

Conference Program

Wednesday 26 September

07:30 – 08:30

CONFERENCE REGISTRATION

Workshops

Savoy Room

Kingston Room

Raffles Room

08:30 – 12:30

(includes morning tea 10:30 – 10:45)

Consent in Research Workshop

Presenters: Professor Ian Kerridge and Professor Paul Komesaroff

Sponsored by PRAXIS

Research Integrity Workshop

Presenters: Jillian Barr, Dr Kandy White and Ms Anne Walsh

12:30 – 13:00

LUNCH BREAK: LUNCH NOT PROVIDED

13:00 – 17:00

(includes afternoon tea 15:30 – 15:45)

HREC Members Training Workshop

Presenters: Dr Conor Brophy and Ms Sara Potts

Ethical Governance of Human Research Data in the Age of Genomics

Presenters: A/Professor Andrew Crowden, Dr Geraldene Mackay, Clare Smith-Moloney

(Contributed: A/Professor Andrew Crowden, Dr Richard Roylance, Dr Geraldene Mackay, Susan Smith, Clare Smith-Moloney)

Strengthening Researcher Capacity in Indigenous Research Workshop

Presenters: Professor Yvonne Cadet-James and Ms Chrissy Grant

18:00 – 20:00

WELCOME COCKTAIL RECEPTION

*Mayoral Forecourt, Council Building Townsville
Hosted by Townsville City Council
Sponsored by James Cook University*

17:45 – 18:00

Drinks on arrival

18:00 – 18:03

Welcome to Country

18:04 – 18:20

Welcome

Welcome by Mayor of Townsville – Cr Jenny Hill

Introduction by THHS – Tony Mooney AM, Board Chair Townsville Hospital and Health Service

JCU Welcome – Rochelle Finlay, Director Research and Commercialisation, James Cook University

18:20 – 18:35

Opening Address – Professor Ian Olver AM

18:35 – 20:00

Cocktail Reception Continues

A time to catch up with old friends and meet new ones

Conference Program

Thursday 27 September

07:30 – 08:45 **CONFERENCE REGISTRATION**

08:45 - 09:00 **Welcome**

09:00 – 10:00 **Keynote Speakers:** *Ms Chrissy Grant and Professor Yvonne Cadet-James*

NHMRC Guidelines for Ethical Conduct in Research with Aboriginal and Torres Strait Islander Peoples and Communities

NHMRC has recently released two revised research ethics guidelines:

- Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities: Guidelines for researchers and stakeholders
- Keeping research on track II.

These guidelines provide a set of principles to ensure research is safe, respectful, responsible, high quality and of benefit to Aboriginal and Torres Strait Islander people and communities. The revised guidelines now encompass all research and include more detailed discussion of the six core values that should inform research conducted with Aboriginal and Torres Strait Islander people and communities, their data or biological samples.

This session will provide an overview of the new research ethics guidelines, their development and key points for researchers and Human Research Ethics Committees (HRECs).

Session Chair: Sue Jenkins-Marsh, THHS

10:00 – 10:30 **Speaker:** *Craig Ritchie, Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS)*

48. Best practices for Aboriginal and Torres Strait Islander research

For 20 years, the AIATSIS Guidelines for Ethical Research in Australian Indigenous Studies (GERAIS) have set the benchmark for ethical practice in Aboriginal and Torres Strait Islander research. The principles of GERAIS ensure that research with and about Aboriginal and Torres Strait Islander peoples follows a process of meaningful engagement and reciprocity between the researcher and the individuals and/or communities involved in the research. AIATSIS is currently reviewing the Guidelines to ensure they continue to reflect the best standard for ethical practice in Aboriginal and Torres Strait Islander research.

Session Chair: Sue Jenkins-Marsh, THHS

Conference Program

Thursday 27 September

10:30 – 11:00

MORNING TEA

Could all conference delegates please ensure they leave the room quickly to enable the room to be reconfigured.

