Clinical Ethics Support Services: An Evolving Concept

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Clinical Ethics Support Service: an evolving concept

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**ABBREVIATIONS:**

**AHD:** Advanced Healthcare Directives

**ASBH:** American Society of Bioethics and Humanities

**CEC:** Clinical Ethics Committee

**CESS:** Clinical Ethics Support Service

**JCAHO:** Joint Commission on Accreditation of Healthcare Organisations

**JCIASHO:** Joint Commission International Accreditation Standard for Healthcare Organisations

**MCD:** Moral Case Deliberation

**REC:** Research Ethics Committee

**UK:** United Kingdom

**UKCEN:** United Kingdom Clinical Ethics Network

**UNESCO:** The United Nations Educational, Scientific and Cultural Organization

**USA:** United States of America
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**ABSTRACT**

Clinical ethics is a sub-domain of bioethics. Clinical ethics focuses on the ethical problems that arise as patients and physicians make decisions together. Such decisions are based primarily on medical indications and patient preferences. Clinical ethics identifies, analyses and attempts to resolve concrete problems that arise in patient care. Clinical ethics must confront and resolve conflicts of values among physicians, patients, families, legal requirement, social mores, religious convictions, institutional consideration and economic constraints. The goal of clinical ethics is to enhance the standard of care by emphasizing that good ethical decision-making is a vital component of good clinical medicine. In the past, the major ethical concern was physician competence and beneficence. Although these retain their importance, consideration of patient goals, values and preference are of importance too. (Siegler and Singer 1988).

Clinical ethics support is the specific sub-domain of clinical ethics. It focuses on providing support for healthcare professionals in order to deal with ethical clinical issues, by the provision of ethics input into clinical education, policy development and the care of individual patients. Formal/explicit services include clinical ethics committees (CEC) and ethics consultation, and the evolution of the concept is inclusive of informal/implicit support services such as Moral Case Deliberation (MCD), ethics rounds, ethics forums and ethics reflection groups. Clinical ethics support aims to improve the ethical quality of patient care practices (McClimans et al 2007). Clinical Ethics Support Services (CESS) have been endorsed by numerous governmental and professional bodies and have been legally mandated in several states in the United States of America (Tulsky et al 1996).

CESS will be most useful if they are designed to match the ethical concerns of the clinicians’ (Hurst et al 2007). In addition, it must function within the policy and procedural framework of the institution providing the service and within the legal framework of the country. Legislation regarding healthcare differs from country to country, so what may be ethical and/or legal in one nation, may not be likewise in another.

The purpose of this project, is to propose, the best service to suit the healthcare institution that has charged me with the development and establishment of CESS.
Knowledge of the tried and tested models, is a must. The following will include, investigation of the roles and functions of prevalent models and strategies, their strengths and weaknesses, and ethical and legal considerations and constraints. The information reviewed will then be discussed in relation to the CESS relevant to the aforementioned healthcare facility.

Prior to recommendation of a particular model of a CESS, each prevalent model requires review and evaluation. Although there are many variations in practices and procedures they may not necessarily be problematic as long as practices are justified and consistent. The service must be fit for purpose and meet the ethical needs of the potential users, for whom the service is established.
INTRODUCTION

Practice of modern medicine, raises a multitude of complex medical, ethical and legal issues. The expectations of patients’, their families and society, demand that decisions made about patient care, treatments and use of healthcare resources, are made not only scientifically, but ethically. Clinical ethics support developed, for a variety of reasons. Some were an institutional response to one or two problem cases. Others developed because clinicians were not only interested in but concerned with the ethical aspects of clinical practice (Slowther et al 2000).

Medical ethics was reincarnated as clinical ethics in the 1960s. Public interest regarding the profession heightened, following the discovery of many atrocities involving medical professionals. Scrutiny of the profession and their practice ensued. Although healthcare professionals are qualified in the healthcare arena, they are seldom qualified to decide on ethical or legal matters which occur within that arena (McLean 2007). Hence the notion of clinical ethics support, was born. Doyal (2001) stated although clinical life continues, but moral and legal indeterminacy within clinical life, cries out for practical resolution.

Traditionally, physicians made decisions for patients in their care in the clinical setting, always intended for the good of the patient. The rapid evolution of the human rights movement gave rise to patients’ right. This in turn, gave rise to the scrutiny of the traditional medical system of paternalism. Questions were being asked by service users, in the context of the doctor-patient relationship, which led to the emergence of a different concept of ethics and doing ethics in the clinical context.

The medical profession came under intense scrutiny post World War II following the discovery of human experimentation atrocities. Following the trials of the perpetrators, who acted from the position of medical profession, the Nuremberg Code was devised in 1947. The Nuremberg Code is a code of ethics made up of ten principles and did not have any official standing. In 1964, The World Medical Association adopted the code as the basis for the first code of research ethics, which became known as the Declaration of Helsinki. This established the principles regarding human research, for the medical community internationally.
Although amended eight times, the fundamental principles have remained unchanged.

The bioethics movement emerged in the 1960s, following the discovery of unethical research practices by physicians in the USA. The news of the inhumane experimentation provoked outrage among the public and within the ethics community. Bioethicists systematically examined the moral basis of clinical and research practices. Theological and philosophical ethics were used to probe and constructively criticize medicine. The movement emphasized patient autonomy, patients' rights and distributive justice in healthcare and research. The Belmont Report was commissioned in 1971 on “basic ethical principles and guidelines (...) that surround the conduct of research with human subjects”. The report established three principles to determine whether proposed research study, involving human participants was ethical: “respect for persons, beneficence and justice” (Ryan et al 1979). Application of these principles requires careful consideration of informed consent, risks-benefit assessment, and selection of subjects of research.

Bioethicists were referred to as the “loving critics” of the medical profession and their goal was always to improve medicine, at least in theory. Leon Kass (1990) criticized the bioethical movement for being too theoretical, philosophical, hyperrational and ideological.

Clinical ethics is a field that emerged from the bioethics movement in the 1960s, directly in response to the challenge of doing bedside ethics (Williamson 2008). The tension between theoretical and the practical, remains one of the central differences between traditional bioethics and the modern concept of clinical ethics. Clinical ethics is a practical field as opposed to theoretical; that helps patients, families and healthcare professionals reach good clinical decisions, by taking into account both the medical facts of the situation and the patients’ personal preferences, values and wishes (Siegler 2011).

Clinical ethics begins with the premise that medicine is an inherently moral enterprise. The foundations of medical morality are the patient-doctor relationship. In this relationship a joint decision is reached by the patient, to be treated and/or cared for by a particular doctor, and that doctor agrees to treat and/or care for that
patient. The initial agreement or moral transaction, creates mutual responsibilities and is the foundation on which joint decision is built (Siegler et al 1988). All decisions that directly impact the welfare, the lives and the interests of patients, must be regarded as ethical decisions (Bartholome 1994).

The rights and wrongs of most clinical decisions are so obvious there is uniform agreement of what, when and why it is done. The basis of this agreement is the universal acceptance of the clinical duties of care: protect life and health, respect for autonomy, be fair, and do all three to an accepted professional standard (Doyal et al 2009).

Clinical ethics support is the specific sub-domain of clinical ethics, focusing on providing support for healthcare professionals in order to deal with ethical issues. CESS’s typically involve the expert ethics input into clinical education, policy development and the care of individual patients. CESS’s not only requires specific knowledge and skills regarding clinical ethical topics but requires skill and knowledge regarding the type of support, the methods and models to be utilized in response to the ethical requests/referrals. This accounts for the large variation of services being provided globally. The form and content of the CESS will vary by the strategies attached to each specific role and/or function of that service depending on the institution and the personnel (Chen et al 2008).

The advent and spread of clinical ethics support is described as a grassroots phenomenon. Increased social, medical and ethical complexities, are the basis for the need to provide formal clinical ethics support. Although growth in such services has been largely ad-hoc and unco-ordinated, it can be argued that clinicians are more aware that being “ethical” in a more complex environment is not straightforward and occasionally assistance is required (Agich 2005; Williamson et al 2007; Larcher et al 2010).

CESS has the potential of being a valuable component of high quality healthcare but for that to happen, it requires support from healthcare institution boards of management, clinicians and the medical ethics community (Slowther et al 2004). The support service not only must work within the framework of the parent organisation but adhere the legal framework of the country (Mc Lean 2007).
Furthermore, hospital ethics committees are constrained by the religious ethos of the healthcare institution (Thompson 2007).
METHODOLOGY

The methodology utilized was a literature review. Electronic databases of PubMed, Cinahl and Google Scholar were searched for English language papers published from 2000-2018. The terms used in different combinations included clinical ethics, medical ethics and law, healthcare ethics, ethics support services and Catholic bioethics. The 300,201 articles generated were re-searched with terms ethic consultant, ethics committee and moral distress, which resulted in 100,320 articles remaining. A further search of the remaining articles clinical ethics, clinical dilemma, moral distress and healthcare ethics reduced the number of articles further. Titles and abstracts of electronically identified articles were reviewed and articles potentially relevant were retrieved for examination. 223 articles were retained.

Inclusion criteria consisted of empirical, qualitative and quantitative studies, theoretical papers, reviews and editorials. Articles about established ethic support services aimed at supporting healthcare personnel in clinical practice were divided into the model/strategy used i.e. clinical ethics committee, individual ethics consultation, moral case deliberation, forum and ethic reflection groups; for the purposes of evaluating their roles and responsibilities, strength and weaknesses, their use and/or non-use.

A separate search for articles using terms medical law and religious bioethics generated 65 articles, 12 of which were retained after review.

Hand searching of the articles retained, referenced older data which provided relevant information pertaining to the evolution/maturing of CESS. Cross referencing hand searched references with the electronically generated articles, validated the reliability of the information presented. Text books were also utilised as a resource.

Research and literary commentary, pertaining to ethic consultation was abundant. In notably fewer articles and not discussed to any extent, were the functions of education and policy development.

Information was sought from other healthcare institutions as to the models and strategies of their CESSs. The major hospitals in Dublin were contacted, but
information pertaining to CESSs was unobtainable. Much confusion was demonstrated between Research Ethics Committee and CEC.

Discussions with peers and clinicians to ascertain their understanding and/or knowledge of clinical ethics in healthcare. Euthanasia and abortion were highlighted as what they considered to be ethics. Few failed to realise everything they do as clinicians, have an ethical component(s).

**Study limitations:**

English language articles were used. CESS of many countries was explored and information may have been available in their native language which could not utilised. Gaining access to and information about Irish CESS was difficult. Accuracy of the prevalence of the service may be questionable.
Chapter 1:

CLINICAL ETHICS SUPPORT SERVICE

Gaylin (1988), suggested there was no new subject called bioethics, but new innovations of modern medicine presented new choices and new moral dilemmas. Science and medicine had given birth to a new interest in old fashioned clinical ethics. The distinctive identity of clinical ethics derives from an environment in which it takes place and the combination of clinical and ethical skills required to perform one’s duties and obligations as clinicians. CESS for dealing with these “new moral dilemmas” in clinical practice, gave rise in part, to the establishment of CEC.

The purpose of establishing a CESS is to provide support and advice to health professionals and patients, on ethical issues arising from clinical practice or patient care (Slowther et al 2004) and should be viewed as the voice of reason (Thompson 2007). The service is primarily a decision-making tool for clinicians, a forum to secure the interests of the patients and next of kin; ideally, they can serve both parties (Reiter-Theil 2003).

National surveys indicate that CESS is well established in English speaking nations of the northern hemispheres (Fox et al 2007; Gaudine et al 2010; Slowther et al 2012). Literature shows that healthcare institutions acknowledge the value of ethics support and integrate clinical ethics into their organisations through ethics committees or ethic consultants. However, the goals of these integrated structures are often not formulated in practice as the goals are generalised in terms of improving patient care. But to gain acceptance and recognition, their goals should be specific and clearly formulated.

Goals

International literature reveals a broad set of goals to be achieved by the CESS. Tulsky and Lo (1992) suggested that the role of the CESS might be more to help patients, families and physicians to negotiate their own resolutions to disagreements. According to the American Society of Bioethics and Humanities’ (ASBH) report (1998), the general goal of healthcare ethics support is to “improve the provision of healthcare and its outcome through the identification, analysis and
resolution of ethical issues as they emerge in clinical cases in healthcare institutions. Aulisio and Arnold (2008) indicated that clinical ethics support aims to help “identify and analyse the nature of the value conflict and uncertainty”. Reiter-Theil (2001) stressed that ethics support is about exchange of information, shared understanding and decision-making. Fox et al (2007) proposed goal of ethic support, is to intervene to protect patient rights, resolution of real or imagined conflicts, changing patient care to improve quality and hence, patient/family satisfaction. Van Laere et al (2010) places emphasis on the importance of moral reflection on a case, reflection on what it means to be a good professional. Clinical ethics support should encourage an ethical climate and culture within the healthcare provider, by education, providing a means to make it possible to discuss ethical issues and develop professionalism (Dauwerse 2013).

Ethics is a component of professionalism. The concept of medical ethics is vital to the notion of medicine as a profession. The Hippocratic Oath, the oldest and most enduring examples of a code of conduct, established medical practitioners as a profession and stipulated the standard of behaviour that those practitioners should adhere to in order to be worthy of the title doctor. The medical profession is grounded in what physicians actually do and how they act, individually and collectively. Medical principles of beneficence and non-maleficence, confers onto the physician the duty to do right and avoid doing wrong, and patients have a right to expect nothing less. As suggested by Dauwerse (2013), the CESS can promote discussion and self-reflection by clinicians, upon the actions taken and the decisions made, not only to improve their knowledge and skills, but to heighten awareness of ethical acts and behaviours thus developing professionalism. (Swick 2000).

