The Role of Clinical Ethics in the Health Care System of New Zealand

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FOREWORD

It is a pleasure to recommend this scholarly and comprehensive work to Health Practitioners in New Zealand, where Clinical Ethical considerations should become ‘Everybody’s business’.

I am impressed that the Health Quality and Safety Commission has taken a lead in sponsoring this work, with a view to promoting a National Clinical Ethical Network within the framework of Clinical Governance over District Health Boards, Hospitals both public and private, and primary care. Clinical Ethics is an integral part of quality improvement and clinical risk management. It is important that the Clinical Ethical Networks are both responsive to acute ethical scenarios, and have a range of expertise to provide respected opinion for referring clinicians, in the increasingly complex and technologically advancing Health Care environment.

Experience to date with the Capital and Coast DHB Clinical Ethical Advisory Group has demonstrated an extraordinary range of referrals sometimes with extremely difficult scenarios, and complex medico-legal interfaces.

Originally when the Group was established we had anticipated a need for opinions on the ethical considerations of appropriate levels of intervention in an increasingly aging and co-morbid patient population, and associated considerations in the developing arena of ‘Advanced Care Planning’. Despite this prediction, there have been perhaps an unforeseen wide range of ethical issues presented.

This document covers the international experience with Clinical Ethics provision, and will provide a sound basis for Clinicians and the HQSC, to present a platform and policy to complement the existing Code of Ethics of the New Zealand Medical Association.
This work is both timely and important. I believe the promotion of Clinical Ethics in New Zealand is a vital step in contributing to the country’s impressive place and leadership in Clinical Governance, Quality Improvement and optimal patient care, and it will be welcomed by Health Practitioners.

GM Robinson FRACP
Chief Medical Officer, Capital and Coast DHB
PREAMBLE

This document is intended for an audience comprising a range of professionals involved in the delivery of health care to New Zealanders at all levels. In comparison to other countries of similar economic and social development, formal clinical ethics provision is notable by its relative absence, and to date there has been no review of clinical ethics and its application to New Zealand health. This report outlines what is currently known about clinical ethics provision, drawing on the experiences of other countries where the service is already operational, and looks at the practical steps needed to facilitate implementation of nationwide clinical ethics service provision in NZ.

A workable strategy must be developed in order to enable the development of a clinical ethics network. It would be the responsibility of everyone involved in the project to help ensure that all New Zealanders experience health care delivery in a way that demonstrates commitment to professional standards; in our view, this cannot happen without a strong commitment to clinical ethics. A commitment to safe practice that recognises the role played by ethics and law in clinical medicine requires leadership and a set of standards that are not just fit-for-purpose, but understood and followed by practising health professionals. This project aims to help facilitate this process and plan for the introduction of a clinical ethics network in NZ.

Opinions have already been sought from various professional bodies, and surveys of a range of health professionals have been undertaken; in addition, international experience has been documented and this report incorporates the result of these enquiries. **The chief recommendation of our report is that a national clinical ethics network in New Zealand is necessary and overdue.** As a next step in
the development of a *National Clinical Ethics Network*, designed to function at local *District Health Board* [DHB] level, a multidisciplinary working party needs to be convened.

While the development of clinical ethics services in New Zealand would need resourcing in order to facilitate implementation, it will be for a Working Party to consider in detail and to identify potential and appropriate sources of funding. Once established, local networks would become the responsibility of individual DHBs. A commitment by DHBs to manage these networks would help put New Zealand on the map in terms of a progressive policy towards health care ethics and law and professional standards, as has happened in the past in other areas of health policy where New Zealand held a pre-eminent position.

“*When I hear the words ‘it’s unethical’ in a conversation about healthcare I realise that the speaker wants to end the conversation rather than start a debate;”* … “*Changing this perception will require that clinical ethics becomes everyone’s business.*” Alastair Macdonald, February 26\textsuperscript{th} 2012.
EXECUTIVE SUMMARY

Introduction

This report describes the current status of clinical ethics support in New Zealand, based upon a number of different lines of investigation undertaken with support from the Health Quality and Safety Commission, New Zealand [HQSC]. The report summarises these investigations and concludes with recommendations relating to proposed next stages in the implementation of a clinical ethics support network.

The task set by the HQSC is to –

i) Write a report suitable for publication on the HQSC website outlining the key issues, differing international approaches and what a national network might look like

ii) Establish the clinical ethics network portal as a private site within the Health Improvement and Innovation Resource Centre website

iii) Share and discuss the report produced with various professional bodies.

Clinical ethics has been narrowly 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)
However, clinical ethics support services are better defined as ‘the availability of formal and informal provision of support to health professionals on ethical issues arising from their clinical practice’.

(Slowther et al, 2001) The definition of clinical ethics support needs to be broad in recognition of the fact that the field of clinical ethics is rapidly evolving, with a range of potential applications; this approach takes into account the fact that if there is greater acceptance of clinical ethics in NZ, and in the early stages it would be difficult to know what shape such a service would need to assume.

Clinical ethics is an important component of the primary and secondary care sectors of any well-developed system for the provision of health care. Ethical involvement in research ethics and in public health in NZ is already well established; however, a review of ethics involvement in these and other areas is beyond the scope of this report. **The focus of this report is on clinical ethics support services in the secondary sector of the NZ public health system.**

Areas covered in the report include –

i) A review of the current status of clinical ethics support in New Zealand

ii) Survey data of various health professional groups describing attitudes and requirements for clinical ethics support

iii) An international overview of old and new clinical ethics networks

iv) Recommendations for the formation of a clinical ethics network in New Zealand.

**Methods**

1. To utilize contacts and experience gained from a sabbatical undertaken in July-September 2009 by AM in Oxford, UK; this was directed at gaining an understanding of the role of clinical ethics in the UK, as well as to consider opportunities for review of
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the development of clinical ethics support in other countries.

2. To use appropriate methods in order to gain an overview of clinical ethics support in NZ; information gained should help to provide the basis for recommendations at the conclusion of this report.

3. To meet with senior representatives of professional colleges and organisations, and to consider –
   i) Surveys of different professional groups both locally and nationally
   ii) Communication with chairs of NZ Clinical Ethics Advisory Groups [CEAGs] already in existence
   iii) Formal and informal discussions with different professional groups
   iv) A review of relevant literature
   v) Travel to various NZ centres for informal discussions
   vi) Make effective use of an honours student skilled in qualitative research methods (relevant to clinical ethics) in conducting interviews with senior doctors in DHBs, under supervision from AM.

Findings

There is evidence suggesting that compared to other similar countries New Zealand has less access to formal clinical ethics advice. There are different ways of approaching clinical ethics (e.g., locally, within District Health Boards [DHBs]). Most day-to-day problems are appropriately managed within the context of clinical practice at individual level and/or in the context of a multidisciplinary team; health professionals may also consult their peers for advice or look to existing policies on ethical issues; others will look to their professional lead body. There may be a small number of individuals who have a special interest in clinical ethics, and some DHBs that have already developed CEAGs. This report finds that
overall there is significant support for the wider introduction of clinical ethics services within DHBs.

Clinical Ethics Advisory Groups

One model for the provision of clinical ethics support is through the establishment of CEAGs. Doubts about the sustainability of such a group in a small DHB have been articulated; however, the presence of a Clinical Ethics Network would help provide support at the local level. The development of CEAGs was mainly the result of interest expressed by clinicians who felt that such an initiative would provide focus and help in addressing ethical problems as and when they arise in practice settings.

Membership of these groups needs to be multidisciplinary and should include lay membership in order to help give validity and ensure patient and public support and engagement. In order for the CEAG to survive, and more importantly to thrive, resources need to be made available, especially in the short to mid-term. This should not be seen as an expansion in the role of the Ministry of Health in administering the system; rather it should be seen as part of the government’s commitment to raising standards and improving quality of care. As we argue later, if patient safety improves, and if health care risks are better understood, the moderate cost that would necessarily be incurred in running the network would be offset by improved efficiency and savings and improvements in clinical quality and safety.

The following key points to be considered include–

i) Education and training for CEAG members

ii) Time involvement by CEAG members, which needs proper recognition

iii) Provision of appropriate levels of administration support
iv) Courses for CEAG members, current and future, which would need to be accessible to clinicians around the country

v) Development of intranet / education resources and a national clinical ethics website

vi) Education directed at informing CEAG members about how to function optimally within a committee / group

vii) Having an ethicist within each group is logical and regarded by some people as necessary and important; however, that opinion is not universally shared; at the present stage of development there are insufficient trained ethicists to be able to meet the demand, and the expertise that is available needs to be utilized effectively.

Terms of reference outlining the main functions of each committee should include –

1. Individual ethical case discussion
2. Broad ethics education within each DHB
3. More specific ethics education for CEAG members
4. Making a contribution to guideline and policy development, nationally and locally.

Surveys indicate that the profile of existing CEAGs (e.g., at Capital and Coast District Health Board) [CCDHB] is not high; this needs to be addressed, since it will adversely affect the number of cases that are going to be referred to a CEAG.

Relevant factors include –

i) Intranet facilities, which should be available to every registered health professional
ii) Case discussion, which would form part of the training for CEAG members

iii) *Grand Rounds*, which are an established way of stimulating discussion and sharing information and expertise (e.g., on ethical issues arising within clinical practice)

iv) Ethics education is essential for clinical staff in training and should comprise an integral part of all health care curricula

v) Local management needs to be aware of the existence of local groups; it could be beneficial for them to be part of the process of policy development and implementation.

Audit and assessment should be carried out routinely; however, barriers to this include –

i) lack of clarity that committee recommendations are advisory only and not legally binding

ii) fear that CEAGs could take over from MDTs

iii) sufficient financial resources might not be available

iv) difficulty in defining outcome measures

v) perceived lack of need for clinical ethics development.

Relationship with clinical governance –

i) There is increasing recognition that if we are to have a public health service that meets the complex health demands of a population that is undergoing demographic change then clinical leadership needs to be at the heart of the decision-making at all levels within DHBs. Clinical ethics must be viewed as a normal part of that process, as an important concept contributing to the success of the DHB’s.
The relationship between the governance group within the DHB and the CEAG should be simple to the extent that there needs to be a clear separation between the activities of each entity.

The Clinical Governance Group should provide the administrative, financial, educational and legal support for CEAGs. However, each CEAG needs to maintain its independence in terms of its processes and deliberations and demonstrate its effectiveness and relevance within the DHB. Accountability can be achieved by CEAGs providing regular reports back to the Clinical Governance Group.

Such a relationship between clinical governance and clinical ethics goes a long way to support the idea that DHBs are committed to the idea that collectively they are continuously improving the quality of their services by helping to create an environment in which excellence in good clinical care is able to flourish.

The role of research ethics committees needs to be considered, but in our view, they should not be reviewing clinical cases, the reason being that these groups are not local, and research ethics review is not the same as clinical ethics review; it requires a different approach and different training to perform a different task; also, committee members are busy coping with changes resulting from a process of review that is currently underway in NZ.

Other sources of ethics support include—

i) Ethics support from professional organisations, which is already available but not at local level.

ii) Ethics support, which ought to be available through university departments of ethics; however, departments often have a strong bias towards research and academic enquiry and are removed from the practical process of clinical decision-making; academic ethicists may
not always have a good understanding of the issues faced by busy practising clinicians.

iii) International ethics support is available through organisations such as UNESCO; however, this kind of support tends to be high-level with limited practical applications on the ground; furthermore, it can be insensitive to local ethical issues and legal frameworks.

Chief recommendations

1. A clinical ethics network should be established with the express purpose of fostering the development of clinical ethics support services in New Zealand.

2. Further development depends on a wider commitment to the development of networks that need to be able to function well at local level.

3. Relations with central government and/or external funders need to be assessed by a Working Party that should be tasked with deciding how to take forward this initiative; (provisional suggestions for implementation can be found in Part 3 of this report).
PART 1: INTRODUCTION

Background

In the 1960s new medical technologies dramatically increased the treatment options in respect of diseases where death or major disabilities were likely outcomes (e.g., through improvements in surgery and infection control, increased use of mechanical ventilation and other life-saving technologies, and benefits arising from a new generation of drugs). Accompanying these developments were changes in social attitudes, such as who should decide what happens next when treating a patient. The development of the concept of patient rights, including but not limited to autonomous decision-making, took place over an extended period in the latter part of the 20th century. (Evans, 2012)

Boundaries of responsibility in relation to who has access to new technological treatments, and who decides when to withhold or withdraw treatment, for example, challenged long-held paternalistic views about how medicine should be practised. Decision-making gradually ceased to be the responsibility of one individual – the physician in charge – and became a shared responsibility, involving patients, their families, and members of the multi-disciplinary team. In addition, where complex legal and ethics decisions had to be made, the role played by specially formed ethics committees began to receive recognition.

The notion of clinical ethics review began to emerge in the USA during the 1980s; these newly-formed committees had to deal with a range of difficult issues, such as brain death, medical futility, and the criteria for organ transplantation. Concepts around the right to life, and to a lesser extent, the right to die, gradually became a part of public discourse, and a tendency towards more consumerist attitudes to health care became more apparent. This meant that doctors could be challenged if they acted in a
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way that was too authoritarian or paternalistic or failed to show regard for the wishes and autonomous rights of their patients.

