



The Royal  
**Children's**  
Hospital  
Melbourne

5-7 SEPTEMBER 2018

10<sup>TH</sup> NATIONAL PAEDIATRIC  
BIOETHICS CONFERENCE

# Ethics in a changing landscape



#rchbioethics10

# Welcome

Dear colleagues,

On behalf of the Children's Bioethics Centre at The Royal Children's Hospital (RCH), it is with great pleasure that we welcome you to the 10th National Paediatric Bioethics Conference, in Melbourne.

The healthcare landscape is changing. This is partly due to the ever-increasing pace of medical science and technology. New drugs can be genomically targeted to individual patients; new wearable monitoring devices produce health data 24 hours a day; artificial intelligence and robotics are starting to change the world of surgery. But social technology is having a huge impact as well. Relationships between health professionals and families have been transformed by the open availability of information from all sorts of sources on the internet, and by exchange of ideas about medical treatment on social media. Parents and families are increasingly wanting to take the lead in healthcare decision-making; and some use crowd-funding to get access to unproven and expensive treatments and devices. All of this is playing out against a social backdrop that is increasingly aware of the rights of children and young people.

The ethical implications of this changing landscape for paediatric health care will be explored in this conference which promises to be as engaging and thought-provoking as ever.

We welcome visitors to our hospital and its world class facilities. We thank our organising committee, conference presenters and our local, national and international delegates.

We would like to acknowledge the generous support of our conference supporters and the Children's Bioethics Centre Development Board chaired by Mr Barry Novy OAM.

The Children's Bioethics Centre acknowledges the generous ongoing support of the RCH Foundation.

We hope you enjoy this exciting program of events.



**A/Prof Jill Sewell**

Clinical Director  
Children's Bioethics Centre  
The Royal Children's Hospital



**Prof Lynn Gillam**

Clinical Ethicist and  
Academic Director  
Children's Bioethics Centre  
The Royal Children's Hospital

#### **Sessions will be held at:**

##### **Ella Latham Auditorium**

Ground floor, West Building

#### **Morning /afternoon breaks**

##### **and lunch will be held at:**

##### **Ella Latham meeting room**

Ground floor, West Building

The Royal Children's Hospital Melbourne  
50 Flemington Road, Parkville  
Telephone (03) 9345 5522

#### **Conference contact:**

**Karen Fellows** 0438 334 378

#### **The conference is proudly supported by**

Mr David and Mrs Mira Kolieb and family  
Mr Barry Novy OAM and Ms Sue Selwyn

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Or use SMS at the event

# The Children's Bioethics Centre

The Children's Bioethics Centre was founded in 2008, with the aim of enabling The Royal Children's Hospital (RCH) to proactively address the ethical challenges of providing health care to children and young people in an environment of technological and social change.

The Children's Bioethics Centre has become an integral part of the hospital and celebrates its 10th Anniversary this year. Located within the hospital, its staff of ethicists and clinicians are actively involved in the daily life of the hospital, providing a well-used clinical ethics service. This service helps to facilitate ethical reflection, promote good communication, resolve ethical conflict, and ease moral distress.

The Children's Bioethics Centre has four major areas of activity: a clinical ethics service, an education and training program, a research program, and development of policy, guidelines and clinical procedures.

The Children's Bioethics Centre offers staff at the RCH advice and support in ethically challenging patient-care matters. A Clinical Ethics Response Group meeting can be convened within 24-48 hours of a referral, with formal documentation provided afterwards. This service is highly valued and frequently used by hospital staff.

The Children's Bioethics Centre has become a national leader in provision of hospital-based clinical ethics services in Australia, and its staff have established international profiles in paediatric clinical ethics. The outstanding quality of work of the Children's Bioethics Centre was internationally acknowledged with the Hans-Joachim Schwager Award for Clinical Ethics Consultation in 2013.

The Centre is proudly supported by The Royal Children's Hospital Foundation.

