



Children's Bioethics Centre: Future Projects

Special projects:

1. *Identifying the range of views and beliefs of Muslims in Melbourne about disabilities in children and prolonging life in children who are dying. (~\$315,000 over 2 years)*

A large proportion of RCH patients are from a Muslim background. Anecdotal evidence and experience suggests that parents' decisions for their children are sometimes profoundly influenced by their religious beliefs in ways that clinical staff do not necessarily understand well. Miscommunication about ethical issues regarding the care of a child from a Muslim family can arise as a direct result of this. This project will engage the Muslim community in dialogue about these issues to promote mutual understanding and form the basis of a training program for staff and educational resources for families within the hospital community.

Includes:

- Full time senior researcher/project officer (2 years @ Level C ~ \$200,000)
- Community consultation, interpreters, publicity, catering (x4 reference group meetings per year @ \$2000 each = \$8000 Total)
- Development and printing of family resources (\$45,000)
- Staff training including production of video based training packages (\$62,000)
- Establishment of an ongoing RCH Muslim Community Ethics Reference Group (no cost)

2. *Communication skills for complex ethical decision making about the care of children: Development of a comprehensive evidence based training program for clinicians. (~\$340,000 per training module)*

Although general communication skills training is provided as part of the medical training program, the paediatric environment presents unique and complex challenges for communication between parents, children, and clinicians. Specialised high level skills are required to promote good communication and decision making for children who have life threatening conditions.

Specific training areas (modules) will include;

- Telling children the truth about their life limiting illness
- Planning for limitation of active treatment and referral to palliative care
- Discussing withdrawal of life sustaining treatment

Includes:

- Project officer (2 years @0.5 EFT AO6 ~ \$85,000)
- Clinical Leader – senior consultant (2 years @0.2EFT ~ \$110,000)
- Production of video based training packages (~\$100,000 per module)
- Development of implementation strategy (included)

Research:

1. *The ethics of changing a child's appearance and behaviour for social rather than medical reasons. (~\$310,000 over 3 years)*

This project investigates the ethics of alterations to children for non-life threatening reasons. Alterations include surgery for intersex conditions, limb lengthening, cosmetic surgery in children eg. surgery for protruding ears and breast enlargement or reduction, pharmacological modifications include growth attenuation in severely disabled children, stimulant medication for behavioural and attention problems and the use of psychoactive medications in children. This project is timely

because of our increasing capacity to 'change' children. As well as surgical and pharmacological alterations, there will be changes brought about by advances in genetics such as the selection of embryos with particular traits – so called 'designer babies'.

- Data collection 12 months
- Data analysis and knowledge transfer (research into practice) 12 months
- Full time senior researcher/project officer (1 year – Level C ~ \$100,000/yr)
- Series of meetings with clinicians from various disciplines

2. *Scoping program to identify what resources and assistance are currently offered to parents to assist them with communicating with their child about their serious medical condition. (~\$90,000 over 12 months)*

Parents sometimes delay or hesitate telling their child about a serious life limiting condition because it is very difficult to do. Unfortunately this can complicate the provision of care and decision making about treatment and sometimes leads to ethical problems. This project will investigate whether and how clinicians offer parents assistance with this difficult task and to what extent this resolves the complications. This project may suggest opportunities for the development of a more formal communication skills workshop for parents of children diagnosed with a serious long term medical condition.

3. *Internet-based research involving young people: Maximizing the benefits and protecting young people's interests (~\$260,000 over 2 years)*

Adolescent health research is entering the cyber-age. Social networking sites such as MySpace can be a rich source of data for researchers whose area of research is children and young people. These sites are potentially an effective way of reaching and researching children and young people and addressing their particular health needs, preferences and concerns. However, internet-based research is also potentially risky and exploitative. The objectives of this project are to document internet-based research studies in major Australian research institutions, identify areas of ethical concern, and collect views of key stakeholders. The ultimate aim is to develop models of best practice in internet-based research.

- Data collection 12 months
- Data analysis and knowledge transfer (research into practice) 12 months
- Full time senior researcher/project officer (1 year – Level C ~ \$100,000/yr)
- Symposium

4. *Pilot program to seek parents' views of ethical aspects of treating children in hospital (~\$60,000 over 6 months)*

An interview based research study with parents examining the feasibility of including parents' perspectives in ethics research. The focus will be on parents' experience of being the medical decision maker for a child with a serious or life-threatening condition.

5. *Mapping the ethical issues in allied health practice at the RCH (~\$45,000 over 2 years)*

The nature and reasons for 'real life' ethical decisions have not been examined either systematically with comparisons being made across allied health professions, or in depth involving allied health professionals working a paediatric setting. Therefore the aim of this project is to map ethical issues in allied health practice at the RCH. The project will involve a combination of interviews, focus groups

and observation. Importantly the data collected from this project will provide evidence about ethical issues faced by allied health practitioners and evidence to inform ethics education relevant to paediatric allied health clinical practice.

Education

6. Public forums on ethical issues involving children (~\$5,000 - \$7,500 each)
Topics could include:
 - Diagnosis of death and organ donation in children
 - Cosmetic procedures for children
 - Infant Male Circumcision

7. Clinical Ethics Fellowships
 - Mental Health (Allied Clinical Social Worker SC34 0.4EFT for 2 years total ~\$78,000)
 - Adolescent Health (Allied Clinical Social Worker SC34 0.4EFT for 2 years total ~\$78,000)
 - Medico-legal (Junior consultant LR11 0.4EFT for 2 years total ~\$160,000)

8. Travelling Scholarships for CBC staff to attend local, national and international conferences (~\$500 to \$5,000)

9. Visiting scholar program for national and international visitors to the CBC (~\$10,000 - \$20,000)

10. PhD Scholarships in Ethics (~\$30,000)

11. Scholarships to fund Masters of Bioethics and Master of Social Health for RCH staff (~\$20,000)

General

12. CBC Clinical Director/ Chair position (Senior Principal Specialist 0.4EFT ~\$108,000/year)
13. Ethics library development including books and journal subscription e.g 'Clinical Ethics', Journal subscription to 'Bioethics' (~\$1,000/year)
14. Clinical Ethics Case Database/ IT system eg TRIM (~\$35,000)

For further information on any of the above projects, please contact Catherine Lees (Business Director CBC) on 9345 4086 or email catherine.lees@rch.org.au.