## Deciding *with Children*

# CONFERENCE PROGRAM

12th National Paediatric Bioethics Conference

**1 – 3 September 2021**

# Welcome

Dear colleagues,

It is with great pleasure that the **Children's Bioethics Centre (CBC)** at **The Royal Children's Hospital (RCH)** welcomes you, conference presenters, local, national and international delegates to our **12th National Paediatric Bioethics E-Conference 'Deciding *with* Children'**, from Melbourne, Australia.

Children have traditionally been seen as having no active role in decision-making about their health care (at least until the point where they become mature minors, apparently able to make all decisions for themselves). On this view, clinicians and parents have the ethical responsibility of deciding for children, and then securing the child's co-operation with whatever decision has been made. More recently, this understanding has been challenged by increasing recognition of the ethical importance of respect for the child, and promotion of the child's voice. The focus is shifting to deciding *with* children.

In this conference, we unpack and reflect on the idea of deciding *with* children. Is this really the ethically best approach? Could it have downsides - can decision-making really be shared with children without compromising their interests? Then there is the practical question of what deciding with children actually amounts to in practice. Is it any different from current best practice in paediatrics? What ethical responsibilities would clinicians have? And what role should parents have? If all children should be involved in some way in decision-making about their care, we need to reconsider what this means for the idea of "Gillick-competent" mature minors and whether this legal construct is useful as an ethical tool.

We would like to acknowledge the generous support of our conference supporters, the **Friends of the CBC Auxiliary** and **The Humanity Foundation**. The CBC acknowledges the ongoing financial support of the RCH Foundation through the generous bequest of the Betty Cosgrove Endowment.

Finally, to everyone who contributed to the conference. CBC staff: Karen Fellows, Georgina Hall & Stephanie McHenry. RCH Creative Services team: Simon Pase, Rob Grant & University of Melbourne staff: Gus Fraser & David Pethick for their high-quality technical support. Thank you for all your excellent work!

We hope you enjoy this exciting program.

**Professor John Massie**
Clinical Director
Children's Bioethics Centre
The Royal Children's Hospital

**Professor Lynn Gillam**
Clinical Ethicist & Academic Director
Children's Bioethics Centre
The Royal Children's Hospital

**Professor Clare Delany**
Clinical Ethicist
Children's Bioethics Centre
The Royal Children's Hospital

Friends of the CBC Auxiliary

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# International Keynote Speaker

## WEDNESDAY 1 SEPTEMBER

**Session 1** (Grand Round) 12:30pm-2:00pm

### Involving Children in Clinical Decision-making: Why it Matters and How Best to Do it

## Professor Douglas S. Diekema MD, MPH

Seattle, United States of America

And Session 9 – 8:30am-10:00am

This plenary session is named in honour of our recent Clinical Director, Associate Professor Jill Sewell. Professor Diekema will open the National Paediatric Bioethics Conference by considering the ethical underpinning of our conference theme, 'Deciding *with* Children'. Deciding with Children is more than a vague abstraction or aspirational goal of children's healthcare workers. Prof Diekema will demonstrate that Deciding with Children matters to the well-being of children and is a vital part of healthcare delivery. He will build on this foundation, using his clinical experience, to consider how best to authentically involve children in healthcare decisions.

### Biography

**Douglas Diekema** is a Professor of Pediatrics at the University of Washington School of Medicine with adjunct appointments in the Departments of Bioethics & Humanities and Internal Medicine in the School of Medicine and the Department of Health Services in the School of Public Health. He is also an attending physician in the emergency department at Seattle Children's Hospital and serves as Director of Education for the Treuman Katz Center for Pediatric Bioethics at Seattle Children's Research Institute. He has been a member of the Seattle Children's Hospital ethics committee since 1991, served as an ethics consultant for 26 years, has been chairperson of the institutional review board since 2000, and founded the Center for Pediatric Bioethics at Seattle Children's in 2004. He is past-Chair of the Committee on Bioethics of the American Academy of Pediatrics and currently serves as an elected Board member for the American Society for Bioethics & Humanities and as Chair of the Secretary's Advisory Committee for Human Subjects Protections (SACHRP) in the U.S. Department of Health and Human Services. Dr. Diekema the author of numerous scholarly publications in medical ethics and pediatric emergency medicine and an editor of *Clinical Ethics in Pediatrics: A Case-based Textbook*. He is an elected Fellow of the Hastings Center and was honored by the American Academy of Pediatrics as the 2014 recipient of the William G. Bartholome Award for Ethical Excellence.

# International Keynote Panellist

## FRIDAY 3 SEPTEMBER

Session 9 – 8:30am-10:00am

## International perspectives: When parents exclude the adolescent in decision-making

## Professor Lainie Friedman Ross MD, PhD

Chicago, United States of America

**Professor Douglas Diekema**
**Professor Lynn Gillam**

This session will consider some case examples where ‘deciding with children’ is not ethically straightforward. When parents exclude an adolescent from being involved in decision-making or when parents disagree with their child/adolescent’s views, clinicians must decide: When and how to advocate for a child to decide? When and why to defer to parents’ views?

Our three speakers, **Professor Lainie Ross**, Professor Douglas Diekema and Professor Lynn Gillam will comment on each case and draw from their own extensive experience in advising and writing about the scope and limits of parental authority and parental autonomy to discuss the question of *what to do when children are excluded from decisions about their healthcare?*

## Biography

**Professor Lainie Friedman Ross** is the Carolyn and Matthew Bucksbaum Professor of Clinical Medical Ethics; Professor, Departments of Pediatrics, Medicine, Surgery and the College; Co-Director of the Institute for Translational Medicine, and Associate Director of the MacLean Center for Clinical Medical Ethics at the University of Chicago.

Dr Ross’ research portfolio concentrates on ethical and policy issues in pediatrics, defining death and organ transplantation, genetics and genomics, and research ethics. She is especially interested in vulnerable populations and how to reduce health care disparities. She has published five books and over 200 articles in the peer-reviewed literature and frequently lectures nationally and internationally.

# National Keynote Speakers

## THURSDAY 2 SEPTEMBER

Session 6 – 12:30pm-2:00pm

### The Use and Abuse of “Gillick” Competence

**Dr Sarah Martin** FRACP FACEM

Queensland, Australia

The term “Gillick competence” is ubiquitous in paediatric clinical practice, frequently appearing in guidelines and documentation around informed consent for young people under 18 years. How is this concept referring to a 1985 legal case being applied in Australia in 2021? Has it found new meaning, or been lost along the way and relegated to lip-service and box-ticking?

Biography

Dr Sarah Martin works currently both as the Clinical Ethics Fellow with the Centre for Children's Health Ethics and Law (CCHEL), and as a Paediatric Emergency Physician at the Queensland Children's Hospital. Her interest in clinical ethics stems from her experience supervising and educating emergency medicine trainees in complex clinical decision-making, and from a realisation that moral distress has a negative impact on the well-being of critical care clinicians. She is hoping to explore this connection further when she commences a PhD next year.

### Getting over Gillick – what’s next?

**Dr Erin Sharwood**

Queensland, Australia

If Gillick leaves us wanting more, what else do we have to offer? Here we can considering ideas about duty of care and a responsibility to recognise, support and promote evolving autonomy in young people.

We will explore models of shared and supported decision making to uphold the obligations of person-centred care and informed consent.

### Biography

**Erin Sharwood** is a member of the Clinical Ethics Consultation Service at the Queensland Children's Hospital, and has recently completed a term as the acting Clinical Lead for the Centre for Children's Health Ethics and Law. Erin worked as the Clinical Ethics Fellow with this service for three years, during which time she completed her Masters in Bioethics through Monash University. She has a particular interest in models of shared decision making between young people, their families, and their clinicians. Erin is also a Paediatric Endocrinologist and is currently working on her PhD investigating links between endocrine and metabolic health and sleep function after treatment for childhood brain tumours.

## Special commentator

### A/Prof Helen Irving MBBS, FRACP, MBioethics

Queensland, Australia

### Biography

**Associate Professor Helen Irving** is the Clinical Lead of the Centre for Children's Health Ethics and Law (CCHEL) Children's Health Queensland Hospital and Health Service and a member of the Brisbane's Metro South Hospitals and Health Service Clinical Ethics Service. She has also been instrumental in the promotion of Schwartz Centre Membership at CHQ, which has recently been attained. Her clinical role is that of Specialist Paediatric and Adolescent Oncologist and Medical Lead for the State-wide paediatric haematology, oncology and palliative care network (QPPHON). Dr Irving's interest in bioethics stems from the challenges of care and decision making in paediatric medicine, particularly around the extent of and conflict around direction of care, staff distress, and innovations in care. She is Associate Professor, University of Queensland Faculty of Medicine and involved in undergraduate and postgraduate medical and inter-disciplinary teaching.

