

## Invited Speakers



### Professor Jocelyn Downie



Jocelyn Downie holds a Canada Research Chair in Health Law and Policy and is a Professor in the Faculties of Law and Medicine at Dalhousie University in Nova Scotia, Canada. She is an elected fellow in the Canadian Academy of Health Sciences as well as the Royal Society of Canada. Professor Downie works at the intersection of law, ethics and health care. Her research interests include women's health, assisted death, research involving humans, and relational theory. Her work is interdisciplinary and collaborative, and it is geared both to contributing to the academic literature and to affecting change in health law and policy and practice.

**Public Lecture:** *Cutting the Gordian knot of futility*



### Professor Michael Ashby

MBBS (Lond) MD (Adel) MRCP (UK) FRCP FRACP  
FACHPM FFPANZCA

Michael Ashby is Director of Palliative Care and the Persistent Pain Services, Royal Hobart Hospital and Southern Tasmania Area Health

Service, and Clinical Leader of the state-wide Palliative Care Clinical Network. He holds a conjoint position as Professor of Palliative Care, Faculty of Health Sciences, University of Tasmania, and is currently Coordinator of Theme 4 (Personal and Professional Development) in the MBBS course, and chairs the Clinical Ethics Committee at RHH.

Professor Ashby graduated from St Bartholomew's Hospital, London University in 1978, and trained in medicine and radiation oncology in the UK, France and Australia. He has held clinical, academic and managerial positions since 1989 in Adelaide and Melbourne prior to moving to Hobart in 2007. He is a Past President of the Australia and New Zealand Society for Palliative Medicine (ANZSPM) and a past Chairman of the Chapter of Palliative Medicine at the Royal Australasian College of Physicians. He has research interests in law, ethics and the humanities as they apply to care and decision-making at the end of life, advance care planning, and pain and symptom management. He is Joint Editor-in-Chief of the *Journal of Bioethical Enquiry*, an editor of the *Journal of Palliative Care and Mortality*, and a reviewer for a number of international journals.

**Presentation title:** *'Natural' death: The causation wars about care at the end of life*



### Ian Freckelton

Ian Freckelton is a barrister in full-time practice at the Victorian Bar, having taken silk in 2007. He has appeared as counsel in a number of Australia's leading cases involving health law and regulation.

He is also a Professor of Law, Forensic Medicine and Forensic Psychology at Monash University and an Honorary Fellow of the Australian College of Legal Medicine. Ian was a long-time member of the AIHLE/ANZIHLE Board. He has been a member of 10 tribunals, including Victoria's Mental Health Review Board, Medical Practitioners Board and Disciplinary Appeals Tribunal and is a Past-President of the Australian and New Zealand Association of Psychiatry, Psychology and Law. He is currently a member of Victoria's Coronial Council. He is the Editor of the *Journal of Law and Medicine* and the Editor-in-Chief of *Psychiatry, Psychology and Law*. Ian is the author and editor of over 400 peer-reviewed articles and of some 39 books on health law, mental illness and the law, causation, coronial law, therapeutic jurisprudence, expert evidence, compensation law, regulatory law, criminal law and the law of scholarly misconduct. In 2009 he co-edited *Appealing to the Future: The Legacy of Michael Kirby*.

**Kirby Oration:** *Unscientific healthcare: Clinical, regulatory and ethical challenges*



### Professor Ken Hillman

Ken Hillman is Professor of Intensive Care at the University of New South Wales (UNSW) and is an actively practising clinician in Intensive Care. He graduated from Sydney University and trained at St Vincents Hospital in Sydney and

St Bartholomews Hospital in London. He became the Director of Intensive Care at Charing Cross Hospital in London before returning to Australia to become Director of Anaesthetics, Intensive Care and Coronary Care at Liverpool Hospital in Sydney. He has over 100 peer-reviewed publications; approximately 50 chapters in textbooks; co-authored an intensive care textbook; co-edited several textbooks; and written a book – *Vital Signs: Stories from Intensive Care* and received over \$8 million in grants. He is the Director of the Simpson Centre for Health Services Research which is affiliated with the Australian Institute of Health Innovation at UNSW.

**Presentation title:** *Dying safely*

## Dinner Speaker



### Ray Moynihan

Ray Moynihan is a health journalist, author, video-maker and academic researcher with a global reputation. His 2005 book *Selling Sickness: How the world's biggest pharmaceutical companies are turning us all into patients*, was described in the New York Times as a "compelling case" and has been translated into more than a dozen languages.

Winner of a Harkness fellowship undertaken at Harvard University, Ray is currently conjoint lecturer at the University of Newcastle, and regular contributor to the British Medical Journal, where he is a Visiting Editor and columnist.

An internationally recognised authority on the business of medicine, Ray is regularly invited to give presentations around the world. His fourth book *Sex, Lies and Pharmaceuticals* was released to much media interest and critical acclaim in Australia and North America in late 2010.

**Dinner Presentation:** *Sex, Lies and Pharmaceuticals*

## Social Functions

### Welcome Reception

Date: 7 July 2011  
Time: 1700-1800  
Venue: Visions, Twin Town Outrigger Resort  
Cost: Inclusive of full registrations/\$25 for additional tickets  
Dress: Smart casual  
Speaker: Professor Jocelyn Downie



Welcome to the Conference! The Welcome Reception is an ideal opportunity to catch up with your interstate colleagues and exhibitors. The reception is a great opportunity to meet delegates who are attending the conference for the first time. The reception will be followed by a public lecture by Professor Jocelyn Downie.

### Conference Dinner

Date: 9 July 2011  
Time: 1900 – till late  
Venue: Visions, Twin Towns Outrigger Resort  
Cost: Inclusive for full registrations/\$60 for additional tickets  
Dress: Smart Casual  
Speaker: Ray Moynihan



Join other delegates at the Conference Dinner for a great night of fine food, wine and entertainment. Our guest dinner speaker is health journalist, author, video-maker and academic researcher Ray Moynihan.

## Clinical Futility Symposium

### *Clinical Futility: A fresh perspective or revisiting old arguments?*

Date: 11 July 2011  
Time: 0900-1500  
Venue: ES Meyers Lecture Theatre, School of Medicine, University of Queensland, Herston, Brisbane  
Cost: Full Delegate \$30 Non-delegate \$150

The Hippocratic oath makes provision for not treating patients who are "over mastered by their disease". This Clinical Futility Symposium revisits this dictum in the light of current medical care. It explores, debates, and may even resolve, some of the thorniest and paradoxically simplest issues in medicine; such as when to stop, in a culture driven by patient hope, colleagues' expectations and fiscal restraint.



Speakers will include Professor Ken Hillman, Professor Grant Gillett, Professor Geoffrey Miller, Dr Victoria Brazil, Professor Lindy Wilmot, Associate Professor Cameron Stewart and Associate Professor Ben White.

A coach will be available to transport delegates from Twin Towns Outrigger Resort to Herston (one-way) early Monday morning for \$20 per head. Please see the program for exact departure time. Travel arrangements at the conclusion of the Symposium are the participant's own responsibility.



# Program

## Thursday 7 July 2011

1500	Registration	
1700 – 1800	<b>Welcome Reception</b> Visions, Twin Towns Outrigger Resort Sponsored by Southern Cross University	
1800 – 1810	<b>Welcome to Participants</b> Professor Peter Lee, SCU Vice-Chancellor	
1810 – 1910	<b>Public Lecture &amp; Discussion</b> <i>Cutting the Gordian knot of futility</i> Professor Jocelyn Downie Sponsored by Faculty of Law, Queensland University of Technology <b>Student Essay winner announced: Max Charlesworth prize in bioethics</b>	

## Friday 8 July 2011

0800	Registration			
0825	Welcome to Country			Visions
0830 – 0910	<b>Opening Plenary</b> <i>'Natural' death: The causation wars about care at the end of life</i> Professor Michael Ashby			
0910 – 1020	<b>Plenary</b> <i>Medical futility, end of life conflict and the case of Isaac Messiha</i> Dr Julie Letts et al			
1020 – 1025	<b>Poster Presentation</b> <i>Aspects and roles of hope at death determination in the Japanese context</i> Yutaka Kato			
1025 – 1055	Morning Tea			
Concurrent Session A (10 minutes presentation followed by 10 minutes discussion)				
	<b>Theory 1</b> Chair: Malcolm Parker Terraces	<b>Hope</b> Chair: Andrew Crowden Visions	<b>Law 1</b> Chair: Bernadette Richards Renaissance	<b>Professional Practice 1</b> Chair: Eleanor Milligan Opal
1055 – 1115	<i>Neurotrauma and the RUB: Where tragedy meets ethics and science</i> Stephen Honeybul et al	<i>What does hope mean in advance directive decision making by baby boomers?</i> Sandra Bradley et al	<i>Patients' refusal of treatment: An emerging Australian jurisprudence</i> Ian Freckelton SC	<i>Shared decision-making and the ethics of risk: Questions of social policy and medical practice</i> Sarah Lee et al
1120 – 1140	<i>Personal identity: The promise and threat of deep brain stimulation</i> Françoise Baylis	<i>Taking a bottom-up approach to combating false hope in end-of-life care</i> Sharyn Milnes et al	<i>Limits on patients' expectations. Advance care directives, law and practice</i> Loane Skene	<i>Implications of how a consumer thinks about health outcomes vis-à-vis a health professional</i> Kay Price
1145 – 1205	<i>Virtues as first bioethics</i> Ian Kerridge et al	<i>Great expectations? The modest hopes of health consumers</i> Ron Paterson	<i>Expectations of a pain free death: Is legislation the only means to achieve this?</i> Colleen Cartwright	<i>False hope and unrealistic expectations? The role of conflicts of interest in surgery</i> Wendy Rogers et al
1210 – 1230	<i>Expectations, hope and the (f)utility of bioethics</i> Colin Thomson	<i>When is hope in clinical research problematic?</i> Sonja Read	<i>End-of-life decision-making, testamentary capacity and wills passing on property; Whose hopes? Whose expectations? Speaking before and after death.</i> Philip Bates	<i>Consumer expectations and priority-setting by public agencies of prescription medicines: New Zealand's Herceptin case</i> Joanna Manning
1230 – 1330	Lunch & AABHL Committee Meeting (Visions 2)			

Concurrent Session B				
	Workshop Terraces	Cafe Renaissance	Workshop Opal	International Perspectives Chair: Ian Kerridge Visions
1330 – 1500	<i>The Health and Disability Commissioner and end of life decisions</i> Cordelia Thomas, Anthony Hill	<i>Balancing expectations, hope and futility in clinical research: A view from an HREC</i> Eleanor Milligan, Richard Roylance, Scott Campbell, Maher Gandhi, Peng Tjun Choy (Metro South HSD HREC)	<i>What are you hoping for? The role of families in end of life decision making</i> Annette Braunack-Mayer, Jaklin Elliott, Lynn Gillam, Ian Olver, Heather Tan, Dominic Wilkinson	<i>Divergent legal approaches to medical futility disputes: Comparing Australia and the United States</i> Thaddeus Pope  <i>Law deferred and referred: Non-adherence and the notion of 'futility' in community-based psychiatry in New Caledonia</i> Antonia Knifton  <i>Nutritional labelling and 'personal responsibility' in public health law: Lessons from 3 countries</i> Roger Magnusson  <i>Developing nations: Pharmaceutical regulation and reform efforts</i> Mabel Tsui
1500 – 1530	Afternoon Tea			
1530 – 1645	<b>Kirby Oration: Unscientific health care: Clinical, regulatory and ethical challenges</b> Professor Ian Freckelton SC			Visions
1645	Sessions end			
1700 – 1800	AABHL AGM – all members are encouraged to attend			Visions
	Free Evening			

### Saturday 9 July 2011

0800	Registration			
0830 – 0910	Presidential Address <i>Not so great expectations: Why we should accept and respect hopelessness and futility</i> Associate Professor Malcolm Parker			
0910 – 1025	<b>Plenary Session: Dying safely</b> Professor Ken Hillman			Visions
1025 – 1055	Morning Tea			
Concurrent Session C (10 minutes presentation followed by 10 minutes discussion)				
	Babies and Children Chair: Sarah Winch Terraces	Futility Chair: Jean Murray Visions	Theory 2 Chair: Garth Thomas Renaissance	Research Ethics 1 Chair: Colin Thomson Opal
1055 – 1115	<i>Futility, babies and the 21st century</i> Neera Bhatia	<i>Deciding about CPR/NFR</i> Barbara Hayes	<i>The discursive death of human embryos</i> Sheryl de Lacey	<i>No place for hope in clinical research: Role-confusion for clinician/researchers and participants</i> Nikola Stepanov
1120 – 1140	<i>No room at the inn: Ethical and legal questions surrounding neonatal bed allocation decisions</i> Andrew Watkins	<i>Patient perspectives on the timing of discussions about refusing 'futile' treatment at the end of life: An ethical and practical dilemma</i> Jaklin Elliott et al	<i>Uncertainty: The crucial factor in considering hope and futility – the perspective of the General Practitioner</i> Ben Gray	<i>What do participants hope for when joining an RCT: Insights for the process of informed consent</i> Clare Delany et al
1145 – 1205	<i>Ethical challenges in management of infants with disorders of sex development: Parents' hopes, children's futures and 'unnecessary surgery'</i> Lynn Gillam	<i>Paramedics and good medical care: Futile care in the emergency out-of-hospital care setting</i> Brian Sengstock et al	<i>A costly separation between withholding and withdrawing medically inappropriate treatment</i> Dominic Wilkinson et al	<i>"You will not benefit from participating in this research": Do HRECs deflate potential research participant's expectations?</i> Nicole Gerrand

	<b>Law 2</b> Chair: Sarah Winch Terraces	<b>Futility</b> Chair: Jean Murray Visions	<b>Theory 2</b> Chair: Garth Thomas Renaissance	<b>Research Ethics 1</b> Chair: Colin Thomson Opal
1210 – 1230	<i>Refusal of treatment “Futility Rules”</i> Alma Rae	<i>Doing nothing isn’t an option: Queensland Health’s response to managing expectations and futility</i> Wendy Corfield	<i>Religious faith and opposition to legalisation of voluntary euthanasia.</i> Neil Francis	<i>Participant hope and clinical research</i> Timothy Adam, Andrew Crowden
1230 – 1330	Lunch			
Concurrent Session D				
	<b>Workshop</b> Terraces	<b>Workshop</b> Renaissance	<b>Workshop</b> Opal	<b>Health Regulation</b> Chair: Colleen Cartwright Visions
1330 – 1500	<i>Abandon hope all ye who enter here. Uncertainty and hope in medical care</i> Anna Holmes	<i>He was my son, not a dying baby’: Parental, ethical and practical considerations in perinatal futility</i> Pauline Thiele, Andrew Watkins, Lachlan de Crespigny, Dominic Wilkinson	<i>Clinical Ethics Workshop: To treat or not to treat. Who decides and how?</i> Garth Thomas, Wendy Rogers, Robert Barnett	<i>Legal and ethical issues around regulating health professionals’ hours of work</i> Bridget Cameron, Fiona McDonald  <i>Compatibility of pharmacy ownership structures with health reform</i> Laetitia Hattingh  <b>Max Charlesworth prize in bioethics winner</b> <i>Personalised medicine in the age of neo-liberal health care</i> Jacqueline Savard
1500 – 1530	Afternoon Tea			
Concurrent Session E (10 minutes presentation followed by 10 minutes discussion)				
	<b>Research Ethics 2</b> Chair: Andrew Crowden Terraces	<b>Clinical Ethics 1</b> Chair: Lynn Gilliam Visions	<b>End of Life</b> Chair: Roger Magnusson Renaissance	<b>Law 3</b> Chair: Colleen Cartwright Opal
1530 – 1550	<i>What are the expectations, hopes and futility of the Human Research Ethics Review processes?</i> Colin Thomson	<i>Consent for progressing the injured patient to organ donor</i> Judith Kennedy et al	<i>Advance care planning and unrealistic expectations</i> Peter Saul	<i>Some conceptual issues in medical law and ethics</i> Andrew McGee
1555 – 1615	<i>Navigating between hope and expectation in research – A cautious approach to Hans Jonas’s Identification Principle</i> George Tomossy	<i>New directions in organ transplantation – the role of patients’ expectations in quality of life transplants</i> Ruby Catsanos	<i>The ethical use of hope in healthcare</i> John Gruner	<i>Patient autonomy and refusal of life sustaining treatment: Conflicts of ethics and law</i> Neil Francis
1620 – 1640	<i>Surgical innovation as sui generis research: Managing expectations and implications</i> Mianna Lotz	<i>Futile research? A philosophical analysis of the vertebroplasty debate</i> Jane Johnson et al	<i>Do end of life care discussions mitigate medical futility?</i> Heather Tan et al	<i>Who can refuse life-sustaining treatment on behalf of an adult who lacks decision-making capacity? Legal, ethical and practical challenges arising from inconsistent powers of substitute decision makers</i> Ben White et al
1645 – 1705		<i>Severe traumatic brain injury: Obtaining consent for life saving but non-restorative decompressive surgery</i> Stephen Honeybul et al	<i>The slippery slope and legalisation of voluntary euthanasia</i> Neil Francis	<i>Patient information and the ethical operation of advanced care directives</i> Noeline Monaghan
1705	Sessions end			
1900 – 2200	Conference Dinner – Visions, Twin Towns Outrigger Resort <i>Sex, Lies and Pharmaceuticals</i> Dinner Keynote – Ray Moynihan			