Concurrent sessions

Savoy Room

Kingston Room

Raffles Room

Developing relationships, engagement and consent

Chair: Andrew Crowden, UQ

Embracing and increasing knowledge

Chair: Trina O'Donnell, Bellberry Limited

Accountability and integrity

Chair: Ted Rohr, UNSW Sydney

11:00 – 11:15

(10 min & 5 min questions)

15. *Facilitating research collaboration with our Aboriginal and Torres Strait Islander partners*

Sue Jenkins-Marsh, Townsville Hospital and Health Service, Australia

7. *On the Problem of "Worldlessness". Do The Declaration of Helsinki, the Council for International Organizations of Medical Science Guidelines and The National Statement Protect the Stateless in the Research Context?*

Deborah Zion, Victoria University, Australia

16. *Exploring the benefits of a HREC Self Evaluation tool and process*

Philomena Horsley, Praxis Australia/University of Melbourne, Australia

11:15 – 11:30

(10 min & 5 min questions)

46. *Ways of Engagement: Using Indigenous Statistics Ethically*

Rebecca Coates, Commonwealth Science and Industry Research Organisation (CSIRO), Australia

9. *Sharing power with community members in health research priority-setting:*

An ethical framework for engagement practice

Bridget Pratt, University of Melbourne, Australia

20. *To submit or not to submit to regulation; the dilemma of success for a voluntary ethics committee in New Zealand*

Lindsey MacDonald, University of Canterbury, New Zealand

11:30 – 11:45

(10 min & 5 min questions)

28. *How are Aboriginal and Torres Strait Islander communities involved in research ethics review?*

Sara Potts, Townsville Hospital and Health Service and James Cook University, Australia

29. *Reflecting Tikanga Māori (appropriate cultural practices) in Animal Ethics Processes at Massey University*

Craig Johnson, Massey University, New Zealand

34. *Data Management, Research Integrity and Ethics*

Kate LeMay, Australian Research Data Commons, Australia

Conference Program

Thursday 27 September

Concurrent sessions	Savoy Room	Kingston Room	Raffles Room
11:45 – 12:00 (10 min & 5 min questions)	<i>41. Participation of non-English speaking people in research projects</i> Richard Larsen and Dr Guliana Fuscaldo, Barwon Health, Australia	<i>32. Institutional Review Board at Singapore Institute of Technology (S.I.T) - Learning experience and Lessons</i> Pon Gopalakrishnakone, Singapore Institute of Technology, Singapore	<i>44. Efficiency vs ethics: Is increasing commercialisation of research ethics consistent with the spirit of the National Statement?</i> Lisa Fry, Barwon Health and Latrobe University, Australia
12:00 – 12:15 (10 min & 5 min questions)	<i>54. How can Human Research be conducted into Radicalisation and Extremism?: Case study highlighting key issues</i> Elizabeth Hill, Victoria University, Australia	<i>55. From theory to practice: sitting on the other side of the fence as an HREC Chair</i> Gordon McGurk, Royal Brisbane and Women's Hospital, Australia	<i>53. Research data and contextual integrity: facilitating participant consent</i> Isobel Cairns, Victoria University of Wellington, New Zealand
12:15 – 13:00	LUNCH		
13:00 – 14:00	Keynote Speakers: Dr Wendy Rogers, Macquarie University, and Dr Jeremy Kenner, NHMRC		
	National Statement on Ethical Conduct in Human Research		
	<p>The National Statement on Ethical Conduct in Human Research, 2007 (National Statement) is the principal ethical guideline setting out the requirements for the ethical design, review and conduct of human research in Australia. In mid-2018, NHMRC issued a revised National Statement, with significant changes to Section 3 and associated changes to Section 5.</p> <p>The revised National Statement provides a new structure for Section 3, based on the elements of a research project (from conception to post-completion). Section 3 begins with a chapter that addresses ethical issues in all research, followed by specialised guidance for research involving human biospecimens, genomics and xenotransplantation. Major substantive changes include guidance related to interventional research, genomics research and the collection, use and management of data and information.</p> <p>This session will provide an overview of the revised National Statement and will be of interest to researchers, students and Human Research Ethics Committee members. This session will also provide an update on the review of Section 4 of the National Statement and a preview of the planned review of Section 5 of the National Statement, both of which will continue into 2019.</p>		
	Session Chair: Gordon McGurk, RBWH		

Conference Program

Thursday 27 September

14:00 – 14:15

SHORT BREAK TO ENABLE CONCURRENT ROOMS TO BE SET UP

Could all conference delegates please ensure they leave the room quickly to enable the room to be reconfigured.