## FRIDAY 3 SEPTEMBER Session 11 – 12:30pm-1:45pm

## Deciding *with* Children: bringing it all together

## Professor Lynn Gillam BA(HONS), MA(OXON), PhD

Melbourne, Australia

Biography

**Professor Lynn Gillam** is a clinical ethicist and Academic Director of the Children's Bioethics Centre at The Royal Children’s Hospital Melbourne with particular interests in paediatric clinical ethics, research ethics and ethics education. Lynn is also Professor in Health Ethics in the School of Population and Global Health at the University of Melbourne.

## Professor Clare Delany

PhD, M HEALTH & MED LAW, M PHYSIO, B APP SC

Melbourne, Australia

Biography

**Professor Clare Delany** is a Clinical Ethicist at the Children’s Bioethics Centre at The Royal Children’s Hospital and at Peter MacCallum Cancer Centre in Melbourne. She is a Professor in Health Professions Education in the Department of Medical Education, Melbourne Medical School, at the University of Melbourne.

## Professor John Massie

MBBS FRACP PhD GAICD

Melbourne, Australia

Biography

**Professor John Massie** is the Clinical Director of the Children's Bioethics Centre at The Royal Children’s Hospital, Melbourne. John has published numerous papers, letters and book chapters on ethical issues relating to paediatric medicine as well papers on screening for inherited diseases, newborn screening, cystic fibrosis and technology dependent children. John is the producer and host of Essential Ethics, the CBC podcast channel presenting thoughtful discussion on the ethical dilemmas that arise when caring for sick children. John is also a paediatric respiratory physician at RCH, looking after children with cystic fibrosis and those requiring ventilator support. John is a Clinical Professor at the University of Melbourne and Research Fellow at the Murdoch Children’s Research Institute.

# DAY 1 Wednesday 1 September

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| 12:15pm-12:30pm | Conference Opening<br>**Prof Ed Oakley**, Acting Chief Executive Officer, The Royal Children's Hospital, Melbourne<br>Welcome address including Acknowledgement of Country<br>**Prof John Massie,** Paediatric Respiratory Physician; Clinical Director, Children's Bioethics Centre, The Royal Children's Hospital, Melbourne |
| 12:30pm-2:00pm | **Session 1:** The Jill Sewell plenary (RCH Grand Rounds)<br>**Deciding *with* Children**<br>**Chair: Prof John Massie** |
| 12:30pm-12:35pm | Introduction |
| 12:35pm-1:30pm | **Involving Children in Clinical Decision-making: Why it Matters and How Best to Do it**<br>**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 |
| 1:30pm-2:00pm | Extended discussion |
| 2:00pm–2:30pm | Break |
| 2:30pm–4:00pm | **Session 2:** Treading carefully: engaging *with* the young person in sensitive contexts<br>**Chair: Dr Georgina Hall,** Ethics Education Coordinator, Children's Bioethics Centre, The Royal Children's Hospital, Melbourne |
| 2:30pm-3:00pm | **How should we involve young adolescents in pre-operative pregnancy screening and testing?**<br>**Ms Amy Carle**, Clinical Nurse Specialist, Day of Surgery Unit, The Royal Children's Hospital, Melbourne<br>**Prof Clare Delany,** Clinical Ethicist, Children's Bioethics Centre, The Royal Children's Hospital, Melbourne |

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| 3:00pm-3:30pm | **PROMs, PREMs and Children: Considerations of Agency and Vulnerability**<br>**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**<br>**Dr Helen Kambouridis,** Senior Psychologist, Gatehouse Centre, The Royal Children's Hospital, Melbourne<br>**Ms Caroline Whitehouse,** Senior Social Worker, Gatehouse Centre, The Royal Children's Hospital, Melbourne |
| 4:00pm-5:00pm | Break |
| 5:00pm-6:30pm | **Session 3:** Hypothetical – When teenagers think they know best!<br>**Chair & Facilitator: Prof Lynn Gillam,** Clinical Ethicist & Academic Director, Children's Bioethics Centre, The Royal Children's Hospital, Melbourne |
| 5:00pm-5:10pm | Introduction |
| 5:10pm-6:30pm | Panellists:<br>**Mr James Marshall,** Paramedic Educator, Ambulance Victoria<br>**Dr Amanda Stock,** Paediatric Emergency Physician/Comfort Kids Paediatrician**,** The Royal Children's Hospital, Melbourne<br>**Dr Michele Yeo,** Department of Adolescent Medicine, The Royal Children's Hospital, Melbourne |
| 6:30pm<br>Back to top | Conclusion Day 1 |

# DAY 2 Thursday 2 September

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| 7:30am-8:30am | **Session 4:** Early morning ethical reflections<br>**Chair:Prof Mark Oliver,** Chair, RCH Medical Staff Association (MSA); Specialist Gastroenterology & Clinical Nutrition, The Royal Children's Hospital, Melbourne |
| 7:30am-8:30am | Hosted by the RCH Medical Staff Association<br>**Case presentation: Our daughter, her condition and our decision as to what would be best for her**<br>Case presented by **Prof Mark Oliver**<br>Facilitated by **Prof Lynn Gillam** |
| 8:30am-10:00am | Break |
| 10:00am-11:30am | **Session 5:** Respect for the child's voice<br>**Chair: Prof Clare Delany,** Clinical Ethicist, Children's Bioethics Centre, The Royal Children's Hospital, Melbourne |
| 10:00am-10:30am | **Deciding with Children with an Intellectual Disability**<br>**Dr Kate Thomson Bowe,** Paediatrician, Specialised Intellectual Disability Health Team (SIDHT), Hunter New England and Central Coast Local Health Districts, NSW Health<br>**Ms Trish Stedman,** Clinical Nurse Consultant and Team Leader, SIDHT, Hunter New England and Central Coast Local Health Districts, NSW Health |
| 10:30am-11:00am | **Infant led approaches to inclusive decision making and ethical practice: Learnings taken from working with infants impacted by family violence**<br>**Dr Wendy Bunston**, wb Training & Consulting, Author, and Mental Health Social Worker Infant Mental Health and Family Violence, La Trobe University<br>**Ms Sarah Jones,** Mental Health Social Worker/Psychotherapist, Child and Family Psychotherapist and Clinical Supervisor to Hospital and Family Services |
| 11:00am-11:30am | **The child's authenticity: Hiding in plain sight?**<br>**Dr Ryan H. Nelson,** Center for Medical Ethics and Health Policy, Baylor College of Medicine, Houston, Texas, USA<br>**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 |

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| 12:30pm-2:00pm | **Session 6:** Keynote Plenary - Getting over Gillick<br>**Chair: Prof Lynn Gillam,** Clinical Ethicist & Academic Director, Children's Bioethics Centre, The Royal Children's Hospital, Melbourne<br>**Special Guest panellist: A/Prof Helen Irving,** Pre-Eminent Specialist, Oncology Services Group; Associate Professor, University of Queensland; Clinical Lead, Centre Children's Health Ethics & Law (CCHEL), Children's Health Queensland Hospital and Health Service, Brisbane, Queensland |
| 12:30pm-12:35pm | Introduction |
| 12:35pm-1:00pm | **The Gillick Principle**<br>**Ms Annabelle Mann,** General Counsel, Legal Services Department, The Royal Children's Hospital, Melbourne<br>**Mr Avi Bart**, Research Intern, Children's Bioethics Centre, The Royal Children's Hospital, Melbourne; MD-MPH Student, The University of Melbourne |
| 1:00pm-1:30pm | **The Use and Abuse of "Gillick" Competence**<br>**Dr Sarah Martin,** SMO; co-DEMT Emergency Department; Clinical Ethics fellow, Queensland Children's Hospital |
| 1:30pm-2:00pm | **Getting Over Gillick – What's next?**<br>**Dr Erin Sharwood,** Paediatric Endocrinologist, Queensland Children's Hospital |
| 2:00pm-2:30pm | Break |
| 2:30pm-5:30pm | **Session 7:** Bringing forward the child's voice<br>**Chair: Dr Rosalind McDougall,** Clinical Ethicist, Children's Bioethics Centre, The Royal Children's Hospital, Melbourne |
| 2:30pm-3.00pm<br>Back to top | **Ethical decision making in Adolescent Health, what is the process and how can it be improved?**<br>**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 | **How long should we wait to hear the child's view? – the ethics of deferring surgery and other interventions in children with intersex variations**<br>**Dr Michele O'Connell,** Paediatric Endocrinologist, Dept of Endocrinology and Diabetes; RCH Gender Service;<br>**Prof Sonia Grover,** Director of Gynaecology; **Ms Chloe Hanna,** Clinical Co-ordinator, Gynaecology<br>**Mr Juan Bortagaray,** Director of Urology<br>All members of the **DSD multidisciplinary team**, The Royal Children's Hospital, Melbourne |
| 3.30pm-4:00pm | Break |
| 4:00pm-5:30pm | **Session 7 Continued:** The child's voice near end of life – cases and discussion<br>**Chair: Prof Lynn Gillam,** Clinical Ethicist & Academic Director, Children's Bioethics Centre, RCH<br>**Special Guest panellist**: **A/Prof Jenny Hynson**, Head, Victorian Paediatric Palliative Care Program |
| 4:00pm-4:05pm | Introduction |
| 4:05pm-4:30pm | **Case 1: Supporting the adolescent voice at end of life**<br>**Ms Tarnya Hotchkin,** Adolescent and Young Adult Clinical Nurse Consultant, Children's Cancer Centre, The Royal Children's Hospital, Melbourne<br>**Ms Leah Rotin**, Palliative Care Bereavement Coordinator, Victorian Paediatric Palliative Care Program |
| 4:35pm-5:00pm | **Case 2: When a child says 'no more': chasing ethical imperatives and optimal outcomes in a complex and tragic case**<br>**Ms Renee Deleuil,** Clinical Ethics Service, Perth Children's Hospital; Clinical Nurse Consultant, WA Paediatric Palliative Care Service, Western Australia<br>**Dr Nadine Caunt,** Child and Adolescent Psychiatrist, public and private practice, Western Australia |
| 5:05pm-5:30pm<br>Back to top | **Case 3: Promoting the child's voice – in advance of loss of capacity**<br>**Dr Carolyn Johnston**, Clinical Ethicist, Monash Children's Hospital, Clayton, Melbourne; Research Fellow, University of Tasmania |
| 5:30pm-7:00pm | Break |