## Sunday 10 July 2011

0800	Registration			
	Concurrent Session F (10 minutes presentation followed by 10 minutes discussion)			
	<b>Reproductive Technologies</b> Chair: Ben White Terraces	<b>Surgery</b> Chair: Colin Thomson Visions	<b>Professional Practice 2</b> Chair: Sarah Winch Renaissance	<b>Genetics</b> Chair: Ian Kerridge Opal
0900 – 0920	<i>Creating 'saviour siblings': Bringing hope, saving life and causing harm?</i> Malcolm Smith	<i>Neurotrauma and the rule of rescue</i> Stephen Honeybul et al	<i>"I just love these sessions". What should clinical ethics consultations hope to achieve?</i> Clare Delany et al	<i>Personalised medicine and healthcare: The expectations versus the reality of direct-to- consumer genetic testing</i> Jacqueline Savard
0925 – 0945	<i>Different hopes for health care budgets: Distributing assisted reproductive technology to women of different ages</i> Drew Carter et al	<i>Hope and expectation in surgical innovation</i> Tony Evers	<i>An ethical review of measures of effectiveness and success for retention of rural health professionals: When do we know we have it right?</i> Fiona McDonald et al	<i>Court-ordered submission to genetic testing: Balancing individual expectations and health care rights with the due administration of justice</i> Tina Cockburn, Bill Madden
0950 – 1010	<i>When do Australians think women should be able to access late abortion?</i> Lachlan de Crespigny et al	<i>The ethics of surgical innovation: Surgeons' perspectives</i> Aydin Pourmoslemi, Mianna Lotz	<i>A qualitative study of communications styles in discussions with critically ill patients.</i> Sharyn Milnes et al	<i>Elements of biohype in nutrigenetics clinical research literature: Are the promoted expectations realisable?</i> Raphaëlle Stenne et al
1015 – 1035	<i>Ethical issues raised by providing a cash incentive for long acting contraception to addicted individuals</i> Jayne Lucke et al	<i>Decompressive craniectomy for severe traumatic brain injury; When does surgical intervention become futile?</i> Stephen Honeybul et al	<i>Redefining the doctor-patient relationship: The central role of trust in experimental treatment</i> Zara Bending	
1035 – 1100	Morning Tea			
1100 – 1215	<b>Plenary Panel</b> <i>The Advance Care Directives draft framework - will it meet expectations?</i> Jean Murray, Julie Letts, Simon Towler, Margaret Brown, Ian Kerridge, Bernadette Richards			
1215 – 1225	Invitation to next conference			
1225 – 1230	<b>Close of Conference</b> Associate Professor Malcolm Parker			
1230	Lunch			

## Monday 11 July 2011

0630	Transfer coach departs Twin Towns for Herston. \$20 per head, please see the registration desk to book
0900 – 1500	<b>Clinical Futility Symposium</b> <i>Clinical Futility: A fresh perspective or revisiting old arguments?</i> Keynote Speaker: Ken Hillman ES Meyers Lecture Theatre, School of Medicine, University of Queensland, Herston, Brisbane

## Local Restaurants

### Bali Hut – Authentic Halal Indonesian Cuisine

Shop 5 / 6 Twin Towns Resort, 1 Wharf Street, Tweed Heads  
(Opp. Twin Towns Services Club)  
Ph: (07) 5599 1477

### Crust – Gourmet Pizza Bar

9/110 Marine Parade, Coolangatta  
Ph: (07) 5599 3333

### O-Sushi – Authentic Japanese cuisine

Shop 32 / 72-80 Marine Parade, 'Showcase on the Beach'  
Coolangatta  
Ph: (07) 5536 5455

### Shank Restaurant & Bar – Fresh seasonal food

Shop 4, Blue C Apartments, Cnr Marine Pde and McLean St,  
Coolangatta  
Ph: (07) 5599 1411

## Bars/Nightlife

### The Coolangatta Hotel – The Coast's best live music venue

Marine Parade, Coolangatta  
Ph: (07) 5589 6888

### Never Land Bar

23 McLean Street, Coolangatta  
Ph: (07) 5536 6666

### Café Fresh Lounge Bar & Shinsen Restaurant

3/78-88 Musgrave Street, Coolangatta, Kirra  
Ph: (07) 5536 1010

## General Information

### Insurance

Registration fees do not include personal travel or health insurance of any kind. The Organising Committee and Conference Design do not take responsibility for any delegate failing to take adequate insurance cover.

### Disclaimer

Whilst we have endeavoured to ensure all information on the conference web site and printed material is accurate all details are subject to change without notice. Any corrections or amendments will be updated on the conference web site as soon as possible. In the event of industrial disruptions or service provider failures, neither the Organising Committee members nor Conference Design Pty Ltd, accept any responsibility for losses incurred by delegates and partners.

### Dress

Dress throughout the conference is neat casual. Dress for each function is indicated in the function description.

### Privacy and Delegate List

Conference Design Pty Ltd will gather and record personal information necessary for your attendance at the Conference. Personal information will be gathered, stored and disseminated in accordance with the National Privacy Principles.

### Smoking

The conference and social functions are non-smoking.

### Name Badges

Name badges will be issued when registering at the conference. For security purposes the conference name badge must be worn at all times during the conference and social functions.

### Baby-Sitting

Please contact your chosen hotel to arrange a baby-sitting service. If you have any queries please contact Conference Design.

### Accommodation Accounts

All accommodation accounts must be settled on check-out.

### Registration Desk

The registration desk will be located in the foyer of the Conference Centre and will be open at the following times:

Thursday 7 July	1500 – 1800
Friday 8 July	0800 – 1700
Saturday 9 July	0800 – 1700
Sunday 10 July	0800 – 1200

### Special Diets

For pre-arranged special dietary requests please make yourself known to the waiting staff at all functions.

### Contact Phone Numbers

Twin Towns Outrigger Resort - Reception	(07) 5536 2121
Police - Emergency	000
The Tweed Hospital	(07) 5536 1133
Tweed Day Surgery	(07) 5599 5522
First Class Taxis	(07) 5522 1525
Tweed Taxis	13 3422
Qantas	13 1313
Virgin Blue	13 6789
Jetstar	131 538







# Living, breathing health

## **Creating healthy communities through world-class research**

Through the work of the Griffith Health Institute we can better understand disease, and improve treatments and services, in pursuit of sustainable health systems.

Our researchers are globally-recognised as health care innovators in areas including aged care, multiple sclerosis, migraine, cardiovascular disease, vaccine development, injury prevention and neurodegenerative disorders.

Griffith University is focused on creating a healthy future for Australia and the world.

**Do some research of your own today at [griffith.edu.au/health](http://griffith.edu.au/health)**

**A Top 10 Australian Research University\***

**GRIFFITH UNIVERSITY**

**Gold Coast - Logan - Mt Gravatt - Nathan - South Bank**

\*Based on fields of research at the 4-digit level in the Excellence in Research for Australia 2010 National Report.





# Abstracts

Australasian Association of Bioethics  
& Health Law 2011 Conference









## THEORY 1

### Neurotrauma and the RUB: Where tragedy meets ethics and science

Stephen Honeybul<sup>1</sup>, Professor Grant Gillett<sup>2</sup>, Dr Kwok Ho<sup>3</sup>, Professor Christopher Lind<sup>4</sup>

<sup>1</sup>Department of Neurosurgery, Sir Charles Gairdner Hospital and Royal Perth Hospital, WA

<sup>2</sup>Dunedin Hospital and Otago Bioethics Centre, University of Otago, Dunedin, NZ

<sup>3</sup>Department of Intensive Care Medicine and School of Population Health, University of Western Australia, WA

<sup>4</sup>Centre for Neuromuscular and Neurological Disorders, University of Western Australia, WA

Decompressive craniectomy is a technically straightforward procedure whereby a large section of the cranium is temporarily removed in cases where the intracranial pressure is dangerously high. Whilst its use has been described for a number of conditions it is increasingly used in the context of severe head injury. As the use of the procedure increases a significant number of patients may survive a severe head injury who otherwise would have died. Unfortunately some of these patients will be left severely disabled. A condition likened to the RUB, an acronym for the Risk of Unacceptable Badness. Until recently it has been difficult to predict this outcome, however an accurate prediction model has been developed and this has been applied to a large cohort of patients in Western Australia. It is possible to compare the predicted outcome with the observed outcome at eighteen months within this cohort. By using predicted and observed outcome data this paper considers the ethical implications in three cases of differing severity of head injury in view of the fact that it is possible to calculate the RUB for each case.

### Personal identity: The promise and threat of deep brain stimulation

Professor Françoise Baylis

*Dalhousie University, Halifax, Nova Scotia CANADA*

Deep brain stimulation (DBS) sometimes results in acute psychological and personality changes. For this reason, it has been suggested that DBS threatens personal identity. This depiction of DBS may be accurate for some patients, for example, patients with Parkinson's Disease or epilepsy where DBS is used to treat tremors. But what about patients with severe depression or obsessive compulsive disorder where a personality change is not a 'possible unwanted side-effect', but is the 'goal of treatment'?

In this presentation, I propose an account of personal identity that is thoroughly relational, and makes transparent the ways in which persons are constituted in and through their personal relationships and public interactions. On this view, persons are interdependent beings and so it is that a person's identity is informed by her personal relationships – relationships characterized by varying degrees and kinds of intimacy and interdependence. Specifically, I develop an account of relational identity as a dynamic socially, culturally, and politically situated communicative activity based in narrative and performance.

I then critically examine the impact of DBS on relational identity with particular attention to the fact that some psychological and personality changes are intended, desired and desirable, both from the perspective of the patient and those with whom she interacts. In closing, I suggest that DBS may be a promising or a threatening intervention. What matters from a patient perspective are the ways in which she is able (or not) to construct and maintain her personal narrative in concert with close and distant others.



## Virtues as first bioethics

**Professor Ian Kerridge, Emeritus Professor Miles Little, Associate Professor Jill Gordon, Pippa Markham, Dr Lucie Rychetnik**  
*Centre for Values, Ethics and the Law in Medicine, University of Sydney, NSW*

Medical ethics is often thought to be principle-based – best understood in terms of respect for autonomy, justice, non-maleficence and beneficence. In different settings, deontic ethics, consequentialism, casuistry and virtue ethics are also invoked as ways to evaluate the rights and wrongs of different actions.

Doctors' views on what constitutes good practice or a good outcome are shaped by their formal education and, most importantly, by enculturation into the contexts of their work. We interviewed 19 doctors in various specialties to explore their values. Each was invited to recall their personal experiences of medical education and practice, and to suggest how medical education might achieve the goals of medicine that each person valued. Each responded with a biographical narrative that emphasised striking memories of interactions with mentors, teachers, patients, families, colleagues and the health system.

Each person's ethical priorities emerged from accounts of quandaries that reflected tensions between personal values and the demands of medicine. Without exception, interviewees privileged virtues as their natural ethical domain. Phronesis and prudence were the most prized meta-virtues, where phronesis is the practical wisdom that achieves good outcomes in difficult contexts, and prudence avoids harm. Reflection on quandaries and their outcomes helps to cultivate phronesis and prudence, and helps clinicians to balance the competing interests generated by apparent dichotomies between self and other and between universal conventions and particular contexts.

Virtue ethics comes naturally to doctors, and deserves appropriate recognition in the education of students and practitioners.

## Expectations, hope and the (f)utility of bioethics

**Professor Colin J. H. Thomson**

*Graduate School of Medicine, University of Wollongong, Wollongong, NSW*

The recent debate between two prominent bioethicists in the United States about the mission and method of bioethics contrasted bioethics as requiring statistical evidence of its application and as the basis for its deployment with bioethics as requiring engagement in moral discourse. This, and other essays critical of current bioethics has prompted this reflection from an Australian perspective and in an Australian context, somewhat less distracted by the shrill ideological rhetoric of US media.

As such, this is as much an agenda for thought and perhaps even research than a considered position.

In canvassing arenas of bioethics – clinical ethics, research ethics, professional ethics and health policy – the paper uses the conference theme to explore what the goals of bioethics are and how can – or should – their achievement be measured.

What expectations do we, as bioethicists, have of our activity? What should we expect? What basis does our Australian track record provide for our expectations?

What do we hope for? Does that hope have a basis?

If we can identify our expectations and hopes for bioethics, are these its goals? Can their achievement be measured?

What is the utility – and the futility – of bioethics?

## HOPE

### What does hope mean in advance directive decision-making by baby boomers?

Sandra L Bradley<sup>1</sup>, Dr Anita De Bellis<sup>1</sup>, Dr Evdokia Kalaitzidis<sup>1</sup>, Dr Jean E Murray<sup>2</sup>

<sup>1</sup>Flinders University School of Nursing and Midwifery, Adelaide SA

<sup>2</sup>Flinders University School of Medicine, Adelaide SA

For some countries, the manner in which people medically choose to live and die can be described to a certain extent through formal advance care directives. These legal instruments were developed to embed personal choice in healthcare and dying as a response to the advent of medical technologies delaying death and prolonging life. The development of these instruments occurred during the maturation of a generation known in Western society as the Baby Boomers. In many ways, advance care directives are the manifestation of the Baby Boomer generation hope to wrest control from this plethora of medical technological advancements. As an example of this expression, in a grounded theory study of Baby Boomer advance care decision-making in South Australia, some participants expressed hope that their directives would be enacted, indicating doubt that the directives would actually be respected. Predominantly, this version of hope was expressed by healthcare professionals. For others, however, their expression of hope centred on not having to enact an advance directive because another medical technological advancement, called a miracle, might occur. This expression of hope came predominantly from non-healthcare professionals. How is it that one instrument can denote two conflicting states of hope? Is it reflective of professional and non-professional experiences? If so, then for advance care directives to deliver on their promise in the coming decades, the medical fraternity will need to identify the different hopes and expectations of healthcare consumers engaged in advance care directive decision-making for intended outcomes to reflect quality not futility.

### Taking a bottom-up approach to combating false hope in end-of-life care

Sharyn Milnes, Deborah Porter

Deakin University School of Medicine

There seems to be a post-modern epidemic in the Western world of unreal expectations in end-of-life care, which is coupled with a historical convention in medicine that clinicians should express hope for full recovery. The literature suggests that doctors are uncomfortable and generally bad at end-of-life discussions. Current data suggest that while junior doctors are particularly bad at these discussions, they are the ones having them with patients and their surrogates.

At Deakin School of Medicine we have taken a bottom-up approach in educating both the students and the current clinical staff at the participating clinical schools via interactive on-line simulations and scenario-based panel discussions focusing on ethics and law. The simulations deal specifically with communication when dealing with hope in healthcare, medical paternalism and futility. The Hypothetical Panel Presentations are developed and presented by the 4th year students at Grand Rounds.

In the Ethics, Law and Professional Development theme (ELPD) the focus in the final year is End-of-Life discussions and decision-making, including legal and ethical considerations. Four interactive on-line simulations have been developed for the four rotations in year 4 (Emergency Medicine, Intensive Care, Palliative Care and General Practice), which use current literature and real scenarios with the student in the role of the treating/communicating physician. Face to face tutorials augment the learning to fill gaps in the student knowledge of law and professional obligations.

## Great expectations? The modest hopes of health consumers

**Professor Ron Paterson**

*Faculty of Law, University of Auckland, Auckland, New Zealand*

The myth of the demanding consumer, who has great expectations of what doctors, nurses, and the health system can deliver, is accepted as fact in contemporary debate about health policy. It is claimed such consumers make unrealistic demands for futile treatment; expect doctors to spend hours explaining remote risks and far-fetched options; believe that treatment success can be guaranteed; complain noisily when their expectations are not fulfilled; and “drive” defensive medicine.

This paper will examine the evidence to support these claims. I will argue that despite the rhetoric about demanding consumers, it is the consumers themselves who are subject to expectations: to be patient; not to waste the doctors’ and nurses’ time; to be grateful for whatever an overstretched health system can deliver; to follow instructions and be compliant; to accept that mistakes happen; to forgive and not complain when presented with the ritual of “open disclosure” and systems learning.

From my experience of handling 1000s of consumer complaints in New Zealand, and of the Australian health system, most health consumers are quiescent and have unduly modest expectations. Even the “informed patient” seeks only a reasonable level of trust, competence, information and care from their health practitioners. The public expects honesty, fairness, transparency and vigilance from the health system, and from the bureaucrats, regulatory authorities and politicians who oversee it.

It often takes a highly motivated, aggrieved consumer and family, media exposure, and a major public inquiry to reveal the failure of the health system to meet the modest hopes of consumers.

## When is hope in clinical research problematic?

**Sonja Read**

*Minter Ellison Lawyers, Brisbane, QLD*

Anecdotally, ‘hope’ plays an important role in the decision-making process of participants when considering whether to participate in clinical research. There is the hope that the research will enable a patient to access treatments that are not otherwise available, although in fact the patient may end up in the placebo arm of a randomised controlled trial. Hope is also generated by terminology such as ‘gene therapy’ (where the technology is not yet known to be therapeutic) and the blurring of roles where a participant’s treating doctor is also an investigator. In practice there are real challenges in distinguishing research from therapy. The therapeutic misconception describes the phenomenon whereby participants believe that the researcher’s involvement is akin to that of a doctor in the doctor-patient relationship.

That is not to say that hope is misplaced in the context of clinical research. Participants who make a genuinely autonomous choice to be involved in clinical research may make that decision for any reason, including that they are hopeful that they will be randomised to the active arm of the trial and that the agent will turn out to be therapeutic. Further, it is hope for better treatments in the future which is the primary driver of clinical research.

The challenge is in establishing effective safeguards to ensure that participants do not provide consent on the basis of a misconception about the nature of the hope that is offered by research.

