

# Deciding with children

## 12<sup>th</sup> National Paediatric Bioethics Conference

1-3 September 2021

Melbourne  
Children's  
A world leader  
in child and  
adolescent health



Supported by The Royal Children's Hospital Foundation

## DAY 1 Wednesday 1 September

12:15pm - 12:30pm	<p>Conference Opening</p> <p><b>Prof Ed Oakley</b>, Acting Chief Executive Officer, The Royal Children's Hospital, Melbourne</p> <p>Welcome address including Acknowledgement of Country</p> <p><b>Prof John Massie</b>, Paediatric Respiratory Physician; Clinical Director, Children's Bioethics Centre, The Royal Children's Hospital, Melbourne</p>
12:30pm - 2:00pm	<p><a href="#"><u>Session 1: The Jill Sewell plenary (RCH Grand Rounds)</u></a></p> <p><b>Deciding with Children</b></p> <p><b>Chair: Prof John Massie</b></p>
12:30pm - 12:35pm	<p><b>Introduction</b></p>
12:35pm - 1:30pm	<p><b>Prof Douglas S. Diekema</b>, 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><a href="#"><u>Session 2: Treading carefully: engaging with the young person in sensitive contexts</u></a></p> <p><b>Chair: Prof Clare Delany</b>, Clinical Ethicist, Children's Bioethics Centre, The Royal Children's Hospital, Melbourne</p>
2:30pm - 3:00pm	<p><b>How should we involve young adolescents in pre-operative pregnancy screening and testing?</b></p> <p><b>Ms Amy Carle</b>, Clinical Nurse Specialist, Day Surgery, The Royal Children's Hospital, Melbourne</p>

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

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## DAY 2 Thursday 2 September

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

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	<b>Dr Bryanna Moore</b> , 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	<b><u>Session 6: Keynote Plenary - Getting over Gillick</u></b> <b>Chair: Prof Lynn Gillam</b> , Clinical Ethicist & Academic Director, Children’s Bioethics Centre, The Royal Children’s Hospital, Melbourne
12:30pm - 12:35pm	<b>Introduction</b>
12:35pm - 1:45pm	<b>Moderated panel discussion, speakers include:</b> <b>Dr Sarah Martin</b> , Clinical Ethics fellow, Queensland Children’s Hospital <b>A/Prof Helen Irving</b> , 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 <b>Dr Erin Sharwood</b> , Paediatric Endocrinologist, Queensland Children’s Hospital
1:45pm - 2:00pm	<b>Ms Annabelle Mann</b> , General Counsel, Dept of Legal Services, The Royal Children's Hospital, Melbourne <b>Mr Avi Bart</b> , Research Intern, Children's Bioethics Centre, The Royal Children's Hospital, Melbourne; MD-MPH Student, The University of Melbourne
2:00pm - 2:30pm	Final comments and discussion
2:00pm - 2:30pm	Break
2:30pm – 5:30pm	<b><u>Session 7: Bringing forward the child’s voice</u></b> <b>Chair: Prof Lynn Gillam</b> , Clinical Ethicist & Academic Director, Children’s Bioethics Centre, The Royal Children’s Hospital, Melbourne
2:30pm – 3.00pm	<b>Ethical decision making in Adolescent Health, what is the process and how can it be improved? ( moving – post Gillick discussion)</b> <b>Dr Ciara Earley</b> , General Paediatrician Monash Children’s Hospital, Clayton, Victoria; Member of Monash Children’s Clinical Ethics Response Group