## The Bioethics team

**Left to right:** A/Prof Jill Sewell, A/Prof Clare Delany, Prof Lynn Gillam, A/Prof John Massie, A/Prof Jenny Hynson, Ms Karen Fellows, Dr Merle Spriggs



# Keynote speakers

## WEDNESDAY 5 SEPTEMBER

*When parents (want to) take control —  
how should we respond?*

### Professor Mark R. Mercurio

MD, MA



Professor of Pediatrics (Neonatology), Chief, Division of Neonatal-Perinatal Medicine, Director, Program for Biomedical Ethics, Yale University School of Medicine, USA

This presentation will consider problems encountered when parents and staff disagree on how much control parents should have in medical management, and when they disagree on what is best for a sick child. Relevant rights and obligations of all involved will be discussed, and an ethical decision-making framework that provides a practical approach will be presented. Specific examples to be considered include extreme prematurity, trisomy 13 and 18, and the continuation of life-sustaining measures in the setting of poor prognosis.

#### Biography

Dr Mercurio is Chief of Neonatal-Perinatal Medicine and Director of the Ethics Program at Yale-New Haven Children's Hospital. He is also Professor of Pediatrics and Director of the Program for Biomedical Ethics at Yale School of Medicine, and a member of the medical faculty for the Fellowships at Auschwitz for the Study of Professional Ethics (FASPE). He received his undergraduate degree in Biochemical Sciences from Princeton University, an M.D. from Columbia University, and a Master's Degree in Philosophy from Brown University. Pediatrics Residency and Neonatology Fellowship were completed at Yale. He has for many years been active in neonatology and medical ethics education for residents, fellows, nurses, attending physicians, PA students, medical students and others. He was an original co-editor of the American Academy of Pediatrics Resident Curriculum in Bioethics, and is the Chair-elect of the American Academy of Pediatrics Section on Bioethics. He is on the editorial boards for the 6 volume text *Bioethics* (formerly the Encyclopedia of Bioethics) and the journal *Pediatric Ethicscope*, Dr Mercurio is widely published, and has been an invited speaker nationally and internationally on medical ethics, particularly in paediatrics. He and his wife Anna live in Branford, Connecticut, and have three grown children.

## THURSDAY 6 SEPTEMBER

*Sharing information with children:  
what the evidence shows*

### Professor Imelda Coyne

PhD, MA, BSc (Hons), HDip N (Hons), RSCN, RGN, RNT, FTCD, FEANS



Professor of Children's Nursing and Co-Director of Trinity Research in Childhood Centre, Trinity College Dublin, Ireland

Communication and information-sharing throughout a child's treatment trajectory is critically important in the delivery of quality healthcare. Internationally government reports and policies emphasise that care provision needs to be child and family-centred and that children receive information to enable them to understand and cope with the illness, and the treatment prescribed. Yet, children frequently receive insufficient information to enable them to knowledgeably and actively participate in decisions about their treatment and healthcare. There is now increased focus on uncovering the different roles parents, children and health professionals occupy in triadic healthcare interactions. Much of Imelda's research has focused on uncovering how information is shared with children and how much involvement they have in healthcare decision from the perspectives of children and adolescents, their parents, and healthcare professionals.

Using empirical data from her research projects, Imelda will discuss how information-sharing in children's healthcare is determined primarily by parental, professional and latterly by individual and situational factors. It appears that children's participation in information-sharing is not about the child's capacity; instead it is about power, control and poor communication. There is a lot more that can be done to ensure optimal information sharing and decision-making can occur for all children.

### Biography

Imelda Coyne is Professor of Children's Nursing and Co-Director of the Trinity Research in Childhood Centre, Trinity College Dublin Ireland. She leads a team of lecturers and researchers in the delivery of high quality teaching, clinical practice, and research. The overall theme of her research is that of children's participation in healthcare interactions and decision-making. Her research focuses on exploring preferences, understanding how children and families are involved, range of involvement, types of decisions, effect on wellbeing, and interventions supporting shared decision-making.

Imelda's past projects include: family-centred care, medication adherence, child and adolescent mental health services, chronic illness management interventions and transition to adult health care services. She has over 300 publications (articles, books, and conference papers) and recently published a textbook on creative techniques for accessing children's voices 'Being Participatory: Researching with Children and Young People' Springer Nature.

