

# AUSTRALASIAN ASSOCIATION OF BIOETHICS & HEALTH LAW **AND** NEW ZEALAND BIOETHICS CONFERENCE



Australasian Association of  
Bioethics & Health Law



UNIVERSITY  
of  
**OTAGO**  
*Te Whare Wānanga o Ōtago*  
NEW ZEALAND

St David Lecture Theatre Complex  
University of Otago | Dunedin | New Zealand  
21-23 November 2019

[aabhlncz2019.w.events4you.currinda.com](http://aabhlncz2019.w.events4you.currinda.com)

## CONFERENCE HANDBOOK 2019

# WELCOME

Haere mai! On behalf of the Organising Committee of the 2019 AABHL and New Zealand Bioethics Conference, we would like to welcome all of you to Dunedin, and to the conference.

This is the first time that the two conferences have been run together. But it made sense to do so, as the AABHL Conference was coming to Dunedin, where the NZ Bioethics Conference is generally held. The two conferences have, in addition, the same basic aim, which is to encourage reflection and debate on major bioethical and health law issues, in Australasia, and around the world.

The abstracts we received certainly suggested that there is a wide range of such concerns. Some topics – such as data use, and issues around the end of life – are particularly well represented, and are clearly exercising the minds of speakers from many different places. Other topics reflect significant issues in particular localities. As far as possible we have grouped papers on shared topics into streams in specific rooms. But we hope we've created enough time between presentations to allow people to move from one room to another if they so desire.

We are privileged to have six excellent plenary speakers. Two of the lectures they are giving are named. The Kirby Oration is named for The Hon. Michael Kirby AC CMG. Barry Poata Smith, Te Manu Kōrero is named for Barry Poata Smith QSM, who many of you will have known. There is a short piece in the programme which recognises, amongst other things, Barry's contributions to both the AABHL and NZ Bioethics Conferences. The name Te Manu Kōrero was suggested by John Broughton (kaumatua for the conference). The Māori terms literally mean the speech of the bird referring metaphorically to a great speech.

We're very grateful to the University of Otago for the use of this wonderful venue. It so happens that this is the 150<sup>th</sup> Anniversary of the founding of the University of Otago. We hope you have the time to enjoy the setting.

*Finally, thank you for attending, and we hope you find the conference engaging and enjoyable.*

*Neil Pickering  
Convenor, Australasian Association of Bioethics & Health Law & New Zealand Bioethics Conference*

## LOCAL ORGANISING COMMITTEE

**Neil Pickering**, Bioethics Centre, Dunedin NZ  
(Convenor)

**Corey Cunningham**, Bioethics Centre, Dunedin NZ

**Grant Gillett**, Bioethics Centre, Dunedin NZ

**Taryn Knox**, Bioethics Centre, Dunedin NZ

**Simon Walker**, Bioethics Centre, Dunedin NZ

**Janine Winters**, Bioethics Centre, Dunedin NZ

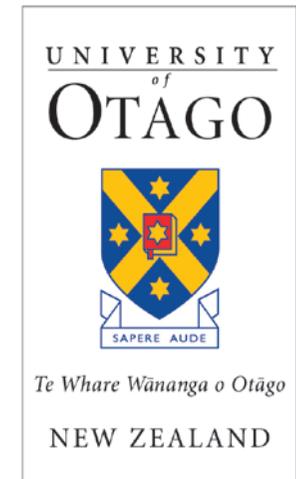
**Sally Boulton** Events 4 You Limited (Secretariat)



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# SPONSORS



Front page image of Tunnel Beach: Danilo Hegg, Opoho, Dunedin

# KEYNOTE SPEAKERS (in order of appearance)

## Professor Catherine Mills

Monash Bioethics Centre, Monash University, Australia



Catherine Mills is a Professor in the Monash Bioethics Centre. Her disciplinary background is philosophy, and her research addresses ethical issues in human reproduction, especially from the perspective of how new reproductive technologies impact on women. She also has expertise in feminist philosophy and aspects of Continental philosophy, particularly the work of Michel Foucault, and debates on biopolitics.

She is the author of three single author books, as well as numerous articles and book chapters. Her books are: *The Philosophy of Agamben* (2008), *Futures of Reproduction: Bioethics and Biopolitics* (2011) and *Biopolitics* (2018).

Recent funded projects include an ARC Future Fellowship (2012-2016) on responsibility in pregnancy. A current ARC Discovery Project (2017-2019) supports research on the ethical and legal issues raised by technologies that permit inheritable modifications to the human genome, such as mitochondrial replacement techniques and CRISPR-Cas9. An earlier ARC Discovery Project supported research on obstetric ultrasound and selective termination of pregnancy.

## Keynote Presentation:

**THURSDAY 21 November 1.45 pm – 2.45 pm**

### **Nuclear Families: mitochondrial replacement techniques and the regulation of parenthood**

Since mitochondrial replacement techniques (MRT) were developed and clinically introduced in the UK, there has been much discussion of whether these lead to children borne of 3 parents. In the UK, regulation of MRT has dealt with this by stipulating that egg donors in MRT arrangements are not genetic parents even though they contribute mitochondrial DNA to offspring.

In this paper, I examine the way that the Human Fertilisation and Embryology Act in the UK manages the question of parentage and consider the implications of this for the prospect of MRT in Australia. Tracing contradictions in the rationalisation of MRT, I argue that the Act remains tied to and protects the heteronormative family unit, redefining genetic parentage in terms of nuclear DNA. In effect, the UK regulation remains bound to a heteronormative imaginary in the process of making legally permissible a technology that challenges the heteronormative family structure. Looking to the possible introduction of MRT in the Australian context, I make a case for an approach to regulatory change that avoids such sleights of hand.

## Professor Joanna Manning

Faculty of Law, The University of Auckland, New Zealand



Joanna Manning is a Professor at the Faculty of Law, the University of Auckland, where she teaches and has published widely on issues of: health law, policy, and ethics; torts, including negligence; and accident compensation, particularly treatment injury. She is a contributing author of the textbook, Skegg and Paterson (eds), *Health Law in New Zealand* (Thomson Brookers, 2015) and the editor of *The Cartwright Papers: Essays on the Cervical Cancer Inquiry 1987-88* (Bridget Williams Books, 2009). She was the consumer representative on the Medical Practitioners Disciplinary Committee for approx 10 years, the lawyer member of the National Ethics Advisory Committee from 2005 to 2011 and the lawyer member of the Scientific Advisory Committee of the Heart Foundation NZ (2011-2014).

### Kirby Oration:

**THURSDAY 21 November 5.15 pm – 6.15 pm**

#### **“Fair, simple, speedy and efficient”? Barriers to access to justice in the Health and Disability Commissioner’s Complaints Process in New Zealand**

Given the absence of a civil damages action for personal injury, the Health and Disability Commissioner’s (HDC) complaints process occupies a pivotal role in New Zealand’s medico-legal regulatory arrangements. It is designed to address complainants’ non-financial motivations in making a complaint after an adverse event in their health care. Professor Manning asks whether the HDC complaints process accords its users, particularly complainants and consumers, acceptable and effective legal mechanisms for asserting their legal rights and securing just outcomes. The process is assessed against the original statutory aims of the complaints process (“fair, simple, speedy, and efficient resolution of complaints”). Quantitative and qualitative evidence is marshalled in support of the conclusion that unacceptable barriers to accessing justice are embedded in the complaints process, as currently designed and operationalised. Of particular note are the lack of any means for a complainant to seek review of the merits of a Commissioner’s decision to take no further action on a complaint, and for either party to challenge the outcome of an HDC investigation. Manning considers four reform options and advocates the inclusion of a mechanism for external review or appeal of adverse HDC decisions.

## Dr Krushil Watene

College of Humanities and Social Sciences, Massey University, NZ



Krushil Watene is a Senior Lecturer in the School of Humanities at Massey University. Krushil specialises in moral and political philosophies of well-being, development, and justice with a particular focus on indigenous philosophies. She works closely with Māori communities to support the revitalisation and sustaining of mātauranga Māori, and the ways in which Māori justice concepts can contribute to global justice theorising. She was elected as a Rutherford Discovery Fellow in 2018, and her work has been supported by the Marsden Fund, Ngā Pae ō te Māramatanga, and the Land and Water National Science Challenge.

### Keynote Presentation:

**FRIDAY 22 November 8.30 am – 9.30 am**

#### **Kaitiakitanga - relationships and responsibilities**

Western civilisation has been built on the primacy of property ownership, individual rights, and on the notion of the environment as a resource without limit. We know that these pillars fail us under the weight of our contemporary realities. The impacts are so far-reaching that people the world over are searching for stronger foundations to take us into the future. At the heart of the sustainable development agenda is a concern for future generations. Development is framed as that which 'meets the needs of the present without compromising the ability of future generations to meet their own needs' and which works toward 'building an inclusive, sustainable and resilient future for people and planet'. In what ways do indigenous communities provide some useful ways of grounding these future-oriented and sustainable concerns. Drawing on Māori narratives, I outline a number of insights for our relationships with and our responsibilities to past and future generations. In so doing, I begin to articulate an approach to intergenerational obligations embedded in the idea of Kaitiakitanga, and in a way that demonstrate some of the contributions of indigenous (and particularly Māori) concepts to our ideas about justice.

## Associate Professor Maui Hudson

Faculty of Māori and Indigenous Studies, The University of Waikato, NZ



Associate Professor Maui Hudson is based in the Faculty of Māori and Indigenous Studies at the University of Waikato. He is an interdisciplinary researcher who explores the interface between Indigenous Knowledge, Science and Technology. He co-authored the Te Mata Ira Guidelines for Genomic Research with Māori, and the He Tangata Kei Tua Guidelines for Biobanking with Māori. Professor Hudson is also the co-convenor for SING Aotearoa (Summer Internship for Indigenous Genomics), a co-founder of Te Mana Raraunga Māori Data Sovereignty Network, and a member of the Senior Leadership Team for Genomics Aotearoa.

## Barry Poata Smith Te Manu Kōrero; The Barry Smith Lecture

**FRIDAY 22 November 1.15 pm – 2.15 pm**

### **Raranga whakaaro - the interface of cultural values, ethical principles and legal rights**

For the Inaugural Barry Smith Lecture I will reflect on the different ways in which Barry contributed to Māori ethical discourse. From his involvement in the creation of guidelines for Māori research ethics to the politicisation of ethical review, from the development of guidelines for genomic research and biobanking with Māori to chairing the Māori Gene Editing Reference Panel for the RSNZ, Barry has been a consistent presence in our journey to develop a bi-cultural approach to ethics. In doing so he set down a solid foundation for understanding the interface of cultural values and ethical principles and exploring the intersection with legal rights in an increasingly research and data-rich environment.

## Barry Poata Smith - Te Manu Kōrero; The Barry Smith Lecture



This lecture is named in honour of Barry Poata Smith, who passed away earlier this year. It is intended that it be given at future New Zealand Bioethics Conferences and have a focus on Māori perspectives in Bioethics.

Barry was of Te Rarawa and Ngāti Kahu descent. He came originally from Kaitaia, but moved to Rotorua in the late 1970s and was based there thereafter.

Barry was a regular delegate to the New Zealand Bioethics Conference over many years, but this was of course only a small part of his contribution to bioethics, which were numerous, various, and highly significant.

A particularly important relatively recent contribution was his role with others in the writing of *Te Ara Tika – Guidelines for health research conducted with Māori* (NZ Health Research Council, 2010). The values which the writing group developed to frame Māori thought relating to health research, have been integrated into subsequent guidelines. These include *Te Mata Ira Guidelines for Genomic Research with Māori* (University of Waikato, 2016), and the soon to be published revised *National Standards for Health and Disability Research and Quality Improvement in NZ* (also known as the NEAC Guidelines). The latter have integrated these values throughout, alongside the traditional values of bioethics.

The work that Barry did on the *Te Ara Tika guidelines* was collaborative – he was one of a group who created them. A contribution to groups is an

important feature of Barry's work. He served on many committees within the ethics regulation structures of New Zealand, including the Health Research Council Ethics Committee (which he also chaired), the Advisory Committee for Assisted Reproductive Technology (ACART) and the Multicentre Health and Disability Ethics Committee (HDEC) which reviewed research taking place nationwide. He was a member of the Guidelines working group which contributed so much to the development of the new NEAC standards. Barry was also a member of the Royal Society of New Zealand Māori Gene Editing Reference Group, which was set up to provide specific Māori input and expertise to the Royal Society Te Apārangi Gene Editing Panel. His influence on all these groups has rightly been recognised.

Amongst his other achievements related to Bioethics – there are too many to list them all – was a Marsden Fund supported project on ethics review culminating in a book, written with Martin Tolich, entitled *The Politicisation of Ethics Review in New Zealand* (Dunmore Publishing, 2015).

Barry's day job was as a Population Health Analyst in the Planning and Funding team at the Lakes District Health Board. Through this work, which built on the skills developed in his education in statistics and research, he was extremely familiar with the inequities in health status which face Māori. He was dedicated to taking practical steps towards putting this right, and this was at least in part the driving force behind his wanting tikanga Māori recognised by health researchers and placed centrally within ethics guidelines.

Barry was also an enthusiast for the development of ethics governance internationally. He presented at the 2016 World Health Organisation (WHO) and UNESCO Global Ethics Summit in Berlin, and the first regional Asia Pacific National Ethics (and Bioethics) Committees (AP-NEC I) meeting in Seoul in 2017. He was instrumental in bringing the second of these regional meetings to New Zealand: that meeting (AP-NEC II) took place in Wellington in October this year.

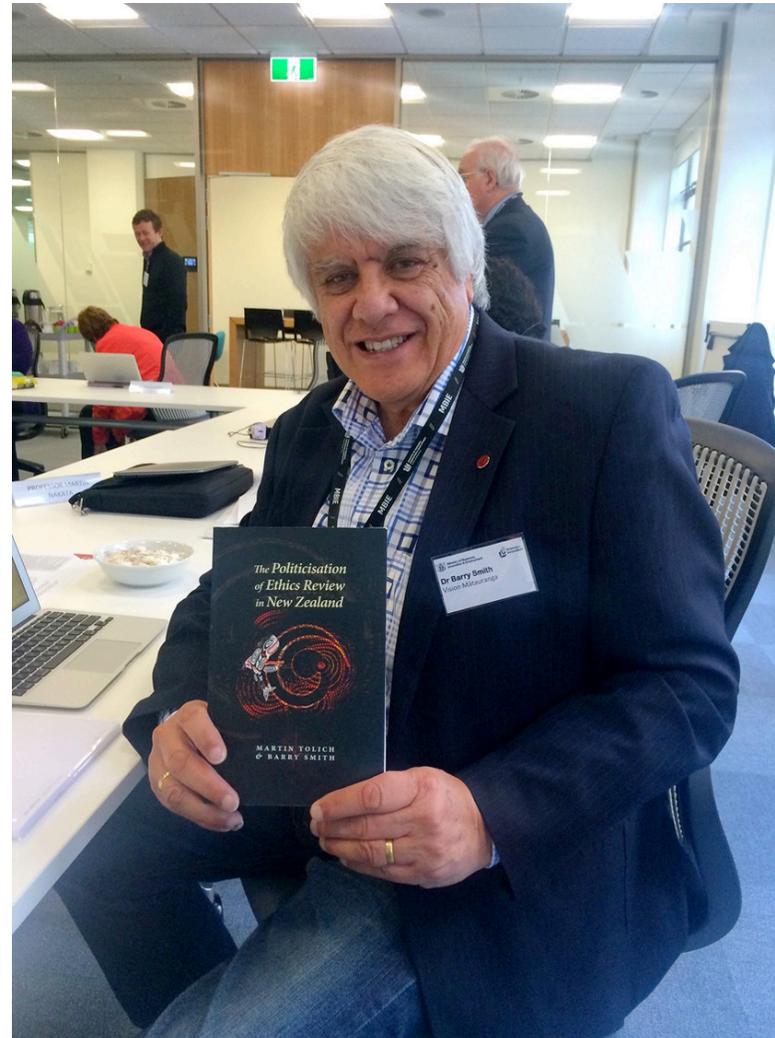
These many engagements with bioethics represent – for our community of bioethicists and health lawyers – the most familiar face of Barry Smith. But if you look for a moment at the celebrations of his life around the internet and in the press, particularly in his home town, Rotorua, you might be forgiven for thinking that another Barry Smith also sadly passed away earlier this year. This Barry Smith was a musician, a lover of the arts, a member of committees such as the Rotorua Civic Arts Trust (of which he was sometime also Chair), he was a lecturer in music at Waikato University, a founder of the Rotorua School of Music (still flourishing now more than 30 years after its founding), and a member of the Board of Opus Orchestra (a highly active musical organisation based in Hamilton). And if you look at photos of Barry, the ones with some of the biggest smiles are the ones of him holding one of his guitars.

