

SOUTH EAST QUEENSLAND COMBINED
HUMAN RESEARCH ETHICS COMMITTEE TRAINING

BOND UNIVERSITY

Gold Coast



Welcome

This is the third of these events to run and this one promises to build on the success of the previous two. The speakers that have been organised for today's event are well-respected in their fields and there is much that we can learn from them. However, there is also a wealth of knowledge to be found amongst your fellow attendees. Human research ethics is a complex field. The people in this room come from diverse backgrounds and each bring their own, unique, perspective to the same problems that we all grapple with. Please, take the opportunity to reflect on your own experiences, engage in the conversations around you, and to question.

The day will consist of a mix of formal presentations and informal case study discussions. The purpose of these training days is not simply to passively learn but also to actively engage in respectful debate and discussion so as to help others to learn from our own experiences and to see the same problems from another perspective.

It is in this spirit of cooperation that I have the pleasure to welcome you to the South East Queensland combined human research ethics training day.

Dr. Mark Bahr

Chair, Bond University Human Research Ethics Committee

South East Queensland Combined Human Research Ethics Training Day

Bond University

Varsity Lakes Campus

17 October 2014



Time	Topic	Presenter
09:15	Registration	Bond University
09:45	Welcome	
10:00 – 10:45	The National Statement	Mr Ian Pieper
10:45 – 11:30	Case Study	Mr Ian Pieper
11:30 – 12:00	Morning tea	
12:00 – 12:45	Office of the Public Guardian	Mr Kevin Martin
12:45 – 13:30	Research Merit and Integrity	Dr Gary Allen
13:30 – 14:15	Lunch	
14:15 – 15:00	Case Study	Dr Mark Bahr
15:00 – 15:45	The Ethical and legal consequences of converging biotechnologies	Prof Michael Lupton
15:45	Close	
	Informal coffee & cheese	

IAN PIEPER

Ethics Consultant

Ethical Futures

Ian has recently begun running Ethical Futures, a human research ethics and governance consultancy service. By doing so, Ian is following a long held interest in normative philosophies and practical ethics. This venture follows on from his practical experience as the Research Governance Officer for the Gold Coast Health and Hospital Service and the Research Grants Officer (Health and Medical) for Griffith University.

Ian has organised combined HREC and researcher training for the GCHHS and the Universities based in SE Qld and Northern NSW. As part of these combined training days provided training in the application of the National Statement in consenting processes. For four years, Ian conducted the induction training for all new members of the GCHHS HREC and acted as a mentor for the Committee, particularly in ensuring compliance with research governance frameworks.

Ian also has extensive experience in providing technical training to technology users, including the use of business computing applications, databases and computer programming.

Ian has formal qualifications from a number of Australian universities - Bachelor of IT, Grad. Cert. HRM, Grad. Cert. Research Ethics and a Masters of Ethics and Legal Studies.

Ian has several peer-reviewed publications on research ethics co-authored with Professor Colin Thomson and has presented on research ethics at national and inter-national conferences.

Publications

Pieper, Ian; Thomson, Colin. 2011. 'Contextualising merit and integrity within human research'. Monash Bioethics Review 29 (4): pp. 15.1 to 15.10.

Pieper, Ian; Thomson, Colin. 2013. 'Justice in Human Research Ethics: A Conceptual and Practical Guide'. Monash Bioethics Review 31 (1): pp 99 - 116.

Case Study 1

Consider the following application for ethics approval

Assumptions:

1. Assume that all of the governance criteria are met. That is, the research team have official approvals from relevant partner institutions, appropriate licensing and blue cards, etc.
2. All of the associated paperwork is included and are in order. The participant information is clear and appropriate.

The purpose of this case study is to think about the research in terms of the principles of the National Statement and to practice using that guide as the point of commonality between researchers and the Committee. Ask yourself and your group:

1. Does this project reflect the values of the National Statement?

Research Merit and Integrity

Respect

Justice

Beneficence

2. What questions would you ask around these principles?
3. What feedback would your group provide to the research team? Put this in terms of the principles of the National Statement.

Trialling an Integrated Approach to Social and Emotional Wellbeing Education in Middle Schools

This is a well-funded two year formative study which aims to extend a successful harm minimisation focussed school education program by identifying and measuring:

1. What broader prevention benefits can be gained when a program of known efficacy in one area of health education (drug & alcohol harm minimisation) forms the basis for an integrated wellbeing program that incorporates sexual and mental health; and
2. What further benefits are provided by taking a whole-school approach?

The study comprises two parts; a small scale needs analysis, followed by a pilot trial. It has relevant government support and is funded through a competitive grant.

