

Deciding with children

12th National Paediatric Bioethics Conference

1-3 September 2021

Melbourne
Children's
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adolescent health



Sponsored by The Royal Children's Hospital Foundation

DAY 1 Wednesday 1 September

12:15pm - 12:30pm	<p>Conference Opening</p> <p>Prof Ed Oakley, Acting Chief Executive Officer, The Royal Children's Hospital, Melbourne</p> <p>Welcome address including Acknowledgement of Country</p> <p>Prof John Massie, Paediatric Respiratory Physician; Clinical Director, Children's Bioethics Centre, The Royal Children's Hospital, Melbourne</p>
12:30pm - 2:00pm	<p><u>Session 1: The Jill Sewell plenary (RCH Grand Rounds)</u></p> <p>Deciding with Children</p> <p>Chair: Prof John Massie</p>
12:30pm - 12:35pm	<p>Introduction</p>
12:35pm - 1:30pm	<p>Prof Douglas S. Diekema, Physician and Director of Education, Treuman Katz Center for Pediatric Bioethics, Seattle Childrens Hospital; Professor in the Department of Pediatrics at the University of Washington School of Medicine, USA</p>
1:30pm - 2:00pm	<p>Extended discussion</p>
2:00pm – 2:30pm	<p>Break</p>
2:30pm – 4:00pm	<p><u>Session 2: Treading carefully: engaging with the young person in sensitive contexts</u></p> <p>Chair: Dr Georgina Hall, Education Officer, Clinical Ethicist & Academic Director, Children's Bioethics Centre, The Royal Children's Hospital, Melbourne</p>
2:30pm - 3:00pm	<p>How should we involve young adolescents in pre-operative pregnancy screening and testing?</p> <p>Ms Amy Carle, Clinical Nurse Specialist, Day Surgery, The Royal Children's Hospital, Melbourne</p>

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	Prof Clare Delany , Clinical Ethicist, Children's Bioethics Centre, The Royal Children's Hospital, Melbourne
3:00pm - 3:30pm	PROMs, PREMs and Children: Considerations of Agency and Vulnerability Mr Patrick Ryan , Medical Student Year 2, University of Sydney For the Sydney Children's Hospital Network Clinical Ethics Support Service (SCHNCESS)
3:30pm - 4:00pm	Exactly what is the child/young person consenting to? Decisions about treatment in a sexual assault/child sexual abuse service. Dr Helen Kambouridis , Senior Psychologist, Gatehouse Centre, The Royal Children's Hospital, Melbourne Caroline Whitehouse , Senior Social Worker, Gatehouse Centre, The Royal Children's Hospital, Melbourne
4:00pm – 5:00pm	Break
5:00pm - 6:30pm	<u>Session 3: Hypothetical – When teenagers think they know best!</u> Chair & Facilitator: Prof Lynn Gillam , Clinical Ethicist & Academic Director, Children's Bioethics Centre, The Royal Children's Hospital, Melbourne
5:00pm - 5:10pm	Introduction Panellists include:
5:10pm - 6:00pm	Mr James Marshall , Paramedic Educator, Ambulance Victoria Dr Amanda Stock , Paediatric Emergency Physician/Comfort Kids Paediatrician, The Royal Children's Hospital, Melbourne Adolescent Health Physician , The Royal Children's Hospital, Melbourne
6:00pm - 6:30pm	Discussion
6:30pm	Conclusion Day 1

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DAY 2 Thursday 2 September

7:30am – 8:30am	<p><u>Session 4: Ethical reflections - Medical Staff Association (MSA) “Breakfast”</u></p> <p>Chair: Mark Oliver, MSA Chair; Specialist Gastroenterology & Clinical Nutrition, The Royal Children's Hospital, Melbourne</p>
7:30am - 8:30am	Case presentation
8:30am – 10:00am	Break
10:00am – 11:30am	<p><u>Session 5: Respect for the child's voice</u></p> <p>Chair: Prof Clare Delany, Clinical Ethicist, Children's Bioethics Centre, The Royal Children's Hospital, Melbourne</p>
10:00am - 10:30am	<p>Deciding with Children with an Intellectual Disability</p> <p>Dr Kate Thomson Bowe and the Specialised Intellectual Disability Health Team (SIDHT), Hunter New England and Central Coast Local Health Districts, NSW Health</p>
10:30am - 11:00am	<p>Infant led approaches to inclusive decision making and ethical practice: Learnings taken from working with infants impacted by family violence</p> <p>Dr Wendy Bunston, wb Training & Consulting, author, and mental health social worker infant mental health and family violence, La Trobe University</p> <p>Ms Sarah Jones, Mental Health Social Worker/Psychotherapist, Child and Family Psychotherapist and Clinical Supervisor to hospital and family services</p>
11:00am - 11:30am	<p>The child's authenticity: Hiding in plain sight?</p> <p>Dr Ryan H. Nelson, Center for Medical Ethics and Health Policy, Baylor College of Medicine, Houston, Texas, USA</p>

