

Paediatric clinical ethics in Australia and New Zealand: a survey.

#Note: Instructions in brackets will not be seen by participants, they are to inform the construction of the online survey by the investigators.

Kesselheim and colleagues kindly shared their survey instrument with us, for use as a guidance document to develop this survey to suit the Australasian context¹.

Informed Consent Page

Purpose. The purpose of this study is to ascertain information about the presence and function of clinical ethics services at tertiary paediatric hospitals in Australia and New Zealand. We would like to invite you to participate in this study. The person completing the survey should be the most senior person available within the ethics service at your hospital, such as the Chair of the Clinical Ethics Service. If there is not a formal clinical ethics service then we suggest the Executive Director of Medical Services would be appropriate.

Risks. There is no risk to any individual or facility by participating in this study. The only burden is the time required to complete the survey. The survey should take approximately 20 minutes to complete.

Confidentiality and anonymity. All responses are non-identifiable and no person or service will be identified. This survey is service based, and will not enquire into individual patient cases so there is no risk to patients from any institution that participates. While no services will be named in our research, it may be possible that people within the paediatric and ethics communities in Australia will recognise hospital based services based on prior knowledge of these services. In this sense, there may be a lack of anonymity for participating services. Another consideration is that when using an overseas owned online survey provider, information is stored overseas and is subject to the laws and legislation of the country in which it is stored, which may be different to Australian laws and legislation. As such, confidentiality of data entered into online surveys cannot be guaranteed by the study team.

Expected benefits. The key benefit of the study is that it will describe current clinical ethics practice in Australia and New Zealand. This information will be of use in comparisons with other international regions and will provide useful background information for further work in service development. The authors aim to publish the study's findings in a peer-reviewed journal. Your facility will receive a copy of the research paper upon completion.

Ethics approval, and contact person. Ethics approval was granted by the following HRECs: Sydney Children's Hospitals Network (LNR/15/SCHN/428, 18/11/2015), Women's and Children's Hospital Network (HREC/15/WCHN/194, 11/03/2016), Queensland University of Technology (1500000971, 13/11/2015), Children's Health Queensland

¹ Kesselheim J, Johnson J, Joffe S. Ethics consultation in children's hospitals: Results from a survey of paediatric clinic ethicists. *Pediatrics*. 2010;125:742-6.

(HREC/15/QRCH/171, 15/09/2015). Formal HREC approval was not required by Monash Health, Royal Children's Hospital or Princess Margaret Hospital for Children.

If you have any questions or require further information about the project, please contact Emma Cottle, the Principal Investigator of the research team (emma.cottle@griffithuni.edu.au).

Do you agree to complete this survey?

- A) Yes (Proceed to Section A)
- B) No (Proceed to final page)

Section A

The following questions seek general information about how your hospital manages clinical ethics issues.

A1. Does the facility at which you work have access to a formal clinical ethics service?

- A) No (Proceed to A2, then final page)
- B) Yes (Proceed to Section B)

A2. How are clinical ethics issues handled at your facility?

Please select all that apply.

- A) Ad hoc multidisciplinary meetings
- B) Discussion with hospital executive
- C) Discussion with legal team
- D) Second opinion from other colleagues
- E) Other.

Section B

The following questions ask general information about your clinical ethics service

B1. Is your clinical ethics service specifically for use by the children's hospital or do you access a service that is part of a larger area health service?

- A) Clinical ethics service specifically for the children's hospital
- B) The children's hospital has access to an area health based service

B2. What services are provided by your clinical ethics service?

Please select all that apply.

- A) Education and training
- B) Original research about ethical issues (ie **not** including HREC review process for research generally)

- C) Policy and guideline development
- D) Other

B3. Which of the following education and training programs are run by your clinical ethics service?

Please select all that apply.

- A) Junior doctor (intern, resident, registrar) teaching
- B) Nursing teaching
- C) Allied health teaching
- D) Specific ethics curriculum run in addition to other clinical teaching programs
- E) Contributing to existing departmental education
- F) General education e.g. Grand Rounds
- G) The service does not provide any education or training

Section C

The following questions are about your role in your hospital's clinical ethics service.

