



## PROVISIONAL PROGRAM

The program overview below is provisional and will be updated as planning proceeds. Please check back regularly.

Wednesday 26 <sup>th</sup> September 2018 / Rydgess Townsville			
07:30 – 08:30	CONFERENCE REGISTRATION		
Workshops	Savoy Room	Kingston Room	Raffles Room
08:30 – 12:30 (includes morning tea 10:30 – 10:45)	<b>Consent in Research Workshop</b> Presenters: Professor Ian Kerridge and Professor Paul Komesaroff <i>Sponsored by PRAXIS</i>	<b>Research Integrity Workshop</b> Presenters: Dr Jillian Barr, Dr Kandy White and Ms Anne Walsh	
<b>LUNCH BREAK: LUNCH NOT PROVIDED</b>			
13:00 – 17:00 (includes afternoon tea 15:00 – 15:45)	<b>HREC Members Training Workshop</b> Presenters: Dr Conor Brophy and Ms Sara Potts	<b>Ethical Governance of Human Research Data in the Age of Genomics</b> Facilitators: A/Professor Andrew Crowden, Dr Richard Roylance, Susan Smith, Dr Geraldene Mackay	<b>Strengthening Researcher Capacity in Indigenous Research Workshop</b> Presenters: Professor Yvonne Cadet-James and Ms Chrissy Grant
18:00 – 21:00	<b>WELCOME COCKTAIL RECEPTION</b> <i>Mayoral Forecourt, Council Building Townsville</i>		
18:00 – 18:05	<b>Introduction by THHS</b>		
18:05 – 18:10	<b>Welcome to Country</b>		
18:10 – 18:15	<b>Welcome by Mayor of Townsville</b>		
18:15 – 18:20	<b>JCU Welcome - Ian Wronski</b>		
18:20 – 19:00	<b>Opening Address – Professor Ian Olver AM</b>		
19:00 – 21:00	<b>Cocktail Reception Continues</b> <i>A time to catch up with old friends and meet new ones</i>		

## Thursday 27<sup>th</sup> September 2018 / Rydges Townsville

<b>07:30 – 08:45</b>	<b>CONFERENCE REGISTRATION</b>		
<b>08:45 - 09:00</b>	<b>Welcome</b>		
<b>09:00 – 10:00</b>	<p><b>Keynote Speakers:</b> <i>Ms Chrissy Grant and Professor Yvonne Cadet-James</i></p> <p><b><i>NHMRC Guidelines for Ethical Conduct in Research with Aboriginal and Torres Strait Islander Peoples and Communities</i></b></p> <p>NHMRC has recently released two revised research ethics guidelines:</p> <ul style="list-style-type: none"> <li>• Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities: Guidelines for researchers and stakeholders</li> <li>• Keeping research on track II.</li> </ul> <p>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.</p> <p>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).</p> <p><i>Session Chair: Sue Jenkins-Marsh, THHS</i></p>		
<b>10:00 – 10:30</b>	<p><b>Speaker:</b> <i>Craig Ritchie, Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS)</i></p> <p><b><i>48. Best practices for Aboriginal and Torres Strait Islander research</i></b></p> <p>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 proactive in Aboriginal and Torres Strait Islander research.</p> <p><i>Session Chair: Sue Jenkins-Marsh, THHS</i></p>		
<b>10:30 – 10:45</b>	<b>MORNING TEA</b>		
<b>Concurrent sessions</b>	<p><b>Savoy Room</b>  <b>Developing relationships, engagement and consent</b>  <i>Chair: Andrew Crowden, UQ</i></p>	<p><b>Kingston Room</b>  <b>Embracing and increasing knowledge</b>  <i>Chair: Trina O'Donnell, Bellberry Limited</i></p>	<p><b>Raffles Room</b>  <b>Accountability and integrity</b>  <i>Chair: Ted Rohr, UNSW Sydney</i></p>
<b>10:45 – 11:00</b> (10 min & 5 min questions)	<p><i>15. Facilitating research collaboration with our Aboriginal and Torres Strait Islander partners</i>  <b>Sue Jenkins-Marsh, Townsville Hospital and Health Service, Australia</b></p>	<p><i>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?</i>  <b>Deborah Zion, Victoria University, Australia</b></p>	<p><i>16. Exploring the benefits of a HREC Self Evaluation tool and process</i>  <b>Philomena Horsley, Praxis Australia/University of Melbourne, Australia</b></p>
<b>11:00 – 11:15</b> (10 min & 5 min questions)	<p><i>46. Ways of Engagement: Using Indigenous Statistics Ethically</i>  <b>Rebecca Coates, Commonwealth Science and Industry Research Organisation (CSIRO), Australia</b></p>	<p><i>8. Engagement as “co-constructing knowledge”: A moral necessity in public health research</i>  <b>Bridget Pratt, University of Melbourne, Australia</b></p>	<p><i>20. To submit or not to submit to regulation; the dilemma of success for a voluntary ethics committee in New Zealand</i>  <b>Lindsey MacDonald, University of Canterbury, New Zealand</b></p>
<b>11:15 – 11:30</b> (10 min & 5 min questions)	<p><i>28. How are Aboriginal and Torres Strait Islander</i></p>	<p><i>29. Reflecting Tikanga Māori (appropriate cultural practices) in</i></p>	<p><i>34. Data Management, Research Integrity and Ethics</i></p>