Concurrent sessions

Savoy Room

Kingston Room

Raffles Room

Developing relationships, engagement and consent

Chair: Michelina Weatherall, University of Wollongong

Embracing and increasing knowledge

Chair: Sara Potts, Townsville Hospital and Health Service

Accountability and integrity

Chair: Anne Walsh, QUT

14:15 – 14:30

(10 min & 5 min questions)

35. The ethics of research involving survivors of sexual victimisation and violence and participants with complex trauma

Rita Shackel, The University of Sydney, Australia

13. Ethics reviewers – what can we learn from each other?

Tony Callahan, University of Melbourne, Australia

17. Should official information statutes be used as a research tool?

Lana Lon, Health Research Council of New Zealand (HRC), New Zealand

14:30 – 14:45

(10 min & 5 min questions)

52. Education Practitioner Research: Ethical Considerations

Christine Joyce Jenkin, Auckland University Of Technology, New Zealand

25. The cultural perception of Ethics: Implications for training researchers and review committee members

Shirin, Jamarani, University of Queensland, Australia

27. Qualitative Research in Mental Health Should Not Claim

Research Interviews Are Therapeutic Interventions

Dr Geraldene Mackay, Clinical Social Worker, Australia

14:45 – 15:00

(10 min & 5 min questions)

4. Engaging Indigenous Pacific Islands Communities in Bioethical Research

Etivina Lovo, Fiji National University, Fiji

37. More than ticking the boxes: Checklists, the National Statement and

ethical human research

Anna Corbo Crehan, Charles Sturt University, Australia

21. Australian HRECS – A Seven Year Report Card

Colin Thomson, Australasian Human Research Consultancy Services Pty Ltd, Australia

15:00 – 15:15

(10 min & 5 min questions)

2. Building a Community of Practice

Ian Pieper, ACT Health, Australia

22. A funny thing happened on the way to the ethics application:

Avoiding routine ethics thinking to balance accountability and integrity

Lesley Batten, Massey University, New Zealand

Conference Program

Thursday 27 September

15:15 – 15:45

AFTERNOON TEA

15:45 - 16:30

Invited Speaker: *Professor Sasha Aikhenvald, James Cook University*

Will you teach me your language? The ethics and the practice of linguistic fieldwork

Doing linguistic research and understanding how languages work involves empirical studies. Linguistic fieldwork with communities in various locations and with varied cultural background is at the heart of what we, as linguists, do (especially at the Language and Culture Research Centre at JCU). The presentation will focus on ethical issues which arise when one attempts to learn, and describe different languages, and the practical challenges one may face, especially in the tropical regions of New Guinea, Australia, and Amazonia.

Session Chair: *Kandy White, Macquarie University*

18:30 – 23:00

CONFERENCE DINNER

*Townsville Yacht Club
Sponsored by AITHM*



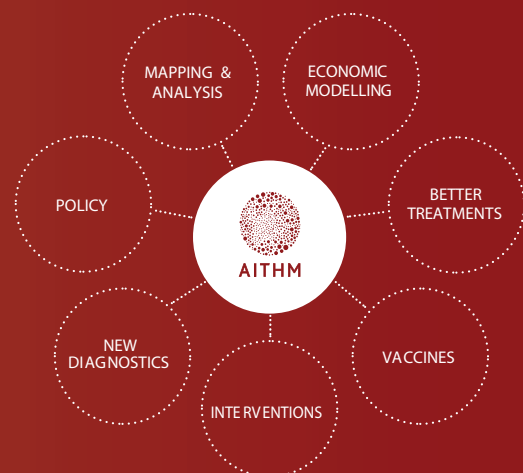
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AITHM is Australia's only dedicated tropical health and medicine research institute. Based in the Tropics of northern Australia at James Cook University, AITHM's research focusses on protecting Australia's biosecurity and enhancing health outcomes for our neighbouring tropical nations.