## Patients' refusal of treatment: An emerging Australian jurisprudence

**Dr Ian Freckelton**

*Professor of Law, Forensic Medicine and Forensic Psychology, Monash University*

A series of decisions by McDougall J in *Hunter and New England Area Health Service v A* (2009) 74 NSWLR 88; Martin CJ in *Brightwater Care Group (Inc) v Rossiter* (2009) 40 WAR 84; Higgins CJ in *Australian Capital Territory v JT* (2009) 232 FLR 322; and Kourakis J in *H Ltd v J* (2010) 240 FLR 402 has built upon prior decisions in New South Wales, Queensland and Victoria. The combination of authority has provided a reasonably homogeneous set of principles on the basis of which future decision-making can take place by clinicians, institutions and courts. It is apparent that, wherever possible, effect will be given to competent patients' wishes in relation to cessation of treatment, nutrition and hydration. However, scrutiny will be applied to patients' capacity in order to examine not the rationality or correctness of their decisions per se but their capacity to make them.

It is probable that a rigorous approach will be taken both to whether patients' mental ill health deprives them of capacity and to whether they are provided with sufficient information to understand the consequences and processes of deprivation of nutrition, hydration and medication.

## Limits on patients' expectations. Advance care directives, law and practice.

**Professor Loane Skene**

*University of Melbourne*

Patients who have executed advance care directives naturally expect that they will be followed, either at the end of the patient's life, or at other times when the patient is incompetent.

In ethics and law, the patient's right to autonomy has replaced the earlier principles of beneficence (the doctor's duty to 'do no harm' and to act in the patient's best interests) and the duty of courts and tribunals to protect the interests of potentially vulnerable patients who are not able to make their own decisions (the *parens patriae* jurisdiction of the courts).

However, when patients are no longer competent, their earlier autonomous wishes may be overridden. Patients' directions can be construed as not applying in the circumstances, if doctors believe that is in the patient's 'best interests'. Patients are not legally entitled to direct that particular treatment (eg 'futile' treatment) be provided for them. Also, the autonomy principles apply only to adults, not to older children who may meet the 'Gillick-competent' test for making other medical decisions

Courts may review clinical decisions by doctors and hospitals. Although they will not direct particular treatment to be provided, there may be a judicial declaration that it would not be lawful for the doctor or hospital to act in a certain way. That may, of course, lead the doctor or hospital to alter the proposed treatment.

Surrogate decisions can also be overridden if a court or tribunal believes that is in the patient's best interests.

## Expectations of a pain-free death: Is litigation the only means to achieve this?

**Professor Colleen Cartwright**

*Southern Cross University, Tweed Heads NSW*

**Background:** Australian research has demonstrated confusion about what is/is not euthanasia, and medical professionals fear litigation if adequate pain and symptom control also hastens death. Recent cases of terminally ill people being left in extreme pain until they died suggests that there has been little progress in this area in Australia over the past decade, in part because of inadequate medical education and in part because of professional arrogance and a reluctance to involve palliative care staff.

Two cases have recently been reported to the author of patients with hip and leg fractures who were left in agony until they died; family members who tried to intervene were bullied and threatened. In a third case, a hospital refused to provide further care for a stroke patient whose family insisted on his wishes for no PEG Feeding.

Several large surveys and in-depth qualitative interviews in Australia identified major issues in relation to pain management and confusion over what is and what is not euthanasia. A literature review identified several US cases of medical practitioners/hospitals being sued for negligence/abuse for leaving terminally ill people in pain but to date there has been no Australian litigation. This paper will consider whether the current law in any Australian state makes it likely that a case here would be successful.

**Conclusion:** Inadequate end-of-life care requires urgent legal action.

## End-of-life decision-making, testamentary capacity & wills passing on property: Whose hopes? Whose expectations? Speaking before and after death

**Conjoint Professor Philip W. Bates**

*Full-time practising barrister, Sydney & Conjoint Professor, School of Medicine & Public Health, The University of Newcastle, NSW*

Bioethics of 'end of life decision-making' typically considers medical and clinical issues. But patients, their families, and 'significant others' also worry about property and material possessions – what will happen to those? 'Wills' on one level affect material possessions, but they also symbolise relationships, and project conversations after death that cannot be answered. The whole dynamics of patient care, up to death, by family and carers for their loved or hated ones, may be skewed by articulated or unstated hopes, expectations, assumptions, rewards or punishments of 'will-making'. Motives, strategies and tactics may flourish. Bioethics needs to consider impure and mixed messages. Legislative amendments, judicial interpretations and changing cultural attitudes have increased the volume of 'will & family provision' litigation in Australia arising out of health care and other settings. Patients may also die without leaving wills, and the distribution of property for such 'intestate' estates may also be challenged by aggrieved relatives or others.

## PROFESSIONAL PRACTICE 1

### Shared decision-making and the ethics of risk: Questions of social policy and medical practice

Dr Sarah Lee<sup>1</sup>, Dr Roger Worthington<sup>2</sup>

<sup>1</sup>Massachusetts General Hospital, Department of Anesthesiology, Boston, MA, USA

<sup>2</sup>Keele University School of Medicine, Staffordshire, United Kingdom

Risk decision-making in healthcare is a complex process and requires careful consideration of the burdens and benefits of various available options. However, the process of balancing these factors is intrinsically dependent on individual patients' preferences, goals, and values, which vary widely from one patient to another. Unfortunately, medical risk assessment is often institutionally determined and uniformly implemented, without regard to these individual factors. Centralised healthcare decision-making can result in blanket responses when dealing with risk. Such top-down decision-making is most often driven by overall numerical targets rather than evaluation of individual patient outcomes. Fear of blame sometimes precipitates a knee-jerk reflex resulting in risk aversion and general restrictions at both a policy and a clinical level. Meaningful engagement in issues of risk are inhibited by the precautionary response of policy-makers, physician fear of negative outcomes that could reflect poorly on performance scores, and physician fear of litigation, influenced by perceptions of a heightened litigious medical culture. Furthermore, risk assessment is often done in a protocol-driven manner, which can easily undermine patient-centred care.

### Implications of how a consumer thinks about health outcomes vis-à-vis a health professional

Associate Professor Kay Price

*School of Nursing and Midwifery, University of South Australia, Adelaide, SA*

A Sharing Health Care Initiative grant funded through the Department of Health and Ageing informs our understanding about what it means for people to live with a chronic condition and how this influences their everyday decision-making. The study was undertaken in three stages. Stage 1 – Developed unique profiles of targeted groups utilising the population datasets of the North West Adelaide Health Study a major biomedical cohort study operating since 2000. Stage 2 – Conducted semi-structured interviews with participants of targeted groups. Stage 3 – Conducted a national computer assisted telephone survey informed by an analysis of findings from Stage 1 & 2 and national workshops.

People make everyday decisions based on what works best for them to cope with their everyday health and social matters – the presence or lack of illness/symptoms is critical in influencing what decisions they make. The greater the impacts on life as a consequence of pain, immobility or fatigue the more likely people are to do different self-care activities. Understanding what it means to live with a chronic condition is important but also as important is the need to explore what a person identifies as a health outcome and implications for them in the context of their lives. In this paper I argue that framing chronic conditions in terms of medically selected health outcomes is of minimal utility to a person living life with chronic conditions. The challenge for health professionals is to debate whether we are fostering people waiting for curative measures rather than actually encouraging preventative measures.



## **False hope and unrealistic expectations? The role of conflicts of interest in surgery**

**Professor Wendy Rogers<sup>1</sup>, Dr Jane Johnson<sup>2</sup>**

<sup>1</sup>*Philosophy Department and Australian School of Advanced Medicine, Macquarie University, NSW*

<sup>2</sup>*Philosophy Department, Macquarie University, NSW*

Progress in surgery is vital to improvements in patient longevity and enhanced quality of life. Such progress is fuelled, in part, by the creativity of surgeons as innovators. Surgeons are routinely required to respond to wide variability amongst patients and to solve inventively problems which arise in theatre. In addition, surgeons have a long and continuing history of devising procedures and techniques to advance their craft. Whilst the congruence between innovation and the role of the surgeon is necessary for progress, there are some potential hazards. Apart from financial conflicts of interest caused by surgeon-innovators' involvement in commercial developments, the quest for prestige and the desire to innovate per se can also act as drivers for conflicts of interest in surgery. These less tangible conflicts have the capacity to create false hope and unrealistic expectations on the part of patients regarding surgical outcomes, and to skew inappropriately surgical decision making. In this paper we focus on prestige and the drive to innovate as generators of non-financial conflicts of interest, and examine ways in which such conflicts might be addressed without compromising innovation in surgery.

## **Consumer expectations and priority-setting by public agencies of prescription medicines: New Zealand's Herceptin case**

**Associate Professor Joanna Manning**

*Faculty of Law, the University of Auckland, Auckland, New Zealand*

Public health systems face the challenge of expanding access to important new treatments, while maintaining cost-effectiveness as a key criterion for public funding and safeguarding the affordability and sustainability of their programs into the future. Consumers increasingly have high expectations of access to new treatments. Inevitably public agencies involved in the priority-setting of prescription medicines will on occasion make controversial decisions denying or limiting access, leading to disappointment and challenge.

In 2005 New Zealand's Pharmac was required to decide whether to extend public funding of Herceptin for use in early breast cancer. The Herceptin case was the most high-profile, difficult and divisive in the agency's history. Its decision was marked by consumer lobbying, intense media pressure, public sympathy for the patients, and the first ever successful patient legal challenge to a Pharmac funding decision. The case became an election issue in 2008, culminating in the new Government overriding Pharmac's funding decision consistently with its election manifesto.

This paper examines Pharmac and its decision-making processes, the Herceptin case, and the context in which this highly controversial funding decision was made. It analyses the litigation, and discusses some features and implications of the episode: first, that it involved the triumph of the Rule of Rescue over the public agency's careful stewardship of a scarce resource, basing its allocation on the utilitarian rationality implicit in cost-effectiveness analysis; and secondly, that the episode challenged Pharmac's legitimacy and the integrity of New Zealand's explicit priority-setting process for medicines.

## WORKSHOPS

### The Health and Disability Commissioner and end-of-life decisions

Dr Cordelia Thomas<sup>1</sup>, Anthony Hill<sup>2</sup>

<sup>1</sup>Chief Legal Advisor

<sup>2</sup>Health and Disability Commissioner

The Health and Disability Commissioner receives many enquiries and complaints regarding end of life care. These range from people who fear that unwanted treatment may be provided at a time when they are unable to express their wishes to family members of patients who object to a clinical decision to withdraw treatment and provide comfort cares only. Sometimes the family member wants a particular treatment to be attempted, which clinician considers to be inappropriate.

In many cases family members lack understanding of the dying process and believe their family member has been neglected.

This presentation will consider the application of the Code of Health and Disability Services Consumers' Rights to end of life care issues and will consider some recent cases in this area.

### What are you hoping for? The role of families in end-of-life decision-making

Annette Braunack-Mayer<sup>1</sup>, Jaklin A Elliott<sup>2</sup>, Lynn Gillam<sup>3</sup>, Ian Olver<sup>4</sup>, Heather Tan<sup>5</sup>, Dominic Wilkinson<sup>6</sup>

<sup>1</sup>Discipline of Public Health, School of Population Health and Clinical Practice, The University of Adelaide, North Adelaide, SA

<sup>2</sup>Cancer Council Australia, Surry Hills, NSW; Discipline of Public Health, School of Population Health and Clinical Practice, The University of Adelaide, North Adelaide, SA

<sup>3</sup>Centre for Health and Society, Melbourne School of Population Health., The University of Melbourne, VIC; Children's Bioethics Centre, Royal Children's Hospital, VIC

<sup>4</sup>Cancer Council Australia, Surry Hills, NSW

<sup>5</sup>Palliative Care Research Team, School of Nursing, Monash University, VIC

<sup>6</sup>School of Paediatrics and Reproductive Health, The University of Adelaide, North Adelaide SA

Current healthcare practice places the individual patient at the centre of the decision-making process. At the end of life, however, families become intimately involved in decision-making, particularly where patients are not competent to make decisions. Families are both affected by and affect the process and outcome. Determining the appropriate timing, nature, and extent of families' participation in end-of-life decisions about patients is often complicated, possibly because of the ways in which patients, families, and decision-making are conceptualised in dominant ethical theory. At times, clinicians are faced with practical uncertainties and ethical dilemmas, where distinguishing between and responding to patient and family needs, expectations, and hopes may be difficult. In this workshop, we will articulate and explore the challenges and necessity (ethical and practical) of involving family in decisions at the end of life. We will combine insights gained through empirical research and theoretical analyses, and consider how families and clinicians can or do negotiate hope and decision-making when options are limited and the certainty or desirability of outcomes can be contested. Annette Braunack-Mayer (ethicist) will introduce and moderate presentations and discussions by a panel including Ian Olver (oncologist and bioethicist), Lynn Gillam (bioethicist), Dominic Wilkinson (paediatrician and ethicist), Heather Tan (palliative and family care counsellor), and Jaklin Elliott (social scientist). Ultimately, we aim to outline and develop an ethically and contextually sensitive approach to engaging family in end-of-life care.

## CAFE

### **Balancing expectations, hope and futility in clinical research: A view from an HREC**

**Dr Eleanor Milligan (A/Chair), Dr Richard Roylance (D/Chair), Dr Scott Campbell (D/Chair), Dr Maher Gandhi, Adam La Caze, Bernard Thomas, Melissa Hagan, Dr Peng Tjun Choy, Beverly Kurkowski, Peter Mollee, John North, Col Sutcliffe, John Bennett, Robert Zubershaw, Dan Siskind, Karam Kostner, Denzil Scrivens, Sean Hatherill, Kerri Holzhauser, Mark Deuble, Mary Boyde, Meg Harward, Lyndall Spencer**

*Metro South Health Services District. Centres for Health Research, Princess Alexandra Hospital, Woolloongabba, QLD*

This café style session will invite delegates to consider how HRECs balance the ethically complex range of competing expectations, hopes and interpretations of futility from a number of stakeholders involved in clinical research.

In determining whether research is 'ethical', under the NHMRC Guidelines, HRECs seek to consider the risks and benefits of participation to the patient with the potential community good that such research can produce. In doing their job HRECs are charged with the task of assessing research merit and integrity, considering whether the proposed research is just, assessing whether participants' autonomy is protected/respected through informed consent, and making a judgment on whether the likely benefits outweigh potential harms (beneficence and clinical equipoise).

However, the research encounter, like the clinical encounter, is predicated on a number of tacit expectations and hopes. Some research interventions will be ultimately futile, due to the advanced disease of the participants. The impact of research participation on patient care at end-of-life raises complex ethical questions concerning the role of 'hope'. In many circumstances participants clearly accept that no tangible benefit, aside from personal satisfaction, will flow from their participation.

Often the hopes and expectations of the various stakeholders are at odds, for example, for a patient the expectation may be cure or prolonged life, for the Principal Investigators, the expectation may be the completion of a training program, or a publication that improves professional credibility, for a sponsoring drug company, the expectation may be increased market share and profit. While these expectations are not always mutually exclusive, the level of risk involved for each stakeholder can be vastly different. In their deliberations, HREC members must consider how such potential cross purposes are conveyed to assist participants to make informed decisions throughout the approval, recruitment and research process.

Three case vignettes will be presented to stimulate debate on the malleable definition of futility, the convergent and divergent hopes generated, and the implicit expectations that research engenders from an ethical, clinical, community, corporate and organisational perspective. HREC's perform a critical ethical role in the independent oversight of clinical research, and members of Metro South HREC will facilitate these case discussions, reflecting upon how these challenging questions are identified, balanced and resolved within our committee.

## INTERNATIONAL PERSPECTIVES

### **Divergent legal approaches to medical futility disputes: Comparing Australia and the United States**

**Professor Thaddeus Mason Pope**

*Associate Professor of Law; Widener University School of Law; Wilmington, Delaware USA; Adjunct Professor of Medical Education; Albany Medical College; Albany, New York USA*

End-of-life medical futility (involuntary euthanasia) disputes continue to produce intense ethical, legal, and policy conflicts in many countries. In this session I present the results of a comparative study of medical futility laws in Australia and the United States.

Health care providers in each of these countries are still struggling to develop a dispute resolution mechanism that appropriately balances patient autonomy against the rational allocation of resources and the integrity of the medical profession. But the United States and Australia have developed strikingly divergent legal mechanisms for resolving medical futility disputes.

In the United States, mediation has long been touted as the magic band-aid to solve end-of-life conflicts. But it has become increasingly obvious that mediation frequently fails in the ever-growing number of intractable medical futility cases. It cannot succeed in the shadow of current health care decisions law that gives surrogates enormous bargaining power. So, providers and policymakers in the United States (and Canada) are now working to equalize bargaining power. Many policymakers, looking to the “model” provided by the Texas Advance Directives Act, seek to give providers a clearly-defined statutory “safe harbor” to unilaterally refuse surrogate decision makers’ requests for inappropriate life-sustaining medical treatment.

In contrast, medical futility laws in Australia (and the UK) already more meaningfully empower health care providers to refuse surrogate demands. After demonstrating these differences using vivid examples of the latest legislative and judicial developments, I analyze their source in the cultural context of each country. Finally, I assess the impact of these disparities on future end-of-life conflict resolution in each country.