The goals of the support service have remained constant through the years. The service aims to minimise the distress and conflict that clinicians and patients experience when faced with ethically difficult clinical decisions, promote respect of autonomy, improving quality of patient care and create better decision-making processes. The support service has the potential to become a valuable component of high quality healthcare, but with any integrated institutional service, for this to happen, it requires the support of the institution, clinicians and the medical ethic community (Slowther et al 2004).
A challenge facing any institutional service is clarifying and maintaining its position within that organisation, and the mission of the CESS is to protect the interests of both individuals and the organisation while retaining a high degree of independence (Dorries et al 2011). The service needs to be cognisant of the needs and goals of the healthcare organisation, to be accommodated within that institution to encourage and promote their utilisation by that organisation. It also requires endorsement to be allowed to function within the organisational structure. Although advisory in nature, they should be autonomous within the governance structure of the healthcare facility, otherwise it may be seen as another tool for management.

The onus lies with the service providers to plan carefully the model and establishment of the service, have specific regulations, strict terms of reference and have a balanced committee membership. Otherwise it could produce scepticism and be viewed as just another committee added to the bureaucratic layers or to fulfil an accreditation or legal requirement. To some extent, this view can be negated by the inclusion of all levels of staff from the “floor right up to the top”, in the planning and establishment of the service. Human nature dictates, if one owns a project, one expends the effort and energy to bring it to fruition. Its success is dependent on the commitment and devotion of its members (Anonymous 2011). The service must be accessible to all healthcare professionals and clear directions how to access the service must be provided for potential users. But if it’s presence within an institution is not visible or a known entity by clinicians, it’s utilization will be limited.

Service providers should be diverse in terms of their culture and skills, experiences and knowledge. Variety inspires debates to obtain new information and consider alternative ideas (Pierce 2002). The legitimacy of members is essentially based on their knowledge and their professional status. Training and educating committee members is paramount to instil confidence of referring clinicians. Jonsen et al (1982) stated that CESS providers should be able to identify, analyse and resolve moral problems which arise in patient care. Fletcher and Siegler (1996), suggested that identifying and supporting the interests, rights and responsibilities of those involved consistent with the ethical norms and standard.
Ethical dilemmas often involve disagreements between the physician and patient or between healthcare workers. They arise from value conflicts, both professional and personal. Clinical ethics support providers must be fit for purpose and knowledge of ethics is not the only requirement. The providers must adhere to legal constraints and give consideration to the policy and procedures of the institution too. Their methods of identification, analysis of the value conflicts, and recommendations should be structured, consistent and transparent. By providing the expertise, being consistent and by the inclusion of the referrers in the discussion/debate, this may facilitate their acceptance into the medical ethics community as players in the ethical world, which is necessary for the service to succeed. Otherwise the service may be deemed amateurish and there will be a reluctance from their intended users to seek their advice. They will be doomed to failure as the service will be considered as “just another committee” set up to satisfy a mandatory requirement.

**Functions**

The functions of the service also have international acceptance. Different services emphasise different functions (Mills et al 2006). The three main functions accredited to the support service are education, policy development and case consultation. Case consultation has received the most scholarly attentions. It is deemed to be the “driving force” of the clinical ethical infrastructure (Mills et al 2005) and the most potentially volatile and labour-intensive function (Moreno 2009). By the time the conflict has escalated to referral for ethic consultation, emotions are high, there is communication breakdown, damage has been done to the doctor-patient relationship, all individuals are less inclined to use compromise as a solution and dialogue between the involved parties is impossible (Carney 2006). In some circumstances, it is not about doing the right thing, but due to the complexity of the situation the right action is not clear (Rasmussen 2011). The CESS has the value of being independent from the conflict and can provide a forum in which the stakeholders in the decision-making process can share their perspectives, deliberate and reach a resolution.
Education is deemed to be the most important and efficient function of the support service by clinical ethicists (Moreno 2009). It has received little scholarly attention and detailed description or recommendations pertaining to the educative role are lacking. It has been suggested for CESS to succeed, it should be combined with an ongoing hospital-wide educational programme (Tulsky et al 1992). The importance of the educative function of CESSs is being realized. Moral Case Deliberation, an education strategy, used in Dutch healthcare, is receiving scholarly attention (Weidema et al 2012; Stopler et al 2016).

Education of the committee members is paramount to ensure their credibility and legitimacy as a support service. Lack of training and expertise of those providing the service could expose the service to loss of confidence, or precipitate legal challenges on the basis that the advice given was deficient or misleading. CESSs cannot advocate or sanction illegal actions. Their role in patient-case discussion considers the medical facts, inclusive of the risks, burdens and benefits of the proposed action, but also consideration for the relevant social, cultural, religious, legal and emotional factors.

Healthcare professionals have codes of ethical and professional conducts which is a framework of the boundaries within which they practice. Legislation sets down the legal expectations of their practice. Developing a basic understanding of what is deemed ethical and the ability to participate in ethical reasoning should not only improve professionals’ comprehension of their ethical codes, but also improve communication between healthcare providers. Improving “moral perception” among clinicians by education, provides them with the potential ability to identify and resolve ethical problems before they grow like tumours into full-blown catastrophes (Sokol 2012). This can be achieved not only by passive absorption of information at seminars but as participants in a structured environment of ethical practice appraisal (moral deliberation). This form of structured discussion allows clinicians to evaluate their practice, reassure them that their practice is valid and effective, identify weaknesses that they may have not had insightful awareness into and provide a time for reflection of practices utilized and their own value system. This may have guided their course of action, all of which is of educative value which in turn will promote a more ethically aware culture in their working environment.
The use of the intranet of the healthcare institution can also be a valuable teaching tool. The creation of electronic newsletters, discussions, updates, training materials and skill resources can be accessible to all staff. Presently there are two clinical networks available, in Europe, The United Kingdom Ethics Network (UKCEN) and The European Clinical Ethics Network. Not only do the networks provide a means of communication between established CESSs, they provide support and education to services being set up; by means of resource packs, updates pertaining to changes in guidelines/legislation, case discussions, themed events, conferences/seminars and newsletters.

**Policy development** function of the CESS has also received little discussion in the literature; usually limited to stating that the institutions ethics committee provides input into institutional policies and guidelines. Policy plays a pivotal role at the interface of medicine and society, and it has been suggested that lack of policy development and implementation can impede and derail the other key functions of CESSs, by not communicating the mission of the institution. Input into institutional policy and guidelines has the potential to influence medical culture at systems level (Geppert et al 2016). The Joint Commission of Accreditation for Healthcare Organisations (JCAHO) (*table 1.0*), demand the establishment of ethics support services, for organisations to receive professional accreditation. The healthcare organisation must demonstrate their ability to deliver healthcare that reaches an acceptable ethico-legal standard. This is achieved through the work of the ethics support framework by their input into formulation of hospital policy in ethicolegal matters (Doyal 2001).

There is no systematic evaluation of the process and impact of the educational and policy formulation functions of CEC. Frolic *et al* (2012) attempted to open the “black box” of healthcare ethics support service practice regarding their policy work. They suggest that given the potential for policy work to impact entire patient populations and organizational systems, it was imperative CESS providers engage in methods to ensure the delivery of consistent, relevant and high-quality ethics policy review.
Table 1.0: JCAHO standards (Campbell 2017)

<table>
<thead>
<tr>
<th>What the accrediting team wants to know:</th>
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<tr>
<td>• Does the hospital applying for accreditation have a clinical ethics committee?</td>
</tr>
<tr>
<td>• Who are its members?</td>
</tr>
<tr>
<td>• Does the hospital have a code of ethics and how was this developed?</td>
</tr>
<tr>
<td>• How does the hospital address ethical issues?</td>
</tr>
<tr>
<td>• How can staff bring an ethical issue to the committee?</td>
</tr>
<tr>
<td>• What types of ethical issues has the committee dealt with in the last year?</td>
</tr>
<tr>
<td>• What education do the committee members receive?</td>
</tr>
<tr>
<td>• What ethical education does the staff of the hospital receive?</td>
</tr>
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</table>

**Case consultation** in comparison to the functions of education and policy formulation, has been extensively debated and has received the most literary attention. The ethics consultation whether it be by a committee or individual, assists by clarifying the values and conflicts involved, advising on the ethical implications of the available courses of action available. Case consultation is the major function of the clinical ethic support service in US but less so in UK (Slowther et al 2012). Methods used in ethics consultation are, retrospective review (a case on which the CESS consulted or handled without ethics input), or concurrent or prospective case consultation (involves members of the CESS, intervening to affect the outcome of an active case). The consultation services vary widely in their approach, intensity and effectiveness (Fox 2002). Ethics consultations have been shown to save healthcare institutions money by reducing the provision of nonbeneficial treatments and length of hospital stays. A by-product of the intervention as opposed to their primary goal to promote sound healthcare decision making, with respect for clinicians, patients and families and support for caregiver’s concerns. (Dowdy et al 1998; Helicser et al 2002; Schneiderman et al 2003).

Approaches to ethics consultations have evolved from authoritarian or pure consensus, both of which were deemed to be inadequate, to “ethics facilitation” (Aulisio 2016). Ethics facilitation, involves clarification of values of the uncertainty or conflict involved and facilitating consensus and determine if the consensus decision is ethically justified (Tarzian and the ABSH Core Competencies Task Force 2013). An approach that facilitates and informs a shared understanding of
difficult ethical issues, can support and reassure both patients and clinicians, without the expectation of there being an ethically correct outcome. The consultation function of the CESS is advisory. The responsibility for any clinical decision rests with the doctor in charge and legally with the healthcare organisation (Forde 2008).

The quality and appropriateness of ethics consultations have received more than its share of scrutiny. Much debate regarding the requisite skill and competencies of those providing the service is ongoing. There are no formal requirements for the constitution, membership or remit of a CESS (Sokol 2009). Should the service provide ethics support, it would suggest that this requires a level of expertise in ethics. CESS should not come into being “simply because someone, someday decided it was a good thing to have one, or because there was an ethical emergency that needed acute attention. This approach is analogous to running before one has learned to walk” (Van der Kloot Maijburg et al 2001).

Ethics is not just common sense but an intellectual discipline that requires discrete skills, knowledge and understanding. It is not only about ethical correctness in decision-making. Case consultation is inclusive of adherence to the requirements of the legal processes and human rights norms. The skill set of any clinical ethics support is vital. Ethicists do not “do medicine”, so it begs the question why healthcare professionals are expected or permitted to “do ethics”. The evolving service requires more than “an interest” in ethics but rather expertise in ethics of its members. The American Code of Ethics and Professional Responsibilities for Health Care Ethics Consultants, in 2014, attests to this and has moved the debate of professionalization forward. This code focuses on the individuals providing healthcare ethics consultation. The process to produce a similar code is underway in the UK.

The central purpose of ethics consultation is to improve the process and outcomes of patient care by helping to identify, analyse and resolve ethical problems (Fletcher et al 1996). Also, is the desire of healthcare providers to share the responsibility for tough decisions (Tapper 2013). When an ethical dilemma has been referred for an ethics consultation, deliberation ensues and the utilisation of an ethical decision-making framework to methodically and systematically review
every aspect of the circumstances presented. The use of an ethical framework ensures consistency and transparency of the process. One example is The Four Principles Approach, developed by Beauchamp and Childress, 1997 (*Table 1.1*).

**Table 1.1: The Four Principles ethical framework** (adapted from Mastersrvedt 2011; Sokol 2012; UKCEN 2012)

<table>
<thead>
<tr>
<th>Principle</th>
<th>Considerations</th>
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<tr>
<td>Respect for autonomy</td>
<td>respecting the decision-making capacities of autonomous persons; enabling individuals to make reasoned informed choices. Is inclusive of truth telling, privacy and confidentiality.</td>
</tr>
<tr>
<td>Beneficence</td>
<td>the obligation to balance the benefits of treatment against the risks and costs; the healthcare professional should always act in a way that benefits the patient.</td>
</tr>
<tr>
<td>Non-maleficence</td>
<td>the obligation to avoid the causation of harm. This does not entail that one should not harm, per se. Healthcare workers harm patients every day, but harming must be clinically necessary or required and it must not be done against the patient’s will.</td>
</tr>
<tr>
<td>Justice</td>
<td>the obligation of fairness in the distribution of benefits and risks; the costs; the notion that patients in similar positions should be treated in a similar manner. It is deemed the most complex of the principles as it refers to a collection of obligations. The obligation to act fairly, to distribute resources fairly, to respect people’s human rights (rights-based justice) and the laws of the jurisdiction (legal justice) and to abide by one’s professional code.</td>
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The Four Principles Approach, is the most widely used framework not only for ethical decision-making but as an education medium (Doyal and Gillon 1998; UKCEN 2012). The character of the framework is to help structure the medical ethical field and to function as a checklist. It does not provide answers but represents a way of thinking (Matersrvedt 2011).

The framework does not provide ordered rules but assists in decision making when consulting or reflecting on ethical issues that arise in the clinical environment. None of the principles takes precedence over the other, however Gillon (2003), argued that the medical principle of respect for autonomy should be the first among equals. Sokol (2012) suggests that there is no fixed hierarchy and the principles opens up discussion by identifying the key issues of the case and evaluating each principle in turn with reference to the key issues, highlighting tensions between the principles and working towards ways of resolving them.

Another ethical framework utilized is The Four Quadrant Approach (*Table 1.2*) devised by Jonsen, Siegler and Winslade, (1982). Unlike the four principles
framework, the four-quadrant approach must be approached in a precise order. No decision is made until all four quadrants are examined.

This approach lays the groundwork to frame ethical dilemmas in such a way that it can be applied to a clinical ethical dilemma and is a relevant case-based way to work through ethical dilemmas (Toh et al 2018). This approach is used by healthcare practitioners and ethics support services in United States and some services in the United Kingdom (Sokol 2008). Each quadrant has questions that should be considered for discussion/deliberation pertaining to the subject matter of that particular quadrant.

