AUSTRALASIAN ETHICS NETWORK

Australasian Ethics Network
Conference 2016

23-25 November
Adelaide, South Australia

Handbook

themeetingpeople.com.au/aen2016/

PRAXIS
AUSTRALIA
Promoting Ethics and
Education in Research

Bellberry Limited
Bb supporting research
and ethics

ARMS
Australasian Research Management Society

CELEBRATING
25
YEARS

University of
South Australia

Australasian
Ethics Network
Conference 2016

Major Sponsors

CELEBRATING
25
YEARS

University of
South Australia

Flinders
UNIVERSITY

50 *years*

THE UNIVERSITY
of ADELAIDE

Sponsor

PRAXIS
AUSTRALIA

Promoting Ethics and
Education in Research

Conference APP Sponsor

Bellberry Limited
supporting research
and ethics
Bb

Session Sponsors

infoEd
GLOBAL

rm
RESEARCH**MASTER**

QUT

THE UNIVERSITY
OF QUEENSLAND
AUSTRALIA

THE UNIVERSITY OF
SYDNEY

The George Institute
for Global Health

Conference Partner

A**R**MS
Australasian Research Management Society

Dinner Sponsor

University Office
ARMS *Gold Corporate Partner*

Contents

Wi-Fi Access

UniSA Wi-Fi access for AEN 2016 – Valid for 7 days

Follow these instructions to register for a guest account to access Wi-Fi at the conference:

- Visit the WES Guest Portal **https://guest.unisa.edu.au/**
- Click on **Create New Account**
- Fill in the online form using **Australian Ethics Committee Network Conference** as the event name
- Submit the form

The details to log in are sent to your email address with the instructions.

Conference APP

Download the conference app here

http://m.confplusapp.com/

Welcome

from the Organising Committee

It is a pleasure to welcome you to the 2016 AEN Conference, hosted within Adelaide's rapidly growing health and medical precinct. The conference is brought to you as a result of the collaboration of Bellberry Ltd, PRAXIS Australia and the Australasian Research Management Society (ARMS), in conjunction with our major sponsor and venue host, the University of South Australia.

The AEN began in 2009 at the University of Wollongong at a time when research ethics was relatively new to the academic sector. The 2016 meeting will mark the 6th conference of the AEN and is a significant landmark, as this event aims to bring together research ethics committee members, administrators, researchers and research support staff across both academic and health settings to encourage cross sector discussion and collaboration.

We are delighted to be bringing this conference to you with the support of all of our major Universities in South Australia: University of South Australia, University of Adelaide and Flinders University.

Two of the organisers of the meeting are Bellberry and PRAXIS. Both are independent Not For Profits organisations. The aim of Bellberry is to promote and improve the welfare of research participants and the quality, efficiency and effectiveness of research. As part of this objective, Bellberry had invested in an education initiative, which was duly spun out in 2015 in a collaboration with the University of Sydney and Monash Universities. The new entity, PRAXIS, aims to support Australian research, by providing targeted education to support the needs of the research sector and researchers.

A key focus of both organisations, and the organizing committee, is therefore how to support the research community and researchers through a time of change. These changes can be seen in many different ways: from the types of research we support, to the technologies under investigation, research methods and analysis, and community acceptance of innovations. To support research going forward, it is vital that the established Human Research Ethics and Governance functions are prepared and empowered to deal with these innovations. This conference aims to support those changes.

We are thrilled to be expecting more than 200 delegates to the conference, and a majority of those plan to take part in our social programme. We will open the conference in the stunning South Australia Health and Medical Research Institute building, known locally as SAHMRI (or affectionately as the cheese grater). Join us there for a conversation about the challenges of research in the future. Our conference dinner will showcase one of Adelaide's rising stars of comedy, who also happens to be a health professional within SA Health.

The pre-conference workshops offered this year build further on the great work of ARMS in the past, with a range of topics for a varied audience. The workshops are almost sold out a month in advance – and we thank our delegates for their strong support of the meeting.

We would like to acknowledge our partners, the Australasian Research Management Society (ARMS), who provide the legal structure to enable this conference, under the ARMS Ethics & Research Integrity Special Interest Group (SIG).

Thank you and enjoy the conference.

Melanie Gentgall and Kylie Sproston

Conference Comittee

Kylie Sproston	*CEO, Bellberry Limited*
Melanie Gentgall	*CEO, PRAXIS Australia Ltd*
Meredith Blesing	*PRAXIS Australia Ltd*
Gokhan Ayturk	*Aboriginal Health Council of SA*
Alison Barr	*SA Health*
Victoria Baldwin	*PRAXIS Australia Ltd*
David Vander Hoek	*SA Health*
Cathy Stevens	*Bellberry Ltd*
Vicki Allen	*UniSA*
Sarah Lawson	*SAHMRI*
Sabine Schreiber	*University of Adelaide*
Michelle White	*University of Adelaide*
Nancy Olszewski	*Calvary Health Care*

Guest Speakers

Professor Ian Olver

Professor Ian Olver, AM is Director of the Sansom Institute for Health Research, Professor of Translational Cancer Research and Dean, Research Strategy in the Division of Health Sciences. A renowned oncologist, cancer researcher and bioethicist his research interests are in anticancer drug studies, symptom control, bio-ethics and psycho-oncology, Ian is author of over 250 journal articles and is a regular commentator on cancer issues in Australia and internationally.

Associate Professor Ian Kerridge

Ian Kerridge is Director and Associate Professor in Bioethics at the Centre for Values, Ethics and the Law in Medicine at the University of Sydney and Staff Haematologist/Bone Marrow Transplant physician at Royal North Shore Hospital, Sydney. He is the author of over 250 papers in peer-reviewed journals and five textbooks of ethics, most recently Ethics and Law for the Health Professions (Federation Press, 2013) He is a member of the Australian Health Ethics Committee (AHEC), Chair of the Australian Bone Marrow Donor Registry Research Committee and a member of the NSW Health Department's Clinical Ethics Advisory Panel. His current research interests in ethics include the philosophy of medicine, conflict of interest, stem cells, drug policy, end-of-life care, synthetic genomics, public health and organ donation.

Professor Paul Komesaroff

Paul is a practicing physician and Professor of Medicine at Monash University in Melbourne, RACP Adult Medicine Division President-Elect and Executive Director of the international NGO Global Reconciliation. He has a PhD in philosophy and an international reputation in health care ethics, and has made a major impact on the field of clinical ethics in Australia.

Paul's work is interdisciplinary: spanning clinical medicine, biomedical research, social research, philosophy and ethical theory, clinical ethics and policy development with respect to ethics and clinical practice.

Paul has authored over 350 peer reviewed articles and 14 books. He is the Chair of the editorial board of the Journal of Bioethical Inquiry and honorary ethics editor for the Internal Medicine Journal. He is extensively involved in the teaching of ethics and the philosophy of medicine at both undergraduate and postgraduate level. He is actively involved in research projects in clinical ethics, including investigations of complementary medicine and relationships with pharmaceutical industry.

Dr Karolyn White

Kandy is the Director, Research Ethics and Integrity at Macquarie University. Kandy has taught research ethics to undergraduate and postgraduate student both in Australia and overseas as well as to ethics committee members. She Chairs a Social Science and Humanities Human Research Ethics Committee. Karolyn is also the Chair of the AEN Advisory Group and co-convenor of ARMS Research Ethics and Integrity SIG.

Guest Speakers

Associate Professor Lilon Bandler

Associate Professor Bandler has broad teaching experience, across the spectrum of undergraduate and postgraduate medical education. As Senior Lecturer in the Indigenous Health Education Unit, she is responsible for the development, integration and implementation of a comprehensive Indigenous health curriculum for the Sydney Medical Program, as well as providing personal and academic support to Indigenous medical students. Dr Bandler has worked in general practice for over 20 years. She serves on a University of Sydney Human Research and Ethics Committee.

Associate Professor Terry Dunbar

Associate Profesor Dunbar, Director Yaitya Purruna Indigenous Health Unit, Faculty of Health Sciences, The University of Adelaide. Teaching, curriculum development, research and management across the Faculty of Health Sciences

Dr Leanna Read

Dr Leanna Read is the Chief Scientist for South Australia. She brings extensive research, executive, board and investment experience, particularly in biotechnology. She currently chairs the SA Science Council and the CRC for Cell Therapy Manufacturing, and is a member of the SA Economic Development Board.

Jillian Barr

Director of the Ethics and Governance at the NHMRC. Jillian's work involves developing a range of ethics guidelines and research standards including the current review of the 2007 *Australian Code for the Responsible Conduct of Research*. Jillian is also responsible for research integrity matters at NHMRC.

Gordon McGurk

Gordon is the Director of NHMRC's clinical trials section. He and his tireless and talented team have worked to complete a significant number of activities under 2 federal Government budget measures. These include the development of the HREA, and the development of Guidance on Safety Monitoring and Reporting in Clinical Trials.

Professor Annette Braunack-Mayer

Prof Annette Braunack-Mayer is Professor of Health Ethics in the School of Public Health at the University of Adelaide, where she teaches research methods and health ethics and leads on ethics and community engagement in chronic disease prevention, Aboriginal and Torres Strait Islander health and vaccination programs and policy. Annette is Presiding Member of the Ethics Health Advisory Council for SA Health, Chair of the Human Research Ethics Committee for Bellberry and Chair of the Animal Ethics Committee for the University of Adelaide.

Conference Information
General Information and Social Functions

Conference Venue

University of South Australia
Sessions will be held in the Barbara Hanrahan Building (BH) and Hans Heyson Building (HH).

City West Campus map can be found at:
www.unisa.edu.au/campus-facilities/maps-tours/city-west-campus/city-west-campus-map/

Transport and Parking

By public transport: Accessible via tram from Glenelg and from The Entertainment Centre and stops along the way, as well Adelaide Metro busses.

Plan your journey: www.adelaidemetro.com.au

Short walk from North Terrace, or Hindley Street where most accommodation properties are located.

There is limited parking in the streets around the University however there is a Wilson Park, 189 Hindley St, entry via Clarendon Street, Early Bird Wed & Thu $18.00 and Fri $17.00.

Registration Desk

There is a conference information and registration desk adjacent to plenary theatre room BH2-09, Barbara Hanrahan Building where staff will be able to assist delegates from 7.30am each morning.

Please visit the information desk for any of the following services:

- **Speaker Support:** Delegates will be assisted in the room of their presentation.
- **Cloaking Facilities:** If you require luggage storage on day of check out please speak with staff at the registration desk.

Chairpersons

Chairs are responsible for introducing each speaker and keeping time. Guidelines will be provided in each room to keep individual sessions on track.

Supermarket/Pharmacy

Mini Supermarkets and a pharmacy can be found on Hindley Street, within a 10 minute walk of the venue.

Welcome Reception & Opening Address

Wednesday 23 November, 6pm-9pm
SAHMRI Building, Foyer

The reception and Opening Address will be held at the South Australian Health and Medical Research Institute (SAHMRI), South Australia's first independent, flagship health and medical research institute and the pioneer of the state's new Health and Biomedical Precinct on North Terrace.

Join us for drinks and canapés and network with new friends and old colleagues to the background sounds of 'cool jazz', then join us for a discussion of one of the most contentious issues in research and bioethics currently , as some of Australia's leaders in research ethics discuss the issues that are regularly debated.

Conference Dinner

**Thursday 24 November, 7pm-11pm**

Join us for a night of delicious food and drink, served to a background of beautiful sounds delivered by a string quartet. There are sure to be laughs galore as you are entertained by one of Australia's leading and internationally renowned comedy acts, Georgie Carroll, in Adelaide's historic Town Hall. This promises to be a night not to be missed! Not your average conference dinner.

Tickets are $110 per person and include dinner, drinks and entertainment.

NB This function is not included in the full registration.