Imelda has been a visiting professor at Mälardalen University and University of Lund, Sweden; University of Malta; Manchester University and the Nuffield Council of Bioethics, UK. As Ambassador for the Children's Participation Hub, Irish government department, she can promote the importance of children's participation at a very senior policy level. Imelda contributes actively to the Children's Research in Ireland and Northern Ireland (CRIINI) network and the International Association for Communication in Healthcare (EACH).

## FRIDAY 7 SEPTEMBER

*The ethics of saying 'no'*

## Professor Lynn Gillam

BA (Hons), MA (Oxon), PhD

Children's Bioethics Centre, The Royal Children's Hospital Melbourne,  
School of Population and Global Health, the University of Melbourne, Australia



During this conference, many situations have been described in which parents of children with a range of medical conditions have formed their own views about what medical treatment their child should have, and sought to have that carried out. These are not refusals of treatment recommended by a doctor; parents want treatment for their child, but have made their own decision about what form of treatment, be it an experimental drug, or a specific type of surgery, or medical device. This level of control over the medical decision-making seems to go beyond the accepted ethical paradigm of shared decision-making. Some of these requests should be refused, but not all. The ethical challenge for clinicians and hospital executives is knowing when and how to say no.

In this paper, Lynn will discuss three aspects of the ethics of saying no — the ethically justifiable *reasons* or *criteria* for denying a request, the ethical importance of a *process* for making such a decision, and what is required ethically in terms of *communicating and explaining* that decision to parents.

### Biography

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

# DAY 1 Wednesday 5 September

11.00am

## Conference registration

Ella Latham Auditorium foyer

12.15 – 12.30pm

## Conference opening and Welcome

Ella Latham Auditorium

**Mr John Stanway**, Chief Executive Officer, The Royal Children's Hospital Melbourne  
including Welcome to Country by Elder

12.30 – 1.30pm

## Session 1: Grand Rounds keynote address

Ella Latham Auditorium

**Chair: A/Prof Jill Sewell**, Consultant Paediatrician; Clinical Director, Children's Bioethics Centre,  
The Royal Children's Hospital Melbourne

### When Parents (want to) take control — how should we respond?

**Prof Mark Mercurio**, Professor of Pediatrics (Neonatology), Chief, Division of Neonatal-Perinatal Medicine,  
Director, Program for Biomedical Ethics, Yale University School of Medicine

1.30pm – 1.45pm Break

1.45 – 3.10pm

## Session 2: Social media

Ella Latham Auditorium

**Chair: Ms Alison Errey**, Executive Director Communications, The Royal Children's Hospital Melbourne

1.45 – 2.10pm

### Social media in healthcare and innovative treatments — parents' views and their use of it

**Dr Sarah Aylett**, Consultant Paediatric Neurologist and Honorary Senior Lecturer UCL-Institute  
of Child Health, Neurosciences Department, Great Ormond Street Hospital, London

2.10 – 2.35pm

### #Uncharted Territory: The new era of social media and its impact on end of life decision-making for critically ill infants

**Dr Neera Bhatia**, Senior Lecturer, School of Law, Deakin University, Melbourne

2.35 – 3.00pm

### Collecting for individuals and causing collective harm: the two sides of crowdfunding for medical treatments

**Dr Keith Amarakone**, Paediatric Emergency Physician, The Royal Children's Hospital Melbourne

3.00 – 3.10pm

## Discussion

3.10 – 3.35pm

Afternoon break

3.35–4.15pm

### Session 3: Children's role in decision-making

Ella Latham Auditorium

**Chair: A/Prof Jenny Hynson**, Head, Victorian Paediatric Palliative Care Program; Coordinator, Clinical Ethics Response Group, Children's Bioethics Centre, The Royal Children's Hospital Melbourne

3.35–3.55pm

#### The Medical Treatment Planning and Decisions Act 2016: Thoughts on the shifting and strengthening of children's autonomy