This was indeed the same Barry Smith: and it speaks of the remarkable energy he had that he managed to be so central a part of both the ethics/ bioethics and the musical communities. In 2008, his work in both tikanga Māori (ethics) and the performing arts was recognised with a QSM.

Perhaps what is most revealing about Barry, are the reactions of people to his passing. Almost universally these speak of the affection and respect in which he was held – whether by his work colleagues, by those who served on committees with him, or by those who benefited from his support and teaching in the world of music. It is a trite statement to say that someone touched the lives of many people – but with Barry it is a true statement.

Ehara taku toa, he takitahi, he toa takitini - My success should not be bestowed onto me alone, as it was not individual success but success of a collective.

Neil Pickering, with many thanks to Alison Douglass, Maui Hudson, Evan Poata Smith, Mary Smith and John Broughton, for their help.



## Professor Martin Wilkinson

Politics and International Relations, The University of Auckland, NZ



Martin Wilkinson has undergraduate and doctoral degrees from Oxford University. He worked in the Department of Political Studies from 1993-2002 and returned in 2009 after several years working in the medical school. In recent years he has worked on ethics in organ transplantation and public health ethics. His book *Ethics and the Acquisition of Organs* (Oxford University Press, 2011: pbk 2015) has been described in reviews as 'slim, rigorous and entertaining' (*Journal of Applied Philosophy*) and 'a first-rate work of philosophy, independent of sub-field' (*Res Publica*). He was Chair of the Bioethics Council and Deputy Chair of the National Ethics Advisory Committee.

### Keynote Presentation:

**SATURDAY 23 November 8.30 am – 9.30 am**

#### **Paternalism and social justice in public health ethics**

Smoking, drinking too much alcohol, overconsuming unhealthy food and drink, underconsuming healthy food and drink, and not taking enough exercise: these all cause not only ill-health but health inequalities. Taxation and regulation might not only make people healthier, they might reduce the health inequalities. Since health inequalities are often thought to be unjust, it may appear obvious that social justice supports taxation and regulation. But it is not obvious as I try to show in discussing the relation between social justice, health, welfare, and the rather mysterious value of health equity. My positive thesis is that social justice can supplement paternalism. Bearing in mind that any paternalistic policy is likely to be good for some people and bad for others, social justice can help swing the case for paternalist policies that especially benefit the worst off. My negative thesis is that social justice is ONLY a supplement to paternalism. A public health intervention could make the worst off healthier and yet worse off in welfare; if it would, social justice would speak against such an intervention.

## Professor Carl Elliott

Centre for Bioethics, University of Minnesota, USA



Carl Elliott is Professor in the University of Minnesota's Center for Bioethics and an affiliate faculty member in the Department of Philosophy and the School of Journalism and Mass Communications. He is the recipient of a 2018 Guggenheim Fellowship and a 2018 National Endowment for the Humanities Public Scholar Award. He is also a former post-doctoral fellow and William Evans Visiting Fellow at the University of Otago Bioethics Centre.

Elliott is the author or editor of seven books, including *White Coat, Black Hat: Adventures on the Dark Side of Medicine* (Beacon, 2010) and *Better than Well: American Medicine Meets the American Dream* (Norton, 2003.) His articles have appeared in publications such as *The New Yorker*, *The Atlantic Monthly*, *The New York Review of Books*, *Mother Jones*, *The New York Times*, *The American Scholar* and *The New England Journal of Medicine*. He is currently working on a book about whistleblowing in research on human subjects.

### Keynote Presentation:

**SATURDAY 23 November 1.50 pm – 2.50 pm**

#### **Honor, shame and exile: The moral geography of whistleblowing in research on human subjects**

When human research subjects are mistreated or abused, it is rare for anyone to blow the whistle. Most bystanders remain silent in the face of wrongdoing. The rare whistleblowers who do speak out present a moral puzzle that needs explanation. First, whistleblowers often feel implicated by wrongdoing in which they had no personal involvement. Second, while whistleblowers claim to act for moral reasons, those reasons are rarely convincing to their medical colleagues, who typically condemn them as disloyal. Third, whistleblowers often understand that they are embarking on a professional suicide mission, yet they act anyway. Fourth, even when whistleblowers succeed, they are deeply traumatized by their experiences and often feel as if they have failed. I will argue that understanding the act of whistleblowing means understanding the language of shame and honor that sociologists have declared obsolete, but whose force many of us still feel.

# WORKSHOPS

## Health Law Stream

**WEDNESDAY 20 November**

Seminar Room A 9.00 am – 1.00 pm

Convenor: Neera Bhatia

This workshop aims to bring together researchers, academics and professionals to work for an informal morning session to have an open conversation to discuss the challenges, conflicts and emerging trends in the area of health law and bioethics as it relates to emerging technology, innovation and artificial intelligence (AI). The aim is to make the workshop a positive collegial opportunity for researchers and academics working in this area to discuss and exchange their scholarly views and ideas as an open dialogue - and identify potential future collaborations.

## Clinical Ethics Stream Workshop

**WEDNESDAY 20 November**

Seminar Room B 9.30 am – 4.00 pm

Convenor: Hazel Irvine

This program has been developed for those who are active or interested in provision of clinical ethics support within Australian and New Zealand health care organisations, such as clinical ethics committee members, clinical ethicists and clinicians. We have brought together a combination of clinical ethics case analysis and interactive discussion, with examination and debate around a host of professional practice and development issues commonly encountered with establishing and running Clinical Ethics Services. All the sessions will be led by people who are passionate leaders in their fields. A more detailed programme has been emailed to participants ahead of the workshop.

## Student/Early Career Researcher Stream

**Thursday 21 November**

Seminar Room A 9.00 am – 1.00 pm

Convenor: Cynthia Forlini

This workshop is suitable for all students and early career researchers, and will highlight the diverse, interdisciplinary nature of bioethics and health law scholarship and careers. Participants will have the opportunity to discuss the evolving fields of bioethics and health law, including aspects of teaching, research, fellowships, mentorships, career pathways, career and research challenges, and possible management strategies. Participants will have the opportunity to meet peers from across Australasia, and engage directly with leaders from diverse areas of bioethics and health law.

# WORKSHOPS CONTINUED

## What is, and isn't, anti-psychiatry -- and why it matters in 2019

**Thursday 21 November**

Seminar Room E 3.50 pm – 4.55 pm

David B Menkes, Vajira Dharmawardene, Jon Jureidini

We are three psychiatrists from different parts of the world, with rather different clinical and academic roles. In this session, we aim to develop a working definition of “anti-psychiatry”, and to consider its present relevance and impacts on clinical practice and public mental health.

We have chosen a recent publication by the UN Human Rights Council to focus discussion; the UN Special Rapporteur's 2017 Report is highly critical of the contemporary role of psychiatry around the world and has attracted commentary from us and others. Drawing on examples from the Report, we will engage the audience in considering the extent to which the Rapporteur's views may be considered “anti-psychiatry”. We plan to extend the discussion by including concepts of social vs biological causation, psychiatric treatment models, stigma and human rights abuses experienced by those with mental illness.

## Research classification in bioethics: What should it be FoR?

**Friday 22 November 7, 2019**

Seminar Room D 11.10 am – 12.15 pm

Ainsley Newson, Angela Ballantyne, Wendy Lipworth, Angus Dawson

Research in Australia and New Zealand is subject to the Australian and New Zealand Standard Research Classification (ANZSRC). This is a set of three classifications for measuring and analysing research: (i) the type of activity; (ii) the socio-economic objective, or SeO; and (iii) the field of research, or FoR.

Anyone who has submitted a grant or lodged a paper in their institution's repository will have been asked to provide these classifications. These then filter through to research quality assessment, such as which panel a grant application is allocated to, or what disciplinary norms should be used when assessing research outputs.

There is much for bioethicists to like about the ANZSRC. Some of the SeOs are explicitly relevant to our research. There are also FoR codes specific to bioethics, which puts us at an advantage compared to some other countries. And yet, the ANZSRC is also a source of frustration...

After a decade of operation, the ANZSRC is currently under review. In that time, we have seen significant changes to bioethics research, not least the greater use of empirical methods.

At this workshop, we will discuss how the ANZSRC can best serve bioethics. Focusing on FoR codes, we will ask:

- Do the current FoR codes work for bioethics? Why or why not?
- Do we need new FoR codes for bioethics? If so, where should they sit?
- Should FoR codes be used to determine who assesses our research? If not, then what?
- How can the ANZSRC best account for interdisciplinarity?

## Ethical Standards for Health and Disability Research and Quality Improvement

**Friday 22 November**

Seminar Room D 11.10 am – 12.15 pm

Nic Aagaard

This workshop will provide training on and discussion of the 2019 NEAC Ethical Standards for Health and Disability Research and Quality Improvement.

## What are the responsibilities of the bioethicist in an age of political cruelty?

**Saturday 23 November**

Seminar Room A 11.15 am – 12.20 pm

In an age of increasing human rights abuse, should bioethics be a discipline in which political neutrality is either possible or desirable? Here, we discuss the way in which bioethical work cannot be characterised as neutral. We begin with the proposition that even the choice of topics is a political decision, through which bioethicists allocate intellectual resources. On this basis we believe that within the field issues of political and social importance that have an impact on global populations should be prioritized, and that bioethicists should investigate and contribute to public policy and debate. Bioethics should be a normative discipline that seeks to make a difference, as well as being academically rigorous.

Our focus today concerns our professional duties to expose human rights violations and advocate for those who are subjected to deliberate cruelty, through discussion of three case studies where bioethicists have sought to bring to light violations of the right to health and acts of injustice, and what obligations might flow from this knowledge. We focus on the situation of asylum seekers in offshore detention, organ harvesting in China, and recent examples of obesity campaigns.

Deborah Zion: **On Beginning with Justice: Bioethics, Advocacy and the Rights of Asylum Seekers.**

Angus Dawson: **Good Bioethics, Academic Quality and Indifference to Making a Difference**

Christopher Jordens: **Cruelty as Political Theatre: Australia's system of Mandatory Immigration Detention**

Angela Ballantyne: **Indirect levers: reflections on how to achieve change**

Kathryn MacKay: **'Click with Compassion': Public Health Communication in a Cruel Age**

## SYMPOSIA

Some elective papers have been grouped into symposiums. While elective papers will keep to their start and finish times as stated on the programme, we cannot guarantee the order of symposium speakers, or their respective speaking times within the symposium as they will be self-managed.

# SOCIAL EVENTS

## Welcome Function

**Venue** Foyer Area, St David Lecture Theatre Complex

**Date** Thursday 21 November

**Time** 6.15 pm – 7.30 pm

**Price** Included in your registration

**Dress** Smart Casual

The Welcome Function is a chance to catch up with colleagues with drinks and canapés in the St David Foyer.

## Celebration of the Career of Professor Grant Gillett

**Venue** Staff Club (Upstairs), University of Otago

**Date** Friday 22 November

**Time** 5.35 pm – 7.00 pm

**Dress** Smart Casual

The Bioethics Centre is hosting a celebration of the career of Professor Grant Gillett. Delegates attending should have rsvp'ed the Bioethics Centre directly. A drink voucher and a cash bar will be provided.

## Conference Dinner

**Venue** Toitu Early Settlers Museum (next to Dunedin Railway Station)

**Date** Saturday 23 November

**Time** 7.00 pm – late

**Price** included in full registration (must indicate attendance – ticket provided)

**Dress** Smart Casual

Join fellow delegates for the official conference dinner at the Toitu Early Settlers Museum, located next to the Dunedin Railway Station. Meal and drinks included. Wine will be on tables with beer and non-alcoholic drinks available at the bar. One of the museum galleries will be open for delegates to view between 7pm and 8pm.

# GENERAL INFORMATION

## Website

aabhlnzb2019.w.events4you.currinda.com

## Registration and Information Desk

The registration desk is situated near the road side of the St David Lecture Theatre Complex. We welcome your enquires on any conference detail including local information. The desk will be open at the following times:

Wednesday	8.00 am – 4.00 pm
Thursday	8.00 am- 7.30 pm
Friday	8.00 am – 5.00 pm
Saturday	8.00 am – 5.30 pm

## Contact Phone Numbers

Registration Desk Staff: 027 562 5949

Dunedin Taxis: 03 477 7777

Super Shuttles [www.supershuttle.co.nz](http://www.supershuttle.co.nz)

Police/Ambulance/Fire 111

Urgent Doctor 03 479 2900

## Abstracts

Abstracts for the keynote speakers are listed with their biographies and are in order of appearance.

Abstracts for the elective presentations are listed in alphabetical order by presenter surname.

Chairpeople for sessions will be available on the electronic version of the handbook once finalised.

## Coffee

Tea and coffee will be provided at refreshment breaks. Barista coffee can be purchased at St David Cafe (situated in the Lecture Theatre Complex) 8 am -4 pm weekdays. On Saturday there will be a coffee cart situated outside the main entrance from 8 am until midday (cash or eftpos available). The Good Earth Cafe is located across the road from the conference venue open 7.00 am - 4.30 pm (8.00 am Saturday)

## Conference Dinner

The conference dinner is included in full registration and delegates indicated their attendance when registering online. Catering numbers have now been confirmed. If you have not booked and wish to attend, please see the registration desk to be put on a waiting list.

## Internet Access

Wireless internet: UO\_Guest

Follow the instructions (You will need to create a user name and password)

## Mobile Phones/Devices

Mobile phones are allowed in the conference rooms, however please turn all devices to silent mode.

## Name Badges

All conference attendees are requested to wear their name badges at all times during the conference and social functions.

We invite you to return your name badge and lanyard to the registration desk at the end of the conference for recycling.

## Parking

There is plenty of street parking in the surrounding streets. Please note that most parking is pay and display (up to 4 hours).

## Smoking

The University of Otago including surrounding property is completely smoke-free.

## Special Diets

Vegetarian options are included in all refreshment breaks. If you have advised any special dietary requirements on your registration these would have been notified to the caterers.

All lamb, beef, chicken served at the main conference venue (University of Otago) is certified Halal. At the conference dinner (Toitu ) only the beef is Halal.

There will be a pre-registered special diets table located in the exhibition area, with all meals labeled by name. Please make yourself known to the catering staff at the main conference venue and at the conference dinner (Toitu) if you require help finding your meal.

## Suggestions for Dining Near to Venue:

Buddha Stix: 678 George Street

Ombrellos 10 Clarendon Street

Eureka 116 Albany Street

Poppas Pizza Albany Street

More dining options are available on the Dunedin Tourism Website: [www.dunedinnz.com](http://www.dunedinnz.com)

## Presenter Information

### Oral Presenters

Powerpoint presentations are to be loaded at the audio visual desk located next to the registration desk.

### AV Desk Times:

THURSDAY 21 Nov

10.00 am – 12.00 noon , 5.30 pm -7.30 pm

FRIDAY 22 Nov

8.00 am – 9.00 am , 12.15 pm -2.15 pm

SATURDAY 23 Nov

8.00 am -9.30 am

Please take your presentation to the audio visual technician on your arrival at the conference and ensure this done the day prior to your presentation. It would be helpful if you would name your file with your surname the day you are presenting and Room (eg: JonesFriA). Due to time constraints, only Keynote Presenters will be able to use their own laptop in the Main Conference Room.

Please note that the total time scheduled includes questions and answers.

## Springer Books

Publishing editor from Springer, a supporter of the AABHL will have a book table in the foyer area near the registration desk with a range of bioethics related books and journals on Nov 21 and 22.