Campus and Site Maps
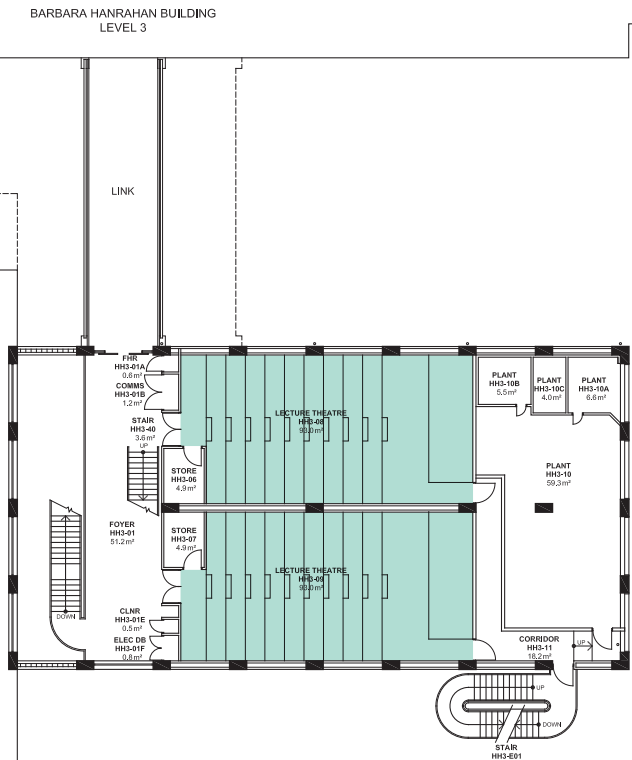
University of South Australia, City West Campus
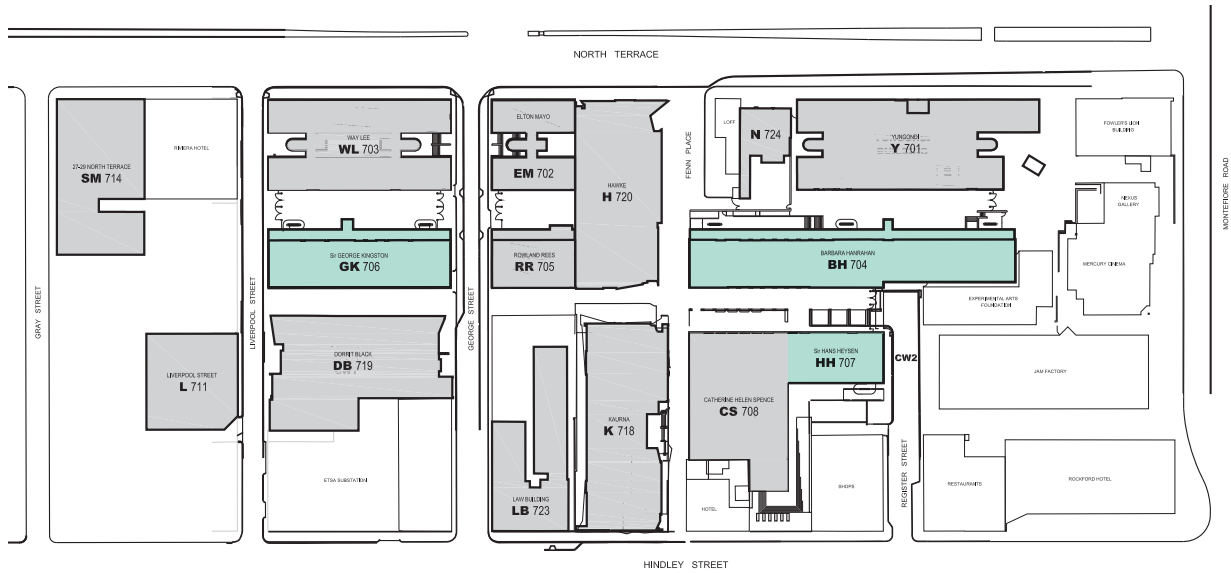
Sir Hans Heysen Building

Level 3 (HH3)
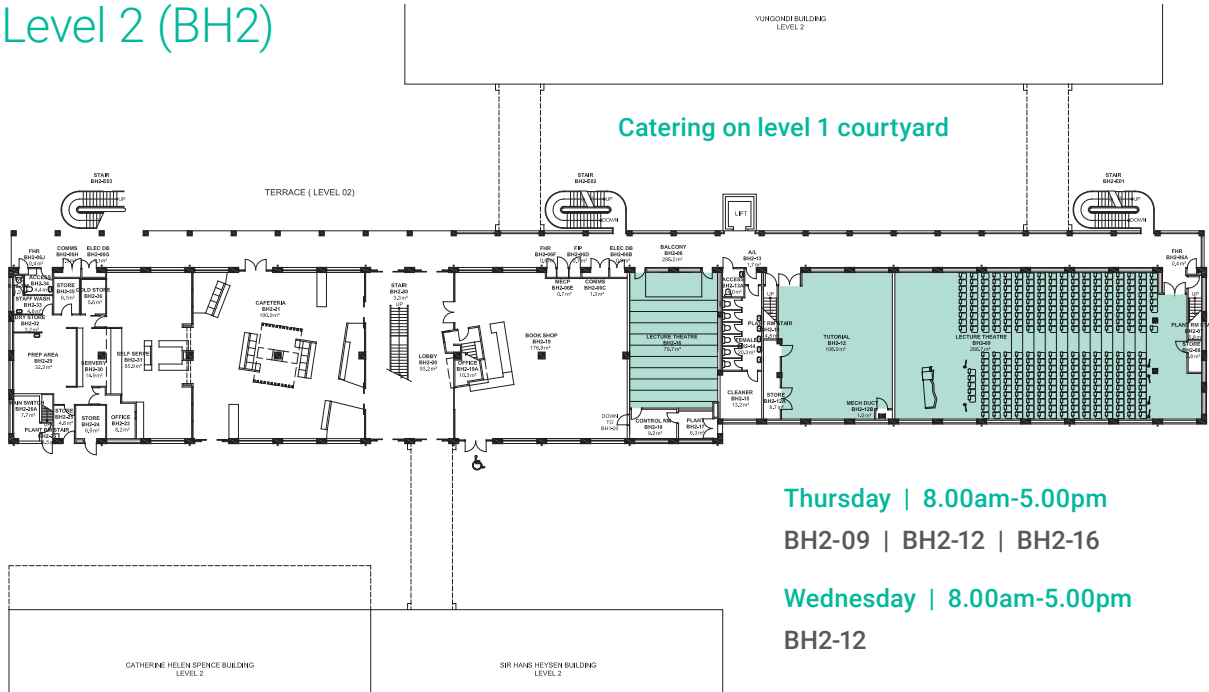
Thursday & Friday | 8.00am-5.00pm

HH3-08 | HH3-09

Site Maps

Barbara Hanraham Building

Level 2 (BH2)

YUNGONDI BUILDING
LEVEL 2

Catering on level 1 courtyard

TERRACE (LEVEL 02)

Thursday | 8.00am-5.00pm

BH2-09 | BH2-12 | BH2-16

Wednesday | 8.00am-5.00pm

BH2-12

CATHERINE HELEN SPENCE BUILDING
LEVEL 2

SIR HANS HEYSEN BUILDING
LEVEL 2

Level 4 (BH4)

YUNGONDI BUILDING
LEVEL 4

Catering on level 1 courtyard

Wednesday | 8.00am-5.00pm

BH4-30 | BH4-33

CATHERINE HELEN SPENCE BUILDING
LEVEL 4

SIR HANS HEYSEN BUILDING
LEVEL 4

Sponsors

Sponsor

Praxis

Formed in April 2015, PRAXIS Australia is an independent not for profit company, the result of the shared vision of three recognised authorities in research and research ethics – Bellberry Ltd, University of Sydney and Monash University – via its partner, Global Reconciliation Ltd.

PRAXIS provides a diverse array of educational offerings, with the purpose of improving research efficiency, driving research outputs and minimising risk and harm to participants.

You can view our leading training models here: **HREC Essentials** and **Research Essentials**.

www.praxisaustralia.com.au

Conference APP Sponsor

Bellberry

Bellberry Limited is a national, private not-for-profit organisation providing streamlined scientific and ethical review of human research projects across Australia. Our aim is to promote and improve the welfare of research participants and the quality, efficiency and effectiveness of research.

As a not for profit company, Bellberry donates surplus funds back into the research community.

NHMRC certified, and recognised in the McKeon review as a Best Practice example, Bellberry Human Research Ethics Committees (HRECs) are professionally managed and operate 24/7 through a dedicated electronic portal providing a paperless and secure HREC process. Tailored, weekly meetings provide high quality, independent ethics reviews. With 6 HREC's, 2 National Scientific Committees, and meetings every week except Christmas, we are able to offer an average turnaround time of 20 days.

See **Bellberry.com.au** to see more about how we can help you.

Conference Partner

The Australasian Research Management Society (ARMS)

Dedicated to Research Management throughout Australia, New Zealand & Singapore

The Australasian Research Management Society (ARMS) is the professional society for research managers and administrators working throughout Australasia and Singapore.

Since its founding in 1999, the ARMS network has grown to involve more than 2100 people from universities, research agencies and institutes, medical research institutes, R&D corporations, research centres, government departments, funding bodies, industrial R&D teams, service providers, commercialisation bodies and consultancies.

ARMS is dedicated to the professional development of research managers and administrators; the promotion of the profession of management; and the enhancement of the research enterprise. The Society fulfills its mission through:

- The establishment of a strong and effective professional network of research managers and administrators at all levels and based on a variety of settings through personal relationships, presentations, formal and informal meetings and publications;
- The development and promotion of professional standards for research management and administrators in Australasia and Singapore consistent with international best practices; and

The improvement of the interface between research and its management.

Sponsors

Major Sponsors

Flinders University

Flinders University is a globally focused, locally connected institution that exemplifies teaching, learning and research excellence. Ranked in the top two per cent of the world's universities*, Flinders offers a world-class education and has a proud reputation for high quality student experience.

With more than 150 undergraduate and almost 300 postgraduate courses, as well as higher degree research supervision across all disciplines, Flinders is a progressive and innovative institution that is bridging the gap between learning and earning through initiatives such as the Flinders New Venture Institute and Flinders Partners, connecting students, business and industry to drive entrepreneurial growth.

Flinders has a strong and growing research profile, with 90 per cent of their research ranked at or above world class by Excellence in Research for Australia (ERA 2015), and 2015 research funding exceeding A$80m.

Times Higher Education World University Rankings 2016-17

University of Adelaide

The University of Adelaide is one of Australia's leading research-intensive universities and is consistently ranked in the top 1% of universities in the world. Established in 1874, it is Australia's third oldest university with a strong reputation for research and teaching excellence and graduates that make an impact on the world.

The University has produced over 100 Rhodes Scholars, including Australia's first Indigenous winner, and has five Nobel Laureates among its alumni community. There are more than 27,000 students with 26 per cent of them international students from more than 90 countries.

University of South Australia

Inspired, Partnered, Excellence

The University of South Australia is a globally connected and engaged university helping solve the problems of industry and the professions. Our teaching is industry-informed, our research inventive and adventurous, and focused on creating impact.
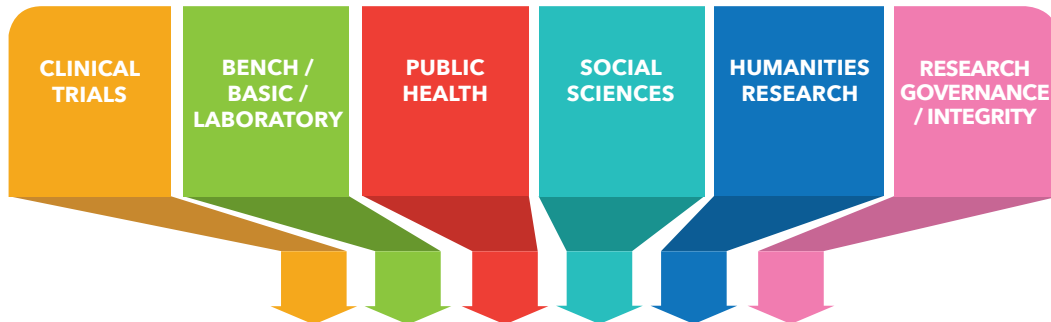
Through our research, we create knowledge that is central to global economic and social prosperity. We are a young university, continuing to set the pace for world-class research and solutions for a changing world.

To learn more about UniSA and our research please visit **unisa.edu.au**

RESEARCH ESSENTIALS

DEVELOPING EXCELLENCE IN RESEARCH DESIGN AND PRACTICE

STEP 1. SELECT YOUR CORE AREA OF RESEARCH

CLINICAL TRIALS	BENCH / BASIC / LABORATORY	PUBLIC HEALTH	SOCIAL SCIENCES	HUMANITIES RESEARCH	RESEARCH GOVERNANCE / INTEGRITY

STEP 2. NOMINATE YOUR CURRENT ROLE

- ▶ RESEARCHER
- ▶ RESEARCH MANAGER
- ▶ RESEARCH CO-ORDINATOR
- ▶ RESEARCH GOVERNANCE
- ▶ RESEARCH INTEGRITY
- ▶ PHARMACEUTICAL / INDUSTRY

GENERATE THE PATHWAY TO YOUR LEARNING

LET THE SYSTEM CHOOSE THE BEST COURSE OF STUDY FOR YOU - OR CHOOSE YOUR OWN PATHWAY

COMMON COMPETENCY UNITS

- SCIENTIFIC CONCEPTS AND RESEARCH DESIGN
- ETHICAL CONSIDERATIONS IN RESEARCH
- RESEARCH MANAGEMENT
- DATA MANAGEMENT AND DISSEMINATION
- RESEARCH CONDUCT GCP AND RESEARCH INTEGRITY
- COMMUNICATION LEADERSHIP AND INTER-PROFESSIONALISM

ELECTIVE STUDY UNITS

SELECT FROM A VARIETY OF ELECTIVE MODULES TO MEET YOUR LEARNING GOALS

CPD / CME RECOGNISED TRAINING

PRAXIS
AUSTRALIA

Call 08 8122 4576
Email info@praxisaustralia.com.au
www.praxisaustralia.com.au

Sponsors

Session Sponsors

InfoEd Global

InfoEd Global – Helping institutions in Australia, New Zealand, and around the world grow and manage their research portfolios for 25 years.