In the USA Institutional Ethics Committees [IECs] began to emerge and to tackle hard cases. IECs (similar to CECs) were based in local hospitals, their objective being to provide advice and support on ethical issues relating to critical episodes of patient care. Further developments occurred in 1983 when the US President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioural Research recommended the development of processes for consulting and reviewing medical cases where ethical issues played a significant part of the decision-making process. By the mid-1980s, IECs had become accepted, when it was estimated that about 60% of hospitals nationwide had such a committee. (President’s Commission, 1983)

One influence that helped broaden the involvement of ethics committees to move beyond end-of-life issues and include paediatric issues was the question of non-treatment of babies born with Downs’ Syndrome, which led the U.S. Department of Health and Human Services to recommend the formation of Infant Care Review committees. High-level ethical activity within the Federal Administration was one of the drivers behind a growth in the number of clinical ethics committees [CECs] in the USA. In 1982 only 1% of hospitals had CECs, whereas just four years later in 1986, 60% hospitals had them in place. Dissemination of the idea that ethics committees were necessary gained momentum, with support coming from the American Medical Association, American Academy of Paediatrics, and the American Academy of Neurologists. (Levine, 1984)

It is only in hindsight that one gets a clear picture of why the formation of ethics committees grew so fast. On the one hand there was an increasingly well-informed critical public, and on the other, there were increasing numbers of ethical problems arising from the way that medicine
was being practiced. In the USA, where these problems often became the subject of malpractice lawsuits (sometimes leading to statutory legislation at state level), the presence of IECs was seen as a helpful way of helping to bring about a speedy resolution in difficult cases, thus leading to less frequent use being made of the courts.

Ethics committees were deliberative rather than adversarial, and making use of IECs was seen as likely to help avoid large compensation pay-outs characteristically seen in the USA. The IEC process was as much about law as it was about ethics; it would be wrong to think that ethics and law were two separate methods of analysing and solving difficult problems – they are complementary frameworks, and one should be seen as being integral to the other. Furthermore, using IECs is inherently democratic in that it draws on both lay and expert opinion, and an IEC can be seen as an effective forum for differing views to be articulated, leading to consensus decisions being made that have a degree of moral authority. An ethics committee should not be seen as ‘just another committee’; rather, it offers a practical, non-confrontational way of helping to address complex, controversial problems. This can help save litigation costs and bring equal benefits to the patient (as a consumer) and the health care provider. Rapid decision-making is often essential, and a clinical team can look to an IEC for help in reaching a quick decision. Clinical ethicists retained by larger hospitals in the USA, such as those run by the Veterans’ Administration, often carry bleeps in much the same way as on-call physicians.

The different forces that we are describing coalesced and formed the basis for the modern bioethics development movement in the USA, mainly in the last quarter of the 20th century. Bioethics discourse covers a wide range of topics, not all of which is about health. (Encyclopaedia of Bioethics, 2003) IEC/ CECs are part of a wider international movement that spans resource allocation, professional and policy issues and all
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forms of governance, as well as health care law, ethics education, and a range of other areas such as environmentalism and sustainability. (Yale Interdisciplinary Center for Bioethics, 2012) In short, clinical ethics is a subset of the discipline known as medical ethics, which in turn is part of the wider movement known as bioethics. In the middle of the first quarter of the 21st century, these disciplines are now discrete and well-established (and better defined).

Ethics and health care services (an overview)

Ethics can perhaps falsely give the appearance of being a complex subject, but in clinical terms it is really about forming a judgment based on the available facts of an individual case and assessing the relative risks, burdens and benefits of different courses of action. This task is done by making reference to appropriate legal and ethical frameworks. While additional training may be needed in order to gain familiarity with these frameworks, it is not necessary for practising health professionals to be expert in these fields. (Worthington, 2011) Primarily, clinicians need to be aware of ethical and legal issues that apply to a case as they go about the process of consultation and making decisions. They need to know when and where to go to seek specialist advice. Complex cases are best reviewed by a committee, which should have the ability to draw on a mix of skills.

In a public health system it is important to respect values and to be mindful of the need for equity and justice. Technological advances, coupled with financial constraints and competition for resources, mean that in clinical practice core values are frequently being challenged and can easily be undermined. Developing a basic understanding of ethical reasoning should make it easier for health professionals to communicate
with each other, with patients and their families to help them reach an understanding on difficult issues.

Failure to respect values that underpin health care can have consequences at the macro or policy level, as well as in relation to individual episodes of clinical care. In our experience, when clinical events have a bad outcome they are more likely to lead to litigation if parties fail to communicate and understand each other’s point of view, for example in paediatrics. (Diekema, 2011) Many patients now have access to the internet and to health information; this has a democratizing effect, but it can also have negative consequences if information is variable in quality, inaccurate and/or difficult to interpret. It is possible that clinicians’ decisions are questioned more often because of patients having access to this additional information. This, coupled with modern health care being increasingly complex, can lead to fresh challenges for the practicing clinician.

Ethical discourse can provide a way of helping resolve complex issues. If this is to become a practical reality and if knowledge of ethics is to become part of everyday activity in the workplace, this has implications in terms of education and training. For example, knowledge has to be about more than just identifying ethical principles; ethical principles can conflict with one another and may not lead directly to a practical solution. However, using appropriate frameworks and reasoning skills can help with making further investigations and doing more detailed analysis (e.g., by a committee). Increased knowledge of ethical principles and reasoning can help promote improvements in the quality of care that health professionals provide for their patients.

While it is naive to suppose that on its own clinical ethics can transform a public health system, ethics should be integrated into the everyday life of all those working in the health service. Clinical ethics can
therefore provide one of the main pillars upon which to try and build a successful future for health care in NZ. The phrase “clinical ethics is everyone’s business” captures the idea that ethical imperatives do not end at local DHB level, and the concept of stewardship of health services is important, especially in relation to the role of government.

Ideas advocated within this report fit closely the stewardship model; this concerns the attainment of health goals aimed at improving the health of the nation, whilst responding to legitimate expectations and providing equality of access for all citizens. This sense of stewardship percolates through all levels of the system to help ensure that these important criteria are met. Travis et al (WHO, 2002) broadly define stewardship as “the careful and responsible management of the well-being of the population”, and in general terms it is “the very essence of good government”.

In summary, health professionals, health institutions and the NZ government need to try and ensure that high ethical standards become an integral part of interactions between patients, families, whanau and health professionals, whatever the clinical setting.

Developments in New Zealand

Modern health care provision has to take account of changes in demographics, the development of innovative but expensive treatments, an increasing prevalence of chronic diseases, and an increase in public expectations of the health service. This mix of factors contributes to increasingly difficult choices in the allocation of scarce resources, and changes in public attitude have led to calls for greater accountability on the part of all those involved in making decisions.

In recent times in the NZ health system there has been an emphasis on medical error, the safety of systems, and improvements in
health care quality. A commitment to such activity is becoming more accepted by the health workforce, and is becoming more integrated within the public hospital system. (Davies, 2003; Barnet, 2004) Over the same period of time there has not been as much emphasis on the development of ethical expertise in the context of clinical decision-making. This has been associated with a relative lack of the widespread articulation of the ethical principles involved in day-to-day care. This part of the report reviews the provision of clinical ethics internationally as well as in the NZ context in the hope that this deficit can be addressed.

In NZ there is a strong commitment to ethics in the public health system; however, this support is mainly directed towards research ethics, not clinical ethics, as evidenced by the 1950 Act that established the NZ Medical Research Council [MRC]. The MRC developed procedures to address the ethics of experimentation; any research project involving experiment on human subjects had to have a properly constituted university or hospital ethics committee (or be seen by the Ethical Committee of the MRC); these committees were charged with examining and agreeing on ethics and governance issues relating to each research proposal. The purpose of these committees was to ensure that all research undertaken by health agencies had to be reviewed by an ethics committee, and that ethical standards had to be applied to all research and treatment protocols on behalf of volunteers and patients.

A major influence in the development of ethics in NZ has been the 1988 Report of the Cervical Cancer Inquiry, which concluded that Area Health Boards [AHBs] should be given the responsibility of establishing ethics committees. Furthermore, the report concluded that the Director-General of Health should–
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- Monitor progress and encourage improvements in ethical committees by heightening the awareness of the importance of strong ethical principles in research and new treatment or management.

- Continue to give urgent consideration to the improvement of ethical standards in the National Women’s Hospital, Auckland.

- Monitor progress and encourage improvements in ethical committees by heightening the awareness of the importance of strong ethics principles in research and new treatment or management.

- Ensure that the patient advocate role is reviewed and developed and that her independence from the administrative structures of the hospital is maintained at all times.

- Ensure that lay representation on the ethical committee approximates one half of the membership.

- Encourage the development of better procedures for scientific and ethical assessment.

Furthermore,

- The University of Auckland should improve the teaching of ethical principles and communication skills at all levels of the medical degree.

- Take responsibility for encouraging community debate on medical ethical topics.

- Ensure that academic staff members are encouraged to take part in ethical or scientific assessment committees. (Cartwright, 1988)

The Health and Disability Services Act (1993) provided for the establishment of a system of advisory committees reporting to the Ministry of Health. The National Advisory Committee on Health and Disability Services Ethics [NACHDSE] was established under this provision; it was made responsible for the accreditation and monitoring of local ethics committees for the health and disability services sector. In addition, these
committees were required to undertake an ethical review of both research and service / treatment issues for health and disability support services.

An Interim task group, under the auspices of NACHDSE, reported to the Director-General in February 1994, indicating that local ethics committees should undertake to provide a process of independent ethical review to evaluate research proposals and innovative treatments. The focus was on the provision of ethical advice relating to individual cases, with input from the community on specific issues such as informed consent.

A revised National Standard for Ethics Committees was introduced in 1996. Recognising that this was an area that needed further work, preliminary guidelines for the provision of advice on ethical aspects of issues regarding health and disability services were drawn up. However, in 1999 the National Advisory Committee on Health and Disability Services Ethics [NACHDSE] was disestablished, and a review concluded that in addition to advice on research ethics, key tasks of NACHDSE were to “provide advice to the Minister of Health on ethical matters of national significance relating to health and disability services” and “provide second opinions on service and treatment issues”. (National Advisory Committee on Health and Disability Services Ethics, 1996).

In line with World Medical Association Declaration of Helsinki: Ethical Principles for Medical Research Involving Human Subjects recommendations, the New Zealand Public Health and Disability Act (2000) mandated the formation of a National Ethics Advisory Committee [NEAC], which would be accountable directly to the Minister of Health.

Committee’s objectives of ethical review included statutory functions for—
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- the provision of advice to the Minister of Health on ethical issues of national significance in respect of health and disability matters (including research and health services)

- the determination of nationally consistent ethical standards across the health and disability sector to provide scrutiny for national health research and health services

- to ensure that operational standard forms the basis for monitoring the operation of ethics committees, which review research and innovative practice, and provide advice on ethical issues relating to clinical decisions about the treatment of specific consumers

- to foster awareness of ethical principles and practices within service providers, researchers and the wider community

- to consider any ethical matters relevant to health and disability services e.g.,
  - withdrawal of life support
  - issues involving difficulty in obtaining informed consent for the use of medication and behaviour control / management procedures
  - resolving how services can ensure the protection of the rights of individuals who have diminished capacity. (New Zealand Public Health and Disability Act, 2000)

Although legislation introduced during this period showed signs of a commitment to clinical ethics, the focus, in reality, was almost entirely on research ethics provision. **It is important to note that, research ethics committees function under a legislative framework that grants them executive powers. This contrasts strongly with proposed models for the introduction of clinical ethics committees, which generally emphasize the advisory role without a need for tight legislative control.**
Some research ethics committees have been consulted on matters relating to clinical ethics, and although it would be difficult to achieve a meaningful quantitative assessment of clinical ethics activities, the task would not be large in scope. A review of research ethics committees is currently underway, and it is not known whether clinical ethics will remain within the rubric of established research ethics committees. The current role of these committees is articulated in the *Constitution of Health and Disability Ethics Committees*, which states that:

“The primary role of a Health and Disability Ethics Committee [HDEC] is to provide independent ethical review of innovative practice and health research that will be conducted in their designated region of authority. HDECs may also provide advice on service delivery issues.”

(Operational Standard for Health and Disability Ethics Committees, 2001)

As regards the current situation, there is a process of review of research ethics committee constitutions and activities; it is unknown whether it will include reference to matters of clinical relevance or what the terms of reference will be for these newly constituted committees. A duty to provide clinical ethics support in addition to its other areas of activity would considerably add to the workload of those groups.

*In short, research ethics committees and clinical ethics committees perform different functions; trying to bring one into line with the other using the same structures and even the same people, is not a viable option and is unlikely to prove effective.*
Current and future provision of clinical ethics support in New Zealand

In 1997 a survey of 23 Crown Health Enterprises [CHEs] indicated that three CHEs had established CECs, two committees were being established, and two had developed alternative arrangements to help resolve ethical dilemmas. Pinnock and Crosthwaite (2004) concluded that “based on our own experience, and that of others, we would recommend that—

- **Clinical ethics committees should be multidisciplinary. Membership should represent the major clinical activity areas. It is essential that committees include awareness and representation of cultural diversity, ethical expertise, and legal expertise. It is desirable also that some health professional members should be external to the institution, to avoid parochialism.**

- **All healthcare practitioners should have access to education regarding ethics—by distance learning if necessary.**

- **Clinical ethics committees should attempt to assess their effectiveness and keep abreast of developments in this area.**

- **Opportunities at a national level for committees to communicate and recognise one another (through a colloquium of chairs, for example) would be helpful to increase expertise and for consistency of practice and procedure.**

- **All healthcare professionals should have a strong grounding in ethics during their undergraduate training. Providers of postgraduate training and continuing education should regularly include ethics in their programmes”**.