	<p><i>communities involved in research ethics review?</i></p> <p><b>Sara Potts, Townsville Hospital and Health Service and James Cook University, Australia</b></p>	<p><i>Animal Ethics Processes at Massey University</i></p> <p><b>Craig Johnson, Massey University, New Zealand</b></p>	<p><b>Kate LeMay, Australian Research Data Commons, Australia</b></p>
<p><b>11:30 – 11:45</b> (10 min &amp; 5 min questions)</p>	<p>41. <i>Participation of non-English speaking people in research projects</i></p> <p><b>Richard Larsen and Dr Guliana Fuscaldo, Barwon Health, Australia</b></p>	<p>32. <i>Institutional Review Board at Singapore Institute of Technology (S.I.T) - Learning experience and Lessons</i></p> <p><b>Pon Gopalakrishnakone, Singapore Institute of Technology, Singapore</b></p>	<p>44. <i>Efficiency vs ethics: Is increasing commercialisation of research ethics consistent with the spirit of the National Statement?</i></p> <p><b>Lisa Fry, Barwon Health and Latrobe University, Australia</b></p>
<p><b>11:45 – 12:00</b> (10 min &amp; 5 min questions)</p>	<p>54. <i>How can Human Research be conducted into Radicalisation and Extremism?: Case study highlighting key issues</i></p> <p><b>Elizabeth Hill, Victoria University, Australia</b></p>	<p>55. <i>From theory to practice: sitting on the other side of the fence as an HREC Chair</i></p> <p><b>Gordon McGurk, Royal Brisbane and Women’s Hospital, Australia</b></p>	<p>53. <i>Research data and contextual integrity: facilitating participant consent</i></p> <p><b>Isobel Cairns, Victoria University of Wellington, New Zealand</b></p>
<p><b>12:00 – 13:00</b></p>	<p><b>LUNCH</b></p>		
<p><b>13:00 – 14:00</b></p>	<p><b>Keynote Speakers: Dr Wendy Rogers, Macquarie University, and Dr Jeremy Kenner, NHMRC</b></p> <p><b>National Statement on Ethical Conduct in Human Research</b></p> <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> <p><i>Session Chair: Gordon McGurk, RCWH</i></p>		
<p><b>14:00 – 14:15</b></p>	<p><b>SHORT BREAK TO ENABLE CONCURRENT ROOMS TO BE SET UP</b></p>		
<p><b>Concurrent sessions</b></p>	<p><b>Savoy Room</b> Developing relationships, engagement and consent <i>Chair: Michelina Weatherall, University of Wollongong</i></p>	<p><b>Kingston Room</b> Embracing and increasing knowledge <i>Chair: Sara Potts, THHS</i></p>	<p><b>Raffles Room</b> Accountability and integrity <i>Chair: Anne Walsh, QUT</i></p>
<p><b>14:15 – 14:30</b> (10 min &amp; 5 min questions)</p>	<p>35. <i>The ethics of research involving survivors of sexual victimisation and violence and participants with complex trauma</i></p> <p><b>Rita Shackel, The University of Sydney, Australia</b></p>	<p>13. <i>Ethics reviewers – what can we learn from each other?</i></p> <p><b>Tony Callahan, University of Melbourne, Australia</b></p>	<p>17. <i>Should official information statutes be used as a research tool?</i></p> <p><b>Lana Lon, Health Research Council of New Zealand (HRC), New Zealand</b></p>
<p><b>14:30 – 14:45</b> (10 min &amp; 5 min questions)</p>	<p>52. <i>Education Practitioner Research: Ethical Considerations</i></p> <p><b>Christine Joyce Jenkin, Auckland University Of</b></p>	<p>25. <i>The cultural perception of Ethics: Implications for training researchers and review committee members</i></p> <p><b>Shirin, Jamarani, University of</b></p>	<p>27. <i>Qualitative Research in Mental Health Should Not Claim Research Interviews Are Therapeutic Interventions</i></p> <p><b>Dr Geraldene Mackay, Clinical</b></p>