The needs analysis is to be conducted in the first year with: a small number of representative schools not involved in the pilot trial; education department stakeholders, and; with national experts on social and emotional wellbeing in schools. Particular emphasis will be placed on understanding the needs of indigenous and other “at risk” students. The needs analysis will consist of semi-structured interviews with individual stakeholders and a systematic review of the literature. The findings of the needs analysis will form the basis of the pilot classroom program. The pilot will be undertaken in the second year of the study and will recruit three middle schools on a voluntary basis. The focus of the trial will be students in year 8 as this is the age when harm minimisation skills are likely to be particularly relevant.

Identified risks: None. The risks of participation in the research are no different from the risks involved in the current standard practice.

Identified Benefits:

- Teachers who deliver the program will be specifically trained; the program takes an integrated, evidence derived, approach to drug and alcohol use and mental and sexual health issues
- The program will be evaluated and reviewed for the purpose of expanding if it is effective.

Participants:

3 groups of approximately 100, 13-14 y/o, school students. The control group will receive the usual curriculum. Initial contact will be through a classroom presentation by the researchers.

Consent: Participation is voluntary, consent will be sought from both the participant and their parent or guardian. The inclusion criteria is that the participant is in Yr 8 at an included school

and that they consent. If they do not consent, they will still be included in that cohort but their data will be excluded from the study.

Participant Groups: Each participating school will be randomly allocated as:

1. Control – no additional program;
2. Comprehensive classroom-based social and emotional wellbeing program that integrates drug and alcohol lessons derived from the Drug Education in Victorian Schools project into a broader curriculum derived from the needs analysis and literature review and that also covers sexual and mental health issues; or
3. The same comprehensive classroom-based program as (2) with an additional whole of school supportive structure also developed from the needs analysis and literature review process.

The effectiveness of the comprehensive classroom-based program will be assessed in terms of better knowledge of, and abstaining from, proscribed behaviours. This will include measuring risky and harmful behaviours.

Research Team: No declared conflicts of interest.

Principal Investigator: BA, BPsych, MPsych, PhD, over 100 relevant publications, relevant ARC grant, national award for excellence in this field.

Role: Research design and methodology; needs analysis; literature review; teacher training; implementation of program; data gathering and analysis; dissemination of findings.

Investigator 2: PhD in Education; Masters of Science in Rehabilitation Science, BA in Physical Education

Role: Conduct of the needs analysis; teacher training; dissemination of findings

Investigator 3: PhD in Education; MEd, Bachelor of Literature in English Teaching. Extensive experience in quantitative research design and data analysis.

Role: Statistical analysis of findings.

Investigator 4: PhD and Masters both in research. Extensive experience researching within secondary schools, particularly in social and emotional learning strategies using participatory action research approaches.

Role: Conduct of the needs analysis; teacher training; dissemination of findings

Data: All data collected will be both anonymous and confidential.

Case Study 2:

The genetic factors that influence human appearance and facial features

This study is part of an ongoing programme of research being conducted by a team of researchers investigating forensic medicine. The lab is well equipped and for some years they have been working with partner investigators outside the institution building a collaborative network. The current project is looking at using genetic markers of human facial features. The long term aim is to use scene of crime samples to predict the likely facial features of victims and perpetrators of crime. They suggest that the technique they are developing will also be of use in the identification of victims of natural disasters who cannot be recognised after trauma.

A pilot project and the literature have identified a large number of target genes responsible for facial shape, bone and muscle distributions, eye and hair colour. An automated technique has been developed to sequence samples and generate a computer model of the appearance of the sample donor. Pilot research indicates that the model developed thus far is capable of generating quite accurate models of donors from the DNA evidence provided. However, the existing pool of donor DNA is small and comes from a relatively homogeneous population that the research team has collected using a snowball sampling technique. The next stage of development of the research is to assess its accuracy against a much larger and more diverse set of DNA samples.

The research team have approached colleagues in the United States of America who have access to large holdings of DNA samples collected as part of criminal investigations with matching photographs, and physical descriptions. They also have access to health records in Britain, and the Middle East including post mortem imagery and associated DNA samples. Access to the three data sources will provide the needed genetic diversity to determine the adequacy of the model developed in the pilot to reconstruct facial models from DNA, and the availability of the photographic imagery enables reliable comparison of the model generated faces to photographs of the donors.

Identified risks: None. The researchers claim that the data required forms part of an existing archival data source. No new data is being collected.

Identified Benefits:

- Refinement of the model will allow better identification of those present at crime scenes.
- Refinement of the model will assist in the identification of crime scene Jane Does or John Does as the case may be.