**Table 1.2: The Four Quadrant Approach** (Sokol 2008)

<table>
<thead>
<tr>
<th>Quadrant 1</th>
<th>Quadrant 2</th>
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<tr>
<td><strong>Indications for medical intervention:</strong></td>
<td><strong>Patient preferences:</strong></td>
</tr>
<tr>
<td>Focuses on the clinical facts. Establishes a diagnosis, treatment options and the prognosis of each treatment option. A preliminary conclusion is made as to what is medically indicated for the patient. The preliminary conclusion can change as the other three quadrants of the framework are considered.</td>
<td>This embodies patient autonomy. It focuses on the wishes of the patient if competent, and his presumed wishes if not. The preferences of the patient may confirm or change the treatment goals in the first quadrant. The medical team are obliged to ensure that the patient is aware of the implications of their choices i.e. what the proposed procedure or treatment entails, the alternatives including doing nothing, the risks of the procedure and alternative treatments and invite and encourage questions from the patient.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Quadrant 3</th>
<th>Quadrant 4</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Quality of Life:</strong></td>
<td><strong>Contextual features:</strong></td>
</tr>
<tr>
<td>Examines the impact of the proposed treatment will have on the patient’s quality of life. Quality of life is subjective and individualized.</td>
<td>Encompasses legal, cultural, familial, religious, economic and other issues that may impact the patient decisions but have not been discussed in the other quadrants.</td>
</tr>
</tbody>
</table>

Ethical principles assist in guiding towards what “ought to be done” but does not take into consideration the emotional responses of the stakeholders, which are an integral part of their perception and assessment of the world and influence their judgements. Gardiner (2003), proposed a virtue-based approach to moral dilemmas in medicine. His framework proposes that having collected all the medical facts, those facts should be analysed using the virtues compassion, trustworthiness, discernment and regret (*Table 1.3*).
Table 1.3: Virtue-based approach (Gardiner 2003)

<table>
<thead>
<tr>
<th>Virtue</th>
<th>Encompasses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Compassion</td>
<td>An active regard for another’s welfare</td>
</tr>
<tr>
<td>Trustworthiness</td>
<td>Cornerstone of the patient-doctor relationship</td>
</tr>
<tr>
<td>Discernment</td>
<td>Sensitive insight, understanding and wisdom of the situation</td>
</tr>
<tr>
<td>Regret</td>
<td>Whatever the outcome there will be regret of what might have been</td>
</tr>
</tbody>
</table>

The virtue-based approach focuses on the person/people, as opposed to the act. Perhaps it could be difficult to put into practice as it requires self-awareness and insight into one’s own value systems and honesty in admitting the emotions caused by a patient refusing one’s recommended treatment, is it frustration? Anger? Undermined? Rather than it being a separate framework, it could be included in the “Contextual Quadrant” or as part of the discussion of the principle of respect for autonomy in the principalism framework.

However, this has been explored further in Moral Case Deliberation (MCD), which is implicit clinical ethics support prevalent in healthcare institutions of the Netherlands. Emotions play a crucial role in moral life, they should neither be followed or put aside. MCD provides the skills of the proper way of dealing with emotions in clinical practice, by finding the middle ground between being overwhelmed and untouched. Being able to determine the appropriate emotional “middle ground” in a given situation is a matter of virtue and character (Molewijk et al 2011).

The method of case analysis for the ethics consultation must be tailored to the clinical reality, the user and the institution. An ethical decision-making framework is designed to facilitate systematic identification and analysis of clinical ethics issues and assists to increase the clinician/ethicist’s perception of what is morally relevant and the moral dynamics at the bedside (Sokol 2008). Whatever framework is employed in the ethics consultation, it is a method of analysis and evaluation of an ethical dilemma. Ethical choices remain difficult choices because they “make conflicting claims upon us or present us with seemingly equally unsatisfactory alternatives” (Fowler et al 1987).
Organisational Ethics is the fourth function carried out by some CESSs. This involves looking at ethical issues which occur on a broader institutional level (Hoffman and Tarzian 2008). Clinical conflict regarding specific patient’s care management typically occurs in the context of applying organizational policies and procedures (Nelson 2017).

Until the 1990s, the study of ethical issues in health care focused on moral conflicts in the clinical setting and focused on the actions of individuals, clinicians, patients and family members, and their accountability and responsibilities were viewed in relation to ethical norms and obligations. In 1995, the JCAHO, introduced a new standard for accreditation. The title of the standards chapter “Patients’ Rights” was changed to “Patients’ Rights and Organisational Ethics” this is now known as the “Governance Leadership and Direction” (GLD) standard in 2017. (Table 1.4). This development in Joint Commission International Accreditation standards (JCIA), attempts to integrate clinical ethics into the institution and the wider healthcare system and is referred to as the “systems” approach and involves looking at ethical issues that arise more broadly within the institution on a system-wide base.

Table 1.4. Organisational and Clinical Ethics GLD.12 (JCIA Standards for Hospitals 2017)

<table>
<thead>
<tr>
<th>Governance, Leadership and Direction Standard</th>
<th>GLD.12</th>
<th>GLD.12.1</th>
<th>GLD.12.2</th>
</tr>
</thead>
<tbody>
<tr>
<td>GLD.12</td>
<td>Hospital Leadership establish a framework for ethical management to promote a culture of ethical practices and decision-making, ensuring patient care is provided within the business, financial ethical and legal norms and protects patients and their rights.</td>
<td>Hospital framework of ethical management addresses operational and business issues, including marketing, admissions, transfers, discharges and disclosure of ownership. Addresses any business and professional conflicts that may not be in patients’ best interests</td>
<td>The hospital ethical management framework addresses ethical issues and decision making in clinical care</td>
</tr>
</tbody>
</table>

Clinical ethics is patient-centred and focuses on the care needs, rights, values and preferences of individual patients. The common goal being, to promote the best interests of the patient. In the organisational setting, ethical conflicts involve diverse goals and interests, hierarchies of power and authority, conflicting roles
and obligations, public and private agendas, long-range plans, decisions that affect populations as well as individuals (Post et al 2015).

Organisational ethics is rooted in the values of both business and health care ethics. Traditional bioethics views organisations merely as a place where individual patients and clinicians meet. Clinical ethics focuses on the ethics of professions, but it does not address the organisational climate that promotes or impedes the ethical delivery of care. Business ethics recognises medicine as a business enterprise but fails to appreciate the distinctive nature of healthcare as good and the special quality of the provider-patient relationship. Policy and procedure at the bedside, are directly influenced by how the organisational core values and goals are structured and framed (Fox 2010). Healthcare organisations are not just a business. They are service providers with moral responsibilities because of the special good(s) they deliver and their goals and values are stipulated in the form of an organizational mission statement and code of ethics, that become an essential part of an organization’s identity.

Much literary commentary has been afforded the fourth function or expanded remit of the CESS. Qualification of the membership of CESS, which is already being questioned and debated, will now require recruits with the skills, qualifications and knowledge of business and finance, should organisational ethics be included. The inclusion reflects the prevalence of an approach that endeavours to integrate clinical ethics into the healthcare institution and the wider healthcare system. In the systems approach, ethics support moves “upstream” to address systematic and structural elements that cause value conflict rather than remaining at the level at where the issue or conflict occurs. This encourages a proactive and preventative approach, as some believe that most ethical conflicts in a given institution have roots at the system level, and a more efficient approach is to have one committee respond to both individual consultation requests as well as to the organizational problems underlying them (Pentz 1999). The CESS can assist the institution to be an accountable organisation by developing and implementing an institutional policy inclusive of its core values. This in turn may lead to careful decision making, e.g. treatment used and patients treated at that particular institution and may motivate the stakeholders to take responsibility and be accountable for their actions (Dauwerse 2013).
Others believe the inclusion of organisational ethics to a service that provides clinical ethic support is not advisable. Clinical ethics and organisational ethics are different but have some overlap in their goals and functions and for this reason they should be kept separate (Sliverman 2000). An expanded role focusing on this overlap, is believed to be essential to ensure changes in healthcare delivery that reflect common ethical concepts for health and healthcare as issues that arise are primarily organisational but also have clinical ramifications (Nelson 2017). Others have suggested that by adding an extra bureaucratic layer to the support service, may decrease the already insufficient time available for clinical concerns and cause suspicion as to their purpose, among the intended users (Hakibabae 2016).

CESSs are developing globally and they are most useful when designed to match the ethical concerns of the clinicians within the healthcare facility. CESS must set down explicit terms of reference and should never exceed these terms. Should the service overreach their advisory role, clinicians may react by not acknowledging their worth in improvement of patient care and as an intrusion into the clinicians’ domain (Doyal 2001) Direction on how, why and by whom the service can be accessed, should be clear and simple. Education needs vary in different organisations, and education programmes should be tailored to best suit the potential users needs which should encourage an ethically aware culture within the organisation. Input into policy development may be extended to organisational policy and procedure. It is the organisational vision and values that dictate what happens at the bedside. If the support service is perceived to be associated with the hospital management structure, this could reduce the confidence in clinical ethics work, increase the number of potential users and undermine one of the principle aims of clinical ethics work - to strengthen the voice of the powerless (Koch 2012).
Chapter 2

PREVALENCE OF CLINICAL ETHICS SUPPORT SERVICES

CESSs are important interdisciplinary committees for the discussion of ethical questions pertaining to conflicts arising in the clinical environment. Ethical conflicts emerge if two principles or values collide with each other or with institutional constraints, which can result in moral distress of healthcare professionals.

Approaches to the setup of a CESS can be either “top-down” or “bottom-up”. There is no universal norm as to how a service should be set up, but depending on the approach used, there may be differences in the nature, purpose and goals of the support they provide (Aulisio et al 2000).

Within the top-down perspective instigated by management, ethical support is provided by an ethical consultant or a group of “experts” which has an influential advisory role or acts as the primary decision maker. This is suggestive that ethical issues in healthcare are too complex to be resolved by or managed by the healthcare personnel, therefore providers facing ethical issues require specialist expertise (La Puma et al 1991). Exclusion of the clinician in the decision-making by “experts”, will not promote the use of such a service by clinicians and could lead to further value conflict between a different service user and service provider.

CESS should offer a practical, non-confrontational process of addressing complex and controversial problems and should bring benefits to all concerned (MacDonald et al 2012). The placing of such a support service within the management hierarchy of the organisation, could limit its use, limit challenges to practices within the institution and questioning whether or not the institution is conducting itself ethically.

The “bottom-up” approach is initiated by clinicians and their everyday experiences of ethical issues in clinical practice. This perspective allows for inclusion of clinicians and discussion to facilitate greater insight into ethical considerations rather than focusing on the decision-making, managing conflicts or supervising a substantial moral position. (Steinkamp et al 2007; Stopler et al 2014). Regulation of the bottom-up service rests with the healthcare institution. “Truth” in matters of
clinical ethics is best approached by creating an opportunity for dialogue in a community of informed individuals (Bartholome 1994).

Although clinical ethics services are evolving and expanding in European countries, the service is generally provided by “mixed” committees, which are combined research and CEC. Research Ethics Committees (REC) are regulatory structures and function under a legislative framework. Their focus is on the rights, wrongs, safety, wellbeing and relevance of the proposed research, involving human subjects. REC came about following the inception of the Nuremberg Code of 1947, which introduced the concept of “informed consent” and set standards for human experimentation. The reason for their creation was to have an independent body with the authority and knowledge to approve or disapprove research proposals/protocols involving human participants. RECs were codified in numerous international documents and legal provisions pertaining to human experimentation e.g. Helsinki Declaration 1964, International Ethical Guidelines for Health-Related Research Involving Humans established by Council for international Organizations of Medical Sciences, (CIOMS) first published in 1993 and most recently 2016, and Good Clinical Practice Guideline 1992 and revised regularly.

In the beginnings of CESSs, most committees were “mixed”, fulfilling both tasks of research ethics and clinical ethics, however, some were established as purely clinical ethics committee. The ‘mixed’ committee is tasked with fulfilling a broad set of functions. The substantial difference between research ethics and clinical ethics reflects the difference between the obligations of a medical researcher with regard to human subjects who participate in experimental research and the obligations of a doctor to his/her patient (MacPherson 1999). The US, the UK and Germany are examples of the division of labour by the establishment of two separate committees. Countries such as Italy and Belgium, are doing likewise.

This chapter will be an overview of the structure of and approaches to CESSs in healthcare institutions globally. CESS have matured an evolved, at different paces globally. Countries selected are to highlight the diversity of services provided or in some cases, lacking.
UNITED STATES:

In America, is where the “grassroots phenomenon” began, its beginnings have been attributed to the decision of the New Jersey Supreme Court decision, in the Quinlan Case in 1976. Its recommendation for a “prognosis committee”, as a means to making decisions on the withdrawal of life support from terminally ill people, was interpreted as formal recognition of the need for a clinical ethic support service in healthcare facilities. The same court recommended that each hospital, establish such a committee composed of physicians, social worker, attorneys and theologians which would serve to “review the individual circumstances of ethical dilemma and which would provide much in the way of assistance and safeguards for patients and their medical caretakers” (Hoffman et al 2008).

Others attribute the development of the ethics support service to the JCAHO. In 1992, the commission mandated that all its approved hospitals, had in place, a means for addressing ethical concerns (JCAHO Standard RI.1.1.6.1 1992). However, clinical ethic support was already available in the 1960s, with the formation of Committees for the Discussion of Morals in Medicine at US Catholic hospitals, abortion review committee, in the 1970s and infant care review committees in the 1980s (McGee et al 2002).