C1. What role do you have within your hospital's clinical ethics service?

Please select all that apply.

- A) Chair of Clinical Ethics Service
- B) Clinical Ethics Fellow
- C) Clinical Ethicist
- D) Executive role requiring involvement with clinical ethics issues (eg Executive Director Medical Services)
- E) Other

C2. What training did you receive to perform your ethics role?

Please select all that apply.

- A) PhD in bioethics, clinical ethics or moral philosophy
- B) Masters in bioethics, clinical ethics or moral philosophy
- C) Clinical Ethics fellowship
- D) Intensive Bioethics mini-course
- E) Ethics certificate program
- F) Mentoring with an experienced ethicist
- G) Experience on the job
- H) Required reading in an ethics manual or resource text
- I) Formal training in mediation
- J) Tertiary qualification in theology
- K) Other

C3. What percentage of your professional time is spent engaging in each of the following work activities?

Please place the proper percentage in each blank so that the sum is 100%.

Patient care	_____
Clinical ethics consultation	_____
Hospital/Organisational ethics, including development or review of institutional ethics policy	_____
Clinical research	_____
Laboratory research	_____
Ethics/Philosophy/Law research	_____
Administration	_____
Teaching/Education	_____
Other	_____

Section D

These questions are about the way that clinical ethics case consultations are performed at your children’s hospital. Please consider only formal ethics consultations as opposed to informal “corridor” consultations.

D1. Does your service provide clinical ethics case consultations?

- A) Yes (Answer the rest of section D)

B) No (Skip to Section E)

D2. When conducting clinical ethics case consultations, how often does your clinical ethics case consultation service do each of the following:

	Never	Rarely	Sometimes	Usually	Always
Meet with more than 1 member of the clinical team					
Notify the patient and/or family about the consult					
Meet with patients and/or families					
Include the patient and/or family in the case meeting/discussion					
Enter a written report of the consultation into the patient's medical record					
Provide a written report of the consultation to the clinical team					
Provide a written report of the consultation to the patient, family, or both					
Follow up with the participants after the consultation is complete to receive clinical updates					
Follow up with the participants after the consultation is complete to receive feedback on the consultation					
Participate in formal review of clinical ethics consultations for educational and/or quality assessment purposes					

D3. Does your clinical ethics case consultation service have a written policy or procedure about how to conduct a consult?

- A) Yes
- B) No (Skip Question D4)
- C) Don't know (Skip Question D4)

D4. Which of the following is addressed in this written policy or procedure about how to conduct a consult?

Please check a box for each row of the table.

	Yes	No	Don't know
Who can request a consultation			
How to contact the ethics service			
How the ethics service responds to requests for consultation			
How the case meeting/deliberation is conducted			
Who is included in the consultation			
Methods for notification of affected persons			
Protection of patient confidentiality			
How the consultation is documented			
Identification of patient groups/situations that trigger an automatic consultation			
How the service handles complaints			

D5. Who can refer a case for clinical case consultation?

Please select all that apply.

- A) Doctors
- B) Any clinical staff member
- C) Patients
- D) Parents or family members
- E) Members of the hospital administration or executive

D6. Does your clinical ethics case consultation group provide specific recommendations (whether considered binding or not) or is the goal solely to facilitate clinical team decision making?

- A) Provides specific recommendations.
- B) Solely facilitate clinical team/patient decision making.
- C) Combination of the above depending on case type.

D7. How quickly can the service respond to a referral?

Please select one.

- A) Within 1 hour
- B) Within 24 hours
- C) Within 48 hours
- D) Within 48hours – 1 week
- E) Within 1-2 weeks
- F) More than 2 weeks

D8. In the last 12 months, how many formal ethics consultations did your ethics service conduct?

Please select one.

- A) 0
- B) 1-5
- C) 6-10
- D) 11-15
- E) 16-25
- F) 26-50
- G) More than 50

D9. How does your clinical ethics service provide clinical case consultations?

Please select one.

- A) Clinical ethics committee or other response group (Skip to E2)
- B) Individual Ethicist (Answer Section E)

- C) Either clinical ethics committee or individual ethicist, depending on case type
(Answer Section E)

Section E

This section is about the training of the Clinical Ethicist and/or make up and training of the clinical ethics case consultation group members.