### **Law deferred and referred: Non-adherence and the notion of ‘futility’ in community-based psychiatry in New Caledonia**

**Antonia Knifton**

*School of Anthropology and Conservation, University of Kent*

Community clinics or dispensaires providing primary healthcare for the majority of rural and the most disadvantaged urban citizens in New Caledonia, are on the frontline of community psychiatric practice. Throughout open-ended interviews, informal observations and work-shadowing, low pay-grade nursing staff used the notion of ‘futility’ to explain conflicts present in everyday decision-making. Outside the territorial capital, Nouméa, specialist psychiatric services are few and far between. Case-management in these conditions relies on nursing staffs’ individualized and localized knowledge of service users, staff teams and practices. In this paper I argue that such everyday clinical decision-making produces individualized and localized law. Codified public health law is both known and acknowledged by staff. However, law’s interaction with the lived practicalities of New Caledonian community psychiatry result in creative adaptation that is calqued on this notion of futility. When non-adherence to treatment, an escalation in positive symptoms and fears for staff and service users’ safety are brought to bear on clinical decision-making, procedural concerns can be bypassed. Referring service users on to centralized, specialist services is experienced as deferring individual service user’s and families issues and day-to-day difficulties either to some other nursing team or to the future. Nursing staff used the notion of futility to justify individualizing and localizing legal decision-making, evoking “respite” and “recuperation” as motives for ‘futile’ referrals. Motivations involved in individualized and localized decision-making are inferred and referred to in specialist services. Nursing staff in both settings identify these ‘futile’ referrals as conflict-generating factors between services, healthcare workers and families.

## Nutrition labelling and ‘personal responsibility’ in public health law: Lessons from three countries

**Professor Roger S Magnusson**

*Professor of Health Law & Governance, Sydney Law School, University of Sydney, NSW*

Personal autonomy and its flipside, personal responsibility, are important values in both medical law, and public health law. In public health law, personal autonomy and responsibility tend to manifest in debates about the merits and risks of government intrusion into the personal lives of individuals, the “nanny state”, and whether the state should seek to influence the preferences of individuals so that they will lead healthier lives.

Some public health laws – including nutrition labelling laws – are intended to inform consumer choices in ways that are consistent with prevailing assumptions about the importance of personal responsibility for one’s health. These laws may not face opposition from consumers, but they raise the possibility that a more informed consumer will make healthier choices that will disrupt the revenues that arise from current (unhealthy) patterns of consumption.

This paper presents a short case study of front-of-pack and restaurant nutrition labelling reform in three countries, noting strikingly similar patterns of opposition from the food industry to interpretive labelling schemes, and the promotion of weaker, non-interpretive, voluntary schemes that pre-empt legislative regulation. This case study casts doubt on the commitment of the food industry to the exercise of personal responsibility by consumers in their food choices.

## Developing nations: Pharmaceutical regulation and reform efforts

**Mabel Tsui**

*Queensland University of Technology, Faculty of Law, Brisbane, QLD*

A consequence of both the desire to reduce costs as well as the forces of globalisation, there has been a rise in the practice of outsourcing drug manufacturing work to and importation of pharmaceutical ingredients from overseas countries by developed nations. While this practice offers financial benefits and increase of human resource, the sourcing nations are countries with developing and problematic regulatory and/or enforcement regimes, which have led to dangerous public health implications. The reality of globalisation, increased demand for medications and financial considerations means that ceasing this practice is neither realistic nor possible. Although there have been global harmonisation and quality assurance efforts undertaken, these have been mainly led by developed nations, with little input from or cooperation with their developing counterparts.

With the broader aim being the legal and regulatory reform of the developing nations and their pharmaceutical industry, a question which arises is what criterion regulatory efforts should be measured against to ensure it is an effective regime? This presentation will consider some characteristics of the United States Food and Drug Administration in questioning its “success” and “failure”. It will also explore how qualitative research could contribute to improving legal reform and effectiveness of the regime as well as cooperation between the government and the pharmaceutical industry. It must be noted that legal reform of developing nations will be a long term, progressive exercise and this presentation does not purport to solve the problem of poor-quality pharmaceutical imports. Rather, it will raise some possible reform avenues via cooperation between the stakeholders, namely developed countries whose public health and well-being rely to a significant degree on the quality of the drugs provided from developing countries.





## PRESIDENTIAL ADDRESS

### Not so great expectations: Why we should accept and respect hopelessness and futility

Associate Professor Malcolm Parker

University of Queensland, Mayne Medical School, Herston, QLD

Medicine and health care attempt to prevent and cure disease, restore lost function, and relieve suffering. These are positive aspirations in the face of disvalued states of being. Part of the approach to countering illness can be to encourage or therapeutically increase such feeling-cognitive states as optimism, emotional well-being, peace and meaning, and to try to decrease mental and existential distress and despair, feelings of vulnerability, feelings of loss and loss of meaning. I briefly examine examples from three fields - cancer, psychotherapy and end-of-life – and the relationships between therapeutic and social pressures for optimism and hope, and well-being, health and freedom. I suggest that in each field there are risks concerning prematurely and/or excessively accentuating the positive, and neglecting the presence and importance of what is conventionally regarded as the negative.

---

---

---

---

---

## PLENARY SESSION

### Dying safely

Professor Ken Hillman

The way we die has slowly changed over the last 30 years. The change has primarily been driven by technological advances in Medicine. While dying used to be mainly managed in people's home, there is now a conveyer belt taking the dying by ambulance to hospital and into Intensive Care Units. Society is no longer aware of whether the illness is amenable or not to what acute hospitals can or, more importantly, cannot offer. In fact many health professionals are not sure of these boundaries and so the patient is involved in an escalation of care, gradually being surrounded by more technology. Other drivers include the medical profession's reluctance to talk about death and dying; a lack of alternative ways of managing the dying; media concentration on the daily reporting of medical miracles and the resultant societal expectations; and the fear of litigation. It has become easier to put patients on the conveyer belt than to pluck them off. As a result, dying is often a prolonged painful process with loss of dignity and control. Moreover, it has become extremely expensive as more health resources are ploughed into hospitals and high technology resulting in unsustainable costs of health care.

As well as avoiding patient suffering and high costs, there are many ethical considerations associated with the medicalisation of dying. These include the conflict between patient choices and cost; the grey zone of who has ultimate responsibility to demand or refuse treatment in the face of futility; and scientific versus 'practical certainty'.

There is beginning to be a discourse with society about how dying has become medicalised and whether this is what people wish for their own end-of-life.

---

---

---

---

---

## BABIES AND CHILDREN

### Futility, babies and the 21st century

**Neera Bhatia**

*Deakin University*

Principles of patient autonomy and the sanctity of life, ironically run parallel to each other in the medical law sphere. The legal system has become entangled in contradiction by attempting to maintain a rigid doctrine of sanctity of life whilst at the same time developing concepts such as 'futility' of existence, and measuring the 'quality' of life of incapacitated neonates.

Understandably medical practitioners, lawyers and judges face significant ethical, social, emotional and legal complexities when making decisions about withdrawing or withholding futile treatment from neonates.

However it is still somewhat concerning that medical practitioners and judges decide what is considered to be 'futile' treatment concerning incapacitated patients, and this is further amplified in the case of critically ill neonates; it cannot be disputed that incapacitated neonates are the weakest, most fragile group of human beings.

This is evident not only in the obvious sense of being dependent upon adults, but by the fact that they cannot express or exercise their 'inherent right to patient autonomy' enshrined in medical law in western countries. In addition, it is far more concerning to recognise through case law decisions that the parallel legal and medical doctrines of the 'sanctity of life', do not protect neonates from death.

The judiciary struggles to align the competing doctrines and this is evident in the disparity of decisions made in leading case law. My paper will examine the interpretation of 'futility' in leading case law that often has a 'life or death' consequence for critically ill neonates.

### No room at the inn: Ethical and legal questions about neonatal bed allocation decisions

**Dr Andrew Watkins**

*Department of Paediatrics. Mercy Hospital for Women, Heidelberg*

Neonatal intensive care cots are a scarce resource and it is very common to have to manage the arrival of a critically ill patient into a unit which is "full". Neonatal intensive care units have fewer choices than adult units, being unable to restrict elective surgery to make space and facing much higher mortality in patients denied admission.

The choices available are: to transfer the baby, whether locally or interstate, to allow the baby to die, or to overload the unit. None of these choices is satisfactory and it has also been suggested that babies who are less unwell should be transferred to make room.

Transfer of the 'index' baby imposes a risk on this baby, sparing others in the unit the risks of overloading. Overloading the unit spares the risk of transfer but exposes all to the infection, mortality and morbidity risks associated. Transfer of a less unstable baby maximises utility, but imposes a risk on one baby in the interests of others.

Parents can legally consent to transfer which is in the interest of their infant. May they consent to a risk for their baby to benefit another?

Decisions such as unit overload impact all babies in a unit. Families are not consulted or informed, despite the risks imposed.

I shall attempt to map out a way forward. Significant legal and ethical issues remain unresolved. Management of these situations has hitherto been rather paternalistic. Better transparency and communication are necessary

## Ethical challenges in management of infants with disorders of sex development: Parents' hopes, children's futures, and 'unnecessary surgery'

Professor Lynn Gillam

*Children's Bioethics Centre, Royal Children's Hospital Melbourne; School of Population Health, University of Melbourne*

For infants born with ambiguous genitalia, two key decisions must be made. One is about sex of rearing – should this baby be raised as a boy or a girl? The other is about surgery, either to remove gonads or other reproductive structures, or to change the appearance or structure of the external genitalia. Should surgery be done at all, and if so, when? Both of these decisions are ethically fraught, and are made in an emotionally charged context. The ethics of genital and gonadal surgery have been discussed in the literature by ethicists, doctors and activists – this is a controversial area, with strong opposition to any genital surgery on children being expressed by some commentators. Recently, my colleagues and I published a paper (Gillam et al, 2010) articulating key ethical principles that we believe encapsulate the ethical issues, and would be acceptable to all parties, and so form a basis for discussion and decision-making.

Balancing these potentially competing principles is tricky, and one of the reasons for this different views about how to respond to the very natural hope of parents to have a “normal” boy or girl. Are the child's interests and rights best served in the long run by responding to this hope with surgery to 'normalise' genital appearance? Or should clinicians aim to change parents' understandings and hopes?

### References:

Lynn H. Gillam, Jacqueline K. Hewitt, Garry L. Warne (2010) Ethical Principles for the Management of Infants with Disorders of Sex Development. *Horm Res Paediatr.* 74:412-418

## LAW 2

### Refusal of treatment: “Futility Rules”

Dr Alma Rae

*Consultant Psychiatrist, Canterbury District Health Board, Christchurch, New Zealand*

This paper dissects a UK court decision in which a 37-year-old woman with Borderline Personality Disorder was denied the right to refuse blood transfusions. She had over many years cut herself and bled almost to death; she had repeatedly been persuaded against her wishes to accept transfusions and so she finally arranged an Advance Directive to prevent this. The hospital applied to the Court for a determination as to the Directive's validity; it was declared invalid on the grounds of the patient's incompetence, while the Court considered that further transfusions when the hospital deemed these necessary would be in her best interest. I take issue with both aspects of this decision in a detailed discussion of relevant legal precedent and applicable ethical principles.

## FUTILITY

### Deciding about CPR/NFR

**Dr Barbara Hayes**

*Northern Health, Bundoora Extended Care Centre, Bundoora; Centre for Health & Society, University of Melbourne, VIC*

A frequently required, end-of-life decision is that of deciding whether or not CPR should be provided in the event of future cardiac arrest. Past research has identified significant variability in how this decision is made.

A model for clinical CPR decision-making is proposed that is based on empirical qualitative research. In this study, hospital-based doctors and nurses were interviewed, and the interview transcripts analysed thematically, to identify the ethically significant elements of the CPR decision. Normative ethical principles have then been applied to develop a model for ethical CPR decision-making.

This approach recognises, and keeps separate, the technical and ethical elements of the decision. It also identifies the ethical significance of the CPR decision-making discussion. A CPR discussion, with specific aims, is recommended for each of four patient groups. A distinction is made between the types of discussions required when CPR could not be effective for restoring a heart-beat and when CPR might be effective. When CPR is judged to be 'physiologically futile' the discussions are directive or deliberative, as described by Emanuel and Emanuel, explaining why CPR is not an option. When CPR is judged to have potential for restoring a spontaneous heart beat then the discussion is an interpretive one, seeking to identify the ethical implications of CPR or no-CPR for that patient. Shared decision-making aims to identify the best CPR decision within the context of the patient's medical condition and their moral values.

### Patient perspectives on the timing of discussions about refusing 'futile' treatment at the end of life: An ethical and practical dilemma

**Dr Jaklin Elliott<sup>1,2</sup>, Ian Olver<sup>1</sup>**

<sup>1</sup>*Cancer Council Australia, Level 1, 12 Chalmers St., Surry Hills NSW*

<sup>2</sup>*Discipline of Public Health, School of Population Health and Clinical Practice, Level 11, 178 North Tce, Adelaide SA*

Within developed nations, the dominant model of medical decision-making at the end of life dictates that patients be provided with all prognostic information, in order to make informed decisions about treatment options, including forgoing treatments deemed medically futile (e.g., CPR in terminally-ill patients dying due to disease). There is little examination, however, of patients' perspectives on when in the disease trajectory such information should be provided. We conducted semi-structured interviews with 23 patients diagnosed with a life-threatening disease (cancer) about the decision to refrain from CPR following cardiac arrest. Using discursive analysis, we argue that determining the timing of discussions appeared problematic for participants, with competing notions of criteria for decision-making working to justify different conclusions. Drawing on a 'modernist' repertoire of self (prioritising rationality), participants agreed that, to legitimately make a decision at the end of life, patients had to pass a 'Sanity test' – being excluded from decision-making if they did not. This worked to recommend early discussions and decision-making before disease progression compromised cognitive functioning. However, a 'romanticist' repertoire (prioritising emotionality) functioned to justify delaying such discussions, with a 'Stability test' available to excuse patients from decision-making. The coexistence of these two repertoires and associated Sanity/Stability tests contributes to an ethical and practical dilemma for patients and clinicians in terms of determining appropriate timing of discussions regarding CPR options and outcomes. The absence of the romanticist repertoire in dominant models of patient decision-making has ethical implications for policy makers and practitioners dealing with dying patients and their families.

## Paramedics and good medical care: Futile care in the emergency out-of-hospital care setting

Dr Brian Sengstock

*University of the Sunshine Coast*

Anecdotal evidence indicates that paramedics and paramedic students may override a patient's autonomy to refuse life sustaining medical treatment in the out of hospital emergency setting. Arguably a patient has the right to refuse treatment and this right is enshrined in both the common law and legislation in most Australian jurisdictions. Whilst this is the case in Queensland, there is an additional level of complexity introduced into the decision making matrix as a result of the wording of the Queensland legislation in this area. The Guardianship and Administration Act 2000 (Qld) integrates a 'consistent with good medical practice' provision into Chapter 5 of the Act and particularly in reference to the withholding and withdrawal of life sustaining measures. What constitutes good medical care is clearly defined in Schedule 2, section 5B as being the accepted practice of the medical profession in Australia. What is not fully understood is whether the out of hospital care environment, in which paramedics operate under a delegated medical model, is covered under the provisions of good medical care. This raises a number of questions in a complex legal environment as it is necessary to determine what constitutes good medical practice in futile care in the out of hospital versus the hospital setting. A favourable outcome in the eyes of the paramedics treating the patient may not be considered to be a favourable outcome by the patient who has had their autonomy overridden by a paternalistic medical model of health care.

## Doing nothing isn't an option: Queensland Health's response to managing expectations and futility

Dr Wendy Corfield

*Queensland Health, GPO Box 48, Brisbane, QLD*

The term "futile medical treatment" remains a point of controversy in medical literature and in clinical practice. One area of contention is where health care teams and patients (and their families) have differing views about the goals of care, particularly about unwanted and unnecessary medical treatment, when the prognosis is imminent death. Another area of potential conflict concerns the use of the term itself, who should determine when a treatment is futile, and why?

The overwhelming message from national and international researchers, specialising in end-of-life care, is that health jurisdictions have an obligation to provide appropriate guidance around clinical, legal and ethical considerations not only to support their health care professionals, but also to appropriately manage the expectations of dying patients and their families.

Queensland Health is well-acquainted with the complexities of clinical, legal and ethical issues around medical treatment that offers no therapeutic benefit for dying patients. Instead of adding to the misinformation and uncertainty by "doing nothing", Queensland Health has tackled the challenge head-on. Queensland Health's advance care planning framework offers wide ranging guidance to its health care professionals, and supports members of the public who wish to know more about advance care planning through its public website, booklets and brochures. This initiative also includes implementing a Statewide form in April 2010, replacing NFR orders with clearly documented resuscitation planning, meeting legal and ethical requirements in Queensland.

The pitfalls and successes of implementing such a grand plan will provide valuable learnings to other health jurisdictions contemplating such an endeavour.

## THEORY 2

### The discursive death of human embryos

Associate Professor Sheryl de Lacey

*Flinders University, SA*

The 'spare' human embryo created through In Vitro Fertilisation (IVF) is rapidly becoming a discrete entity devoid of corporeal attachment in public and scientific discourse. IVF embryos are now visualised by IVF patients and scientists alike through the use of high quality magnification technology yet the way they are discursively constructed differs depending on whose 'gaze' the embryo is subjected to.

In the laboratory embryos are subject to, arguably, objective assessments of their perceived quality and capacity to implant, their metabolism, their genetic integrity, and their potential for pathology. They are viewed as being detached and as having individual interests. David Gardner, an eminent Australian embryologist made a profound statement when presenting a paper on the pathology of an embryo and the possibility of therapeutic manipulations at a recent conference. He said, "It won't be long before the embryo has its own set of case notes". Just as the embryo is embedded in biological discourse in laboratory practices, in Australian law the human embryo is defined as a discrete entity in purely biological terms.