(Pinnock, 2004)

Pinnock was also involved in an attempt to develop a national committee to address ethical issues arising in the care of paediatric
patients. In 2001 a discussion document was prepared for the Paediatric Society of NZ and the Board of Paediatrics and Child Health of the Royal Australasian College of Physicians. The recommendation was that a National Clinical Child Health Advisory Committee should be established. The function of this committee would be to provide clinical ethics guidance for clinicians and families in the context of problems arising in the care of children. However, to date no such committee has been convened.

An update on the situation in 2010 suggested that there had been a modest expansion in the number of committees in NZ. While the actual state of formal clinical ethics support provision for clinicians is currently not known, there was strong support for the introduction of specific clinical ethics support in the NZ public health system, such as clinical ethics committees or clinical ethicists working within DHBs. (Dare, 2010; Pinnock, 2004) A clinical ethics committee was the most favoured model, but some health professionals expressed concern about the feasibility of providing clinical ethics support in general, and clinical ethics committees in particular. Concerns included–

- The cost of setting up such a service
- The need for a rapid response to requests for advice in urgent clinical situations
- The establishment of yet another committee, thus increasing bureaucracy within the DHB
- The clinical autonomy of health professionals could be compromised.
The introduction and formation of clinical ethics committees

The Auckland DHB CEAG recently surveyed staff that had already referred issues to the committee. The survey sample was small and elicited 18 responses, although some cases had come to the committee more than once, and by national and international standards, this group had a fairly busy workload. The committee also provided policy advice to the DHB management and participated in grand rounds and continuing professional development during the survey period. The majority of professional staff attending the committee during the survey period comprised doctors (61%); however, the Committee also heard cases brought by nurses and midwives (11% for each group), and other respondents who did not describe their professional status or grouping. (Dare, 2010)

Respondents were overwhelmingly positive. Everyone said that they would recommend the CEAG to colleagues, and 94% thought the opinion was provided within the expected time, and 65% thought the opinion helped with clinical decision-making. This means that even those who did not find the opinion useful in clinical decision-making would nonetheless recommend making use of the committee to colleagues. The cases covered by these responses are just a fraction of clinical decisions presenting with significant ethical components made by practitioners within the Auckland DHB and across NZ every day.

In relation to experiences of CECs currently operating in the UK, a recent opinion piece describes CECs as being the ‘elephant in the room’. In 2009 a research group led by Dr Daniel Sokol surveyed a total of 70 CEC chairpersons. Less than half (30) responded, but as Sokol said—

“The results were worrying: Although all the respondents said that their committee welcomed individual cases, 10% had not considered a single active (or “live”) case in the past 12 months,
43% had considered between one and three cases, 30% had considered between four and six, 13% between seven and nine, and 3% (one committee) between 10 and 15.

There was no correlation between the duration of a committee’s existence and the number of active cases that they considered. The conclusion was that: “at the moment, the stark reality about CECs in the UK is that clinicians are not using them.” (Sokol, 2009) attributes these failures to a number of issues, including lack of payment, problematic recruitment policies, difficulty acquiring ethics expertise given low referral rates, lack of ethics training, an inability to respond to urgent cases, and having to deal with intimidating committees.

The impetus for establishing CECs commonly came from concerned clinicians rather than from managerial initiatives. Committee membership was multidisciplinary and included lay members. In most cases the committee was chaired by a senior medical doctor. There was a perceived need among CEC chairmen for formal ethics education to be provided for committee members, as is commonly the case in the USA. Ethics education should focus initially on the identification and articulation of the morally relevant facts within a case, and the process of making morally challenging decisions. Specific knowledge of moral theories was not seen as essential for all members but might be desirable at a later stage. Training in how to function effectively as a committee was also necessary very; however, few clinical ethics committee members in the UK had any specific ethics training. Barriers to providing ethics education for committee members included funding issues, time commitment for members and a general lack of appropriate courses.

There is a divergence of views amongst CEC chairmen as to the benefit of having an ethicist or moral philosopher on board. The
experience of some committees is that an ethicist is not essential to the successful functioning of the committee. Others, however, find having an ethicist to be of great value. If a committee does not have an ethicist then ethics education of the committee becomes even more important.

Terms of reference that relate to established CECs in the UK describe three main functions—

i) providing support for individual clinicians

ii) having input into trust policy and guideline development

iii) providing education for health professionals within the trust.

Most committees concentrate on the second of these areas, although in a few cases, carrying out individual case consultations is seen as being the committee’s main function. Reasons cited for not providing education for committee members include lack of financial resources, lack of time, and lack of confidence in the committee’s own knowledge and ability to provide ethics education for others.

Raising the profile of the CECs within each Trust is seen as being a priority if the committee is to function effectively. Few committees are well known within their trust and are therefore accessed only by a small group of clinicians. However, it is important that when a committee is first established it develops credibility in one or two areas before expanding any further.

Evaluation and audit are essential if CECs and other clinical ethics support services are to develop further within the UK (Sokol, 2009); to date only one CEC has carried out a formal evaluation of its work. Reasons for this include difficulty in defining outcome measures, lack of clarity in terms of the committee’s aims, and lack of financial resources. In
general, the relationship between CECs and clinical governance needs some clarification.

Most chairmen of established CECs in the UK viewed consideration of ethical issues as an integral part of providing high quality patient care, and so by inference, an essential part of clinical governance. However, others considered it more important for the clinical ethics committee to be seen as separate from normal processes for monitoring clinical governance.

Several health authorities and health boards have begun to address the ethical issues around resource allocation and priority setting. There is a lack of consensus amongst health authorities on whether ethical issues relating to other areas of clinical practice are their concern, or whether they fall more within the remit of Trusts. Even within the area of resource allocation there is no clear boundary between health authorities and trusts as to where the responsibility for ethical input lies. However, there is a recognised need for health authorities to provide ethics support to primary care groups and trusts on issues arising from clinical practice and resource allocation. Given the major health reforms that were recently introduced into the NHS in the UK following the Health and Social Care Act (2012) passing into law, it may be a while before organisational clarity and boundaries such as the ones we describe can be properly achieved.

In terms of clinical ethics support by professional organisations, many health professionals view their professional organisations as a source of ethics support on clinical issues. Several lead professional organisations produce guidelines on specific issues; these provide a useful framework for clinicians, but perform a different role from CECs. Concern has been expressed that advice from a national body is too
generalised to be helpful in local circumstances and that professional organisations need to act as a resource for local support services.

Few university departments of medical ethics provide regular clinical ethics advice to health professionals; for example, in New Zealand, there has previously been significant academic involvement in clinical ethics in Otago, through a collaborative relationship between the university and the DHB, but this relationship is no longer fully functional.
PART 2: GLOBAL PERSPECTIVES

International Perspectives on Bioethics

The move towards incorporating bioethics into clinical medicine and health care education is international, and has been championed (among others) by The United Nations Educational, Scientific and Cultural Organisation [UNESCO]. (UNESCO, 2005) The 2005 Declaration on Bioethics and Human Rights sets down global minimum standards in biomedical research and clinical practice; it is the first international agreement to link human rights with bioethics, and New Zealand is a signatory to this declaration. (Adorno, 2007).

Article 19 states that “independent, multidisciplinary and pluralist ethics committees should be established, promoted and supported at the appropriate level in order to–

(a) assess the relevant ethical, legal, scientific and social issues related to research projects involving human beings

(b) provide advice on ethical problems in clinical settings

(c) assess scientific and technological developments, formulate recommendations and contribute to the preparation of guidelines on issues within the scope of this Declaration

(d) foster debate, education and public awareness of, and engagement in, bioethics.”

Article 23 goes on to say that–

“In order to promote the principles set out in this Declaration and to achieve a better understanding of the ethical implications of scientific and technological developments, in particular for young people, States should endeavour to foster bioethics education and
Bioethics discourse gradually entered the domain of public policy and health care, and it is now frequently the subject of media attention and online discussion. (BioEdge Online; BioNews Online) It has grown from being something experimental and outside of mainstream culture to being more a part of public consciousness, especially in relation to medicine and the professions.

There is a large and growing body of literature on patient rights to autonomy, and in the 21st century in modern democratic society it is both morally and legally unacceptable for doctors to treat their patients in a spirit of paternalism and overrule the fundamental right of patients to self-determination. (Worthington, 2004; GMC, 2008) For this to be respected properly there has to be engagement on the part of the clinician; this engagement necessarily entails a process of consensus-building with those involved in the care of a patient, not least with the actual patient, provided s/he has legal capacity. It follows from this that clinicians need basic training in medical ethics and law, and this has been widely incorporated into medical curricula in most post-industrial nations. (MedEd Portal) It also follows that there needs to be a mechanism for consultation between interested parties when difficult decisions have to be made. Without appropriate education and training and mechanisms being in place, talk about patient rights and autonomy could otherwise be seen as empty rhetoric. (Clinical Ethics; J. of Clinical Ethics)

Developments in the provision of clinical ethics support in the USA

One of the first committees systematically to address a clinical ethics problem was convened in Seattle back in 1961. On the basis of
previously agreed criteria the committee decided which patients should receive a newly developed technology, namely haemodialysis. The new technology expanded the number of patients who could potentially benefit from receiving haemodialysis, and this number was far beyond the limited capacity of the dialysis unit. The allocation of scarce resources and deciding how they should be distributed between patients was not easy, and for the patients affected by the outcome of those decisions it meant a choice between life and death.

Clinical, economic and moral reasoning all had to be applied, and not surprisingly, the committee became known as ‘the God committee’. Very soon the committee was criticized for making moral judgments, because, for instance, it tended to value people highly who were white, educated, young, married, employed, and male. The problem of dialysis was addressed in 1972 when federal government took the decision to finance treatment for anyone who needed it, extending Medicare coverage to anyone under 65 years old with end-stage kidney disease. In some ways, these attempts at establishing criteria for making difficulty resource-allocation decision paved the way for the development of clinical ethics, and in the USA the first Clinical Ethics Service [CES] appeared around the same time—i.e., in the early 1970s. Institutional or health care ethics committees were based in local hospitals, their objective being to provide advice and support on ethical issues relating to patient care. By the mid-1980s such committees had become more accepted, and it was estimated that nationwide around 60% of hospitals had institutional ethics committees. (Rubin, 1984)

Although in North America clinical ethics services (CESs) became an established part of health care, clinical ethics support services took longer to be established in other countries (e.g., in, Australia, New
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Zealand, Europe and South America). Different models of clinical ethics support include –

i. Ethics committees

ii. Clinical ethicists

iii. Ethics consultation groups

iv. Clinicians trained in ethics

v. Combined research and clinical ethics committees

vi. Frameworks for consideration of ethical issues in practice.

To the best of our knowledge no systematic, large-scale evaluation of the effectiveness of clinical ethics services has been undertaken in North America, Europe or Australia, and there are no internationally recognised standards for clinical ethics support. However, a national survey of clinical ethics was carried out in the USA with random sampling from 600 US hospitals, the findings of which were published 2007. Despite self-reported limitations, the study was–

“the first to provide a representative snapshot of national ethics consultation practices. It also raises several concerns that suggest a need for additional research. Although the prevalence of ECSs in U.S. hospitals is quite high, there appear to be wide variations in practice, a lack of formal training, and few mechanisms for quality control.” (Fox, 2007)

The type of outcomes measures that are applied routinely in evaluating the efficiency and effectiveness of health systems and services do not necessarily work when applied to moral reasoning, where on their own, numbers do not necessarily speak for themselves. Empirical ethics research is undertaken in specialist university centres, but it requires
significant resources for teams to be able to carry out qualitative research studies into the use of clinical ethics support.

**Analysis of the current state of clinical ethics support in the UK**

Initiatives to provide clinical ethics support were developed by some NHS trusts, mainly over the last few years; other UK NHS Trusts are planning similar initiatives. (UK Clinical Ethics Network) It seems likely that clinical ethics support services will increase over the next few years following the pattern seen in North America. Developments in Europe and Australia appear to be showing similar trends.

In the UK a number of different models for the provision of clinical ethics support have developed within Trusts, using both new and existing structures. It is not clear which model, or models, is considered most useful or appropriate for more widespread use and implementation. The structure of support varies, depending on the circumstances of each individual trust; however, such services are likely to share certain common aims and needs, and Trusts need to be able to prove that clinical ethics support helps provide an effective service to the benefit of patients and health professionals.