# AUSTRALASIAN ASSOCIATION OF BIOETHICS & HEALTH LAW AND NEW ZEALAND BIOETHICS CONFERENCE

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## PROGRAMME

(may be subject to change)

### Wednesday 20 November 2019

Time	Session	Location
8.00 am – 10.00 am	Workshop Registration	Foyer
9.00 am – 1.00 pm	Workshop: <b>Health Law Stream</b> (optional, pre-booked)	Room A
9.30 am – 4.00 pm	Workshop: <b>Clinical Ethics Stream</b> (optional, pre-booked)	Room B

### Thursday 21 November 2019

Time	Session	Location
8.00 am onwards	Registration	Foyer
9.00 am – 1.00 pm	Workshop: Student/Early Career Workshop (optional, pre-booked)	Room A
1.00 pm – 1.45 pm	<p><b>Official Welcome</b>  <b>John Broughton Kaumatua</b>, University of Otago  <b>Bernadette Richards</b>, President Australasian Association of Bioethics &amp; Health Law  <b>Lynley Anderson</b>, Head of Department, Bioethics Centre, University of Otago  <b>Aaron Hawkins</b>, Mayor of Dunedin                      Performance by Kings and Queens High School Kapa Haka Group</p>	Main Conference Room
1.45 pm – 2.45 pm	<p><b>Keynote Presentation 1:</b>  <b>Catherine Mills</b>, Monash Bioethics Centre, Monash University, Australia                      Nuclear Families: mitochondrial replacement techniques and the regulation of parenthood id#1188</p>	Main Conference Room
2.45 pm – 3.15 pm	Afternoon Tea	Foyer

**Thursday (continued) 21 November 2019**

3.15 pm – **Elective Session 1**  
4.55 pm

	Main Conference Room	Room A	Room B	Room C	Room D	Room E	Room F
3.15 pm – 3.45 pm	<b>Janine Winters</b> Legalizing Assisted Death in New Zealand- Learning from the Canadian Experience <i>id# 813</i>	<b>Serene Ong</b> Sharing Health-related Data for Precision Medicine: An Exploration of Ethical Concerns in Singapore <i>id# 983</i>	<b>Bernadette Richards</b> Device Representatives in the Clinic: Help, hindrance or liability? <i>id# 812</i>	<b>Mary Butler</b> Good people exist: how is that possible? <i>id# 1088</i>	<b>Alice Toms</b> The regulation of Surgical Innovation: A qualitative study <i>id# 940</i>	<b>Snita Ahir-Knight</b> Unruly behaviour: the role of the healthcare system <i>id# 1017</i>	<b>Calvin Ho</b> Precaution and Benefit in Research involving Implant of Neurodevices <i>id# 1054</i>
3.50 pm – 4.20 pm	<b>Malcolm Parker</b> Cause of death under VADA17: unethical obfuscation or beneficent legal fiction? <i>id# 932</i>	<b>Rebekah McWhirter</b> Between the anecdotal and the universal in assessing genomic data sharing practices: a scenario-based methodology for analysing complex landscapes <i>id# 989</i>	<b>Stephanie Jowett</b> The current legal and clinical framework for treatment of gender diverse youth in Australia <i>id# 907</i>	<b>Minna Paltiel</b> International transfer of health data: individuals' privacy concerns and the role of the law <i>id# 1004</i>	<b>Tamra Lysaght</b> The direct-to-consumer market for stem cell-based interventions in Australia: Exploring the experiences of patients left in a regulatory vacuum <i>id# 939</i>	<b>WORKSHOP:</b> (60 minutes) What is, and isn't, anti-psychiatry -- and why it matters in 2019 Convenor: <b>David Menkes</b> <i>id# 1001</i>	<b>Elizabeth Hill</b> What ethical considerations exist at the intersection between social media, bioethics and research? <i>id# 1067</i>
4.25 pm – 4.55 pm	<b>Russell Shute</b> The limits of autonomy in advanced cancer and palliative care <i>id# 938</i>	<b>Norah Grewal</b> Law and genomic data sharing: beyond consent <i>id# 1006</i>	<b>Naty Guerrero-Diaz</b> My Pain and Suffering is not Negated by My Death - A paper exploring whether a plaintiff's right to general damages should be preserved after their demise <i>id# 908</i>	<b>Grant Gillett</b> Neuroethics as a guide to ethics <i>id# 1087</i>	<b>Max Charlesworth Prize Winner: Katie Ben</b> Isn't it a woman's prerogative to change her mind? The ethical issues of requesting medical intervention in labour for which consent had previously been declined. <i>id# 1000</i>	<b>WORKSHOP:</b> What is, and isn't, anti-psychiatry -- and why it matters in 2019 <i>id# 1001 continued</i>	<b>Hilary Stace</b> No longer merely 'vulnerable' participants: a new focus on disability and disabled people in the National Ethics Advisory Committee standards for health and disability research <i>id# 900</i>

**Thursday (continued) 21 November 2019**

Time	Session	Location
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5.15 pm – 6.15 pm	<b>Keynote Presentation 2: Kirby Oration</b>	Main Conference Room
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*This session is open to the public*

**Joanna Manning**, *The University of Auckland, NZ*  
 "Fair, simple, speedy and efficient"? Barriers to access to justice in the Health and Disability Commissioner's Complaints Process in New Zealand *id#1190*

6.15 pm – 7.30 pm	<b>Welcome Reception</b>	Foyer
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**Friday 22 November 2019**

Time	Session	Location
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8.00 am	<b>Delegate Registration</b>	
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8.30 am – 9.30 am	<b>Keynote Presentation 3:</b>	Main Conference Room
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**Krushil Watene**, *College of Humanities and Social Sciences, Massey University, NZ*  
 Kaitiakitanga - relationships and responsibilities *id#1194*

**9.35 am – 10.05 am Elective Session 2**

	Main Conference Room	Room A	Room B	Room C	Room D	Room E	Room F
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9.35 am – 10.05 am	<b>Rosalind McDougall</b> "This is uncharted water for all of us": Views of Victorian hospital staff about voluntary assisted dying from a survey of 7 health services. <i>id# 963</i>	<b>Angela Ballantyne</b> Who owns clinical data? <i>id# 1022</i>	<b>Carolyn Johnston</b> Use of DIY technologies in diabetes management and child welfare <i>id# 911</i>	<b>Jordan Parsons</b> PrEP in Prisons: An ethical approach to HIV harm-reduction in incarcerated populations <i>id# 839</i>	<b>Ainsley Newson</b> What is the ethical value of genetic kinship? A critical interpretive review. <i>id# 1008</i>	<b>Neil Pickering</b> Cautious paternalism in psychiatric ethics <i>id# 914</i>	<b>Selina Metternick-Jones</b> Next-of-kin consent to research in WA: a conflict between law and ethics <i>id# 1078</i>
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10.05 am – 10.35 am	<b>Morning Tea</b>	Foyer
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**Friday (continued) 22 November 2019**

10.35 am – **Elective Session 3**  
12.15 pm

	Main Conference Room	Room A	Room B	Room C	Room D	Room E	Room F
10.35 am – 11.05 am	<p><b>Colin Thomson and Lindsey Te Ata MacDonald</b> The development and future needs of guidance for the conduct of ethical research involving indigenous peoples in New Zealand and Australia: footnotes to Te Ara Tika in honour of the late Barry Smith <i>id# 1056</i></p>	<p><b>Megan Pricor</b> HeLEX symposium on health data and the limits of the law: ‘Conceptual incoherence’: are data breach notification laws fit for healthcare contexts? <i>id# 955</i></p>	<p><b>Tsung-Ling Lee</b> Street Food Vending: Can we move from a Food Safety to a Nutritious Food Regime? <i>id# 1002</i></p>	<p><b>Jon Cornwall</b> What should happen to our medical records when we die? <i>id# 843</i></p>	<p><b>Christopher Mayes</b> On the multi-births of bioethics: US, Australia and New Zealand <i>id# 1023</i></p>	<p><b>Giles Newton-Howes</b> From substitute decision making to supported decision making in psychiatry <i>id# 913</i></p>	<p><b>Anita Ho</b> Supporting Patients, Families, and Palliative Care Clinicians in the New Legislative Era of Assisted Dying <i>id# 1042</i></p>
11.10 am – 11.40 am	<p><b>WORKSHOP</b> (60 minutes): Ethical Standards for Health and Disability Research and Quality Improvement Convenor: <b>Nic Aagaard</b> <i>id# 1044</i></p>	<p><b>Mark Taylor</b> HeLEX symposium on health data and the limits of the law: Health research and de-identified data: time to protect group privacy? <i>id# 956</i></p>	<p><b>Kerstin Knight</b> Who is the patient? Tensions between Advance Care Planning and Shared Decision Making <i>id# 943</i></p>	<p><b>Diego Silva</b> An attempt to articulate and apply ‘coercion’ as a mid-level principle in public health <i>id# 960</i></p>	<p><b>WORKSHOP</b> (60 minutes): Research classification in bioethics: What should it be FoR? Convenor: <b>Ainsley Newson</b> <i>id# 1005</i></p>	<p><b>Taryn Knox</b> Consensual Conversion Therapy: Individual Autonomy v. Harm to the Gay Community <i>id# 944</i></p>	<p><b>Andrew McGee</b> Is voluntarily stopping drinking and eating a form of suicide? <i>id# 975</i></p>

**Friday (continued) 22 November 2019**

**Elective Session 3 (continued)**

	Main Conference Room	Room A	Room B	Room C	Room D	Room E	Room F
11.45 am – 12.15 pm	<b>WORKSHOP</b> continued: Ethical Standards for Health and Disability Research and Quality Improvement <i>id# 1044</i>	<b>Tess Whitton</b> HeLEX symposium on health data and the limits of the law: Adaptive governance: flexibility to counteract limits of traditional health data governance? <i>id# 957</i>			<b>WORKSHOP</b> continued: Research classification in bioethics: What should it be FoR? <i>id# 1005</i>	<b>Samuel Wolfman</b> Bioethical Dilemmas in the area of Mental Health Care and Law: Involuntary Detention and Treatment of the Mentally Ill <i>id# 905</i>	<b>Jordan Parsons</b> When is it in the interests of permanently cognitively impaired patients to forego dialysis? <i>id# 1014</i>

Time	Session	Location
12.15 pm – 1.15 pm	<b>Lunch</b>	Foyer
1.15 pm – 2.15 pm	<b>Keynote Presentation 4: Barry Poata Smith Te Manu Kōrero; The Barry Smith Lecture</b> <b>Maui Hudson</b> , <i>Faculty of Māori &amp; Indigenous Studies, University of Waikato, NZ</i> Raranga whakaaro - the interface of cultural values, ethical principles and legal rights <i>id#1191</i>	Main Conference Room

**2.20 pm – 2.50 pm Elective Session 4**

	Main Conference Room	Room A	Room B	Room C	Room D	Room E	Room F
2.20 pm – 2.50 pm	<b>Angus Dawson</b> Harm Minimisation: what is it and when can it be ethically justified? <i>id# 961</i>	<b>Eleanor Milligan</b> Private Lives and Public Goods: The ethics of consent to the use of personal data on public social media platforms in research <i>id# 1049</i>	<b>Lisa Mitchell</b> Conscientious and non-conscientious objections to Voluntary Assisted Dying. <i>id# 1020</i>	<b>Nicole Shepherd</b> Student perceptions of learning about medical ethics in clinical case-based tutorials. <i>id# 1034</i>	<b>Cynthia Forlini</b> Must we? The ethical and practical challenges of implementing consumer preferences for participation in dementia research <i>id# 997</i>	<b>Asher Soryl</b> The 'Myth' of Bambi: Idealising Nature and the Grim Reality of Wild Animal Suffering <i>id# 1016</i>	<b>Jing-Bao Nie</b> From Eugenics to Human Gene Editing: Ideology and Engineering Life in China in a Global Context <i>id# 1086</i>

**Friday (continued) 22 November 2019**

Time	Session						Location
2.50 pm – 3.20 pm	<b>Afternoon Tea</b>						Foyer
3.20 pm – 5.35 pm	<b>Elective Session 5</b>						
	Main Conference Room	Room A	Room B	Room C	Room D	Room E	Room F
3.20 pm – 3.50 pm	<p><b>Eliana Close</b> Balancing patient and societal interests in decisions about potentially life-sustaining treatment: An Australian policy analysis <i>id# 1027</i></p>	<p><b>John McPhee Prize Winner: Caitlin Davis</b> Patient Autonomy and Informed Consent in Birth Trauma Litigation <i>id# 993</i></p>	<p><b>SYMPOSIA:</b> 'Overt and covert recordings in healthcare' contexts: <b>Megan Prictor</b> Digitally-enabled overt consultation recording in Australia: an analysis of legal concerns <i>id# 1066</i></p>	<p><b>Jessica Pace</b> Formulating an Ethics of Pharmaceutical Disinvestment: A Critical Interpretive Review <i>id# 999</i></p>	<p><b>John Gruner</b> Scanlon's contractualism and the doctor-patient relationship in bioethics. <i>id# 968</i></p>	<p><b>Anson Fehross</b> Twelve Angry Proxies: Moving to Distributed Proxy Decision Making <i>id# 1038</i></p>	<p><b>Melanie Rock</b> More-than-human solidarity in practice: Insights from a veterinary school about One Health and its promotion <i>id# 951</i></p>
3.55 pm – 4.25 pm	<p><b>Jing-ru Li</b> Is Chinese practice of non-disclosure a product of 'familism'? A sociological and ethical study <i>id# 1028</i></p>	<p><b>Belinda Bennett</b> Technology and the future of health law and bioethics <i>id# 1065</i></p>	<p><b>Mark Taylor</b> Patients taking photos, audio recordings and video in the health care context – when is it wrong and what can you do about it? <i>id#1068</i></p>	<p><b>Chris Degeling</b> Balancing the benefits and risks of technologically enhanced communicable disease surveillance systems: A report on 4 community juries <i>id# 969</i></p>	<p><b>Robert Sparrow</b> Ethical issues of social robots in medicine <i>id# 1080</i></p>	<p><b>Chris Gyngell</b> Drugs, Genes and Screens: The ethics of preventing and treating Spinal Muscular Atrophy <i>id# 962</i></p>	<p><b>SYMPOSIA:</b> Gene Editing Technologies: Refining our understanding of obligations and key concept <i>id#931</i> Chair: <b>Tamra Lysaght</b></p>

**Friday (continued) 22 November 2019**

**Elective Session 5 (continued)**

	Main Conference Room	Room A	Room B	Room C	Room D	Room E	Room F
4.30 pm – 5.00 pm	<b>Justin Oakley</b> Aristotelian medical virtues, Christian medical virtues, and end-of-life decision making. <i>id# 1035</i>	<b>Timothy Kariotis</b> Ethico-Legal Considerations for an Integrated Electronic Health Record in the Australian Mental Health System <i>id# 1051</i>	<b>Neera Bhatia</b> Child medical tourism: opportunities and hazards of 21st century global healthcare <i>id# 949</i>	<b>Rebecca Duncan</b> Proactive Provision of Contraception to Adolescents in New Zealand: a Concept <i>id# 966</i>	<b>Wendy Lipworth</b> Is it really all about the money? Non-financial conflicts of interest in health and biomedicine <i>id# 912</i>	<b>Emma Tumilty</b> Conscientious Defiance: Using moral courage for action rather than objection <i>id#928</i>	<b>Markus Labude</b> Two challenges for the requirement of 'societal consensus' <i>id# 1076</i>
5.05 pm – 5.35 pm	<b>Dominique Martin</b> Perversity, profits and paradoxical effects: how the production, use and control of information creates ethical complexities in the context of end stage kidney disease care <i>id# 1073</i>	<b>Jane Kaye</b> The New Frontier of Health Data Governance <i>id# 1029</i>	<b>Aminath Mariya</b> Do physicians have a duty to report medical device adverse events in patients? <i>id# 1046</i>	<b>Anson Fehross</b> Against Accuracy: A Defence of Value Congruence in Proxy Decision-Making <i>id# 1025</i>	<b>Lisa Dive</b> Biobank networks, medical research and the challenge of globalisation <i>id# 1015</i>	<b>Nathan Emmerich</b> Should Professional Interpreters be able to Conscientiously Object in Healthcare Settings? <i>id# 1018</i>	<b>Owen Schaefer</b> Refining our understanding of obligations and key concept: Silence and Complicity in the Case of the First Gene-Edited Babies <i>id# 1075</i>

Time	Session	Location
5.35 pm – 7.00 pm	<b>Function to celebrate Grant Gillett's professorship / retirement (by RSVP)</b> Hosted by the Bioethics Centre	<b>University of Otago Staff Club</b> Leith Walk, University of Otago Campus

**Saturday 23 November 2019**

Time	Session	Location
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8.00 am	Registration	
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8.30 am – 9.30 am	<b>Keynote Presentation 5:</b>		Main Conference Room
	<p><b>Martin Wilkinson</b>, <i>Politics and International Relations, The University of Auckland, NZ</i>                  Paternalism and social justice in public health ethics  <i>id# 1187</i></p>		