- The model can assist in identification of disaster victims where physical identification is no longer possible.

Participants:

4 sets of DNA samples collected variously in the United States of America, Britain, and the Middle East, with matching photographic identification of facial features, some medical and criminal history is provided where known. Samples vary in size between 300 and 1700 cases. The sample includes broad racial diversity. The largest sample comes from data collected during criminal investigations.

Consent: The researchers have obtained personal letters of release from individuals working currently with the data for other projects. Researchers have undertaken to de-identify the data provided by the donor organisations.

Participant Groups: The data will be merged into a single combined holding with data being drawn from:

4. Two data sets are proposed to be used from sources in the United States, one medical from Hospital records, and the other from a crime database.
5. A sample from the UK obtained from hospital mortuary records.
6. A Middle Eastern sample is provided by a researcher who works with hospital mortuary records.

The effectiveness of the facial modelling will be assessed by blind rating of similarity of computer models of faces and donor images by a panel of expert judges, and by machine scoring of points of difference between the model reconstructions and donor faces.

Research Team: No declared conflicts of interest. The research team is multinational and the data will be stored on a cloud repository to enable different aspects of the computer model to be worked on by researchers based in the UK, the Middle-East and Australia.

Principal Investigator: B.Sc. Microbiology; Ph.D. Molecular Genetics. Appropriate medical expertise for working with DNA evidence, a history of practical application of DNA use in investigations arising from a period of work experience with an intelligence agency. Nationally competitive funding has previously been obtained for the technical work in the pilot study, and placed well in a national award for excellence in this field.

Role: Research design and methodology; needs analysis; literature review; identification of target sequences; implementation of the program; liaison for data gathering, collection and transport of data and DNA samples from the donor sites, analysis and dissemination of findings.

Investigator 2: B.Sc.; Ph.D. Molecular Genetics, Post Doctoral work in Forensic criminology Gillem Enclave, Georgia. USACIL (US Army Criminal Investigation Command).

Role: Plan and supervise automated sequencing of DNA samples. Sequencing to be conducted by a suitably qualified lab technician (yet to be appointed). Responsible for data audit, sequence integrity checks and selection of sampling frame.

Investigator 3: B.Sc. Information systems, Ph.D. Software engineering, computer modelling.

Role: Software integration of DNA sequencer data and Computer generated model.

Data: Data will be identified by source and as it is to be matched to photographic representations of the donors' record numbers identifying the sample and photographic data are shared by the donating data sources.

DR GARY ALLEN

Senior Policy Officer

Office for Research, Griffith University

During the past 16 years Gary has worked with a number of research ethics committees in Australia, Canada, the United Kingdom and Vietnam. He has a degree in education and a professional doctorate in social sciences.

His knowledge and expertise in regards to the national and international governance of ethical conduct in research has resulted in him serving as a training facilitator for the NHMRC and advising the committee reviewing the National Statement on proportional review. He has completed consultancy work for the CMC, CSIRO, NHMRC, FaHCSIA, various universities and health commissions, and for the Tasmanian Human Research Ethics Committees.

Gary is a frequent presenter at conferences and has been invited by a number of Australian universities to conduct workshops on the National Statement and the Australian Code. In 2007, his work in human research ethics was recognised by the ALTC with a national Citation for Outstanding Contributions to Student Learning.

He is a member of the sub-committee responsible for research ethics of the Australian and New Zealand Society of Criminology

MARK BAHR

Chair Bond University Human Research Ethics Committee

BA, Pg. Dip App. Psych, Ph.D.

Mark has served as the Chair of the Bond University Human Research ethics committee since 2005. As a research methodologist he is interested in the opportunity serving on ethics committees provides to engage with many different methodologies and to keep informed as to research developments across disciplines.

Mark was involved in the rollout of the National Statement to the committee when it was introduced in 2007. Later, he took part in the HOMER consultations and was a member of the first Australian Ethics Network Conference committee with Ian Pieper and Gary Allen.

He has also been involved in the establishment of procedures for animal ethics work conducted at Bond University and the establishment of Bond Universities Biosafety Committee.

He will also be a contributing member of the newly established Australian Institute of Psychology Ethics Committee in Brisbane.

As a researcher he is interested in the assessment theory, the assessment of skill development across the life span and age associated cognitive decline. He has taught research methods and statistics since the early 1990's, and is interested in the intersection of research ethics and research methods.