E1. In the job description for the Clinical Ethicist at your hospital, what qualifications are essential?

Please select all that apply.

- A) PhD or Master in bioethics, clinical ethics or moral philosophy
- B) Clinical Ethics fellowship
- C) Intensive Bioethics mini-course
- D) Ethics certificate program
- E) Mentoring with an experienced ethicist
- F) Experience on the job
- G) Required reading in an ethics manual or resource text
- H) Formal training in mediation
- I) Tertiary qualification in theology
- J) Other

E2. How many people are members of your clinical ethics committee/response group pool (specifically the pool of people that may be called on to respond to a clinical case consultation, not members who are involved only in retrospective review)?

Please select one.

- A) 1
- B) 2 - 5
- C) 6-10
- D) 11-15
- E) 16-20
- F) More than 20
- G) We do not have a committee/response group

E3. Which of the following groups are required to be represented on your clinical ethics committee?

Please select all that apply.

- A) Lawyer
- B) Allied health care professionals
- C) Nursing
- D) Medical staff
- E) Philosopher
- F) Clinical Ethicist
- G) Other university academics
- H) Community member/layperson
- I) Chaplain/member of religious community
- J) We do not have a committee/response group

E4. What experience or training in ethics is required for members of the clinical ethics committee?

Please select all that apply.

- A) PhD or Master in bioethics, clinical ethics or moral philosophy
- B) Clinical Ethics fellowship
- C) Intensive Bioethics mini-course
- D) Ethics certificate program
- E) Mentoring with an experienced ethicist
- F) Experience on the job
- G) Required reading in an ethics manual or resource text
- H) Formal training in mediation
- I) Tertiary qualification in theology
- J) No specific training in ethics required
- K) Other
- L) We do not have a committee/response group

Section F

You have almost completed the survey, approximately 3 minutes to go.

The following questions ask about the structure, function and funding of the ethics service at your children's hospital.

F1. Does your ethics service have its own budget?

Please select one.

- A) Yes
- B) No (Skip to F4)
- C) Not sure (Skip to F4)

F2. Which of the following does the budget for your ethics service support?

Please select the appropriate response for each of the following.

	Yes	No	Don't know
Salary for Clinical Ethicist.			
Salary for clinical staff (eg Fellow, Registrar, Nurse) employed specifically by the clinical ethics service			
Salary for management staff.			
Salary for administrative support staff.			

F3. If you have salary support for the following positions, please specify, to the nearest whole number, the percent full time equivalent (FTE) that the individual(s) devotes to the ethics service. If there is no salary support for the position, please enter '0'.

	FTE (%)
Salary for Clinical Ethicist.	
Salary for clinical staff (eg Fellow, Registrar, Nurse)	
Salary for management staff.	
Salary for administrative support staff.	

F4. How much is your ethics service budget? Do not include estimated value of in-kind support from universities or other affiliated organisations.

Please select one.

- A) No dedicated budget (Skip to F6)
- B) Less than \$10,000
- C) \$10,000- \$49,999
- D) \$50,000- \$99,999
- E) \$100,000- \$149,999
- F) \$150,000- \$199,999
- G) >\$200,000
- H) Don't know

F5. Identify the source(s) of funding that your service receives from the options below.

Please select all that apply.

- A) Local Health Service
- B) Philanthropic
- C) Charity organisation eg hospital foundation
- D) Competitive grants/funding
- E) In-kind support from university partners
- F) Other

F6. Who is involved in the clinical ethics service at your facility?

Please select all that apply.

- A) Staff employed by the clinical ethics service
- B) Clinical staff employed elsewhere in the health service who contribute time to the clinical ethics service
- C) Academics from partner universities
- D) Hospital chaplains or other representatives of religious communities

E) Other

F7. To whom does your clinical ethics service report?

Please select one.

- A) Board of Trustees
- B) Organisation CEO or equivalent
- C) Organisation Executive
- D) No clear line of reporting exists
- E) Other

Final Page: Thank you very much for your participation in this survey.