In order to facilitate the achievement of high ethical standards in patient care in the UK, the use of clinical ethics should probably be expanded as a matter of public policy, but we recognise that this is subject to a number of influences that are mostly political and economic in nature. (Worthington, 2005) In the absence of any clear lead from central government, individual clinical ethics support provision is fragmented, and a common feature of UK clinical ethics committees is that they tend to be unaware of the existence of other committees. (Slowther, 2011)
There is clearly a need to share information and experience among clinical ethics committees and other support services, and the development of a national network of clinical ethics support services would help in providing information, education and support for developing initiatives. While a national clinical ethics network exists in the UK, it is largely a web-based resource (developed with funding from the Department of Health for England and Wales) rather than a fully developed advisory service. (UK Clinical Ethics Network)

Further development of a national network of clinical ethics support services in the UK would be helped by sharing information and expertise in relation to providing education and support for clinical ethics services. In order to assess whether a particular model of clinical ethics support is effective in achieving its aims, support needs to be available to help make provision for—

i)  Expertise to support and develop the service
ii) Appropriate training for those involved
iii) Administrative support
iv) A recognised status for the service supported by local management
v) Protected time for those providing the service.

Prior to the recommendation of particular models of clinical ethics support, each model needs to be evaluated in terms of both process and outcome. Internal (local) evaluation is required to help measure the effectiveness of the service against local aims and objectives. In addition, independent external (national) evaluation is advisable in order to provide a generalizable assessment that can be used to inform national guidelines and recommendations.
This method of local and national evaluation that has been used previously in the context of local initiatives has national implications, and an appropriate strategy for future development would be to use external funding to support specific initiatives in order to promote models of best practice. A recommended period of three years would be necessary to enable the service to develop to a stage whereby meaningful evaluation was then possible.

Specific initiatives could be established to help develop models of best practice appropriate to the roles of different Trusts and groups for clinical commissioning. (Health and Social Care Act, 2012) A formal evaluation of these initiatives could usefully be carried out, including local evaluation and independent evaluation against national guidelines. Because of major reforms taking place in England and Wales, clinical ethics support is unlikely to receive high priority in terms of national policy. However, we argue that it should be considered an essential part of providing quality care, and therefore it is not something to be put off until the economic climate is otherwise less constrained. Therefore, in order to facilitate further development of a national network of clinical ethics services in the UK, initiatives are needed to help develop models of best practice appropriate to the roles of different health care providers, which should include mechanisms for formal evaluation.

Frameworks for UK research ethics governance and review has also undergone a process of significant change, and while this makes it hard to compare clinical ethics support with established methods of research ethics evaluation, the situation remains that the two types of committee perform essentially different functions. (Human Research Authority) We do not believe that research ethics committees should take on the role of providing clinical ethics support service; their training and expertise is different, and their way of working does not allow them to provide a fast and responsive service for clinical ethics support, in the UK.
or elsewhere. In summary, clinical ethics services are increasing in the UK, as is their involvement in consultation. This expansion over the past 10 years suggests that there is a perceived place for CECs in the NHS. While this growth is encouraging, it has come with variations in practices and procedures. These are not necessarily problematic as long as the practices are justified.

Further qualitative research is needed in order to gain a better understanding of how CESs conduct their business. While the development of evaluation criteria is needed, research evidence alone may not be sufficient to drive a change in practice. As the presence of CESs in the UK increases, there is also a need for better co-ordination at national level (e.g., with help from guidelines published by the Department of Health to help promote best practice). Government recognition of CECs in the UK would also make it easier to put into place the appropriate support and scrutiny, such as that required by other health care services; to date, recognition of the part played by clinical ethics in the UK has not come from central government. Instead, the growth of clinical ethics committees has been incremental, reflecting increasing local awareness of the importance of clinical ethics. The process of expansion that has gone on in the last 10 years has been fostered by the UK Clinical Ethics Network (UKCEN). One of the functions of UKCEN is to provide a practical guide to assist members of established committees and to provide information and assistance to others who are in the process of setting up committees.

In 2000 there were 20 clinical ethics committees in the UK, and ten years later 85 committees or groups were known to the Network. The structure of each committee, the functions it performs and its relation with local health care organisation varies; each has developed in the context of local needs, circumstances and resources. (Slowther, 2011)
European countries where clinical ethics support provision is being developed include Germany, France, Italy, Croatia, and Ireland. This type of service covers all areas of medicine, including pediatrics and family medicine. While we argue that the case for clinical ethics is strong and relatively easy to substantiate, such provision is not without its critics, and several concerns have been expressed regarding clinical ethics committees. These include interference with the doctor-patient relationship, erosion of the professional autonomy of doctors, reduction of the patient’s freedom of choice, and fear that they will create a further layer of bureaucracy in hospitals. (Mimi 2000; Incovarti 2000; Kerridge, 2001; Wenger, 2002; Dorries, 2003; Manning, 2002; Borovecki, 2005)

These criticisms are unfounded if it remains the clinician’s decision to consult a committee (i.e., if decision-making responsibility is not shifted on to a committee). None of the clinical ethics committees that have reported on their activities consider that their opinions should be binding. We believe that these committees are, however, here to stay, and we predict that with time they will play a significant role in patient care. Challenges for the future include more objective assessments of effectiveness, and the ethical education members of such committees will require.

Within a NZ context, the relationship of these committees to the national structure and guidelines for ethics committees remains to be resolved, and it is eminently desirable for there to be a common understanding about the role and composition of clinical ethics committees and an opportunity to share expertise and experience.
New Zealand is currently lagging behind the UK and the USA in implementing international recommendations in relation to health care education and clinical practice. In NZ a small number of CEAGs have evolved in response to the need to address clinical ethics problems. However, many DHBs have no formal clinical ethics support at all. In addition, there is little communication between DHBs on clinical ethics matters; therefore, clinical expertise and experience that currently exist are not being shared.

The Health Quality and Safety Commission [HQSC] has funded this project, the aim of which is to provide a rationale for the formation of a National Clinical Ethics Network. Plans to develop the project include writing a report to review international developments in clinical ethics; in addition, a website will be developed, and both these initiatives will form the basis for exploring what a New Zealand clinical ethics network might look like. Large surveys will also be undertaken to explore the views of health professionals in terms of the perceived need and relevance of clinical ethics in their everyday work. These surveys will provide the basis for further discussions with key personnel in various professional bodies that are relevant to the development of a clinical ethics network.

In the short to medium term, the plan is to raise the profile of clinical ethics to the extent that “Clinical ethics should be everyone’s business”, and to this end is hoped that ultimately all clinicians will have access to a CEAG.

In terms of the history of clinical ethics in NZ, in the late 1980s, as a result of the Cartwright Report (1988), there was great interest in the role of ethics in the health services. However, the momentum for ethical development has predominantly been directed towards research ethics. Given the relatively greater presence of clinical ethics in countries of
similar socio-economic status to NZ, we argue that it is time to pay greater attention to the provision of clinical ethics support in NZ.

An important factor in the development of greater clinical ethics presence in NZ is the role of the public in this process. Health professionals (ought to) serve the best interests of the public and their health; the public, as individuals and as members of families and whanau, has a right to expect to receive the best available health care in a way that affords them the respect they deserve. Involvement of the public is not just a noble aim, it is a necessity, and while different ways of achieving meaningful public engagement have been tried around the world, the extent of public involvement in health policy development varies greatly.

It is important to remember that in NZ the public funds the majority of health services, and they should be able to make a significant and meaningful contribution to how health care services are run. Modern healthcare is a multidisciplinary undertaking, and a knowledge of clinical ethics means that health professionals need a common language to be able to articulate the principles of clinical ethics; promoting understanding and effective communication between these two groups is vital to improving the quality of care.

NZ has less well developed systems in place as compared to other countries in the world; one way to try and tackle this deficit is for government to take the lead and critically examine how to develop viable and sustainable clinical ethics support in NZ’s public hospitals. The existence of clinical ethics committees in NZ at present is not widespread, and this does beg the question, “why not?”

In neighbouring Australia the situation is patchy, there also appears to be little by way of cohesive structures as regards clinical ethics advisory groups. There is an online “Clinical Ethics Resource”, in New South Wales, and the Australasian Association of Bioethics and Health Law has
formed a special interest group with the aim of bringing together interest and expertise; however, overall the situation is uneven and these groups are not well resourced. (AABHL)
PART 3: POLICY IN PRACTICE

Risk evaluation

We are unaware of any significant risks attaching to this project, provided that resources are available to ensure that it is appropriately funded. The ideals that underpin the formation of a clinical ethics network are closely aligned with those of the Health Quality and Safety Commission, and the only significant risk of which we are aware is that because the project is funded by the HQSC, if the project fails to deliver on its aims, the implications of that failure could affect HQSC as well as the network itself. AM has comprehensively documented the need for such an initiative, and many people have come out in support of the proposal; the expectation, therefore, is that the establishment of a clinical ethics network will occur (in accord with the stated aims) within the suggested time-frame.

Another fundamental reason for wanting to improve clinical ethics knowledge, expertise and practice is to help promote human rights and ensure that patients receive treatment that is appropriate to their needs (or in their best interests in the case of patients who lack legal capacity). CEAGs often deal with cases which have the potential to become divisive, and it is important that CEAGs see consensus as being one of their main goals. There should also be a commitment to education in its widest sense so that ethical concerns become part of the day-to-day ‘fabric of health care’.

Following on from wider ethical involvement within an institution it is important for health professionals to be able to bring up ethical issues in the management of specific patients. Every member of the health care team should have an input in these deliberations, especially in end-of life-care, and this dialogue must involve the patient and his/her family, as
appropriate. Shared decision-making should be the ‘norm’, from both a legal and ethical perspective, (GMC, 2008) and in the UK, CECs mediate to help bring this about. (McClimans, 2012) It is our belief that conformity to such practice standards can reasonably be expected to help reduce risks associated with litigation. Implicit in the establishment and function of CECs is a primary obligation to promote standards of good practice. This concept is allied to an explicit declaration that in NZ it is not the role of a CEAG to enforce standards or to investigate when things go wrong.

**CEAGs must retain their independence and not be seen as part of the regulatory process; that responsibility has to lie elsewhere. In short, we recommend that introducing CECs should be part of every DHB’s strategy of risk reduction.**

**Patient safety**

In a broader context, when things go wrong with patient care and become the subject of public scrutiny they have an adverse effect on the perception of standards of health care within the system as a whole. While involvement of a CEAG in an individual case could alter this perception, this should not be seen as the primary reason for having a CEAG. Nonetheless, patient safety can be compromised as the result of conflict within teams or between teams and patients or families, and when the focus of care shifts from the patient to wider organisational pressures, such as meeting targets and allocation of resources, these can have a marked negative impact on patient safety. *(Mid Staffordshire NHS Foundation Trust Inquiry, 2010)*

Ethical scrutiny of such clinical practice, as part of a wider investigative process, has the potential to improve patient safety; “*all involved in health care want to do be able to do the right thing, in the right time, at the right way, for the right people – those who will most benefit*
Furthermore, “Recurring ethics issues can have a detrimental impact on both the quality of patient care and the culture of a healthcare organisation”. (Nelson, 2010) While it is difficult to prove a negative, it is fully consistent with logical reasoning that having respect for ethical values and actively demonstrating understanding for legal frameworks behind patient care should have a positive and beneficial effect.

In common with other countries, NZ will struggle to provide health services in an increasingly resource-constrained environment, and variations in the availability and accessibility of services could become much more critical than they are today. Robust ways of making and justifying hard choices that have the potential to reduce these differences need to be embedded in national policy and be factored in to decision-making in the wider context of health politics and economics. An awareness of clinical ethics should be part of this process, and the collective aim of the Network is to ensure that clinical ethics becomes an integral part of all health services. The formation of a clinical ethics network in New Zealand can be seen as a way of introducing the language of ethics into public policy deliberations, as well as in the everyday work of health professionals.

Policy options and recommendations

Policy options include keeping the status quo, or the formation of a clinical ethics support network or other form of ethical support; the implications of this choice should be informed by research-based evidence, and in view of this it is clear to the authors that the second of these options is far preferable. (Regrettably, it is not possible to cost this option at present on account of the number of unknowns; by inference this means there is presently no certainty on the question of funding; these
matters need to be considered as a matter of urgency by the Working Group if the Government’s response to this initiative is generally favourable).

Evidence in support of this preference include results from local and national surveys carried out by AM in NZ; documentary evidence of the current status of clinical ethics in NZ, and a review of local and international literature on clinical ethics, all of which can be found in other parts of this report. In addition, AM held discussions on these issues with key individuals in NZ and overseas, which have helped to inform this analysis.

Based on our own experience, and that of others, we recommend the following:

1. **All healthcare practitioners should have access to a clinical ethics committee via their employer; small centres can gain access to ethicists / clinical ethics committees via teleconferencing, or through individual committee members making a visit (as needed or as a part of a scheduled activity).**

2. **Clinical ethics committees should be multidisciplinary; membership should represent all major areas of clinical activity.**

3. **Committees must be mindful of the need for adequate representation and awareness of cultural diversity; membership should reflect social diversity, as far as is reasonably practical, and it should include ethical as well as legal expertise and a health professional who is external to the institution (to avoid parochialism).**
4. All healthcare practitioners need to have access to ethics education and training (methodology and detail of how this should be provided forms part of a separate but parallel discussion).

5. All healthcare professionals ought to have a grounding in ethics as part of their formal undergraduate training; it is equally important for providers of postgraduate training and continuing education to strive to include ethics in their programming.

6. Clinical ethics committees should periodically assess their effectiveness and strive to keep their skills-base and knowledge up-to-date.