**9.35 am – 10.05 am Elective Session 6**

	Main Conference Room	Room A	Room B	Room C	Room D
9.35 am – 10.05 am	<p><b>Malcolm Smith</b>                      The significance of the decision in PBU &amp; NJE v Mental Health Review Tribunal [2018] VSC 564: human rights perspectives on decisions about electroconvulsive therapy  <i>id# 1036</i></p>	<p><b>Isobel Cairns</b>                      ‘Not approved’: Cambridge Analytica’s research ethics application and what it means for the data discussion  <i>id# 1061</i></p>	<p><b>Fiona McDonald</b>                      Air pollution disasters: legal issues associated with the provision of personal protective interventions (facemasks)  <i>id# 950</i></p>	<p><b>Hilary Bowman-Smart</b>                      Testing for adult-onset conditions using non-invasive prenatal testing: ethical and regulatory issues  <i>id# 970</i></p>	<p><b>Sumytra Menon</b>                      Advance care planning in a multi-cultural family-centric community: A qualitative study of healthcare professionals’, patients’ and caregivers’ perspectives  <i>id# 1085</i></p>

**10.10 am – 10.40 am Morning Tea**

**10.40 am – 12.20 pm Elective Session 7**

	Main Conference Room	Room A	Room B	Room C	Room D	Room E
10.40 am – 11.10 am	<p><b>Katrine Del Villar</b>                      Preventing “bad deaths”: would the Australian “mercy killing” cases be avoided by legalising voluntary assisted dying?  <i>id# 1033</i></p>	<p><b>Vicki Xafis</b>                      An Ethics Framework for Big Data in Health and Research  <i>id# 1069</i></p>	<p><b>Ben Gray</b>                      Ethics as Culture; Euthanasia and Gun Control  <i>id# 971</i></p>	<p><b>Lynley Anderson</b>                      Kid’s cage fighting - it should be banned, right?  <i>id# 987</i></p>	<p><b>Christopher Gyngell</b>                      Legality of Embryonic Gene Editing in Australia  <i>id# 937</i></p>	<p><b>SYMPOSIA:</b> What Can Deliberation Do in and for Bioethics?: <b>Chris Degeling</b> What sort of health policy problems can be addressed by a citizens’ jury?  <i>id# 1123</i></p>

**Saturday (continued) 23 November 2019**

**Elective Session 7 (continued)**

	Main Conference Room	Room A	Room B	Room C	Room D	Room E
11.15 am – 11.45 am	<b>Rebecca Meehan</b> Is that really the case? An analysis of ‘fact-based’ arguments of Victorian politicians during the 2017 voluntary assisted dying debate. <i>id# 1050</i>	<b>WORKSHOP</b> (60 minutes): What are the responsibilities of the bioethicist in an age of political cruelty? Convenor: <b>Deborah Zion</b> <i>id# 1055</i>	<b>David Matas</b> International standards and remedies for organ transplant abuse <i>id# 1030</i>	<b>Lauren Notini</b> Puberty suppression for non-binary young people: clinicians’ practices, views and decision making <i>id# 936</i>	<b>Lisa Eckstein</b> Why Somatic Cell Gene Editing Research Could Be Slipping Through Australian Regulatory Cracks <i>id# 953</i>	<b>Simon Walker</b> Deliberation, disagreement, and common morality <i>id# 1124</i>
11.50 am – 12.20 pm	<b>Courtney Hempton</b> Practices of (Mortal) Freedom: Voluntary Assisted Dying and the Conduct of ‘Choice’ <i>id# 1024</i>	<b>WORKSHOP</b> continued - What are the responsibilities of the bioethicist in an age of political cruelty? <i>id# 1055</i>	<b>Sam Boyle</b> How should the law determine capacity to refuse treatment for anorexia? <i>id# 1010</i>	<b>Merle Spriggs</b> “I just lied to a kid for eight hours ...”: When parents ask clinicians to withhold information from their child <i>id# 990</i>	<b>Lisa Dive</b> The value of autonomy <i>id# 1011</i>	<b>Stacy Carter</b> So What Can Deliberation Do In and For Bioethics? A Commentary <i>id# 1125</i>

Time	Session	Location
12.20 pm – 1.50 pm	<b>Lunch</b>	Foyer
12.20 pm – 1.50 pm	<b>Australasian Association of Bioethics &amp; Health Law Annual General Meeting</b> Open to AABHL Members only	Room A
1.50 pm – 2.50 pm	<b>Keynote Presentation 6:</b>  <i>This lecture is open to the public</i>	Main Conference Room
	<b>Carl Elliott, Centre for Bioethics, University of Minnesota, USA</b> Honor, Shame and Exile: The Moral Geography of Whistleblowing in Research on Human Subjects <i>id# 1193</i>	
2.50 pm – 3.20 pm	<b>Afternoon Tea</b>	Foyer

**Saturday (continued) 23 November 2019**

3.20 pm – 5.00 pm <b>Elective Session 8</b>					
	Main Conference Room	Room A	Room B	Room C	Room D
3.20 pm – 3.50 pm	<b>Derrick Au</b> Improving choice and care near end of life through legislating advance directives in Hong Kong: Issues and Enabling Factors <i>id# 986</i>	<b>Karel Caals</b> Ethical Evaluation of Policy Transfer on Human Resources for Health in the 'More-than-National' Health System of Timor-Leste <i>id# 1071</i>	<b>Julia Duffy</b> Decision-making by and for persons with cognitive disabilities: an interpretation of article 12 of the Convention on the Rights of Persons with Disabilities - the right to legal capacity - that takes into account economic, social and cultural rights. <i>id# 967</i>	<b>SYMPOSIA:</b> Prioritisation of Vaccination Groups in an Influenza Pandemic: <b>Angus Dawson</b> Ethics framework for prioritising pandemic vaccine <i>id# 1039</i>	<b>Pat McConville</b> Phenomenology and artificial hearts <i>id# 1013</i>
3.55 pm – 4.25 pm	<b>Tarishi Desai</b> Testing times: How to regulate DIY diagnosis? <i>id# 1009</i>	<b>Mascha Hoexum-Moerenburg</b> Moral case deliberations using the dilemma method, a Dutch perspective <i>id# 909</i>	<b>Kanny Ooi</b> Decision making and consent: Helping patients make informed decisions about their care <i>id# 948</i>	<b>Chris Degeling</b> Participant perspectives from 3 citizens' juries <i>id# 1041</i>	<b>Miriam Wiersma</b> Doctors' use of Unconventional Medicine and Emerging Treatments in Australia: Is Additional Regulation Required? <i>id# 929</i>
4.30 pm – 5.00 pm	<b>Vikki Entwistle</b> Equality in healthcare: why socio-relational theorising matters for healthcare improvement <i>id# 972</i>			<b>Jane Williams</b> Pandemic vaccination strategies: direct vs indirect protection <i>id# 1040</i>	
Time	Session			Location	
5.00 pm – 5.35 pm	<b>Awards &amp; Closing</b>			Main Conference Room	
7.00 pm – late	<b>Conference Dinner</b>			Toitu Early Settlers Museum 31 Queens Gardens – Next to Railway Station	

# ELECTIVE SPEAKER PRESENTATIONS

In Alphabetical Order (presenting author surname)

id #1044

## **WORKSHOP (60 minutes): Ethical Standards for Health and Disability Research and Quality Improvement**

**Nic Mr Aagaard<sup>1</sup>**

*1. Ministry of Health, Mount Cook, Wellington, New Zealand*

This workshop will provide training on and discussion of the 2019 NEAC Ethical Standards for Health and Disability Research and Quality Improvement.

id #1017

## **Unruly behaviour: the role of the healthcare system**

**Snita Ahir-Knight<sup>1</sup>**

*1. Philosophy, Victoria University of Wellington, New Zealand*

A degree of unruly behaviour in children and youth is developmentally appropriate, such as the wailing toddler and the door-slammng teenager. However, when unruly behaviour becomes frequent and persistent in children and youth, then the behaviour may no longer be developmentally appropriate. The behaviour sometimes results in a diagnosis of oppositional defiant disorder or conduct disorder. However, there are some reasons to believe that children and young people displaying this behaviour do not have a mental disorder but are badly behaved, so this is not a matter for the healthcare system.

In this paper I ask when unruly behaviour warrants a mental health diagnosis and what this tells us about the role of the healthcare system. This consideration has importance for the treatment of children and youth, and for how we understand the mental health of children and young people.

id #987

## **Kid's cage fighting - it should be banned, right?**

**Taryn Knox<sup>1</sup>, Lynley Anderson<sup>1</sup>**

*1. University of Otago, Dunedin, New Zealand*

Cage-fighting (also known as Mixed Martial Arts) combines many elements of other combat sports, meaning the fighter can wrestle, kick, punch and so on. Cage-fighting is undeniably violent and has been compared to bar-room brawls and human cock-fighting. It is debatable whether adults ought to be free to engage in risky sport. Further difficulties arise regarding children's participation in cage-fighting, as there is a tension between the parental right to make decisions on behalf of their child and the right of the child to be protected from harm. In the first part of the paper, we consider which standard or concept should be used to determine whether parental rights should be overridden. We propose that parents need not make decisions in the best interests of their child, but that parental decisions may only be overridden if they fall outside Gillam's (2016) 'Zone of Parental Discretion' (ZPD) or unduly minimises a child's right to an open future (Feinberg 1980). The second part of the paper outlines a rubric (Anderson 2007) that determines whether an activity such as kid's cage-fighting should be banned that considers both likelihood and severity of harm. Together, the two parts of the paper demonstrate that whether children's cage-fighting should be banned requires much more analysis. Contrary to the title of this paper, perhaps kid's cage-fighting should not be banned.

1. Anderson, L. (2007). Doctoring risk: Responding to risk-taking in athletes. *Sports, Ethics and Philosophy*, 1(2), 119-134.
2. Feinberg, J. (1980). The child's right to an open future in whose child. *Children's rights, parental authority, and state power*, 123-153.
3. Gillam, L. (2016). The zone of parental discretion: an ethical tool for dealing with disagreement between parents and doctors about medical treatment for a child. *Clinical Ethics*, 11(1), 1-8.

id #986

## Improving choice and care near end of life through legislating advance directives in Hong Kong: Issues and Enabling Factors

**Derrick Au**<sup>1</sup>

1. *CUHK Centre for Bioethics, The Chinese University of Hong Kong, China*

Advance Directives (AD) in Hong Kong is facilitated under common law framework rather than statutory legislation. A valid and applicable AD should in principle be respected in medical decision making at end of life, or when a patient falls into irreversible coma. The Hospital Authority (HA) promulgated a set of AD Guidance for public hospitals in 2010, and Guidelines on Advance Care Planning in 2019. While gradual adoption of AD is observed, practical difficulties are encountered in clinical practice, and there are views that AD under the common law framework has significant legal uncertainties in its relation to Mental Health Ordinance provision (allowing treatment without consent to mentally incapacitated persons based on best interests principle) and Fire services Ordinance clauses (which require ambulance officers to always put resuscitation and saving life as the eminent duty). In 2019, the Government is considering to consult the public on legislating AD in Hong Kong, to better facilitate choice and care near end of life. This presentation considers the ongoing discussion of key issues in Hong Kong, enabling factors and challenges in future practice.

1. C.Y. Tse. Advance Care Planning and Advance Directives in Hong Kong: Concepts and Developments. <http://www.ioa.cuhk.edu.hk/en-gb/casebook/backgrounders/advance-care-planning-and-advance-directives-in-hong-kong-concepts-and-developments>
2. Guidance for HA clinicians on advance directives in adults. Hong Kong: Hospital Authority; 2010/2014/2016.

id #1022

## Who owns clinical data?

**Angela Ballantyne**<sup>1</sup>

1. *Bioethics Centre, Dunedin*

Who owns clinical health data? Claims of data 'ownership' are increasingly central to debates about the appropriate management of clinical data. Here I explore competing narratives about clinical data ownership. Potential owners include: (1) patients (e.g. calls for patients to be financial reimbursed for secondary

uses of 'their' clinical data); (2) public sector agencies (attempting to provide cheaper, more efficient health services for populations); (3) private companies (trading in EHRs, mining data and selling data analytic services); and (4) calls for Indigenous Data Sovereignty (e.g. Te Mana Raraunga in New Zealand). I argue that the language of ownership acts as an umbrella concept that bundles together various different concerns, in particular the disenfranchisement of citizens in the existing data ecosystem. Too often, we jump straight from 'ownership' to a simplistic account of private property. But we can distinguish between two senses of ownership: data can be 'about the patient' without necessarily 'belonging to the patient'. This distinction allows us to recognise and manage patients' interests in data, without concluding that patient consent is necessary for all future uses; and allows us to acknowledge other interests in the data. Clinical data is equally 'about' families, communities, diseases and health systems. On this broader account of ownership, the relevant harm is the severing of the connection between the patient and collectives and their data, and the solution is to reengage and reconnect patients and collectives to the data research enterprise. I present examples of this process of reconnection.

id #1000

## Isn't it a woman's prerogative to change her mind? The ethical issues of requesting medical intervention in labour for which consent had previously been declined

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The management of pain in labour consists of a spectrum from non invasive, non pharmacological treatments (aromatherapy, warm water immersion, massage), through to pharmacological treatments (opioids, inhaled nitrous oxide) and finally to invasive pharmacological methods (epidural analgesia with the administration of local anaesthetic agents into the epidural space near the spinal nerve roots). While largely safe, epidural analgesia is not without risks, in some cases significant risks, albeit with very infrequent incidence. Insertion of an epidural for the relief of labour pain is therefore subject to the same clinical guidelines regarding informed consent as other medical interventions.

This essay will look at the ethical issues and difficulties that clinicians face when patients change their mind having previously declined an intervention. I will start with a case description (based on a number of clinical experiences throughout my career as an anaesthetist) and then explore the ethical concepts of autonomy and the ability to give informed consent which are

highlighted. I will argue that the patient was able to give informed consent to a decision regarding a medical procedure while in pain using a syllogism analysis. In terms of the question regarding respect for autonomy, I will argue that the patient made two autonomous decisions at different points in time and that, while contradictory, both autonomous decisions were respected at the times they were made. I will also briefly suggest how such a situation could be avoided to the benefit of both patient and clinician in the future.

**id #1065**

## **Technology and the future of health law and bioethics**

**Belinda Bennett**<sup>1</sup>

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Artificial intelligence, robotics and precision medicine are all set to transform the delivery of health care. These developments will also raise new issues for health law and bioethics. This paper analyses evolving understandings of health and health care in the context of these new technologies. It explores the impact of contemporary developments in health care technology for key concepts such as autonomy, vulnerability, and privacy. Finally, the paper considers the contributions that health law and bioethics can make to debates about technology and the implications of advances in technology for the future development of health law and bioethics.

**id #949**

## **Child medical tourism: opportunities and hazards of 21st century global healthcare**

**Neera Bhatia**<sup>1</sup>

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Disagreements between parents and healthcare professionals about treatment decisions for critically ill children have recently received global attention. High-profile U.K cases like Ashya King and Charlie Gard have illuminated greater involvement of parents in medical treatment decision making. They have highlighted the increasing role of social media and the internet to gain social support, and information about innovative treatments being readily available, without real world considerations about their efficacy or appropriateness. Innovative treatments may be available in a global market, increasing pressure on parents to access them through child medical tourism.

Child medical tourism might occur in circumstances where parents take their

child from their home country to a destination country to receive medical treatment. It is relatively common, but little research has been conducted to understand the 'why', 'what' and 'where': of parents seeking to take their child overseas for treatment, and the resulting impact on the child. Child medical tourism raises a number of opportunities and hazards, including concerns about the rights of the child, privacy and balancing cultural differences between countries.

Innovative treatments offer hope to parents and the child where conventional treatments have failed. Access to unproven innovative treatments can increase the risk of medical quackery, despite this, child medical tourism seemingly offers increased access to treatments for the child and increased choices for parents. Further, potentially relieving the strain on the healthcare system of the home country and injecting funds into the destination country. Do the opportunities of child medical tourism outweigh the concerns?

**id #970**

## **Testing for adult-onset conditions using non-invasive prenatal testing: ethical and regulatory issues**

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Non-invasive prenatal testing (NIPT) uses a maternal blood sample to provide highly accurate information about a variety of genetic conditions in the foetus. NIPT is currently used primarily to screen for trisomy disorders such as trisomy 21 (Down syndrome), which are immediately apparent at birth. The suite of conditions for which NIPT is available may increase in the future. It is possible to use NIPT to detect adult-onset disorders and risk profiles for conditions which manifest later in life (including through whole genome sequencing). NIPT raises unique concerns as a prenatal testing technique due to ease of use, low risk, and availability early in gestation.