Discover more at **InfoEdGlobal.com**

Queensland University of Technology

The University of Queensland positively influences society by engaging in the pursuit of excellence through the creation, preservation, transfer and application of knowledge. UQ helps shape the future by bringing together and developing leaders in their fields to inspire the next generation and to advance ideas that benefit the world. UQ strives for the personal and professional success of its students, staff and alumni. UQ ranks in the top 50 as measured by the Performance Ranking of Scientific Papers for World Universities. The University also ranks 51 in the QS World University Rankings, 52 in the US News Best Global Universities Rankings, 60 in the Times Higher Education World University Rankings and 55 in the

Academic Ranking of World Universities.

ResearchMaster

ResearchMaster Enterprise 6 (RME6) is a highly automated, fully integrated, cloud-based research management system providing online Ethics forms designed to match your reporting requirements and workflow processes for the entire Ethics lifecycle.

RME6 is designed, developed and supported in Australia for Australian and New Zealand organizations. It is the most comprehensive Ethics solution on the market.

ResearchMaster has the products to make you more productive and the people to show you how.

www.researchmaster.com.au

The George Institute

The George Institute for Global Health is a global medical research institute headquartered in Sydney, Australia with major centres in China, India and the United Kingdom and offices worldwide. Established in 1999 in Sydney, the Institute is affiliated with The University of Sydney, Oxford University and Peking University Health Science Centre, employs over 600 staff, has over 1100 collaborators globally ranging from industry, academia, health and government, and projects in over 50 countries. The George Institute has been ranked among the top ten research institutes in the world for scientific impact and its research has driven major improvements in the prevention and treatment of heart disease, stroke, diabetes, kidney disease, road safety and many other common killers and causes of disability globally as part of mission to improve the lives of millions of people worldwide.

www.georgeinstitute.org

The University of Queensland

The University of Queensland positively influences society by engaging in the pursuit of excellence through the creation, preservation, transfer and application of knowledge. UQ helps shape the future by bringing together and developing leaders in their fields to inspire the next generation and to advance ideas that benefit the world. UQ strives for the personal and professional success of its students, staff and alumni. UQ ranks in the top 50 as measured by the Performance Ranking of Scientific Papers for World Universities. The University also ranks 51 in the QS World University Rankings, 52 in the US News Best Global Universities Rankings, 60 in the Times Higher Education World University Rankings and 55 in the Academic Ranking of World Universities.

Sponsors

Session Sponsors

Dinner Sponsor

University of Sydney

Established as Australia's first university in 1850, today the University of Sydney is one of the world's leading, comprehensive research and teaching institutions.

Our reputation for global leadership in research and education is reflected in our ranking in the world's top 50 universities.

Our diverse community of more than 60,000 students and 6,400 academic staff come from more than 130 countries.

We offer Australia's broadest range of disciplines so our students can shape their education to their interests and society's newest challenges. That's why you'll find our 300,000 alumni sharing our style of thinking in more than 170 countries around the world.

The University's investment in multidisciplinary research is unrivalled in Australia, and it's strategy aims to harness its research strengths – including a breadth and depth of disciplinary expertise unique in Australia – to address some of the major global challenges of our time, including:

- obesity
- diabetes and cardiovascular disease
- nanoscale science and technology
- mental health and neurosciences.

The University of Sydney was founded on the principle of providing people from any background with the opportunity to realise their potential through education.

We were one of the first universities in the world to admit students solely on academic merit, and women on the same basis as men.

It's a principle that drives us today, encouraging our people to push conventions, shape change and improve lives.

University Office

University Office is an international leader in research management and administration applications and solutions.

Our goal is to minimise the administrative workload faced by researchers and research managers, while effectively addressing any research-related risk facing institutions within our Integrated Research Management Application (IRMA). IRMA is a modular based solution that offers extensive functionality for both human and animal ethics.

University Office is the only Australian-based research management systems provider which is a member of ORCID and we are the inaugural Gold corporate sponsor of the Australian Research Management society (ARMS).

Program

Australasian
Ethics Network
Conference 2016

AUSTRALASIAN
ETHICS NETWORK

Conference Program

Wednesday 23 November

7.30am-5.00pm	**Registration, Barbara Hanrahan Building, UniSA, City West Campus, Yungondi Courtyard**
9.00am-5.30pm	**Pre Conference Workshops**

Pre Conference Workshops

9.00am-1.00pm **Privacy in Research – What do you need to know?** *(GK4-30 (Sir George Kingston))*

Facilitator: Anna Johnson, Director Salinger Privacy

Workshop Summary: Ethical research requires consideration of "privacy and confidentiality" in research design. Federal, State and Territory privacy law delegates some important decision-making about when the use and disclosure of "personal information" will be legally allowed. What do these phrases mean? Where does 'consent' fit in? When can privacy considerations be overridden? This 4 hour workshop is specially designed to explain Federal and local jurisdictional privacy law, and its application to research and is applicable to anyone involved in research design, conduct, ethical review and governance.

Through small-group discussions, and the use of hypotheticals and case studies, we will cover the following topics:

- What is privacy?
- What is personal information?
- De-identification
- The privacy principles
- Which law applies when?
- Consent and capacity
- The research exemption
- A step-by-step flowchart guide, using hypotheticals
- Resources

Conference Program

Pre Conference Workshops

9.00am-1.00pm   **The Invisible Link: Essential skills for HREC, Research and Research Governance Managers and Administrators** *(BH2-12 (Barbara Hanrahan))*

Facilitators: Dr Karolyn (Kandy) White, Director, Research Ethics and Integrity, at Macquarie University. Dr Philomena Horsley, La Trobe University and University of Melbourne, Director of PRAXIS Australia. Dr Tamika Heiden, Principal with Knowledge Translation Australia. Dr Angela Watt, Director of Research Governance and Ethics at Melbourne Health (The Royal Melbourne Hospital)

9.00am-9.30am	Role of the Administrator in Research	Dr Angela Watt, Melbourne Health
9.30am-10.00am	Challenges of Research Administration	Dr Philomena Horsley, La Trobe University
10.00am-10.30am	Research Integrity and the role of the research office	Dr Kandy White, Macquarie University
BREAK		
11.00am-11.30am	Building relationships and understanding behaviours	Dr Tamika Heiden, Knowledge Translation Australia
11.30am-12.00pm	Research Translation: Supporting researchers to plan for translation	Dr Tamika Heiden, Knowledge Translation Australia
12.00pm-12.30pm	Group activities (scenario based)	
12.30pm-1.00pm	Panel Discussion	

10.30am-11.00am   **Morning Tea, Yungondi/Barbara Hanrahan Courtyard**

Conference Program
Wednesday 23 November

Pre Conference Workshops

9.00am-1.00pm   **HREC Essentials Workshop** *(BH4-30 (Barbara Hanrahan))*

This face to face workshop is provided to students who have undertaken the PRAXIS HREC Essentials online course as the final step to completing this nationally accredited training.

Workshop Summary: The purpose of the course is to provide Human Research Ethics Committee (HREC) Members, HREC Administrators and those involved with the planning, conduct and review of research involving humans with a deeper understanding of the purpose and function of an HREC and their role within these committees.

The workshop is designed to provide an important opportunity for students to engage with thought leaders and their peers in a supportive learning environment and to have the opportunity to demonstrate the application of their skills and knowledge in a practical way, including through discussion of HREC scenarios tailored to the needs of the participants. The workshop is facilitated by leading experts in the field of human research ethics.

On successful completion of this course students will receive a certification that is endorsed through our partner in VET accredited training, RMIT University.

Facilitators: Professor Paul Komesaroff, Practicing physician and Professor of Medicine at Monash University in Melbourne, RACP Adult Medicine Division President-Elect and Executive Director of the international NGO Global Reconciliation

Professor Ian Kerridge, Professor of Bioethics and Medicine at the Centre for Values, Ethics and the Law in Medicine (VELiM) at the University of Sydney and Staff Haematologist/Blood and Marrow Transplant (BMT), physician at Royal North Shore Hospital, Sydney.

Pre Conference Workshops

1.30pm-5.30pm　**AIATSIS – Cultural Safety – Understanding the ethical considerations for research with Aboriginal and Torres Strait Islander Peoples** *(BH2-12)*

Facilitators: Chrissy Grant and AIATSIS HREC Members. Chrissy is an Aboriginal (Kuku Yalanji) and Torres Strait Islander (Mualgal) woman from Far North Queensland. Chrissy is Chair of the AIATSIS HREC and is an adviser to the NHMRC on ATSI research policy and guideline development.

Workshop Summary: Indigenous peoples have inherent rights, including the right to self-determination. The principles in the Guidelines for Ethical Research in Australian Indigenous Studies (GERAIS) are founded on respect for these rights. These include rights to full and fair participation in research processes, projects and activities that impact on them, and the right to control and maintain their culture and heritage. AIATSIS considers that these principles are not only a matter of ethical research practice but of human rights. It is essential that Indigenous people are full participants in research projects that concern them, share an understanding of the aims and methods of the research and share in the results of this work.

In this workshop we will be discussing the principles of GERAIS and applying those principles through case studies.

Conference Program
Wednesday 23 November

Pre Conference Workshops

1.30pm-3.30pm   **NHMRC – HREA in practice** *(GK4-30 (Sir George Kingston))*

Facilitators:

Dr Robert Rigby, Assistant Director Clinical Trials Section, National Health & Medical Research Council.

Joel Ceramidas, Project Officer at National Health and Medical Research Council

Workshop Summary: NHMRC has developed the Human Research Ethics Application (HREA) to replace the National Ethics Application Form (NEAF). The functionality associated with the HREA is powerful and will provide institutions that support it with an ability to combine it with their existing workflows to optimise the ethics submission and review process.

The application is based on the principles of ethics rather than on a checklist philosophy. In addition, the IT solution in which the application has been integrated is powerful and flexible and will lead to a bespoke output customised to reflect the methodology and participant group being utilised in the research. This approach means that the application will be able to be used for all human research, regardless of level of risk associated with the research. These factors, aligned with the flexibility in output format and submission options will simplify application completion, ethical review and will encourage more consideration of the ethical aspects of research than may have been achieved with the NEAF.

The workshop will be presented as a lecture with an interactive demonstration with audience participation encouraged. It is aimed at executive officers and administrators, particularly those that who support ethics review of human research.

Workshop content will include:
- A background to the concept and development of the HREA,
- The innovative features that streamline ethics applications and review,
- A demonstration of preparing and submitting applications, and
- How the HREA can integrate with institutions' existing research governance workflows.
- Interactive completion or amendment of an application
- Demonstration of changing the content of the HREA to reflect changes eg. National Statement
- 'Pro' Tips and tricks for efficient use of the HREA

The learning outcomes of this workshop will be:
- Understanding of how the HREA was developed
- Understanding the functionality of the platform
- A working knowledge of how to prepare and submit ethics applications using HREA
- The ability to support institutional applicants using the HREA
- Understanding of how to integrate the HREA into their institution's workflows

Attendees will be encouraged to bring laptop or portable device in order to support interactive demonstration.