PROFESSOR MICHAEL LUPTON

Professor Faculty of Law, Bond University,

Bond University Human Research Ethics Committee

Michael started his academic career at the University of Fort Hare where he was Head of the Department of Private Law. He joined the University of Natal in 1975 where he remained until 2001. While at Natal he served as Director of the Faculty of Law (1990 to 1994), on Senate (1991 to 2001) and on the University Council (1995 to 2001).

His many publications are mainly in the field of Biotechnology. He presents internationally in the area of bioethics, and has expertise in the area of the ethics of stem cell, human cloning and the Law. He has delivered papers at 16 international conferences and at many local conferences on topics in human reproduction and genetics.

He was admitted as an Advocate of the High Court of South Africa (1970) and acted as pro bono Counsel in more than 60 murder trials. He also sat as an assessor on the Supreme Court Bench in many trials.

Michael joined the Bond University Law School in 2002 and teaches Law of Succession & Contemporary Issues in Law & Society, Personal Property Transactions and Medicine and Law. In that period he has served several terms with the Bond University Ethics Committee.

KEVIN JAMES MARTIN

Public Guardian of Queensland

BA, B Com LLM, Barrister Supreme Court Queensland

Extensive career in Queensland Public Service occupying positions including:

- Assistant Crown Solicitor
- Deputy Under Secretary Department of Justice
- Parliamentary Counsel of Queensland
- Public Trustee of Queensland
- Director General Department of Justice

Appointed Adult Guardian of Queensland on 13 August 2013.

Appointed Public Guardian of Queensland on 1 July 2014.

Whilst Public Trustee of Queensland, liaised with Queensland Law Reform Commission in its initial Report on Assisted Decision Making and Guardianship in Queensland.

Whilst Director General of Queensland Justice Department:

- oversaw the initial legislation [Powers of Attorney Act 1998] that introduced Enduring Powers of Attorney, Advanced Health Care Directives and Statutory Health Authorities.
- established the Office of the Adult Guardian and arranged appropriate resources and recruited the first Queensland Adult Guardian.

Long term interest in Human Rights from extensive involvement in areas of Intergovernmental relations in Australia including:

- Ratification by Australia of International Covenant on Civil and Political Rights
- Establishment of the first Australian Human Rights Commission
- Attendance as the States Representative on the first report by Australia to the UN Human Right Committee in Geneva.



The Office of the Public Guardian

On 1 July 2014 a new independent statutory body—the Office of the Public Guardian (OPG)—took responsibility for protecting the rights and wellbeing of vulnerable adults with impaired decision making capacity and children and young people in out-of-home care (foster care, kinship care) residential care and youth detention.

Why was the Office of the Public Guardian created?

Following mounting public concern over the increasing number of children and young people coming into care, in July 2012, the Queensland Child Protection Commission of Inquiry was established under the leadership of the Honourable Tim Carmody QC (the Carmody Inquiry).

The Carmody Inquiry was charged with conducting a far reaching review of Queensland's child protection system; to find out if the system was failing children and, if so, why and what should be done to fix it.

The report—*Taking responsibility: A Roadmap for Queensland Child protection*—released in July 2013 concluded that the existing system was not ensuring the safety, wellbeing and best interests of children as well as it should. It went on to make 121 recommendations to improve Queensland's child protection system; 115 of these recommendations were accepted by the Government in full while the remaining six were accepted in principle.

One recommendation accepted in full—recommendation 12.7—was that the role of the Child Guardian be refocused to provide individual advocacy for children and young people in the child protection system. To achieve this it was recommended that the role of Child Guardian—then part of the Commission for Children, Young People and Child Guardian (CCYPCG)—should be combined with that of the existing Adult Guardian to form a new independent statutory body, the Office of the Public Guardian.

Why combine the Child Guardian with the Adult Guardian?

The purpose of the Child Guardian and Adult Guardian are very similar; they both protect the rights, interests and wellbeing of vulnerable people. They also share similar functions, particularly in their role of visiting people in different types of out-of-home accommodation—visitable locations—to ensure they are safe and well and to help resolve any issues the residents may have.

Combining the two areas means the Office of The Public Guardian can share resources and so better protect the rights and wellbeing of vulnerable Queenslanders of all ages.

What is the Public Guardian's responsibility for adults?

For adults, the Public Guardian replaced the existing Office of the Adult Guardian on 1 July 2014. The OPG took over all the Adult Guardian's responsibilities for protecting the rights of vulnerable adults with impaired decision making capacity. This includes protecting adults with impaired capacity from neglect, exploitation and abuse by acting as substitute decision maker as last resort, investigating complaints, mediating in disputes concerning finances, care arrangements and making health decisions.

All operations previously undertaken by the Adult Guardian have been transfer to the OPG, so while the name has changed the services the Office of the Public Guardian provides to adults with impaired decision making capacity and their carers remains unchanged.