Although expanded prenatal testing enhances reproductive choice and informed decision-making, the use of NIPT to detect adult-onset conditions raises significant ethical concerns about the welfare of the child to be born, particularly where a woman chooses to continue a pregnancy following a positive foetal diagnosis. For example, it may interfere with the child's 'right to an open future'. It is necessary to assess the importance of the welfare of the child to be born when making decisions concerning prenatal testing. However, there is little clinical guidance in the Australian context on how to balance the

interests of prospective parent(s) and the child to be born.

Currently NIPT is available to Australian women on a privately-funded basis and not specifically regulated. In this paper, we explore the ethical issues raised by NIPT for adult-onset conditions and make some preliminary proposals for regulating NIPT in the future.

**id #1010**

## **How should the law determine capacity to refuse treatment for anorexia?**

**Sam Boyle**<sup>1</sup>

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How to determine the capacity of a person diagnosed with anorexia to refuse medical treatment has been called the 'hard case' of capacity law. I demonstrate that courts have used a process of circular reasoning when making this determination, where treatment refusals are simultaneously used as evidence of cause (anorexia) and effect (incapacity). This reasoning means that anyone with the diagnosis of anorexia will be found to lack capacity to refuse its treatment. The circular reasoning has a negative effect on the law, and means that indicia of capacity that ought to be considered by the court can be ignored. The result is a procedure in which the person diagnosed with anorexia has no voice, and an outcome against which he or she has no effective legal recourse.

I argue that this problem can be mitigated in two ways. Firstly, courts must make sure that the 'functional' test of capacity is properly applied, meaning any finding of incapacity must rest on evidenced deficits in decision-making ability. Secondly, courts must properly engage with the subjective reasoning of the person making the treatment refusal.

1. Boyle, Sam (2019) 'How should the law determine capacity to refuse treatment for anorexia?' 64 *International Journal of Law and Psychiatry* 250.

**id #1088**

## **Good people exist: how is that possible?**

**Mary Butler**<sup>1</sup>

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Virtue ethics manifest in various ways. In different cultures, the virtues have been expressed through confucianism in China, through yoga in India and through tikanga in Te Ao Maori. One interpretation of virtue ethics considers that goodness is enacted in practices. The virtue of a builder is demonstrated in the building of a good house; a good doctor applies themselves in ways that bring about health for a patient. How does a person become good then? The flourishing of the individual practitioner is crucial to the development of the practice. Our practices are ethical sources. They are sites where aspects of the good are disclosed to us as well as the primary scene of our ethical education. In this paper, I explore that the practice of virtue is intrinsic to the way that occupational therapists understand an assessment of doing. I argue further that this form of assessment can also be enacted as a research method. These arguments are traced through the practices of walking and dance. In these examples the goodness of an individual can be recognisably intertwined with the practices that they engage in.

**id #1071**

## **Ethical Evaluation of Policy Transfer on Human Resources for Health in the 'More-than-National' Health System of Timor-Leste**

**Karel Caals**<sup>1</sup>, **Calvin W. L. Ho**<sup>1</sup>

*1. National University of Singapore, Singapore*

The emergence of increasingly transnational geographies of policies on governance presents many ethical challenges. This is particularly so in the context of the circulation, regulation and distribution of human resources for health (HRH) in low-resource settings. While the ethics literature has focused primarily on the implications of foreign assistance of various kinds, there has arguably been more limited attention on the ethical implications of policy transfer, which (as Russell Prince observes) links this process with the extension of the hegemonic 'regimes of truth' that define policy norms. Drawing on ongoing qualitative research in Timor-Leste, we first provide an empirical account of the HRH landscape in Timor-Leste with the aim of demonstrating how various competing and potentially incompatible ethical goals and governance features

cohere as a matter of systemic arrangements. This phenomenon reinforces our proposition that the construct of an emerging health system like that of Timor-Leste's is 'more-than-national'. We then examine the ethical and regulatory implications of such an assemblage on quality of care, as well as the ultimate goal of achieving universal health coverage. We conclude with some reflections on how qualitative research on HRH, with focus on geographies of health, could be developed to better support normative deliberation and evaluation.

**id #1061**

### **'Not approved': Cambridge Analytica's research ethics application and what it means for the data discussion**

**Isobel R Cairns<sup>1</sup>**

*1. Victoria University of Wellington, New Zealand*

Research ethics committees are consistently faced with the challenge of approving research that proposes new uses for data, and with little empirical evidence on what has widespread 'social licence'. Cue the Cambridge Analytica scandal of March 2018 – a watershed moment for understanding how the public feels about having their information harvested.

Aleksandr Kogan, the academic involved in the company that collected the data, applied to Cambridge University for ethics approval to use the data in research and was declined. Documents of the review made available under the Freedom of Information Act include 126 pages of submissions, re-submissions and appendices – the backstage workings of the research ethics committee.

In this presentation I'll draw on experience at my own institution as well as the literature to consider what we can learn from this detailed account of disagreement. How does this case inform how research ethics committees should assess data science projects, the role of the committee more broadly, and what does it show about how these projects interact with the society whose data they trade on?

**id #1125**

### **SYMPOSIA: So What Can Deliberation Do In and For Bioethics? A Commentary**

**Chris Degeling<sup>1</sup>, Simon Walker<sup>2</sup> Stacy Carter<sup>1</sup>**

*1. University of Wollongong, NSW, Australia*

*2. Bioethics Centre, University of Otago, New Zealand*

This symposium will explore the use of deliberative methodologies in bioethics and policymaking, which have been increasingly promoted as a means for permitting more reflective discussions among stakeholders. Deliberative processes promote respectful dialogues among diverse stakeholders which allow them to articulate their values and concerns as well as to understand those of others, in a manner that is much less likely to occur in more traditional aggregative or confrontational approaches to decisionmaking particularly in contentious domains. Chris Degeling will address the issue of what sort of health problems can be addressed by a citizens' jury in order to bring public values and marginal voices into decision-making, and disentangle two types of policy questions that might be addressed using citizens' juries in cases that require consideration of values and evidence, as well as limitations of citizens' juries. Simon Walker will examine deliberation, disagreement, and common morality, reflecting on a 2018 citizens' jury in New Zealand about potential law change associated with euthanasia, in order to consider what entrenched disagreement might mean for traditional views of morality. Stacy Carter will consider the relationship between deliberation and bioethics. What can deliberation offer empirical bioethics, and what can bioethics potentially add to deliberative research? The symposium will conclude with an open discussion of methodology and methods for deliberative bioethics research.

**id #1027**

### **Balancing patient and societal interests in decisions about potentially life-sustaining treatment: An Australian policy analysis**

**Eliana Close<sup>1</sup>, Ben P White<sup>1</sup>, Lindy Willmott<sup>1</sup>**

*1. Australian Centre for Health Law Research, Queensland University of Technology, Brisbane, QLD, Australia*

Decisions about withholding and withdrawing life-sustaining treatment are usually centered on the patient, with doctors making assessments about treatments that may be 'futile' or 'non-beneficial'. However, in publicly-funded health systems such as Australia, these decisions are made against a backdrop of the need to use scarce health resources efficiently. A previous study we conducted indicated doctors who make end-of-life decisions are conflicted by being the 'gatekeeper' to treatment, and perceive a lack of adequate regulatory support for resource-based decisions. It also demonstrated that for some the concept of 'futility' is a mask for conscious and unconscious rationing, raising concerns about transparency. Medical policies (including codes of ethics and professional guidelines) are one mechanism that can promote fair and

transparent processes to guide decision making and conflict resolution in this area, however, the Australian policy environment is under-studied.

This review of publicly-available policies on withholding and withdrawing life-sustaining treatment found that there is limited guidance about how to reconcile patient interests with distributive justice. Although the policies emphasise doctors' obligations to be stewards of scarce resources, overall there is inadequate guidance about how to operationalise this in practice. End-of-life decision making would be enhanced by an Australian policy environment that has a greater emphasis on transparent decision making and more community engagement with the resource implications of these decisions.

**id #843**

## **What should happen to our medical records when we die?**

**Jon Cornwall<sup>1</sup>, Kathryn McAuley<sup>1</sup>**

*1. University of Otago, Dunedin, Otago, New Zealand*

Digital innovation is transforming healthcare, and the digital medical data currently being generated by our population will have increasing utility over time. Despite the seemingly logical and inevitable application of medical data from deceased persons in research and healthcare applications both now and in the future, the issue of how best to manage the growing repository of posthumous medical records is currently unclear. This includes elements of resource governance, issues of law, and infrastructural challenges. Our project explored the views of the local Dunedin (New Zealand) population to the use of posthumous medical records. Using focus groups (10 x 6-person, 1-hour, age-groups from 18-65+ years-old) we explored issues relating to posthumous medical record use, including questions surrounding governance, anonymity, law, and commercialisation. Transcriptions of focus groups were analysed thematically. Findings indicated strong support for the use of posthumous medical records in New Zealand, with beneficence of participants a strong theme. As a resource, a centrally collated and Government-governed resource of posthumous healthcare data was almost universally supported, with varying caveats around how such a resource should be utilised. Family rights to data of the deceased were not universal, with limited case-by-case access supported despite almost unanimous support for descendants to benefit from personal, historical medical data. Current challenges including development of an ethically and culturally appropriate governance system, alterations to current law to protect posthumous medical records from destruction or misuse, and implementation of a fit-for-purpose technology infrastructure.

**id #993**

## **Patient Autonomy and Informed Consent in Birth Trauma Litigation**

**Caitlin Davis<sup>1</sup>**

*1. Australian National University, Lyneham, ACT, Australia*

This paper will explore the contested doctrine of informed consent in the context of childbirth. It will be argued that despite there being risks associated with vaginal delivery, Australian negligence law and policy creates barriers for pregnant women to make informed choices about the mode of delivery and interventions such as forceps or vacuum, that may be used during delivery. Firstly, this paper will explore the history of the denial of reproductive choice across various jurisdictions including Australia. This will be followed by a discussion of the ordinary principles of informed consent and causation with the reference to the doctor-patient relationship more generally. Thirdly, this paper will address why childbirth is considered unique with regard to informed consent and choice. Part II of this paper will address a number of birth trauma cases across various Australian jurisdictions and the approaches taken by the courts in assessing informed consent in childbirth. This will be followed by a discussion of the United Kingdom (UK) decision in *Montgomery v Lanarkshire Health Board*,<sup>[1]</sup> and whether Australia is likely to follow the court's decision to impose a duty upon obstetricians to offer alternative methods of delivery to women.

[1][2015] 1 AC 1430 (*Montgomery*).

**id #961**

## **Harm Minimisation: what is it and when can it be ethically justified?**

**Angus Dawson<sup>1</sup>**

*1. Sydney Health Ethics, University Of Sydney, NSW, Australia*

Harm minimisation (HM) is a key aim of many actual or proposed public health policies (e.g. supply of clean needles/syringes for injecting drug users; drug testing at music festivals; promoting e-cigarettes over burning tobacco etc). In this talk I try and do two things. First, there is conceptual work to do. Can HM be clearly distinguished from related concepts such as harm reduction, harm prevention and harm avoidance etc? I will argue that it is important to be clear about what we are talking about. Second, assuming we have a clear

concept of HM, where, if at all, is it justifiable to use it as a policy aim? I will argue that it would make no sense to have HM as an overall policy aim, as in at least some cases it makes sense to weigh the chance of harms arising from a policy against other important considerations (such as benefits). It looks as though cases where HM is most plausible as a policy aim are where people are held to be going to act in a harmful way anyway, and we seek to minimise the chances of (preventable) harm arising from such acts. I will explore the nature of this justification in two ways. First, we should note that it takes the form of a conditional, where the antecedent involves an empirical claim which may be contested. Second, it might be argued that HM necessarily involves complicity in harms that it would be better to prevent.

id #1039

## **SYMPOSIA: Prioritisation of Vaccination Groups in an Influenza Pandemic: Ethics framework for prioritising pandemic vaccine**

**Jane Williams<sup>1</sup>, Angus Dawson<sup>1</sup>**

*1. Sydney Health Ethics, University of Sydney, NSW, Australia*

The WHO urges all countries to have a pandemic influenza plan in place and suggests that planners must consider ethical issues raised by responses to a pandemic. Some countries have developed plans, but few attend to ethics of vaccine rationing. The literature offers normative arguments for this purpose but they tend to focus on generalities and are insufficiently sensitive to context. We build upon the findings from our review of the literature and propose a new framework for prioritising pandemic vaccines.

We suggest that due to the unpredictability of virus characteristics, uncertainties in vaccine development, efficacy and effectiveness of the vaccine, as well as the potential differing impact on different population groups, no single answer as to how to guide priorities for pandemic vaccines can be produced in advance. Instead we propose a staged framework as follows: Step 1: define a set of procedures that must necessarily underpin resource allocation in pandemic situations as a foundational requirement (this can be proposed and discussed in advance). Step 2: define a clear aim or set of aims for the pandemic vaccination programme (this can be debated in advance, but can only be finalised once the nature of the virus and vaccine are known). Step 3: propose a flexible and dynamic set of questions to guide decision making about priorities. Some priorities may be determined in advance of a pandemic, e.g. where there are important and ongoing commitments to certain groups. Others will be decided in view of the particular pandemic situation.

id #969

## **Balancing the benefits and risks of technologically enhanced communicable disease surveillance systems: A report on 4 community juries**

**Chris Degeling<sup>1</sup>, Stacy M Carter<sup>1</sup>, Antoine van Oijen<sup>2</sup>, Jeremy McAnulty<sup>3</sup>, Vitali Sintchenko<sup>4,5</sup>, Annette Braunack-Mayer<sup>6</sup>, Trent Yarwood<sup>7</sup>, Lyn Gilbert<sup>8,5</sup>**

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*8. Sydney Health Ethics, School of Public Health, The University of Sydney, NSW, Australia*

Outbreaks of infectious disease cause serious health and social problems. New technologies –whole genome sequencing of pathogens (pathogenomics) and big data analytics – could limit outbreaks and save lives and resources, but social licence is lacking. Their routine use to capture more precise personal health information would be potentially intrusive and a threat to privacy. To elicit the views of well-informed citizens about acceptability and legitimacy of:

- using pathogenomics with deidentified personal data in public health *research*
- adding data-linkage and “smart” analytics to pathogenomics for routine public health *surveillance*

4 citizens’ juries in metropolitan and regional NSW. 50 participants of diverse backgrounds, genders and ages were recruited by random-digit-dialing and social-media advertising. Juries were presented with, and able to question experts on, evidence supporting varied perspectives on potential benefits and risks of technologically-enhanced communicable disease research and/or surveillance. Almost all jurors supported using pathogenomics of routinely

collected patient isolates, with de-identified data-linkage, for public health research. However operationalizing this, using artificial intelligence methods, for routine surveillance was highly contentious; three juries voted in favour and one against, by narrow margins. Those against cited loss of privacy and lack of trust in governments to manage secure, effective systems.

An informed public would likely support use of pathogenomics with data-linkage for research. Combining them with artificial intelligence-based data analytics for routine surveillance would be controversial, despite potential public health benefits, because of lack of public trust. Private sector involvement or commercialisation of personal health data were unanimously rejected.

**id #1041**

### **SYMPOSIA: Prioritisation of Vaccination Groups in an Influenza Pandemic: Should we seek to protect the most vulnerable or maximise vaccine utility during an influenza pandemic? – Participant perspectives from 3 citizens’ juries**

**Chris Degeling<sup>1</sup>, Jane Williams<sup>2</sup>, Peter Massey<sup>3</sup>, Lyn Gilbert<sup>2,4</sup>, Rob Moss<sup>5</sup>, Stacy Carter<sup>1</sup>, Patti Shih<sup>1</sup>, Annette Braunack-Mayer<sup>1</sup>, Jodie McVernon<sup>1</sup>**

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*5. Melbourne School of Population and Global Health, University of Melbourne, VIC, Australia*

The Australian government is committed to providing vaccine to all Australians during an influenza pandemic. Irrespective of how long it takes for a vaccine to become available, initial supply will be limited and exceeded by demand. Community juries were convened in Wollongong (NSW), Melbourne (Victoria) and Kalgoorlie (Western Australia) to assess the public acceptability and perceived legitimacy of pandemic vaccination distribution strategies that aim to:

- directly protect people at high risk of adverse outcomes from influenza infections
- indirectly protect the population by vaccinating primary school students who are most likely to spread infection

34 participants of diverse backgrounds, genders and ages were recruited by random-digit-dialing and social-media advertising. Juries were presented with, and able to question experts on, factual evidence and model-based simulations supporting varied perspectives on potential benefits and risks of vaccine distribution strategies that aim for direct and indirect protection.