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TOWNSVILLE // CAIRNS // MACKAY // THURSDAY ISLAND

Conference Program

Friday 28 September

07:30 – 08:50 CONFERENCE REGISTRATION

08:50 – 09:00 Welcome

09:00 – 10:00 **Keynote Speakers:** Jillian Barr, NHMRC, and Justin Withers, ARC

Australian Code for the Responsible Conduct of Research 2018 and Guide to Managing and Investigating Potential Breaches of the Code

In mid-2018, NHMRC, the Australian Research Council (ARC) and Universities Australia released:

- The Australian Code for the Responsible Conduct of Research 2018 (the Code), and
- A Guide to Managing and Investigating Potential Breaches of the Australian Code for the Responsible Conduct of Research (the Investigation Guide).

The 2018 Code establishes a new, principles-based framework that articulates the expectations for the conduct of research in Australia or research conducted under the auspices of Australian institutions.

The Investigation Guide will help institutions to identify breaches of the Code, determine necessary corrective actions and will promote greater consistency in the research sector for managing any departures from the principles of responsible research conduct.

This session will provide an overview the Code and Investigation Guide, including how the new definitions and terms used in the Investigation Guide might enhance investigations at institutions.

Session Chair: Ted Rohr, UNSW Sydney

10:00 – 10:30 **MORNING TEA**

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Conference Program

Friday 28 September

Concurrent sessions	Savoy Room	Kingston Room	Raffles Room
	<p>Developing relationships, engagement and consent</p> <p><i>Chair: TBA</i></p>	<p>Developing relationships, engagement and consent</p> <p><i>Chair: Gordon McGurk, RBWH</i></p>	<p>Accountability and integrity</p> <p><i>Chair: Kandy White, Macquarie University</i></p>
<p>10:30 – 10:45 (10 min & 5 min questions)</p>	<p>5. <i>Research ethics regulation as a communicative transaction of trust</i></p> <p>David Hunter, Flinders University, Australia</p>	<p>12. <i>Deferred consent in a clinical trial within paediatric intensive care units and emergency departments: An ethical dilemma</i></p> <p>Rebecca Doyle, Children’s Health Queensland, Australia</p>	<p>50. <i>Use of Imported Human Biospecimens in Research</i></p> <p>Conor Brophy and Anne Walsh, Queensland University of Technology, Australia</p>
<p>10:45 – 11:00 (10 min & 5 min questions)</p>	<p>18. <i>Utilising the unethical to promote strong ethical research practice: a survey tool</i></p> <p>Erich von Dietze, Murdoch University, Australia</p>	<p>33. <i>HREB approval should serve as a provisional proxy consent for research</i></p> <p>Daryl Pullman, Memorial University, Canada</p>	<p>30. <i>Dealing with Breaches of the Research Code in Human Ethics</i></p> <p>Ted Rohr, UNSW Sydney, Australia</p>
<p>11:00 – 11:15 (10 min & 5 min questions)</p>	<p>19. <i>Down the line, the forgotten player in the research ethics equation – bridging between institutional ethics committees and the host research site</i></p> <p>Pamela Spall, Meg Jones, Creche and Kindergarten Association (C&K), Australia</p>	<p>45. <i>Obtaining research consent: under-recognised ethical challenges for the physician-investigator</i></p> <p>Helen Petsky, Griffith University, Australia</p>	<p>24. <i>How risky are Low and Negligible Risk assessment processes?</i></p> <p>Philomena Horsley, Praxis Australia/University of Melbourne, Australia</p>
<p>11:15 – 11:30 (10 min & 5 min questions)</p>	<p>59. <i>Children in social research: Do higher payments make them more likely to participate in riskier studies?</i></p> <p>Jenny Chalmers, University of New South Wales, Australia</p>	<p>49. <i>Clinical Trials and Fully Informed Consent in a Catholic Hospital</i></p> <p>Odette Petersen, Research Ethics Consultant, Australia</p>	<p>40. <i>What to do when it goes wrong?</i></p> <p>Katherine Shaw and Jude Vienna-Hallam, University of Tasmania, Australia</p>