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<p>3:00pm – 3.30pm</p>	<p><b>How long should we wait to hear the child’s view? – the ethics of deferring surgery and other interventions in children with intersex variations</b></p> <p><b>Dr Michele O’Connell</b>, Paediatric Endocrinologist, Dept of Endocrinology and Diabetes and RCH Gender Service; <b>Chloe Hanna</b>, Clinical Coordinator DSD, Dept of Gynaecology; <b>Juan Bortagaray</b>, Paediatric Urologist, Dept of Urology; <b>Prof Sonia Grover</b>, Director, Dept of Gynaecology; <b>Prof Clare Delany</b>, Clinical Ethicist, Children’s Bioethics Centre</p> <p><b>The Royal Children's Hospital, Melbourne</b></p>
<p>3.30pm - 4:00pm</p>	<p>Break</p>
<p>4:00pm – 5:30pm</p>	<p><b><u>Session 7 Continued: Bringing forward the child’s voice</u></b></p>
<p>4:00pm - 4:05pm</p>	<p><b>Introduction</b></p>
<p>4:05pm - 4:15pm</p>	<p><b>Ms Tarnya Hotchkin</b>, Adolescent and Young Adult Clinical Nurse Consultant, The Royal Children's Hospital, Melbourne</p>
<p>4:15pm – 5.30pm</p>	<p><b>Panel discussion</b></p> <p><b>Case 1: Supporting the adolescent voice at end of life</b></p> <p><b>Ms Tarnya Hotchkin</b>, Adolescent and Young Adult Clinical Nurse Consultant, The Royal Children's Hospital, Melbourne</p> <p><b>Ms Leah Rotin</b>, Social Worker, Victorian Paediatric Palliative Care Program</p> <p><b>Case 2:</b></p> <p><b>Dr Carolyn Johnston</b>, Clinical Ethicist, Monash Children’s Hospital, Clayton; Research Fellow, University of Tasmania</p> <p><b>Case 3: When a child says ‘no more’: chasing ethical imperatives and optimal outcomes in a complex and tragic case</b></p> <p><b>Ms Renee Deleuil</b>, Clinical Ethics Service, Perth Children’s Hospital; Clinical Nurse Consultant, WA Paediatric Palliative Care Service, Western Australia</p>



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	<p><b>Panellists:</b>  <b>A/Prof Jenny Hynson</b>, Clinical Associate Professor; Head, Victorian Paediatric Palliative Care Program  <b>Ms Tarnya Hotchkin</b>, Adolescent and Young Adult Clinical Nurse Consultant, The Royal Children's Hospital, Melbourne  <b>Ms Leah Rotin</b>, Social Worker, Victorian Paediatric Palliative Care Program  <b>Dr Carolyn Johnston</b>, Clinical Ethicist, Monash Children's Hospital, Clayton; Research Fellow, University of Tasmania</p>
5:30pm - 7:00pm	Break
7:00pm – 8:30pm	<a href="#"><u>Session 8: Hearing from young people: reflections on health care decision-making</u></a>
7:00pm - 7:05pm  7:05pm - 8:30pm	<p><b>Introduction</b></p> <p><b>Young people panel</b> moderated by <b>Professor John Massie</b>, 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 4 September

8:30am – 10:00am	<p><a href="#"><u>Session 9: Keynote Plenary – When parents exclude the adolescent in decision-making</u></a></p> <p><b>Chair: Prof Clare Delany</b>, Clinical Ethicist, Children's Bioethics Centre, The Royal Children's Hospital, Melbourne</p>
	<p><b>Dr Lainie Ross</b>, 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><b>Prof Douglas S. Diekema</b>, 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>Extended discussion</p>
10:00am - 10:30am	Break
10:30am – 12:00pm	<p><a href="#"><u>Session 10: Respecting refusal?</u></a></p>
10:30am - 11:00am	<p><b>So How Do We Listen to Children Who Won't Listen to Us?</b></p> <p><b>Dr Tahira Dosani</b>, Paediatric Registrar, Clinical Ethics Fellow; Anne Preisz, Network Manager, SCHN Clinical Ethics; David Isaacs, SCHN Clinical Ethics, CHW; Henry Kilham, SCHN Clinical Ethics;</p> <p><b>Sydney Children's Hospital Network (SCHN), Westmead, NSW</b></p>

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