	<b>Technology, New Zealand</b>	<b>Queensland, Australia</b>	<b>Social Worker, Australia</b>
<b>14:45 – 15:00</b> (10 min & 5 min questions)	<i>4. Engaging Indigenous Pacific Islands Communities in Bioethical Research</i> <b>Etivina Lovo, Fiji National University, Fiji</b>	<i>37. More than ticking the boxes: Checklists, the National Statement and ethical human research</i> <b>Anna Corbo Crehan, Charles Sturt University, Australia</b>	<i>21. Australian HRECS – A Seven Year Report Card</i> <b>Colin Thomson, Australasian Human Research Consultancy Services Pty Ltd, Australia</b>
<b>15:00 – 15:15</b> (10 min & 5 min questions)	<i>1. A strengths approach to research data collection with marginalized and vulnerable groups</i> <b>Emma Crawford, University of Queensland, Australia</b>	<i>2. Building a Community of Practice</i> <b>Ian Pieper, ACT Health, Australia</b>	<i>22. A funny thing happened on the way to the ethics application: Avoiding routine ethics thinking to balance accountability and integrity</i> <b>Lesley Batten, Massey University, New Zealand</b>
<b>15:15 – 15:45</b>	<b>AFTERNOON TEA</b>		
<b>15:45 - 16:30</b>	<b>Invited Speaker: Professor Sasha Aikhenvald, James Cook University</b>  <b>Will you teach me your language? The ethics and the practice of linguistic fieldwork</b>  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.  <i>Session Chair: Kandy White, Macquarie University</i>		
<b>18:30 – 23:00</b>	<b>CONFERENCE DINNER</b> <i>Townsville Yacht Club</i>		

## Friday 28<sup>th</sup> September 2018 / Rydges Townsville

<b>07:30 – 08:45</b>	<b>Conference registration</b>		
<b>08:45 – 09:00</b>	<b>Welcome</b>		
<b>09:00 – 10:00</b>	<b>Keynote Speakers: Dr Jillian Barr, NHMRC, and Justin Withers, ARC</b>  <b><i>Australian Code for the Responsible Conduct of Research 2018 and Guide to Managing and Investigating Potential Breaches of the Code</i></b>  In mid-2018, NHMRC, the Australian Research Council (ARC) and Universities Australia released: <ul style="list-style-type: none"> <li>• The Australian Code for the Responsible Conduct of Research 2018 (the Code), and</li> <li>• A Guide to Managing and Investigating Potential Breaches of the Australian Code for the Responsible Conduct of Research (the Investigation Guide).</li> </ul> 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.  <i>Session Chair: Ted Rohr, UNSW Sydney</i>		
<b>10:00 – 10:30</b>	<b>MORNING TEA</b>		
<b>Concurrent sessions</b>	<b>Savoy Room</b> Developing relationships,	<b>Kingston Room</b> Developing relationships,	<b>Raffles Room</b> Accountability and integrity <i>Chair: Kandy White, Macquarie</i>