7. Opportunities should exist at national level for committees to communicate with each other (e.g., through a colloquium of chairs) to share best practice and ensure consistency of practice and procedure.

**Project timelines and delivery**

The work necessary to establish a clinical ethics network begins as soon as funding becomes available, and personnel required to commence the endeavour will be immediately available. Early discussions are already underway with regard to the establishment and development of a clinical ethics website. Nationally (and internationally) there are interested parties who continue to support the development of this project; AM has have received permission from these individuals to provide details of who they are, if required. In January 2012 AM was a co-chair involved in a panel discussion on the role and development of local CEAGs at the NZ Bioethics Conference in Otago. This provided the opportunity to increase
the profile of the clinical ethics network to an audience with expertise in the area of clinical ethics.

If, as anticipated, there is incremental interest in a clinical ethic network, then an important part of the project will be to examine future funding arrangements so that the network becomes sustainable. The acquisition of funding is a vital early part of the strategy of the clinical ethics network; however, for the purposes of continuation, provision of clinical ethics should not in future be reliant on funding from central government or external agencies. While we perceive it as playing a vital part in the NZ health system in the future, we believe that funding should ultimately come from local sources; i.e., with responsibility shared between individual hospitals and DHBs.

A specific date for the delivery of the full project is impossible to give because there is no fixed endpoint; nonetheless, as models for clinical ethics support continue to evolve, from observations in the UK and elsewhere, the process of introducing this service is likely to be gradual and incremental. That should be not be attributable to any lack of clarity or lack of commitment to the project as a whole; rather, it is likely to reflect realities on the ground in terms of changing the culture of how clinical decisions are made.

**Categories to which the project relates**

1. **Improving patient safety**

A national clinical ethics network is one of the drivers for the development of local clinical ethics expertise. Ethics education and familiarization with ethics concepts at local level mean that health professionals can add another dimension to their clinical expertise. A greater ethical knowledge could even contribute to greater work satisfaction on the part of the health professional, since a better
understanding of ethical principles helps focus the attention of health professionals on the things that really matter when caring for a patient. For example, when a health professional is involved in sensitive discussions about end of life, advance care directives or resuscitation decisions, the health professional should have the necessary experience, expertise and knowledge to be able to have those difficult discussions. That means taking full account of the legal and ethical dimensions of clinical decision-making. Familiarity with ethics can therefore help to improve the patient journey by respecting patient rights and giving patients, families and all members of the health care team proper recognition.

Currently, there is no formal way to ensure that such clinical ethics expertise or knowledge exists. Knowledge of basic ethical principles is not uniform, and placing greater emphasis on clinical ethics has the potential to help to improve this situation. Modern healthcare is a multidisciplinary undertaking, and understanding the role played by clinical ethics should help health professionals to communicate more effectively. For instance, should a clinical dilemma progress to the point where impasse occurs, then a referral to a clinical ethics committee will provide a means of clarifying the issues, helping to find a satisfactory resolution to the problem.

Quality decisions based on sound ethics and peer support can and should contribute to patient safety by promoting high-level ethical debate in clinical practice about real life events, facilitating shared learning on matters including patient consent, confidentiality and quality of life. This practical example of patient-centred care is designed to benefit individual patients while providing support for health care professionals and promoting respect for core ethical values such as autonomy and justice.
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2. Fostering quality improvement

Ethical clinical decisions help promote quality improvement locally and nationally; sound decision-making directly relates to how health care is delivered and how it is received and perceived by patients. (McClimans, 2012) This proposal for the creation of a national clinical ethics network will help to foster quality improvements by providing a forum for debate and critical analysis of clinical ethical dilemmas. In turn, this should help boost levels of knowledge on health care ethics and law, which feeds directly into the clinical experience of the professional and quality patient care. Timely access to relevant information through the use of clinical ethics support has the potential to improve the quality of decision-making in clinical practice and reduce time delays and stress for patients and professionals in the context of day-to-day clinical medicine.

3. The Triple Aim: Improved quality, safety and experience of care

Better understanding of clinical ethics by medical professionals ought to enhance respect for patients as individuals and facilitate better consumer engagement; improving quality of care improves patient outcomes, reducing the risk of having adverse clinical events. For instance, ethical difficulties around informed consent often arise in clinical medicine; this links directly to HQSCs objective of enhancing and enabling consumer engagement in decision-making. This proposal should help medical professionals to improve their communication skills and better understand the obligations they have to involve patients in decision-making.

4. Equity and population health

Clinical ethics networks, among other things, can provide a forum
for discussing, debating and balancing human rights for a wide range of issues at the level of public policy and population health. For example, one of the primary aims of the New Zealand Health and Disability Act, 2000, is “the promotion of the inclusion and participation in society and independence of people with disabilities”. This practical expression of the principles of social justice and respect for human rights sits well with a fundamental tenet of the network, namely, that it is to be socially inclusive at all times, seeking to provide benefit to all population groups on the basis of need, without regard for someone’s health, ethnic or socio-economic status.

Establishing clinical ethics committees and showing commitment at the local level to fostering knowledge of clinical ethics, can help in addressing topical issues, such as access to dialysis and implementing advance care directives. CEAGs can help ensure that when cases are discussed, by giving proper consideration to ethical opinion, the concept of equity and fairness can be applied in a practical sense to actual clinical situations. Individual clinical decisions as well as policy decisions can be constructively scrutinised by making appropriate reference to legal and ethical frameworks. The present ad hoc nature of ethical decision-making in NZ is problematic, and from an ethical standpoint, it is inherently unfair.

Implementation, and policy implications

The existence of a National Clinical Ethics Network has at least the potential to mitigate the effect of some of these inequities through the development of CEAGs.

The network and website should provide value for money. While the virtual network will have a physical base in Wellington, there is no need for it to have a separate work space or building. Furthermore, future costs associated with the running of committees will be borne by DHBs,
including clinical ethics activities and education and training cost for committee members.

In 2010 AM conducted a national survey of Chief Medical and Nursing Officers; this indicated a considerable variation in clinical ethics availability, with very few DHBs having a fully-functional clinical ethics committee. A recurring theme from these surveys was that health professionals wanted clinical ethics support, and the reality for many of them is often that the availability of such advice does not extend beyond informal advice from professional colleagues. In addition, AM conducted local surveys of RMOs and nurses, analysis of which reflects the requirement for greater access to clinical ethics experience and expertise in order to support health care decisions that are dealt with on a daily basis. (Appendix)

The presence of a CEAG (or equivalent) in a local DHB should mean that clinical ethics advice is readily available. Membership of the CEAG should include people with diverse backgrounds, and such diversity needs to be reflective of the plurality of views that pertain to a particular case. The resolution of such differences will depend (among other things) on the maturity, composition and credibility of the CEAG.

Clinical ethics education is part of the undergraduate curriculum for most medical students, but following graduation clinicians often have little or no formal ethics education. To try to fill this gap AM has held clinical ethics discussions with various professional groups (such as nurses, RMOs, midwives, dieticians, social workers and occupational therapists) at CCDHB. This appeared to be the only time that these groups had ever been part of such an initiative.

The National Bioethics Centre at the University of Otago in Dunedin is an academic ethics unit. Interestingly, there is no clinical ethics committee in the Otago DHB; however, there is strong local support for
the development of such a capability. In preliminary discussions with the
Otago Bioethics Centre there seems to be a potential for mutual
development of clinical ethics expertise within NZ. As the Chair of the
CCDHB ethics committee AM has fostered informal relationships with
individuals in Northland, Waitemata, Waikato, Auckland, Middlemore,
Nelson, Hawkes Bay, Rotorua, Wairau, Hutt, Taranaki, Mid-Central,
Otago and Wairarapa DHBs.

If the proposal does not go ahead then we have to reflect on how
NZ would be placed in terms of international comparisons. For example:

1) Many other countries have recognised the role of CECs /
CEAGs. Implicit in this is the recognition that health is now
undertaken by multidisciplinary teams. Clinical ethics committees
are also comprised of members who have a wide variation of
professional expertise; diversity of association amongst health
professionals and members of CEAGs should encourage
understanding and communication between groups and individuals
in a meaningful way.

2) In the USA, clinical ethics has been an integral part of health for
over thirty years. It is even a mandatory requirement of health care
organisations for accreditation by the Joint Commission on the
Accreditation of Healthcare Organisations. In addition, Clinical
ethics networks have been established in many Canadian
provinces (e.g., in Alberta, where there has been a clinical ethics
network for over 30 years).

3) In the UK, over the last 15 years an increasing number of trusts
(=DHB) have established clinical ethics committees. ETHOX
(Ethics at Oxford) is the centre that administers the national clinical
ethics network. (UKCEN)

4) In many other European countries national clinical ethics
networks have been set up. E.g., in Denmark, the Danish Council
of Ethics takes the issue of teaching ethics further to the extent that
it is now part of the curriculum of adolescents.

Given the likelihood that ethical problems will become an
increasing and integral part of health care in NZ, we have to think about the best way of dealing with complex problems.

**Network aims**

1. **To promote the development of ethics support in clinical practice in NZ**

2. **To promote a high level of ethical debate in clinical practice in NZ**

3. **To facilitate communication between all NZ clinical ethics advisory groups**

4. **To help make clinical ethics ‘everyone’s business’.**

The aims of a network are to encourage the development of CEAG within DHBs. Some DHBs may feel that they are too small to have their own CEAG; in which case they may want to align themselves with a larger, regional CEAG. Following on from the development of CEAGs, there should be a commitment to the promotion of ethics support and debate more widely within the NZ health system. This requires a commitment to develop further relationships with key personnel in each DHB who are identified as people who can promote the idea of clinical ethics support.

The website is at the centre of the Clinical Ethics Network in NZ. A fully functional website provides—

- A forum for sharing of information and best practice between members through electronic communication, plus the opportunity to discuss ethical issues in real time

- A point of contact for established and newly developed CEAGs in NZ
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- A link to documents, policies and practical advice needed for setting up a local CEAG

- A forum for members of the network

- The opportunity to do a ‘stock-take’ of clinical ethics support in NZ to help guide future development of the website

- The ability to communicate with registrants on the website, including the development of a moderated blog

- The opportunity to develop teaching materials, discussion papers and workshops, addressing common issues such as:
  - Informed consent
  - Withholding and withdrawing treatment
  - Mental capacity
  - Do Not Resuscitate Orders
  - Advance Directives
  - Competent refusal of treatment
  - Confidentiality
  - Complex reproductive decisions.

- The collation of anonymised cases to address common issues has value; similarly, sharing valuable information allows a collective wisdom to develop

- The development of a shared template promotes an improved way of documenting clinical ethics opinions

- Opportunities for planning a national conference for CEAG members and other interested parties would be greatly facilitated

- Establishing links with future national and international clinical ethics conferences
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- The development of useful links with journals, patient organisations and professional organizations

- The opportunity for invited commentaries from outside experts on ethical and legal issues in health care, including commentaries on key legal cases and new legislation

- Communication between health professionals via a regular newsletter

- Disclaimer notice in terms of aspects of the website content, and a general statement that the website is intended to be informative and not to be construed as offering advice in any specific case; it would also address any copyright issues

- The provision of ‘contact us’ information is essential to the process of providing web-based support.

Organisation accountability, leadership and administration

If there is agreement that a clinical ethics network should be created, an early initiative would be the establishment of a National Board of Trustees. Trustees would be nominated by the members of CEAGs and individuals who have registered with the network. Candidates for membership of the Board of Trustees would be sought from the wider community. A Board of Trustees would provide oversight of the conduct of the affairs of the network; in addition, the Board would seek to ensure that CEAGs maintain standards for ethical deliberation, education and membership. A separate (minimal) administrative support structure would need to be created for the maintenance and development of the Clinical Ethics website.
An important function of a clinical ethics network is the provision of ethics information. This should be of high academic standard and communicated efficiently and with clarity. The appointment of an *editorial board* would be an early undertaking. The Network itself would be made up of members of CEAGs, clinical ethics groups, and individuals with an interest in clinical ethics; it would play an important role in helping shape the future of clinical ethics in NZ.

In terms of audit, several have already been conducted on different health professional groups; these will provide a benchmark for later surveys to be conducted in 2012-13. (AM has engaged the services of a member of the Quality and Risk Unit at CCDHB in this audit activity; she has already put together a survey tool to ensure quality of data that will allow for comparisons over time). The surveys have concentrated on the level of understanding and ways to access clinical ethical advice in hospitals; those conducted so far comprised a national survey of Chief Nursing and Medical Officers, a survey of nurses (250 replies), and a survey of junior doctors (55 replies).

**The time-frame for implementation**

AM has presented the case for a clinical ethics network in a variety of different fora. Conference presentations to date have included–

a. The annual conference of the *Association of Salaried Medical Specialists*, Wellington, 2010
b. Regional ethics conference, Auckland, 2010
c. Auckland Clinical Ethics Meeting, Auckland, 2011
d. Law and ethics conference, Wellington, 2011
e. New Zealand Bioethics Conference, Dunedin, 2012
Presentations to DHBs took place at–

b. Hutt Valley DHB, 2011
c. Wairarapa DHB, 2011
d. Taranaki DHB (x2), 2011
e. C&C DHB: Many ethics presentations to different health professional groups (including SMOs, RMOS, Nurses, Dieticians, Medical Students and Social Workers); these centred around the concept of a CEAG against the background of a National Clinical Ethics Network.

