Are you thinking of establishing a Clinical Ethics Support Service? Lessons from the first 18 months of a new Australian service – A case study

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Abstract

Background

Although the importance of clinical ethics in contemporary clinical environments is established, development of formal clinical ethics services in the Australia health system has, to date, been ad hoc. This study was designed to systematically follow and reflect upon the first 18 months of activity by a newly established committee, to examine key barriers and facilitators to establishing a new service in an Australian hospital setting.

Methods: how the study was performed and statistical tests used

A qualitative case study approach was utilised. The study gathered and analysed data using observations of committee meetings, document analysis of agendas and minutes, and semi-structured interviews with committee members to generate semantic themes. By interpreting the thematic findings in reference to national capacity building resources, this study also aimed to provide practice-based reflections for other health agencies.

Results: the main findings

An overarching theme was a strong shared commitment to supporting clinicians with difficult decisions about patient care, and with navigating difficult discussions with patients and families. The role of the new committee in providing a pathway to raise with senior managers system-wide issues experienced by clinicians was also a key theme. Consumer and community participation in the new service remained a challenge in spite of strong clinical engagement, as did unresolved governance issues and a need for clearer policy relationship between the committee and the organisation.

Conclusions: brief summary and potential implications

Considering these themes in relation to the national capacity building resources, three areas are likely to require ongoing negotiation and further development: the clinical ethics committee as link between workforce and Executive; incorporating consumers and patients; and ethical reasoning. There is scope to increase clarity for the committee on its role at a governance and policy level, and on how to engage consumers, patients and families in the practices of the service. The capacity of the committee to reflect on complex cases may be enhanced by explicitly discussing different ethical frameworks and ways of deliberating.

Introduction

At a time when health systems are under great pressure, a clinical ethics lens is valuable in addressing contemporary community expectations about access to and delivery of health care, and supporting health professionals to deliver technologically and ethically complex medicine.¹ Although the importance of clinical ethics in a contemporary clinical environment is established, its practical application in
Australia in the form of formal clinical ethics support services (CESS) has been ad hoc, with a limited number of established CESS in the health care system.\(^2\) In contrast to northern America and many northern European countries where such services are well established, in some cases for over twenty years,\(^3\)–\(^5\) it was not until 2015 that the Australian Health Ethics Committee (AHEC) of the National Health and Medical Research Council (NHMRC) published a consensus statement\(^6\) and resource manual designed to support more systematic provision of clinical ethics support in Australian health care organisations.\(^1\) This capacity-building initiative complements the recent inclusion of CESS as a requirement of formal hospital accreditation guidelines.\(^7\)

Internationally, despite CESS being well established, empirical studies that critically examine how these services work in practice are limited; descriptive studies about CESS prevalence, structure, composition and function have instead been prominent.\(^8\) Where formal evaluation has been conducted, surveys using the domains of “satisfaction, ethicality (ethical acceptability), education and conflict resolution” have commonly been used.\(^5\) Multi-centre US and national Norwegian survey-based studies of CESS have reported high levels of stakeholder satisfaction.\(^9\),\(^5\) While such study designs provide some measure of effectiveness and comparability between CESS, it is acknowledged that these data tend to provide ‘thin descriptions’ of the content discussed by CESS,\(^8\) and reveal little about how CESS operate in practice and the effectiveness of these practices and processes. Several recent studies have turned to qualitative approaches to gain deeper understandings of practices involved in CESS and to expand methodological approaches for assessing the quality of a CESS.\(^5\),\(^8\),\(^9\) These qualitative studies have provided insights about the nuanced ways in which these services work for stakeholders, including differences in perspectives, and provided rich analyses of what quality in clinical ethics consultations and deliberations looks like.\(^5\),\(^8\),\(^9\) In the recent study by Kana et al,\(^8\) two domains of quality (satisfaction and value) were found to be important for health professionals who had used ethics consultation services, with qualitative analysis emphasising how the process of consultation created valuable moral space, promoting thoughtful and ethical responses to dilemmas in patient care.\(^8\) The importance of stakeholder participation (i.e. patients, relatives and professionals), even when their presence brought tension and conflict to the consultation and possible dissatisfaction with outcomes, has also been highlighted as a key contributor to well-functioning CESS.\(^5\)

Building on these recent studies, this research was designed to systematically follow and reflect upon the first 18 months of activity by a newly established CESS, examine the key barriers and facilitators to establishing a new service in an Australian hospital setting (at a time when the COVID-19 global pandemic emerged), and provide direction to the organisation on how to further develop and improve the service. By further interpreting the empirical findings in reference to the foundational NHMRC clinical ethics capacity building resources,\(^16\) this study also aimed to provide practice-based reflections for use by other health agencies that may be interested in developing their own CESS.