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| 7:00pm-8:30pm | **Session 8:** Hearing from young people: reflections on health care decision-making<br>**Chair & Facilitator: Prof John Massie,** Paediatric Respiratory Physician; Clinical Director, Children's Bioethics Centre, The Royal Children's Hospital, Melbourne |
| 7:00pm-7:05pm | Introduction |
| 7:05pm-8:30pm | Panellists<br>**Ms Evelyn Culnane,** Manager, Transition Support Service, The Royal Children's Hospital, Melbourne<br>**Ms Morgan Cataldo,** Senior Manager Youth Engagement at Berry Street; Independent Participation Practitioner<br>**Ms Rachael Parrot,** Veterinary Receptionist with a passion for animal care<br>**Mr Oliver Pizzey-Stratford,** Actor and Competitive Tennis Player<br>Moderators<br>**Mr Avi Bart**, Research Intern, Children's Bioethics Centre, The Royal Children's Hospital, Melbourne; MD-MPH Student, The University of Melbourne<br>**Ms Sarah Winthrope,** MD/BMedSc student, Monash University; past intern, Children's Bioethics Centre, The Royal Children's Hospital, Melbourne |
| 8:30pm<br>Back to top | Conclusion Day 2 |

| DAY 3 | Friday 3 September |
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| 8:30am-10:00am | **Session 9:** International perspectives: When parents exclude the adolescent in decision-making<br>**Chair: Prof Clare Delany,** Clinical Ethicist, Children's Bioethics Centre, RCH Melbourne |
|  | **Prof *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<br>**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<br>**Prof Lynn Gillam,** Clinical Ethicist & Academic Director, Children's Bioethics Centre, The Royal Children's Hospital, Melbourne |
| 10:00am-10:30am | Break |
| 10:30am-12:00pm | **Session 10:** Respecting refusal<br>**Chair: Prof Richard Doherty**, Board Member, The Royal Children's Hospital, Melbourne; Department of Infectious Diseases, Monash Children's; Professor, Department of Paediatrics, Monash University, Clayton, Victoria |
| 10:30am-11:00am | **So How Do We Listen to Children Who Won't Listen to Us?**<br>**Dr Tahira Dosani,** Clinical Ethics Fellow; CHW Paediatric Registrar, Sydney Children's Hospital Network (SCHN), Westmead, New South Wales |
| 11:00am-11:30am | **Shifting the bar: Can an adolescent be both 'competent' and not?**<br>**Dr Angie Kumar**, Junior Medical Officer, Eastern Health, Victoria<br>**Prof Sonia Grover,** Director of Gynaecology, The Royal Children's Hospital, Melbourne |

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| 11:30am-12:00pm | **Check your privacy settings: should a child's illness journey be shared on social media?**<br>**Ms Elise Burn,** Queensland Children's Hospital Centre for Children's Health Ethics and Law |
| 12:00pm-12:30pm | Break |
| 12:30pm-1:45pm | **Session 11:** Deciding with Children: bringing it all together<br>**Chair: Ms Maria Flynn,** Executive Director Nursing & Allied Health, The Royal Children's Hospital, Melbourne |
| 12:30pm-12:35pm | Introduction |
| 12:35pm-1:45pm | **Prof Lynn Gillam,** Clinical Ethicist & Academic Director, Children's Bioethics Centre, The Roya Children's Hospital, Melbourne<br>**Prof Clare Delany,** Clinical Ethicist, Children's Bioethics Centre, The Royal Children's Hospital Melbourne<br>**Prof John Massie,** Paediatric Respiratory Physician & Clinical Director, Children's Bioethics Centre, The Royal Children's Hospital, Melbourne |
| 1:45pm-2:00pm | **Announcement of Patron's prize for best conference paper**<br>Presented by **A/Prof Hugo Gold,** founding Clinical Director, Children's Bioethics Centre; retired Paediatrician, The Royal Children's Hospital, Melbourne |
| 2:00pm-2:15pm | Closing remarks & Conference close<br>**Mr Robbie Friedman,** President, Friends of the CBC Auxiliary<br>**Prof John Massie,** Paediatric Respiratory Physician & Clinical Director, Children's Bioethics Centre, The Royal Children's Hospital, Melbourne |

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# Biographies

(In program order)

## Day 1: Wednesday 1 September

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| 12:30pm-2:00pm | **Session 1:** The Jill Sewell plenary (RCH Grand Rounds)<br>**Deciding *with* Children**<br>**Chair: Prof John Massie** |

### Involving Children in Clinical Decision-making: Why it Matters and How Best to Do it

**Douglas Diekema** *(please refer page 3 of Program)*

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| 2:30pm–4:00pm | **Session 2:** Treading carefully: engaging *with* the young person in sensitive contexts<br>**Chair: Dr Georgina Hall,** Education Officer, Clinical Ethicist & Academic Director, Children's Bioethics Centre, The Royal Children's Hospital, Melbourne |

### How should we involve young adolescents in pre-operative pregnancy screening and testing?

**Amy Carle** is a clinical nurse specialist in the day of surgery unit. She attended university in the United States where she received her bachelor's degree in psychology before moving to Melbourne to study nursing at the University of Melbourne. She has worked in day surgery at the Royal Children's Hospital for over 13 years and is currently working on a clinical guideline for pregnancy screening pre-operative adolescent patients. She recently completed the BEST practice program researching nurses' concerns and support needs when pregnancy screening in a paediatric population.

**Professor Clare Delany** is a Clinical Ethicist at the Children's Bioethics Centre at The Royal Children's Hospital and at Peter MacCallum Cancer Centre in Melbourne. She is a Professor in Health Professions Education in the Department of Medical Education, Melbourne Medical School, at the University of Melbourne.

### PROMs, PREMs and Children: Considerations of Agency and Vulnerability

**Patrick Ryan** is a 2nd year medical student at the University of Sydney, and is currently undertaking a clinical ethics program at The Sydney Children's Hospital Network Clinical Ethics Support Service (SCHNCESS).

### Exactly what is the child/young person consenting to? Decisions about treatment in a sexual assault/child sexual abuse service

**Helen Kambouridis** is a senior psychologist and Program leader of the Research, Education and Training program at the Gatehouse Centre, Royal Children's Hospital. She has worked in the Victorian child sexual abuse sector for over 25 years and her PhD, completed in 2014, developed principles of practice for therapists in the sexual assault sector working with families who have experienced sibling sexual abuse. Prior to working in this sector, Helen worked as a psychologist in Disability Services and as a Secondary School teacher.

**Caroline Whitehouse** is a senior social worker, family therapist and manager of sexual assault support services for the Gatehouse Centre, Royal Children's Hospital.  She has been providing psycho-social assessment and treatment to vulnerable children, young people and their families for over 20 years.  Caroline is a PhD candidate, her thesis examines the experiences of children and young people in the acute stages of trauma and how health and justice systems respond to them in those first hours following a sexual assault.

5:00pm-6:30pm

### Session 3: Hypothetical – When teenagers think they know best!

**Chair & Facilitator: Prof Lynn Gillam,** Clinical Ethicist & Academic Director, Children's Bioethics Centre, The Royal Children's Hospital, Melbourne

**James Marshall** has been a paramedic with Ambulance Victoria since 2005, working chiefly in central Melbourne. Apart from his operational role, he has worked extensively in clinical guideline development and also in education, both in formal training settings and also in developing and delivering classroom content. His clinical interests revolve around finding ways to deliver the optimum level of care to populations that frequently don't require an emergency response, and in adapting to the rapidly changing world of out-of-hospital emergency care. When not wearing a uniform James spends his time caring for his children and revisiting his wasted youth spent as an archaeologist.