**Dr Kate Middleton**, Junior Resident Medical Officer, The Royal Children's Hospital Melbourne

3.55–4.15pm

#### The swinging pendulum of children's assent in clinical care

**Dr Lauren Notini**, Research Fellow in Biomedical Ethics, Melbourne Law School, the University of Melbourne, Biomedical Ethics Research Group, Murdoch Children's Research Institute

4.15–4.20pm

Break

4.20–5.30pm

### Session 4: Children's health and children's rights

A joint session, hosted by the RCH Alumni Association and Children's Rights International

Ella Latham Auditorium

**Chair: Prof Garry Warne AM**, Honorary Secretary, RCH Medical Alumni and Board member, Children's Rights International

#### A new approach in keeping children with family — the Family Drug Treatment Court

**Magistrate Kay Macpherson**, Regional Coordinating Magistrate, Children's Court of Victoria

#### Expert commentator

**Prof Mark Mercurio**, Professor of Pediatrics (Neonatology), Chief, Division of Neonatal-Perinatal Medicine, Director, Program for Biomedical Ethics, Yale University School of Medicine

5.30pm

Conclusion

6.00–9.30pm

6.00pm  
pre-dinner drinks

6.30pm  
guests seated

### Conference dinner

#### The Woodward Centre

Level 10, Law Building, the University of Melbourne, 185 Pelham Street, Carlton

**Master of Ceremonies: A/Prof John Massie**, Paediatric Respiratory Physician, Department of Respiratory Medicine; Deputy Chair of the RCH Clinical Ethics Committee, The Royal Children's Hospital Melbourne; Clinical Associate Professor, the University of Melbourne; Research Fellow, Murdoch Children's Research Institute

#### The five million dollar boy

Case discussion led by A/Prof John Massie.

#### Expert commentary by:

**Prof Mark Mercurio**, Professor of Pediatrics (Neonatology), Chief, Division of Neonatal-Perinatal Medicine, Director, Program for Biomedical Ethics, Yale University School of Medicine

**Prof Lynn Gillam**, Clinical Ethicist and Academic Director, Children's Bioethics Centre, The Royal Children's Hospital Melbourne

Dinner guests will be engaged in a lively discussion

# DAY 2 Thursday 6 September

7.45–8.45am

## Session 5: Breakfast session

*Proudly sponsored by the Medical Staff Association (MSA)*

Health, Education and Learning Precinct, Level 1, The Royal Children's Hospital Melbourne

Chair: **Dr Peter Simm**, Consultant, Endocrinology and Diabetes, The Royal Children's Hospital Melbourne

### Dealing with 'difficult' families — confrontations and complaints

**A/Prof Jill Sewell**, Consultant Paediatrician; Clinical Director, Children's Bioethics Centre, The Royal Children's Hospital Melbourne

9.00–10.15am

## Session 6: Parents 'driving' treatment: Pushing the boundaries of shared decision-making

Ella Latham Auditorium

Chair: **Dr Giuliana Antolovich**, Consultant Paediatrician, Neurodevelopment and Disability, The Royal Children's Hospital Melbourne; Honorary Fellow, Murdoch Children's Research Institute

9.00–9.25am

### Selective Dorsal Rhizotomy — ethical considerations of consumer driven health models

**Dr Neil Wimalasundera**, Consultant in Paediatric Rehabilitation, Victorian Paediatric Rehabilitation Service, The Royal Children's Hospital Melbourne

9.25–9.50am

### The ethics of greater family choice

**Ms Helen Stewart, Ms Claire Gaunt and Ms Leah Robinson**, Social Workers, Complex Care Hub, The Royal Children's Hospital Melbourne

9.50–10.15am

### Who has responsibility for emerging technologies in diabetes management

**Dr Carolyn Johnston**, Senior Research Fellow, Melbourne Law School, the University of Melbourne

**A/Prof Bernadette Richards**, Associate Dean (Research), Director, Research Unit for the Study of Society, Ethics and the Law (RUSSEL), Adelaide Law School, University of Adelaide

**Prof Fergus Cameron**, Department of Endocrinology and Diabetes and Centre for Hormone Research, The Royal Children's Hospital Melbourne; Murdoch Children's Research Institute; Department of Paediatrics, the University of Melbourne