**Methods**
Study design and setting

To gain in-depth understandings of how a local clinical ethics service developed in a challenging and complex environment, a qualitative case study approach was utilised. Case study designs are particularly useful to facilitate the exploration of complex phenomena within a natural setting through the use of multiple research methods. Taking a pragmatic orientation, the study gathered and analysed data using observations, document analysis, and semi-structured interviews to generate semantic themes reflecting an understanding of how this CESS established itself within its local health network setting, and to identify the key enablers and challenges in developing the capacity of this new CESS. Data were gathered between May 2020 and December 2021 and were confined within the newly established Clinical Ethics Committee (CEC) in a large Australian metropolitan local hospital network serving a population of almost 500,000, with several centralised regional tertiary and quaternary clinical services. This CEC was established in response to the emerging COVID-19 pandemic in anticipation that clinical ethics would be a key aspect to delivering ethically justifiable health services at this time. The NHMRC consensus statement and resource manual were used to guide the development of the new committee. The committee's membership included consumer advocates and representatives, a variety of senior clinicians, representatives from the organisation's senior management including in-house legal counsel, First Nations representatives, university academics, non-health-care public servants, and a health ethicist. The research team included two partner investigators who were both committee members. To avoid a conflict of interest, these partner investigators did not have access to primary data from interviews (neither audio nor transcripts), but were involved in analysis and interpretation once initial themes were generated.

Recruitment

Given the bounded and small sample in this case study, participant recruitment included several layers of informed consent. First, permission was sought from all CEC members and occasional meeting attendees for a researcher to observe the committee meetings in real time. Potential participants were advised that where informed consent was not provided by all, the researcher would not observe the meeting but instead have access to the agendas, minutes and supporting documents (redacted for privacy) of the committee meeting, with consent of the chairperson. Second, all committee members and staff who had engaged with the committee were invited, via the secretariat to the committee, to participate in a semi-structured interview. It is noteworthy in terms of sample generation, that although clinical staff who had engaged with the committee (through case review consultations or providing expert advice) were invited by the secretariat to participate in the research, none followed up this invitation. Participant characteristics are not detailed because providing detail about discipline, age, gender, or seniority/years of practice could compromise participant anonymity.

Patient And Public Involvement
There was no patient or public involvement in the design of the study. The committee forming this case study included membership representation from consumers and community, and as such they were invited to participate in the study. The study findings were presented to the consumer and patient advocate reference group at the local health network and their feedback, including practice-focused recommendations, are now being considered and actioned by the committee.

**Data Collection And Analysis**

Data collection began with a qualitative researcher (EH) observing the CEC meetings from May 2020 to December 2021, using Silverman’s approach to inform guiding questions: What are people doing? What are they trying to accomplish? How exactly do they do this? What assumptions do they make?\(^{13}\) Observations of these online meetings were recorded on a template (see supplementary table 1), which formed the basis of reflective field notes generated by the researcher and discussed by the team. These reflective notes were supplemented by a review of committee meeting agendas, minutes and supporting documents. Observations were not extended to case review consultations performed by the committee as the team did not want to further burden patients or their families by asking for their consent to participate in the study. The CESS tried to minimise the research team’s exposure to patients’ data by only providing case consultation meeting notes, which were redacted to decrease identifiability. This meant that the researchers had some access to non-identifiable patient data as necessary to study the work of the committee. Preliminary learnings and themes generated from reflexive thematic analysis\(^ {14}\) of data from this phase informed the development of questions for semi-structured interviews with committee members, conducted between August and October 2021 by EH. The questions focused on the experiences and expectations of the committee, the main achievements and challenges for the committee, the processes of the committee (including deliberation and how the representation of views were managed in meetings), and its place within the organisation (see supplementary table 2 for interview schedule). The interviews were conducted in person or via telephone or video teleconference, according to participants’ preferences. All interviews were digitally audio-recorded and transcribed verbatim.

The analysis of interview data was informed by thematic analysis\(^ {14}\) and conducted using NVivo 12 software (QSR International Pty Ltd, Doncaster, Victoria, Australia). Interview transcripts were read and re-read to enable immersion in the data. Initially, semantic inductive coding\(^ {12}\) of two interviews was conducted by two researchers (EH and JEd), who worked collaboratively to develop thinking about codes and patterns within the data. Coding of all interview data was then undertaken. Preliminary generation of themes was conducted through reflective discussion between two researchers (EH and JEd), to challenge thinking, build depth to the themes and enhance rigour. Discussions about emerging themes then occurred with all researchers, including the partner investigators, until consensus about the themes was reached. The findings were presented back to the CEC to encourage their reflections on whether the themes resonated with the collective experience of the committee, with some subsequent refinement of the theme labels and descriptions.
Findings

Observations of committee meetings occurred from June 2020 through to December 2021 (9 meetings), document analysis of meeting agendas and minutes for this same time period was undertaken, and semi-structured interviews with 12 participants were conducted. The overall thematic map of findings from these data collection phases is shown in Fig. 1.