Other presentations included–

a) Health Quality and Safety Commission, 2010
b) Chief Medical Officers group: 2010 and 2012
c) National Ethics Advisory Commission: 2010 and 2012
d) Wellington Rotary Club, 2011
e) Health Workforce New Zealand, 2012
f) New Zealand Medical Association, 2012
g) Medical Council of New Zealand, 2012

From surveys and talks that have already taken place right across NZ there is evidence of considerable interest within the health profession groups for this type of network. A summary of this data can be found in the Appendix, together with brief comments.

AM is a senior doctor at Capital and Coast DHB and it will be useful to get first-hand feedback from colleagues from different health
professional groups. AM is also extensively involved in ethics teaching, and in such fora it makes sense to alert people to the existence of a Clinical Ethics Network. Such feedback has the potential to provide constructive criticism that will help inform further development of the network. AM is in regular contact with other health professionals across different disciplines and in other DHBs, which allows him to assess progress at an informal, anecdotal level.

The project will roll out across other regions of NZ; the aim is to provide mechanisms for clinical ethics support in be in place in every DHB two years after the publication of this report. Although traditionally clinical ethics committees have overwhelmingly been involved with issues which arise in hospital settings, it is natural and right that such issues should also be addressed in primary care settings. Currently, there is little overlap in matters of clinical ethics in the primary and secondary sectors, and it is our belief that this kind of ethical involvement should provide opportunities for improved communication and cooperation between the two areas.

For example, an important area where a more formal ethical presence is needed is in care of the elderly; the interface between primary and secondary care is important, as ethical problems commonly arise for this group in both primary care and acute emergency settings. Timely access to good ethical advice to support decision-making in these situations is needed sooner rather than later. Another area that needs a higher clinical ethics profile is within mental health. In the context of the CCDHB clinical ethics committee, a number of difficult problems have arisen, requiring ethics referral and specialist advice in order to help achieve a good outcome.

Some CECs in the UK, for example, meet regularly once per month. Where that is the case, discussion will of necessity be retrospective. This means that by the time a committee meets certain
aspects of the case will almost certainly have changed. Ethical dilemmas do not present themselves in an orderly, timely way, and there is sometimes a need for immediate ethical input. As noted in Part 2, while ‘on-call’ clinical ethics is a relatively common phenomenon in the USA, it is not common elsewhere (e.g., in the UK).

Clinical ethics consults requiring immediate discussion in order to help resolve a dilemma place different requirements on a CEC / CEAG from discussion that takes place within the relative luxury of a retrospective review. In most hospitals, ethical problems arise on an almost daily basis, and early discussion of the issues is often essential. At the policy level it is important to differentiate the type of ethics support that is being addressed; throughout this report we have tried to make clear which type of ethics provision is under discussion and when.

It should be noted that this report does not consider the introduction of ethics consultations at the bed-side; instead, it should be clear that we propose a model of advisory groups to function as part of a national network, and supported by resources that will be available online. The practising clinician will have access these combined resources, which with improvements in ethics education, should help to benefit patients, the public, and all health professionals working in NZ.
PART 4: LEGAL AND POLICY FRAMEWORKS

Health policy and practice

Some would say that health care is in a constant state of crisis, and it is an inherent part of the political process of taking public responsibility for health systems for ministers to prioritize setting short-term goals; this phenomenon is not in any way restricted to NZ. (Worthington, 2011)

If CECs are to be set up in NZ, it helps to look at how others have approached this issue. For example, in Minnesota in 1984 an ethics network was formed in response to local issues with paternalistic care, and the spread of clinical ethics was seen as a way of promoting consensus on important issues such as withdrawing life-prolonging care. While the network fared well for several years it ran into difficulties when the lead person retired, and it took time for others to gain the experience and confidence needed in order to rebuild the process. One problem was that the initial arrangement lacked structure and formal recognition, which is something that should be guarded against when CEAGs begin to spread across NZ. (Moldow, 2002)

Legitimacy is an issue that has to be addressed, and questions that arise include--

i. Are CEAGs self-serving?

ii. Do they improve clinical practice?

iii. How do they know that they are performing a useful function?

iv. What are the competences of CEAG members?

Although NZ has been comparatively late in its development of ethics committees, nevertheless, there is benefit from being able to learn from the experience of others. (DuVal, 2001)
In the last 15 years a small number of DHBs have established CEAGs. The presence of a *National Clinical Ethics Network* should provide an impetus for other DHBs to follow suit. It is likely that the growth in the numbers of CEAGs will be incremental and gradual, rather than as in some jurisdictions, where committee structures were formed as the result of central government initiatives (e.g., in Croatia and Israel, and in the USA, where in some states it is a requirement that in order for hospitals to be accredited they have to demonstrate that they have clinical ethics services in place).

**Planning for the future**

The process of forming committees needs to be done with care; too much central control creates too much bureaucracy, and too little control results in piecemeal development with no clear over-arching policy. One thing is clear, namely that education will be an important part of the process in terms of planning for the future. The internet provides opportunities for sharing educational materials and resources amongst CEAG members; however, the experience of sitting at a computer is no substitute for face-to-face discussion and an integrated educational experience. DHBs will need to develop their own educational programmes; web materials have a number of uses but on their own they are not a complete solution.

It is helpful to identify the core competencies that members of CEAGs will need, and in the USA a task force identified three core competencies for individual ethics consultants. (Aulisio, 2000)

1. **Skills** include an ability to identify ethical principles and be able to determine and differentiate between related but different dimensions of a case (such as legal, psychiatric and medical).
2. **Knowledge** is a variable requirement; for some, a basic knowledge of ethics is sufficient, but for others an appropriate level of expertise is required (such as knowledge of health systems, the roles of different health care providers, local policies on confidentiality and consent, and various codes of ethics).

3. **Character traits** include the possession of virtues such as patience, compassion, honesty, humility, courage, integrity and tolerance.

In NZ it is premature to expect such expertise to suddenly emerge, given that ethics support services are at an early stage of development. In future, however, it is appropriate that plans for ethics development in NZ should include the development of core competencies in current as well as prospective members of CEAGs. Patients, families, and health care providers have a right to expect that committee members are able to deal competently with the complex issues that they will be asked to address.

At present, CEAGs in NZ have a voluntary status; CEAGs that currently exist formed in response to various initiatives, including local enthusiasm and leadership. How this works in the future is something that the Working Group will need to consider.

Each CEAG should have legitimacy with the DHB, and given that many referrals will be made in the context of ethically challenging situations, there may be considerable scope for disagreement. Healthy, robust debate should be an integral part of the deliberations of a CEAG. However, a consensus opinion is usually the best outcome and should be achievable in most circumstances; this is more likely to occur if CEAG members have the core competencies that are required.

The legitimacy of CEAGs forms the basis upon which health professionals will make referrals. Currently there are no national standards for the appointment of members, no standards for core competencies of members, no generally agreed governance relationships, no legal regulations, no agreed policies with regard to patient and family
representation at CEAG meetings, and no agreed policies on education. This situation is neither satisfactory nor sustainable and will similarly need to be addressed by the Working Group.

Although there are 20 DHBs in New Zealand, there is a wide variation in the availability of clinical ethics expertise and experience. If clinical ethics does indeed become ‘everyone’s business’, then it is imperative that a national working party be convened so that a proper plan can be formulated. This report is intended to provide the catalyst for such action.

Faced with a similar situation in 2005, the Royal College of Physicians (UK) convened a working party and produced a report “Ethics in practice - Background and recommendations for enhanced support”. The reason for the report was the increasing role of ethical deliberation in the management of health issues. Responsibility for managing these problems was widening, and the locus of control no longer sat principally with the medical profession.

Membership of the UK working party was diverse and included nursing, medical, lay, management and ethical perspectives, and the most important outcome was that “the provision of timely, comprehensive ethics support should no longer be left to chance or be dependent on the enthusiasm of individuals”. (Watson, 2005) The general approach to clinical ethics in the UK embodied in this report provides a good template for similar provision in NZ.

Legal issues

A lack of proper training and expertise could expose a CEAG to legal challenges. Whilst individual members will be covered by indemnity arrangements, CEAGs could be challenged on the basis that advice given was deficient or misleading. Although this argument can be dispelled if the
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advisory nature of the committee is clearly articulated and the clinical responsibility of the management team duly emphasised, the dividing line between perception and reality can become blurred. It behoves a committee to ensure that there is a spread of expertise, both individually and collectively, so as to minimise the chance of legal proceedings being instituted.

CEAGs should have a clause in their terms of reference explicitly stating that if a member feels that they have a conflict of interest in a particular activity being pursued by the CEAG, that conflict should be declared; if it is confirmed then that member should withdraw from further participation in the issue under discussion.

Committees will be unable to function effectively if they are not sustainable. This will depend on their legal status, the level of support that they receive from health professionals, how they are constituted, and on matters of local leadership. Ideally, a clinical ethics advisory group should be autonomous within a governance structure, and an important consideration of how each committee functions is how it addresses potential (or actual) conflicts of interest.

Sustainable success of a CEC will depend on–

i) Good administration support

ii) Balanced committee membership and composition

iii) Good committee leadership

iv) A defined range of activities beyond consultation

v) Development of effective networks with other CEAGs and DHBs

vi) Good education programmes for committee members (and for referring clinicians)
vii) **Regularity of meetings**

viii) **Having a proper constitution and terms of reference.**

There is no statutory obligation for DHBs to establish clinical ethics support services; likewise, there is no obligation for clinicians and others to seek their advice. In NZ the CEAG role is therefore informal and extra-legal. Although no legal action has been taken against a CEAG this may not always be the case. As the number of CEAGs increase, and as their role in case discussion/review attains a higher profile, the demands on the service are bound to increase; with the increase in volume of activity and raised profile comes a greater risk of facing legal challenges in the future.

CEAGs cannot advocate or sanction illegal actions. It therefore seems wise for them to have access to legal advice, which may also be necessary for other functions (e.g., education, or policy drafting). Records of CEAG discussions of individual cases may be considered in law to form part of a patient’s record; therefore, the criteria that should be applied are the ones Common Law demands.

While the responsibility for carrying out these duties rests upon individual members rather than on CEAGs, the clearest potential for legal responsibility occurs when CEAGs give advice concerning the management of particular patients rather than on general matters of principle.

It is a growing practice for Trusts in the UK to indemnify CEC members against actions for negligence, whereby patients might argue that there has been a failure by the CEC to act with due care. Even if the role of CEAGs is advisory, not determinative, CEAG members will need
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the protections offered by this type of insurance. Such cover is widely available in the USA, but not at present in Australia. In NZ indemnity insurance is, however, available (e.g., DHB members of the local CEAG are covered by an indemnity policy taken out by the C&C DHB), and such indemnity arrangements are becoming an increasing reality in the UK. (Larcher, 2009)

In terms of negligence, a potential hazard concerns the extent to which CEAGs are seen to be exercising (or not exercising) their duty of care in terms of ethical decision-making. However, in that their role is advisory rather than determinative, this ought not to cause concern. Put simply, CEAGs should give proper consideration to relevant medical facts, coupled with risks, burdens and benefits pertaining to the course of that is being proposed, including social, cultural and emotional factors relevant to the patient in question (and his/her family).

CEAG members should be aware of the skill and expertise of those seeking advice, of the facilities that they possess, and of the need to obtain valid consent and respect confidentiality. They should be able to provide a reasoned analysis of a patient’s best interests and be aware of whether patient rights are supported by legislation or not. To make a successful claim in negligence a patient would need to show that: s/he was owed a duty of care, that there was a breach of that duty, and that as a consequence s/he suffered harm. However, it could be argued that the duty of care owed by the CEAG is to the clinician seeking advice, not the patient, with whom there is no contractual relationship.

It is unclear what the law would require of a committee member, but it seems likely that the standard expected would be that of a ‘reasonable person’. Only if a committee failed in its duty to review a case in a reasonable and timely way, or if its members failed to have regard to the rights of patients and their families, or if it failed to act professionally in discharging its business would it be likely for a CEAG to be taken to task.
for not fulfilling its duty. Given that the function of CEAGs varies, standards would be hard to define if they were anchored to anything other than what a reasonable person might expect.

As McLean and others have indicated, CECs in the UK may have other collective and procedural duties, and under common law, failure to observe them could lead to decisions being referred for judicial review. (Maclean, 2007) These scenarios might include—

i) Failure to act within the terms of reference that established the CEAG

ii) Improper constitution of a CEC, e.g., with respect to the selection of members

iii) Failure to have proper working procedures/standing orders

iv) Failure to demonstrate proper, accountable and reasonable actions.

Although no such actions have been taken against CEAGs thus far, this may not always be the case. As the number of CEAGs increases and their role in case discussion/review attains a higher profile, the potential for requests for review of a committee’s advice could be expected to increase. Courts may either accept or reject a CEAGs analysis, but as a result of going through a process of review, at least some clarification of their legal status could result.