By contrast, women in several qualitative studies of patients' decisions for excess frozen IVF embryos define their embryos in social or relational terms. This paper draws on the findings of an Australian study in which 64 women who had made a decision for the fate of their frozen unused embryos were interviewed. Women who had donated embryos for reproductive use, discarded embryos and donated embryos for research were represented in the sample. They were therefore able to articulate their rationale and provide valuable insight into the context and processes of their decision.

In the final decision for the disposition of unused IVF embryos women are offered a 'smorgasbord' of choices which include opportunities for the embryo to implant and options that involve the 'death' of the embryos through their discard or use in scientific research. There is an emerging trend for clinics to offer the practice of 'compassionate transfer', that is the transfer of 'spare' embryos at a time when implantation is highly unlikely.

In particular this paper focuses on the decision to discard embryos. Women who selected this outcome for their embryos described this not so much as a choice but as a senseless act made necessary by policy limitation of storage time, and a pointless waste. They chose this option not because they were driven by a belief that discarding an embryo was the right thing to do but because they believed that either donating it to another couple or agreeing to its destruction in research was the wrong thing to do. In the study reported here, some women chose to collect their embryos and personally discard them. Their experiences and thinking provide unique insight into the ways in which the life and death of an embryo is constructed by IVF patients.

## Uncertainty: The crucial factor in considering hope and futility – the perspective of the General Practitioner

Dr Ben Gray

University of Otago Wellington, Wellington, New Zealand

In discussing “Futile care” what we are in fact discussing is “probably futile care” If there was no uncertainty most cases would be easily resolved. “Hope” depends on uncertainty; the possibility that there will be a good outcome. If death is certain then all hope is gone. To understand these two ideas we need to understand uncertainty.

Clinical specialties vary in their tolerance of uncertainty. One of the hallmarks of General Practice is an acceptance of and comfort working with uncertainty, compared to a lesser tolerance in hospital medicine. The risk is that the doctor will only cease “futile” treatment when they are absolutely sure it is futile due to discomfort of living with the possibility that they might have got it wrong.

Hospital practice is better able to provide “excess” care for the patient in front of them and completely ignore the patient on the waiting list in a way that general practice cannot; they are less adept at balancing the community interest against the individual interest; achieving a just distribution of resources. Providing “futile care” particularly in New Zealand is at the expense of another patient who receives no care.

There is significant variation between cultures in tolerance of uncertainty. Hofstede describes uncertainty avoidance as one of 5 variables that vary significantly between countries (and between individuals) ; think Jamaicans (tolerant) and Germans (intolerant) as in the movie “Cool Runnings.” We must find out what tolerance of uncertainty the patient has as this will affect treatment decisions.

Hofstede GHH, Gert Jan, Minkov M.: *Cultures and organizations: software of the mind: intercultural cooperation and its importance for survival*. 3rd ed. ed. New York: McGraw-Hill; 2010.

## A costly separation between withholding and withdrawing medically inappropriate treatment

Associate Professor Dominic Wilkinson<sup>1</sup>, Professor Julian Savulescu<sup>2</sup>

<sup>1</sup>Robinson Institute, Discipline of Obstetrics and Gynecology, University of Adelaide, North Adelaide, SA

<sup>2</sup>Oxford Uehiro Centre for Practical Ethics, University of Oxford, UK

Ethical analyses, professional guidelines and legal decisions over more than 2 decades have uniformly supported the Equivalence Thesis for life-sustaining treatment: if it is ethical to withhold treatment, it would also be ethical to withdraw the same treatment. Yet the majority of practicing doctors and nurses appear to endorse non-equivalence, and prefer to withhold treatment that is judged to be medically inappropriate or futile rather than withdrawing it.

In this article we explore reasons why the majority of medical professionals disagree with the conclusions of ethical analysis. In particular we will focus on intensive care admission and discharge decisions. Resource allocation is considered by clinicians to be a legitimate reason to withhold but not to withdraw intensive care treatment. We analyse 5 arguments in favour of non-equivalence, and find only relatively weak reasons to restrict rationing to treatment withholding. The most likely reasons underlying this preference are status quo and omission biases. On the contrary, resource allocation provides a strong argument in favour of equivalence: non-equivalence causes preventable death in critically ill patients. We outline two proposals for increasing equivalence in practice: (1) reduction of the mortality threshold for treatment withdrawal, (2) time-limited trials of intensive care. These strategies would help to move practice towards more rational treatment limitation decisions.

## Religious faith and opposition to legalisation of voluntary euthanasia

Neil Francis

*Chairman and CEO, YourLastRight.com Limited, Blackburn, VIC*

Relevance: a paper that “Explores philosophical approaches to defining life, hope and healthcare,” and “Critiquing notions of medical paternalism,” and “Proposes and argues ethical perspectives on hope and futility that relate to contemporary healthcare”

Medical aid-in-dying for patients near end of life where both medical and palliative futility apply is currently illegal in all States and Territories of Australia, though it is legal in a number of jurisdictions around the world. Legislation to change the law is before the South Australian Parliament, and reform bills have been announced for both Tasmania and NSW. Opinions vary about legalisation of physician-assisted dying among both healthcare workers and the general public.

A literature review of research into the role of religious faith, its correlation with opposition to physician-assisted dying, and pathways which may explain the correlation, will be discussed. A model in which the ethical perspectives of both opposed healthcare workers (including those on grounds of religious faith) and of requesting patients may be respected, will be proposed.



## RESEARCH ETHICS 1

### No place for hope in clinical research: Role-confusion for clinician/researchers and participants

**Nikola Stepanov**

*Dual faculty PhD candidate, Topic-Empirical evidence in human research, University of Melbourne: Centre for Health and Society (MDHS) & Centre for Applied Philosophy and Public Ethics (Arts), Parkville, VIC*

The defining end of doing clinical research is that it will contribute to generalisable knowledge. This is the ethical justification for embarking on projects that create burden and impose risk on research participants. The intent is future directed.

Contemporary clinical research often involves the clinician/ researcher practicing in a dual capacity. In conducting research the clinician/ researcher is asking participants to take on a risk or a burden for the purpose of answering a scientific question regarding a disease. The ethical and legal obligation of the clinician/ researcher extends to a protective duty of the participant however their principal duty is to science and society.

A review of the literature reveals that troubling ethical implications for the clinician/ researcher arise when they confuse their protective duty as a researcher, with a clinical duty to act in the interests of the participant. Participants also experience role confusion and are often unaware that the duty of the clinician/ researcher is not to act in their (the participants) best interests but in the interests of generating new knowledge.

Research is conducted from a state of clinical equipoise and clinician/ researchers must be aware of their ethical obligations to ensure that participants understand the purpose of research and not consent to trials in the 'hope' of a cure or treatment. To offer participants 'hope' creates the illusion that a beneficial end for themselves as participants might be expected.

### What do participants hope for when joining an RCT: Insights for the process of informed consent

**Dr Clare Delany, Aishath Mahfooza, Dr Helena Frawley**

*Physiotherapy Department, School of Health Sciences, the University of Melbourne, VIC*

When participants provide their informed consent to research, it is assumed that they understand the nature of their participation. This qualitative study nested within a multi-national, multi-centre randomised controlled trial (RCT) known as the Pelvic Organ Prolapse Physiotherapy (POPPY) trial, examined the experiences of women with pelvic organ prolapse (POP) participating in this RCT of physiotherapy treatment. The research identified reasons for and experiences of participating in the trial via in-depth interviews with 15 women. A unifying explanation of the reasons for 'signing in' was the concept of 'hope' categorised as 'self-interest,' 'altruistic' and 'passive' hope. The women expressed diverse 'understandings,' interpretations and hopes about their participation within the trial. Their identity as research participants and the role they thought they should assume was constructed on the basis of their individual understanding, their preconceived beliefs and values, and experiences of living with POP. This in turn resulted in varied examples of 'adherence' to the research protocol.

A key implication of these findings is a need for a more individualised, participant-centred approach to obtaining informed consent, rather than a structured approach as is currently practiced in research. The therapeutic nature of this physiotherapy-based and other similar trials means that if researchers are to ensure their participants understand the requirements and participate as the research protocol requires, they should individualise information, enquire about participants' hopes and adopt a participant-centred approach to informed consent.

## **‘You will not benefit from participating in this research’: Do HRECs deflate potential research participant’s expectations?**

**Dr Nicole Gerrand**

*Conjoint Fellow, School of Humanities and Social Sciences, University of Newcastle, NSW*

HRECs are usually concerned that the benefits of research are not overstated to potential participants. At the same times a significant percentage of medical research offers therapeutic options to potential participants and for some research may be one of the few remaining therapeutic options. Is it possible for the potential benefits of therapeutic research to be accurately presented to potential participants who may be hoping for some curative result?

## **Participant hope and clinical research**

**Dr Timothy Adam, Dr Andrew Crowden**

*The University of Melbourne, “Dunvagan”, Ballarat VIC*

The role of participant hope and expectation in research ethics rests on contested ground. In Australia research ethics has understandably been firmly situated historically and culturally within an “ultra-rationalistic” framework that promotes and privileges an enlightenment view of human capacity and decision-making. The role of hope and expectations has either been neglected as part of the process, or understood as being inimical to ethical decision making within the boundaries of consent in health research. Consent in research ethics is primarily understood to be a process by which the researcher ascertains the cognitive capacity of the individual to understand and manipulate information in such a way that they can give “informed consent” to either participate or not in what is being offered. However, over the past decade and a half, the role of hope and expectations in human research has been increasingly debated within philosophy, positive psychology and other disciplines. In this paper we will give a succinct overview of relevant literature and research on participant hope in human research. Then a more nuanced understanding of the role of hope and expectations when people consent to be a participant in clinical research will be outlined.

## WORKSHOPS

### **Abandon hope all ye who enter here: Uncertainty and hope in medical care**

**Dr Anna Holmes**

*Bioethics Centre, University of Otago/Otago Community Hospice*

Hope is an integral aspect of medical care and healing. Without hope life has no meaning or purpose and healing is not possible.

The traditional medical paradigm offered care on the uncertain journey from birth until death. It believed that patients sought healing and care while cure was an occasional extra. Death was seen as the normal end of life.

The current biomedical paradigm seeks certainty in cure. Death is seen as failure. When cure is not possible, biomedicine has no alternative response. Such patients are referred back to general practitioners or to hospices and feel angry, abandoned and hopeless. This conflict of medical paradigms has reduced trust between patients and doctors.

There are three main factors in reducing hope. The first is the loss of trust between patients and doctors. The second is presenting technological findings as truth when they are only a part of the information and may be wrong or misleading. The last is the demand of regulators and patient advocates for full disclosure of all information. Patients often interpret possibilities as certainties.

There is an urgent need to rediscover the art of holding clinical information and living with uncertainty until the truth of the situation emerges.

This workshop will explore the ethical and regulatory aspects of care. It will seek to find the fine line between holding unproven possibilities and giving adequate information, while maintaining hope.

### **'He was my son, not a dying baby': Parental, ethical and practical considerations in perinatal futility**

**P Thiele<sup>1</sup>, A Watkins<sup>2</sup>, L de Crespigny<sup>3</sup>, D Wilkinson<sup>4</sup>**

<sup>1</sup>*Monash University, Frankston*

<sup>2</sup>*Mercy Hospital for Women, Heidelberg*

<sup>3</sup>*Research Associate, Oxford Uehiro Centre for Practical Ethics, University of Oxford, United Kingdom*

<sup>4</sup>*Robinson Institute, Discipline of Obstetrics and Gynecology, University of Adelaide, Adelaide, SA*

Congenital abnormalities with a high likelihood of fetal or neonatal death are considered by some obstetricians to be 'lethal'. Termination of pregnancy is the common choice and seen by some as normative. When parents choose not to terminate, medical staff are sometimes reluctant to offer antenatal or perinatal management options on the grounds of 'futility'.

In this workshop we will look at the example of trisomy 18. In the first section, we present the personal experience of one of the authors who made a choice to continue her pregnancy, facing apathy, misunderstanding, miscommunication, and even hostility from medical professionals. We will summarise the common themes in patient narratives following the diagnosis of a lethal congenital abnormality, highlighting the potential conflict between parental and medical expectations.

We will next consider and analyse the potential harm to the fetus of providing active obstetric and paediatric management and resuscitation for fetuses with abnormalities of this sort. Claims of futility are often based on misleading survival data or misapprehensions about the goals of treatment. Concerns about the harms of active management may represent a form of paternalism.

In the last part of the workshop we will address the personal and practical challenges for professionals faced with patients who make choices that conflict with the doctor's own values. We provide a set of recommendations for professionals facing requests for perinatal treatment that is perceived to be futile.

## Clinical Ethics Workshop: To treat or not to treat. Who decides and how?

Dr Garth Thomas<sup>1</sup>, Associate Professor Wendy Rogers<sup>2</sup>, Dr Rob Barnett<sup>3</sup>

<sup>1</sup>Gabba Anaesthetic Services, Mater Medical Centre, South Brisbane, QLD

<sup>2</sup>Dept of Philosophy and Australian School of Advanced Medicine, Macquarie University, NSW

<sup>3</sup>Holy Spirit Northside Hospital, Chermside, QLD

Some of the more difficult decisions confronting clinicians and policymakers concern whether or not to offer treatment to patients in situations where any postulated benefit is less than clear. The difficulty may be compounded where resources are limited by either supply or demand constraints. An essential part of the decision-making process will involve dialogue with the patient and other stakeholders, both to convey information relevant to their evaluations, and to familiarize clinicians and others with the patient's attitudes and beliefs regarding their illness and their options. Yet, final decisions can still be difficult, often demanding a fine balance between clinical, ethical and legal considerations. Even with the best of intentions and the best of processes, dialogue and decision-making can be impeded by competing interests and subsequent disagreement.

Using a clinical scenario from practice involving critical illness at the end of life, this workshop aims to explore the multiple strands of interest and concern that necessarily inform any decision to treat or not to treat. The workshop will provide opportunities for discussion of questions including:

1. How are patients' interests and preferences identified and balanced against competing demands for limited resources?
2. What weight should be given to clinical opinion where a patient presents with the hopeful expectation of therapy, yet caregivers are ambivalent concerning the benefit of treatment?
3. In the case of intractable disagreement, who will be the final arbiter and on what grounds?
4. What kinds of institutional procedures protect patients' interests, provide transparency and meet the requirements of justice?

By engaging with these and related questions, the workshop hopes to generate discussion and sharpen our understanding of the issues that inform a difficult area of clinical medicine.

## HEALTH REGULATION

### Legal and ethical issues around regulating health professionals' hours of work

Bridget Cameron<sup>1</sup>, Dr Fiona McDonald<sup>2</sup>

<sup>1</sup>Student, School of Law, Queensland University of Technology, QLD

<sup>2</sup>Lecturer, School of Law, Queensland University of Technology, Gardens Point Campus, Brisbane, QLD

The impact of health professional fatigue on patient safety and health care quality has been highlighted by reports, research and incidents where patients were harmed (McDonald, 2008). Accordingly, internationally governments have faced some pressure to regulate the working hours of health professionals to safeguard the public interest (Wiesing 2007), resulting in a variety of regulatory approaches to the issue (McDonald 2008). Any form of regulation in this area does not occur in a moral vacuum, it occurs in a context where each stakeholder in the process (health professionals, health professions, organisations providing health services and health systems managers) potentially stands in an ethically conflicted position. These conflicts may impact upon the regulation, policy or practices regulators put in place and the degree of adherence of the regulated to any regulatory scheme. This paper examines the role of government as a regulator, in particular the interface between regulation and the ethical challenges confronting governments around these issues.

### Compatibility of pharmacy ownership structures with health reform

Dr Laetitia Hattingh

School of Pharmacy, Gold Coast Campus, Griffith University, QLD

Pharmacy ownership in Australia is mainly restricted to pharmacists and the number of pharmacies that a pharmacist may own is regulated. Although ownership legislation falls under state and territory control, Pharmacy Location Rules are administered by the Commonwealth Government. Ownership legislation and structures are therefore multi-tiered and complicated.

The regulation of pharmacy ownership has been a topic of discussion for decades, often causing tension amongst the various role players as there are differing opinions as to who should be allowed to own a pharmacy, whether ownership should be opened to non-pharmacists, and the level of location control required.

Although the legislation in the various jurisdictions prescribe the number of pharmacies that one pharmacist can own or co-own, it is possible for one pharmacist to own up to 30 pharmacies across a number of jurisdictions. There have subsequently been claims that the current structure favours the pharmacy profession and serve to protect the retail pharmaceutical distribution industry, creating a monopoly for pharmacy owners.

The discussion of the regulation of pharmacy ownership should be open to dialogue in an effort to balance the need for regulatory control against changes in Australia's health and competition policies. Pharmacy ownership regulation is indeed complicated and should involve consideration of a range of issues such as public safety and the need to have minimum standards of practice in place, timely access to medicines at affordable prices, the financial attractiveness and viability of investing and owning a pharmacy and the Government's proposed primary health care objectives.