All three community juries voted in support of employing a vaccine distribution strategy aimed at achieving indirect protection; Melbourne by a 10-2 majority and Wollongong and Kalgoorlie by consensus verdicts. Jurors in all 3 groups reasoned that indirect protection will benefit more people and is more likely to be more acceptable to the public – in Wollongong protecting children was also a key concern. Jurors were not opposed to prioritising groups at higher risks of adverse outcomes, but chose the indirect strategy because of its assumed effectiveness and efficiency in implementation, such that the fairest outcomes for all were most likely to be achieved by prioritising population benefits.

**id #1123**

### **SYMPOSIA: What Can Deliberation Do in and for Bioethics?: What sort of health policy problems can be addressed by a citizens’ jury?**

**Chris Degeling<sup>1</sup>**

*1. Australian Centre for Health Engagement, Evidence and Values, School of Health and Society, University of Wollongong, Keiraville, NSW, Australia*

Governments make health policy to address problems. For some problems policymaking is orderly because there is broad agreement about the solution. However, some policy problems are controversial because of disagreements about their nature, their relative importance or the best approach to their resolution. In these circumstances, arriving at a politically acceptable definition of the problem, and identifying and evaluating the costs, benefits and implications of likely solutions, become central to policymaking activities. Deliberative methods like Citizens’ juries (CJs) can be organized to bring public values and marginal voices into each of these decision-making dimensions. Especially when the problem –and, thereby, decisions as to its solution requires a deeper consideration of both values and evidence. CJs have been used to address two basic and sometimes overlapping types of policy questions:

- (i) those that focus explicitly on resource allocation, and,
- (ii) those about which policy options are most justifiable and/or legitimate.

Both question types are inherently normative and may produce evidence that supports or challenges both current and future policy decision-making.

In conducting a CJ, researchers need to consider their goals in respect to the trade-offs between maintaining research independence and seeking to formally integrate the outcomes into established policy processes. Maintaining independence can provide valuable insights into otherwise hidden issues, but risks failing to meet the political/evidentiary needs of relevant institutions. Conversely, projects driven by policymakers' agendas may exclude politically unpalatable community interests or values and may be perceived by community members as lacking independence or tainted by conflicts of interest.

id #1033

## Preventing “bad deaths”: would the Australian “mercy killing” cases be avoided by legalising voluntary assisted dying?

**Katrine Del Villar<sup>1</sup>, Lindy Willmott<sup>1</sup>, Ben White<sup>1</sup>**

1. *Queensland University of Technology, Brisbane, QLD, Australia*

One argument in favour of legalising voluntary assisted dying (VAD) is that terminally ill people are ending their lives in “desperate, determined and violent ways” because there is no other way to end their suffering. It is asserted that these “bad deaths” can be prevented by introducing legislation permitting VAD.

Numerous criminal prosecutions have been brought in Australia against a person who has either assisted a loved one to commit suicide, or killed them, as an act of compassion and mercy, to put an end to their suffering. This paper reviews the Australian cases concerning assisted suicide and “mercy killings” against the eligibility criteria for VAD under the *Voluntary Assisted Dying Act 2017* (Vic).

The paper concludes that the deceased in many of the “mercy killing” cases would not have qualified for VAD under the Victorian legislation, for two main reasons. Firstly, VAD will only apply where a request to die is voluntarily made by a person with capacity. Several of the ‘mercy killing’ cases concern people who were not competent, by reason of dementia, severe stroke or disability. Secondly, a person will only be eligible for VAD if they are suffering from a terminal medical condition. The majority of the assisted suicide and “mercy killing” cases involved a request to die made by a person whose condition was not terminal. Because VAD is targeted at a narrow range of deaths, of those who are already dying, its legalisation will not prevent “bad deaths” from continuing to occur in Australia.

id #1009

## Testing times: How to regulate DIY diagnosis?

**Tarishi Desai<sup>1</sup>, Kate Whittaker<sup>2</sup>**

1. *McCabe Centre for Law and Cancer, Melbourne, Victoria, Australia*

2. *Cancer Council Australia, Sydney, New South Wales, Australia*

Companies in Australia and abroad are marketing various ‘health checks’ directly to consumers, without individual consultation with qualified medical practitioners. These are known as direct-to-consumer (‘DTC’) tests, which can be genetic or non-genetic in nature. These DTC tests include purported non-genetic cancer marker screening tests for diseases such as ovarian, bowel and prostate cancer from blood samples. Some companies are promoting DTC cancer marker tests to healthy consumers with the aim of ‘democratising’ pathology and healthcare and encouraging consumers to ‘take control’ of their health, while also potentially capitalising on fears of a cancer-related death. While some applaud the development of DTC tests, such tests raise ethical, medical and legal concerns. Whereas DTC genetic tests are subject to specific legal and policy regulation in Australia, DTC non-genetic tests — such as DTC cancer marker tests — are not. Australian regulation of such tests is piecemeal and fragmented. Using DTC cancer-marker tests as a case study, this presentation will examine the key ethical, medical and legal challenges of DTC non-genetic tests; the current regulatory framework in Australia; and will provide an opportunity to discuss ways to improve the regulation of these devices. As the concerns and challenges faced in Australia are likely to mirror those of other comparable jurisdictions and form an emerging example of technology disrupting traditional medical practice, this presentation will contribute to the exchange of learnings and ideas; highlight the need for effective regulation; and may identify potential future collaborative work on responding to innovation in healthcare.

id #1011

## The value of autonomy

**Lisa Dive<sup>1</sup>**

1. *University of Sydney, Camperdown, NSW, Australia*

In this presentation I will argue that we should treat autonomy as something that has instrumental value only, rather than it being something that is valuable in and of itself. To support this claim, I will review and assess some of the arguments for autonomy having intrinsic value. I will argue that the main arguments put forward for seeing autonomy as intrinsically valuable are

problematic and that seeing autonomy as instrumentally valuable is not only justifiable but also has a number of advantages. For example, we can explain autonomy's value by seeing it as a vital component of human flourishing, and this can provide sound reasons for overriding autonomy claims where they result in potential harms. Therefore, we have good reason to see autonomy as something which has instrumental value, rather than being intrinsically valuable.

**id #1015**

### **Biobank networks, medical research and the challenge of globalisation**

**Lisa Dive<sup>1</sup>, Christine Critchley<sup>2</sup>, Miriam Wiersma<sup>1</sup>, Edwina Light<sup>1</sup>, Paul Mason<sup>3</sup>, Catherine Waldby<sup>1</sup>, Robert Cumming<sup>1</sup>, Cameron Stewart<sup>1</sup>, Emma Kowal<sup>4</sup>, Wendy Lipworth<sup>1</sup>, Ian Kerridge<sup>1</sup>**

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Biobanks of human biological materials and data are increasingly being linked together in networks that seek to maximise their capacity to identify causes of and treatments for disease, in order to benefit medical research, clinical medicine and public health. These biobank networks raise considerable ethical, legal and socio-cultural concerns about control and custodianship, benefit sharing, exploitation of vulnerable groups, and fulfilling cultural obligations. These concerns are magnified and increase in complexity as biobanks network across international borders.

We will present findings of a national research project analysing the ethical, legal and social issues raised by biobank networks and the challenge of globalisation. This included a survey of the perspectives and practices of Australian biobanks with respect to networking and globalisation, a survey of the Australian public to assess their attitudes to participation in global biobanks and networks, as well as qualitative interviews with both stakeholder groups. Empirical work was complemented by conceptual analysis incorporating globalisation theory, and detailed consideration of ethical concepts such as trust.

This presentation will synthesise the study results and offer several recommendations for policy and practice in global biobanking

**id #967**

### **Decision-making by and for persons with cognitive disabilities: an interpretation of article 12 of the Convention on the Rights of Persons with Disabilities - the right to legal capacity - that takes into account economic, social and cultural rights**

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Article 12 of the UN Convention on the Rights of Persons with Disabilities (CRPD) provides that persons with disabilities enjoy legal capacity equal with others and that they be supported to exercise such capacity. This means that they are to make their own decisions in relation to healthcare, accommodation, finance and other personal matters. The imperative to introduce supported decision-making for adults with cognitive disabilities as the default practice has been widely embraced; but the practical way forward for people with profound and severe cognitive disabilities is far from clear. The United Nations Committee on the Rights of Persons with Disabilities interprets the CRPD as prohibiting substituted decision making in all guises and in all cases. The Australian Law Reform Commission and others propose that substituted decision making be retained as "a last resort" and as a protective measure in "hard cases." But it is important for such representative decision making not to fall back into a paternalistic model. An approach which interprets article 12 in the context of the whole of the CRPD, applying the doctrine of indivisibility of human rights is proposed to enable a human rights-based approach to substituted or representative decision making in cases of severe and profound cognitive disabilities. An interpretation of article 12 through the lens of indivisibility would place the adult with impairment as the subject of rights – especially in upholding economic, social and cultural rights to health, housing, even when a representative may make a decision "as a last resort."

**id #966**

### **Proactive Provision of Contraception to Adolescents in New Zealand: a Concept**

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In NZ, 98% of pregnancies in adolescents aged 11-14 are unplanned, and 93% of pregnancies in adolescents aged 15-19 are unplanned. In this population, 41%

of adolescents aged 16-19 have had sex and 58% of sexually active adolescents consistently use contraception.

Barriers to contraceptive access include financial cost, opportunity cost, lack of awareness, and persistent myths and misconceptions about different methods. We propose a proactive contraception provision programme to overcome these barriers.

With a proactive approach, all adolescents would be approached, regardless of sexual activity, and offered a free confidential consultation. Each consultation should include a discussion about safe sex (including STI protection), and a tiered contraceptive counselling approach. Adolescents would then be offered their contraceptive method of choice.

In this presentation we will look at acceptability of such a programme, and discuss three key questions:

1. Which contraceptives should be offered?
2. Which age group should this programme be offered to?
3. Should this be offered to all adolescents, or only female adolescents?

In conclusion, proactive contraception provision is a concept that offers some clear benefits. It could improve adolescents' contraceptive knowledge, and decrease unintended teenage pregnancy by empowering adolescents to control their fertility in whatever way suits them best.

**id #953**

## **Why Somatic Cell Gene Editing Research Could Be Slipping Through Australian Regulatory Cracks**

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Gene editing promises revolutionary medical advances. To date, 38 clinical trials involving somatic cell gene editing are listed on [www.clinicaltrials.gov](http://www.clinicaltrials.gov), 18 of which are recruiting or currently active. Although no such trials appear to have commenced in Australia, it is likely only a matter of time. Robust safety reviews of gene editing trials will be essential. However, complexities and gaps in the Australian regulatory system raise questions about which bodies will provide such review and their capacity to do so.

- The Office of the Gene Technology Regulator reviews trials involving genetically modified organisms. However, reviews expressly delegate consideration of risks to participants to the Therapeutic Goods Administration (TGA) and Human Research Ethics Committees (HRECs) to avoid potential regulatory

duplication.

- The TGA administers the Australian therapeutic goods legislation, including prohibitions on the supply of unapproved therapeutic goods. However, the Administration only assesses product safety directly for trials conducted under the Clinical Trials Exemption (CTX) scheme, as compared with the far more common Clinical Trials Notification (CTN) scheme. The CTX scheme is only mandatory for certain high risk biologicals, which may not include all gene editing products.
- HRECs review all Australian clinical trials, including the trial's risk-benefit profile, but not all will have the necessary expertise to assess highly innovative trial products such as gene editing constructs and vectors.
- Institutional Biosafety Committees ensure the safe, compliant and appropriate use of biologically hazardous materials. However, this review addresses only a small portion of the risks that might arise from gene editing trials.

**id #1018**

## **Should Professional Interpreters be able to Conscientiously Object in Healthcare Settings?**

**Nathan Emmerich<sup>1</sup>, Christine Phillips<sup>1</sup>**

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Whilst the notion that healthcare professionals are able to conscientiously object to certain medical practices, such as abortion and euthanasia, is well established it remains a topic of academic debate. Some reject think we should disallow such claims entirely. Others advocate for a relatively wide acceptance of such claims. However most seek to delimit its scope or the boundaries of its license. In an attempt to illuminate something of this issue, we consider whether or not professional interpreters working within healthcare should be afforded the same or similar access to established conscientious objections i.e. those to which healthcare professionals can lay claim. Focusing on Australia, we argue that the conscientious objections of interpreters should not be accommodated. This conclusion is consistent with the Code of Ethics promulgated by their own professional body, the Australian Institute of Interpreters and Translators (AUSIT). Having drawn this conclusion we then consider its implications for the way conscientious objection should be understood. We suggest that whilst the existence of a reasonably well-founded moral objection is essential, more is required to establish a broader right of being able to conscientiously object to some act or activity. Thus, we develop the view that conscientious objections

are socio-political devices that serve to accommodate good faith moral disagreement in some cases, such as healthcare professionals, but need not do so in all cases, such as professional interpreters working in healthcare.

id #972

## Equality in healthcare: why socio-relational theorising matters for healthcare improvement

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Many health services repeatedly generate examples of staff treating patients dismissively, or with disdain, or behaving with arrogance or aloofness in ways that position people who use health services as subordinates or supplicants. These behaviours are particularly problematic and prevalent in the treatment of already socially disadvantaged groups. However, they are rarely tackled in healthcare improvement initiatives and hardly feature in discussions of equality in healthcare, which tend to focus on distributive patterns of health and of access to healthcare.

In this paper we suggest that socio-relational accounts of equality have as-yet untapped potential for normative analyses of healthcare, and particularly of the cluster of (often micro-) communicative behaviours associated with disrespect and superiority/subordination. Socio-relational equality focuses on how people view each other and relate to each other as equals. It can help illuminate that and why a discourse of equality that focuses exclusively on distributions of goods between patients goes awry in healthcare improvement contexts as it effectively aligns with Professor Henry Higgins from George Bernard Shaw's *Pygmalion* as he tells Eliza «The question is not whether I treat you rudely, but whether you ever heard me treat anyone else better».

There are clearly questions to be addressed about the application of socio-relational equality in professional healthcare contexts, but we will suggest it has significant generative potential for recognising and understanding the ethical relevance of healthcare relationships and ideas about person-centred care, including in the contexts of broader socio-cultural forms of disadvantage and discrimination.

id #1025

## Against Accuracy: A Defence of Value Congruence in Proxy Decision-Making

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For proxy decisions to carry the same weight as those made contemporaneously by patients, they must meet a criterion of normative authority. The substituted judgement standard identifies normative authority with accuracy: proxy decisions should accurately replicate the decision the patient would have made under the circumstances were they competent (Buchanan and Brock 1992). However, studies have consistently demonstrated that proxies are only accurate around 68% of the time (Shalowitz, Garrett-Mayer, and Wendler 2006). Indeed, even after proxies have engaged in focused discussions with patients regarding their wishes, proxy accuracy does not significantly improve (Bravo, Sene, and Arcand 2018). This has motivated some commentators to suggest that we should either ditch proxy decision-making in favour of advance directives, or simply act in line with the patient's best medical interests.

I suggest that falling back on these options is unnecessary. Instead of requiring that proxies accurately replicate patient wishes, I argue that they should make *value congruent* decisions. My position is that a proxy's decision carries normative authority insofar as it reflects what the patient values, and that this is the case even if it fails to replicate exactly what the patient would have chosen. I end by noting that insofar as value congruence ought to be the aim of proxy decision-making, the current model of proxy appointments is inadequate. As I will show, proxies should be appointed because they share key medically relevant values with the patient. This value-sharing confers the kind of epistemic access required to produce value congruent decisions.

id #1038

## Twelve Angry Proxies: Moving to Distributed Proxy Decision Making

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In the context of substitute decision-making, patients standardly appoint a

single proxy to make medical decisions on their behalf. This single-proxy model makes sense: after all, many patients are reluctant to discuss what they would like to happen to them once they lose competence with a single individual, let alone several. Moreover, even when presented with the possibility of appointing multiple decision-makers to act on their behalf, most patients still prefer to appoint one person (Frey, Hertwig, and Herzog 2014; Frey, Herzog, and Hertwig 2018).