**Amanda Stock**
In my job as a paediatric emergency physician I have the privilege to work with patients and their families at the messy, challenging and pointy end of life .It is always my aim for people to feel more empowered, informed and cared for when they leave our department particularly in these Covid times of uncertainty....to feel more certain about the aspects of life we can feel certain about.... such as the health and wellbeing of our children.

**Michele Yeo** is a paediatrician and adolescent physician at the Department of Adolescent Medicine and Centre for Adolescent Health. She is the Medical Lead in the Royal Children's Hospital Eating Disorders Program.
Her main areas of interest are eating disorders, adolescent risk behaviours, chronic illness, teaching and health services research. Michele also enjoys being outdoors and has two teenage children who roll their eyes at her when she tries to use her clinical skills on them!!

# Day 2: Thursday 2 September

7:30am-8:30am

### Session 4: Early morning ethical reflections

**Chair: Prof Mark Oliver,** Chair, RCH Medical Staff Association (MSA); Specialist Gastroenterology & Clinical Nutrition, The Royal Children's Hospital, Melbourne

**Case presentation: Our daughter, her condition and our decision as to what would be best for her**

**Mark Oliver** is a Consultant Gastroenterologist at The Royal Children's Hospital and has held this post for over a quarter of a century. He has wide interests within the specialty including Cystic Fibrosis, Inflammatory bowel disease and organ transplantation. He has served on various Ethic's Committees at the hospital and holds a senior post at the University of Melbourne as a Clinical Professor.

**Lynn Gillam** *(please refer page 7 of Program)*

10:00am-11:30am

## **Session 5:** Respect for the child’s voice

**Chair: Prof Clare Delany,** Clinical Ethicist, Children’s Bioethics Centre,
The Royal Children’s Hospital, Melbourne

### Deciding with Children with an Intellectual Disability

**Kate Thomson Bowe** is a paediatrician with a passion for disability, improving service delivery and access and moving towards an inclusive and safe community for all. Kate is a Melbournite who trained at RCH and worked in Developmental Medicine. She moved to Newcastle NSW in 2016 and is the Deputy Head of General Paediatrics at the John Hunter Children’s Hospital and the paediatrician on the Specialised Intellectual Disability Health Team for Hunter New England and the Central Coast.

**Trish Stedman** has worked in the disability sector for 27 years across both the government and non-government sectors. A large portion of her career has been at the Large Residential Centres working in many roles including CNC, NUM and Principal Nurse Manager. Trish enjoys working with people and families to provide the best experience when accessing health care. As the CNC she was the liaison across inpatient settings, providing support to both the patient and the care teams. Trish is currently the CNC and Team Leader of the Specialised Intellectual Disability Health Team for Hunter New England and Central Coast Local Health District, having established this team in January 2020. Trish’s interests are working with people with an intellectual disability to ensure the sector hears the voice of the person, the person has access to services in a way that meet their needs by making reasonable adjustments and assisting people to live their best life.

### Infant led approaches to inclusive decision making and ethical practice: Learnings taken from working with infants impacted by family violence

**Dr Wendy Bunston** is an international author, presenter, researcher and clinician specialising in working therapeutically with infants and their families impacted by family violence. Wendy’s PhD on the experience of infants in women’s refuges won the distinguished ‘Nancy Millis’ award in 2016 and was as a finalist in the highly prestigious 2019 Victorian Premier’s Health and Medical Research Awards. Her current book, Supporting Vulnerable Babies and Young Children, co-edited with Sarah J Jones is published by UK publishers Jessica Kingsley Publishers.

**Sarah Jones** is a Mental Health Social Worker, Child & Family Psychotherapist in Private Practice and Consultant Clinical Supervisor to several major teaching hospitals. She worked in the RCH Mental Health Service from 1988-2003 as both a clinician and program manager. She is a member of the RCH Bioethics Clinical Ethics Response Group and co-edited the book with Wendy Bunston tiled: *Supporting Vulnerable Babies and Young Children in 2020.*

### The child’s authenticity: Hiding in plain sight?

**Ryan H. Nelson** is an Assistant Professor at Baylor College of Medicine’s Center for Medical Ethics and Health Policy, where he also completed a postdoctoral fellowship in clinical ethics. He has a Ph.D. in philosophy from the University of Utah. His research interests include the philosophy of medicine and disability.

**Bryanna Moore** is an Assistant Professor at the University of Texas Medical Branch's Institute for Bioethics and Health Humanities. She completed postdoctoral fellowships at Baylor College of Medicine's Center for Medical Ethics and Health Policy and the Children's Mercy Bioethics Center in Kansas City. She has a Ph.D. in philosophy from Monash University. Her research interests span pediatric ethics, end-of-life issues, virtue ethics and medical decision-making.

12:30pm-2:00pm

## Session 6: Keynote Plenary - Getting over Gillick

**Chair: Prof Lynn Gillam,** Clinical Ethicist & Academic Director, Children's Bioethics Centre, The Royal Children's Hospital, Melbourne
**Special Guest panellist: A/Prof Helen Irving** *(please refer page 6 of Program)*

### The Gillick Principle

**Annabelle Mann** is General Counsel in The Royal Children's Hospital Legal Services Department, where she has worked since 2010. A usual day may see her providing advice to procurement regarding a purchase agreement, a doctor regarding a summons to give evidence, the CEO regarding reporting obligations, a social worker regarding consent for treatment and the Privacy Officer regarding release of patient information. Annabelle's involvement in Clinical Ethics at the RCH commenced in 2008 when she joined the Clinical Ethics Committee as an independent legal practitioner. Since then, Annabelle has completed a Masters of Bioethics and developed a keen interest in the intersection, and interaction, between law and ethics in the health sector and how this plays out in the paediatric setting.

**Avi Bart** is a final year MD-MPH student at The University of Melbourne and an aspiring paediatrician. He recently completed a 6-month research internship at the Children's Bioethics Centre exploring the appropriateness of Gillick competence as a tool for medical decision-making in adolescence. As a Friends of the CBC auxiliary member, Avi has been active in creating opportunities for students to engage with bioethics. Avi is also an Orthodox Rabbi who holds communal and educational roles in the Melbourne Jewish Community and was recently appointed Assistant Rabbi at the Blake Street Hebrew Congregation.

### The Use and Abuse of "Gillick" Competence

**Dr Sarah Martin** *(please refer page 5 of Program)*

### Getting Over Gillick – What's next?

**Dr Erin Sharwood** *(please refer page 5 of Program)*

2:30pm-5:30pm

## Session 7: Bringing forward the child's voice

**Chair: Dr Rosalind McDougall,** Clinical Ethicist, Children's Bioethics Centre, The Royal Children's Hospital, Melbourne

### Ethical decision making in Adolescent Health, what is the process and how can it be improved?

**Ciara Earley** is a general paediatrician at Monash Children's Hospital. She is also a member of the Clinical Ethics Response Group at Monash Children's. She has recently completed her Masters of Bioethics through Monash University. This talk is based on her research project that was submitted as part of her Masters.

### How long should we wait to hear the child's view? – the ethics of deferring surgery and other interventions in children with intersex variations

The Royal Children's Hospital Melbourne was the first paediatric centre in Australia to establish a multidisciplinary team to co-ordinate clinical care and complex decision-making for children and adolescents with differences of sex development (DSD). The DSD multidisciplinary team consists of **Michele O'Connell**, Paediatric Endocrinologist, **Sonia Grover**, Paediatric and Adolescent Gynaecologist), **Juan Bortagary,** Paediatric Urologist) and **Chloe Hanna,** Clinical co-ordinator.
They will discuss the ethics of deferring surgery and other interventions in children with intersex variations.

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| 4:00pm-5:30pm | **Session 7 Continued:** Bringing forward the child's voice<br>**Chair: Prof Lynn Gillam,** Clinical Ethicist & Academic Director, Children's Bioethics Centre, The Royal Children's Hospital, Melbourne<br>**Special Guest panellist: A/Prof Jenny Hynson** |

**Jenny Hynson** is a specialist in Paediatric Palliative Medicine and heads the Victorian Paediatric Palliative Care Program based at The Royal Children's Hospital, Melbourne. Jenny was a founding member of the Children's Bioethics Centre and continues to contribute to clinical ethics on campus as a member of the Clinical Ethics Response Group.

### Case 1: Supporting the adolescent voice at end of life

**Tarnya Hotchkin** is an Adolescent and Young Adult, Oncology Clinical Nurse Consultant working within the Children's Cancer Centre at The Royal Children's Hospital for the past six years. Tarnya has over two decades of Oncology nursing specialising in the care of adolescents and young adults. Working for not for profit organisations has contributed to her wealth of knowledge in all aspects of cancer care including acute and palliative care. Tarnya is committed to understanding the voice of the young person and incorporating the fundamentals of adolescent health and well-being into the cancer trajectory factoring in developmental stages of her patients. Her longstanding interest and expertise in Adolescent Health has seen her obtain her Graduate Diploma in Child and Adolescent Grief Counselling. It is evident that Tarnya's passion is ensuring she empowers the young person to have their voice heard throughout their cancer experience.