## MAX CHARLESWORTH PRIZE IN BIOETHICS WINNER

### Personalised Medicine in the Age of Neo-Liberal Health Care

Jacqueline Savard

*M Beth (Honors) - The Centre for Values, Ethics and the Law in Medicine (VELiM), The University of Sydney, Medical Foundation Building, K25, Level 1, 92-4 Parramatta Rd, Camperdown, NSW*

In recent years we have seen a shift in health care aims and goals along with a new approach to health care, an idea of personalised medicine. Personalised medicine flourishes in the current neo-liberal health care landscape, where the commercialization of the body, genetic knowledge and health has encouraged individual citizens to be active and autonomous agents in the pursuit of and maintenance of their state of good health. The argument is that these interacting social ideas about how one can best access, organize and receive health care have created both a commercial and social need for personalised medicine. In this paper I critique the emergence of personal medicine by examining the ways in which personalised medicine is already impacting upon health and health care delivery.

## RESEARCH ETHICS 2

### What are the expectations, hopes and futility of human research ethics review processes?

**Professor Colin J. H. Thomson**

*Graduate School of Medicine, University of Wollongong, Wollongong, NSW*

The current structure and processes of human research ethics review began in the 1970's when Australia followed the United States' lead in establishing a process of prior ethics committee review for any medical research that involved human participants.

The United States lead was triggered by disclosure of the infamous Tuskegee syphilis study conducted for forty years without sound scientific basis and without consent from any of the subjects, many of whom died. Australia had no such basis but followed suit – as did many developed nations.

In the most recent decade of its 40 year history, the review and approval system has been extended to research in disciplines that use methodologies and have histories starkly different from those that triggered its initiation. This has exposed the system to fresh criticism of its futility to assure its stated aim of protecting the welfare of research participants.

In responding to these criticisms, this paper explores the expectations the system has of its users: researchers, institutions and committee members; the hopes it has for its beneficiaries and seeks to assess the extent (if any) of the futility of its use for any human research.

### Navigating between hope and expectation in research – A cautious approach to Hans Jonas' 'identification principle'

**George F. Tomossy**

*Senior Lecturer, Macquarie Law School*

Justifying research involving human subjects remains a central question in medical ethics. Traditionally, this has been done on the basis of furthering the advancement of science and human health. Amidst such an (arguably) noble social imperative, subjects continue to be called upon as research 'participants', premised upon the existence of a potentially conflated sense of altruism, duty and enlightened self-interest. The onset of commercial forces, which have transformed the nature of the research endeavour, however, has necessitated fresh scrutiny of the 'research imperative', including its underlying justifications (Callahan 2003; Tomossy 2008). To further advance this line of inquiry, an appeal to the 'identification principle', as presented by Hans Jonas (1969) in his seminal treatise on research ethics, provides renewed relevance. This paper will explore Jonas' proposition that subjects must 'identify' with the aims of research, as part and parcel of their informed consent, within the modern research setting amidst the current landscape of commercialisation, socially constructed legal and ethical fictions relating to informed consent, and the ever-present spectre of the therapeutic misconception. The notion (and an argument for the avoidance) of an 'altruistic conception' will be advanced.

While it could be argued that a subject's identification with epistemological or melioristic goals may be argued, this cannot be done in the case of commercial aims. Informed consent to participate in research should therefore also include consent to the aims of research, particularly when these are primarily commercial in nature.

## Surgical innovation as *sui generis* research: Managing expectations and implications

Mianna Lotz

*Philosophy, Macquarie University*

Successful innovative 'leaps' in surgical technique can contribute exponentially to surgical advancement, and thereby to significant health benefits for human patients.

Such 'leaps' often occur relatively spontaneously, without substantial forethought, planning or preparation. And it is this feature of surgical innovation that makes it resistant to classification as 'research', with all the attendant methodological and ethical obligations of planning, regulation, monitoring, reporting and publication. Yet there are strong grounds – both conceptual and pragmatic – for thinking that innovation ought indeed to be classified as research, albeit perhaps of a *sui generis* kind. This paper examines the implications of a '*sui generis* research' classification for surgical innovation, focusing in particular on whether specific forms of ethical review and oversight might be developed which are more amenable to the specificities of innovation in the surgical context, and more compatible with the needs and expectations of surgeon innovators.



## CLINICAL ETHICS 1

### Consent for progressing the injured patient to organ donor

Dr Judith Kennedy<sup>1</sup>, Dr Michael Kennedy<sup>2</sup>

<sup>1</sup>Adjunct Lecturer, School of History & Philosophy, University of New South Wales

<sup>2</sup>Conjoint Senior Lecturer, Department of Medicine, University of New South Wales

The desire to increase the availability of organs for transplantation has given rise to a significant shift in what hospital staff may do to the acutely injured patient who is a potential organ donor. By the term 'acutely injured patient' we mean the severely compromised patient who has made it into ICU and onto a respirator, but for whom it is known, from the time of initial presentation, that full recovery is impossible due to the nature of the injury. The shift is from holding off organ donation considerations until after such patients have died (the brain death scenario and standard 'removal of futile treatment' scenario) to, once it has been decided to let the patient die, facilitating a particular kind of death within a particular time-frame for organ transplantation purposes. Concomitant with this shift in practice, is lack of detail about it in organ donation material and voice being given to notions that are at odds with current understandings on consent such as signing on for the Organ Donor Registry is the same as consenting to pre-mortem organ preservation procedures; relatives not allowing organ donation to proceed is the same as over-ruling the patient's wishes and, in the absence of explicit refusal to donate, no consent for organ donation is the same as consent for organ donation. We examine bed-side consent in this milieu and the importance of routine reporting of all deaths that follow withdrawal of life support and, in particular, those deaths labelled "donation after cardiac death".

### New directions in organ transplantation – the role of patients' expectations in quality of life transplants

Ruby Catsanos

PhD Student, Macquarie University, NSW

The earliest organ transplants were reserved for patients facing imminent death and so were considered ethically justified despite low post-transplant survival rates. Subsequent advances in both surgical techniques and anti-rejection therapies led to an expansion of transplants beyond those classified as life-saving to encompass those that improve the quality and/or length of life. However, as these traditional transplants become routine, the field of non-life-saving transplants is expanding into controversial areas, such as hand, face and uterus transplantation. Recipients of these 'quality of life' transplants appear to be motivated by factors other than straightforward improvements in mortality or morbidity. Out of this situation has grown a potential tension between what is technically feasible and the hopes and expectations of some recipients. This paper traces the history of organ transplantation ethics from the early days of life-saving kidney and heart transplants through to morally complex and contentious hands, faces and uteri. The focus of the paper is to explore the question: What conception of 'best interests' underlies the push towards these kinds of quality of life transplants?

### Futile research? A philosophical analysis of the vertebroplasty debate

Dr Jane Johnson, Professor Wendy Rogers

Macquarie University

The point of medical research is to investigate the safety and efficacy of different treatments – to tell us what works, and provide the evidence for Evidence-Based Medicine. We expect research that will answer important questions and guide clinical decision-making. This assumption however can be problematic. In this paper we examine the ongoing and often heated debate about the merits or otherwise of percutaneous vertebroplasty as a treatment for painful osteoporotic vertebral fractures. In spite of the proliferation of research on this topic there is no agreement over its indications, safety or efficacy. Advocates for and against vertebroplasty are apparently talking (and researching) at cross purposes, perpetuating a long and costly stream of potentially futile research. We identify some of the philosophical and ethical issues at the heart of this debate, and make a number of suggestions about how to standardize and improve evidence gathering in order to prevent situations such as this one occurring again in the future.

## Severe traumatic brain injury: Obtaining consent for life saving but non restorative decompressive surgery

Stephen Honeybul<sup>1</sup>, Dr Kwok Ho<sup>2</sup>, Susan O'Hanlon<sup>1</sup>

<sup>1</sup>Department of Neurosurgery, Sir Charles Gairdner Hospital and Royal Perth Hospital, WA

<sup>2</sup>Department of Intensive Care Medicine and School of Population Health, University of Western Australia

**Aims:** The aim of this study was to assess whether objective assessment of the risk of an unfavourable outcome would influence healthcare workers' decision-making to recommend decompressive craniectomy for patients with severe traumatic brain injury (TBI).

**Methods:** A two-part structured interview, before and after knowing the predicted risks of unfavourable neurological outcomes at 6 months, was used to assess participants' recommendation to perform decompressive craniectomy for three patients who had very severe traumatic brain injury. Participants rated their preferences in different scenarios. A visual analogue scale (1-10) was used to assess the strengths of their opinions. The opinions of the participants before and after knowing the predicted risks of unfavourable outcomes were compared.

**Results:** Five hundred healthcare workers participated. The participants were significantly more likely to recommend decompressive craniectomy for their patients than for themselves (mean difference in VAS  $-1.5$ , 95% confidence interval  $-1.3$  to  $-1.6$ ). Patients preferences were more similar to patients who had advance directives. The participants' preferences to perform the procedure for themselves and their patients both significantly reduced after knowing the predicted risks of unfavourable outcomes, and changes in attitude were consistent across different specialties, amount of experience in caring for similar patients, religious backgrounds, and positions in the specialty of the participants.

**Conclusions:** Participants were influenced by the outcome data and it is debatable whether they would provide truly informed consent if they were the injured party.

## END OF LIFE

### Advance care planning and unrealistic expectations

Dr Peter Saul<sup>1</sup>, Julie Letts<sup>2</sup>

<sup>1</sup>John Hunter Hospital, NRMCC, Newcastle, NSW

<sup>2</sup>NSW Health, North Sydney, NSW

Planning in advance for an uncertain, sometimes unimaginable future is fraught with philosophical and practical difficulties. Attempts to promote advance care planning for patients with chronic disease often stumble over this difficulty, leading to reluctance to confront increasingly real and probable outcomes.

Recent research (Volandes 2009) showed that a video depiction of advanced dementia was influential both on the choices made by a group of elderly subjects, and on the stability of those choices over a period of time afterwards. This suggested the possibility that patients and their carers facing a future of advanced dementia may be better placed to make choices if given the opportunity to see advanced dementia on a DVD.

With this in mind, the DVD “Advance Care Planning – Making Choices for someone with Advanced Dementia” was funded by NSW Health with the aim of improving health literacy in this condition and thereby functioning as a decision aid for family and carers of a person with loss of decision making capacity and deteriorating health.

In this presentation, we propose to show a clip from this DVD to invite discussion on how best to approach this relatively new concept, and whether the introduction of video-based materials raises novel ethical questions.

### The ethical use of hope in health care

John Gruner

*Monash Centre for Human Bioethics*

How we use hope in health care warrants examination in bioethics as hope is a significant component of care. Empirical studies suggest hope has a therapeutic effect of its own.

In this paper I provide a working definition of hope, and argue that the therapeutic effect of hope does not necessarily justify the giving of false hope, or a carer giving hope itself.

I also develop an argument that in both Evidence Based Medicine (EBM) and Complementary Medicine (CM) the giving of false hope is a special moral harm. I argue that it is morally permissible for a carer to give grounds for hope, but that carers ought not and cannot give hope itself.

Health carers promise that they will be loyal to their patients and their patients’ best interests, and such care aims to assist patients maintain or evolve their unique autonomous journey through their life’s cycle. Therefore health carers should see themselves as providing knowledge and expertise to guide their patients to have ‘informed hope’.

## Do end of life care discussions mitigate medical futility?

Dr Heather Tan<sup>1</sup>, Dr Susan Lee<sup>2</sup>, Professor Margaret O'Connor<sup>3</sup>

<sup>1</sup>Palliative Care Research Team, Monash University, Frankston, VIC

<sup>2</sup>Palliative Care Research Team, Monash University, Frankston, VIC

<sup>3</sup>Vivian Bullwinkel Chair of Palliative Care Nursing, Monash University, Frankston, VIC

As part of a NHMRC funded project investigating end of life (EOL) decision making processes in a major metropolitan health service, a retrospective chart audit was undertaken of fifty randomly selected charts of patients who had died in the previous six months from chronic illnesses other than cancer. One consideration in the analysis of these data was evidence that EOL care discussions mitigated the possibility of futile medical treatment. As some patient notes were minimal it was not always possible to determine if EOL care discussions took place and if they had any impact on possible futile treatment. However in twenty cases it was evident that EOL care discussions had mitigated possible medical futility, while in six cases it seemed likely that futile treatment had taken place despite these discussions. Several factors were identified as being important in making it more likely that EOL care discussions would not mitigate medical futility. These included: slow or no agreement between medical staff and the patient (or their surrogate) about appropriate care; insufficient staff time for family discussion; the use of language open to multiple interpretations such as “comfort care” or “no aggressive treatment”; and discussion focusing on what would not be done and failing to explain what care would be applied. In these situations family distress was documented and staff reluctance and probable anguish evident. Despite the current attention to Advance Care Planning the bioethical question of who, and in what circumstances, decides what is futile treatment remains.

## The slippery slope and legalisation of voluntary euthanasia

Neil Francis

Chairman and CEO, YourLastRight.com Limited, Blackburn, VIC

Relevance: a paper that “Critiques notions of medical leadership, medical paternalism and good medical care in the context of providing futile care [or its alternatives],” and “assesses the legal complexities surrounding the provision of futile medical care [and its alternatives].”

Legalisation of one form or another of physician-aided dying is either in Parliamentary debate in or mooted for several Australian jurisdictions, sparking passionate debate amongst both healthcare workers and the general public.

The “slippery slope” is the most frequent argument given against legalisation of physician-aided dying. The foundations of the slippery slope will be outlined, and a literature review of research into it as it applies to aid-in-dying in the medical context will be discussed. Data from qualitative interviews conducted by the author in jurisdictions where physician-aided dying is legal, with arguments on both sides, will also be presented.

A critique of the evidence for and against the slippery slope will be presented, and its authenticity to denying an alternative to futile medical and palliative care will be suggested.

## Some conceptual issues in medical law and ethics

**Dr Andrew McGee**

*Lecturer, School of Law, Health Law Research Program, Queensland University of Technology, Brisbane, QLD*

This presentation will focus on one conceptual issue, a recent argument advanced by Agata Sagan and Peter Singer in the context of their case for the permissibility of embryonic stem cell research. Famously, Singer has claimed that in debating the issue of the moral status of the embryo or the foetus, we must choose our terms carefully in a way that does not prejudice the substantive issues at stake. The answer to these deep questions, he says, “cannot depend on a stipulation about how we shall use words”. However, recent arguments advanced by Sagan and Singer concerning the applicability of the concept of potentiality amount precisely to a stipulation about how that word should be used, and therefore undermines their otherwise important case. My aim in the presentation is to expose this problem and to show how, more generally, Singer’s arguments and the arguments of many other bioethicists, often amount to a recommendation of different linguistic conventions from which they derive substantive conclusions, rather than the neutral account of the nature of the embryo they purport to be offering. My argument will be that, once these manoeuvres are exposed, the way is clear for genuine progress in the debate.

## Patient autonomy and refusal of life-sustaining treatment: Conflicts of ethics and law

**Neil Francis**

*Chairman and CEO, YourLastRight.com Limited, Blackburn, VIC*

Relevance: a paper that “Critiques notions of medical leadership, medical paternalism and good medical care in the context of providing futile care [or its alternatives],” and “assesses the legal complexities surrounding the provision of futile medical care [and its alternatives].”

Informed consent and respecting patient choice are established tenets in contemporary medical practice. But what happens when a patient or substitute decision-maker requests withdrawal of treatment that is life-sustaining?

Until recently, the law has been opaque, leaving doctors and institutions at risk of prosecution for murder or assisted suicide if they were to comply with the request. Or is the doctor/institution at risk of prosecution for committing medical trespass if they fail to withdraw medical intervention as requested? Who ultimately decides what is in the patient’s “best interests”? In a contest of differing moral and legal views about whether medical or palliative care is futile in a particular case, which shall prevail? Who are the recognised decision-makers in cases of patient competence and non-competence, and what is the scope of decisions they are empowered to make?

The judgements of crucial Supreme Court cases from Western Australia, Victoria, NSW, and the ACT will be discussed, along with implications for practitioners.

## Who can refuse life-sustaining treatment on behalf of an adult who lacks decision-making capacity? Legal, ethical and practical challenges arising from inconsistent powers of substitute decision-makers

Associate Professor Ben White<sup>1</sup>, Professor Lindy Willmott<sup>1</sup>, Associate Professor Malcolm Parker<sup>2</sup>,  
Professor Colleen Cartwright<sup>3</sup>

<sup>1</sup>Health Law Research Program, Faculty of Law, Queensland University of Technology, QLD

<sup>2</sup>School of Medicine, University of Queensland, QLD

<sup>3</sup>Foundation Professor of Aged Services, Director of the Aged Services Learning and Research Centre, Southern Cross University

Decisions to stop or not commence life-sustaining medical treatment are significant ones because the death of an individual will follow. Where a person has capacity to make health care decisions, his or her decision not to receive treatment is not controversial, either legally or ethically. A person's right to make such a decision is recognised as arising from a competent individual's right of self-determination. The situation is more complex, legally, ethically and practically, where the person involved lacks capacity to make such decisions.

This complexity is compounded by inconsistent decision-making powers granted to various substitute decision-makers. Guardianship legislation exists in all Australian States and Territories to facilitate health care decisions being made on behalf of an adult who lacks capacity. The statutes provide for such decision-makers to be authorised in different ways – appointment by a Tribunal or Board, by the individual him- or herself before losing capacity, or by reason of his or her relationship with the individual. Depending on the particular jurisdiction, the substitute decision-maker may have different powers depending on the nature of the appointment. This difference is particularly significant in the context of decisions to refuse life-sustaining treatment because some substitute decision-makers have a clear power to refuse such treatment, and some do not. This divergence raises the question of whether it is appropriate for some substitute decision-makers, but not others, to have this power. This paper explores the legal framework in three Australian jurisdictions, Queensland, New South Wales and Victoria, as well as ethical and practical considerations that arise from this question.