An important overarching theme identified was the strong commitment to supporting clinicians, and a key contributing factor to this was a desire by many on the committee to support clinicians who face clinical and moral complexities in their work. There was general agreement that a key role of the CEC is to support clinicians with ‘tricky’ and ‘difficult’ clinical decisions about patient care, with observations including:

Supporting teams when they're faced with the cases that haunt you.

and

I thought it was better that we influence tricky decisions than the poor people at the coalface ... the RMO [resident medical officer] or registrar at two o'clock in the morning deciding who got the last ventilator.

Several participants noted that their decision to nominate for the new committee was driven by a desire to support their peers through the COVID-19 pandemic. Another contributing factor to this overall theme was the role of the committee in highlighting systemic issues within the organisation. It was widely recognised that the CEC provided a new forum and pathway to raise with senior managers system-wide issues that could be usefully clarified with an ethical lens:

[clinicians are] starting to use us a little bit more as a resource for the really complex cases, and also as a way of highlighting some of the system issues that don't have a pathway to management particularly well at the moment.

and

It's really important that even if you resolve the issue, we still talk about these because then it's documented ...it's flagged as a recurring concern, and this is something the organisation needs to work to address.

A further contributing factor identified within this overall theme of a strong commitment to supporting clinicians was supporting clinicians in negotiating care with patients and their families. Relationships between clinicians and patients and their families are subject to the expectations of consumers and their families, and in the contemporary health setting, where community members are encouraged and often empowered to advocate for themselves, it was understood that clinicians may need organisational support in these negotiations.
[When] ... it’s like, “Well, I don’t trust you. You gave me the wrong advice and you’re not listening to me. I want this and you’re not letting me have it.” Whatever it is, then that’s really difficult for clinicians.

Many committee members expressed the desire to ‘be there’ for their colleagues and acknowledged that because the CEC sits within an established formalised governance system, there is the potential to respond to their colleagues’ needs at an organisational level. As such, there was a strong shared commitment to developing a well-functioning forum, linking the clinical ethics needs of staff to senior management.

I think it’s very credible in terms of the breadth of clinical expertise as well as Executive buy-in....

and

I’ve been on many committees where attendance is poor, engagement is poor, pre-reading, sharing, that doesn’t happen. That’s not this Committee. This Committee has an energy and a vitality and a commitment and an interest that is just fantastic.

Although there was strong shared commitment to a well-functioning CEC, three further themes related to tensions and unaddressed issues that require attention to extend the clinical ethics capacity of the CEC and the organisation. The first related to an unresolved governance and policy relationship between the CEC and the organisation. There were divergent views within the CEC about whether its role should be to influence or contribute to the wider policy agenda of the organisation. To date, the main focus of the CEC has been case review, but beyond that direct and specific support for clinicians, for some members it was ‘still ambiguous as to what we’re supposed to be contributing to’. This stemmed from a lack of clarity about broader questions of governance and purpose. Despite universal acknowledgement of strong Executive support, questions still to be resolved included: What role does the committee have in policy development? What expectations does the organisation’s Executive have of the CEC? How can the outcomes of the case studies or minutes be used by the organisation beyond case review, to improve clinical ethics reasoning?

We’ve created our own ... pathway or decided how we think, we as a Committee, we could influence or improve things. But I’d be interested in whether that aligned with the institution’s goals when we were created.

A further key theme highlighted ongoing uncertainty about how to effectively engage consumers. Despite a widespread philosophical commitment to involving patients, their families, and the wider community (consumers and other stakeholder agencies) and strong consumer advocacy throughout CEC discussions and deliberations, there remained uncertainty about some of the practical application of this intent. This theme connects closely to the unresolved governance issues, and raised the following questions: How can a wide range of community voices be best represented on the CEC? What are the mechanisms for consumers and their families to initiate a clinical case review, and how should consumers be represented at a case review meeting? Further, how should the CEC report advice that is generated by a clinical ethics
case review? In what form and where should such advice be stored, taking account of the need to balance the need for transparency of committee processes, while ensuring confidentiality of consumer information?