The referral process and the role of a clinical ethicist

The establishment of a clinical ethics committee should be accompanied by clear directions for potential users of the service. This information should be available on a single-page factsheet, which should be available on the DHB intranet. The following issues would need to be addressed—
a) Who can request a consultation? (e.g., can patients / families / whanau request a consultation?)

b) How can a CEAG be contacted, and who responds to a request?

c) What is the consultation process, and who is included in the consultation?

d) What is the process for appropriate notification of the affected persons?

e) What processes are in place in order to protect patient confidentiality?

f) Where / how is the process and outcome of the consultation documented?

g) Has the advisory nature of advice given by a committee been made clear to all parties?

It is likely that if CEAGs become established in NZ, many of them will not have ready access to a clinical ethicist. This is the result of a lack of availability of clinical ethical specialists combined with the relative physical isolation of some DHBs. The credibility of clinical ethical can be dependent on expert advice from such professionals, and as the clinical ethics network evolves, the use of teleconferencing and/or travel to other sites may be deemed necessary. The onus will be on CEAGs to ensure they make the most of the limited expertise that is available; this can be channelled in different ways; e.g., into case consultation, education and/or policy development.

CEAGs must determine their role in the process of drafting and reviewing institutional policy and procedures. Policies for withholding and
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withdrawing treatments such as cardiopulmonary resuscitation or clinically assisted nutrition and hydration, for example, may need amending to reflect input from local CEAGs. The same may apply to other types of policy such as institutional policies and procedures.

A successful new policy is one that changes behaviour or outcomes in a positive way, and policy changes relating to the role of clinical ethicists need to be evaluated by a process of audit, especially where they pertain to institutions as opposed to individuals. A Working Party should examine the variability, visibility, accountability and complexity of clinical ethics services that develop in each individual DHB, and audit requirements should be a part of this deliberation. More broadly, it is important that clinical ethics provision in NZ is set up in such a way that it will be responsive to the needs of health professionals and all New Zealanders in a range of different settings.

Educational requirements for Clinical Case Consultations

Whereas the American Society for Bioethics and Humanities [ASBH] has a publication on “Core Competencies for Health Care Ethics Consultation” representing a consensus view of qualifications necessary for those involved in clinical ethics case consultation, (ASBH, 1998) in NZ there is no such equivalent. Currently, no specific educational requirements have been set in respect of CEAG membership and no specification in terms of core competencies. Membership is often based on a combination of enthusiasm, interest and professional standing rather than on formal expertise; additionally, there is no uniform process for the appointment of new CEAG members. It is neither reasonable nor practicable to require the immediate implementation of educational and competency standards for all CEAG members.
Within the foreseeable future it is hoped that this issue will be addressed, and the existence of a network would allow extensive consultation with CEAGs (and their members) on a national basis, so that reasonable criteria for CEAG membership could be agreed and then implemented. Such a process is already taking shape in the UK, although it is worth noting that this is happening ten years after the introduction of a clinical ethics network. (Larcher, 2010)

Problems, past present and future

One problem that health systems around the world currently face concerns the use of scarce resources. Knowledge of ethics and a familiarity in applying ethical concepts to the allocation of scarce resources are an important (but widely neglected) part of policy decision-making.

In the past, the word ‘rationing’ has been used to justify limitations on the use of scarce resources, but rationing is rarely explicit and it rarely takes ethics into consideration. (Worthington, 2011) A CEAG network could help remediate this moral deficit by examining the way in which decisions are made, and by focusing less on monetary and political considerations and more on underlying ethical and policy considerations. CEAGs may not be directly involved in resource allocation policy-setting, planning, or cased-based decision-making; however, they contribute to the moral value of how the health service is run and how it is meant to serve the needs of the population.

_The development of CEAGs in NZ is currently piecemeal, and this is neither satisfactory nor sustainable._

In this report we have addressed the critical components of clinical ethics, and what might be entailed in setting up a national network. Ultimately, what is required is the political will to make change happen; without that it could be another 10-15 years before any progress is made,
which in our view would be bad for the health and well-being of New Zealanders. Involvement of the public in their health service is vital, and their active involvement at practical levels similarly ought to be encouraged. Where possible, the public needs to be engaged and consulted, including but not limited to the introduction of national network of CEAGs.

Twenty-five centuries ago, Hippocrates said “It is not enough for the physician to do what is necessary, but the patient and attendants must do their part as well, and the circumstances must be favourable”. For a long time in the history of health services, these wise words were either ignored or subsumed into a culture of paternalism. But we should not forget that public health services are funded by public taxation, and it therefore makes sense for the public to be involved in the governance of their health system.

Often compromises need to be made, and sometimes it is the unenviable job of a responsible ethics committee to attempt to find just such a compromise after considering all the issues and balancing possible risks, burdens and benefits. The complexity of the issues emphasises the importance of the ethics committee process, and as with the courts, public confidence in the outcome of ethics committee deliberations depends on a belief that it is fair, free from interference, and takes into account all the relevant issues.

**Why clinical ethics is ‘everyone’s business’**

Aotearoa / New Zealand is now a country of cultural diversity, and it prides itself on its inherent sense of fairness and equality. These principles sit very comfortably within the Treaty of Waitangi framework, with its emphasis on the principles of partnership, protection and participation. The Treaty is at the foundation of guiding principles that
are present throughout the health system, and the framework offers an excellent guideline for thinking about the responsibilities of the Clinical Ethics Network for all New Zealanders.

The Government has made it a key priority to reduce the health disparities that affect Māori. If Māori are to live longer, have healthier lives, and participate fully in NZ society, then factors that cause disparities in health need to be addressed.

During the preparation of this paper there was no specific consultation with Māori, however, it is essential that such consultation occurs as a priority. This would ensure that Māori would indeed be involved in the context of the principles of partnership protection and participation. The Treaty principles are inherently ethical, and their application in the context of the wider public demonstrates the existence of a natural synergy that needs to be harnessed in order to ensure that clinical ethics indeed becomes “everyone’s business”.

At an individual level, the basis of the therapeutic relationship provides the context for all clinical interaction, and whether you are a junior doctor dealing with an intoxicated person in the emergency room, a nurse comforting a patient with terminal cancer, or a senior doctor breaking bad news to a patient, the success of that interaction depends in part on how well the health professional respects the rights and values of the patient.

In complex cases this necessarily involves others, including members of the multidisciplinary team and members of the family; if the patient has capacity then s/he is central to the whole discussion. Sometimes this needs input from others who are not directly connected with the case. Making this facility available to every health professional, and by inference to every patient, is the ultimate goal behind implementation of a clinical ethics support network. (As we know, NZ is lagging behind other countries in following through this process).
An important part of the development process is the design of web-based materials that will be accessible from any hospital or health care facility in NZ. Work on this should start straight away; however, it would be prudent to hold back from launching a web-based system of support until the infrastructure is properly in place (i.e., as a starting point, with committee chairs in post and contactable within every DHB).

A working party needs to be established as a matter of urgency to move things forward, ideally addressing infrastructure and ethical content simultaneously so that systems are in place if / when HQSC is ready to press ‘go’. Then, and only then should a well-publicised launch take place. Piecemeal development, as in the UK, comes with attendant problems, such as lack of proper co-ordination and no clear model of implementation or infrastructure support, resulting in poor levels of awareness and poor uptake by clinicians. The opportunity to implement an effective nationwide system comes only once; it is our belief that the opportunity is there now and should be seized with both hands.

As part of the wider process, the role of the media needs to be considered. This could be either beneficial or damaging, depending on how it is handled; as is well-known press coverage can be of variable quality and is sometimes attendant with undeclared vested interests. One reason why bioethics is not generally handled well by the media is because of the inbuilt tendency to grab a headline and gloss over hidden complexity behind the issues. Credibility, accountability, legitimacy, and patient and public involvement are important underlying principles that need careful consideration as the project moves forward.
SUMMARY AND CONCLUSION

Based on work done in the UK, including a national survey, (Slowther, 2008; 2011) our analysis leads us to believe that the following points are relevant to the task of introducing a Clinical Ethics Network in NZ–

i. The provision of timely, comprehensive ethics support should no longer be left to chance or be dependent on the enthusiasm of individuals. Healthcare institutions should review existing arrangements for providing advice and education, developing and implementing guidelines on the recognition and handling of ethical uncertainties and dilemmas in clinical practice. This should be carried out by an identified lead individual working with others and with the support of local management.

ii. Some of the time a combination of informal advice from seniors and peers supplemented by national sources of advice, may be considered adequate. It is essential that key personnel able to provide advice are clearly identified, and that ready access to sources of advice should be available 24/7. Information on where this information can be found should be included in induction packs for newly appointed staff.

iii. In some institutions, complex ethical dilemmas occur frequently enough to justify establishing a local CEC. This resource should be available to neighbouring, smaller institutions that do not have a CEC, so that directly or indirectly, all clinicians have access to ethics support.

iv. Where the establishment of the CEC is necessary, it is essential that the various challenges that it is likely to encounter are identified early, and addressed.
v. Membership of a CEC should include a range of expertise (clinical, legal, ethical, managerial etc.); it must include the patient perspective and be small enough to function effectively.

vi. Each CEC should have between eight and ten core member, and additional expertise (e.g., a clinical specialist) should be brought in as required. The role of input from members who are independent, or who come from a lay ethics or spiritual guidance background, should be made clear.

vii. For an effective CEC there should be an agreed statement of core competencies, and appropriate training and education should be available for members to help them achieve these competencies. Training therefore needs to be on-going.

viii. CECs must be culturally aware; i.e., responsive to different beliefs, languages and practices among members of the population that they serve.

ix. All CECs should have mechanisms in place to ensure that they are able to respond to requests for support in a timely fashion, and where necessary, be able to provide acute support and advice for dealing with urgent cases.

x. The legal status of any advice – whether guidance, support or direction – has to be made clear at the outset.

xi. The existence of a CEC should be publicised throughout the host and other local institutions, and there should be a clear procedure for the referral of new cases.

xii. In order for them to have an impact, CECs should ensure that resources are available for disseminating guidelines and policies and for feeding back (to the right people at the right time) on the outcome of case discussions.
xiii. CEC activities should be audited to ensure that advice is consistent; measures should also be in place to enable a health care provider to assess CEC contributions to an organisation’s ethic, memory and conscience; from time to time there should be a review of the role of clinical ethicists within the health service as a whole.

xiv. From the outset, resources should be agreed so as to help ensure the long-term viability of the CEC. Its ‘location’ within the institution (particularly with respect to governance structures) and its reporting mechanisms should be made clear but without jeopardising its independence.

xv. Policies should be established to ensure that CEC case discussions are recorded in patient notes; where possible, the outcome of instructive cases should be disseminated, but without infringing patient confidentiality.

xvi. In some situations it could be helpful to have specialised CECs, particularly in highly technical areas such as fertility and genetics services.

xvii. There should be a commitment to developing an effective interface between a local CEC and national forms of clinical ethics support (e.g., through the UK Clinical Ethics Network).

Although the UK report focussed on clinical ethics support for practitioners, as part of the development process this should be accompanied by the development of appropriate awareness, skills and attitudes in doctors and other health professionals through the provision of effective education and training. Clinical ethics should be regarded as a core subject in under and postgraduate medical and nursing
curricula, and in the continuing professional development of all clinical staff.

Key recommendations for the introduction of clinical ethics support in New Zealand

1. On the basis of discussions, surveys and personal experience, clinical ethics support should be available wherever health care is provided, including (but not limited to) all public hospitals in NZ; ethics support is needed everywhere that health care is provided, and the provision of timely, comprehensive ethics support should not be left to chance or be dependent on the enthusiasm of one or more individuals.

2. Health care institutions should review their arrangements for providing advice and education, developing and implementing guidelines on the recognition and handling of ethical uncertainties and dilemmas in clinical practice; this should be carried out by a lead individual working with others, preferably with support from local management.

3. It is essential that key personnel who are to provide advice are qualified to do so clearly and identifiable; ready access to national and international sources of advice should be available 24/7 in a location known to everyone working in an institution or health care facility.

4. In some institutions, complex ethical dilemmas occur frequently enough to justify establishing a local Clinical Ethics Advisory Group; this resource should be available to neighbouring institutions that do not have a CEAG, so that directly or indirectly, all clinicians have access to ethics support.
5. Each CEAG should have between eight and ten core members, and additional expertise (e.g., a clinical specialist) should be brought in as required; the role of input from members who are independent, or who come from a lay ethics or spiritual guidance background, needs to be made clear.

6. For an effective CEAG there should be an agreed statement of core competencies (e.g., defined by a NZ working party); appropriate training and education should be available for members to help them to achieve these competencies; training therefore needs to be on-going.

7. The development process for introducing CEAGs should be accompanied by the development of appropriate awareness, skills and attitudes in all health professionals through the provision of effective education and training; clinical ethics should be regarded as a core subject in under- and postgraduate medical and nursing curricula, and in the continuing professional development of all clinical staff.

8. From the outset resources should be agreed so as to help ensure the long-term viability of the CEAG; its ‘location’ within the institution (particularly with respect to governance structures), and its reporting mechanisms should be made clear but without jeopardising its independence.

9. CEAGs should be aware of, and responsive to, the beliefs, languages and practices of the population they serve; they should develop mechanisms to ensure that they are able to respond in a timely fashion and be able to provide support and advice in urgent cases.