However, it is now well known that individual proxies exhibit appreciable unreliability. They frequently fail to accurately replicate decisions that the patient themselves would have made under the circumstances were they able (Shalowitz, Garrett-Mayer, and Wendler 2006). Meanwhile, a body of empirical literature suggests that group deliberation, under felicitous conditions, produces more reliable decision-making than reasoning performed by individuals. This seems to license the conclusion that our reasoning capacities are much improved when they are embedded in a dialogical context (Mercier and Sperber 2011).

We will argue that patients, in at least some cases, would be better served by appointing multiple proxy decision-makers to act on their behalf. We begin by outlining the evidence in favour of distributed decision making, before applying these insights to the context of proxy deliberation. Given the substantial difficulties besetting proxy decision making, we aim to show that there are significant benefits to moving to a distributed model involving multiple, jointly appointed, proxies.

id #997

## Must we? The ethical and practical challenges of implementing consumer preferences for participation in dementia research

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The World Health Organization has declared dementia a public health priority. The process of aligning the research agenda with this priority elicits significant challenges in studying the prevention, detection, and treatment of dementia. For example, emerging technologies such as speech tracking through smartphone apps are being investigated as tools to detect cognitive decline. However, studies are limited by ethical and legal concerns for adequate consent and privacy hindering recruitment of essential research participants with moderate

to severe cognitive impairment. Overall, these challenges may be preventing valuable translational research that would benefit the health, care and quality of life of dementia consumers. Robust justification to support whether and how the policies and practices that govern dementia research should be changed remains elusive. In two steps, this paper addresses the perennial question in ethics of whether *descriptive* data can provide an ethical impetus for what *ought* to be done. First, we present the results of a scoping review of dementia consumers' preferences for participation in research according to six ethically challenging themes: (1) motives for research participation, (2) informed consent, (3) recruitment, (4) potential risks, (5) data sharing, and (6) use of technology. Second, consumer preferences from the scoping review are situated in the context of current research ethics policies to demonstrate how their implementation might create opportunities for dementia research or pose collateral practical and ethical challenges. This analysis initiates a dialogue about options for reforming dementia research and continues the debate on the normative nature of patient engagement activities.

id #1087

## Neuroethics as a guide to ethics

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The neural underpinning of ethical reasoning comprehensively involves structures throughout the brain. That anatomical correlate ranges from areas involved in sensory function, to motor, language-related, emotive, and social functions. Such an inclusive neural basis indicates the scope of ethical engagement as a cognitive task, various aspects of which are the focus of various kinds of ethical deliberation and discussion. An inclusive view inspired by brain integration as the highest level of neural function equips human beings for situated or ethological self-development. That engagement rests on sensory, motor, and other function which are more organic and dynamic than the conceptualisations of many philosophical accounts can capture. Work in brain dynamics and ecologically situated cognition which draws and builds on our natural and relational tendencies can indicate and enrich our understanding of ethics. That enrichment can inform areas such as environmental ethics, animal ethics, the ethics of entitlement and marginalisation, and many new initiatives that do not fit well into a framework of cognition and propositional attitudes as currently conceived. These new and inclusive directions should be informed by the analyses and debates that neuro-philosophical approaches embody.

id #971

## Ethics as Culture; Euthanasia and Gun Control

**Ben Gray<sup>1</sup>**

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In his books *Sapiens* and *Homo Deus*, Yuval develops his thesis that humans have succeeded as a species because groups of people with language and abstract thought developed shared stories that enabled them to live together in larger groups than was possible for the great apes.

Broadly the stories fell into three groups:

1. Stories that explained the world; where food was to be found, when to plant crops according to season, how to catch fish, how to use tools. These stories in the modern world are now largely the domain of science
2. Stories that were developed to enable living together in larger groups. Harari gives two good examples. Money and the corporation, both of which only “exist” in legislation and practice. Other examples would be shared weights and measures.
3. Stories describing “right behaviour”, the domain of ethics.

I would argue that what he is describing here is culture, and that ethics is not only culture bound but an inherent feature of a particular culture.

For this presentation I want to demonstrate the utility of this hypothesis in considering two current ethical debates; Euthanasia and Gun Control.

This hypothesis determines that the goal is to work out how people who disagree (who have different cultural views on an issue) can live together.

Relevant questions are:

1. Why do the disagreeing parties hold their particular view?
2. How to move forward despite disagreement; the ethics of compromise.
3. What are the limits to the use of power?

Harari YN. *Homo deus : a brief history of tomorrow*. First U.S. edition. ed. New York, NY: Harper, an imprint of HarperCollins Publishers; 2017.

1. Harari YN. *Sapiens : a brief history of humankind*. First U.S. edition. ed. Purcell J, Watzman H, Gower N, editors. New York, NY: Harper, an imprint of HarperCollinsPublishers; 2015.

id #1006

## Law and genomic data sharing: beyond consent

**Norah Grewal<sup>2, 1</sup>, Ainsley J Newson<sup>2, 1</sup>**

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A key aspect of genomics is the sharing of genetic and related health data: across borders, among unrelated entities, and between clinical and research contexts. But uncertainty abounds, both because these contexts are intermingling and because technological advances put pressure on existing regulation. In this paper, we draw on relevant examples to explore and assess potential legal barriers to genomic data sharing in Australia. We find that it can be difficult to utilise the nascent concept of ‘translational research’ because the Australian information privacy statutes treat research and healthcare as discrete purposes. For example, a laboratory that wishes to share existing clinical data for research must satisfy a ground such as consent each time. But even when people give consent to share, in some states the laboratory might only be able to share with interstate or overseas recipients when the obtained consent is specific to this transfer. That is, broad consent – commonly used when obtaining research permissions in clinical practice – is not sufficient for all cross-border genomic data transfers. However, consent is merely one of several lawful grounds for sharing. If other grounds like ‘public interest’ are under-explored, then consent risks becoming an unjustified ‘cure-all’, impractical to apply at scale. Similar grounds exist within the new European General Data Protection Regulation. In response, we highlight opportunities for Australian legal reform that build on existing grounds for sharing genomic data beyond consent. These would harmonise the current overlapping regime without requiring a complete overhaul, nor specific regulation.

id #968

## Scanlon’s contractualism and the doctor-patient relationship in bioethics.

**John Gruner<sup>1</sup>**

1. *Monash Bioethics Centre, Clayton, VIC, Australia*

As a clinician, sometimes I must justify to patients and myself how far my professional role may extend as their doctor, particularly in cases of misunderstanding or disagreement over a clinical issue. For example, in attempting to advise a parent who is strongly against childhood vaccination, I

have found that it might be misconstrued as disrespectful, and it is ineffective to simply cite “best available evidence”, if we cannot agree on how to determine what are the potential possible harms and benefits of vaccination. The parent may argue that they have other values that take precedence over my comparatively narrow conception of health. However, plausibly there is room for debate if I may engage in dialogue over beliefs and values if not “evidence”. This paper argues that common conceptions of the doctor - patient relationship not only have a philosophical basis more fitting some forms of contractualism than other ethical theories, but that by using contractualism, doctors and patients can decide together, what health beliefs and values that pertain to health, either party can reasonably tolerate or support. While I briefly detail several philosophical accounts of contractualism, I defend an account of contractualism that has a strong focus on what individual doctors and patients owe each other. I argue that Scanlon’s ethical theory fits well with several models of the ideal doctor patient relationship, particularly Emmanuel and Emmanuel’s widely cited “ideal deliberative model”.

id #908

## **My Pain and Suffering is not Negated by My Death - A paper exploring whether a plaintiff’s right to general damages should be preserved after their demise**

**Naty Guerrero-Diaz<sup>1</sup>, Janine McIlwraith<sup>1</sup>**

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In most Australian jurisdictions, if a plaintiff in a claim for damages for personal injury dies as a result of the medical negligence, the cause of action survives for the benefit of the estate, with the exception of the rights of the estate to the recovery of damages for pain and suffering for bodily or mental harm or for the curtailment of expectation of life. In contrast, the position was specifically varied by legislation in relation to asbestos exposure claims so the entitlement to general damages survives the plaintiff’s death. This paper explores the foundation for the rule and whether the distinction between asbestos exposure claims and other personal injury claims can be justified in modern litigation, with particular reference to the potential incentives for defendants to delay and the resultant injustice of the rule in expedited hearings for medical negligence.

id #962

## **Drugs, Genes and Screens: The ethics of preventing and treating Spinal Muscular Atrophy**

**Chris Gyngell<sup>1</sup>**

1. University of Melbourne, Clifton Hill, VIC, Australia

Spinal muscular atrophy (SMA) is the most common genetic disease that causes infant mortality. Its treatment and prevention represent the paradigmatic example of the ethical dilemmas of 21<sup>st</sup>-century medicine. New therapies (nusinersen and AVXS-101) hold the promise of being able to treat, but not cure, the condition. Alternatively, genomic analysis could identify carriers, and carriers could be offered IVF and PGD. In the future, gene editing could cure the condition at the embryonic stage. How should these different options be evaluated and compared within a health system? In this paper, we discuss the ethical considerations that bear on the question of how to prioritise the different treatments and prevention options for SMA, at a policy level. We argue that despite the tremendous value of what we call ‘ex-post’ approaches to treating SMA (such as using pharmacological agents or gene therapy), there is a moral imperative to pursue ‘ex-ante’ interventions (such as carrier screening in combination with prenatal testing and preimplantation genetic diagnosis, or gene editing) to reduce the incidence of SMA. There are moral reasons relating to autonomy, beneficence and justice to prioritise ex-ante methods over ex-post methods.

id #937

## **Legality of Embryonic Gene Editing in Australia**

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1. University of Melbourne, Carlton, VICTORIA, Australia

The recent birth of the first ever gene edited children raises imminent questions about the future of embryonic gene editing research. The use of the CRISPR-cas9 genome editing system (CRISPR) to edit embryonic cells initially raised widespread criticism and calls for an international ban on genome editing research based on concerns that research would inevitably lead to reproductive applications. Despite this, governments around the world are now reviewing the regulatory frameworks that oversee genetic technologies and embryonic gene editing research is progressing in some jurisdictions.

In Australia, although the use of genome editing in reproduction is clearly prohibited, the legality of embryonic gene editing research remains unclear. The *Prohibition of Human Cloning for Reproduction Act 2002*(Cth) and the *Research*

*Involving Human Embryos Act 2002*(Cth) expressly regulate the use of genome editing in early human embryos. In this paper we analyse how these two Acts regulate research involving CRISPR and the implications of this for research practices in Australia. We argue that, given the current regulatory uncertainty around the legality of genome editing research in Australia, legislative reform is needed. We propose some reforms that would provide greater clarity in this area and ensure the availability of suitable embryos to make gene editing research feasible.

id #1024

## Practices of (Mortal) Freedom: Voluntary Assisted Dying and the Conduct of 'Choice'

**Courtney Hempton<sup>1</sup>**

1. Monash University, Clayton, VICTORIA, Australia

On 19 June 2019 the Voluntary Assisted Dying Act 2017 (Vic) came into effect, making Victoria the first state in Australia to establish a regime of physician-assisted death. As described by the Department of Health and Human Services, the legislation “provides a safe legal framework for people who are suffering and dying to *choose* the manner and timing of their death”<sup>1</sup>. If voluntary assisted dying entails some kind of state-sanctioned ‘freedom’ to choose death—albeit contingent on a medicalised rendering of ‘suffering and dying’—then what kind of freedom is it? While a rhetoric of ‘choice’ is pivotal to the institution of voluntary assisted dying, the model enacted offers individuals neither a positive or a negative claim to medical assistance to die. In this paper, I draw on Michel Foucault’s conception of biopolitics to account for the kind of freedom produced by the state’s management of voluntary assisted dying. Construed in terms of relations of power, I argue the state’s voluntary assisted dying apparatus does not make individuals any ‘freer’ per se; it is necessary to already *be free* in some relevant sense. Instead, the conditions of voluntary assisted dying function to circumscribe the ‘field of possibilities’ within which freedom may be exercised (i.e. the ‘conduct of conduct’)—to be realised, voluntary assisted dying necessitates a *practice* of (mortal) freedom. Productively, this understanding of freedom enables the sketching of a fuller biopolitical account of voluntary assisted dying, allowing for the consideration of governmentality, an ‘ethics of the self’, and possibilities for resistance.

1. Victorian Government Department of Health and Human Services. Voluntary assisted dying: Overview. [health.vic.gov.au/hospitals-and-health-services/patient-care/end-of-life-care/voluntary-assisted-dying/vad-overview](http://health.vic.gov.au/hospitals-and-health-services/patient-care/end-of-life-care/voluntary-assisted-dying/vad-overview). Accessed 15 July 2019.

id #1067

## What ethical considerations exist at the intersection between social media, bioethics and research?

**Elizabeth Hill<sup>1</sup>**

1. Victoria University, Melbourne, VICTORIA, Australia

The use of social media is becoming more prevalent in every aspect our lives. More researchers are using social media both as a means to recruit research participants for studies and as a source of raw data. People using social media make certain assumptions as to how their data is protected and used.

In this discussion, social media is defined as any social online data except for email. Health related uses of social media can include discussion forums, chatrooms and blogs. These online forums are used by both private (password protected) groups or public forums.

This presentation discusses issues such as the terms and conditions of the social media platforms, user assumptions, the concept of implied agreement, when informed consent is needed, and issues of privacy and anonymity.

I will focus on a number of examples of health/medical based research projects involving social media and related problematic issues. Also discussed will be when informed consent is needed, this issue of difficulty of determining if children or other vulnerable individuals have posted their information to these sites and minimising risk.

id #1042

## Supporting Patients, Families, and Palliative Care Clinicians in the New Legislative Era of Assisted Dying

**Anita Ho<sup>1</sup>, Soodabeh Joolaei<sup>1</sup>, Kim Jameson<sup>1</sup>, Christopher Ng<sup>1</sup>, David Kirchhoffer<sup>2</sup>, Chi-Wai Lui<sup>2</sup>**

1. University of British Columbia, Vancouver, British Columbia, Canada

2. Australian Catholic University, Brisbane, Australia

As legislation regarding medically assisted death develops and evolves in Canada and Australia, healthcare organizations are establishing guidelines and processes to address ethical issues and support patients, families, and clinicians in the new legal landscape. This presentation will focus on findings from our qualitative content analysis of semi-structured interviews with 26 interprofessional palliative and hospice care providers (PHCPs) in Vancouver, Canada. The interviews elicit PHCPs’ experience caring for patients who inquired about or requested assisted dying. They focus on PHCPs’ views

of what is working well when engaging in end-of-life (EOL) discussions and providing EOL care since the legalization of assisted dying, challenges and dilemmas PHCPs have encountered or foresee, and what resources may help to enhance their ability to manage various challenges and provide high-quality care in the new legislative era. Participants highlighted the moral dimensions of their evolving roles and responsibilities in supporting patients and families. In particular, they noted logistical and symbolic similarities and differences in advising and supporting patients, families, and colleagues through natural vs assisted deaths. They discussed how assisted dying evokes different forms of moral distress for PHCPs of various roles and belief systems, and also requires different bereavement support for families. This presentation will explore how these factors intersect as PHCPs and institutions adjust to the new legal and organizational realities. Findings will inform international practices and guidelines that can help to support interprofessional care providers, patients, and families as they navigate the new ethical and legal terrain in EOL care.

**id #1054**

## **Precaution and Benefit in Research Involving Implant of Neurodevices**

**Calvin Ho<sup>1</sup>, Karel Caals<sup>1</sup>**

*1. National University of Singapore, Singapore*

The principles of precaution and beneficence are introduced by the Nuffield Council on Bioethics (2013) in its proposed ethical framework for novel neurotechnologies. The principle of precaution does not mean that research should only proceed when in the absence of any risk of harm to participants. Rather, it is recognition of the need to accept some risks, and uncertainties around them, provided that the research could confer a significant benefit to existing patients or advances public good. In turn, the principle of beneficence relates to the responsibility to do good where possible. While these principles require risks to participants to be identified and minimised, and participants should be carefully selected to minimise risks and enhance benefits, it is less clear if a participant should be involved in the research where there is no conceivable benefit but the prospect of harm is likely to be minimal. This paper considers ethical contentions that arise from the involvement of especially vulnerable persons (tetraplegic patients, for instance (Clausen et al., 2017)) in research that involves the implantation of neurodevices with the intent of enabling these persons to communicate and/or control an external assistive device in real time. As many of these novel neurotechnologies are mediated by artificial intelligence (AI) programs, key ethical and regulatory

implications are also examined in this context, with focus on the ethical roles and responsibilities of ethics review committees and research funders in meeting the ethical requirements of caution and benefit.