**Leah Rotin** is a social worker who has been working as part of the state-wide Victorian Paediatric Palliative Care Program since 2012. Leah is passionate about promoting the role of social work in paediatric palliative care and is committed to expanding allied health support to children with life limiting conditions and their families. Leah is currently redefining the social work role at the VPPCP to enhance bereavement care and coordination for families following the death of a child.

### Case 2: When a child says 'no more': chasing ethical imperatives and optimal outcomes in a complex and tragic case

**Renee Deleuil** is the Clinical Nurse Consultant with the WA Paediatric Palliative Care service based at Perth Children's Hospital, prior to that Renee held senior nursing roles in organ donation and immunology. Renee has completed her Masters by Research, graduate certificate in palliative care and is currently working towards Masters of Nurse Practitioner specialising in paediatric palliative care. Renee has sat on the Clinical Ethics Service since 2018.

**Dr J Nadine Caunt** is a child and adolescent psychiatrist working in public and private practice in Western Australia for the past 25 years. She is the Director of Advanced Training in Child and Adolescents and lectures extensively in local postgraduate programs. Over the course of her career she has held multiple positions locally and binationally within the Royal Australia and New Zealand College of Psychiatrists. She holds sessional positions in the State Administrative and Mental Health Tribunals and provides expert opinions to systems within the framework of critical incidents including coronial reports. Her interests beyond teaching, training and supervision include psychosocial development and psychotherapeutic interventions with individuals and families.

## Case 3: Promoting the child’s voice – in advance of loss of capacity

**Dr Carolyn Johnston** is a Clinical Ethicist at Monash Children’s Hospital, Melbourne. She has published on clinical ethics services and is co-author of the textbook *100 Cases in Clinical Ethics and Law* (2016, CRC Press). Carolyn is Research Fellow at University of Tasmania, contributing to the *Returning Raw Genomic Data: Patient Autonomy or Legal Minefield?* Project, and holds an honorary appointment (Senior Fellow, law) with Melbourne University. She is currently providing academic input for the 2020 - 2021 art + science residency at the Australian Network for Art & Technology.

7:00pm-8:30pm

## **Session 8:** Hearing from young people: reflections on health care decision-making

**Chair: Prof John Massie,** Paediatric Respiratory Physician; Clinical Director, Children’s Bioethics Centre, The Royal Children’s Hospital, Melbourne

**Evelyn Culnane** leads the Transition Support Service at the Royal Children’s Hospital (RCH) Melbourne supporting the care of young people and their parents and carers as they transition from paediatric to adult health care. In 2020, the Transition Support Service was pleased to be awarded the inauguaral Exemplar Practice Award from the Australian Commission on Safety and Quality Healthcare.
She is passionate about enabling young people to be active participants in their health care and along with her team, assists young people to develop the skills and confidence to successfully negotiate and navigate complex systems, such as health, disability and education.
In addition to her clinical role at the RCH, Evelyn is involved in a number of research initiatives including an international study on transition care from all disciplines, improving outcomes for children and adults with cerebral palsy, national guidelines for attention deficit hyperactivity disorder, a national strategic action plan for congenital heart disease, international guidelines for oesophageal atresia.

**Morgan Cataldo** has worked within the for-purpose sector for the past 10+ years in a range of policy, advocacy, and service development roles. She currently supports organisations understand the role of power in their everyday work and ways they can partner with people with a lived experience of socioeconomic disadvantage to design and shape more meaningful policies, programs, and services. Morgan is currently the Senior Manager Youth Engagement at Berry Street, one of Australia’s largest independent family service organisations. Separate to her work at Berry Street, in her independent consultancy practice, Morgan advises, coaches, and consults with organisations who are seeking to partner with people with a lived experience relevant to their purpose.

**Sarah Winthrope** is studying Medicine at Monash University. In the past she has worked as a research intern with the Children's Bioethics Committee, and is currently working with other medical students to engage more student Friends of the CBC. Sarah will be undertaking Honours in Bioethics through Oxford University next year and is interested in paediatric autonomy, issues of consent and resource allocation. Sarah loves working with high school students as an informal educator, mentoring younger medical students and working with people with disabilities.

**Avi Bart** is a final year MD-MPH student at The University of Melbourne and an aspiring paediatrician. He recently completed a 6-month research internship at the Children's Bioethics Centre exploring the appropriateness of Gillick competence as a tool for medical decision-making in adolescence. As a Friends of the CBC auxiliary member, Avi has been active in creating opportunities for students to engage with bioethics. Avi is also an Orthodox Rabbi who holds communal and educational roles in the Melbourne Jewish Community and was recently appointed Assistant Rabbi at the Blake Street Hebrew Congregation.

# Day 3: Friday 3 September

8:30am-10:00am

## **Session 9:** International perspectives: When parents exclude the adolescent in decision-making

**Chair: Prof Clare Delany,** Clinical Ethicist, Children's Bioethics Centre, RCH Melbourne

**Professor Lainie Friedman Ross** *(please refer page 4 of Program)*

**Professor Douglas Diekema** *(please refer page 3 of Program)*

**Professor Lynn Gillam** *(please refer page 7 of Program)*

10:30am-12:00pm

## **Session 10:** Respecting refusal?

**Chair: Prof Richard Doherty**, Board Member, RCH Melbourne; Department of Infectious Diseases, Monash Children's; Professor, Department of Paediatrics, Monash University

### So How Do We Listen to Children Who Won't Listen to Us?

**Tahira Dosani** is a Paediatric Trainee at the Children's Hospital at Westmead and the Sydney Children's Hospital Network Clinical Ethics Fellow. Having previously worked with street-involved and at-risk youth, she has a particular interest in supporting socially vulnerable children and families. Outside of work, Tahira enjoys the chaotic company of 2 children and 2 dogs.

### Shifting the bar: Can an adolescent be both 'competent' and not?

**Professor Sonia Grover** has been involved in paediatric and adolescent Gynaecology for many years and has an extensive track record of publications in this field. Many of the areas she has worked within have been challenging medically, surgically and ethically.

**Angie Kumar** is an intern at Eastern Health who is passionate about child and adolescent health and well-being. She is particularly interested in young women's sexual and reproductive health issues.

### Check your privacy settings: should a child's illness journey be shared on social media?

**Elise Burn** is a paediatric nurse in Brisbane with an interest in bioethics. She completed a Master of Nursing through Queensland University of Technology in 2016 with a specialisation in Paediatric, Child and Youth Health Nursing. In 2020 Elise completed a Master of Bioethics through Monash University and undertook research into the moral permissibility of parents or carers publicly sharing their child's illness journey on social media. Elise is interested in the interaction between healthcare and social media and the ethical complexities of navigating this, particularly within a paediatric environment.

12:30pm-2:00pm

## **Session 11:** Deciding with Children: bringing it all together

**Chair: Ms Maria Flynn,** Executive Director Nursing & Allied Health, RCH Melbourne

**Professor Clare Delany, Professor Lynn Gillam, Professor John Massie** *(please refer page 7 of Program)*

# Abstracts

(In program order)

## Day 1: Wednesday 1 September

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| 12:30pm-2:00pm | **Session 1:** The Jill Sewell plenary (RCH Grand Rounds)<br>**Deciding *with* Children**<br>**Chair: Prof John Massie** |

### Involving Children in Clinical Decision-making: Why it Matters and How Best to Do it

**Douglas Diekema** *(please refer page 3 of Program)*

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| 2:30pm–4:00pm | **Session 2:** Treading carefully: engaging *with* the young person in sensitive contexts<br>**Chair: Dr Georgina Hall,** Education Officer, Clinical Ethicist & Academic Director, Children's Bioethics Centre, The Royal Children's Hospital, Melbourne |

### How should we involve young adolescents in pre-operative pregnancy screening and testing?

Despite a low prevalence of teenage pregnancies in Australia, there are important risks associated with not detecting pregnancy in a young girl who is undergoing anaesthesia, surgery, or receiving certain medications. There are also emotional and psychological risks associated with pregnancy screening and testing processes for adolescent girls and their families.

In this presentation we discuss the development of a clinical guideline for pre-operative pregnancy screening for the Day of Surgery Unit at RCH. We highlight the ethical complexity of developing a pre-operative guideline. Although the process of pregnancy screening and/or testing acknowledges the developing physical maturity of a young person, it also requires that clinicians be attuned to a young person's developing autonomy and need for privacy and safety within and outside of their family.

Asking a child about whether they could be pregnant is an example of involving the child and 'giving them a voice' in important aspects of their healthcare. However, as we will discuss, pre-operative pregnancy screening and testing is ethically nuanced requiring careful balancing of benefits, risks and burdens.