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	Dr Bryanna Moore , Institute for Bioethics and Health Humanities, Department of Preventative Medicine and Population Health, University of Texas Medical Branch Galveston, Texas, USA
11:30am–12:30pm	Break
12:30pm – 2:00pm	<u>Session 6: Keynote Plenary - Getting over Gillick</u> Chair: Prof Lynn Gillam , Clinical Ethicist & Academic Director, Children's Bioethics Centre, The Royal Children's Hospital, Melbourne
12:30pm - 12:35pm	Introduction
12:35pm - 1:45pm	Panel discussion moderated by Prof Lynn Gillam. Speakers include: Dr Sarah Martin , Clinical Ethics fellow, Queensland Children's Hospital A/Prof Helen Irving , Pre-Eminent Specialist, Oncology Services Group; Associate Professor, University of Queensland; Clinical Lead, Centre Children's Health Ethics & Law (CCHL), Children's Health Queensland Hospital and Health Service, Brisbane, Queensland Dr Erin Sharwood , Paediatric Endocrinologist, Queensland Children's Hospital Ms Annabelle Mann , General Counsel, Dept of Legal Services, The Royal Children's Hospital, Melbourne Mr Avi Bart , Research Intern, Children's Bioethics Centre, The Royal Children's Hospital, Melbourne; MD-MPH Student, The University of Melbourne
1:45pm - 2:00pm	Final comments and discussion
2:00pm - 2:30pm	Break
2:30pm – 5:30pm	<u>Session 7: Bringing forward the child's voice</u> Chair: Dr Rosalind McDougall , Clinical Ethicist, Children's Bioethics Centre, The Royal Children's Hospital, Melbourne
2:30pm – 3.00pm	Ethical decision making in Adolescent Health, what is the process and how can it be improved? Dr Ciara Earley , General Paediatrician Monash Children's Hospital, Clayton, Victoria; Member of Monash Children's Clinical Ethics Response Group

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3:00pm – 3:30pm	<p>How long should we wait to hear the child's view? – the ethics of deferring surgery and other interventions in children with intersex variations</p> <p>Dr Michele O'Connell, Paediatric Endocrinologist, Dept of Endocrinology and Diabetes and RCH Gender Service; Chloe Hanna, Clinical Coordinator DSD, Dept of Gynaecology; Juan Bortagaray, Paediatric Urologist, Dept of Urology; Prof Sonia Grover, Director, Dept of Gynaecology; Prof Clare Delany, Clinical Ethicist, Children's Bioethics Centre</p> <p>The Royal Children's Hospital, Melbourne</p>
3.30pm - 4:00pm	Break
4:00pm – 5:30pm	<p><u>Session 7 Continued: Bringing forward the child's voice</u></p> <p>Chair: Prof Lynn Gillam, Clinical Ethicist & Academic Director, Children's Bioethics Centre, The Royal Children's Hospital, Melbourne</p>
4:00pm - 4:05pm	<p>Introduction</p>
4:05pm - 4:15pm	<p><i>Voicing My Choices: A Planning Guide for Adolescents and Young Adults</i></p> <p>Ms Tarnya Hotchkin, Adolescent and Young Adult Clinical Nurse Consultant, Children's Cancer Centre, The Royal Children's Hospital, Melbourne</p> <p>Ms Leah Rotin, Palliative Care Bereavement Coordinator, Victorian Paediatric Palliative Care Program</p> <p>Link to sample of the document: https://fivewishes.org/docs/default-source/Samples/vmc-sample.pdf?sfvrsn=4 </p>
4:15pm – 5.30pm	<p>Panel discussion</p> <p><u>Case 1: Supporting the adolescent voice at end of life</u></p> <p>Ms Tarnya Hotchkin, Adolescent and Young Adult Clinical Nurse Consultant, Children's Cancer Centre, The Royal Children's Hospital, Melbourne</p> <p>Ms Leah Rotin, Palliative Care Bereavement Coordinator, Victorian Paediatric Palliative Care Program</p>