Further developments in US firmly planted the concept of clinical ethic support in healthcare facilities. The inclusion of medical ethics education in medical school curriculum, began in 1976 (Brian et al 2012). In 1980, the American Board of Internal Medicine began including questions on medical ethics in its certification exam. The President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioural Research 1983, reported that when “deciding to forego life-sustaining treatment”, exploration and evaluating the use of CEC was recommended in decision-making in issues that have life-or-death consequences (Orlowski et al 2006). The American Medical Association's Judicial Council, published guidelines for CEC in 1985. In 1986, The New York State Task Force on Life, encouraged resolving dilemmas on patient care at hospital level, rather than by turning to the courts and suggested ethics committees may mediate such
disagreements. On foot of these developments, was the mandate of the JCAHO in 1992.

A national study carried out in 2001, found that the presence of clinical ethical support structures had increased from 1% in 1983, to 90% in 2001 (McGee et al 2001). A further study by Fox et al (2007), found that during its three-decade history, the CESS had evolved into an organised and widely accepted healthcare service. Some states have adopted statutes that provide CEC with legal status, however, in most jurisdictions they remain unregulated and lack homogeneity in structure and operation, although share common characteristics i.e. they are multidisciplinary in membership and exist to address ethical dilemmas that occur within healthcare institutions (Hoffman et al 2008).

Whilst Statutes have given clinical ethic support services significant authority they have imposed little requirement on committee composition, competence or process. Currently there is no licensing of ethics consultants, they rely on self-regulation by way of professional societies or on the norms governing the professions they belong to. In 2014, the American Society for Bioethics and Humanities approved the Code of Ethics and Professional Responsibilities for Healthcare Ethics Consultants, thus advancing the professionalization debate. This first code of ethics focuses on the individuals who provide ethics consultation in the clinical area. Bioethics has been progressed from a movement to a specialized field (Tarzian et al 2015).

**EUROPE**

**Belgium**

Ethics committees are the most important instrument of ethics support in Belgium. They have three functions:

- Ethical review of experimental protocols
- Advising on the ethical aspects of healthcare practice
- Ethics consultations.

Their beginnings were initiated as a matter of internal regulation by the Belgian Order of Physicians in 1984 when they published guidelines, that all research protocols involving human subjects must be evaluated by a REC. A second set of
guidelines were published in 1992 by The Order of Physicians’ National Council, extending the role of the REC, to provide for the systematic reflection on the ethical and philosophical aspects of practice in healthcare. There was no suggestion of a second committee being formed to carry out this task. Due to this, ethics committees had to combine both the task of research and clinical ethics.

External regulations of the ethics support came into being in 1994. The Royal Decree obligated every hospital to establish a “local healthcare committee”. The committee was assigned to provide a guiding and consultative task with regard to the ethical aspects of hospital care and a review task to protocols involving experimentation with human subjects. By law, the existing committee also acquired the task of ethics consultations that would provide support for the healthcare personnel when confronted with an ethically problematic dilemma.

The Royal Decree also governed the composition of the ethics committee. It stipulated there should be at least eight members, no more than 15. Membership should represent both sexes, and the majority of members must be associated with the hospital as physicians. It was obligatory to have at least a lawyer, a nurse, and a GP external to the healthcare facility.

In 2000, The Belgian Court of Arbitration removed the “ethics consultation” function from the committees’ tasks, as conflicts related to healthcare was a task that should be dealt with by regional authorities, not a local committee. The Federal Advisory Committee of Bioethics in 2001, proposed inclusion of a philosopher or a representative of the humanities experienced in medical ethics, to the membership. This person could play an important role in formulising and steering the ethical discussion. Information on the functioning and activity of CEC is presented annually by the Advisory Committee on Ethics.

In 2004 the functioning of the existing ethics committees changed due to a new law on human experimentation that introduced the provisions of the EU Clinical Trials Directives 2001/20/EU. The predominant function of the ethics committee was reinforced by introducing competing timelines which research protocols had to be reviewed. The new law also introduced funding for REC, but committees whose focus was clinical ethics did not qualify for financial support.
Today, ethics committees are regulated on a national level. Despite legislation, some institutions have established separate research ethics and clinical ethics (Tschudin 2001). Overall the function of the “local healthcare ethics committee” or “mixed committee”, is dominated by the obligation to review protocols on human experimentation, which is to the detriment of the clinical ethics related tasks, particularly to the guidance and ethics consultation tasks, set down by The Decree Royal in 1994 (Meulenbergs et al 2005). Although the establishment of these committees began as a “bottom-up” approach, due to legal obligations, they evolved into a “top-down” approach.

Croatia

The healthcare system presents itself as a hierarchical and bureaucratic entity, rife with power games, political involvement in medical decision-making, which are not uncommon in countries in a transitional state. Croatia became a democratic state in 1995 after years of corruption and manipulation with people’s rights. Trust in the medical profession was lost during those years but medical practice and physician’s professional behaviour has been evolving from the paternalistic attitude to teamwork, involving other medical professions and patients in decision-making (Oreskovic 2009).

The Law on the Health Protection of 1997 obliged all healthcare institutions to create an ethics committee (Table 2.0) and included directive and advisory tasks.

**Table 2.0: Directive and advisory tasks of ethics committees** (Oreskovic 2009).

<table>
<thead>
<tr>
<th>Tasks of the ethics committee by law</th>
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<tbody>
<tr>
<td>• follow the implementation of ethical principles of medical profession</td>
</tr>
<tr>
<td>• approve the research activities within the healthcare institution</td>
</tr>
<tr>
<td>• oversee the drug and medical device trials</td>
</tr>
<tr>
<td>• oversee organ procurement from the dead person</td>
</tr>
<tr>
<td>• solve other ethical issues in the healthcare institution.</td>
</tr>
</tbody>
</table>

By law each committee should have five members, two of which should not be from the medical field. The committee was required to combine the functions of research and clinical ethics support. Healthcare institutions have the purpose to
protect the wellbeing of patients, foster their healing process and help patients and families to cope with illness and disease. Exclusion of patient representatives can lead to serious doubts as to the purpose of the committee and the respect for patients’ opinions, in a healthcare facility that promotes such a membership structure. Revision of the law in 2003 left legal requirement of the establishment of ethics committees unchanged (Borovecki et al 2010).

Croatia has decided on the “top-down approach” and are “mixed committees” and an exact replica of the structure required by law. Such a legalistic framework has created confusion regarding the tasks of the healthcare ethics committee, most of which have made analysis of research protocols their main function (Van der Kloot Meijburg et al 2001).

Germany

CESSs were established in 2000, following a proposal to compliment the REC with another committee responsible for clinical ethics. The main responsibilities of this committee were to support responsibility, autonomy, mutual trust, respect and empathy, both in clinical decision-making and in relationships between doctors, nurses, patients and relatives. The aims of the committee are to aid in promoting an environment in which patients were satisfied with their care and professionals were satisfied with their working conditions. The functions of the committee are:

- Sensitization of staff for matters of medical ethics
- Ethics education
- Moral case deliberation or ethics counselling
- Development of ethical guidelines

There are no legal regulations regarding CESSs. However, all hospitals registered in the Christian Association of hospitals are mandated to establish a CESS. The advent of patient rights, increased ethical awareness, expansion of medical interventions, legal aspects of informed consent, end of life decisions and advance healthcare directives, prompted the need for such a support service throughout the healthcare service (Reiter-Thiel 2000).
The membership is a total of eighteen. Five of the members must be lay people, a judge, hospital chaplain and the other three represent patient perspectives, from self-help groups and a representative of health-related interests of ethnic minorities or migrants. Patients have a right to access the ethics consultation service, protected by the CEC’s statutes, and they can request or reject the involvement of other people pertaining to their case. If a clinician requests a consultation, the patient is not present, to protect them from the potential harm arising from a detailed though speculative discussion. However, if the case is about patient autonomy, the patients’ attendance is mandatory (Fournier et al 2009). Schochow et al (2015), showed that 86.4% of German hospitals have a functioning CESS.

Ireland

CESS appear on the whole to be absent. Four services were accessed. Two institutions choose the ethics committee model. One was a “bottom-up” approach and the other “top down”. Both committees use the four-quadrant approach ethical framework for evaluation and analysis of ethical dilemmas in clinical practice. Both have a clinical ethicist as members.

One of the committees is established for many years in a private healthcare facility, run by a religious order. The purpose of the committee is to “promote an awareness of fundamental values as they relate to the mission and the philosophy” and is responsible to “assure the implementation” of that philosophy as it relates to “medical ethical issues”. Included in their terms of reference is their participation in policy, guidelines and procedure development and to identify educational needs of personnel. Also included is their participation in granting ethical approval for the conduct of clinical research within the institution, this is provided by a Research Ethics Subcommittee. It can be therefore presumed that this committee is a “mixed committee”.

The other, in a public hospital, was developed over the last two years and opened for business in February 2018. The role of this committee is to provide “support and advice to staff members, patients and their families, who find themselves in an ethically-challenging situation in the course of providing or receiving healthcare”. The committee will also act as an educational resource on request, to provide staff
with training in relation to specific ethical issues. Their terms of reference do not include any involvement in research approval. Their information pamphlet specifically states that they should not be confused with the REC or patient complaints office.

The third support structure, in a private healthcare organisation, is a policy. It is a “top-down” approach, and the onus for suitably trained personnel to address ethical concerns lies with the management team. The management team is also charged with providing advice, consultation, a forum for ethical decision making, and to assist in clarifying available options. Advice can be sought by the management team, from the REC. Should the consultation and/or discussion of a specific case lie beyond the expertise of those involved, advice is sought from an external ethicist. To date, one ethically challenging case was resolved with input of a clinical ethicist. Otherwise, a member or members of the management team deal with resolution of clinical ethical dilemmas when they arise. Addressing educational needs or development of hospital policies in not included in the support structure.

The fourth service established a CEC, but it has been dormant for the last number of years. Presently clinical ethical dilemmas are resolved locally. If not resolved locally, the Chief Executive Officer and Director of Nursing intervene and manage the situation to bring it to resolution. The establishment of the support service was a “top-down” venture and remains as such.

Further information gleaned from hospital websites, suggest that CEC where present, were “mixed” committees not only involved in research approval, but assisting the Board in fulfilling their responsibilities. These include, ensuring the availability of assistance and guidelines for those involved in the provision of patient care. Education provisions to foster an ethically aware workforce were absent. There is uncertainty as to whether these committees are active or dormant. Web sites of disability services and psychiatric facilities, advertised Patient Rights Committees, but information pertaining to them, could not be accessed.
In 1996, following the launch of an initiative by clinicians, politicians and health authorities, the establishment of clinical ethic support services ensued. In 2000 the Norwegian Parliament approved a recommendation by the Ministry of Health and Social Affairs requiring the establishment of CEC as the clinical support service. The committees were set up with the globally accepted functions of education, consultation and policy development, to assist in decision making for the healthcare team. In 2001 The Patient Rights Act was passed and committees were viewed as a way to increase the voice of the patient and their families in difficult controversial medical decisions (Fournier et al 2009).

In 2011, the Ministry of Health and Care Services mandated that each health trust must have a CEC. Regulation and national co-ordination of the clinical ethics support system is the responsibility of The Centre of Medical Ethics, Oslo University. Their responsibilities include the professional development of the committees by supervision, evaluation and performing research related to the committees’ work. The health trust is responsible for establishing and maintaining the committee. Presently there are 23 health trusts and 37 committees.

The committee has 10-12 members and must have at least two lay members e.g. patient representative, and external members such as some ethicist, lawyer or personnel from another healthcare institution.

In 2016, the government, called upon healthcare ethics committees’ involvement with The National Council for Priority Setting in Healthcare. Although the committees have an advisory role only without decision-making capacity, it was deemed that as a multi-professional body with competence in law, ethics and a patient representative, were best placed to discuss ethical issues pertaining to utility, resource use and severity, in broad terms, organisational ethics (Forde et al 2014). Of note, the mandate in 2011 by the Ministry of Health, stipulated that one of the tasks of the committee was to “contribute to increased understanding of the relationship between clinical-ethical issues and questions related to resource management and priorities in the healthcare trusts”.

Although typically involved in education, ethics consultation and policy development, a study by Magelssen et al (2017), showed that organisational
ethics i.e. resource management, principle of justice when the hospital allows its own economic incentives override the principle of fair treatment, now comprises a sizeable proportion of their cases. Examples of issues the CESS were consulted on included requirement of patient compliance when treatment is expensive, the logic of closing beds, reducing staff numbers, and early discharges from hospitals due to resource constraints.

The study suggests that the role of the Norwegian CEC will be impacted upon. Some roles will remain the same i.e. analyst, advisor and moderator, but from a broader platform, other roles may be disseminator (to create awareness and disseminate knowledge among clinicians), co-ordinator (connect different levels of healthcare institutions, watch-dog (recognise unfair prioritizations and alerting relevant authorities) and guardian of values and laws (ensure legitimacy and fairness in line with common values) (Magelssen et al 2017).

Poland

CESSs were few and far between in 2007. There are no legal or ethical regulations concerning their establishment, structure or membership. Ethical support is provided on national and regional levels by the Medical Ethics committee of the Medical Council and the Chamber of Physicians and Dentists. Their influence on healthcare policy and clinical decision-making is limited. Local CESS where established, are monodisciplinary, membership restricted to medical doctors. Each committee is governed by their own statutes and differs from other committees’ in accordance to the regulations pertaining to organisational and functional issues (Steinkamp et al 2007).

A study by Czarkowski et al (2015), highlighted that the establishment of CESSs had not progressed since 2007. In the few hospitals that do have the service; it's structure, services and workload are inadequate. In order to provide a quality CESS, development of relevant legislation, standard operating procedures and well-trained members is urgently needed.
The Netherlands

Healthcare ethics committees were established in the 1970s, they were mostly mixed committees and began as “bottom-up” enterprises and have maintained this approach.

The Dutch Minister of Healthcare (2005) suggested the need for thoughtful consideration of the structure of moral case deliberation within healthcare organisations. The CEC began transforming into a steering group, which aimed to develop moral competencies of healthcare professionals. This movement away from the traditional roles and functions of the committee, was to promote and guarantee an ethics climate throughout the whole institution (Dartel 1998).

