

AUSTRALASIAN ETHICS NETWORK AEN CONFERENCE

10 May 2023 - Preconference Workshops

11 - 12 May 2023 - Conference

Jasper Hotel, Melbourne, Victoria



AEN CONFERENCE 2023 PROGRAM

Wednesday 10 May 2023

07:30 – 08:30			PRECONFERENCE WORKSHOP REGISTRATION OPEN		
Workshops		Room 3 & 4		Room 8	
08:30 – 12:30 (Inc M/Tea)		<p><u>Workshop 1</u></p> <p>Upskilling Workshop for Research Ethics Professionals <i>Dr Nitya Phillipson, Murdoch Children's Research Institute, Elizabeth Hill, Victoria University & Jennifer Rowland, Macquarie University</i></p>		<p><u>Workshop 2</u></p> <p>Human Research Ethics Committee Chairs Roundtable <i>Dr Karolyn White, Macquarie University & Professor Richard Chenhall, The University of Melbourne</i></p>	
LUNCH BREAK					
13:00 – 17:00 (Inc A/Tea)		<p><u>Workshop 3</u></p> <p>The Victorian Aboriginal Health, Medical and Wellbeing Research Accord: What Does it Mean for Ethics? <i>Ms Olivia Payne, Victorian Aboriginal Community Controlled Health Organisation (vaccho)</i></p>		<p><u>Workshop 4</u></p> <p>Upskilling for New Committee Members <i>Prof Lynn Gillam, Clarissa Martin, & Suzana Kovacevic, The University of Melbourne</i></p>	

Thursday 11 May 2023

08:00 – 09:15		CONFERENCE REGISTRATION
09:15 – 09:30		<p>Welcome <i>Conference Chairs: Prof Lynn Gillam & Prof Richard Chenhall</i></p>
09:30 – 10:30		<p>Keynote Speaker: Associate Professor Angela Ballantyne <i>Department of Primary Health Care & General Practice, University of Otago Wellington</i></p> <p>Inclusion, trust and consent in research ethics</p> <p>What is the main role of RECs – to protect potential research participants from harm or to facilitate socially valuable research? Research ethics has traditionally taken a protectionist stance, with a primary focus on avoiding and minimising research harm. On this view, research is optional, and RECs should be conservative about including any populations in research without their express consent. More recently, there has been growing recognition of the social value of research. Research can be seen as essential to the provision of evidenced based medicine in the future – saving lives and improving wellbeing. On this view, it is important that all populations have fair access to the benefits of research and RECs should facilitate inclusion of different populations in research, perhaps even if they cannot or have not consented. In this talk I will consider the tension between inclusion and protection in two case studies: (1) the use of health data or biological samples for research without consent and (2) research with patients who lack capacity.</p> <p><i>Session Chair: Prof Lynn Gillam</i></p>
10:30 – 11:00		MORNING TEA