10. The legal status of any advice – whether guidance, support or direction – has to be made clear at the outset, and the existence of the CEAG must be well-publicised throughout the host institution and other local institutions, and there should be a clear procedure for the referral of cases.
11. In order to have an impact CEAGs should ensure that resources are available for disseminating guidelines and policies and for feeding back (to the right people at the right time) on the outcome of case discussions.

12. CEAG activities should be audited to ensure that advice is consistent; measures should also be in place to enable a health care provider to assess CEAG contributions to an organisation’s ethic, memory and conscience; from time to time there should be a review of the role of clinical ethicists within the health service as a whole.

Please note, these recommendations should be regarded as provisional and subject to review in the light of further experience, as the process unfolds.
GLOSSARY OF TERMS AND ABBREVIATIONS

Area Health Boards [AHBs]
American Society for Bioethics and Humanities [ASBH]

Bioethics: an umbrella term covering a wide range of different areas in moral philosophy, including environmentalism

Capital and Coast District Health Board [CCDHB]

Clinical ethics: where theoretical discourse on ethics translates into practical decision-making in health care

Clinical Ethics Advisory Group [CEAG]
Clinical Ethics Committees [CECs]

Crown Health Enterprises [CHEs]
Health and Disability Ethics Committee [HDEC]
Health Quality and Safety Commission, New Zealand [HQSC]

Institutional Ethics Committee [IECs]

Medical ethics: a defined (major) subset of bioethics

Medical Research Council [MRC]

National Advisory Committee on Health and Disability Services Ethics [NACHDSE]

National Ethics Advisory Committee [NEAC]

Research Ethics Committees [RECs]

United Kingdom Clinical Ethics Network [UKCEN]

United Nations Educational, Scientific and Cultural Organisation [UNESCO]

Whanau (Maori): Extended family

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REFERENCE LIST


Australasian Association of Bioethics and Health Law (Cf.) http://aabhl.org/page/clinical_ethics.html


BioEdge (Cf.) http://www.bioedge.org/

BioNews (Cf.) http://www.bionews.org.uk/home


Clinical Ethics (Cf.) http://ce.rsmjournals.com/

Clinical Ethics Special Interest Group Australasian Association of Bioethics and Law http://aabhl.org/page/clinical_ethics.html

Dare T. Ethics Notes (Newsletter of the Health research Council of New Zealand), 2010


The Role of Clinical Ethics in the Health Care System of NZ


http://jme.bmj.com/content/27/suppl_1/i24.short


DOI:10.1080/15265160601109085


Health and Social Care Act (UK), 2012.
http://www.legislation.gov.uk/ukpga/2012/7/enacted


Larcher V. *The Development and Function of Clinical Ethics Committees (CECs) in the UK*. Diametros, (2009); 22: 47-63
http://www.diametros.iphils.uj.edu.pl/pdf/diam22larcheren.PDF


Levine C. *Questions and (some very tentative answers) about hospital ethics committees*. Hastings Center Report (1984); 14;(3): 9-12

86


Mid-Staffordshire NHS Foundation Trust (Francis Report), 2010.


Moldow G. Rejuvenating the Minnesota network of healthcare ethics committees. HEC forum (2002); 14(3): 265-270


Nelson W, Gardent P, Shulman E, Splaine M. Preventing ethics conflicts and improving healthcare quality through system redesign. Qual. & Safety in Health Care (2010); 19:526-530


www.moh.govt.nz/notebook/nbbooks.nsf/0/.../DraftOperationalStd.pdf

Paediatric Society of NZ; Board of Paediatrics and Child Health, Royal Australasian College of Physicians (Discussion document, 2001). Disagreements between Professionals and Families about Health-care for Children and Young Persons.


UK Clinical Ethics Network (Cf.) http://www.ethics-network.org.uk/

The Role of Clinical Ethics in the Health Care System of NZ


http://adc.bmj.com/content/90/9/943.abstract


Worthington R. *Ethical dichotomies and methods of seeking consent*. *Anaesthesia* (2004); 59:525-527


Yale Interdisciplinary Center for Bioethics. (Cf.) http://www.yale.edu/bioethics/

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LEAD PROFESSIONAL BODIES IN NEW ZEALAND

- Medical Council of New Zealand
- Nursing Council of New Zealand
- New Zealand Ministry of Health
- Health and Disability Commissioner
- Health Quality and Safety Commission
- Association of Salaried Medical Specialists
- New Zealand Medical Association
- Royal Australasian College of Physicians
- Royal Australasian College of Surgeons
- Australian and New Zealand College of Anaesthetists
- Royal New Zealand College of General Practitioners
- Royal Australian and New Zealand College of Psychiatrists
- Royal Australian and New Zealand College of Radiologists
- Royal Australian and New Zealand College of Ophthalmologists
- Royal Australian and New Zealand College of Obstetricians and Gynaecologists
- College of Intensive Care Medicine of Australia and New Zealand
- Australasian College of Emergency Medicine
- Royal College of Pathologists of Australasia
- New Zealand Nurses Organisation
- Royal Australasian College of medical Administrators
- New Zealand College of Public Health
- Council of Medical Colleges in New Zealand
- Allied Health Professional Associations’ Forum
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Roger Worthington MA, PhD is an independent academic and researcher. He holds appointments at Yale University, Connecticut (Assistant, Adjunct Professor of Medicine), and at Bond University, Queensland (Honorary Associate Professor of Medical Ethics and Law). He is the former lead on healthcare ethics and law at Keele University School of Medicine, England, and a former consultant on standards, ethics and education at the General Medical Council (UK). His Ph.D (Philosophy) is from the State University of New York at Buffalo, New York. Recent publications include Health Policy and Ethics, A critical examination of values from a global perspective (Radcliffe, 2011).
APPENDIX

Summary of surveys

Surveys were completed by the following professional groups during 2011 and 2012. All those partaking in the survey were members of Association of Salaried Medical Specialists.

1) Nursing staff at CCDHB: Wellington and Kenepuru Hospitals (254 replies)

2) Junior Doctors at CCDHB (57 replies)

3) National survey of SMOs (senior doctors) employed in DHBs throughout New Zealand (157 replies).

The survey questions were similar and adjusted so that they were appropriate for each professional group. The figures quoted in each box (below) are a percentage of the total number of participants.
The Role of Clinical Ethics in the Health Care System of NZ

Question 1

*International experience suggests that the following situations are the most common reasons for health professionals seeking clinical ethics support. Have you found any of the following problematic in your last six months of practice? (tick as many as applicable)*

<table>
<thead>
<tr>
<th>Issue</th>
<th>Nurses (254)</th>
<th>RMO (57)</th>
<th>SMO (157)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Informed consent</td>
<td>33 %</td>
<td>53 %</td>
<td>34 %</td>
</tr>
<tr>
<td>DNR / End of life</td>
<td>47</td>
<td>47</td>
<td>33</td>
</tr>
<tr>
<td>Behaviour of patients/families</td>
<td>73</td>
<td>63</td>
<td>67</td>
</tr>
<tr>
<td>Inter-professional conflict</td>
<td>53</td>
<td>47</td>
<td>48</td>
</tr>
<tr>
<td>Immigration issues</td>
<td>21</td>
<td>33</td>
<td>26</td>
</tr>
<tr>
<td>Resource allocation</td>
<td>45</td>
<td>26</td>
<td>44</td>
</tr>
<tr>
<td>Paediatric issues</td>
<td>20</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Care of the elderly</td>
<td>26</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mental health issues</td>
<td>34</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Disclosing errors</td>
<td>30</td>
<td></td>
<td>16</td>
</tr>
<tr>
<td>Patient confidentiality</td>
<td>20</td>
<td></td>
<td>20</td>
</tr>
</tbody>
</table>

Question 2

*How did you deal with these issues? (tick as many options as applicable)*

<table>
<thead>
<tr>
<th>Action</th>
<th>Nurses</th>
<th>RMO</th>
<th>SMO</th>
</tr>
</thead>
<tbody>
<tr>
<td>Advice from DHB legal services</td>
<td></td>
<td></td>
<td>29</td>
</tr>
<tr>
<td>Discussion with other RMOs</td>
<td></td>
<td>75</td>
<td></td>
</tr>
<tr>
<td>Sought advice from a senior colleague</td>
<td>84</td>
<td>93</td>
<td>94</td>
</tr>
<tr>
<td>Accessed hospital policies or guidelines</td>
<td>56</td>
<td>17</td>
<td>32</td>
</tr>
</tbody>
</table>
The Role of Clinical Ethics in the Health Care System of NZ

<table>
<thead>
<tr>
<th>Activity</th>
<th>Nurses</th>
<th>RMO</th>
<th>SMO</th>
</tr>
</thead>
<tbody>
<tr>
<td>Accessed relevant College or professional body policies or guidelines</td>
<td>11</td>
<td>11</td>
<td>16</td>
</tr>
<tr>
<td>Utilised ethical principles taught at undergraduate level</td>
<td>23</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Reviewed relevant literature</td>
<td>23</td>
<td>14</td>
<td>24</td>
</tr>
<tr>
<td>Sought formal ethics review</td>
<td>0</td>
<td></td>
<td>5</td>
</tr>
<tr>
<td>Advice from Medical Defence Union</td>
<td></td>
<td></td>
<td>16</td>
</tr>
</tbody>
</table>

**Question 3**

Are you aware of any formal clinical ethics support available to you?

<table>
<thead>
<tr>
<th>Source</th>
<th>Nurses</th>
<th>RMO</th>
<th>SMO</th>
</tr>
</thead>
<tbody>
<tr>
<td>Other clinicians with an ethics interest</td>
<td>29</td>
<td></td>
<td>56</td>
</tr>
<tr>
<td>DHB policies</td>
<td>77</td>
<td>54</td>
<td>41</td>
</tr>
<tr>
<td>Professional colleges</td>
<td>71</td>
<td>63</td>
<td>63</td>
</tr>
<tr>
<td>CEAG or equivalent</td>
<td>38</td>
<td>23</td>
<td>44</td>
</tr>
<tr>
<td>Access to ethicist</td>
<td>6</td>
<td>2</td>
<td>13</td>
</tr>
</tbody>
</table>

**Question 4**

If clinical ethics advice is available is it adequate for your needs?

<table>
<thead>
<tr>
<th>Adequacy</th>
<th>Nurses</th>
<th>RMO</th>
<th>SMO</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>33</td>
<td>38</td>
<td>44</td>
</tr>
<tr>
<td>No</td>
<td>15</td>
<td>2</td>
<td>19</td>
</tr>
<tr>
<td>Not aware of any ethics support</td>
<td>52</td>
<td>60</td>
<td>37</td>
</tr>
</tbody>
</table>
Question 5
Which of the following sources of clinical ethics support would be most relevant and practical to the clinical practice of a nurse / midwife / RMO / SMO?

<table>
<thead>
<tr>
<th>Source of Support</th>
<th>Nurses</th>
<th>RMO</th>
<th>SMO</th>
</tr>
</thead>
<tbody>
<tr>
<td>Referral to ethics committee</td>
<td>35</td>
<td>23</td>
<td>52</td>
</tr>
<tr>
<td>Policies and guidelines</td>
<td>54</td>
<td>40</td>
<td>27</td>
</tr>
<tr>
<td>Access to ethicist</td>
<td>35</td>
<td>26</td>
<td>52</td>
</tr>
<tr>
<td>Access to designated senior colleague</td>
<td>64</td>
<td>80</td>
<td>60</td>
</tr>
<tr>
<td>In service clinical ethics training</td>
<td>74</td>
<td>42</td>
<td>36</td>
</tr>
<tr>
<td>Clinical ethics is not relevant to job</td>
<td>7</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Comments on surveys of health professionals

a. A recurring theme is that a significant number of people are unaware of any clinical ethics support being available.

b. Where clinical ethics support is available, most of the time it addresses the needs of the referring clinician.

c. A significant number of respondents would like to be able to avail themselves of the services of a clinical ethicist. There is some doubt as to how realistic this is in terms of acute availability in the event of an ethical dilemma; in addition, the number of clinical ethicists in NZ is limited geographically and numerically.

d. The survey emphasises the importance of collegiality in resolving ethical dilemmas. Although reference to DHB policies, professional college guidelines and the advice from colleagues can be helpful,
sometimes a better way to achieve a degree of resolution to an ethical dilemma may be through referral to a CEAG. Groups that have been established are seeing increasingly complex cases.

e. It is disturbing to discover that a small number of RMOs felt that clinical ethics was not part of their job.

f. The survey emphasises the importance that health professionals attach to in-service training in clinical ethics.

**Survey of CMOs and CNOs**

In 2010 a preliminary postal survey was carried on Chief Nursing Officers and Chief Medical Officers. 13/20 DHBs responded, and their feedback can be summarised as follows:

1) *Every respondent saw the need for clinical ethics support services*

2) *An overwhelming majority were in favour of a national network*

3) *A national clinical ethics network would support local initiatives in clinical ethics*

4) *A network would allow consistency, an ability to share expertise, and encourage joint problem-solving*

5) *Respondents recognised the closeness of the relationship with clinical governance*

6) *A small number of respondents saw the opportunity to educate the public*

7) *Some respondents recognised that small local groups would need to be supported externally by neighbouring CEAGs*

8) *Some respondents recognised that this initiative would provide an opportunity to raise the profile of ethics in public health.*