**Amy Carle,** Clinical Nurse Specialist, Day of Surgery Unit, The Royal Children's Hospital, Melbourne
**Prof Clare Delany,** Clinical Ethicist, Children's Bioethics Centre, The Royal Children's Hospital, Melbourne

### PROMs, PREMs and Children: Considerations of Agency and Vulnerability

Children are a vulnerable cohort and protecting their interests is an important and inherent obligation of healthcare professionals (HCPs). The role of HCPs and health care institutions regarding the completion of PROMs (tools that measure a patient's wellbeing and health status) and PREMs (tools that measure a patient's experience in a health setting) to hear the 'child's voice' in their own healthcare journey may raise ethical tensions. While utilising PROMs/PREMs to promote the agency and developing autonomy of children or young persons (CYP) in healthcare decision making and to gain valid data about this cohort are worthy aims, there may also be inherent if unintentional harms when the main goal for a sick child in hospital is to receive timely, safe and effective healthcare. Ethical questions include:

- Do children understand why their data are being collected, and concepts of public good?
- As vulnerable patients, do children have agency (real or perceived) to reject the completion of PROMs/PREMs?
- How do we reasonably protect socioeconomically or culturally marginalised cohorts of children or those with a trauma background or less literacy?
- How do healthcare practitioners balance their primary duty to care with a data collection role?

**Patrick Ryan,** Medical Student Year 2, University of Sydney, For the Sydney Children's Hospital Network Clinical Ethics Support Service (SCHNCESS)

### Exactly what is the child/young person consenting to? Decisions about treatment in a sexual assault/child sexual abuse service

Children & young people who have experienced sexual abuse have been silenced in ways beyond many of our imaginings. At best their voices have been manipulated/deliberately twisted to suit the needs of the person who has abused them; groomed, made to feel responsible or at best complicit, they often present in therapy as riddled with guilt and shame that are simply not theirs to hold. Someone has betrayed their trust, violated them, with no thought to their needs, let alone to seeking their consent (even where it is something they might be able to give). Then, in the aftermath of disclosure, they are brought to therapy to talk about something they generally do not want to talk about. As professionals, we know that therapy is helpful, but how do we balance that with not replicating part of the dismissive, invalidating dynamic that was undoubtedly part of their abuse? How do we work from where the child is at, while also juggling the anxiety and needs of their parent – mostly for their child to "get better" sooner rather than later? This presentation will explore these dilemmas through the vehicle of a case study and consider the issues associated with bringing the child/young person's voice clearly to the fore in the decision-making process.

**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

5:00pm-6:30pm

## Session 3: Hypothetical – When teenagers think they know best!

**Chair & Facilitator: Prof Lynn Gillam,** Clinical Ethicist & Academic Director, Children's Bioethics Centre, The Royal Children's Hospital, Melbourne

In this hypothetical, we follow 14 year old Hunter through a series of encounters with health care professionals. Hunter collapses on the street, has an interaction with a paramedic that is not ethically straightforward, and finally ends up in the Emergency Department, which is not where he wanted to be. He has an acute injury, as well as underlying health issues. Hunter doesn't want anything to do with his parents at this point, but he needs surgical treatment and hospital admission for at least a couple of days. Now the ED physician encounters some ethical challenges. Should she proceed on the basis of Hunter's decisions about treatment, without involving his parents – or bring them in against Hunter's wishes? Does that depend entirely on what decisions he is actually making? Is this about Hunter's privacy, or his decision-making capacity? Meanwhile, Hunter's parents are waiting anxiously in the waiting area. Do they have a right to know what is going on, regardless of what Hunter wants? These questions follow Hunter into his in-patient stay, where the social situation behind his health issues begins to come out. The stakes for Hunter are getting higher – but does that mean he should get more say in the decisions, or less?

# Day 2: Thursday 2 September

7:30am-8:30am

## Session 4: Early morning ethical reflections

**Chair: Prof Mark Oliver,** Chair, RCH Medical Staff Association (MSA); Specialist Gastroenterology & Clinical Nutrition, The Royal Children's Hospital, Melbourne

### Case presentation: Our daughter, her condition and our decision as to what would be best for her

Lynn will outline some key concepts related to the ethics of decision-making with children and adolescents, focusing on where parents fit in as the adolescent's perspective takes on more ethical significance.

Mark will then present a patient scenario from his specialty of Gastroenterology who tested the concept of "deciding with children" and their families. The case will highlight the many challenges for both parties and look at ways of resolving such issues at the coal face.

Lynn will navigate the attendees through the case, inviting discussion of the competing considerations, the possible options, and the decisions that were taken by the clinician, the parents and the adolescent.

10:00am-11:30am

## Session 5: Respect for the child's voice

**Chair: Prof Clare Delany,** Clinical Ethicist, Children's Bioethics Centre, The Royal Children's Hospital, Melbourne

### Deciding with Children with an Intellectual Disability

NSW Health has funded six SIDHTs providing a consultative service to people living with an Intellectual Disability and a current unmet health need. The HNE/CC SIDHT has been in operation since early 2020 seeing adults and children with a variety of health problems, working closely with the usual health care and disability service providers.

We propose to explore decision making with children and adolescents with an Intellectual Disability. We will use two illustrative case studies to draw out themes including:

- Partnering with children with an intellectual disability. There are many systemic and individual challenges for people with an intellectual disability in accessing services, in being heard and understood and in consenting and collaborating with recommended treatment.
- The clinic and its processes. These SIDHTs are designed to provide excellent care to patients and to enhance the skills of other Health Care providers. Our capacity building occurs informally day-to-day and with inpatient consultation, detailed reports feeding back to usual health care providers and with formal opportunities to speak with groups
- When behaviours of concern are the presenting complaint. A large proportion of unmet health needs relate to the behaviour of people with Intellectual disability. Interpretation of behaviour is paramount and often much can be done to improve the understanding of the people surrounding the patient, about the meaning of the behaviour. In children and adolescents we also careful consider the contribution of communication, household dynamics, pain or other health conditions, the patient's developmental stage and self-regulation, their occupations and interests and puberty. We ask: Who is this behaviour a problem for?

- When parents disagree with treating team recommendations. There is a gap between child protection and guardianship around the ages of 16-18years. SIDHT have noted that where the “zone of parental discretion” falls into neglect or patient harm for children aged 16-18, resolution is complicated.

Hopes for the future:

- Capacity of health providers across the region
- Lifespan view of people with intellectual disability – with individual developmental progress in Choice-making, communication, Activities of daily living, interests and behaviours
- Consent and decision-making as a continuum
- Decision-making partners – formal and informal options for an individual, community advocates Council for Intellectual Disability, Disability Advocacy and structural supports (NDIS, NCAT)
- Taking our clinic to the next level!

**Dr Kate Thomson Bowe** and the Specialised Intellectual Disability Health Team (SIDHT),
Hunter New England and Central Coast Local Health Districts, NSW Health

### Infant led approaches to inclusive decision making and ethical practice: Learnings taken from working with infants impacted by family violence

Research into the neurophysiological development of infants, in utero and from birth has demonstrated that the subjectivity of the infant emerges from the very beginning. Whilst shaped by their relationship with their caregiving world, the infant, in and of themselves have experiences and responses to the world which are their own; separate to, but intimately connected to others. Furthermore, infants are impacted by and possess physiological memories of traumatic events. Making space to consider and explore how to invite the infant into decisions which directly impact them may have once been considered impossible or even magical thinking, however, “infant led” work undertaken in the family violence space suggests otherwise.

Infant led practice is a “blatant and political decision; this is a deliberate demand to recognize the infant’s right to be seen, thought about, engaged with and her or his experiences reflected on, and cogently inserted” (Bunston, Frederico, & Whiteside, 2020, p. 82)* into any decision-making process which involves and impacts them. This presentation challenges our thinking about the infant and their capacities, proposing a way forward within which to seeks to invite the infant’s perspective. Using case discussions this presentation introduces an approach which considers how the learnings taken from infant led practice in addressing family violence can be applied in medical settings. It will also explore what ethical responsibilities might clinicians have to both recognise and support a severely compromised infant, whose subjectivity may become subsumed by her medical complexity?

* Infant-led Research: Privileging Space to See, Hear, and Consider the Subjective Experience of the Infant, Australian Social Work, 2020, 73:1, 77-88, DOI: 10.1080/0312407X.2019.1676457

**Wendy Bunston** – wb Training and Consulting, La Trobe University
**Sarah Jones**, Mental Health Social Worker, Child and Family psychotherapist, in private practice

### The child’s authenticity: Hiding in plain sight?

The range of decisions considered permissible in pediatrics is typically understood to involve a balance between the child’s interests and parental authority or discretion. In this presentation, we argue that there is a distinct consideration relevant to pediatric decision making that is often neglected or unacknowledged—the child’s authenticity. While novel in the context of pediatric ethics, the concept of authenticity is employed as a distinctive normative standard in adult decision-making. This standard asks not what is best for the patient, or what the patient would choose, but rather what is most consistent with who the patient is—that is, with their authentic self. We begin our presentation with an overview of the best interest standard and suggest that authenticity can elucidate considerations that fall between a child’s strictly medical interests and broader familial or relational interests. Next, we discuss authenticity in greater detail, noting the limits of applying certain philosophical conceptions of authenticity in pediatrics.