10.15–10.45am Morning break

10.45–11.30am

## Session 7: Ethics, gender & medicine

Ella Latham Auditorium

Chair: **Prof David Coghill**, Financial Markets Foundation Chair of Developmental Mental Health, Departments of Paediatrics and Psychiatry, University of Melbourne; Professor of Child and Adolescent Psychiatry, The Royal Children's Hospital Melbourne

10.45–11.05am

### Offering chest surgery to trans males aged under 18: ethical concepts and considerations

**Dr Rosalind McDougall**, Senior Lecturer in Health Ethics, Melbourne School of Population and Global Health, the University of Melbourne

11.05–11.25am

### To block or not to block? The role of puberty blockers in young people with a non-binary gender identity

**Dr Ken Pang**, Paediatrician, RCH Gender Service, Department of Adolescent Medicine, The Royal Children's Hospital Melbourne; Clinician Scientist Fellow, Murdoch Children's Research Institute

**A/Prof Michelle Telfer**, Paediatrician, Head of Department of Adolescent Medicine, The Royal Children's Hospital Melbourne

11.30am–12.30pm Lunch break



12.30-1.30pm

## Session 8: Keynote: Telling the truth to children

Ella Latham Auditorium

**Chair: A/Prof Matt Sabin**, Executive Director Medical Services and Clinical Governance; Chief Medical Officer, The Royal Children's Hospital Melbourne

12.30-12.40pm

### Overview: Ethics of telling the truth to children

**Prof Lynn Gillam**, Clinical Ethicist and Academic Director, Children's Bioethics Centre, The Royal Children's Hospital Melbourne

12.40-1.30pm

### Keynote: Sharing information with children: what the evidence shows

**Prof Imelda Coyne**, Professor of Children's Nursing, Co-Director of Trinity Research in Childhood Centre (TRICC), School of Nursing and Midwifery, Trinity College Dublin

1.30-1.45pm

Break

1.45-3.00pm

## Session 9: Telling the truth to children continued

Ella Latham Auditorium

**Chair: Prof Fiona Newall**, Donald Ratcliffe and Phyllis McLeod Director of Nursing Research; Clinical Nurse Consultant, Clinical Haematology; Professorial Fellow, Departments of Nursing and Paediatrics, the University of Melbourne; Honorary Research Fellow, Murdoch Children's Research Institute

1.45-2.10pm

### Children's interests in truth-telling

**Dr Merle Spriggs**, Senior Research Fellow, Children's Bioethics Centre, The Royal Children's Hospital Melbourne

2.10-2.35pm

### Engaging children in communication within healthcare encounters: How is supporting the 'child's voice' achieved

**Prof Lesley Stirling**, School of Languages and Linguistics, the University of Melbourne

2.35-3.00pm

### Clinicians' experiences of being asked not to disclose to children

**Mr Will Sim**, Medical Student (MD4), the University of Melbourne

**Dr Merle Spriggs**, Senior Research Fellow, Children's Bioethics Centre, The Royal Children's Hospital Melbourne

**Prof Lynn Gillam**, Clinical Ethicist and Academic Director, Children's Bioethics Centre, The Royal Children's Hospital Melbourne

3.00-3.30pm

Afternoon break

3.30-4.45pm

## Session 10: Intersex variations — changing paradigms

Ella Latham Auditorium

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

3.30-3.50pm

### What do clinicians say to parents? An exploration of communication for intersex variations

**Mr Ali Maudarbocus**, Medical Student (MD4), the University of Melbourne

3.50-4.20pm

### Social change and interventions for intersex variations ('DSDs')

**Deputy Mayor Tony Briffa**, JP, Councillor, Hobson's Bay; co-executive director of Intersex Human Rights Australia; vice-president of the Androgen Insensitivity Syndrome Support Group Australia

**Mr Morgan Carpenter**, JP, MBioeth (Sydney), co-executive director of Intersex Human Rights Australia; signatory of the Yogyakarta Principles plus 10; PhD candidate, Sydney Health Ethics, The University of Sydney