Moral case deliberation consists of a meeting with care givers, who systematically reflect on the moral questions that arise in their daily clinical practice (Molewijk et al 2008)

The reflection process is facilitated by an ethicist or a person trained in moral case deliberation methods, who does not give advice or morally justify or legitimize a specific decision. The focus of the process is facilitation of the group members reaching their own answers and decisions. MCD always pertains to experiences and actual situations encountered in practice. The rationale for this premise, dates back to Aristotle’s approach to ethics where he claimed the (moral) wisdom and knowledge originates from reflections on and within concrete situations, there is no moral truth independent from experience (Molewijk et al 2008).

CEC remain important explicit vehicles of clinical ethics support. Moral case deliberation is an implicit strategy of clinical ethics support. Combining both is considered a good way to embed ethics integrally in the organisation. It also opens up the notion of clinical ethics being everyone’s responsibility, and not just the responsibility of the select members of the support service (Dauwerse et al 2014).

United Kingdom

The Royal College of Physicians and the Nuffield Council of Bioethics, declared their support of for ethic support services, but with limitations on performance (Williamson 2008). The United Nations Educational, Scientific and Cultural
Organisation (UNESCO), (2005), strongly endorsed the development of ethics committees as ideal platforms for ensuring human rights, in healthcare practices.

UK are considered one of the pioneers in Europe, in the development of clinical ethic support services (Hajibabaee et al 2016). A number of local reasons, including institutional response to particular problematic cases and clinician concerns about the ethical aspects of clinical practice, were involved in the setting up of the first clinical ethics support structure, i.e. ethics committee in the UK in 1995 (Slowther and Hope 2000). This initial ethics committees continues as an integral feature of professional life within the healthcare provider and is a sub-committee of the institution’s Clinical Governance Committee and Medical Director.

In 2001 the UK Clinical Ethics Network, was established, with the express purpose of generating sufficient “critical mass”, to “embed” clinical ethics as a core element of health care by facilitating communication between all UK ethics committees (Slowther 2008). The network supports established institutional CESSs by providing education, information and facilitates sharing of information between committees about best practice. It also provides assistance for healthcare institutions setting up a CESS. The UK Government partly funds the network.

In the UK the CESS remain ad hoc bodies generated for a variety of reasons and with different goals, structures, membership, methods of work and functions (Doyle 2001). There are no formal requirements for their constitution, membership or remit, “most of them review hospital policies and provide advice on ethically problematic cases” (Sokol 2009). The findings of a study by Slowther et al (2012), describing the current provision of ethics support in the UK, showed that a wide variation in committee membership, processes and levels of institution support, prevails. There is no legal or professional obligation to consult the ethics support service where they exist, nor is any recommendation made or conclusion reached, binding on anyone who seeks an ethics consultation.

The most common issues raised with UK ethics committees are withholding and withdrawing treatment, consent and Do Not Resuscitate Orders. Many of the ethics committees’ primary function is policy development. One such committee, while reviewing an organisational policy, that stipulated care provided is
researched based best practice, advocated the use of homeopathic interventions, which was not a researched based intervention. (Szeremeta et al 2001)

WESTERN PACIFIC REGION:

Australia

There is minimal information regarding clinical ethic support services. Some ethics support initiatives are underpinned by the increased ethical complexities of clinical practice. Support on a national level is provided by the Australian Health Ethics Committee which provides advice and guidance on ethical issues. At a state level the Ministry of Health produced guidelines and policy directives relating to specific ethical issues such as organ donation, end of life decisions and not-for-resuscitation. There has been no evaluation of these initiatives.

A critical analysis of Australia's CEC was published by Mc Neill, (2001). It was suggested it was difficult to identify what is and what is not, a currently functioning CEC and that, they were not the most “common vehicle for resolution of ethical issues”. All public and private hospitals were surveyed and estimated that 120 (10%), of the institutions had a functioning clinical ethics committee that fulfilled a policy development or educational role. There were doubts regarding the accuracy of the 10%, as it was believed there had been confusion by the participants between clinical ethics and REC (McNeill 2001).

Two reports published regarding specific CEC, were positive in their conclusions and argued for a wider adoption of ethics committees (Gill et al 2004; Gold et al 2011). The few committees that do exist are local initiatives and there are considerable variations in their constitution, processes and activities and appear to be on the periphery of attempts to promote good quality healthcare. The development of the service is ad hoc, uncoordinated and sparse (Doran et al 2015).

In 2012, the NSW Ministry of Health commissioned a research project to be carried out by the Centre of Values, Ethics and Law in Medicine at the University of Sydney, to provide a comprehensive summary of published international literature about clinical ethics support and services between the years 2000-2012.
The published report was intended to be a resource for local decision-making about providing clinical ethics support (Doran et al 2015).

New Zealand

There are eight CESSs, which serve more than one district health board. Their establishment in 2008 was initiated by clinicians who believed that such a service would provide focus and help in addressing ethical issues as and when they arise in the clinical environment (MacDonald et al 2012). The model utilised was a committee-style advisory group composed predominantly of clinicians, known as Clinical Ethics Advisory Groups. Their terms of reference were:

- To provide a consultative advisory and support mechanism to assist healthcare professionals to make informed ethical decisions in the management of their patients
- To facilitate education in the area of ethics and to foster a culture of ethical awareness, hence equipping healthcare providers with the means to approach ethical problems and conflicts (Dai and Ballantyne 2016).

An update in 2010 suggested that there had been a modest expansion in the prevalence of CESSs, the actual state of formal ethics support is unknown. However, there is strong support for the introduction of this service whether it be a committee model or clinical ethicists working within the district health boards (Dare 2010).

In 2012, the Health Quality and Safety Commission offered a grant to support the establishment of a New Zealand Clinical Network to support existing clinical ethics advisory groups and to facilitate the establishment of new services nationwide. This project is current.

CESSs are prevalent globally. In some countries the service has evolved and matured, but in others, it is lacking (Table 2.1) Reasons for their prevalence, arose from a clinician's awareness, in present day medicine and that help was needed in situations, in the clinical environment, as to what they “ought to do”. Other reasons include mandatory establishment of the service, either to achieve accreditation or to fulfil a legal requirement. Some support services, are mixed and provide research ethics approval and clinical ethics support. REC operate within a legal framework,
are homogenous, regulated and are decision makers. CEC are advisory, self-regulating and heterogenous.

**Table 2.1: Comparison of diversity of CESS**

<table>
<thead>
<tr>
<th>Country</th>
<th>Established</th>
<th>Prevalence</th>
<th>Structure</th>
<th>Guidelines</th>
</tr>
</thead>
<tbody>
<tr>
<td>United States</td>
<td>Established 1976 – Quinlan case</td>
<td>Widely accepted and practised</td>
<td>Structure state dependent</td>
<td>Guidelines at local level</td>
</tr>
<tr>
<td>Belgium</td>
<td>1984 – Belgian Order of Physicians</td>
<td>Obligated by royal decree nationally</td>
<td>Structured and regulated 'Mixed'</td>
<td>Guidelines in place nationally</td>
</tr>
<tr>
<td>Croatia</td>
<td>1997 – Law on the Health Protection</td>
<td>Legal requirement</td>
<td>Hierarchical and bureaucratic 'Mixed'</td>
<td>Clear objectives but hierarchical</td>
</tr>
<tr>
<td>Germany</td>
<td>2000</td>
<td>Not legal requirement; mandated in Christian Assoc. hospitals</td>
<td>Structured within the Christian Assoc.</td>
<td>Guidelines only at local level</td>
</tr>
<tr>
<td>Ireland</td>
<td>2002</td>
<td>Not widely accepted</td>
<td>Unstructured, unregulated</td>
<td>Guidelines in place, but unclear</td>
</tr>
<tr>
<td>Norway</td>
<td>1996; mandated in 2000</td>
<td>Mandatory in all hospitals</td>
<td>Structured and regulated</td>
<td>National guidelines, clear objectives</td>
</tr>
<tr>
<td>Poland</td>
<td>2007</td>
<td>Not widely accepted or practised</td>
<td>Unstructured</td>
<td>Unclear</td>
</tr>
<tr>
<td>Netherlands</td>
<td>1970’s</td>
<td>Widely Accepted</td>
<td>Unstructured</td>
<td>Unclear</td>
</tr>
<tr>
<td>United Kingdom</td>
<td>1995</td>
<td>Widely accepted</td>
<td>Structured</td>
<td>Clear goals and objectives. Multiple policies</td>
</tr>
<tr>
<td>Australia</td>
<td>Approx. 2001</td>
<td>Not widely accepted</td>
<td>Minimal info, unstructured</td>
<td>Unclear, non-uniform goals</td>
</tr>
<tr>
<td>New Zealand</td>
<td>2008</td>
<td>State accepted, not national</td>
<td>Structured</td>
<td>Clear goals and objectives</td>
</tr>
</tbody>
</table>
Chapter 3
MODELS AND CHALLENGES

Professional organisations provide guidelines for professional and ethical conduct, some include guidelines on specific issues and these provide a useful framework for professionals. Such guidelines are too nonspecific to be helpful in a specific local situation and it has been suggested that such guidelines should be used as a resource for more local and specific clinical ethics support (MacDonald et al 2012).

The CESS is ideally composed of individuals who bring a balance of the knowledge and skills required for effective provision of such a service. Three service models are evident to be thriving in a wide variety of healthcare facilities:

1. Multidisciplinary Clinical Ethics Committee
2. Sub-committee or Team Model
3. Individual Ethic Consultants

Each model has its strengths and weaknesses. Frequently, they are associated with extreme cases such as advising on withdrawal of life support treatment (Goldim et al 2008). Each model is capable of providing the universal accepted functions of CESS. Those involved in ethics consultations advocate the combination of all three models to maximise on the strengths and minimise the weaknesses and suggest the consultation task itself will dictate which model should be used (Fox 2010).

1. Multidisciplinary Clinical Ethics Committee

This comprises of a stable group of 6 to 20 members from varying disciplines. Inclusion of patient representatives and lay persons is not widespread. This is the most utilised model globally. Such a model facilitates collective proficiency and access to diverse perspectives, allowing for wide discussions and it is the multidisciplinary membership that is considered to be its main strength (ABSH 2009).

Being part of the organisational structure, it may have more influence, on policy and procedure guideline development. It is a model that can be easily
established, useful in institutions introducing the concept of ethical support services and developing the service.

However, the committee may be seen as another bureaucratic layer and has been designed to protect institutional interests. This could potentially reduce patients’ wanting to access the committee due to competing interests i.e. interests of the hospital and its staff or interests of the patient.

The model is not suited to issues that require immediate response, from a logistics’ perspective. Time would be needed to get all members to a required location. This model defuses responsibility and also has the potential of contributing to “group think”. However, it allows for peer regulation in regards to completion of allocated tasks, self-education, professional development and ensuring members activities remain within the terms of reference stated.

The committee model may be more suited for referrals of potential “ethical dilemmas”, as opposed to solving immediate clinical dilemmas. The multidisciplinary group would be best placed to manage the situation by planning best course of action to prevent escalation of the situation. Guidelines could be developed for future potential events as it has been suggested that the committee could also be useful for ensuring organisational input in clinical dilemmas that might establish institutional precedent, receive media attention or end up in court (Berkowitz et al 2016).

2. Sub Committee/ Team Model

The ethics support is shared by a small group of people, selected from the committee for their knowledge and skills as the circumstances dictate, education, policy and guidelines input or ethic consultation. The model lends itself to a more rapid response and logistically presents fewer hurdles an ensures diverse perspectives and expertise, as the team members will vary depending on the situation.

This model is a compromise between an individual consultation and the full committee model. Logistically, it is less efficient than the individual consultant. There are fewer members, hence fewer views.
3. Individual Ethics Consultants

In this model one person, either an independent or “solo” consultant, or a member of the clinical ethics committee is assigned to perform the consultation alone. The main advantage of this model is facilitating rapid response to an urgent request.

The disadvantages are that the consultant must possess all the required knowledge and skills to perform the task. There are fewer checks to protect against the intrusion of the consultant’s own values and beliefs. The onus is on the individual to recognise their strengths and weaknesses and seek assistance when needed. To encourage self-awareness and insight, the consultant should discuss with the committee/team, the particulars of the referral and options for resolution.

The individual consultant model may allow for the referring clinicians to “retain” control of a situation by choosing whom they want to assist in a given circumstance. This can be promoted by the individual consultant building relationships within the institution, being visible, known and including those with the expertise he/she may lack, pertaining to any given task.

New Innovations evolving the concept of clinical ethic support services:

**Moral Case Deliberation** (MCD) is an implicit form of clinical ethics support developed in the Netherland (Molewijk et al 2011). MCD is a meeting of a multidisciplinary group of healthcare professionals, to deliberate systematically on an actual situation and the ethical/moral issues encountered within that situation. Self-reflection requires a sophisticated awareness of the underpinning principles and values that pertain to specific situations, that go beyond their professional code of conduct guidelines (McLean 2009). The purpose of reflection is to increase awareness of different aspects of an issue which may lead to the ability of solving an issue (Schon 2003).

The MCD meeting is facilitated by a specifically trained facilitator whose main role is to stimulate an ethical discussion and to highlight the ethical aspects of the case (Garcia 2001). The facilitator provides the theoretical principles and their application to practical situations. It aims to combine reflection on concrete cases with methodical procedures to foster moral learning (Magelssen et al 2016).
MCD is an experiential education model, which aids healthcare professionals to reflect systematically on ethical questions and find answers themselves. It has been argued that approaches based on reflection/deliberation may generate insight, and heighten awareness of other aspects, of ethically difficult situations in their clinical practice which they were unaware of previously (Moon 2013, cited by Rasool et al 2017).