What is the Public Guardian's responsibility for children in the child protection system?

The Public Guardian has specific responsibilities to support children and young people in the child protection system. As part of these duties it took over running of the Community Visitor Program for children in out-of-home care from the CCYPCG which ceased operations on 30 June 2014.

In line with recommendation 12.8 of the Carmody Inquiry, the Community Visitor Program for children has been refocused to provide more help and support to the most vulnerable children and young people in out-of-home care, as well as children and young people in residential care, mental health facilities and young people in detention or prison.

The Public Guardian—as part of recommendation 12.7 of the Carmody Inquiry—has also been given special responsibilities to provide individual advocacy for children and young people in the child protection system; ensuring their views and wishes are taken into consideration when decisions are made about them and their care arrangements. Through a statewide network of child advocacy officers the Public Guardian provides children in out-of-home care with advice, information, help and support:

- mediating disputes
- making complaints
- before, during and after meetings, court hearings and tribunals.

Is the Public Guardian part of Government?

No. The Office of the Public Guardian is an independent statutory body. Although like the Adult Guardian—from whom it took over responsibility for protecting the rights of vulnerable adults—it reports to the Attorney-General and Minister for Justice, it remains independent of Government.

How can I contact the Office of the Public Guardian?

Although the OPG is a single organisation with similar functions, it supports two very different groups of clients; adults with impaired decision making capacity, and children and young people in the child protection system.

Our clients have quite different requirements and to ensure incoming enquiries are dealt with as quickly and efficiently as possible there are different ways of contacting the OPG depending on whether you want to speak to someone about vulnerable adults, or children and young people in the child protection system. However, there is no wrong way to contact the OPG; if you call the wrong number by mistake, don't worry, we will re-direct your enquiry to the best part of the Office of the Public Guardian to help.

Adult guardianship

As all the functions of the previous Adult Guardian were merged into the new Public Guardian, all phone numbers—for example, 1300 753 624 for health decisions for adults with impaired capacity—were transferred to the OPG and so remain the same. The OPG does have a new website address www.publicguardian.qld.gov.au and the email address for the area of the Public Guardian for adults with impaired decision making capacity has changed to AdultGuardian@publicguardian.qld.gov.au.

Child visiting and advocacy

You can contact the Office of the Public Guardian's child visiting and advocacy services on our new free call number 1800 661 533. In addition to phoning, you can contact the OPG through the Office of the Public Guardian's new website www.publicguardian.qld.gov.au, by emailing Child@publicguardian.qld.gov.au, SMS messaging—0418 740 186—and through social media.



The Public Guardian

Protecting the rights and interests of adults with impaired decision-making capacity

Who we are

The Office of the Public Guardian is an independent statutory body responsible for protecting the rights of vulnerable adults with impaired decision making capacity and children and young people in Queensland's child protection system.

Established on 1 July 2014 by the Public Guardian Act 2014, the Public Guardian has all the functions and powers of the former Adult Guardian, along with the advocacy and visiting functions of the Commission for Children, Young People and Child Guardian (CCYPCG).

While independent of the government of the day, the Public Guardian is accountable to the people of Queensland by reporting to Parliament through the Minister for Justice and Attorney-General.

Our role in relation to vulnerable adults

The Public Guardian's role in relation to vulnerable adults is part of the framework of human rights protection in Queensland and is to protect the rights and interests of adults who don't have capacity to make some or all of their own decisions due to an illness or disability.

Our charter is to:

- make personal and health decisions for adults with impaired capacity if we are appointed as their guardian or attorney
- investigate allegations of abuse, neglect or exploitation of adults with impaired capacity
- advocate and mediate for people with impaired capacity, and educate the public on the guardianship system
- support the important protective role that Community Visitors have in Queensland.

What we do

Protect Adults from harm

We investigate allegations of abuse, neglect and exploitation of adults with impaired capacity. We seek to determine if the allegations are true on the balance of probabilities, to identify the level of risk for the vulnerable person and the action needed to best protect them.

Where possible, we attempt to have allegations resolved informally. However, the Public Guardian has the power to suspend an attorney's decision making (under an Enduring Power of Attorney) or to refer matters to the Queensland Civil & Administrative Tribunal (QCAT) or to the police.

We also support the Adult Community Visitor Program, which involves independent monitoring of accommodation facilities where vulnerable adults with impaired capacity live. The role of community visitors is to protect people's human rights. Community visitors will investigate problems and try to resolve complaints. If necessary, complaints will be referred to other agencies for further investigation.