**Ms Bonnie Hart**, president of the Androgen Insensitivity Syndrome Support Group Australia; Bachelor of Behavioural Science [Honours Psychology] candidate, Queensland University of Technology

4.20-4.45pm

### Discussion

4.45pm

Conclusion

# DAY 3 Friday 7 September

8.45-10.15am

## Session 11: The expanding scope of genomics in health care

Ella Latham Auditorium

**Chair: Prof Martin Delatycki**, Medical Director, Victorian Clinical Genetics Services; Director, Bruce Lefroy Centre for Genetic Health Research, Murdoch Children's Research Institute

8.45-9.05am

### Challenges with the introduction of genomic sequencing in medicine: genetic health professionals' perspectives

**Dr Danya Vears**, Research Fellow, Biomedical Ethics Research Group, Murdoch Children's Research Institute; Melbourne Law School, the University of Melbourne

9.05-9.25am

### Rapid challenges: ethics and genomic neonatal intensive care

**Dr Christopher Gyngell**, Research Fellow in Biomedical Ethics, Department of Paediatrics, the University of Melbourne; Biomedical Ethics Research Group, Murdoch Children's Research Institute

9.25-9.45am

### Can consent to genomic testing be valid if it is not fully informed?

**Dr Julian Koplin**, Melbourne Law School, the University of Melbourne; Biomedical Ethics Research Group, Murdoch Children's Research Institute

9.45-10.05am

### Carrier screening for inherited diseases is a healthcare right

**A/Prof John Massie**, Paediatric Respiratory Physician, Department of Respiratory Medicine, The Royal Children's Hospital Melbourne; Clinical Associate Professor, the University of Melbourne; Research Fellow, Murdoch Children's Research Institute

10.05-10.15am

### Discussion

10.15-10.45am

Morning break

10.45-11.30am

## Session 12: Moral distress

Ella Latham Auditorium

**Chair: A/Prof John Massie**, Paediatric Respiratory Physician, Department of Respiratory Medicine, The Royal Children's Hospital Melbourne; Clinical Associate Professor, the University of Melbourne; Research Fellow, Murdoch Children's Research Institute

10.45-11.05am

### Moral distress in the era of shared decision-making

**Dr Trisha Prentice**, Neonatologist, Neonatal Medicine, The Royal Children's Hospital Melbourne

11.05-11.25am

### Moral distress and the role of clinical ethics services

**Dr Melanie Jansen**, Senior Registrar, Paediatric Intensive Care Unit, Lady Cilento Children's Hospital; Steering Committee, Centre for Children's Health Ethics and Law, Children's Health Queensland; Lecturer, Faculty of Medicine, University of Queensland

11.30am-12.30pm Lunch break

12.30-1.30pm

### Session 13: Ethical frameworks

Ella Latham Auditorium

**Chair: Prof David Isaacs**, Senior Staff Specialist, Department of Infectious Diseases and Microbiology, Clinical Professor in Paediatric Infectious Diseases, University of Sydney, The Children's Hospital at Westmead, NSW

12.30-1.00pm

#### The ethics of saying 'no'

**Prof Gillam**, Clinical Ethicist and Academic Director, Children's Bioethics Centre, The Royal Children's Hospital Melbourne

1.00-1.15pm

#### Making sense of it all: ethics in simple, complicated, complex and chaotic times

**A/Prof Clare Delany**, Clinical Ethicist and Academic Director, Children's Bioethics Centre, The Royal Children's Hospital Melbourne

1.15-1.30pm

#### Conference reflections

**Prof Mark Mercurio**, Professor of Pediatrics (Neonatology), Chief, Division of Neonatal-Perinatal Medicine, Director, Program for Biomedical Ethics, Yale University School of Medicine

1.30-1.45pm

#### Patron's prize for conference best paper

**Introduced by A/Prof Jill Sewell**, Clinical Director, Children's Bioethics Centre

**Presented by A/Prof Hugo Gold**, founding Clinical Director, Children's Bioethics Centre

1.45pm

Conference close

## Notes

