerned that in the case he referred to the CEAG, the written opinion he received erred on the side of defensiveness. “I think the intensity of the written feedback I received was probably a little too legal and a little too um... butt-covering, as opposed to really encapsulating the issues, if you see what I mean? It was a bit, there was organisational protection going on.” (3)

Participant 11 suggested that often the most challenging part of making ethically fraught decisions, for example, around resource allocation, is not the process of decision-making but in justifying those decisions to a patient.

I think when we have to start dealing with those issues, because there's going to be people who are upset, people who are angry, disappointed, you know, disillusioned, whatever. And they will insist, and then there will need to be some processes around managing that as well. You can't just [offer treatment] because they're angry. That's not the right reason to be doing it. And again, having some level of support or backup to help you with that. (11)

He went on to state that this is easier for clinicians to do if they can demonstrate that a decision has been made by a formal process by an independent body, that some decisions are easier to justify to a patient in a consult room if the clinician can say, “Look Mrs Brown, I'm sorry, this is something we can't provide. And this is the reason...” (11)

**Ethics as a core clinical competency and enhancing ethics capacity**

This section addresses the views of participants on the need for increased ability of clinicians to manage their own ethical issues in clinical practice and the decentralisation of ethical expertise.

Most participants felt that the most useful activity of an ethics support service, where one exists, would be to enhance the ethical capacity of the clinical workforce. Many felt that the end goal was not to have ethics as a distinct field of practice, but to help clinicians attain a degree of fluency in ethics such that external ethical consultation is not required, except perhaps in exceptional circumstances.

I think rather than do that [refer to external ethical consultation services], you should be able to handle the ethical issues of your own practice, and be trained to a standard to do it... I wouldn't have thought [referring to external ethical consultation services] would be
necessary, the same way I don't have to have haematologists around to interpret all my blood results. Hopefully I can look at them myself without asking him. I wouldn't have thought it's going to be required at every turn. (9)

Participant 1 suggested that the aim of a CESS should be to foster ethics capacity throughout the hospital, devolving the responsibility from the top of the hierarchy throughout the health workforce. “How would you support ethical decision-making and ethical clinical governance? Rather than having a central committee, my prejudices are, you need to distribute it... which is more of a network than a committee.” (1)

**Providing meaningful ethical education**

Following on from the discussion above, participants addressed the role of the CEAG in the ongoing ethical education of doctors. Key ideas were that ethics education needs to be practical and integrated into the workplace, and that it needs to break down medical cultural barriers to open ethical discourse.

Participants who felt further education in ethics was of value stressed the importance of ethical education that is pragmatic and clinically relevant. “I think really it is about support and training. But actually at the coalface. It should be part of everyday work.” (1)

Many participants suggested that ethical support services could provide education using existing structures by which clinicians keep their practice up-to-date: for example, including an ethicist within multidisciplinary education sessions like the Grand Round. “Having an ethicist as part of a panel is actually quite helpful, like the Grand Round... People who come from a different angle having a dialogue, that’s often quite good.” (13)

Two participants stressed that pragmatic ethical education does not preclude learning the theory behind ethical reasoning. They emphasised rather that the theory is easier to learn once you have practical experience to hang the theory on. “I think it would be kind of interesting to have a little bit of theory. I suppose once you get into it, some of the theory becomes more complex and that may be beyond our immediate capacity to have time to do.” (13)

*The key is trying to equip people more effectively by whatever training there might be. And it's like you can teach anatomy by getting them to read a book, or you can just say, "Come and do an operation". But if you've got a little bit of book knowledge, maybe the operation's going to make a bit more sense.* (9)

Participants had a range of ideas on how to foster ethical development of trainee clinicians. Many participants talked about concepts like mentorship and ensuring that the culture of practice
environments is open to ethical dialogue across the traditional barriers of hierarchy. Some stated that this culture of openness was something they tried to foster within their own departments, but they acknowledged that they felt barriers to ethical dialogue remained in many areas.

Conflict resolution as an ethical skill

When asked to describe ethical challenges encountered in their scope of practice, most participants cited examples of difficult communication and relationship breakdown as either an ethical challenge in itself or as a frequent source of ethical dilemmas. Most participants regarded managing conflict in the doctor-patient relationship as being a key skill in resolving ethical dilemmas. While only two participants, Participants 4 and 10, explicitly suggested that conflict resolution is an important function of a CESS, participants’ general reflections on ethical challenges suggest that mediation of interpersonal conflict would be a useful function of clinical ethics support.

We’ve had on some occasions three family meetings with different members of the family that can’t even sit in the same room as each other. So that makes it difficult. And involving external agencies in that would possibly be helpful. So I think conflict resolution would be one occasion where we would seek external validity and external ethical help. (4)

Conclusion

In summary, clinicians had a broad spectrum of views about the value of CESSs, but there was a consensus on the importance of clinical ethics competence to the medical profession. Interestingly, participant perspectives on the value of CESSs seemed to be most strongly shaped by their conception of the services’ aims. Where clinicians felt that they would have to devolve ethical responsibility to a CESS, they were less likely to perceive it as a positive thing. However, clinicians who felt that the availability of CESSs either protected or enhanced their ethical autonomy were more likely to perceive ethics support to be of value.

The practical considerations in the provision of clinical ethics support are indicative of the environment in which doctors have to make ethical decisions: they are often under time pressure and they know that they will have to take responsibility for outcomes of decisions made in what can feel like an emotional pressure cooker. Participants take their ethical responsibilities as doctors seriously and want to feel better equipped to manage them, but solutions have to work in with the pace and complexity of clinical realities to meet their needs.