3.00pm-3.30pm   **Afternoon Tea, Yungondi/Barbara Hanrahan Courtyard**

Welcome Address and Reception – SAHMRI Building

6.00pm-6.30pm	**Arrival Drinks** *SAHMRI Foyer*
	MC: Dr Melanie Bragg, Australian Science Media Centre
6.35pm	**Welcome to Country**
	Welcome *Dr Ted Rohr, Kylie Sproston, Melanie Gentgall*
	Introduction *MC: Dr Melanie Bagg*
	Opening Address – Panel Discussion:
	Should ethics get out of the way to pave the way? *SAHMRI Theatre*
	Prof Ian Olver, Prof Ian Kerridge, A/Prof Lilon Bandler, Prof Annette Braunack-Mayer
7.45pm-9.00pm	**Welcome Reception** *SAHMRI Foyer*

Bb Bellberry Limited supporting research and ethics

Not-for-profit

**Independent
& Streamlined**
Science and Ethics Review

NHMRC-Certified
HREC meetings held weekly,
49 weeks of the year

**Health & social science
reviews**

**Study submission
deadline**
every Wednesday

**Electronic application
and review system**

Full-time secretariat
providing support services

**Independent site
monitoring**

**Research Ethics
Education**

Call for more information
or apply online
www.bellberry.com.au

P 08 8361 3222 **F** 08 8361 3322
E bellberry@bellberry.com.au

Conference Program

Thursday 24 November

7.30am — **Registration, Uni SA, Barbara Hanrahan Building**
(Courtyard Barbara Hanrahan/Yungondi – adjacent to BH2-09, lower level)

9.00am — **Opening Plenary – Research challenges of a changing world** *(BH2-09)*
MC: Lyndal Byford, Australian Science Media Centre
Prof Steve Wesselingh, Dr Leanna Read, Prof Paul Komesaroff, A/Prof Terry Dunbar

10.30am — **Morning Tea**

11.00am-12.30pm — Concurrent Session 1

Technology	Processes	Impacts
BH2-09	*HH3-09*	*HH3-08*
The perfect storm of Big Data capabilities and privacy frameworks	**Values, relationships and emotions: what is the responsibility of the HREC?**	**The Changing Face of Consent and Information Processes**
Chair: Kylie Sproston	*Chair: Dr Ted Rohr*	Kindly sponsored by: The University of Sydney *Chair: Prof Ian Kerridge*
Can Big Data ever be de-identified? Emerging privacy issues arising from the growing field of data analytics. *Malcolm Crompton*	Deciding with Feeling: ethical emotional decision making *Charles Grinter*	Dynamic Consent *Prof Ian Kerridge*
Are privacy concerns about big data overrated? Impressions from a public health researcher *Prof Annette Braunack-Mayer*	Review as Relationship: what do committee responses reveal? *Brian Finch*	Moving Forward on Informed Consent Through Multimedia Technology *Lisa Eckstein*
Big Data or big divide? Views of a clinician researcher *Prof Steve Wesselingh*	A Clash of Values the ethics of professional practice and the ethics of research *Chris Jenkin*	The Forgotten Group: Involving disabled people in research *Dr Philomena Horsley and Prof Paul Komesaroff*
Roundtable discussion to identify the issues from the research sector *Kylie Sproston (Chair)*		

12.30pm — **Lunch**

Conference Program

Thursday 24 November

1.30pm-3.00pm   Concurrent Session 2

Technology	Processes	Impacts
HH3-08	*BH2-09*	*HH3-09*
Using Technology in Research	**Ctrl-Alt-Delete: Restarting Ethics and Governance**	**Ethical Considerations Arising from a Changing World**
Kindly sponsored by: ResearchMaster *Chair: Dr Karolyn White*	*Chair: Melanie Gentgall*	*Chair: Kylie Sproston*
The Ethics of Phishing Research: Balancing Ethical Considerations with Ecological Validity *Kathryn Parsons*	The Challenges and Rewards of Rebuilding Ethics from the Ground Up *Nicole Shively*	The Increasing Use of FOI Applications Seeking Disclosure of Information about Research and it's potential impact on HEI Research Review Practices *Mary Wyburn*
Ethical Conduct of Social Media Research *Anne Walsh*	Innovation in process and practice: a pathway to enabling and achieving research governance service innovation within the South Australian research governance framework *Camilla Liddy*	Negotiated Ethics: Using Social & Visual Technology in Newly Post-Conflict and/or Fragile State Fieldwork *Dr Rochelle Stewart-Withers*
Internet research and the implications for ethical research practice *Annmaree Jackson*	New approaches to PICF *Simon Windsor*	Is the race for innovation compromising good ethical practice? Lessons from corporate scandals *Amy Salapak*

3.00pm   Afternoon Tea

3.30pm-5.00pm   Concurrent Session 3

Technology	Processes	Impacts
HH3-08	*BH2-09*	*HH3-09*
Using Technology for Ethics Review	**Research Integrity and Monitoring**	**The Changing Field of Research Ethics**
Chair: Dr Philomena Horsley	*Chair: Dr Ted Rohr*	*Chair: Prof Ian Kerridge*
Out with the Paper: opportunities & obstacles of bringing an HREC online *Selina Metternick-Jones*	Monitoring of approved research *Anne Walsh*	The Expanding Disciplinary Scope of Research Ethics: a story of resistance *Dr Karolyn White*
Innovations in a HREC: streamlining with technology *Sara Potts*	Addressing Research Breaches: educative not punitive *Sue Jenkins-Marsh*	Getting back to basics for research ethics and governance *Jan-Louise Durand, CAHLN, SA Health*
	Boundaries between Research Ethics and Integrity *Dr Ted Rohr*	Becoming Dangerous: a Foucauldian discourse analysis of researchers at the dawn of research governmentality *Kate O'Connor*

5.00pm   Close for the Day

7.00pm   Conference Dinner – Adelaide Town Hall, Banquet Room *128 King William St, Adelaide*

WHY ARE WE SO BLOWFLY EASILY TEXT MESSAGE DISTRACTED WHEN DOING LED ZEPPELIN EVERYDAY TASKS ITCHY KNEE?

Brain focus research: **making a difference.**

Flinders University is exploring ways to increase our ability to focus and decrease the likelihood of being easily distracted while performing tasks such as driving and operating machinery.

In fact Flinders is big on brains.

Other projects that are already making a difference include defining the influence of mind on body and creating techniques to reprogram our body clocks, a boon for shift workers and frequent travellers, or being part of a global network of Brain Banks that preserve and share brain tissue to help understand and reduce the impact of degenerative brain disease.

We are also helping people exercise the creative side of their brains to train the entrepreneurs of tomorrow and imagineer new enterprises and employment opportunities.

Ideas becoming innovations that make a difference.

It's one reason we're ranked in the top 2% of the world's universities.

It's driven us for the last 50 years and will for the next fifty and the fifty after that.

Flinders
UNIVERSITY

CELEBRATING
50 years
OF INSPIRING
ACHIEVEMENT

50.flinders.edu.au

Tackling the world's greatest challenges.

> Where will we source our energy?

> Can we save our planet?

> Is it possible to feed the world?

> Why can music move us to tears?

> Can we help endangered species prevail?

> Can we secure a healthy future for our children?

Some of the world's best researchers are striving to address these questions – and more – through their research at the University of Adelaide.

Consistently ranked in the top 1% of universities worldwide the University of Adelaide has five Nobel Laureates among its alumni and has contributed to game-changing inventions throughout history including x-ray crystallography, insulin, penicillin and the Olympic torch and cauldron.

To learn more about our research or to explore opportunities to join our passionate team, visit adelaide.edu.au/research

CRICOS Provider Number 00123M

adelaide.edu.au

seek LIGHT

Conference Program

Friday 25 November

8.00am	**Registration, Uni SA, Barbara Hanrahan Building** *BH2-09*
9.00am	**Plenary – National Regulator Update** *Chair: Dr Robert Rigby* Kindly sponsored by: InfoEd Global
	Development of a principles-based Australian code for the responsible conduct of research 2007 and supporting better practice guides, *Jillian Barr, Dr Karolyn White*
	NHMRC Clinical Trials Update, *Dr Gordon McGurk*
	Panel Discussion
10.30am	**Morning Tea**
11.00am-12.30pm	**Concurrent Session 4**

Technology	Processes	Impacts
HH3-08 **Innovations in Research Methods** *Chair: Dr Ted Rohr*	*HH3-09* **Becoming an approachable HREC** *Chair: Dr Meredith Blesing*	*BH2-09* **Ethical Principles of Research with Aboriginal and Torres Strait Islander Populations** *Chair: A/Prof Lilon Bandler*
Digital ethics: measuring the impact of online wellbeing initiatives for minors utilising online passive data collection ethically *Carmel Taddeo*	A Friendly Face: Ethics Clinics at UTS *Yordanka Krastev*	Ethical Values in Aboriginal Research *Kim Morey and Annapurna Nori*
Ethics and the Digital Camera: what is research imaging data in the age of the smartphone? *Adrian Dyer*	Does your HREC have an Image Problem? The potential for marketing to improve relationships and streamline processes *Melanie Randle*	Institutional Barriers that Aboriginal Researchers Face when Conducting Human Research, and why it needs to change *Mandy Downing*
Using Facebook to reach the un-reachable - does it actually work? *Dr Holly Seale*	Knowing More but Asking Less: Supporting Researchers in an increasingly regulatory world *Glynn Stringer*	Turbulent water: Challenges and adaptations conduction PAR with diverse consortia partners and communities *Beverley Turnbull*

12.30pm	**Lunch**

Conference Program

Friday 25 November

1.30pm-3.00pm   **Concurrent Session 5**

Technology	Processes	Impacts
HH3-08 **mHealth, eHealth, Telehealth: Applications to solve the tyranny of distance, reach across languages, and enable new research** Kindly sponsored by: The George Institute Australia *Chair: Kylie Sproston*	*BH2-09* **Updates on the National Statement and the Human Research Ethics Application Form** *Chair: Prof Colin Thomson*	*HH3-09* **Impacts of Technology on HRECs** *Chair: Dr Meredith Blesing*
Towards Research Equity for CALD Patients through Mobile Health Ethics and Research Information *Prof David Story*	The Review of the National Statement on Ethical Conduct in Human Research 2007 *Jillian Barr*	The Changing of the Arrangement of Ethics Meetings *Lana Lon*
Reflections on the nexis between ethics and health promotion in the NT: Challenges and Opportunities *James Smith*	The HREA: Overcoming disruption with disruption *Dr Gordon McGurk*	Quality Assurance or Research? A more coherent process for Negligible Risk Research. *Melissa Cadwell*
	Panel discussion	

3.00pm   **Afternoon Tea**

3.15pm   **Panel Discussion – Session 6**

Technology
BH2-09 **The Changing Landscape of Research Governance** *Chair: Dr Angela Watt*
Results of Governance Best Practice Pilot *Dr Robert Rigby*
The lived experience of a Clinical Trial Liaison Officer *Jenny McGrath, Elena Voss, Richard Verelli, Alison Barr*
Panel discussion *Dr Angela Watt (Chair)*

4.30pm   **Conference Closes**

Abstracts

Australasian
Ethics Network
Conference 2016

11am-12.30pm – Technology: The perfect storm of Big Data capabilities and privacy frameworks

Can Big Data ever be de-identified? Emerging privacy issues arising from the growing field of data analytics

Malcolm Crompton

Roundtable discussion to identify the issues from the research sector

Kylie Sproston

11am-12.30pm – Processes: Values, relationships and emotions: what is the responsibility of the HREC

Deciding with feeling: ethical emotional decision making

Charles Grinter
Auckland University of Technology, Auckland, New Zealand

When it comes to sitting around the table to engage in ethical decision making, the dominant model is almost exclusively focussed on the use of reason. This produces consistent results within known frameworks. It is recognised however that this model has difficulties when applied in innovative and unknown contexts, and that it is liable to become too distant from lived realities. There has been discussion recently around the role that emotions can usefully play in ethical or legal decision making. This paper briefly defines two emotions, love and anger. It examines ways in which these may have been unhelpful in achieving sound ethical decisions. As a contrast to this, the paper then proposes ways in which these two emotions may be effective companions to reason in ethical decision making. It then explores how these emotions could usefully inspire and strengthen sound decisions, in new contexts as well as familiar ones. A middle way is proposed in which love and anger along with reason may be seen as essential to sound ethical decision making.

Review as relationship: what do committee responses reveal?

Brian Finch
Massey University, Manawatu, New Zealand

Ethics review literature often describes committees as being dominant and overly bureaucratic, stifling worthy research. This investigation posed two questions about the written responses to researchers from three committees; it looked at what aspects of applications were most attended to and what kinds of relationships with researchers were created through the response language used. A sample of each committee's responses over a year were analysed for both the ethics content and the tenor of the language used, by adapting and extending the protocol of Dixon-Woods et al. (2007) to uncover detail about the ways that the review committees define ethical practice and position themselves in relation to researchers through the discourse of their responses. Evidence about the impact of an innovation to highlight ethical concerns to applicants, ahead of documentation correctness, was gathered through this project. The findings will be discussed in terms of how the tensions between a collegial and a compliance focus are conveyed. The implications of the analyses for future research into committee functioning and for institutional engagement with ethics review will be discussed.

A clash of values: the ethics of professional practice and the ethics of research.