We then sketch our own account of pediatric authenticity and distinguish it from the related concepts of subjective interests and assent. We conclude with a discussion of several cases that illustrate the normative significance of authenticity in pediatric care. The aim of our presentation is to highlight the unique, often-overlooked features of the child that may serve as a guide and a justification in pediatric decision-making.

**Ryan H. Nelson**, PhD[1] **Bryanna Moore**, PhD[2] Jennifer Blumenthal-Barby, PhD[1]

Institutional Affiliations:
1. Center for Medical Ethics and Health Policy, Baylor College of Medicine, 1 Baylor Plaza, Houston, Texas 77030
2. Institute for Bioethics and Health Humanities, Department of Preventative Medicine and Population Health, University of Texas Medical Branch, Galveston, Texas 77550

12:30pm-2:00pm

## Session 6: Keynote Plenary - Getting over Gillick

**Chair: Prof Lynn Gillam,** Clinical Ethicist & Academic Director, Children's Bioethics Centre, The Royal Children's Hospital, Melbourne
**Special Guest panellist: A/Prof Helen Irving** *(please refer page 6 of Program)*

### The Gillick Principle

'Gillick competence' is the term given to the legal principle which underpins a mature minor's right to consent to medical treatment. It derives its name and content from the 1985 UK House of Lords decision in *Gillick v West Norfolk and Wisbech Area Health Authority* and provides that children are competent to consent to their own medical treatment once they 'achieve sufficient understanding and intelligence to understand fully what is proposed'. In 1992, the Australian High Court expressed strong approval for the doctrine in 'Marion's Case' (*Secretary of the Department of Health and Community Services v JWB and SMB*) and it has been accepted as the law in Australia since that time.

**Ms Annabelle Mann,** General Counsel, Legal Services Department, The Royal Children's Hospital, Melbourne

### The Use and Abuse of "Gillick" Competence

**Dr Sarah Martin** *(please refer page 5 of Program)*

### Getting Over Gillick – What's next?

**Dr Erin Sharwood** *(please refer page 5 of Program)*

2:30pm-5:30pm

## Session 7: Bringing forward the child's voice

**Chair: Dr Rosalind McDougall,** Clinical Ethicist, Children's Bioethics Centre, The Royal Children's Hospital, Melbourne

### Ethical decision making in Adolescent Health, what is the process and how can it be improved?

The adolescent population are a unique group between younger paediatric patients who lack capacity to consent to medical procedures and competent adults. The process of ethical decision making can be difficult and the concept of "Gillick competency" plays a significant role in this process.

Relying on the concept of Gillick Competency has become problematic. Factors that are involved in the assessment of Gillick Competency can be difficult to measure. There are several case examples where adolescents are assessed to be competent to accept medical treatment but not to refuse treatment. This clashes with the concept of respect for their autonomy.

In my discussion, I intend to examine the factors that influence autonomous decision making in adolescents. These include familial religious beliefs and whether these should be accepted as representative of the adolescents' views. I will also discuss the role of peer influences on the adolescent and how this may impact their medical decisions. These factors are particularly relevant in significant illnesses such as cancer and eating disorders.

I hope to propose a more practical framework for clinicians to improve the decision-making process. I think that a change in the process is required that enables promotion of the autonomy of the adolescent but is balanced by an assessment of the "reliability" of their decisions.

**Dr Ciara Earley,** General Paediatrician Monash Children's Hospital, Clayton Victoria, Member of Monash Children's CERG (Clinical Ethics Response Group)

### How long should we wait to hear the child's view? – the ethics of deferring surgery and other interventions in children with intersex variations

Differences of sex development (DSD) or intersex variations are umbrella terms to describe differences in genital, chromosomal or gonadal sex. A number of key ethical principles underpin the clinical care of children with intersex variations; amongst these, is consideration of the views and wishes of the child or adolescent. This ethical principle is also framed as protection of each child's right to autonomy and bodily integrity. Based on this right, Human Rights bodies and intersex advocates nationally and internationally, are calling for prohibition of 'deferrable medical interventions (including surgery and hormone treatment) that alter the sex characteristics without the child's personal consent'.

In this presentation, we will begin by endorsing the importance of promoting and protecting a child's voice and autonomy as a key value underpinning care for a person with intersex variation. Drawing from representative clinical case examples, we will also highlight some of the ethical complexities which arise when giving effect to this right when caring for children and families. In particular we highlight specific challenges that may arise when a child's right to self-determination is protected / promoted via prohibition of specific treatments. Our discussion aims to examine possible changes to care models including a collaborative, holistic and co-designed approach to clinical care for children with intersex variations. It is hoped that a model that allows consideration of all factors specific to a given child, may be more sustainable and supportive of these children and their families than blanket legislation which prescribes and prohibits particular treatments.

**Michele O'Connell, Chloe Hanna, Juan Bortagaray, Sonia Grover, Clare Delany,** DSD multidisciplinary team, The Royal Children's Hospital, Melbourne

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|---|---|
| 4:00pm-5:30pm | **Session 7 Continued: Bringing forward the child's voice**<br>**Chair: Prof Lynn Gillam,** Clinical Ethicist & Academic Director, Children's Bioethics Centre, The Royal Children's Hospital, Melbourne<br>**Special Guest panellist: A/Prof Jenny Hynson** |

### Case 1: Supporting the adolescent voice at end of life

Adolescents and young adults (AYA) are a unique population, characterised by distinctive physical, cognitive, social and psychological developmental needs (Knapp et al, 2010). Adolescents and young adults grapple with emerging autonomy and fledgling independence as they transition away from their parents as their decision makers.

Adolescents forced to consider their own mortality in the context of a life-limiting illness face many unique challenges. They are asked to consider scenarios which are far from the normal developmental decisions of young people at this age. Decision-making for adolescents is likely to be influenced by immediate family, social media, peers, personal characteristics of healthcare providers and concerns regarding confidentiality (Fletcher et al 2018). Healthcare professionals are often fearful of having Advance Care Planning (ACP) discussions with adolescents due to concerns about causing distress for patients and their family, and extinguishing hope (Fletcher et al 2018; Knapp et al 2010; Donovan, Knight & Quinn 2015).

This presentation will draw on practice wisdom from working with adolescents who have a terminal oncology diagnosis at the end of their lives. It will draw on case examples of collaborative work between the oncology and palliative care teams to discuss some of the unique ethical challenges faced by health professionals supporting adolescents with decision making with regards to their own end of life care including working with young people who do not want to talk about their end of life and managing the sometimes different voices of adolescents and their parents. We will also propose a set of guiding principles to support other health professionals navigate this space with adolescents.

**Tarnya Hotchkin:** Adolescent and Young Adult Clinical Nurse Consultant – RCH
**Leah Rotin**: Social Worker – Victorian Paediatric Palliative Care Program

References: Donovan KA, Knight D, Quinn GP. Palliative care in adolescents and young adults with cancer. Cancer control. 2015;22(4):475-9.

Fletcher S, Hughes R, Pickstock S, Auret K. Advance care planning discussions with adolescent and young adult cancer patients admitted to a community palliative care service: a retrospective case-note audit. Journal of Adolescent and Young Adult Oncology. 2018;7(1):112-9.

Knapp C, Madden V, Wang H, Curtis C, Sloyer P, Shenkman, E. Spirituality of parents of children in palliative care. Journal of Palliative Medicine. 2011; 12:427-442

## Case 2: When a child says 'no more': chasing ethical imperatives and optimal outcomes in a complex and tragic case

**Background:** The Clinical Ethics Services (CES), Acute Consult Team met with the oncology and Aboriginal liaison teams regarding an 11 year old Child A with acute leukaemia who was refusing treatment.

**Case presentation:** Disease control had earlier been achieved in Child A, however ongoing treatment was required to provide the best chance of survival. Longer-term chances of survival were estimated at 70% if planned treatment continued. Delays of any more than 1 to 2 weeks risked relapse and dramatic reduction in long-term survival. At this treatment junction Child A refused to come to the hospital.

Child A had led an unstructured life, growing up in a regional town and facing challenging social issues within his family including chronic disease and alcohol use. Child A was felt to understand he would die without treatment, although not mature enough to provide consent on treatment decisions.

The treating team raised two specific questions regarding enforcement of treatment and allowing a minor to decide to cease treatment

The CES team assessed Child A's capacity to understand and fully appreciate the implications of his decision, while recognising the consequences for Child A, his family and community. This case also challenged all involved in Child A's care; a satisfactory resolution for all was felt almost unachievable.

Child A's longer-term survival was dependent on receiving ongoing medical treatment, with a strong chance of long-term survival. Child A's family had not been able to provide the hospital vigil he so dearly craved to make this possible. Consideration was given to medical intervention to achieve compliance, with awareness this would increase Child A's alienation.