	Function Hall Subtheme - Research Ethics and Integrity <i>Chair: Kandy White</i>	Room 3 & 4 Subtheme - Research Ethics and Integrity <i>Chair: Prof Richard Chenhall</i>
11:00 – 11:25	National Statement Review: Where we are and what's next <i>Mr Jeremy Kenner, NHMRC</i>	Not a Lottery – A process for random selection for clinical trial participation <i>Ms Sophie Gatenby, The Royal Children's Hospital and Ms Katherine Lieschke, Murdoch Children's Research Institute</i>
11:25 – 11:50	Keeping the PEACE: Applying an interview model to research integrity investigations <i>Dr Nitya Phillipson, Murdoch Children's Research Institute</i>	What is human research ethics training for? <i>Dr Mark Hooper, Tricky Goose Training</i>
11:50 – 12:15	Building together: A scoping review to inform better consenting practices for the most vulnerable in healthcare research <i>Associate Professor Kristen Gibbons, Metro South Health</i>	Lessons learned from an ethics and governance model of a multi-collaborator cancer proteomics program. <i>Dr Priya Duggal, Children's Medical Research Institute</i>
12:15 – 13:15	LUNCH	
13:15 – 14:15	<p>Panel Session - Dealing with ethical challenges of incidental findings in research</p> <p>Research that collects data about participants' bodies or physical function may produce incidental findings – information about a participant that was not intentionally sought out, but has nevertheless come to light. Genetic testing and genomic sequencing, MRI or other imaging are well-recognised examples, but even more mundane activities such as measuring blood pressure or heart rate can produce unexpected results. Some incidental findings might have clear, immediate and actionable implications for a participant's health, but the significance of others can be quite uncertain. The possibility of incidental findings raises a number of questions about what is ethically required in planning research studies, and carrying them out. In this session, a panel of researchers and research ethicists will lead an interactive discussion of these tricky questions, including:</p> <ul style="list-style-type: none"> • When is a plan for managing incidental findings ethically required? Only when such findings are easily foreseeable and quite likely, or even when the chances are remote or merely theoretical? • Does the possibility of an incidental finding count as a risk (possible harm) to participants • Should all incidental findings be communicated to individual participants, or is it ethically acceptable not to disclose some findings (if they are of minor or uncertain significance)? • Should participants be asked at the outset if they want to receive any incidental findings? But what if they say no, and something actionable is found? • What is a supportive enough plan for communicating incidental findings? Are there minimum standards? • Is there some research that should not be done because the possibility of incidental findings would be too distressing or harmful to participants? <p>Panellist: <i>Jeremy Kenner, NHMRC</i> <i>Professor Martin Delatycki, Murdoch Children's Research Institute</i></p> <p>Session Chair: <i>Prof Lynn Gillam</i></p>	
14:15 – 14:20	MOVE TO BREAKOUT SESSIONS	
	Function Hall Subtheme - Research Ethics and Integrity <i>Chair: Dr Nitya Phillipson</i>	Room 3 & 4 Subtheme - Research Ethics and Integrity <i>Chair: Suzana Kovacevic</i>
14:20 – 14:45	NHMRC's Research Quality Strategy: Achievements and next steps <i>Ms Jillian Barr, NHMRC</i>	Developing HREC guidelines for reviewing and supporting First Nations Research <i>Professor Marilynne N Kirshbaum & Ms Hayley Germaine, Charles Darwin University</i>
14:45 – 15:10	Health research for all: A dedicated resource to drive inclusive health and medical research <i>Ms Tehani Paiva & Dr Helene Kammoun, Murdoch Children's Research Institute</i>	Can research ethics codes be a conduit for justice? An examination of Aboriginal and Torres Strait Islander guidelines in Australia, and the VACCHO accord <i>Associate Professor Deborah Zion, Victoria University</i>
15:10 – 15:35	Improving Data Management Planning using Infonetica <i>Dr Shannon Smith & Jennifer Rowland, Macquarie University</i>	
15:35 – 16:00	AFTERNOON TEA	

16:00 - 17:00	<p>Panel Session – Ethical issues in data management- balancing privacy, cyber security, open access and public trust.</p> <p>Human research ethics committees and researchers are increasingly being required to consider complex issues in human research data management, with a range of ethical and legal considerations surrounding sensitive data for research. Many institutions, funding agencies and publishers are now explicitly requiring research data to be shared, however recent public cyber attacks and data breaches have impacted on the community’s trust and confidence in data security. This panel session will explore some of the key considerations for researchers and ethics reviewers in collecting, managing and sharing sensitive research data ethically and legally.</p> <p>Panellist: <i>Associate Professor Angela Ballantyne, University of Otago Wellington</i> <i>Dr Fiona Lynch, Murdoch Childrens Research Institute</i> <i>Clarissa Martin, The University of Melbourne</i> <i>Keith Russell, Australian Research Data Commons (ARDC)</i></p> <p>Session Chair: <i>Jennifer Rowland</i></p>
17:00 – 19:00	CONFERENCE WELCOME RECEPTION