Chris Jenkin, Charles Grinter
Auckland University of Technology, Auckland, New Zealand

Increasingly, the research focussed university community has become home to new academic disciplines with an established culture of professional practice and codes of ethical practice.

Their new home in the University results in a need for people who have both professional and academic roles to produce research and publish as well as teach. Doing research requires these professionals to interact with people differently. Their existing codes of professional practice do not always marry well with those that govern research. This paper examines two case studies in which we look at how different codes of ethics relate to each other.

Firstly, we look at Early Childhood Educators. The principles of early childhood education are empowerment, holistic development and family and community. Educators frequently use team self-review as a form of action research. The second case study is journalism where respect for truth and the public's right to information are overriding principles, with interviews as means of research.

This presentation will explore how issues of insider research, professional protectionism and autonomy are valued differently in professional practice and research and suggests some resolutions in terms of autonomy, partnership and protection.

11am-12.30pm – Impacts: The Changing Face of Consent and Information Processes

Dynamic Consent

Prof Ian Kerridge

Moving Forward on Informed Consent Through Multimedia Technology

Rebekah McWhirter, Lisa Eckstein
University of Tasmania, Tasmania, Australia

Modern national and international research ethics guidelines recognize that, with limited exceptions, persons should be empowered to make a voluntary choice whether to participate in research. In most research, potential participants are provided with the requisite information through a written patient information sheet and consent form. However, large numbers of participants show significant gaps in

their understanding of studies to which they have consented raising questions about the process's sufficiency. Recognition of the growing challenges in participant understanding has led to efforts to modify consent documents and procedures. One such approach seeks to harness the benefits of multimedia technologies to move the consent process beyond paper-based forms. Although this strategy has theoretical merits, evidence of its efficacy has been mixed.

We report on a project seeking to advance the informed consent debate in Australia by identifying the needs of the three main stakeholder groups in the research process in relation to multimedia consent practices. Interviewees comprised researchers, ethics committee members and research participants in Tasmania and the Northern Territory, including indigenous researchers and participants. An innovative feature of the interviews was our development of an iPad app for the purposes of seeking study consent. The app provided a focus for discussion on the respective costs and benefits of multimedia technologies as a tool for facilitating informed consent, including the various functionalities that may be harnessed. Several subsequent research projects have sought permission to adapt the source code for the app, suggesting its potential for broader implementation.

The Forgotten Group: Involving disabled people in research

Dr Philiomena Horsley and Prof Paul Komesaroff

1.30pm-3pm – Technology: Using Technology in Research

The Ethics of Phishing Research: Balancing Ethical Considerations with Ecological Validity

Kathryn Parsons[1], Dragana Calic[1], Marcus Butavicius[1], Malcolm Pattinson[2], Agata McCormac[1]
[1]Defence Science and Technology Group, Adelaide, SA, Australia, [2]The University of Adelaide, Adelaide, SA, Australia

Phishing is a malicious attempt to acquire personal or sensitive information, such as usernames, passwords and bank account details, and it is usually conducted via email. Recent reports suggest that falling for phishing emails is the most common security incident, and the direct financial cost of these cyber-attacks was estimated at a staggering USD $4.6 billion in 2015 (RSA Security, 2015). These statistics highlight the importance of studying phishing to enhance our understanding of which computer users are most susceptible. We conceptualise phishing research as a trade-off between the ethical concerns of deception, such as the lack of informed consent, and the practical benefits or ecological validity of the research findings. For instance, a common practice of many phishing studies has been to employ an 'in-the-wild' approach, whereby participants are sent phishing emails without informed consent (Ferguson, 2005; Jagatic, Johnson, Jakobsson, & Menczer, 2007).While this approach may be ecologically valid, it involves deception. In another common methodology, informed participants are presented with images of emails, and asked to identify which are phishing (Furnell, 2007). As these participants have been advised that they will be presented with phishing emails, their performance is unlikely to reflect real-world performance, which may limit the ecological validity of this research, also raising ethical concerns. In an attempt to balance ethical considerations with the need for ecological validity, we discuss alternative methods to evaluate phishing, including role-play and training-centred real-world approaches. This is imperative in order to stay abreast of rapidly evolving cyber-threats.

Ethical Conduct of Social Media Research

Anne Walsh, Jane Jacobs
Queensland University of Technology, Brisbane, Australia

Social media has been embraced by the research community as a rich source of data, a platform to observe human behaviour and a gateway to access a bounty of potential research participants. The opportunities that social media research presents also pose some important ethical considerations concerning privacy, user expectations and recruitment methodologies. This presentation will outline common ethical challenges of social media research as experienced by a University HREC and the ethical frameworks used to address them. The presentation will include a discussion on possible ethical frameworks to address future developments in social media research and to explore ways to foster and maintain online community trust so that research opportunities in social media can continue.

Internet research and the implications for ethical research practice

Annmaree Jackson, Charlotte Brownlow, Tanya Machin
University of Southern Queensland, Toowoomba, Queensland, Australia

The Internet has extended the opportunity for researchers to investigate human actions and interactions. This presentation is based on a recent study which aimed to critically examine the various ways that ethical considerations associated with Internet-Mediated Research (IMR) are constructed as a social reality by Australian Human Research Ethics Committee (HREC) and the implications for research practice. This project built on research undertaken in the United States by Buchannan and Ess (2009) which examined US Institutional Review Boards (IRBs) and the state of Internet research ethics. An explanatory sequential mixed method design was conducted (Creswell & Plano Clark, 2003). Quantitative data was collected and analysed in Study 1 via an online survey of Australian Human Research Ethics Committee members. Semi-structured interviews (n=3) were then conducted with Chairpersons of Australian Human Research

Ethics Committees and analysed in Study 2 to further explain and clarify results found in the first data collection phase. Results of Australian HRECs current processes and practices from Study 1 were found to be similar to those reported by US IRBs and suggested that ethical review boards may be ill-equipped and ill-trained to navigate the review of IMR protocols. However, the addition of a qualitative overlay via the Australian HREC Chairperson's interviews in Study 2 provided additional detail that suggested that reviewing IMR protocols is more complex than previously understood. Thematic analysis of the interview data identified that the ethical review of IMR protocols is thoroughly undertaken via a principle-based process as it is not viewed as being different to any other research method or tool. Additionally, ethical responsibility is shared amongst the HREC, researchers, and participants themselves. This presentation will also provide a brief overview of specific considerations for IMR practice, such as online consent, use of data from discussion groups, and participant identify within social media.

1.30pm-3pm – Processes: Ctrl-Alt-Delete: Restarting Ethics and Governance

The Challenges and Rewards of Rebuilding Ethics from the Ground Up

Nicole Shively
The University of Queensland, Brisbane, Queensland, Australia

The University of Queensland undertook an external review of its human ethics systems and processes and procedures in 2015. Following that review, the University undertook a major initiative to establish two new HRECs and rebuild all processes and procedures from the grass roots level. This included reviewing the processes undertaken at the School level for Low and/or Negligible Risk research for students. These are the types of changes that would only occur at an organisation about once every fifteen years.

While it was challenging to recruit committee members for two committees and completing the registration process, implementing a series of significant changes in a complex organisation proved even more challenging, and was met with substantial resistance in the research community. By implementing careful communication strategies and engaging a team of experts to lead the changes, the climate gradually changed for the better.

The rewards are many, and the lessons learned invaluable. Would we do it differently next time? Probably. Would we do it again in the future? Absolutely!

Innovation in process and practice: a pathway to enabling and achieving research governance service innovation within the South Australian research governance framework.

Camilla Liddy, Andrea Averis

Women's and Children's Health Network, North Adelaide, SA, Australia

In Australia, research ethics and research governance have been split into two distinct phases of the health research approval process. A raft of legislative requirements underpins the research governance and research ethics systems of each Australian jurisdiction. Additionally, every Public Health Organisation (**PHO**) in Australia has its own policies and processes for managing institutional research governance.

SA Health policy requires each South Australian Local Health Network (**LHN**) to have a Research Governance Officer (**RGO**). The RGO will risk assess every research project in light of institutional requirements and SA Health policy.

In December 2015, the National Health and Medical Research Council (NHMRC) completed the first phase of a Good Practice Process (**GPP**) pilot project. The GPP focussed on strategies for enabling clinical trials of investigative medicines and therapeutics in Australia by identifying opportunities for streamlining research governance processes from beginning (feasibility assessments) to end (final authorisation of a research project at site). Some key enablers of a streamlined process were identified as consistency, communication and timeliness. It should be noted that there is room for improvement by all parties and at all points along the research governance timeline.

Along with other South Australian LHNs, the Women's and Children's Health Network (**WCHN**) Research Secretariat participated in the first phase of the GPP. We saw this as an opportunity to identify areas of potential improvement and points in our review process that could be readily streamlined. WCHN has reassessed our processes and has already actioned some of our ideas which arose from the GPP. This paper will also consider the success of existing innovations, feasibility of future improvements for research governance process improvement, and potential for innovation, such as the use of technology to enable research offices and researchers to access a single-point electronic submission and review process.

New approaches to PICF

Simon Windsor

1.30pm-3pm – Impacts: Ethical considerations Arising from a Changing World

The Increasing Use of FOI Applications Seeking Disclosure of Information about Research and its Potential Impact on HEI Research Review Practices

Mary Wyburn

University of Sydney Business School, Sydney NSW, Australia

Innovative research conducted in higher education institutions can be controversial and if it is, it is bound to attract the attention of other researchers working in the field, as well as the news media and the general public. Some of those other researchers will hold strong views about the nature of the

research being conducted in their area of expertise. A few will see themselves as having a responsibility to alert their research community and the public to practices that may adversely affect that research area. There are parts of the news media interested in exposing controversies involving higher education institutions. The news media also recognises it can readily find a readership for material addressing the general public's concern about public moneys being used appropriately and this includes its use for research supported through government grant funding bodies and the public universities.

Given the interest in research conducted at higher education institutions, in particular the attention focused on controversial research, the increasing use of freedom of information applications to gain access to details about these research activities should come as no surprise to researchers, their institutions or their funding bodies. The information being sought includes not only details about the content and methodologies of the research and the sources of its funding but also details about the progress of research projects through peer review of grant applications, ethics approval and post approval complaints and reviews. This paper examines these developments and discusses their potential effect on the future behaviour of researchers, higher education institutions and grant funding bodies. Will they help to foster fairer and more impartial practices or will they have a chilling effect on the practices that support the current framework for the review of research at higher education institutions?
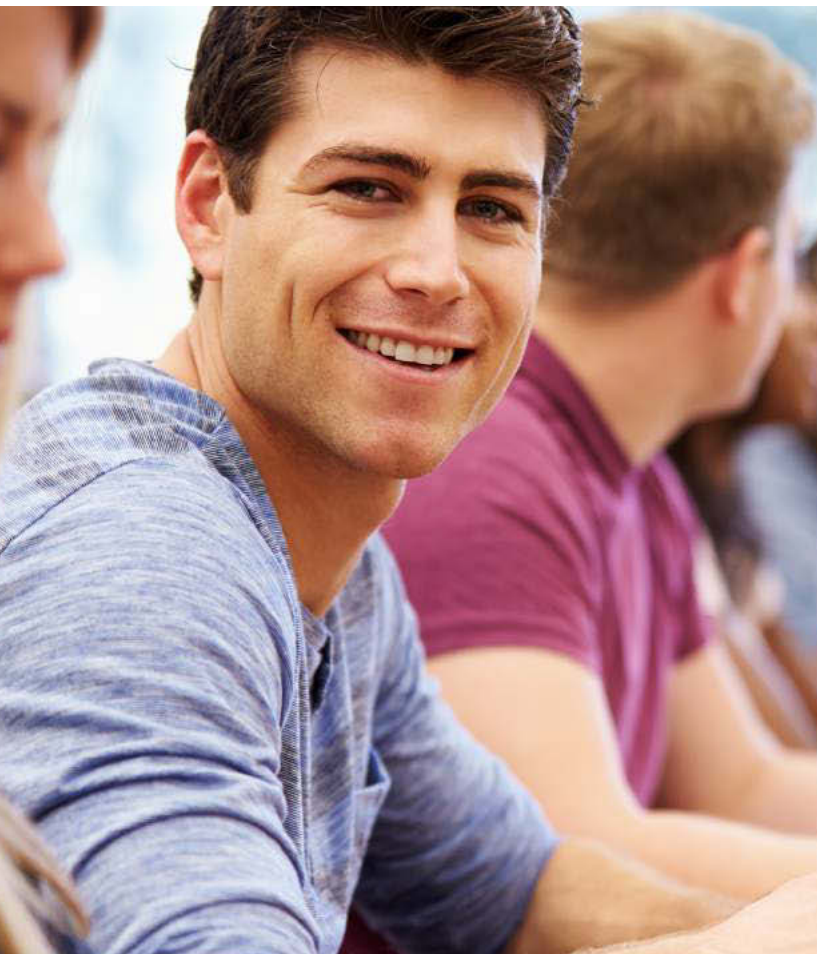
Negotiated Ethics: Using Social and Visual Technology in Newly Post-Conflict and/or Fragile State Fieldwork

Rochelle Stewart-Withers

Massey University, Palmerston North, New Zealand

The rapid adoption of Information and Communication Technologies (ICTs) by even some of the poorest developing nations has been argued 'as the end of isolation for the poor, even those said to live at the "bottom of the pyramid"' (Berdou 2011:5). Even the most marginalised, in the most fragile environments, are using for example, mobile phones to stay connected - whether this be to family, financial services and markets or to the various people whom they meet as they go about their daily, often complex, lives. ICT and internet-connecting devices have not only revolutionised day to day life for those living in the Third World but they have changed markedly travel and the academic fieldwork experience - for better and worse.