## Patient information and the ethical operation of advanced care directives

Noeline Monaghan

*Rehabilitation Studies Unit, Sydney Medical School, The University of Sydney, NSW*

**Introduction:** It is a legally accepted principle that competent adults have the autonomous right to consent to or to refuse treatment. Advance directives (ADs) are instructions about future health care. They are intended to operate if capacity is lost. ADs often include stipulations about refusal of treatment in certain contingencies. Case law and statutes affect the operation of ADs within Australia and attempt to incorporate ethical principles especially that of autonomy.

**Methods:** This presentation considers the impact of four recent Australian Court cases, the principle of autonomy and the consequences of refusal on the ethical operation of advance directives.

**Results:** For consent to treatment to be valid, the patient's decision must be based on full information, including treatment risks and benefits. In contrast, under current Australian common law, refusal of medical treatment is valid even when based on incorrect information. A valid refusal may be based upon religious, social or moral grounds, or even no apparent rational grounds.

A recent case, *Brightwater Care Group (Inc) v Rossiter* [2009], described the circumstances where it is feasible to ensure that the patient is given full information about the consequences of decisions to discontinue treatment. This view is consistent with the views in English and Canadian cases where emphasis was placed on the need for an informed decision to discontinue life support.

**Conclusion:** Information would enable people drafting an AD to make better decisions and provide clear instructions for example. the provision of analgesics for sedation and pain relief as death approaches.



## REPRODUCTIVE TECHNOLOGIES

### Creating 'saviour siblings': Bringing hope, saving life, and causing harm?

Dr Malcolm K. Smith

*Lecturer, School of Law, Queensland University of Technology, Brisbane, QLD*

Over the past decade there have been a number of families who have utilised assisted reproductive technologies (ARTs) to create a tissue-matched child, with the purpose of using the child's tissue to cure an existing sick child. This inevitably brings such families a sense of hope as the ultimate aim is to overcome a family health crisis. However, this specific use of reproductive technologies has been the subject of significant criticism, most of which is levelled against the potential harm to the 'saviour' child. Families seeking to access reproductive technologies in this context are therefore required to justify their motives to an ethics committee in order to establish, amongst other things, whether the child will suffer harm once born.

This paper explores the concept of harm in the context of conception, focusing on whether it is possible to 'harm' a healthy child who has been conceived to save another. To achieve this, the paper will evaluate the impact of the 'non-identity' principle in the 'saviour sibling' context, and assess the existing body of literature which addresses 'harm' in the context of conception. As will be established, the majority of such literature has focused on 'wrongful life' cases which seek to address whether an existing child who has been born with a disability, has been harmed. Finally, this paper will distinguish the harm arguments in the 'saviour sibling' context based on the fact that the harm evaluation concerns the 'future-life' assessment of a healthy child.

### Different hopes for health care budgets: Distributing assisted reproductive technology to women of different ages

*Dr Drew Carter, Amber Watt, Dr Jason Gordon, The ASTUTE Health Study group  
School of Population Health and Clinical Practice, The University of Adelaide, SA*

What one hopes to achieve in any distribution of health care resources dramatically shapes what the final distribution will look like. We illustrate this by examining what four different distributive hopes (or aims) commend in one hypothetical scenario.

Six cycles of publicly funded assisted reproductive technology (ART) must be distributed between a younger and an older woman. For these two women, successive ART cycles offer different – and differently diminishing – benefits (considered as increases in the probability of a live birth). We demonstrate how a futile cycle factors into distribution of the six cycles. Foremost, we compare the diverse consequences of distributing in the hope of: (1) maximising the total benefit; (2) proportionally meeting need (defined by Anthony Culyer as the resources required to exhaust all capacity to benefit); (3) restoring health states to population averages; and (4) equalising final health states. In doing this, we differentiate four distributive hopes (or aims) and empower their assessment.

We also address the question of whether ART public funding should feature a female-age cut-off. In our hypothetical scenario, solely the distributive hope of maximising the total benefit supports such a cut-off. All other illustrated hopes commend equal or more funding for the older woman (pre-menopause, at least).



## When do Australians think women should be able to access late abortion?

Associate Professor Lachlan De Crespigny, Dr Dominic Wilkinson, Dr Thomas Douglas, Mr Mark Textor,  
Professor Julian Savulescu

1,050 Australians were asked whether they believed that doctors should face sanctions for performing late-abortion in a range of clinical and social situations. Stratification ensured good representation in this anonymous online survey. This study provides the first detailed survey of Australian attitudes to late-abortion.

There is community support for late-abortion being a woman's choice. In most of the wide range of circumstances a woman might choose to seek abortion, the majority of respondents supported access after 24 weeks gestation. There was relatively little support for professional sanctions against doctors.

Support for lawful access to abortion is higher when there are maternal or fetal complications than when there are personal reasons. But less than 50% of respondents indicated that a doctor should be sanctioned for performing an abortion after 24 weeks even when no medical reason for the termination.

Australians who nominate a religious affiliation are only slightly less likely to oppose sanctions than those who say they have no religion.

A simplistic division between 'pro-choice' and 'anti-abortion' does not accurately reflect the views of Australians. Individuals have nuanced views.

Professional public opinion research can have a major impact on government policy. Simple yes/no polls may give a misleading picture of public opinion. The more permissive attitude elicited when context is provided may carry over to other debates, such as euthanasia and producing stem cells.

Opinion surveys, no matter how robust, should not dictate law or policy. Such policies and laws should be grounded on good ethical analysis.

## Ethical issues raised by providing a cash incentive for long-acting contraception to addicted individuals

Jayne Lucke, Wayne Hall

*University of Queensland Centre for Clinical Research, Royal Brisbane and Women's Hospital Site, Herston, QLD*

Project Prevention is a US-based organisation that provides a financial incentive of around \$300 to individuals who are addicted to drugs if they agree to permanent or long-acting contraception. The organisation aims to reduce the number of infants who are exposed to illicit drugs because of their mother's addiction. It has already expanded into the UK and it was recently reported to be setting up in Australia (The Age, 20 October 2010). Project Prevention has been criticised for its eugenicist aims, for targeting poor women from minority groups, and for representing attempts to treat addicts as futile. I examine the ethical issues raised by Project Prevention and especially the impact that a substantial cash incentive may have on the ability of addicted individuals to give autonomous informed consent to undergo a procedure which, in the case of sterilisation, may remove any hope of having future children. The paper also examines some potential benefits of focusing on the sexual and reproductive health of addicted people. Finally, the paper will outline some recommendations to provide better contraceptive and drug treatment access to addicted people in the Australian healthcare context.

## SURGERY

### Neurotrauma and the rule of rescue

Stephen Honeybul<sup>1</sup>, Dr Kwok<sup>2</sup>, Professor Christopher Lind<sup>1,3</sup>, Professor Grant Gillett<sup>4</sup>

<sup>1</sup>Department of Neurosurgery, Sir Charles Gairdner Hospital and Royal Perth Hospital, Western Australia;

<sup>2</sup>Department of Intensive Care Medicine and School of Population Health, University of Western Australia

<sup>3</sup>School of surgery, University of Western Australia;

<sup>4</sup>Dunedin Hospital and Otago Bioethics Centre, University of Otago, Dunedin, New Zealand

**Objective:** To compare the healthcare requirements between two groups of patients who had had a decompressive craniectomy for traumatic brain injury and discuss the ethical issues regarding life saving but non restorative surgery

**Setting and subjects:** A Population based retrospective observational cohort study of one hundred and sixty four patients who had had either a unilateral or bifrontal craniectomy for traumatic brain injury in Perth, Western Australia between the years 2004 and 2009.

**Method:** Hospital ethics committee approval was obtained. Using the CRASH collaborators outcome prediction model, the outcomes of patients with a high predicted-risk of unfavourable neurological outcome >80% were compared to patients with a lower predicted-risk of unfavourable outcome (<80%). Categorical and continuous variables with skewed distributions were compared by chi-square and Mann-Whitney test, respectively

**Results:** At eighteen month follow up, of the forty three with a higher predicted risk only six had returned home. Three of these patients were severely disabled and required twenty four hour care from either parents, partners or both. Of the one hundred and twenty one with a lower predicted risk, one hundred and two (84%) were adjudged to have made a good recovery and had returned home. Only nine (7%) required nursing home care and one patient remained in rehabilitation.

**Conclusions:** When considering life saving but non restorative intervention the discussion regarding realistic outcome cannot be dichotomised into simply life or death. Similarly the utility of the procedure cannot be rationalised on a mere cost benefit analysis.

A compromise has to be reached to determine at what point either the likely outcome would be unacceptable to the person on whom the procedure is being performed or the social utility gained from the rule of rescue intervention fails to justify the utilitarian value of resource allocation.

### Hope and expectation in surgical innovation

Professor Tony Eyers

*Professor of Ethics in Surgery and Medicine, Australian School of Advanced Medicine, Macquarie University, NSW*

This paper will revisit some past experiences with the introduction of new operations into surgical practice, giving regard to the following particular view of the process. At the outset, all expectations of a new surgical intervention amount to little more than hope; the expectations become realistic only with the acquisition of experience. But hope is necessary for innovation to occur in the first place. The hoping process has various participants; importantly the surgeon, the patient and the patient's family. The hopes of these three have a lot in common, but each adds an individual dimension. Perhaps they fuel one another, but the protagonists can become over-optimistic, and this over-optimism has often been difficult to dispel, despite considerable experience with the procedure. The learning curve of the new procedure involves the honing of skills, equipment and teamwork, but it also involves encountering the unexpected, and devising algorithms to adapt. That there will be human casualties is inevitable. Not all innovations will be successful. Or successful all the time. Or successful at first. Many hopes will not be realised.

At present, systems of oversight for surgical innovation are evolving. Those called upon to make a decision seem little troubled by innovation when the hope it carries is the only hope; when there is no alternative (non-futile) treatment available. However it is difficult to sit in judgment when equipoise exists between an innovation and an established line of treatment. Not only is this problem experienced by committees approving innovative projects, but also by the equivalent of data safety monitoring committees watching the learning curves. Perhaps the answer lies in valuing hope for hope's sake. In accepting that risk mitigation may be beyond the committees' brief. In looking instead for evidence of altruism, coupled with structures to ensure that lessons are learned when things do not turn out as hoped. Risk-taking behaviour is at the core of human progress.

## The ethics of surgical innovation: Surgeons' perspectives

Dr Aydin Pourmoslemi, Dr Mianna Lotz

*Philosophy department, Macquarie University, NSW*

Innovation is the cornerstone of surgical advancement. Yet innovation in surgery comes with risks, most significantly for patients but also, relatedly, for surgeons and their institutions. Surgeons themselves have a critical role to play in the management of the ethical challenges that may arise in surgical innovation. It is surprising, therefore, that to date there has been little systematic study worldwide – and none within Australia – of surgeons' perspectives in relation to the ethical issues posed by innovative surgical practices. In this paper we report on preliminary findings from our current qualitative study into Australian surgeon's understanding of the ethical dimensions of innovative surgery. The study explores surgeons' definitions of innovative surgery, their views of the potential ethical challenges and issues raised by surgical innovation, and their attitudes toward the current mechanisms of ethical oversight and management of innovative surgical practices and procedures.

## Decompressive craniectomy for severe traumatic brain injury: When does surgical intervention become futile

Stephen Honeybul<sup>1</sup>, Dr Kwok Ho<sup>2</sup>, Professor Christopher Lind<sup>3</sup>, Professor Grant Gillett<sup>4</sup>

<sup>1</sup>*Department of Neurosurgery, Sir Charles Gairdner Hospital and Royal Perth Hospital, Western Australia*

<sup>2</sup>*Department of Intensive Care Medicine and School of Population Health, University of Western Australia*

<sup>3</sup>*Department of Neurosurgery, Sir Charles Gairdner Hospital and Royal Perth Hospital, Western Australia School of surgery, University of Western Australia*

<sup>4</sup>*Dunedin Hospital and Otago Bioethics Centre, University of Otago, Dunedin, New Zealand*

A number of studies have shown that decompressive craniectomy can reduce intracranial pressure and may improve outcome for patients with severe head injury. However whilst a number of patients achieve a good functional recovery, many are left severely disabled. To what degree that outcome is acceptable to those patients is difficult to establish. Up until now outcome prediction has been difficult.

This cohort study assessed the long-term outcome of neurotrauma patients who had a decompressive craniectomy for severe head injury in Western Australia between 2004 and 2008. The web-based outcome prediction model developed by the CRASH trial collaborators was applied to the cohort. Predicted outcome and observed outcome were compared.

Among a total of 1,786 adult neurotrauma patients admitted during the study period, 147 patients (8.2%) had a decompressive craniectomy. A significant number of patients achieved a good long term functional recovery however; once the prediction of an unfavourable outcome was greater than 80% most of those patients that survived were observed to be severely disabled at eighteen month. This raises important ethical issues that need to be considered prior to performing a decompressive procedure for someone with severe traumatic brain injury.

### **“I just love these sessions:” What should clinical ethics consultations hope to achieve?**

**Dr Clare Delany, Georgina Hall**

*Children's Bioethics Centre, Royal Children's Hospital, Melbourne, VIC*

The refrain 'I just love these sessions' is one that is often heard from health professionals after attending clinical ethics discussions in a large paediatric hospital. In this paper we identify key features of clinical ethics consultations held in one hospital over a period of 2 years. We suggest possible reasons for this common refrain, based on insights and documentation by the attending authors. Our observations and analysis of the discussions provide a counter argument to those who suggest that clinical ethics discussions may interfere with the doctor-patient relationship, and further erode doctors' professional autonomy.<sup>1,2</sup> The positive comments are made irrespective of the outcome of the meeting being a clear decision or a discussion about complexity and multiple perspectives.

Our documented features of the sessions and the observations (hopes and satisfaction) of attendees both point to the importance of the clinical ethicist's role to construct a basis for cooperation and engagement in dialogue, identify shared values and contribute to a rational discussion. We conclude the sentiment 'I just love these sessions' emerges from clinical ethics discussions that are collaborative, affirm and augment professional autonomy and assist clinicians to learn a language and set of concepts that clarify the moral dimensions of their work. It does not derive from being told from an authoritative source, what to do or say in clinical practice. The satisfaction and hopes for what a clinical ethics discussion should and could achieve derives from a much richer notion of clinical ethics discourse.

<sup>1</sup>Gillon R. *Clinical ethics committees—pros and cons*. *Journal of medical ethics*. 1997;23(4):203.

<sup>2</sup>Sokol DK. *Observations: Ethics Man: The unpalatable truth about ethics committees*. *BMJ*. 2009;339:b4179.

### **An ethical review of measures of effectiveness and success for retention of rural health professionals: When do we know when we have it right?**

**Dr Fiona McDonald<sup>1</sup>, Dr Christy Simpson<sup>2</sup>**

<sup>1</sup>*School of Law, Queensland University of Technology, Brisbane, QLD*

<sup>2</sup>*Department of Bioethics, Dalhousie University, Canada, Nova Scotia, Canada*

Many claims are made about the effectiveness of various strategies for retaining rural health professionals. In a recent article, Buykx, Humphreys, et al (2010) conducted a systematic review of retention strategies for health professionals in rural areas to measure their 'effectiveness'. This led us to reflect on what we mean by 'effectiveness' and/or 'success' in this context, as these terms are often used interchangeably yet may have different moral implications. Using an ethics framework, this paper will begin to, first, unpack the concepts of effectiveness and success. For example, is effectiveness appropriately measured in terms of the financial impact of different retention strategies? Should success be measured by how long a health professional stays in a rural community? Second, we ask who should define what success or effectiveness means. Accordingly, we review the concepts of effectiveness and success at the macro (government), meso (community) and micro (health professional) levels with respect to retention. For example, from a national or state level, success may be viewed very differently as driven by health policy imperatives than from a community perspective which is driven by the community's need for accessible health care. Engaging with these concepts at each level helps lead us towards a more comprehensive, integrated understanding of the ethical challenges related to how we measure the 'effectiveness' and 'success' of retention strategies. This understanding, coupled with being as clear as possible when we talk about 'effectiveness' and 'success' may lead to more robust policies for the retention of health professionals in rural areas.

## **A qualitative study of communication styles in discussions with critically ill patients**

Sharyn Milnes<sup>1</sup>, Charlie Corke<sup>2</sup>, Trisha Dunning<sup>1,2</sup>

<sup>1</sup>*Deakin University School of Medicine*

<sup>2</sup>*Barwon Health*

Acute hospital in-patients with complicated co-morbidities are often admitted to the intensive care unit (ICU) following an acute episode, based on a decision of the patient's best interest by resident medical staff. In these situations patients rarely have an opportunity to understand the consequences of an ICU admission relevant to their own understanding of what is their medical and personal best interest.

**Study Objective:** To discover differences in communication methods between experienced ICU nurses, ICU consultant and resident medical officers working in ICU.

**Methods:** Six health care professionals from each of the study groups were asked to discuss admission to ICU with a patient (medical actor). The patient had an admission diagnosis of disseminated bowel cancer who was currently suffering respiratory difficulties and hypotension of unknown origin. In-depth interviews were recorded and transcribed for thematic exploration and description.

**Results:** Although the discussions were unscripted, each interview followed a very similar course. Given the similarity in interview progression and content, clear themes emerged between each of the groups. The over-arching theme that came across as the defining difference between each professional group's discussions is labelled "Professional Agenda". The agenda for each group was generic and this in turn informed the direction of the discussion. Further sub-themes emerged that were informed and influenced by the agenda particular to the professional group. The sub-themes were: dealing with hope, setting patient goals, ambiguity and decision-making relationship. No differences were observed between genders and age was not considered as a measured variable.