MCD differs from the committee model and/or consultations in that it fosters dialogue pertaining to ethical questions and reflection on ethical dilemmas, rather than decision-making in ethically challenging situations (Table 3.0). Other forms of reflection practices include ethics rounds, discussion groups and reflection groups.

**Table 3.0 Goals of moral case deliberation** (Dauwerse 2013)

<table>
<thead>
<tr>
<th>The goals of moral case deliberation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reflection on a case and to improve the quality of care within that specific case</td>
</tr>
<tr>
<td>Reflect on what it means to be a good professional</td>
</tr>
<tr>
<td>Enhance professional’s moral competencies</td>
</tr>
<tr>
<td>Promote professional development</td>
</tr>
<tr>
<td>Reflect on institutional or organisational issues and improve the quality of care at that level.</td>
</tr>
</tbody>
</table>

The Hub and Spokes strategy was developed by the Joint Centre for Bioethics at the University of Toronto in conjunction with 10 affiliated hospitals. It contributes to improved clinical ethics effectiveness in three ways (Table 3.1)

The core innovation of the strategy is it builds capacity through ethical expertise, radiating from the centralised ethics expertise Hub, to the clinical and general staff, through the Spokes. It recognises clinical ethics support being “an integrated part of everyone’s role” (MacRae et al 2005)

The Spokes, are individuals that take the ethics lead within a clinical area and are the first point of contact and ethics resource in the event of an ethical issue. The spokes facilitate discussion with personnel in that clinical area and refer the issue to the clinical ethics committee or Hub should the issue be beyond their scope of knowledge, or if the issue requires a wider range of perspectives.
Table 3.1: Hub and Spokes strategy contributions to clinical ethic effectiveness. (Gibson et al 2008)

<table>
<thead>
<tr>
<th>Contributions to clinical ethic effectiveness</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Ethics integration</strong></td>
</tr>
<tr>
<td>Positioning of “spokes” locally</td>
</tr>
<tr>
<td>Support accessible to staff, patients and families</td>
</tr>
<tr>
<td>Early identification of ethical issues and/or potential ethical issues</td>
</tr>
<tr>
<td>Educational needs easily identified</td>
</tr>
<tr>
<td>Immediate incorporation into patient care decision-making</td>
</tr>
<tr>
<td><strong>Sustainability</strong></td>
</tr>
<tr>
<td>The integrated structure not dependent on single individuals</td>
</tr>
<tr>
<td>Less risk of isolation and burnout</td>
</tr>
<tr>
<td><strong>Accountability</strong></td>
</tr>
<tr>
<td>Formalises accountability</td>
</tr>
</tbody>
</table>

However, there may be difficulty ensuring appropriate ethics expertise of the “spokes”, there is a potential of insufficient review of their case deliberation and their views may be limited.

**Integrated Ethics** is a systems approach ethic support model. A systems approach does not focus on the individuals as objects for improving, but rather on “examining interrelationships, communication, ongoing processes, and underlying causes of behaviour, with an eye towards changing interactions or redesigning the system to produce different behaviours” (Silverman 2000). The approach is proactive, not just reactive and each intervention is seen as an opportunity to understand the “root cause” of a problem or behaviour; thus, allowing for suggested changes or alternative systems, to reduce the ethical difficulties for clinicians and patients (MacRae et al 2005)

Singer et al, (2001), identified the need to integrate the work of the clinical ethics services into the culture of the organisation and the organisation to improve their accountability for clinical ethics. Ethical issues of a healthcare organisation impact the functioning of the broader context, in which they exist. Systems thinking, encourages collaborative practice among departments within the institution. This can impact on the perceived notion that clinical ethics support operates in relative isolation from the rest of the organisation (Blake 1992). Hence this approach can improve ethics accountability by the organisation by the systemic commitment to ethics from “boardroom to bedside” (MacRae et al 2005). This in turn may bridge the perceived/actual gap between organisational and clinical domains (Folgia et al 2004).
A systems approach can assist clinicians, managers and ethics facilitators to understand and address the components of the systems that drive ethical care and behaviour (MacRae et al 2008). Such an approach can also help to decrease moral distress and disempowerment among healthcare providers. Moral distress has been defined as “what happens when a staff person knows the right thing to do, but institutional constraints make it nearly impossible to pursue the right action” (Jameton 1984).

The major challenge, to the implementation, of the systems thinking approach, is changing organisational behaviours and/or cultures.

**Challenges to the clinical ethic support service**

The effectiveness and sustainability of the CESS, is dependent on their organizational status, the support received from healthcare professions and the organization, the legitimacy of those providing the service and local leadership (MacDonald 2012). CESS is advisory in nature and should, ideally, be autonomous within the institutional governance. The two major challenges, prevalent to CESS globally are utilisation and evaluation of the service.

**The Utilisation challenge**

For any support service model to be sustainable it must be utilised. Many studies have been carried out to determine why clinicians do or do not use formal clinical ethic support services (Table 3.2). The findings have been consistent throughout the years and suggest that the barriers to utilisation of the service can be a combination of personal and professional (McLean 2009). A support service that is not clearly part of the hospital organisational structure, risks being ignored and will not be utilised if it has no recognised authority within the institution (Dorries et al 2011). Absence of a clear role and position within the institution may cause the service to be avoided. The failure to thrive can arise from lack of organisation support (Mills et al 2006). No particular model appears to flourish or fail, but for it to be used, its purpose must be understood and valued and should be structured to meet the ethical concerns of the potential users (Tweedale 2001).
Table 3.2: Why clinicians use or do not use the CESS

<table>
<thead>
<tr>
<th>Authors</th>
<th>Users</th>
<th>Non-users</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Seek assistance:</td>
<td>Lack of confidence in the competence of those providing the service</td>
</tr>
<tr>
<td></td>
<td>• in deciding what to do</td>
<td>Service providers may not have the clinical expertise to grasp the intricacies of the case</td>
</tr>
<tr>
<td></td>
<td>• to identify a practical solution</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• to implement a practical solution</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• to make a decision or plan care</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• to resolve conflicts</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• to interact with a difficult family, patient or surrogate</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Addressing a potential conflict before it crystallises.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Support shared decision making</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Reassurance that the correct decision is being made</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Better able to face the people who thought a decision was inappropriate</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Emotion such as fear, frustration, or being uncomfortable with a situation</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Educational needs/clarification re guidelines/ legalities of care e.g. patient competency, end of life decisions as per families but physician disagrees.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Professional development</td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>Negative use:</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Withdrawal from a case to allow the conflict be managed by someone else, thus avoiding conflict and attempting to protect their integrity as a physician, their conscience and reputation.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Avoiding the threat of legal action</td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>Perceptions:</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• they are proficient in ethics</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• they are the only decision makers, not supporters of shared decision-making</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Ethics support services intrude on the doctor-patient relationship</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Loss of confidence in their ability, by patients, should they require and seek support</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Seeking support is deemed loss of control</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Abdication of their responsibilities</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Relinquishing autonomy over decision making while retaining accountability for patient outcomes</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Although aware support services are advisory, may feel compelled to follow advice</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Consultation may raise further issues, deeming the support is more of a hindrance than help</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Ethics is a theoretical, medicine is practical and on a practical level theoretical argument, do not matter</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Medicine requires immediate decision, not prolonged reflection</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• The law will dictate how to behave</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• There is no right or wrong answer, just different opinions</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Religious views will guide behaviour</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Ethics takes medical decisions away from physicians.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Fear of being scrutinised</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Consider the service to be the “ethics police”</td>
<td></td>
</tr>
</tbody>
</table>
Traditionally, clinicians sought support, on what they “ought to do”, from their peers or senior colleagues in “kerbside” conversations. Informal and formal ethical support is advisory in nature, and optional. Barriers to accessing both were highlighted by Pinnock and Crosswaite (2004) and Dai and Ballantyne (2016). They included isolation and a medical culture inhibiting both help-seeking behaviours and constructive criticism. The same culture makes it difficult to raise concerns about colleagues’ practice, in particular senior colleagues, and seeking advice is often perceived as a sign of weakness.

Formal ethical support may have insufficient institutional support from management, and this may lead to concerns and fears that the committee seeks to take control of the clinician’s decision-making (Doyal et al. 2009). What is undisputed, is the intention that clinical ethics support provides structure to improve team communication, an objective confidential setting, case related ethical reflection, while maintaining clinical discretion and responsibilities of the healthcare providers (Jansky et al. 2013).

Physicians bear the responsibility for medical treatment decisions, while facing many constraints. Decision-making has gradually ceased to the responsibility of one individual and has become a shared responsibility, involving patients, their families and members of the multidisciplinary team. Research suggests physicians most likely to use the service “believe in shared decision making”. Those that do not, have not embraced this concept, but believe it is their responsibility to “resolve issues with patients and their families” as they are “proficient in ethics” (Orlowski et al. 2006). It was suggested doctors do not use the support service provided because of the “fear of appearing foolish or ignorant” (Sokol 2009).

Healthcare professionals may not recognise an ethical dilemma or the potentiality of a situation escalating into one, but rather purely as a clinical one. Clinical dilemmas, have legal and ethical components and for this reason ethicists “are rarely the last decision makers in a medical situation” (Spielmann 2001). An individual ethicist confronted with a difficult case will have the same problems of moral and legal indeterminacy that clinicians themselves face. Like clinicians, ethicists also disagree on the interpretation and application of principles to practice (Doyal et al. 2009).
The heterogeneity of the support services prevalent, the lack of standards of practice, oversight and accountability, all accounts for the variation in the quality of the service provided. (Schiedermayer et al 2012). Quality in regards to ethic consultation, considers the competence of the service providers, do the providers have the necessary knowledge and skills in healthcare ethics and law. Given the indications from literary evidence, the CESSs are provided by people with an interest, basic training and/or knowledge in ethics and claims to ethical/moral expertise are questionable (Slowther et al 2012). Whilst there is an acceptance of the potential value of CESSs, the need appears to have been assumed. No systematic studies have been initiated to establish clinicians’ need for formal CESS (Dauwerse et al 2011).

**The evaluation challenge**

There is little doubt about the benefit of CESSs. In some instances, their presence is preferable to the alternative, not having access to a clinical ethic support service (Somerville 2004). Healthcare has become an environment dominated by performance quality and cost effectiveness. The Royal College of Physicians (2005) advised that clinical ethic support services should demonstrate its value to be afforded “adequate resourcing” and should show that it does “not waste resources” (ASBH 2009).

The need to evaluate services is widely acknowledged and the CESS is no different. Evaluation is important to help ensure that the ethics service is transparent and accountable, both of which allow the service to win user confidence. Evaluation is defined as the process “of determining the merit, worth or value of something, or the product of that process” (Scriven 1991), and the sustainability of CESS, requires evaluation.

Ethics services that do not consider evaluation are in danger of becoming institutionally isolated, lose credibility and forfeit long-term viability (UNESCO 2005). Evaluation can justify their presence, in terms of staff time and financial investment and they show evidence of their effectiveness (Royal College of Physicians 2005). Evaluation is important in helping to improve performance and can be used to plan future activities to achieve greater impact (Van Allen et al 1989).
Evaluation of performance is paramount for service accountability. Evidence of accountability, lends itself to confidence and respect from potential users to use the service (UNESCO 2005; Craig et al 2006). Ongoing systematic assessment of the operation, compared to a set of explicit or implicit standards, is a means to evaluate the validity of the service and allow for continuous improvement (Weiss 1998 cited by Berkowitz et al 2016).

Evaluating the quality of CESS has proved difficult. Studies have concentrated on specific activities as a measure of quality. Using outcome measures as an evaluation tool, has received much criticism, as the outcome measures are more appropriately used evaluating standard clinical interventions. Quantitative studies calculating the number of tasks performed by a service or tallying up cost savings, for some, is not a measure of quality (McLean 2009; Pfaffian et al 2009). Satisfaction surveys also has its critics. They may be helpful in assessing quality, should be used with caution as its validity as a measure of quality is questionable owing to its subjectivity. Generally, clinicians are the main service users surveyed, not patients (Williamson et al 2007). The number of referrals and ethic consultation is not a measure of quality either, as one service may be little more than a “rubber stamp”, whereas another service may provide rigorous ethical analysis on fewer cases (Williamson 2007). Cost saving is not a meaningful indication of quality and measuring such an outcome can lead to the loss of trust, should clinicians and/or patients perceive that this is the purpose of the support service (Mill et al 2005).

What evaluation studies have lacked thus far, is the evaluation of the “ethical content”. Although ethics requires to be measured in its “own terms”, how to evaluate or measure this, has remained an elusive notion. (Williamson et al 2007). ABSH (2009) has suggested that ethics consultations need to be evaluated using “ethicality” as an outcome, the degree to which clinical practices conform to ethical standards. By the establishment of goals and processes and linking a goal with a specific process, CESS can evaluate the effectiveness and worth of an intervention. (Mitchell 2000). External evaluation may be more credible as internal assessors have a vested interest in the service’s success (Squires 2010).
CESS has evolved from the committee model, a group of people with the remit of providing ethics support to clinicians, to a model that integrates ethics “into the everyday life of those working in the health service” (MacDonald et al 2012). It is widely acknowledged that there has been mixed success in the establishment and sustaining CESSs. Regardless of the model, some flourish, others fail (Conrad 2006). The CESS, should be designed to meet the needs and demands of its potential users and confidence in the service and its providers, is paramount for its utilisation.

Evaluation of a service is a necessity to prove its value and success and as a guide to required improvements. Due to the lack of guidance and standards, CESSs are mostly self-regulatory and heterogenous, the debate of how it should or can be evaluated, continues.
Chapter 4

CONSIDERATIONS AND CONSTRAINTS

CESS are advisory bodies. Leeman et al (1997) suggested that it would only be a matter of time before the CESS would be held liable for a bad outcome, an ethics disaster waiting to happen.