Friday 12 May 2023

08:00 – 08:50	CONFERENCE REGISTRATION
08:50 – 09:00	<p>Welcome Conference Chairs: Prof Lynn Gillam & Prof Richard Chenhall</p>
09:00 – 10:00	<p>Keynote Speaker Professor Ingrid Winship <i>Chair, NHMRC Australian Health Research Ethics Committee</i></p> <p>How do HREC’s move with the times?</p> <p>The second decade of the 21st century brings a host of new developments in and challenges for Australian researchers and HRECs. The expansion of research that involves sharing or linkage of data or use of social media is one example of this. Challenges include the way that benefit and risk are defined and assessed, the viability of individualised consent and the way that human research is governed. In addition, research involving artificial intelligence and machine learning, gene editing and other techniques used in genomic research will require the need for new expertise and, potentially, new models for assessing the ethical appropriateness and scientific merit of research. The Australian Health Ethics Committee of the National Health and Medical Research Council, is currently considering these important issues.</p> <p>A streamlined, harmonised, and predictable operating environment is essential for a vibrant health and medical research ecosystem. On a structural level, work led by the Australian Government Department of Health and Aged Care in collaboration with all governments is delivering several initiatives aiming to address long-term challenges. These include a nationally consistent approach to accreditation of health service organisations conducting clinical trials and work to develop a One Stop Shop approach for health-related human research, including clinical trials. Work is also underway to develop an accreditation scheme for human research ethics committees that participate in the National Mutual Acceptance scheme to strengthen the acceptability of ethical reviews across jurisdictional borders. There is also scope for the extension of the scheme to include appropriately accredited ethics committees operating across more diverse settings.</p> <p>The solutions to these challenges are a ‘work in progress.’ This presentation will elaborate on the issues and invite you to contribute to this work.</p> <p>Session Chair: <i>Prof Lynn Gillam</i></p>
10:00 – 10:30	MORNING TEA

	Function Hall Subtheme - Keeping up with Data <i>Chair: Vivienne Moyle</i>	Room 3 & 4 Subtheme - Research Ethics and Integrity <i>Chair: Kandy White</i>
10:50 – 11:15	Health Studies Australian National Data Asset (HeSANDA) <i>Ms Katie Ozdowska, University of Melbourne and Dr Rhys Williams, Australian Research Data Commons</i>	A strong human research ethics advisor network: promoting and enhancing a university culture of responsible research conduct <i>Ms Elizabeth Hill, Victoria University</i>
11:15 – 11:40	Negotiating Withdrawal of Consent <i>Ms Anne Walsh & Mr Alex Stewart, Queensland University of Technology</i>	Increasing data and research integrity via RDMOnline training <i>Dr Shannon Smith & Dr Paul Sou, Macquarie University</i>
11:40 – 12:05	‘But the data is already public’: When is ethics review required? <i>Ms Isobel Cairns, Victoria University of Wellington</i>	Strengthening Research Integrity with Trust Markers <i>Dr Leslie McIntosh, Digital Science</i>
12:05 – 12:30	Integrating data stewards into HREC <i>Dr Laura Hurley & Dr Jennifer Rowland, Macquarie University</i>	Information Forms - Box Ticking Vs Practical Engaging <i>Mr Mark Davies, University of Western Australia</i>
12:30 – 13:30	LUNCH	
13:30 – 14:30	Invited Speaker: Dr Mishel McMahon <i>Aboriginal Rural Health Coordinator, Office of La Trobe Rural Health, La Trobe University</i> First Nations Research Circle Ethical First Nations research necessitates key principles and processes to be addressed, understanding this term includes research led by First Nations people, with First Nations people or First Nations people are the population focus. Key principles and processes will be introduced through this presentation, and then applied through application of the First Nations Research Circle. <i>Session Chair: Prof Richard Chenhall</i>	
14:30 – 14:50	AFTERNOON TEA	
14:50 – 15:50	Panel Session - Incidental disclosures and mandatory reporting Incidental disclosures occur particularly in qualitative research, when in the course of an interview, a participant may reveal to a researcher something the researcher has not directly asked about and was not intending to find out about. Disclosures of child abuse are particularly troubling and may take the researchers into the realm of mandatory reporting. Other types of disclosures (eg, about criminal or unprofessional activity, untreated physical and mental health problems, or intimate partner violence) do not invoke mandatory requirements and may be even more difficult for researchers and HRECs to manage. This panel will discuss what HRECs should be vigilant for in reviewing applications, how prescriptive they should be in how any disclosures should be managed, and what researchers’ responsibilities are in this area. Panellist: <i>Phillip Johnstone, Barrister at the Victorian Bar</i> <i>Prof Maurice Eisenbruch, Monash University</i> <i>Dr Patricia McNamara, The University of Melbourne</i> <i>Bronwyn Tarrant, The University of Melbourne</i> <i>Session Chair: Prof Lynn Gillam & Kandy White</i>	
15:50 – 16:00	Conference Close	

**Preliminary program is subject to change at discretion of the conference organisers.*