Merely doing fieldwork in the developing context brings a multitude of complexities; it is not unusual for Third World researchers to find themselves in situations which do not marry well with various institutional ethical requirements. When intersected with an age of advancing technology and innovation these complexities multiple. In addition, researchers are finding they are faced with ethical questions about not only their own use of ICTs in the field but that of their participants.

With this in mind, and in drawing on examples from fieldwork in newly post-conflict nations or 'fragile' states, this paper considers from an ethical perspective the use of ICTs, specifically social

technology and visual tools use. Consideration will be given to privacy and confidentiality, notions of risk and harm and the importance of relationships. The intention is add to broader conversations about ethics in practice and the importance of seeing ethics as not only ends but means and ends.

Is the race for innovation compromising good ethical practice? Lessons from corporate scandals

Amy Salapak[1,2]

[1]Edith Cowan University (Human Research Ethics Committee), Perth, WA, Australia, 2Department of Health, Perth, WA, Australia

We are in an ideas and innovation boom. An age where research and technology are big business and there is a rapidly growing emphasis on investing in, and supporting, innovative start-ups. The focus on Australia reaching new heights in the areas of science and research also carries with it the critical importance of maintaining good ethical practice. Particularly, where the research involves individuals as participants. But what happens when ethics are lost to innovation, profit margins, dividends, market dominance and the commercial pressures to produce breakthrough research, products and technology? What is the impact on companies, institutions, researchers, participants, and the public at large? This presentation will explore some key cases both in Australia and overseas to see what we can learn from instances where corporate entities and researchers chose to promote "innovation" over good ethical practice. It will consider both the ethical and legal ramifications of this conduct and the frameworks that apply. This presentation will address how as human research ethics committee members we can balance the tension of encouraging new research while ensuring for thorough risk management strategies and robust ethical review. It will also look at the responsibilities and the pivotal role institutions and researchers play in balancing this tension.

3.30pm-5pm – Technology: Using Technology for Ethics Review

Out with the paper: opportunities and obstacles of brining an HREC online

Selina Metternick-Jones, Sean Howarth, Aron Chakera

Department of Research, Sir Charles Gairdner Hospital, WA, Australia

The Sir Charles Gardiner and Osborne Park Healthcare Group (SCGG) ethical review process has been operating effectively for almost 20 years. Through this process around 150 research studies are reviewed annually by its Human Research Ethics Committee (HREC). The ethical review process is designed to promote ethically sound and scientifically rigorous human research.

For an HREC to operate effectively it must be supported by efficient policies and processes. Until recently, the SCGG HREC has relied on manual, paper-based processes for all aspects of submission, review and monitoring of research. This resulted in inefficiencies for the HREC Office and those involved in research within the SCGG. The key issues identified in a review of the HREC process included significant paper wastage, inefficient use of staff time and printing costs being inadvertently absorbed by hospital departments. In response, the HREC Office has transitioned to an electronic process of submission, review and monitoring.

The transition to an electronic system was a multifaceted project involving the harmonisation of four key milestones. The first involved a retrospective scanning project and transition to an electronic record management system, HPE RM. The second included implementation of an online board management system that allows HREC members to review research proposals electronically. Thirdly, internal processes were reformed to manage the submission of proposals and amendments via email. The final milestone involved rewriting key policies to reflect the new, electronic process including Terms of Reference and Standard Operating Procedures.

A number of challenges were faced in the transition period, including reluctance to change by some committee members and hospital departments. It is expected that the implementation of this electronic system will have positive implications for the hospital and the HREC Office including improved sustainability, decreased time taken to process documents and a reduced burden on those submitting research for review.

Innovations in a Human Research Ethics Committee: streamlining with technology

Sara Potts[1], Nikola Stepanov[1,2], Sue Jenkins-Marsh[1], Wendy Smyth[1,2]

[1]Townsville Hospital and Health Service, Townsville, QLD, Australia, [2]James Cook University, Townsville, QLD, Australia

This paper considers some of the challenges faced by regional Human Research Ethics Committees (HREC), and innovative approaches to addressing those challenges. In particular it looks at the impact of four key reforms on: the efficiency of research ethics review; changes to workflow in HREC operations; workload distribution on HREC members; and HREC member retention.

The four key reforms implemented were:

- establishing clear guidance around what constitutes as being 'non-research', 'negligible or low risk research' and 'greater than low risk research'; and then providing defined and transparent ethics review pathways for each category;
- moving to a bi-monthly roster and low risk review roster to reduce HREC member workloads;
- implementing technology to transition to paperless research ethics reviews;
- utilising technology to review and manage research activity post approval.

To date, the results have been promising. Establishing clear guidelines for ethics review pathways, in conjunction with education on research and non-research definitions, has delineated between true research submissions and quality assurance and service evaluation projects. This has resulted in a more simplified application process, and more efficient ethics reviews. The ethics review processes and workflows are now clearer for both researchers and HREC members. Increasing committee member numbers whilst reducing individual member workload through the roster system has resulted in also reducing member time commitments. And, by utilising technology to improve committee operations, the administrative burden and time for approvals has been reduced for HREC staff, HREC members, and researchers.

Overall, the innovations have resulted in improved membership retention and satisfaction, and reduced turnaround times for application reviews. Future changes include planned improvements for paperless submissions and online reviews, which will significantly improve the application process for local and remote researchers and streamline the review process for members.

3.30pm-5pm – Processes: Research Integrity and Monitoring

### Monitoring of approved research

Anne Walsh, Jane Jacobs

Queensland University of Technology, Brisbane, Australia

Our national ethics guidelines require institutions to monitor approved research. The QUT policy for 'Monitoring Approved Research' was implemented in early 2016. This policy provides the framework and mechanism to assess projects according to ethical conditions of approval. In addition, monitoring of approved research presents the opportunity to build relationships between researchers, the review body and Office of Research Ethics and Integrity (OREI) and provide an educative opportunity for both researcher/s and the review body. This presentation will describe the innovative monitoring framework and processes that support the policy to enable QUT to meet its monitoring obligations. Case studies and examples will be used to illustrate these mechanisms.

UNIVERSITY OFFICE
Leading Research Management Systems Innovation.
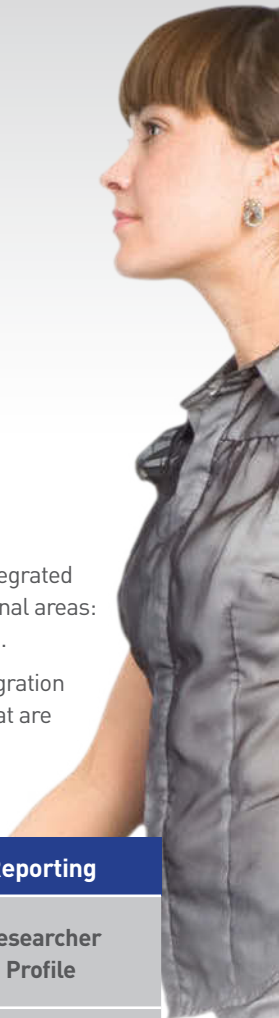
We are a leading software and services organisation focused entirely on research management. Our research management solution, IRMA, is a leading solution that delivers rapid and real benefits to universities and research institutions wanting to leverage the power of their research management information.

What IRMA delivers.

IRMA is a highly configurable, web-based research management application consisting of nine fully integrated modules. These modules cover four distinct functional areas: Foundation, Administration, Integrity and Reporting.

IRMA's modular design provides a high level of integration as well as the flexibility of choosing the modules that are relevant to your research organisation's needs. IRMA is ERA 2015 compliant.

	Foundation	Administration	Integrity	Reporting
Projects	People	Grants and Contacts	Human Ethics	Researcher Profile
Centres	People	Grants and Contacts	Human Ethics	Researcher Profile
Contact Management	Organisational Structures	Research Outputs	Animals Ethics	ERA
Web Services	Organisational Structures	Research Outputs	Animals Ethics	ERA
Repository Interfaces	Security Permissions & Profiles	Higher Degree By Research	Biosafety	Report Writer & Reporting Wizards
Snapshot	Security Permissions & Profiles	Higher Degree By Research	Biosafety	Report Writer & Reporting Wizards
Regulatory Interfaces	Workflow	Commercialisation	Risk Management	External Reporting Integration
Online Forms Designer	Workflow	Commercialisation	Risk Management	External Reporting Integration
Competencies	Workflow	Commercialisation	Risk Management	External Reporting Integration

Integration
IRMA's design allows for collaboration through data exchange between IRMA and systems being used by research institutions and government departments, as well as enterprise systems. IRMA uses configurable web services, allowing integration and collaboration on any scale.

IRMA now integrates directly with services provided by the Australian Research Council, National Health and Medical Research Council, ORCID and Ringgold.

Reporting
An in-built reporting tool means there's no reliance on third-party products, and the system also has a number of reporting wizards, all of which comply with government requirements. Standard tools extend to performance reporting, such as the Excellence in Research for Australia (ERA), and the system's structure allows for fast adaptability to changing reporting specifications.

Security
Access to data and functions is restricted through role-based security barriers, ensuring data integrity and enabling extensive auditing. Authentication is secured through encryption protocols, as is all the information exchanged between users and the application.

Collaboration
IRMA is a 100% web-based application designed with a strong focus on user requirements that facilitates collaboration and sharing of information between researchers, administrators and project teams. IRMA provides anywhere, anytime research management solution.

Ease of implementation
University Office is proud to be the market leader in fast and low-cost implementation through the use of integrated web tools, pre-defined configuration, customisable forms, and flexible and dynamic configuration options.

universityoffice.com.au

thirst studios

Ringgold

University Office
ARMS Gold Corporate Partner

ARMS
Australasian Research Management Society

ORCID
Connecting Research and Researchers

Member Organization

Addressing research breaches – educative not punitive (Innovation in processes)

Sue Jenkins-Marsh, Sara Potts, Leanne Griffiths, Kelly Parker, Nikola Stepanov

Townsville Hospital and Health Service, Townsville, Australia

Background

The *National Statement on Ethical Conduct in Human Research* requires that a HREC must at regular periods, and at least annually, receive reports from principal researchers on matters including:

a. Progress to date or outcome in the case of completed research.
b. Maintenance and security of records.
c. Compliance with the approved protocol.
d. Compliance with any conditions of approval.

In addition, the *National Statement* Section 5.5.5 requires researchers to not only report at least annually to the HREC but also to the relevant institutions.

With the commencement of single ethics review for multi-centre studies it has become more time consuming for researchers to keep track on what is required to be reported and to whom.

In addition, the commencement of single ethics review for multi-centre studies has made it difficult for some researchers to understand the differing ethics submission, review and approval process and the site specific assessment submission, review and authorisation process. This difficulty is particularly apparent for those researchers who come from organisations where there is still not a separation between research ethics review and approval and site specific assessment and authorisation.

Innovation

This presentation will show how a regional organisation has identified, through the use of an IT platform, research breaches which have occurred, how these breaches were managed in an educative fashion and what steps have been implemented to ensure research breaches are minimised in the future.

Examples will be given on:

- Studies conducted with HREC approval but without institutional authorisation
- Studies conducted after HREC approval expiry date
- Potential research misconduct cases
- Studies conducted without annual reports submitted

The steps implemented will include demonstrations of the collaboration between the HREC & Research Governance team, the use of an IT platform to notify researchers of their responsibilities and the education implemented.