CESS serve important roles in the law courts. Their participation as an advisory body and their facilitation in decision-making, precludes the need to pursue the legal route. Should a case reach the courts, their recommendations have a significant impact and influence on the judicial result (Pope 2009).

Judicial review of clinical ethical dilemmas, is believed to be an inappropriate mechanism for resolving such disputes. CESS is “more rapid and sensitive” and “closer to the treatment setting” (President’s Commission 1983 at 169), in comparison to the cumbersome time-consuming and expensive legal route. Courts are a public arena and healthcare disputes deserve privacy. Clinicians’ decision-making is encroached upon by the courts (Wilson 2002).

As predicted in 1997, the CESS interaction with the courts has increased. They are now the targets of legal action, as are, their potential users. Clinicians are being sued for using or misusing the CESS. In Maryland and Texas, it was claimed that a hospital was negligent for failing to consult the CESS and both plaintiffs alleged that a reasonably prudent caregiver would have consulted a CEC under the circumstances (Neustadt v. Holy Cross Hospital of Silver Springs 2009; Giron v. Baylor University Medical Centre 2007). In 2009, parents filed a lawsuit against the CESS as they had not been included in the CESS deliberation and claimed they had never been informed that the service had no decision-making power (Lewis 2009). In 2010, Michelle Harte, a terminally ill cancer patient in Ireland, claimed that the hospital had denied her an abortion on the instructions of the CESS. The hospital counter claimed that the CESS had “guided” but had not “instructed” her caregivers (Hough and OSullivan 2010).

John Robertson’s organisation framework of CESS, proposed that consultation with the service could be optional or mandatory (Robertson 1984;1991). In some states in America, statutes stipulate mandatory consultation (Table 4.0). Although
CESS decisions are not legally binding, their recommendations have the effect of being “practically binding”. Patient users of the service, perceive the CESS as authoritative. But when aware that they are an advisory body only, do not have the financial resources to challenge those decisions. According to Pope (2014), the courts give significant deference to the decisions of the CESS, although they are not required to do so.

**Table 4.0: Situations of mandatory consultation with CESS.** (Pope 2014)

<table>
<thead>
<tr>
<th>State</th>
<th>Mandatory Consultation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Maryland</td>
<td>Life sustaining measures inconsistent with accepted standards of patient care</td>
</tr>
<tr>
<td></td>
<td>Options for medical treatment in life threatening conditions</td>
</tr>
<tr>
<td>New Jersey</td>
<td>Care providers has concerns re:</td>
</tr>
<tr>
<td></td>
<td>• Patient’s decision-making capacity</td>
</tr>
<tr>
<td></td>
<td>• Appropriate interpretation and application of terms of advance care directives</td>
</tr>
<tr>
<td>West Virginia</td>
<td>Conflict between surrogate’s decision and patients’ best interest</td>
</tr>
<tr>
<td>Texas</td>
<td>When a patient is unable to give direction re withholding or withdrawal of life sustaining treatment and has no legally appointed guardian or surrogate</td>
</tr>
<tr>
<td></td>
<td>Conflict among decision makers in the withholding or withdrawal of life sustaining treatment</td>
</tr>
</tbody>
</table>

The propensity to litigate has increased over the years and CESSs, are not immune. The debate about developing standards for ethic consultation has been in part, driven by legal liability of the service provided (The Ethox Centre 2004).

The service lies within the infrastructure of the healthcare institution and adheres to the operating policy and procedures of the institution. The institution can be sued for negligence if the support provided by the CESS does not deliver what could be reasonably expected. The fundamental expectation of the members is the ability to identify and analyse clinical ethical issues, to use reasonable clinical judgement, to communicate and educate the team, patient and family, to negotiate and facilitate negotiations and assist in problem resolution (DuVal 1997). This may not be achieved due to the service providers’ lack of appropriate training and experience. The institution could be seen as having breached their duty and be
liable for negligence. Legal indemnity, afforded by the institution, extends only to the acts and omissions arising from the normal duties of the CESS providers.

The Human Rights Act and case law developments relating to treatment decisions, suggests healthcare organisations will face challenges relating to fairness/justice in decisions which may be perceived as adversely impinging on the rights of patients and their families. CESS input on policy and guideline development or advice in individual cases, could be subject to a judicial review on hospital policy or treatment decisions. The CESS could be challenged on the advice provided on the grounds that it acted unreasonably or took into account, irrelevant considerations.

Members of the CESS owe not only an ethical duty of confidentiality, but a professional and legal duty, to patients and other third party non-healthcare professionals. Only in exceptional circumstance, can that confidentiality obligation be breached.

In addition to moral obligations, CESS is bound by the national legal framework. They cannot sanction illegal actions and should be aware of what is legal and illegal. Knowledge and/or access to relevant national guidelines, e.g. DNR, Informed Consent and laws pertaining to medical practice is a must. It has been suggested that CESS should have a member with legal training/expertise. Lawyers can contribute to the CESS but their inclusion has been challenged (Hendrick 2001). The legal representative may be responsible for ensuring adequate attention is paid to concepts such as due process, procedural justice and application of law. It has been argued that this may lead to a limited ability of the committee to “do ethics”, by the potential dominance of that person “doing law”. On the other hand, the legal representative may minimise the attention to due process issues and this could lead to minority voices being unheard (McLean 2009).

Lawyers have been members of ethic committees throughout their evolution, but usually as lay members, and as legal representatives of the institution. Conflict of interest may cause concern regarding the latter. Most of the CESS providers are employed by the institution within which the CESS resides. Ideally CESS are independent and neutral forums, and their purpose is to provide many
perspectives on a specific ethical dilemma. Pope (2014), posits the objectivity of the CESS could be seriously compromised, as structural factors may inhibit their ability to act impartially. CESS may not promote patient interests that conflict with institutional interests e.g. financial goals, legal liability exposure. CESS was formed specifically to serve a risk-management and a legal protection role for the institution.

Law and ethics are interconnected and share the same vocabulary in terms of rights, duties, responsibilities and obligations, alongside concepts of justice, fairness and equality. “It would not be correct to say that every moral obligation involves a legal duty; but every legal duty is founded on a moral obligation” (Coleridge In Rv. Intstn [1893] 1 QB 450). A member with legal training could play a role in all functions of the CESS (Table 4.1), and in doing so help to protect service providers and users, by making them aware of applicable law and provide a forum for discussion of legal issues (Gillon 1997).

**Table 4.1: Legal input to the functions of CESS** (Adapted from Hendrick 2001)

<table>
<thead>
<tr>
<th>Function</th>
<th>Legal contribution</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Education</strong></td>
<td>About the law&lt;br&gt;Dispel common legal myths&lt;br&gt;What the law allows&lt;br&gt;Legal aspects of medical treatment(s)&lt;br&gt;Updates re law, guidelines and legal requirements</td>
</tr>
<tr>
<td><strong>Ethics consultations</strong></td>
<td>Ensure proper procedures are adhered to&lt;br&gt;Ensure rights of patients and others are protected&lt;br&gt;Advice on the legal ramifications of decisions made&lt;br&gt;Clarify issues&lt;br&gt;Provide awareness on the legal perspective and the development of the law</td>
</tr>
<tr>
<td><strong>Policy formulation</strong></td>
<td>Scrutinise words of the policy, guidelines or modifications.&lt;br&gt;Alert to the subtle ambiguities and uncertainties in wording used&lt;br&gt;Ensuring the wording is clear</td>
</tr>
</tbody>
</table>

Others propose that knowledge of the law can help service providers and users understand what the actual risks of civil and criminal liability are and thus alleviate excessive fears (Cranford et al 1987). Lawyers can provide understanding of the legal perspectives of ethical issues such as informed consent and confidentiality, the relevance of human and constitutional rights and their application in clinical
practice. This could provide for a more robust platform for ethical analysis (Weinberg 2012).

Like ethics, law is not simply a matter of applying common sense. Ethics is aspirational, setting universal goals that should be met without there being penalties should they not be attained. Law is mandatory, setting a minimum standard if not attained or maintained, have penalties, risk of civil or criminal liability (Hendrick 2001). Its utilisation requires expertise and understanding.

The CESS involvement in dispute resolution obliges adherence to basic process guidelines and once both its procedures and substantive rules are applied it might resemble a mini-court and the elements of their deliberation become more legal orientated than ethical (Agich et al 1991). It has also been suggested that it is easy to move from “advice to authority and from commentary to decision making” (McLean 2008). McLean also suggests that CESS do not have sufficient diversity, composition, training or resources and lack neutrality and independence, in mediating ethical disputes in the healthcare institution in which they are employed.

The contentious issue of according due process in CESS deliberation is not new. As the powers of the CESS increase, the concern of their fairness also increases. Due process should be accorded to deliberation of clinical disputes, otherwise CESS can be taken to task, regarding the unfairness of their advice/decision, and may lose credibility as being an objective and non-judgmental forum (Pope 2014). (Table 4.2).

**Table 4.2: Risks of not according due process to deliberation/decision-making.** (Pope 2011)

<table>
<thead>
<tr>
<th>Decision</th>
<th>Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>Biased Decision</td>
<td>Reflects a pattern of unfairness</td>
</tr>
<tr>
<td></td>
<td>Ignores the interests of certain persons or classes of persons e.g. decision maker prejudiced against a race of people</td>
</tr>
<tr>
<td>Careless decision</td>
<td>Ill considered, unsupported beliefs</td>
</tr>
<tr>
<td></td>
<td>Due to decision-makers lack of training</td>
</tr>
<tr>
<td>Arbitrary decision</td>
<td>An abuse of the appropriate process norms.</td>
</tr>
<tr>
<td></td>
<td>Caused by the failure to obtain relevant information or engage in adequate deliberation</td>
</tr>
<tr>
<td>Corrupted decision</td>
<td>Results from the self-interest of the decision-maker, e.g. duty to the institution</td>
</tr>
</tbody>
</table>
Article 40 of the Irish Constitution affords its citizens the right to fair procedures and those “making decisions that affect them, must treat them fairly”. Values underlying the obligation to accord due process are similar to those of medical ethics, i.e. the necessity to respect the individual who is affected by the decision, the obligation to allow the individual to be heard (Wolfe 1992). Article 21 of The Universal Declaration of Human Rights affords all the right to a fair hearing.

The stated purpose of CESS in the US, is to protect the interests of patients, especially those patients who could not speak for themselves (Hoffman 1991). In the UK, CESS is described as the provision of support and advice to healthcare professionals and patients on ethical issues arising from clinical practice or patient care (Slowther et al 2004). Considering that advice, pursuant of CESS deliberation, if accepted, will most likely affect the patient, the patients’ role in that process is uncertain (Agich et al 1991).

Adequate consideration must be given to the “quality of the procedures and processes” and in turn should inform how the decision was reached. Decisions should be made with certainty and be consistent (McLean 2008). When it can be demonstrated that decisions reflect good procedural practices, this will constitute a strong defence of the rational appropriateness of the decision reached (Doyal et al 2009). This reflects procedural justice which strives to promote “moral legitimacy for outcomes”, which is essential to legitimise ethical deliberation provided by CESS. Patient involvement in that process is a necessary component (Ballantyne et al 2017).

There is no indication that patients are a part of the process. Literature suggests that they are not reliably informed about the existence of the CESS, the ground rules of case review, given notice about the review of their case, or provided with the adequate tools to access the service or participate in the process (Wolf 1992; Fournier et al 2009). Contributing factors to a sustainable service is visibility within the organisation and the provision of clear directions for potential users of the service (MacDonald et al 2012: Doran 2015).

Patient participation is diverse globally. Suggested reasons for this are a reflection on “the political and sociological realities of the institutional setting, as well as its conception of and commitment to ideals of patient care and professional
responsibilities” (Agich et al. 1991; Fournier et al. 2009). “Secretive deliberation”, does not lend itself to accord due process, but open honest conversation between all players, does (Daniels 2001).

Advocating patient participation in ethical discussion and deliberation has its opponents, who have concerns pertaining to problematic ethical issues that may present with patient participation in the CESS process (Reiter-Theil 2003; Neitzke 2007; Rari et al. 2009).

The practice of ethic consultation is a balancing exercise, and it is important to provide appropriate respect to patient autonomy, avoiding bias and favouritism to particular stakeholder(s). It has been argued the more involved, patients, become in the ethics consultation, the greater the emphasis, will be placed on respect of their autonomy (Fournier et al. 2009; Reiter-Theil 2003). Others have suggested that it is more likely that the clinicians’ position may be overemphasised, particularly when the majority of the committee members are employees of the institution. This can lead to authoritative physicians, which may cause difficulties for other committee members to formulate an independent unbiased opinion (Forde 2008). Others suggest strengthening patient autonomy should not lead to overemphasising individual interest (Schurmann 2014).

Confidentiality and privacy may be ethically challenging with patient participation. The more the patient is included in the process the more CESS members they will interact with, and the sharing of private details and circumstances could undermine confidentiality. Neitzke (2007) posits there are four reasons why patient participation in the process can undermine confidentiality and privacy (Table 4.3). Neitzke also proposes written informed consent of disclosure of private information from the patient and explicit written confirmation, from the CES providers, to confidentiality, should help resolve some of the confidentiality challenges in ethics consultations.
Table 4.3: Challenges to confidentiality and privacy (Adapted from Neitzke 2007)

<table>
<thead>
<tr>
<th>Challenges to confidentiality and privacy</th>
</tr>
</thead>
<tbody>
<tr>
<td>How to guarantee respect of confidentiality among members, particularly lay members</td>
</tr>
<tr>
<td>How to guarantee confidentiality of the ethics consultation of those involved</td>
</tr>
<tr>
<td>How to ensure non-disclosure of information, by clinicians, irrelevant to the ethics consultation</td>
</tr>
<tr>
<td>Information collected during the process and how to discriminate what can be disclosed</td>
</tr>
<tr>
<td>• to the patient about the doctor</td>
</tr>
<tr>
<td>• to the doctor about the patient</td>
</tr>
</tbody>
</table>

The exclusion of patients suggests, only part of the issue is addressed. Moral deliberation without the patients input, can lead to it being a theoretical activity; a one-sided affair, removed from the “real-life” of those involved. This practice may be acceptable in the case where the purpose of the CESS is to support clinicians in their work e.g. UK (Newson 2009). The process of the ethics consultation should be inclusive of the moral positions, attitudes and convictions of all stakeholders not merely a theoretical process of abstract principles or moral rules (Fournier 2005).