	<p><u>Case 2: Promoting the child’s voice – in advance of loss of capacity</u></p> <p>Dr Carolyn Johnston, Clinical Ethicist, Monash Children’s Hospital, Clayton, Melbourne; Research Fellow, University of Tasmania</p> <p><u>Case 3: When a child says ‘no more’: chasing ethical imperatives and optimal outcomes in a complex and tragic case</u></p> <p>Ms Renee Deleuil, Clinical Ethics Service, Perth Children’s Hospital; Clinical Nurse Consultant, WA Paediatric Palliative Care Service, Western Australia</p> <p>Panellists: A/Prof Jenny Hynson, Clinical Associate Professor; Head, Victorian Paediatric Palliative Care Program Ms Tarnya Hotchkin, Adolescent and Young Adult Clinical Nurse Consultant, Children’s Cancer Centre, The Royal Children’s Hospital, Melbourne Ms Leah Rotin, Palliative Care Bereavement Coordinator, Victorian Paediatric Palliative Care Program Dr Carolyn Johnston, Clinical Ethicist, Monash Children’s Hospital, Clayton, Melbourne; Research Fellow, University of Tasmania</p>
5:30pm - 7:00pm	Break
7:00pm – 8:30pm	<p><u>Session 8: Hearing from young people: reflections on health care decision-making</u></p> <p>Chair: Prof John Massie, Paediatric Respiratory Physician; Clinical Director, Children’s Bioethics Centre, The Royal Children’s Hospital, Melbourne</p>
<p>7:00pm - 7:05pm</p> <p>7:05pm - 8:30pm</p>	<p>Introduction</p> <p>Young people panel moderated by Professor John Massie, Paediatric Respiratory Physician; Clinical Director, Children’s Bioethics Centre, The Royal Children’s Hospital, Melbourne</p>
8:30pm	Conclusion Day 2

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DAY 3 Friday 3 September

8:30am – 10:00am	<p><u>Session 9: Keynote Plenary – When parents exclude the adolescent in decision-making</u></p> <p>Chair: Prof Clare Delany, Clinical Ethicist, Children's Bioethics Centre, The Royal Children's Hospital, Melbourne</p>
	<p>Dr Lainie Ross, Carolyn and Matthew Bucksbaum Professor of Clinical Ethics; Associate Director of the MacLean Center for Clinical Medical Ethics; Co-Director of the Institute of Translational Medicine; Professor, Departments of Pediatrics, Medicine, Surgery and the College, University of Chicago; Academic Pediatrician, University of Chicago Comer Children's Hospital, University of Chicago, USA</p> <p>Prof Douglas S. Diekema, Physician and Director of Education, Treuman Katz Center for Pediatric Bioethics, Seattle Childrens Hospital; Professor in the Department of Pediatrics at the University of Washington School of Medicine, USA</p> <p>Prof Lynn Gillam, Clinical Ethicist & Academic Director, Children's Bioethics Centre, The Royal Children's Hospital, Melbourne</p>
10:00am - 10:30am	Break
10:30am – 12:00pm	<p><u>Session 10: Respecting refusal?</u></p>
10:30am - 11:00am	<p>So How Do We Listen to Children Who Won't Listen to Us?</p> <p>Dr Tahira Dosani, Paediatric Registrar, Clinical Ethics Fellow; Anne Preisz, Network Manager, SCHN Clinical Ethics; David Isaacs, SCHN Clinical Ethics, CHW; Henry Kilham, SCHN Clinical Ethics; Sydney Children's Hospital Network (SCHN), Westmead, NSW</p>



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11:00am - 11:30am	<p>Shifting the bar: Can an adolescent be both ‘competent’ and not?</p> <p>Dr Angie Kumar, Junior Medical Officer, Eastern Health, Victoria; Prof Sonia Grover, Director of Gynaecology, The Royal Children's Hospital, Melbourne</p>
11:30am - 12:00pm	<p>Check your privacy settings: should a child's illness journey be shared on social media?</p> <p>Ms Elise Burn, Queensland Children's Hospital Centre for Children's Health Ethics and Law</p>
12:00pm - 12:30pm	Break
12:30pm - 2:00pm	<u>Session 11: Deciding with Children: bringing it all together</u>
12:30pm - 12:35pm	Introduction
12:35pm - 1:30pm	<p>Prof John Massie, Paediatric Respiratory Physician & Clinical Director, Children's Bioethics Centre, The Royal Children's Hospital, Melbourne</p> <p>Prof Lynn Gillam, Clinical Ethicist & Academic Director, Children's Bioethics Centre, The Royal Children's Hospital, Melbourne</p> <p>Prof Clare Delany, Clinical Ethicist, Children's Bioethics Centre, The Royal Children's Hospital, Melbourne</p>
1:30pm - 2:00pm	Extended discussion
2:00pm - 2:05pm	<p>Announcement of Patron's prize for best conference paper</p> <p>Presented by A/Prof Hugo Gold, founding Clinical Director, Children's Bioethics Centre; retired Paediatrician, The Royal Children's Hospital, Melbourne</p>
2:05pm - 2:15pm	<p>Closing remarks & Conference close</p> <p>Prof John Massie, Paediatric Respiratory Physician & Clinical Director, Children's Bioethics Centre, The Royal Children's Hospital, Melbourne</p>