Conference Program

Friday 28 September

Concurrent sessions	Savoy Room	Kingston Room	Raffles Room
11:30 – 12:00	<p>38. <i>Mortui Vivos Docent (Let the dead teach the living): The Ethics of Research with Deceased ‘Participants’</i></p> <p>Dr Jenny Jones, Metro South Hospital and Health Service, Australia</p> <p>Note: Extended presentation (25 min & 5 min questions)</p>	<p>14. <i>Using Facebook to locate and re-engage lost participants</i></p> <p>Shannon Bennetts, La Trobe University and Murdoch Children’s Research Institute, Australia</p> <p>Note: 11:30 – 11:45 (10 min & 5 min questions)</p> <hr/> <p>36. <i>Consent for data sharing</i></p> <p>Kate LeMay, Australian Research Data Commons, Australia</p> <p>Note: 11:45 – 12:00 (10 min & 5 min questions)</p>	<p>10. Ethical oversight of a multi-collaborator cancer proteomics program</p> <p>Priya Duggal, Children’s Medical Research Institute (CMRI), Australia</p> <p>Note: 11:30 – 11:45 (10 min & 5 min questions)</p> <hr/> <p>39. <i>Ethics and Compliance – getting the balance right</i></p> <p>Kate Organ, Charles Sturt University, Australia</p> <p>Note: 11:45 – 12:00 (10 min & 5 min questions)</p>
12:00 – 13:00	LUNCH		
13:00 – 14:00	<p>Invited Speaker: Professor Robert Sparrow, Monash University</p> <p>Regulating Research on ‘Revolutionary’ Technologies</p> <p>Revolutionary technologies are all the rage. Gene editing, Artificial Intelligence, Big Data, induced pluripotent stem cells, nanotechnology... each has been proclaimed to represent the next scientific and technological revolution. The claim that a technology is revolutionary is usually made in order to secure research funding or generate publicity... or both. However such claims generate legitimate fears that any such revolution might produce losers as well as winners. They also imply that research to develop such technologies is especially deserving of regulatory oversight: the more we expect a technology to generate social impacts, the more it seems that the public deserves to have a say in its development. Yet the very potential of these technologies to generate research breakthroughs and unexpected social consequences poses especial challenges to regulating them. This presentation will discuss these challenges and suggest some means whereby they may be met.</p> <p>Session Chair: Andrew Crowden, UQ</p>		
14:00 – 14:30	<p>AFTERNOON TEA</p> <p><i>Could all conference delegates please ensure they leave the room quickly to enable the room to be reconfigured.</i></p>		

Conference Program

Friday 28 September

Concurrent sessions	Savoy Room	Kingston Room	Raffles Room
	Developing relationships, engagement and consent <i>Chair: Tania Signal, CQU</i>	Embracing and increasing knowledge <i>Chair: TBA</i>	Accountability and integrity <i>Chair: Conor Brophy, QUT</i>
14:30 – 14:45 (10 min & 5 min questions)	26. <i>Implementation of the Australasian Tele-Trial Model – increasing engagement between researchers, health administrators and regulatory bodies to transform clinical trials</i> Melanie Poxton, Townsville Hospital and Health Service, Australia	6. <i>Big Data, social data, personal data: Ethics review in a rapidly changing data landscape</i> Paula Swatman, Swinburne University of Technology and Bellberry Limited, Australia	43. <i>Genomics Research Compliance: From Clinic to Bench to Dataset</i> Leanne Wallace, University of Queensland, Australia
14:45 – 15:00 (10 min & 5 min questions)	47. <i>Working Collaboratively: The need for Ethics Committees and Research Governance Officers to work together</i> Leanne Griffiths, Townsville Hospital and Health Service, Australia	3. <i>Research Ethics in the Facebook age - A case study</i> Nitya Vipin Phillipson, Macquarie University, Australia	51. <i>Monitoring research: how can we learn from incidents, complaints and breaches? What is the role of trust in research relationships?</i> Kate Murphy, The University of Melbourne, Australia
15:00 – 15:15		11. <i>“It’s not black and white”: The ethics of recruiting, retaining and tracing research participants online</i> Sharinne Crawford, La Trobe University, Australia	42. <i>Research Governance Frameworks For Multi-Site Projects And Consortia</i> Anjali Henders, The University of Queensland, Australia
15:15 – 15:30	END OF CONFERENCE – WRAP UP <i>Raffles Room</i>		