	<b>engagement and consent</b> <i>Chair: Richard Roylance, QH</i>	<b>engagement and consent</b> <i>Chair: Gordon McGurk, RCWH</i>	<i>University</i>
<b>10:30 – 10:45</b> (10 min & 5 min questions)	5. <i>Research ethics regulation as a communicative transaction of trust</i> <b>David Hunter, Flinders University, Australia</b>	12. <i>Deferred consent in a clinical trial within paediatric intensive care units and emergency departments: An ethical dilemma</i> <b>Rebecca Doyle, Children’s Health Queensland, Australia</b>	50. <i>Use of Imported Human Biospecimens in Research</i> <b>Conor Brophy and Anne Walsh, Queensland University of Technology, Australia</b>
<b>10:45 – 11:00</b> (10 min & 5 min questions)	18. <i>Utilising the unethical to promote strong ethical research practice: a survey tool</i> <b>Erich von Dietze, Murdoch University, Australia</b>	33. <i>HREB approval should serve as a provisional proxy consent for research</i> <b>Daryl Pullman, Memorial University, Canada</b>	30. <i>Dealing with Breaches of the Research Code in Human Ethics</i> <b>Ted Rohr, UNSW Sydney, Australia</b>
<b>11:00 – 11:15</b> (10 min & 5 min questions)	19. <i>Down the line, the forgotten player in the research ethics equation – bridging between institutional ethics committees and the host research site</i> <b>Pamela Spall, Meg Jones, Creche and Kindergarten Association (C&amp;K), Australia</b>	45. <i>Obtaining research consent: under-recognised ethical challenges for the physician-investigator</i> <b>Helen Petsky, Griffith University, Australia</b>	24. <i>How risky are Low and Negligible Risk assessment processes?</i> <b>Philomena Horsley, Praxis Australia/University of Melbourne, Australia</b>
<b>11:15 – 11:30</b> (10 min & 5 min questions)	59. <i>Children in social research: Do higher payments make them more likely to participate in riskier studies?</i> <b>Jenny Chalmers, University of New South Wales, Australia</b>	49. <i>Clinical Trials and Fully Informed Consent in a Catholic Hospital</i> <b>Odette Petersen, Research Ethics Consultant, Australia</b>	40. <i>What to do when it goes wrong?</i> <b>Katherine Shaw and Jude Vienna-Hallam, University of Tasmania, Australia</b>
<b>11:30 – 12:00</b> (25 min & 5 min questions)	38. <i>Mortui Vivos Docent (Let the dead teach the living): The Ethics of Research with Deceased ‘Participants’</i> <b>Dr Jenny Jones, Metro South Health, Australia</b>	14. <i>Using Facebook to locate and re-engage lost participants</i> <b>Shannon Bennetts, La Trobe University and Murdoch Children’s Research Institute, Australia</b>	10. <i>Ethical oversight of a multi-collaborator cancer proteomics program</i> <b>Priya Duggal, Children’s Medical Research Institute (CMRI), Australia</b>
	<b>Note: Extended presentation</b>	36. <i>Consent for data sharing</i> <b>Kate LeMay, Australian Research Data Commons, Australia</b>  <b>Note: 11:45 – 12:00 (10 min &amp; 5 min questions)</b>	39. <i>Ethics and Compliance – getting the balance right</i> <b>Kate Organ, Charles Sturt University, Australia</b>  <b>Note: 11:45 – 12:00 (10 min &amp; 5 min questions)</b>
<b>12:00 – 13:00</b>	<b>LUNCH</b>		
<b>13:00 – 14:00</b>	<b>Invited Speaker: Professor Robert Sparrow, Monash University</b>  <b>Regulating Research on 'Revolutionary' Technologies</b>  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.  <i>Session Chair: Andrew Crowden, UQ</i>		



14:00 – 14:30		AFTERNOON TEA		
Concurrent sessions	Savoy Room Developing relationships, engagement and consent <i>Chair: Tania Signal, CQU</i>	Kingston Room Embracing and increasing knowledge <i>Chair: Lynn Woodward, JCU</i>	Raffles Room 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> <b>Melanie Poxton, Townsville Hospital and Health Service, Australia</b>	6. <i>Big Data, social data, personal data: Ethics review in a rapidly changing data landscape</i> <b>Paula Swatman, Swinburne University of Technology and Bellberry Limited, Australia</b>	43. Genomics Research Compliance: From Clinic to Bench to Dataset <b>Leanne Wallace, University of Queensland, Australia</b>	
14:45 – 15:00 (10 min & 5 min questions)	9. <i>Sharing power with community members in health research priority-setting: An ethical framework for engagement practice</i> <b>Bridget Pratt, University of Melbourne, Australia</b>	3. <i>Research Ethics in the Facebook age - A case study</i> <b>Nitya Vipin Phillipson, Macquarie University, Australia</b>	51. <i>Monitoring research: how can we learn from incidents, complaints and breaches? What is the role of trust in research relationships?</i> <b>Kate Murphy, The University of Melbourne, Australia</b>	
15:00 – 15:15 (10 min & 5 min questions)	47. <i>Working Collaboratively: The need for Ethics Committees and Research Governance Officers to work together</i> <b>Leanne Griffiths, Townsville Hospital and Health Service, Australia</b>	11. <i>“It’s not black and white”: The ethics of recruiting, retaining and tracing research participants online</i> <b>Sharinne Crawford, La Trobe University, Australia</b>	42. <i>Research Governance Frameworks For Multi-Site Projects And Consortia</i> <b>Anjali Henders, The University of Queensland, Australia</b>	
15:15 – 15:30	END OF CONFERENCE – WRAP UP			