Boundaries between Research Ethics and Integrity

John Hunt, Leonne Thompson, Ted Rohr

UNSW Australia, Sydney, NSW, Australia

Human research may be subject to complaints or allegations from a number of sources, including participants, researchers, the general public and or institutional or government officers. The nature of these complaints or allegations varies considerably, from direct impacts on the health or wellbeing of participants, to allegations of non-compliance with protocols approved by ethics committees, to objection to the research topics and more. Some of the complaints or allegations may be resolved quickly by a discussion between ethics committees and researchers while others may need urgent action to collect evidence if research misconduct is suspected. Identifying the appropriate pathway at an early stage is important, since the wrong choice can have significant implications for those involved. The Australian Code for the Responsible Conduct of Research provides some theoretical guidance on evaluating the seriousness of such issues , but there is little practical guidance available to help determine appropriate pathways. Here, we present case scenarios of complaints and allegations received through a number of sources, discuss the challenges they represent, and suggest possible pathways to resolve them fairly and appropriately.

3.30pm-5pm – Impacts: The Changing Field of Research Ethics

The Expanding Disciplinary Scope of Research Ethics: a story of resistance.

Karolyn White[1], Lisa Wynn[1], Colin Thomson[2,1], Mark Israel[3], Luke Mills[1], Ziyan Guan[1]

[1]Macquarie University, NSW, Australia, [2]University of Wollongong, NSW, Australia, [3]University of Western Australia, WA, Australia

The history of the roll out of ethics review in Australia in which ever more disciplines were required to submit their research for ethics review has been described as the "ethics imperialism narrative" (Israel 2016) or "mission creep" (Haggerty 2004). Unlike other countries, the roll out of ethics review to new disciplines in Australia was not prompted by ethics scandals. As Chalmers (2001) noted, the move from ethics self-regulation to external ethics oversight occurred at the time of greater demands for public accountability, expanded civil liberties and consumer rights. Moreover, the move was initiated with little consultation with the new disciplines. It is little wonder then that ethics review has been criticised by researchers in these disciplines both in terms of the values expressed in the national guidelines and how the guidelines were applied to them. Many of the criticisms of how ethics committees review research from these disciplines centres on the lack of expertise about innovative research methods which are commonly used.

In this paper we will explore the impact of this roll out on the disciplines most recently drawn into the ethics narrative; and to explore the impact of this review when committees fail to understand innovative research methods. We will present qualitative and quantitative data to measure the level of support for ethics review among academic disciplines, including those most critical of the review process. We will conclude with a response to the question of whether some disciplines are more resistant to or more adversely affected by ethics review.

Getting back to basics for research ethics and governance

Jan-Louise Durand

CAHLN, SA Health

Low and Negligible Risk (LNR) studies are often investigator initiated and often led by researchers less familiar with the requirements of both ethics and governance than experienced clinical trial researchers.

With the implementation of the LNR Ethics Form and LNR Site Specific Assessment (SSA) Form came confusion about what was required for both submissions.

There was significant delay between ethics submission, approval, and SSA submission, or no SSA submission at all.

We needed to review the processes and get back to what we really needed. Focus should be on a comprehensive research protocol and any additional forms should be very simple.

Becoming dangerous: a Foucauldian discourse analysis of researchers at the dawn of research governmentality

Kate O'Connor[1,2]

[1]Auckland University of Technology Ethics Committee (AUTEC), Auckland, New Zealand, [2]Northern B Health & Disability Ethics Committee, Auckland, New Zealand

During the twentieth century a range of ethics discourses sought to reveal the truth about researchers through the examination of them by group review. This paper turns its gaze, not to the century when Research Ethics Committees (RECs) bloomed with disciplinary power, but to the centuries before. This historical-political analysis locates the emergence of the now familiar discourses of research dangerousness. These discourses produced a triptych of new subjects: the researcher as like someone Foucault called "the individual to be corrected"; the research participant as someone to be protected from absolute danger, and; the new groups empowered to judge, control and discipline. In this paper, I trace the

mobilisation of particular accounts of dangerous researchers, from Herophilis to Neisser, examining the conditions of possibility for an increasing 'pathologification' of the research professions which made the descent of RECs as forecasters of danger seem natural and inevitable. I illustrate the earliest example of researchers becoming subjects of REC-like sovereign structures. By first concentrating on dangers' discursive powers to link researchers to their offences and to create fear and anger, I proceed to link the new power /knowledge of research government at the dawn of the twentieth century in Germany, held together by the notion of danger, to the disciplinary and panoptical technologies of normalisation practiced by RECs to defend populations from the risk of research grotesques as well as lesser infractions. In revealing the discontinuous eruption of these force-relations prior to the research crises of Nazi Germany, especially those which required researchers to confess, and to be subjected to others' judgement, this inquiry is part of a re-thinking of the traditional, linear historiography of research government that portrays it as evolving continuously from The Nuremberg Code forward in response to the new ethical challenges of innovative research.

End of Abstracts for Thursday

Inspired, Partnered, Excellence

The University of South Australia is a globally connected and engaged university helping solve the problems of industry and the professions. Our teaching is industry-informed, our research inventive and adventurous, and focused on creating impact.

Through our research, we create knowledge that is central to global economic and social prosperity. We are a young university, continuing to set the pace for world-class research and solutions for a changing world.

To learn more about our research please visit **unisa.edu.au**

CELEBRATING
25
YEARS

University of
South Australia

9am-10.30am – Plenary Session: National Regulator Update

Development of a principles-based Australian code for the responsible conduct of research 2007 and supporting better practice guides

Jillian Barr[1], Karolyn White[2]

[1]*NHMRC, Canberra, ACT, Australia, [2]Macquarie University, Sydney, NSW, Australia*

The National Health and Medical Research Council (NHMRC) is Australia's leading expert body for supporting health and medical research, developing health advice for the Australian community, and providing advice on ethical behaviour in the conduct of health and medical research.

For 2015–18, one of NHMRC's main priorities is to further develop a strong research integrity framework. It is important that this framework can accommodate new innovations in practices and processes that may emerge in the Australian research community. As such, NHMRC regularly reviews the three national research standards that comprise this framework: the *Australian code for the responsible conduct of research 2007 (the Code);* the *National statement on ethical conduct in human research;* and the A*ustralian code for the care and use of animals for scientific purposes*. These reviews involve extensive consultation with the research sector to ensure the standards remain relevant and implementable. This talk will outline the review of the Code.

The Code is an important reference for researchers and administrators across all disciplines, and promotes community trust in Australian research. Adherence to the Code is a requirement of all funding provided by the NHMRC or the Australian Research Council (ARC). These guidelines are co-authored with ARC and Universities Australia (UA).

Feedback from the research sector noted the heterogeneous nature of the requirement for guidance by different institutions. As such, the revised Code has been streamlined into a principles-based document that outlines the broad responsibilities of researchers and institutions. Detailed guidance about implementation of the Code will be provided in better practice guides.

The talk will present the draft principles-based Code and the better practice guide on managing departures from the Code. It will explore key differences to the current Code and discuss how the principles-based approach allows for better on-going adaptation to the changing research landscape.

NHMRC Clinical Trials Update

Gordon McGurk

11am-12.30pm – Technology: Innovations in Research Methods

Digital ethics: measuring the impact of online wellbeing initiatives for minors utilising online passive data collection ethically.

Carmel Taddeo, Barbara Spears, Alan Barnes

University of South Australia, South Australia, Australia

The ever-increasing numbers of youth engaging online, coupled with an exploding array of e-wellbeing resources, calls for new research methods and research ethics, appropriate for digital spaces, especially where minors are concerned. An innovative research approach involves passive data, which is automatically generated through user engagement with websites/apps. Together with user-inputted data, it has traditionally been used to generate revenue and online traffic. The arrogation of companies' rights to use such data is often concealed in terms and conditions. In contrast to this lack of "informed" consent, researchers are held to higher standards and seemingly greater restrictions than commercial counter parts.

The Australian government funded Young and Well Co-operative Research Centre, Safe and Well Online project (approximate N = 4,500), sought

to determine the efficacy of four youth-centred, co-designed online social media campaigns, which aimed to nudge youth attitudes and behaviours towards positive wellbeing and help-seeking. This project extended traditional methods of data collection by incorporating online passive data collection of participants' engagement with the campaigns, tracked by Unique ID and mapped against self-reported survey data.

Given the massive uptake by youth of the online environment, it is imperative to understand how digital efforts to intervene in health/wellbeing initiatives, are received and adopted. The tracking of youth online behaviours and engagement with such initiatives in naturalistic settings, is critical to better understanding effective initiatives.

There is however, a need for cross-sectoral ethics protocols and processes to be considered by multiple stakeholders: including ethics committees, educators, health professionals, parents and technology experts with regard to young people's participation in reputable online studies that utilise innovative data collection methods. This paper will detail the passive data collection employed in the project and will discuss the ethical challenges of measuring authentic youth engagement along with learnings and opportunities for progressing this important agenda.

Supporting research ethics and integrity at QUT

The Office of Research Ethics and Integrity (OREI), Division of Research and Commercialisation, assists researchers in seeking ethical approval and governance of all human, animal and biological related research. OREI assists researchers to meet their statutory obligations and provides education support that promotes responsible research practices.

www.orei.qut.edu.au

QUT

a university for the real world®

Ethics and the digital camera: what is research imaging data in the age of the smartphone?

Adrian G. Dyer[1]*, Jair E. Garcia[1] and Ted Rohr[2]

[1]RMIT University [2]UNSW Australia

Up until the end of the 20th century, photographic images were relatively expensive, slow to produce and, in professional research contexts like universities or teaching based hospitals, often managed with a large degree of control over distribution. These physical constraints somewhat simplified the management of ethical issues, and many policy settings remain adjusted to this previous reality. Digital cameras, including high resolution and internet-capable mobile devices, now provide researchers and medical practitioners with a high degree of autonomy in how large volumes of image data can be rapidly captured and communicated. An image captured on a smart phone can potentially have a worldwide audience within minutes. Such images often contain specific identifiable data. We discuss comparative case studies from the use of digital photographs in science, medicine, forensics and the social sciences, how these respective fields currently regard the ethical use of digital images, and who is perceived to own the copyright of images in particular contexts. We discuss frameworks for digital image data maintenance and disposal protocols and emerging software solutions that could be implemented by research intensive organisations. We aim to stimulate discussion on how digital imaging research can be ethically managed during the 21st century.

Using Facebook to reach the un-reachable - does it actually work?

Holly Seale

It has been suggested that using social media tools such as Facebook, twitter etc. is an effective approach to recruiting participants onto studies. Especially participants that are usually hard to reach by other traditional approaches. However, does the evidence support this claim? This presentation will explore the evidence that has been published and will also examine some common pitfalls and potential strategies to avoid them.

11am-12.30pm – Processes: Becoming an Approachable HREC

A friendly face: Ethics Clinics at UTS

Yordanka Krastev, Valeria Passo

University of Technology Sydney, NSW, Australia

This presentation outlines the experience of the Ethics Secretariat at the University of Technology Sydney (UTS), in facilitating the ethics application process for researchers and research students across the university via the provision of "Ethics clinics". In 2015 the UTS Ethics Secretariat introduced a new initiative called "ethics clinics" to help researchers with addressing ethical issues related to their research, resolve challenges with various application forms and to improve the quality of the ethics submissions .

A booking system for a half an hour face to face consultation with the Research Ethics Officer was implemented on a set day of the month in three locations: Faculties of Science, Arts and Social Sciences, and Health. The bookings were made online and each Faculty had a specific link and password for each month. Initially six stakeholder groups in three locations were included in the pilot. After 6 months, the ethics clinics were opened to all other Faculties and continued to operate in 2016.

In the presentation, we will also share some statistics on the uptake of the clinics in the past year, some reflections on the impact of ethics clinics on the quality of ethics applications, on the researchers understanding of the ethics process, and on the workload of the Ethics Secretariat and the Committee. The process proved to be a unique opportunity for the Ethics Secretariat to better engage with researchers and create invaluable relationships with our internal stakeholders.

Does your ethics committee have an image problem? The potential for marketing to improve relationships and streamline processes

Melanie Randle

University of Wollongong, Wollongong, Australia

Human research ethics committees (HRECs) serve a vitally important role in Australian universities, and as such should be held with esteem and respect by researchers and institutions alike. However, research has highlighted the tensions that can exist between researchers and HRECs. Empirical studies reveal researcher criticisms of HRECs to include a failure to understand researchers and methodologies, being more motivated by risk management concerns than protecting human subjects, and a perception of unfair or disrespectful treatment of researchers. Meanwhile, ethics committees can also experience frustrations with researchers, including haphazard approaches to the preparation of ethics applications and a lack of explanation regarding issues that may be confusing or controversial. Combined, these perceptions can lead to mistrust and poor relations between researchers and committees, and create tension and conflict within the institution.