There was a lot of debate about who would document that opinion [generated by the committee's case review process], where would it sit, would it actually be available to the general patients still, and their families through sort of the rights to freedom of information?

and

I just wonder whether [we need] a citizen, who is not an advocate for patients and who's not a clinician.

Many of the CEC members acknowledged that translating the CEC's intent to involve consumer and patient voices into practice was challenging and required careful development of appropriate policies and procedures by the CEC and the wider organisation.

A final theme related to a need for explicit discussions of different ethical frameworks and ways of deliberating. Although some members didn't see the need for further theoretical discussion of ethical frameworks, others argued that in order to improve ethical deliberations, members should be explicit about the ethical approach being drawn upon in their reasoning, and there should be opportunities to discuss alternative ethical approaches.

I think it’s really important to think about different ethical approaches and that people can come to the same or different decisions and still be coming from an ethical perspective, but perhaps a different model of ethical reflection.

To date, there has been limited explicit discussion about the different substantive ethical orientations that members may be bringing to deliberation (e.g., consequentialist or deontological positions), as well as the procedural or deliberative frameworks that could be employed in deliberation, and this was acknowledged as a potential source of tension or misunderstanding between CEC members.

Discussion

So, what might a prospective Clinical Ethics Committee expect to grapple with in its initial stages of development? The NHMRC Consensus Statement and Resource Manual (henceforth ‘Guidelines’) were used as guides in the establishment and development of the CEC, and several of the key themes discussed above relate to elements of this resource that we recommend prospective committees consider closely. In an established tertiary health setting, where case referrals will emerge from the predictable needs and capacities of the workforce and organisation, we consider the following three areas to be likely domains of negotiation and development: the CEC as link between workforce and Executive; incorporating consumers and patients; and ethical reasoning.
The CEC as link between workforce and Executive

Having experienced difficult or complex medicine, and wanting to support their colleagues experiencing the same, presents an important motivation for those clinicians who nominate for CEC membership. However, members place value in assisting colleagues with specific cases and in benefitting the organisation, by improving its ethical culture and highlighting systemic issues that may require Executive attention and resolution. Often, case consultation requires attention to this linking function: as the Guidelines note, a final question to ask in the consultative process is: ‘are there any individual, organisational, systemic, educational or policy issues to follow up as a result?’ (‘Tools for consultation and case analysis’, Section 4.2, p. 21). Our findings reinforce the relevance of this question.

The CEC is viewed by its members as a specific and independent forum in which the medical, nursing, and allied health workforce can seek the support of colleagues, which, by virtue of being integrated in the organisational structure, also provides the opportunity for the organisation to respond to unaddressed patient and workforce needs. A ‘well-functioning’ CEC, then, will have direct and strong links to and support from the Executive and will have considered closely where it fits in the governance structure. Where CEC members come together with a shared commitment to a well-functioning and useful CEC, without a clear sense of how their work links the day-to-day of ‘difficult medicine’ to governance and policy, member engagement may falter. Similarly, members who prefer practical clinical discussion with clear outcomes may experience frustration if operational and process questions are not resolved quickly. Section 3.1 of the Guidelines (‘Governance, accountability and reporting’, p. 13) provides a useful starting point for thinking through some operational issues in the form of specific process questions relating to, for example, the storage of case notes, engagement with the hospital community, and communication with Executive. Answers to these questions will flow from an understanding of the CEC as providing a crucial link between the day-to-day of ‘difficult medicine’ and more overarching concerns of governance and policy.

Involving consumers and patients

When developing a CEC, the question of how to incorporate consumer, community, and patient and family voices is critical. The Guidelines do not emphasise community representation as a necessary component of committee membership (‘Membership considerations’, Section 2.8, p.11), however, there is a strong trend towards incorporating consumer voices in health settings and the membership of the CEC being studied also considered it a priority. Recognising the importance of membership from outside the health service workforce raises key questions about the nature and purpose of consumer representation, with answers potentially depending on the specific setting and goals of the CEC. What is the difference between a community voice, a consumer voice, and a patient voice, and do all of them need to be represented? If part of the purpose of the CEC is to support clinician-peers with difficult medicine, in what ways is support extended to patients and families? How might a patient, their family, or their advocate raise and/or be involved in their own case consultation? What are members’ expectations about what a consumer voice is or does in practice, whose voice it should be, and when and where it should be heard?
These questions can be contentious, sensitive, and difficult to resolve, and may require periods of reflection and adjustment as a committee matures.