Agich and Youngner (1991) proposed clinical ethic consultation contains a risk of diffusion of responsibility. The legal responsibility for interventions remain with the clinician, the moral responsibility for the advised interventions will be shared among the CESS providers, patients and clinicians. This should promote the notion of “shared decision-making”, of modern medicine.

Ballantyne et al (2017) propose the minimal standards of patient involvement (Table 4.4), but do not advocate their involvement during deliberation, as it may hinder free discussion. They suggest, as CESS mature, further involvement of patients will evolve. The minimal standards satisfy the principles of patient-centred care and due process. Patient involvement in the US CESS is above the minimum standard as they are generally more evolved and mature. For CESS in their infancy or less evolved, the minimum standards of patient involvement are a pertinent starting point.
Table 4.4: Minimum standards of patient involvement in CESS referrals. (Ballantyne et al 2007)

<table>
<thead>
<tr>
<th>Minimum standard</th>
<th>Principle</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient Informed of referral</td>
<td>Respect for the person who may be affected by the decision</td>
</tr>
<tr>
<td>Patient has the opportunity to speak with a member of CESS</td>
<td>Obligation to allow the patient to be heard.</td>
</tr>
<tr>
<td>Informed by CESS of the outcome</td>
<td>Obligation to inform the patient of result</td>
</tr>
<tr>
<td>Opportunity to discuss outcome and how it was reached.</td>
<td>Obligation to inform patient why and how the result was arrived at.</td>
</tr>
</tbody>
</table>

CESS aim to deliberate and advise on complex ethical values in healthcare. Their recommendations must coincide with the values of the institution and must be legal. To ensure fairness and efficiency patient input is required, inclusive of their values and beliefs.

Religious beliefs impact on patients’ healthcare decisions, as does the religious ethos of the healthcare institution. (Table 4.5). The CESS is obliged to afford consideration to such beliefs and the context in which it impacts on the patients’ treatment choices. Similarly, what is allowed and not allowed depending on the religious ethos of the hospital. Determining the patient objective “best interest” may be difficult, as the given value is deeply held and would require a major transformation in the persons belief system and the religious ethos of the institution (Holm 2017). Where treatment is not available in the US, due to the religious ethos of the healthcare facility, patients are advised to go elsewhere for that treatment.
<table>
<thead>
<tr>
<th>Principle</th>
<th>Application</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Dignity of person</strong></td>
<td>Every person deserves equal respect</td>
</tr>
<tr>
<td></td>
<td>An alienable right</td>
</tr>
<tr>
<td><strong>The Social Nature of the Person</strong></td>
<td>The person cannot live or develop to their potential outside of human relationships and community</td>
</tr>
<tr>
<td><strong>The Right to life</strong></td>
<td>Human life is a gift from God</td>
</tr>
<tr>
<td></td>
<td>We are minders of our lives and bodies</td>
</tr>
<tr>
<td><strong>Informed Conscience</strong></td>
<td>Moral conscience flows from dignity</td>
</tr>
<tr>
<td></td>
<td>Persons are bound to inform themselves of the ethical norms and act accordingly to their informed conscience</td>
</tr>
<tr>
<td><strong>Double-Effect</strong></td>
<td>Beneficial and harmful consequences of an action.</td>
</tr>
<tr>
<td></td>
<td>Harmful effects, not wanted, but allowed</td>
</tr>
<tr>
<td><strong>Legitimate co-operation</strong></td>
<td>Applies to the double-effect principle, if act performed by more than one person</td>
</tr>
<tr>
<td><strong>Totality and integrity of the person</strong></td>
<td>All persons must develop</td>
</tr>
<tr>
<td></td>
<td>Use, care for and preserve their natural physical and psychic functions</td>
</tr>
<tr>
<td></td>
<td>Basic capacities, that define personhood, are never sacrificed, unless to preserve life.</td>
</tr>
</tbody>
</table>
Chapter 5

DISCUSSION

CESSs are developing globally and they are most useful when designed to match the ethical concerns of the clinicians within the healthcare facility. The support service offers a just, independent process of resolving ethical dilemmas that uses a transparent and systematic approach to ethical deliberation, an opportunity for education, and professional development in the management of ethical issues by self-reflection, within a multidisciplinary network (Dai et al 2016). Service providers must have the knowledge and expertise to fulfil this role and instil confidence in their potential users. The service must be integrated into the organisation, be visible and retain its autonomy from the organisational governance structure.

The literature demonstrates the heterogeneity of the services provided globally and the benefit of combining models depending on the circumstances. The service must meet the needs of the service users, otherwise it will neither be required or used, and hence there is no agreed ‘best practice’ model. The functions of CESS are also internationally recognised, and priority functions vary from service to service.

Despite their prevalence and evolution, CESS is viewed by some, as an intrusion on the clinicians’ domain and are underutilised. Research has provided many reasons for this, and they have remained consistent over the years.

One of the purposes of CESS is to raise ethical awareness of healthcare workers and promote an ethical environment. CESS providers should have the knowledge and skills to be fit for purpose and in turn should be the educators/resource to promote ethical awareness among clinicians.

The challenge of teaching ethics to healthcare workers has been a topic that has been afforded much literary attention. Ability “to do” clinical ethics, is perceived by some can be achieved by “passive acquisition” or as a “baptism of fire”, others believe it to be “something that’s made up as one goes along” (Dai 2013). Clinical ethics teaches clinicians practical knowledge to produce ethically knowledgeable care workers. The modern standard of care requires a working knowledge of ethical subjects, such as informed consent, truth telling, confidentiality, end of life
decisions. Advice given must conform with the national legislative and bureaucratic healthcare facility, frameworks. Patient expect technical proficiency from their providers and the ability to recognise and respond to ethical issues (Siegler 2011). For clinicians to meet this demand, education in clinical ethics is vital to promote ethical awareness and culture at the bedside.

By providing education and training to service users, the CESS becomes a proactive service as opposed to a reactive service. The intention of the Hub and Spokes model supports this. Early detection of potential ethical dilemmas can be dealt with before they require reactive interventions. MCD provides knowledge of basic ethical principles and allows clinicians to find their own answers which will help them in future situations. Similarly, strategies that involve interdisciplinary ethics rounds, raises clinicians’ awareness, not only of the CESS existence but awareness of potential ethical issues and diffusion of such issues before they escalate (Csikai 1998). Recognising potential ethical issues is not inherent in everyone. Raising one’s ethical awareness can promote recognition of potential ethical dilemmas.

Words, such as “moral” and “ethics” have a negative association with healthcare workers, and a service providing such support is deemed too removed from the “work floor” and deemed “fairly heavy” (Dauwerse 2013). Ethics can falsely give the appearance of being a complex subject, but in clinical terms, it amounts to forming a judgement based on the available facts, assessing the relative risks, burdens and benefits of different courses of action (Macdonald et al 2012).

CESS being proactive, fit for purpose, visible and accessible can dispel misconceptions about ethics. The service providers have the responsibility to provide the service that fits the needs of their potential users, setting down the terms of reference of the service provided and never overreach the boundaries of their remit. Clear simple instructions of whom, how and why the service can be accessed is paramount for its utilisation. Evaluation of the service, although a challenging exercise, provides for its validation and worth within the institutional structure. It also allows for service improvement and evolution.
Chapter 6

RECOMMENDATIONS AND CONCLUSIONS

Information about the functioning of CESS in Ireland is difficult to assess. The purpose of the project was to investigate the prevalence of CESS globally, in order to propose a service to fit the needs of a specific healthcare facility. Presently, there is a structure in place providing clinical ethics support, it provides reactive interventions. Education for employees is not provided for. Education promotes awareness. Promotion of ethical awareness and culture, within the healthcare facility, requires ongoing education.

Further research is warranted. Firstly, to assess the ethical awareness and educational needs of the healthcare providers. Secondly, to determine the model(s) of education required, to best meet learning needs. Recommendation of setting up a CEC, may be premature, in view of the information gleaned from literary investigation and peer discussions. Concentrating on the foundations of ethical awareness through education, forums and ethical rounds, should lead to a more explicit structured CESS framework in the future, by having implicit CESS structures grounded in the healthcare facility’s service provision framework. For implicit structures to be utilised, organisational approval and support is a must. Care is required to ensure that implicit CESS is not regarded as another bureaucratic tool. It should be a “bottom-up” approach.

The future of Irish CESS will be an era of many challenges. Legislation and guidelines are being planned which will impact healthcare providers. The two most topical are legalisation on abortion and advance healthcare directives (AHD).

The Protection of Life During Pregnancy Act 2013 defined the circumstances and process within which abortion in Ireland could be legally performed. The referendum in May 2018 broadens the legal availability in Ireland. Clinical guidelines and new regulations are pending prior to the writing of new legislation. The Act of 2013, provided for conscientious objection to performing the procedure, by obligating the hospital to transfer the pregnant woman to a facility that would perform the procedure necessary. CESS may be called upon to advise in situations, where although the procedure is deemed legal, the ethos of the hospital may not allow it.
The Assisted Decision-Making Act 2015, part 8, provides for AHD. The Code of Practice regarding AHD is presently in the consultation phase. When this code has been approved, the CESS may be required to advice upon issues regarding the validity of the directive. Although, AHD are not legally binding, consideration must be afforded the patient’s choices during the decision-making process regardless of the decision-makers values or beliefs. The 2015 Act provides for conscientious objection and the proposed guidelines, outlines the process required. CESS advice may be sought to advice on conscientious objections by care providers, particularly in refusals of treatment and patient capacity.

Manning and Smith (2002), suggested that from proven evidence, CESS was here to stay and how they develop and function would impact on the quality of healthcare. Nelson et al (2010), stated, recurring ethics issues impact negatively on both the quality of patient care and the culture of the healthcare organization. Globally, CESS, are established and maturing or are at the beginnings of development and evolution. Evidentially, in Ireland, CESS is a minority but occupies the fortunate position of learning from how the service has evolved. Owing to the litigious society of today, resolution of clinical ethical conflict should begin early to avoid escalation. Ethical awareness of healthcare providers is paramount and beneficial for both service providers and users. CESS, tailored to the needs of the potential users, is best placed to provide proactive support and interventions.
References:


Brody, H and Thomlinson T (1986). ‘Ethics in Primary Care: Setting aside common misunderstandings’. Primary Care,13 (2): 235-240


Dartel, H. van (1998). From ethics committee to steering committee. On the implementation of moral deliberation with the quality policy of healthcare institutions. CELAZ-/Nederlandse Zorgederatie, Utrecht, the Netherlands


Doyal, L and Gillon, R (1998). ‘Medical ethics and law as core subject in medical education. A core curriculum offers flexibility in how it is taught- but not that it is taught’. *British Medical Journal*, 316: 1623-1624


Forde, R and Ruud Hansen, TW (2014). ‘Do organisational and clinical ethics in a hospital setting need different venues?’ Healthcare Ethics Committee Forum, 26:147-158.


Gillon, R (2003). ‘Ethics needs principles-four can encompass the rest- and respect for autonomy should be first among equals’. *Journal of Medical Ethics*, 29:307-312.

Giron v. Baylor University Medical Centre (2007) No. 06-02257-M (298th Judicial District, Dallas, Tex.) on appeal, No. 05-09-00825-CV (5th Ct. App.)


Hoffman, DE and Tarzian AJ (2008). The role and legal status of healthcare ethics committees in the United States. [https://respositoty.library.georgetown.edu](https://respositoty.library.georgetown.edu)


In R v. Intstman [1893] 1 QB 450


Neustadter v. Holy Cross Hospital of Silver Spring, 28 No. 10 Verdicts, Settlements & Tactics art. 19 (Oct 2008).


President’s Commission for The Study of Ethical Problems in Medicine & Biomedical & Behavioural Research, Deciding to Forgo Life Sustaining Treatment: Ethical, Medical and Legal Issues in Treatment Decisions 159 (1983) at pp169


Singer, P., Pellegrino, ED and Siegler M (2001). ‘Clinical Ethics Revisited’. *British Medical Council Medical Ethics*, 2(1)


The Ethox Centre (2004). *A practical guide for clinical ethics support*. 1st edn. Published by the Ethox Centre, Department of Public Health and Primary Care, University of Oxford, Oxford OX3 7LF


Wilson, RF (2002). ‘Rethinking the shield of immunity: Should Ethics Committees be accountable for their Mistakes?’ *Healthcare Ethics Committee Forum*, 14:187-188.

**Bibliography**


Cesta, T (2011). ‘Every day, the case management department faces multiple dilemmas over ethics; An ethical dilemma found in a case study; Solution: committees on organisational ethics’. *Hospital Case Management*, 2011:118-121.

Chalmers, I and Lindley, R (2000). *Informed consent in medical research*. The role of effective communication in obtaining informed consent: Double standards in


Moss, AH and Glover, JJ. West Virginia Network of Ethics Committees: Starting an ethics committee, questions to consider and first steps. Available at: http://www.hsc.wvu.edu/chel/wvnec/index.htm.


Osborne, LW and Martin CM (1989). ‘The importance of listening to medical students’ when teaching them medical ethics’. Journal of Medical Ethics, 15: 35-38