**Discussion:** Refusal of treatment is a rare occurrence in paediatric oncology. The CES formed the view that Child A should not be considered competent to make a decision that would have the effect of ceasing all treatment. There remained the question of whether it was ethical to enforce treatment.

Consideration to Child A's family and social environment were central to discussions. It was essential to ensure Child A would not receive lesser social support or medical therapy because of this. In ethical terms, this was to ensure Child A was treated equitably.

Regardless of social or cultural origins, members found it hard to imagine as equitable any decision that would lead to a very ill minor returning to an environment, where he would likely die.

The CES presented options for Child A's care going forward. These related to treatment and care, capacity and consent, 'who provides what' and supporting the supporters.

**Renee Deleuil,** representing Clinical Ethics Service, Perth Children's Hospital, WA

### Case 3: Promoting the child's voice – in advance of loss of capacity

This presentation will explore how the views of a young person with a life limiting condition can and should be considered in advance of loss of capacity. We illustrate the legal, ethical and practical concerns through presentation of a case deliberated by MCH and RCH CERGs.

*A 17-year-old young woman (AZ) with a diagnosis of Neuroaxonal dystrophy (characterised by progressive loss of function and cognitive capacity) is now a severely disabled young woman and she will die within the next few years. She can no longer speak, but she can communicate by crying, wincing, smiling and laughing. AZ is receiving PEG feeding and her parents have differing views about the continuation of this feeding.*

*Two years ago it was considered that she did not have the capacity to comprehend long-term neurodegeneration, and that there was no opportunity to engage in a discussion with her about what her wishes were for future treatment.*

In our **panel discussion** we will consider the practicality of ascertaining AZ's wishes about ongoing treatment and her views about PEG feeding and when it would have been appropriate to initiate a discussion with her.

We will draw out some key ethical and practical considerations including:

- Respect for AZ's autonomous wishes and the meaning of 'autonomy' in this context.
- The virtue of truth-telling and the harm of disclosing a terminal diagnosis.
- Who is best placed to make decisions about future care where the patient lacks the lived experience?

We will invite the audience to participate in the discussion.

7:00pm-8:30pm

## Session 8: Hearing from young people: reflections on health care decision-making

**Chair: Prof John Massie,** Paediatric Respiratory Physician; Clinical Director, Children's Bioethics Centre, The Royal Children's Hospital, Melbourne

In this session we will hear from three young people who have 'graduated' from RCH but are able to look back on their journey with us and consider the medical decisions that had to be made. There were big decisions and small ones; their doctors and parents were involved; some decisions were shared with the young people and some were not. Did we do the right thing? What really matters when decisions have to be made with young people? These reflections will be important as we develop our conception of 'Deciding *with* Children' through the conference.

8:30am-10:00am

## Session 9: International perspectives: When parents exclude the adolescent in decision-making

**Chair: Prof Clare Delany,** Clinical Ethicist, Children's Bioethics Centre, RCH Melbourne

**Professor Lainie Friedman Ross** *(please refer page 4 of Program)*
**Professor Douglas Diekema** *(please refer page 3 of Program)*
**Professor Lynn Gillam** *(please refer page 7 of Program)*

## **Session 10:** Respecting refusal?

10:30am-12:00pm

**Chair: Prof Richard Doherty**, Board Member, RCH Melbourne; Department of Infectious Diseases, Monash Children's; Professor, Department of Paediatrics, Monash University

### So How Do We Listen to Children Who Won't Listen to Us?

Shared decision-making is a framework which can present challenges at the best of times, particularly within the model of child- and family-centred care. However, additional challenges arise when caring for children and young people with social vulnerability, particularly in the context of chronic disease.

The balance between supporting the developing autonomy of young people in medical decision-making, whilst maintaining our moral obligation to act in their best interests in our roles as healthcare providers can result in a tension between values.

We explore the role of social vulnerability and the impact this may have both on shared decision-making and on the ethical obligation of healthcare providers, and consider proportionality and the line between 'containment' and 'coercion'. How can we honour the developing agency and capacity of a young person and maintain a therapeutic alliance when we feel compelled to over-rule their autonomy, albeit 'in their best interest'? Further, what weight should we give parents' and families' input into decision making in the context of child- and family-centred care, but where there may be intergenerational trauma and dislocation?

In this presentation, we view this tension through the young person's lens in meeting Alex*, a young woman with end-stage kidney disease who is currently under a public guardianship order in response to her 'non-compliance' with dialysis.

**name changed for privacy reasons*

**Tahira Dosani, Paediatric Registrar, Clinical Ethics Fellow,** Anne Preisz, Network Manager, SCHN Clinical Ethics Service, David Isaacs, SCHN Clinical Ethics, CHW, Henry Kilham, SCHN Clinical Ethics

### Shifting the bar: Can an adolescent be both 'competent' and not?

Adolescence is a distinct developmental stage. It encompasses the transition between childhood and adulthood, in which a young person develops their personal and sexual identity and establishes independence and autonomy. The challenge for healthcare professionals is to accommodate this unique stage and respect an adolescent's voice and preferences, without compromising their interests.

'Gillick competence' refers to the capacity of a young person under the age of 16 to autonomously make healthcare decisions. When an adolescent demonstrates an understanding of the consequences and significance of their choice, we consider them to be competent. Confusion mounts and tensions arise, however, when our threshold for competence fluctuates…

Lucy is 14 years old. She engages in high-risk behaviours and is referred to the hospital for contraception in the context of recently giving birth to a child, whom she has placed for adoption. After discussion, she decides on an intrauterine device (IUD) to prevent future pregnancy and is deemed to have the capacity to consent to this procedure.

However, Lucy re-presents 4 months later, now asking for her IUD to be removed. While we previously recognised Lucy's competence in accepting treatment, we now refuse to withdraw the same treatment in order to avoid harm to Lucy and risks to her potential offspring, should she become pregnant again.

Sam is also 14 years old. She is a transgender adolescent expressing a desire to medically transition so that her physical characteristics more closely align with her gender identity. She demonstrates sufficient maturity to consent to puberty suppression treatment which will halt the progression of unwanted physical changes and is reversible in its effects. However, when Sam expresses a wish for gender affirming hormone treatment, which will induce desired physical changes that are not reversible, her clinician questions whether Sam truly is competent enough to consent…

These cases raise the question of whether it is ethically appropriate to lift and lower our bar of competence in adolescent decision making. What factors are at play that allow a young person to clear the bar for one choice, but not another? Is it higher when refusing potentially beneficial treatment than when accepting?

And is it harmful to foster an adolescent's sense of autonomy but then override it? Or is it more important that we remain flexible and act in, what we may perceive to be, their best interests?

**Dr Angie Kumar**[a,b], **Prof Sonia Grover**[a,c]
[a] Murdoch Children's Research Institute, Parkville, VIC, Australia
[b] Eastern Health, VIC, Australia
[c] Royal Children's Hospital, Parkville, VIC, Australia

### Check your privacy settings: should a child's illness journey be shared on social media?

It is generally accepted that parents have the right and responsibility to make decisions on behalf of their children with regards to their child's medical treatment due to a child's developmental immaturity and consequent lack of autonomy. It is also accepted that children, regardless of their capacity, also have a right to confidentiality as a patient where it regards their medical care. The phenomenon of 'sharenting', whereby parents share news and images of their child on social media is becoming increasingly common among families where children have chronic illness and disability, and some families manage a public social media account dedicated to their child's medical journey. This phenomenon highlights a clash between the rights of parents and children: does the parent's right and responsibility to manage their child's care override the child's right to privacy and confidentiality as a patient? Some children have illness or disability such that they may never develop capacity or live to be autonomous adults. Research into the child's perspective of sharenting is emerging, however, it is predominantly conducted amongst young people who have reached maturity and have the capacity to participate in research. As a result, children who experience illness or disability are largely absent from current research, however, have a perspective that warrants exploration. In this presentation I explore the child's right to privacy and their own identity in the context of a parent publicly sharing their child's illness journey on social media and explore the moral consequences of sharenting in a medical context.

**Elise Burn,** Queensland Children's Hospital Centre for Children's Health Ethics and Law

12:30pm-2:00pm

## **Session 11:** Deciding with Children: bringing it all together

**Chair: Ms Maria Flynn,** Executive Director Nursing & Allied Health, RCH Melbourne

In this final session, we will review key ideas presented throughout the conference and contained within the conference theme: "Deciding *with* Children'

John Massie will discuss the meaning of 'deciding 'with' rather than 'for' a child and adolescent including whether this involves a clinician coaching the child and family towards greater child involvement.
Lynn Gillam will focus on the meaning of 'deciding' and unpack different aspects of what is involved in making a decision, and how an adolescent may be capable or ready in some aspects of decision making more than others.

Clare Delany will highlight what it means for 'clinicians' to cultivate a safe and holding clinical environment which enables 'deciding with children' to occur and even flourish.