**Moral reasoning**

The Guidelines (‘Tools for consultation and analysis’, Section 4.2, p.18) note that diverse formal approaches to ethics consultations share an aim to ‘widen the sources of moral input’, to foster reflection on one’s own and others’ moral views and biases, and to foster learning from shared experience. Due to the predominantly clinical nature of a CEC, one might expect that membership will be primarily clinical, with members who by training and practice are comfortable with principles-based, linear approaches to ethical dilemmas. However, given the diversity of disciplines possibly represented on the CEC, as well as the presence of community, pastoral, and cultural representatives, case deliberation may involve discussion across substantive ethical positions (e.g., care or relational ethics, virtue ethics, or religious ethics); furthermore, different deliberative tools and processes may also be prioritised by some members. Being explicit about the features and orientations of different approaches to ethical reasoning may help avert any misunderstandings arising within the committee. In addition, explicit discussions of alternative ethical frameworks and ways of deliberating may provide insights for committees both in negotiating differing viewpoints and in incorporating ethical insights from a widened range of sources relevant to the healthcare setting. To foster such discussions, prospective committees may wish to actively recruit members with formal ethics training (e.g. clinical ethicists, academic ethicists), as noted in the Guidelines (‘Membership considerations,’ Section 2.8, p.11), and explore the full range of deliberative frameworks identified by the Guidelines (‘Tools for consultation and analysis’, Section 4.2, p.19).

Finally, several limitations in the study design implementation should be acknowledged. Although the study aimed to include data from consumers and staff who had interacted with the CEC, the researchers were unsuccessful in recruiting participants from this stakeholder group. This limits the range of experiences and perspectives included to only the committee members and it is acknowledged that a future priority for the committee will be to evaluate the quality of this new service from a wider perspective. In relation to transferability of findings, it is acknowledged that, while this case study design allowed in-depth exploration of many processes operating in the specific context of this committee in a particular health organisation, to ensure anonymity, contextual details about the organisational setting have been limited in the reporting of the study which may affect the ease of transferring the findings to a different health context. In relation to understanding the impact of COVID-19 on this committee’s development, it is important to acknowledge that as Australia closed its international borders for 2020-21, the impact of COVID-19 on the health system was different to many other countries, and although the system was severely stressed, it was not overwhelmed, and care rationing was not as much of a problem here as it was in some European countries or the US.

**Conclusion**
The study has provided the opportunity to describe the challenges and enablers which accompany the establishment of a CEC in real time. Consumer and community participation remain a challenge in spite of strong clinical engagement. Our findings provide a pathway for subsequent deliberate development of CECs, particularly in terms of ensuring the relationship between the CEC and senior management is made explicit, and that ethical frameworks to guide and support ethical deliberation and advice formation are introduced. Further opportunities exist for developing resources to support consumer and community participation.

**Abbreviations**

AHEC  
Australian Health Ethics Committee  
CEC  
Clinical ethics committee  
CESS  
Clinical ethics support services  
NHMRC  
National Health and Medical Research Council

**Declarations**

**Ethics approval and consent to participate**: This study received ethics approval from the Central Adelaide Local Health Network Low Risk Ethics committee (Reference number 13025). Written informed consent was obtained from all interviewees. All procedures were performed in accordance with the National Health and Medical Research Council of Australia's National Statement on Ethical Conduct of Human Research.

**Consent for publication**: Not applicable

**Availability of data and materials**

The datasets generated and/or analysed during the current study are not publicly available due to the small number of participants in the study who may be at risk of being identified by the in-depth interview data. Summary results data are available from the corresponding author on reasonable request.

**Competing interests**

The authors declare that they have no competing interests.

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Authors' contributions

EH was involved in research design and planning, data collection, data analysis, results synthesis, manuscript drafting and review, JEd was involved in data analysis, results synthesis, manuscript drafting and review, GH was involved in research design and planning, data analysis, results synthesis, manuscript drafting and review, JEl was involved in research design and planning, data analysis, results synthesis, manuscript drafting and review, DC was involved in research planning, results synthesis, manuscript drafting and review, SM was involved in research planning, results synthesis, manuscript drafting and review, TM was involved in research planning, results synthesis, manuscript drafting and review, GO was involved in research planning, results synthesis, manuscript drafting and review.

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Drew Carter and Stewart Moodie are co-authors but were not part of the research team.

Authors' information (optional)

Supplementary files

Supplementary Table 1: Observation template for committee meetings.

Supplementary Table 2: Interview questions.

References


**Figures**
Figure 1

Final key themes generated by analysis, including relationships between themes.

Supplementary Files

This is a list of supplementary files associated with this preprint. Click to download.

- SupplementaryTable1.pdf
- SupplementaryTable2.pdf