Acknowledging the potential negative consequences of these tensions, researchers have called for studies that examine "effective ways to improve the committee's image in the eyes of the investigators it serves" (Keith-Spiegel et al, 2006, p.78). Previous studies have investigated researcher-HREC relationships from an organisational justice or regulatory perspective. Instead, this paper takes an alternative perspective and considers the issue in the context of marketing, whereby researchers are 'customers' and the ethics review and approval process is a 'service' being provided. The protection of research participants, through thorough review processes and ensuring that principles underpinning the National Statement are practically applied through research protocols, is central to the integrity and quality of the 'service' provided. In doing so, this paper considers how marketing principles, such as brand image management and relationship marketing, might be applied to improve relationships, increase customer satisfaction and streamline processes. Suggestions are made for actions HRECs could take to improve its image and relationships, both with individual researchers and across the university as a whole.

Knowing More but Asking Less – Supporting researchers in an increasingly regulatory world.

Glynn Stringer, Ann Morgan

University of South Australia, Adelaide, SA, Australia

Researchers often voice their concern that they have less time to undertake their research due to the large number of forms and documentation they are required to complete. The concept of 'administration' is seen as an unnecessary overhead and a burden distracting researchers from the 'real work' of undertaking research. On the other side of the coin, the collection of administrative information is crucial to enable universities to protect the interests of research participants, to ensure contractual obligations are met, and to prove the value of research to society and funding agencies.

At the University of South Australia we are implanting solutions to 'cut red tape' and minimise the amount of time spent on administrative tasks. In this presentation, we will show how university information systems can be harnessed to minimise overheads through the adoption of carefully selected support principles and business analysis. The details of two initiatives in support of research ethics (one related to human ethics and one related to animal ethics) will be presented.

11am-12.30pm – Impacts: Ethical Principles of Research with Aboriginal and Torres Strait Islander Populations

Ethical Values in Aboriginal Research

Kim Morey, Annapurna Nori

AHCSA

Institutional Barriers that Aboriginal Researchers Face when Conducting Human Research, and Why it Needs to Change

Mandy Downing, Philip Moore, Sean Gorman
Curtin University, Perth, Western Australia, Australia

Aboriginal researchers are constrained by institutional barriers that exist within the governance structure of Human Research Ethics Review, yet no literature exists on the experiences of Aboriginal researchers. This presentation will showcase the research conducted by an Aboriginal Research Ethics Officer from Curtin University who has engaged with Aboriginal research academics located in Western Australia regarding their experiences of the ethical review process in Australia. As Aboriginal and Torres Strait Islander people, we remain trapped in a colonial discourse, where our battle for self-determination has taken a hit with the stigmatisation that surrounds Aboriginal and Torres Strait Islander People as a 'vulnerable' population in ethical guidelines. The National Statement on Ethical Conduct in Human Research disempowers Aboriginal researchers by applying additional hurdles to manage cultural competence for non-Indigenous people. Is there another way that ethical review can occur for Aboriginal and Torres Strait Islander people's research or will we forever remain to be seen as 'vulnerable'?

Turbulent waters: Challenges and adaptations conducting PAR with diverse consortia partners and communities.

Petra Buergelt, Beverley Turnbull, Elaine L Maypilma, Julia McPhee, Timothy Skinner, Anne Lowell, Simon Moss
Charles Darwin University, Darwin, Australia

As per the National Innovation and Science Agenda Report (2015) Australia's federal government has directed researchers to conduct more research in partnership with industry to increase the impact of their research. This directive, in tandem with the increasing competition over funding resources, is likely to increase researchers conducting projects in collaboration with consortia consisting of a diverse mix of businesses, government departments and NGOs. As a result, more research will be conducted as participatory action research projects in specific field sites to address 'real world' challenges. In addition, the diverse and often conflicting interests, needs and expectations among consortia members, and between consortia members and communities are likely to create complex, rapidly changing and challenging research contexts. To navigate these new research contexts effectively will require researchers to carefully plan their research protocols and to respond quickly to a wide diversity of unanticipated ethical and methodological challenges and dilemmas as they arise throughout the research process. These aspects may challenge research integrity and HREC processes.

This presentation draws on experiences and learnings gained during an innovative nationally funded consortia participatory action research project with Indigenous communities and the ethical challenges and considerations that can arise. We will provide these insights from two parallel perspectives; that of the researchers and from the HREC.

1.30pm-3pm – Technology: mHealth, eHealth, Telehealth: Applications to solve the tyranny of distance, reach across languages, and enable new research

Towards Research Equity for Culturally and Linguistically Diverse (CALD) Patients through Mobile Health Ethics and Research Information: A Proof of Concept Study

Robyn Woodward-Kron[1], Anna Parker[1], John Hajek[1], Jo Hughson[1], Clare Delany[1], Tuong Phan[1,2], David Story[1]
[1]University of Melbourne, Parkville, VIC, Australia,
[2]St Vincent's Hospital, Fitzroy, VIC, Australia

People from culturally and linguistically diverse backgrounds (CALD) remain excluded from clinical trials due to a range of language, literacy

and cultural factors such as the literacy needed to understand paper-based Participation and Information Consent forms (PICF). These barriers can be compounded when this population is ageing. Exclusion of these populations contributes to health inequalities for migrant groups; it also limits the generalisability of medical research findings. There is some evidence that multi-media technologies can assist to overcome cultural concerns and language and literacy barriers to research participation (author ref blinded for review, 2016a), yet ethics committees need to be confident that novel consent processes adhere to ethical principles.

A multidisciplinary research team of clinicians, linguists, educators, and ethicists at the University of Melbourne have developed a prototype mobile health (m-Health) resource, *Let's talk medical research/ Parliamo di ricerca medica* (blinded review 2016a): an interactive tablet delivered web-app, providing bilingual audio-visual research information for patients and their families, including exploratory technology informed consent processes (blinded review, 2016b). This paper reports on the findings of a proof of concept study into the acceptability, feasibility, and utility of the prototype resource to be conducted at St Vincent's Hospital, Melbourne, in July-August 2016.

The study design is qualitative and utilises observation, a brief survey, and interviews with 10-15 Italian speaking patient participants, 10-15 English speaking patient participants, 7-10 family members for each language group, and 10 researchers/trial recruiters and ethics administrators in total. The interviews will be conducted by a bilingual researcher, and analysed in terms of content and themes.

The findings will provide proof of concept evidence of the prototype including findings on its acceptability, utility, and feasibility from patient, family, researcher, and regulatory perspectives. The findings will also inform a methodology for adapting the resource to other CALD groups.

Reflections on the nexus between ethics and health promotion in the Northern Territory: Challenges and opportunities

James Smith[1,2], Dagmar Schmitt[3,4], Jason Bonson[5], Lisa Fereday[3]

[1]Office of Pro Vice Chancellor - Indigenous Leadership, Charles Darwin University, Darwin, Australia, [2]Collaboration for Evidence, Research and Innovation in Public Health, Curtin University, Perth, Australia, [3]Health Development Branch, NT Department of Health, Darwin, Australia, [4]School of Health, Charles Darwin University, Darwin, Australia, [5]Office of Men's Policy, NT Department of Local Government and Community Services, Darwin, Australia

Background

Ethics and health promotion has emerged as a hot topic in health promotion literature over the past decade. Various scholars have discussed theoretical and practical considerations associated with what health promotion ethics constitutes and its respective implications for policy and practice contexts. In this reflective paper, we draw on our collective experiences of having worked in senior specialist health promotion roles in the Northern Territory Department of Health. There are particular factors associated with navigating the uneasy nexus between ethics and health promotion within policy, practice and health service delivery contexts in the Northern Territory. For example, formal ethics committees are not necessarily a viable option within some small community or organisational contexts; there is limited professional capacity and capability to embed a focus on ethics and health promotion into professional development, education and training opportunities; established human research ethics committees within higher education institutions play a vital role in health promotion research, yet rarely extend to policy, practice and service delivery contexts; and there are differences between mainstream ad Indigenous ways of approaching ethics. The challenges and opportunities these factors create will be discussed. Understanding and addressing impeding factors is critical. There are unique considerations about the nexus between ethics and health promotion that

are specific to small jurisdiction contexts, such as the Northern Territory. Consideration of such issues needs to be considered in broader national and global discussions on this topic.

1.30pm-3pm – Processes: Updates on National Statement and the Human Research Ethics Application Form

The review of the National Statement on Ethical Conduct in Human Research, 2007

Jillian Barr

NHMRC, Canberra, ACT, Australia

The National Health and Medical Research Council (NHMRC) is Australia's leading expert body for supporting health and medical research, developing health advice for the Australian community, and providing advice on ethical behaviour in the conduct of health and medical research.

One of NHMRC's main priorities is to further develop a strong research integrity framework. This framework must accommodate new innovations in research that may emerge in the Australian research community. As such, NHMRC regularly reviews the three national research standards that comprise this framework: the *Australian code for the responsible conduct of research 2007 (the Code);* the *National statement on ethical conduct in human research* (the National Statement)*;* and the A*ustralian code for the care and use of animals for scientific purposes.*

This presentation will focus on our revision of the National Statement.

After the National Statement was last fully reviewed, the NHMRC Council endorsed a 'rolling review' approach to review of these guidelines. This approach enables updating or reviewing the document in response to changes in research nationally, or internationally.

A 2013-14, survey of National Statement users identified Sections 3, 4 and 5 as sections in need of review and focused on review of Section 3: *Ethical considerations specific to research methods or fields.* This review is currently underway and public consultation on a revised Section 3 and consequential changes to Section 5 is scheduled for late 2016.

The review of Section 3 was driven by, and specifically focused on, new approaches to guiding the ethical conduct of researchers in all types of research, both in more conventional and more innovative research disciplines, fields and methods. Many of the proposed changes address novel approaches to research, such as research using social media, and the expanded scope and evolving technologies that characterise areas of research such as genomic research.

The HREA: Overcoming disruption with disruption

Robert Rigby

3pm – Impacts: Impacts of Technology on HRECs

The changing of the arrangement of ethics meetings

Lana Lon

Health Research Council of New Zealand, Auckland, New Zealand

Ethics committees used to exclusively use face-to-face meetings to conduct ethics review and undertake approval deliberations. In recent years, mostly due to the volume of workload, some ethics committees have established more than one pathway for this process. The choice of pathway seems to depend on the level of risks of the research. Out of the 15 ethics committees approved by the Health Research Council of New Zealand, only one does not have more than a single pathway for ethics review. The format of the meetings for the different

pathways differ. Quite often, the low risk or expedited review will be considered electronically while all other applications are considered at face-to-face meetings.

But the question remains, what are the drivers for the use of different modes of meetings and for utilizing different pathways for ethics review? But, more importantly, what are the ethical challenges associated with the use of electronic meetings?

Quality Assurance or Research? A More Coherent Process for Negligible Risk Research.

Melissa Cadwell, Kristin Wallis, Lisa Fry, Giuliana Fuscaldo

Barwon Health, Geelong, Vic, Australia

There is sometimes uncertainty about what level of ethics oversight is required for quality assurance (QA) and audit activities and confusion about whether a proposed project should be considered as a research project or QA.

Further, the current guidelines for the ethical review of research applications recognise three different levels of risk but provide only two types of application. Greater than low risk research is associated with risk of harm; low risk research is associated with risk of discomfort; and negligible risk research entails no more than inconvenience. However, the current review processes and national ethics application forms combine negligible risk and low risk research and do not provide a clear application process for the review of quality assurance, and audit activities. Increasingly peer reviewed journals require evidence of ethics oversight for all projects involving human participants, including audit and quality assurance activities. The national guidelines advise that research that involves no more than low risk research (including QA and negligible risk research) 'must be reviewed by people who are familiar with the NS and have an understanding of the ethical issues that can arise; and have due regard to privacy regulations (laws) and is reviewed to ensure that it does not require review by the Human Research Ethics Committee (HREC).

However, standard ethics review processes do not easily accommodate QA and audit projects. We suggest that attempts to clearly separate QA from research are not always helpful. Further we argue that negligible risk projects should be a separate category to low risk research. We describe a process for accommodating both researchers and journals need for evidence of ethical review of audit and QA, and which provide greater coherence and alignment with the intention of the national guidelines in relation to negligible risk activities.

Technology: The Changing Landscape of Research Governance

Results of Governance Best Practice Pilot

Gordon McGurk

NHMRC

The lived experience of a Clinical Trial Liaison Officer

Jenny McGrath, Elena Voss, Richard Verelli, Alison Barr

End of Abstracts for Friday

AUSTRALASIAN
ETHICS NETWORK

themeetingpeople.com.au/aen2016/