## **Redefining the doctor-patient relationship: The central role of trust in experimental treatment**

Zara Bending

*Macquarie University*

Following the British tradition, the doctor-patient relationship is characterised under Australian Law as a contractual and commercial transaction in which each party is the holder of an interest.

The aim of this paper is to examine the plausibility of this conception in light of all the circumstances relevant to this relationship within the legal, sociological and professional ethics discourse regarding experimental treatment. I will claim that this conception is flawed, because it cannot account for the central role of the trust that doctors owe to patients. Furthermore I will propose an alternative view, namely, the 'Trust Model'. The main thesis of the 'Trust Model' is that aspects of the doctor-patient relationship are fiduciary in nature. While the contractual view places emphasis on shared medical decision-making and the autonomy of both patient and treating physician, the trust model acknowledges the power imbalance manifested by the doctor's position to give advice, and patient's reliance on it.

In essence, this paper will argue that the marketplace assumption of 'two wary bargainers' is not a legitimate way of characterising the doctor-patient relationship, and that reform is required to reflect this reality.

## GENETICS

### **Personalised medicine and healthcare: The expectations versus the reality of direct-to-consumer genetic testing**

Jacqueline Savard

*PhD candidate, Centre for Values, Ethics and the Law in Medicine, University of Sydney*

Health care in developed nations is increasingly moving towards a personalised medicine approach. This approach is promoted by advances in personal genomics, by the increased coupling of genetic polymorphisms with medical treatment and by the market imperatives which sell genetic tests as a means by which individuals can “know” and “control” their health and illness. Unfortunately, there is often a discrepancy between expectations of what genetic tests may tell you and what information or power they actually deliver. Indeed, it is quite unclear as to whether the expectations and promises of such a technology equate with what the public needs and wants from their healthcare system. As a consumer of personal genome testing, I offer an auto-ethnographic look at personal genome testing – documenting my expectations of the technology, what my experience of being tested was like and how – for me, the results can be used both as an argument in favour of personalised medicine and as a warning regarding what might be lost in the rush to genomics.

### **Court-ordered submission to genetic testing: Balancing individual expectations and health care rights with the due administration of justice**

Associate Professor Tina Cockburn<sup>1</sup>, Bill Madden<sup>2</sup>

<sup>1</sup>Associate Professor, School of Law, Queensland University of Technology, Brisbane, QLD

<sup>2</sup>National Practice Group Leader, Medical Law Slater & Gordon, Adjunct Fellow, School of Law, University of Western Sydney, Sydney, NSW

Patients entrust themselves to the medical care of doctors when they are in a vulnerable state due to illness or when seeking to maintain their health. Accordingly, doctors have a responsibility to use their special knowledge and expertise to improve and maintain the health of their patients. Doctors are guided in their conduct with patients by ethical principles, including autonomy and privacy. These ethical obligations are enshrined in the Australian Medical Council's Good Medical Practice: A Code of Conduct for Doctors in Australia. Patients' rights to privacy in relation to their medical information and autonomy in the sense of full participation and inclusion in decisions and choices about health care have been expressly included in the Australian Charter of Health Care Rights. Accordingly, all patients are entitled to have a reasonable expectation that their autonomy and privacy will be respected when they engage with the Australian health care system. However, these fundamental expectations of autonomy and privacy may be eroded when a person seeks to make a compensation claim following injury. This situation arises because, in the interests of the due administration of justice and a fair trial, in cases where a person's physical or mental condition is relevant to the litigation, the courts have powers to make orders requiring plaintiffs to disclose medical information and / or to undergo a medical examination (including tests or medical procedures). This presentation considers how the law balances the expectations and rights of the various stakeholders, through an analyses of recent cases, including cases in which individuals have been required to submit to genetic testing.

## Elements of biohype in nutrigenetics clinical research literature: Are the promoted expectations realisable?

Raphaëlle Stenne, Thierry Hurlimann, Béatrice Godard

*University of Montreal, Bioethics Programs, C.P.6128, Succursale Centre-Ville, Montreal QC, Canada*

Nutrigenetics is the study of the impact of genetic variations on the metabolism of dietary intake and the resulting phenotype. It is a field that emerged after the completion of the human genome project. Its development is associated with several expectations. These are, among others, prevention of diseases in healthy people that have genetics susceptibilities and the development of personalized dietary interventions. It appears that some of these expectations are introduced in scientific literature even with the presence of several methodological limitations known to nutrigenetics clinical research (NCR). In order to acknowledge if NCR literature is a medium of overexpectation, a phenomenon also known as biohype, we identify through a semantic analysis publications that contain interpretive claims – claims that are explicitly referring to broader applications of research findings. We then compare them with the intrinsic methodological limitations that may affect the potential medical applications deriving from these findings. We observe that interpretive claims are made to support personalized medicine development, public health interventions and health promotion. On the other hand, we find that claims are made in studies containing methodological limitations arising from study designs, dietary assessment tools, sample size and genetic information enquiries. Even though these actual limitations are well recognized by authors, it does not prevent the formulation of interpretive claims. In such a context, are the promises associated to the development of nutrigenetics premature or overestimated? Biohype is not a neutral phenomenon; it can have significant impacts on the development of NCR and the public health agenda.

## PLENARY PANEL

### The Advance Care Directives draft framework – will it meet expectations?

**Facilitator:** Julie Letts<sup>1</sup>

**Presenters:** Jean Murray<sup>2</sup>, Simon Towler<sup>3</sup>

**Panel:** Margaret Brown<sup>4</sup>, Ian Kerridge<sup>5</sup>, Bernadette Richards<sup>6</sup>

<sup>1</sup>Advance Care Directives Working Group member and Principal Policy Analyst, Health Research and Ethics Branch, NSW Health, North Sydney NSW

<sup>2</sup>Advance Care Directives Working Group writer/researcher and Senior Lecturer, School of Medicine, Flinders University, Adelaide SA

<sup>3</sup>Advance Care Directives Working Group Chair and Chief Medical Officer, WA Health, Subiaco WA

<sup>4</sup>Adjunct Research Fellow, Hawke Research Institute, University of South Australia, Underdale SA

<sup>5</sup>Haematologist, Westmead Hospital, Associate Professor in Bioethics and Director of the Centre for Values, Ethics and the Law in Medicine, University of Sydney, Sydney NSW

<sup>6</sup>Senior Lecturer, Law School, University of Adelaide, Adelaide SA, [bernadette.richards@adelaide.edu.au](mailto:bernadette.richards@adelaide.edu.au)

Recognising the diversity of legislated and common law advance directives around Australia, in 2008 Australian Health Ministers required a Working Group to develop nationally consistent guidelines for Advance Care Directives. In late 2010 the draft Advance Care Directives Framework was released for consultation [accessible at <http://www.hwlebsworth.com.au/acdframework>]. Many AABHL members received the consultation draft and several provided submissions. At the time of abstract submission, the Framework was finalised but not released.

The Framework was drafted by a cross-jurisdictional Working Group of the Clinical, Technical and Ethical Principal Committee of the Australian Health Ministers Advisory Council, chaired by Dr Simon Towler, Chief Medical Officer of WA Health. It resulted from extensive research and consultation and built upon work already done in several jurisdictions. The Framework scope includes ACDs that appoint a substitute decision maker and those that record personal preferences and instructions, and recognises that Australian ACDs are not limited to medical decisions at the end of life but cover a broad range of health and personal decisions and apply to any period of impaired decision making capacity.

Advance Care Directives deal with hope, expectations and futility. They are written and applied in hospital, community and institutional settings, and in peoples' homes. They are completed in the hope and expectation that care provided during periods of impaired decision making capacity and at the end of life will accord with personal values and preferences. People who complete ACDs sometimes seek all available medical interventions, whether futile or not, and sometimes seek to avoid intrusive interventions at the end of life, whether beneficial or not.

The presenters will explain the rationale and process of the development of the Advance Care Directives Framework and summarise the key intended outcomes. The panel will be invited to comment from a range of perspectives: Ian Kerridge from the clinical perspective, Margaret Brown from the community perspective and Bernadette Richards from the legal perspective. The session will then be opened for questions and discussion from the floor.



## Delegate List

Title	First Name	Last Name	Organization	State/Country
Ms	Marie	Alford	Alzheimer's Australia	SA
Prof	Saud	Alrasheed	King Abdullah Medical City	SAUDI ARABIA
Prof	Philip W	Bates	Sir Owen Dixon Chambers	NSW
Prof	Francoise	Baylis	Dalhousie University	CANADA
Miss	Zara	Bending	Macquarie University	NSW
Miss	Neera	Bhatia	Deakin University	VIC
Dr	Patricia	Bolster	"Childrens Hospital, Westmead"	NSW
Mr	Craig	Bossie	Chaplaincy Services	SA
Mrs	Sandra L	Bradley	Flinders University	SA
Prof	Annette	Braunack-Mayer	University Of Adelaide	SA
Dr	Michael	Briffa	Royal Adelaide Hospital	SA
Ms	Margaret	Brown	"Hawke Research Institute, University Of SA"	SA
Ms	Bridget	Cameron	QUT Faculty Of Law	QLD
Dr	Nunzia	Cannovo	Ethics Committee Of Federico II University	ITALY
Dr	Drew	Carter	School Of Population Health & Clinical Practice	SA
Prof	Colleen	Cartwright	"SCU, Health and Well-Being Research Cluster"	NSW
Mrs	Ruby	Catsanos	Macquarie University	NSW
Dr	Peng Tjun	Choy	Metro South HSD Human Research Ethics Committee	QLD
A/Prof	Tina	Cockburn	QUT Faculty Of Law	QLD
Dr	Betty	Collerson	Queensland University Of Technology	QLD
Dr	Ray	Cook	Department of Health & Ageing	ACT
Dr	Wendy	Corfield	Queensland Health	QLD
Dr	Andrew	Crowden	University Of Melbourne	VIC
Mrs	Katherine	Curnow	University Of Queensland	QLD
A/Prof	Lachlan	De Crespigny	Oxford Uehiro Centre For Practical Ethics	VIC
A/Prof	Sheryl	De Lacey	Flinders University	SA
Mrs	Sandy	Dealy	Redcliffe Hospital	QLD
Dr	Clare	Delany	"Children's Bioethics Centre, Royal Children's Hospital"	VIC
Ms	Joanna	Dellit	Peninsula Health	VIC
Ms	Jane	Dennis	Prince Of Wales Hospital & Sydney Eye Hospitals	NSW
Dr	Mark	Deuble	Brisbane South Palliative Care Service	QLD
Prof	Jocelyn	Downie	Dalhousie University	CANADA
Ms	Julie	Duffield	"Child, Youth & Women's Health Service"	SA
Dr	Jaklin	Elliott	Cancer Council Australia	SA
Prof	Tony	Eyers	Macquarie University	NSW
Mrs	Anne Marie	Fabri	Northern Health	VIC
Mr	Neil	Francis	YourLastRight.Com Limited	VIC
Dr	Ian	Freckelton SC	Barristers' Clerk Howells	VIC
A/Prof	Maher	Gandhi	Metro South HSD Human Research Ethics Committee	QLD
Dr	Nicole	Gerrand	University Of Newcastle	NSW
Prof	Lynn	Gillam	"Royal Children's Hospital, Children's Bioethics Centre"	VIC
Dr	Ben	Gray	Otago University Wellington	NEW ZEALAND
Mr	John	Gruner	Monash Centre For Human Bioethics	VIC
Ms	Emma	Harris	"Access Improvement Service, Centre For Healthcare Improvement"	QLD
Ms	Meg	Harward	Metro South HSD Human Research Ethics Committee	QLD
Ms	Anita	Hathaway	Griffith University	QLD
Dr	Laetitia	Hattingh	Griffith University	QLD
Dr	Barbara	Hayes	Bundoorra Extended Care Centre	VIC

Prof	Ken	Hillman	University Of New South Wales	NSW
Mrs	Christine	Hofmeyer	Lyell McEwin Palliative Care Service	SA
Dr	Anna	Holmes	Bioethics Centre University Of Otago/Otago Community Hospice	NEW ZEALAND
Mr	Stephen	Honeybul	Sir Charles Gairdner Hospital	WA
Dr	Fiona	Hum	Monash University	VIC
A/Prof	Theresa	Jacques	"ICU, The St George Hospital"	NSW
Dr	Jane	Johnson	Macquarie University	NSW
Mr	Yutaka	Kato	Osaka University Graduate School Of Medicine	JAPAN
Dr	Judith	Kennedy	University Of New South Wales	NSW
A/Prof	Ian	Kerridge	"Centre For Values, Ethics & The Law In Medicine"	NSW
A/Prof	Henry	Kilham	"Childrens Hospital, Westmead"	NSW
Ms	Antonia	Knifton	University Of Kent	NEW CALEDONIA
Dr	Vedantam Sampath		Kumar Peninsula Health	VIC
Ms	Beverley	Kurkowski	Metro South HSD Human Research Ethics Committee	QLD
Dr	Adam	La Caze	Metro South HSD Human Research Ethics Committee	QLD
Dr	Sarah	Lee	Keele University	UNITED STATES
Professor	Peter	Lee	"SCU, Health and Well-Being Research Cluster"	NSW
Dr	Richard	Lennon	Royal North Shore Hospital	NSW
Ms	Julie	Letts	"Research, Ethics & Public Health Training"	NSW
Ms	Gillian	Lewis	Department Of Health	SA
Dr	Wendy	Lipworth	University Of New South Wales	NSW
Dr	Mianna	Lotz	"Dept Of Philosophy, Macquarie University"	NSW
A/Prof	Jayne	Lucke	University Of Queensland	QLD
Prof	Roger	Magnusson	"Sydney Law School, University Of Sydney"	NSW
A/Prof	Joanna	Manning	"Faculty Of Law, University Of Auckland"	NEW ZEALAND
Dr	Fiona	McDonald	Queensland University Of Technology	QLD
Dr	Andrew	McGee	QUT Faculty Of Law	QLD
Dr	Eleanor	Milligan	Queensland Health	QLD
Ms	Sharyn	Milnes	Deakin University	VIC
Ms	Noeline	Monaghan	Rehabilitation Studies Unit Sydney Medical School	NSW
Mr	Ray	Moynihan	University Of Newcastle	NSW
Dr	Jean	Murray	Flinders University	SA
Dr	Sue	Nightingale	Hillmorton Hospital	NEW ZEALAND
Dr	John	North	Metro South HSD Human Research Ethics Committee	QLD
Dr	Karen	O'Connell	University Of Technology Sydney	NSW
Prof	Ian	Olver	Cancer Council Australia	NSW
A/Prof	Malcolm	Parker	University Of Queensland	QLD
Ms	Michelle	Parker	Wilmot Ltd	UNITED STATES
Prof	Ron	Paterson	"University Of Auckland, Faculty Of Law"	NEW ZEALAND
Prof	Thaddeus	Pope	Widener University School Of Law	UNITED STATES
Dr	Aydin	Pourmoslemi	Macquarie University	NSW
A/Prof	Kay	Price	University Of South Australia	SA
Dr	Alma	Rae	Canterbury District Health Board	NEW ZEALAND
Ms	Sonja	Read	Minter Ellison	QLD
Mrs	Bernadette	Richards	University Of Adelaide	SA
Ms	Gail	Roberts	Deakin University	VIC
Prof	Wendy	Rogers	Macquarie University	NSW
A/Prof	Richard	Roylance	Metro South HSD Human Research Ethics Committee	QLD
Dr	Sharon	Ryan	John Hunter Children's Hospital	NSW
Dr	Peter	Saul	John Hunter Children's Hospital	NSW
Miss	Jacqueline	Savard	"Centre For Values, Ethics & The Law In Medicine"	NSW

Dr	Brian	Sengstock	University Of The Sunshine Coast	QLD
Mr	Michael	Sinnott	Princess Alexandra Hospital	QLD
Prof	Loane	Skene	Melbourne Law School	VIC
Dr	Malcolm	Smith	Queensland University Of Technology	QLD
Dr	Andrew	Stacey	Middlemore Hospital	NEW ZEALAND
Mrs	Raphaëlle	Stenne	University Of Montreal	CANADA
Ms	Nikola	Stepanov	University Of Melbourne- Centre For Health & Society	VIC
Dr	Kimberly	Strong	“Centre For Values, Ethics & The Law In Medicine”	NSW
Dr	Heather	Tan	Monash University	VIC
Ms	Pauline	Thiele	Monash University	VIC
Dr	Garth	Thomas	Gabba Anaesthetic Services	QLD
Dr	Cordelia	Thomas	Wellington Office Of The Health & Disability Commissioner	NEW ZEALAND
Prof	Colin	Thomson	“University Of Wollongong, Graduate School of Medicine”	NSW
Mr	George	Tomossy	Macquarie Law School	NSW
Mr	Andrew	Took	Avant	NSW
Dr	Simon	Towler	Department Of Health	WA
Ms	Mabel	Tsui	Queensland University Of Technology	QLD
Dr	Andrew	Watkins	Mercy Hospital For Women	VIC
Dr	Karolyn	White	Macquarie University	NSW
A/Prof	Ben	White	Queensland University Of Technology	QLD
A/Prof	Dominic	Wilkinson	University Of Adelaide	SA
Ms	Kathryn	Williams	Department Of Health	SA
Prof	Lindy	Willmott	Queensland University Of Technology	QLD
Dr	Sarah	Winch	University of Queensland School of Medicine	QLD
Dr	Mark	Woodrow	Wesley Hospital	QLD