1. Nuffield Council on Bioethics, *Novel Neurotechnologies: intervening in the brain*. London: Nuffield Council on Bioethics, 2013.
2. Clausen J, et al. Help, hope, and hype: Ethical dimensions of neuroprosthetics. 2017. *Science* 356(6345):1338-1339.
- 3.

**id #909**

## **Moral case deliberations using the dilemma method, a Dutch perspective**

**Mascha J Hoexum-Moerenburg<sup>3,1,2</sup>**

1. *Post Graduate Student Bioethics, Otago University, Dunedin, New Zealand*
2. *Speech Language Therapist, Allied Health, Waitemata DHB, Auckland, New Zealand*
3. *Takai Clinical Ethics Consulting, Mairangi Bay, Auckland, New Zealand*

Ethical dilemmas are part of daily work in a clinical situation. Dilemmas are often resolved directly within the relevant clinical setting. However, with current medical advances, emerging technologies and issues like a growing ageing population with more complex comorbidities, dilemmas are at times, not easily solved. Traditionally a Clinical Ethics Advisory Group (CEAG) would be approached. Research and experience, however, has shown that this is not always the case. In The Netherlands, a trend has been observed whereby hospitals and long-term care facilities are implementing a moral case deliberation (MCD) service. This service often operates alongside the more traditional setting of a CEAG. The aim of moral case deliberations using the dilemma method (DM) is to use a facilitated dialogue based on self-reflection in order to solve a moral dilemma. The moral dilemma is explored with the health care professionals who are involved in the case, as opposed to an expert opinion being provided by an external party such as a CEAG. This presentation aims to provide a brief overview of moral case deliberations using the dilemma method in the Netherlands, how it can be used in conjunction with a CEAG and its potential for Australasia.

id #911

## Use of DIY technologies in diabetes management and child welfare

**Carolyn Johnston<sup>1</sup>, Chriselle Hickerton<sup>2</sup>**

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2. *Murdoch Children's Research Institute, MCRI, Melbourne, VIC, Australia*

This paper explores the legal and ethical concerns raised where parents use DIY technologies to manage their child's type 1 diabetes. A DIY system in diabetes management refers to a continuous glucose monitor and insulin pump which are linked using open source software, and insulin is delivered automatically, based on real-time glucose levels. DIY hybrid closed loop systems have not undergone the usual testing and analysis required by therapeutic approval processes and hence cannot be relied upon as being safe within the scope of the Therapeutic Goods Act 1989. There is anecdotal evidence that some people with diabetes in Australia, including some under 18 years old, are using DIY systems. Diabetes Australia issued a position statement stating that if a person with type 1 diabetes (or a parent or family member) chooses to build a DIY system, they must continue to receive support and care from their diabetes healthcare professional and the health system. However, healthcare professionals working in diabetes management may have valid concerns about their legal liability if they treat or support patients using DIY systems. We will report on findings from a qualitative study of paediatric endocrinologists, diabetes educators, medical indemnity insurers, software developers, social workers and parents about their views on risks and benefits of DIY systems.

Our presentation will consider issues of child welfare, the role of parental discretion and whether use of DIY systems could ever raise an issue of child protection.

1. Johnston C, Gillam L. 'Legal and Ethical issues arising from the use of emerging technologies in paediatric type1 diabetes' QUT Law Review (2018) 18 (2) 93 – 110

id #907

## The current legal and clinical framework for treatment of gender diverse youth in Australia

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Legal, ethical and clinical complexities surrounding consent to medical treatment

for gender dysphoric youth in Australia continue to develop. Significant but inconsistent changes to case law principles are requiring lawyers, policymakers, clinicians and youth to grapple with an ever-shifting context. Until recently, all gender diverse youth seeking treatment were required to seek either judicial approval of treatment or judicial assessment of *Gillick* competency, depending on the stage of treatment sought. In significant developments, judicial decisions in *Re Jamie* in 2013 and *Re Kelvin* in 2017 removed the need for court oversight of treatment in many circumstances. However, those decisions contained conceptual difficulties, the situation for minors falling outside the ambit of those decisions is relatively unexamined, and subsequent decisions by Family Court judges have left this area unsettled. In addition, new *Australian Standards of Care and Treatment Guidelines* specific to this group represent a significant development in the clinical context. While in early court judgements treatment for gender diverse youth could have been viewed as novel, and perhaps deserving of judicial scrutiny, there is now relatively established medical consensus on appropriate treatment. Despite this, the legal context remains unclear and the law's conformity with fundamental legal principles warrants scrutiny. This presentation outlines recent developments in the law and clinical guidance relating to consent for medical treatment of gender diverse youth, with particular focus on the 2017 case of *Re Kelvin* and subsequent cases. Conclusions are drawn regarding implications for law, clinical practice, and gender diverse youth.

id #1051

## Ethico-Legal Considerations for an Integrated Electronic Health Record in the Australian Mental Health System

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People with complex mental health conditions may access many services across the health, mental health and social care systems (1). To provide high-quality care, it is essential that these services share information and collaborate; though in reality information sharing is limited in part due to privacy concerns (2). The need for greater information sharing is also occurring at a time of increasing digitisation of our health system. A 2014 review into Australia's mental health system by the National Mental Health Commission proposed the idea of a care

plan that would be contained within an electronic health record accessible by all of the services that people with complex mental illness may access (2). This aligns with the idea of an integrated electronic health record (iEHR), which has been conceptualised in the literature as a record that is longitudinal, prospective, comprehensive, and person-centred (3).

This work aims to map the ethico-legal privacy considerations for an iEHR in Australian mental health contexts. To do this, we will undertake an analysis of key legal and normative documents at federal, state, professional, and organisational levels in Australia. This analysis will uncover key legal and ethical themes regarding information privacy, which will be used to frame considerations for an all-services iEHR in Australia.

Early findings point to a lack of clarity around how the ethical and legal norms regarding sharing information with other care providers will be applied in the case of an iEHR which changes the time-frame in which information is shared and received.

1. Lee, Crowther, Keating, & Kulkarni. (2013). What is needed to deliver collaborative care to address comorbidity more effectively for adults with a severe mental illness? *Aust NZ J Psychiatry*, 47. doi:10.1177/0004867412463975
2. National Mental Health Commission. (2014). *The National Review of Mental Health Programmes and Services*. Retrieved from <http://www.mentalhealthcommission.gov.au/our-reports/contributing-lives,-thriving-communities-review-of-mental-health-programmes-and-services.aspx>
3. Garde, Knaup, Hovenga, & Heard. (2007). Towards semantic interoperability for electronic health records. *Methods of Information in Medicine*, 46(03), 332-343. doi:10.1160/ME5001

## id #1029

### The New Frontier of Health Data Governance

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There is a growing interest from governments around the world and institutions in both the public and private spheres, to derive benefits from the access and use of health data. Much of this data is routinely collected by patients and healthcare professionals in clinical and diagnostic settings; or through self-monitoring mobile applications offered by global companies such as Google, Apple and Samsung; as well as self-reported data provided through social

media sites that allow citizens to post and compare details about their health condition. International research consortia also collect and share genomics and other clinical data for different purposes across borders, and research platforms allow these to be accessed by researchers across the globe. These aggregated datasets hold an immense wealth of information which can be unlocked with AI and machine learning technologies, so that some commentators have referred to health data as the “new oil”. However, we have seen social media corporations harvest data collected by millions of individuals, to generate revenues in multiple ways, that are not directed at public benefit.

The purpose of this paper is to critically explore some of the new models of governance that are being proposed for data infrastructure: such as the idea of the Medical Information Commons, the self-regulation model proposed by Google, facebook and Amazon, and individual data dividends. How do we maximise the monetary and technological benefits for individuals and the wider society, without inadvertently increasing health inequalities and unduly profiting private companies.

## id #943

### Who is the patient? Tensions between Advance Care Planning and Shared Decision Making

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Shared decision making takes many forms, involving different kinds of agents who share the requirement that they must have sufficient decision making capacity for the decision in question. Advance care planning (ACP) is commonly viewed as a form of shared decision making between carers and patients who anticipate losing decision making capacity. What is unclear in this situation is the identity status of the individuals who have become mentally incapacitated and how to evaluate their rights and interests. This is known as the identity problem of ACP.

This paper suggests that the identity problem can be most convincingly addressed by understanding ACP based on narrative views of identity. These views, however create a tension in our current medico-legal framework for attributing decision making capacity. Current laws and guidelines favor maximum inclusiveness and hence mandate supported decision making for those with reduced or only focally preserved decision making capacity. Yet, an ACP framework based on narrative identity and the relevant capacities to construct such narratives results in more demanding capacity requirements than current medico-legal practice requires. The law thus espouses conflicting

views as to who can be an appropriate decision making authority for patient care. I therefore conclude that the law governing medical care needs to be clearer about how to resolve the identity problem of ACP. It needs to either revisit its position on ACP or change its stance on supported decision making for those who have only focally preserved decision making capacity.

**id #944**

## **Consensual Conversion Therapy: Individual Autonomy v. Harm to the Gay Community**

**Taryn Knox<sup>1</sup>**

*1. University of Otago, Dunedin, OTAGO, New Zealand*

Conversion therapy consists of methods used to alter an individual's sexuality, predominantly from homosexual to heterosexual. While conversion therapy is currently ineffective, the advances of neuroscience mean this may change (Earp et al 2014). As effective conversion therapy may reduce the suffering of gay people, then so long as it is consensual conversion therapy may be ethically acceptable. There are two main counterarguments. The first is that given the maltreatment of gay people, conversion therapy cannot be truly consensual (Cruz in Earp et al 2014, 9). The second – the focus of this presentation - is that effective, truly consensual conversion therapy harms the Queer community (Behrmann and Ravitsky 2014; Gupta 2012) and so is unacceptable. The presentation considers the tension between an individual's autonomy to make choices that benefit themselves and limiting autonomy to minimise harm to the community (in this case, the Queer community.)

1. Berhmann, Jason and Vardit Ravitsky. 2014. Turning queer villages into ghost towns: a community perspective on conversion therapies. *AJOB Neuroscience*, 5, 14–16.
2. Earp, Brian D., Anders Sandberg, and Julian Savulescu. 2014. Brave new love: the threat of high-tech 'conversion' therapy and the bio-oppression of sexual minorities. *AJOB Neuroscience*, 5, 4–12.
3. Gupta, Kristina. 2012. Protecting sexual diversity: rethinking the use of neurotechnological interventions to alter sexuality. *AJOB Neuroscience*, 3, 24–8.

**id #1076**

## **SYMPOSIA: Gene Editing Technologies: Refining our understanding of obligations and key concept: Two challenges for the requirement of 'societal consensus'**

**Markus Labude<sup>1</sup>, G. Owen Schaefer<sup>1</sup>, Vicki Xafis<sup>1</sup>, Wei Leong Chew<sup>2</sup>, Alexandre Erler<sup>3</sup>, Tamra M Lysaght<sup>1</sup>, Poh San Lai<sup>4</sup>**

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Over the past few years, a large number of reports, statements, and commentaries have specified the conditions under which heritable genome editing should be permissible in humans. Several of these documents state that there needs to be 'societal consensus' for any germline intervention before that intervention can go ahead. Call this the 'SC requirement'. In this paper, we raise two challenges that arise when the SC requirement is applied outside the context of wealthy democracies. The first challenge is that the SC requirement may put resource-challenged countries at a disadvantage. Defenders of the SC requirement tend to assume that the consensus is valid only if it arises from a certain type of deliberation, involving public consultation with broad civil participation. Yet, conducting such public consultation is a resource-expensive exercise, especially for countries with little existing capacity for engaging the public in robust bioethical debate. The second challenge is that the SC requirement may be an unrealistic requirement for countries that make societal or policy decisions through governing authorities without open consultation. Would it be morally permissible for such countries to engage in clinical applications of germline editing even in the absence of democratically reached societal consensus? If the answer to this is 'no', then this would preclude a large number of countries from reaching the threshold for morally acceptable germline editing.

id #1002

## Street Food Vending: Can we move from a Food Safety to a Nutritious Food Regime?

**Tsung-Ling Lee<sup>1</sup>**

1. *Taipei Medical University, Taipei, Taiwan*

Street food vending is ubiquitous in much of Asian cities: street food vending is a common source of employment, offering ready-to-eat and inexpensive food to working individuals and families. Regulating street food vending typically concerns with food safety issues such as lack of basic amenities, unhygienic practices, and microbiological containment. However, with the growing incidence of non-communicable diseases (NCDs) in Asia, which now are the leading causes of death in the Asia-Pacific according to the Asian Development Bank, the lack of nutritional-related regulations in street food vending is concerning. A strong scientific consensus exists that sustained consumption of high-in-fat, -sugar and -salt food increases the risks of NCDs, which are beginning to exert visible strains on healthcare systems. Public awareness on the importance of healthier processed food has seen Big Food under public scrutiny and have engendered more progressive regulatory efforts worldwide to curb unhealthy practices through taxation and information disclosure, for instance. Paradoxically, “small food” – i.e., street food vending – there is little, if none, demand, for similar efforts, even though street food vending is a significant contributor of NCD risks in some Asian countries. With its alluring appeal of convenience and promises of authentic cultural experiences, street food vending continues to exist as an unregulated source of unhealthy food. Focusing on Taiwan as a case study, the paper seeks to highlight the current regulatory gap in the realm of food consumption. In particular, the paper considers plausible regulatory strategies to improve the healthiness of street food vending.

id #1028

## Is Chinese practice of non-disclosure a product of ‘familism’? A sociological and ethical study

**Jing-ru Li<sup>1</sup>**

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Patients in China are often not informed about their diagnosis or prognosis, particularly in cancer care. Instead, doctors will often inform the patients’ relatives, who then usually withhold the bad news from patients. It is widely believed that this practice is shaped by and compatible with the Chinese culture of ‘familism’ and is therefore ethically acceptable. In this presentation,

I will briefly outline part of the findings of a qualitative study I undertook to investigate this practice in two cities in northern China: Tianjin and Beijing. On the basis of these findings, I will argue that the culture of familism may not be the fundamental contributor to such non-disclosure, and that a more crucial, and often neglected factor, is the difficulty most families have in breaking bad news to their family members, and a lack of professional support in doing this. In addition, I will argue that non-disclosure is often not beneficial in the ways that are supposed, and can result in adverse consequences, including but not limited to delayed treatment, non-compliance with treatment, mistrust between patients and relatives. As a solution, I propose a culturally sensitive approach to truth-telling, with special concern on how to decide if the patient should be informed and how to inform the patient.

id #912

## Is it really all about the money? Non-financial conflicts of interest in health and biomedicine

**Wendy Lipworth<sup>1</sup>, Miriam Wiersma<sup>1</sup>, Narcyz Ghinea<sup>1</sup>, Ian Kerridge<sup>1</sup>**

1. *University of Sydney, University Of Sydney, NSW, Australia*

In this presentation, we will address a pressing organizational ethics issue: how should *non-financial* conflicts of interest be understood, assessed and managed by those governing health and biomedicine? This is a crucial question to answer because non-financial interests—such as those stemming from religious and secular beliefs, relationships and personal ambition—can compete and conflict with other important interests—such as generating and disseminating useful knowledge, making policy in the public interest, and caring for patients. These conflicts can, in turn, generate biases that can distort health and biomedical research, publication, education, policymaking and practice. Despite this, non-financial interests are currently almost entirely neglected by those charged with managing institutional and individual conflicts of interest (who tend to focus exclusively on *financial* interests, such as those that arise in the context of interactions with industry). Furthermore, some argue that this is as it should be—i.e. that non-financial interests *cannot* and *should not* be managed alongside financial interests. In this presentation, we will present the arguments against creating a false dichotomy between financial and non-financial conflicts of interest. After making the case that non-financial conflicts of interest *can* and *should* be managed alongside financial conflicts of interest, we will present a preliminary framework for doing so in a morally and politically acceptable way.

id #939

## The direct-to-consumer market for stem cell-based interventions in Australia: Exploring the experiences of patients left in a regulatory vacuum

**Tamra Lysaght<sup>1</sup>, Catherine Waldby<sup>2</sup>, Tereza Hendl<sup>3</sup>, Megan Munsie<sup>4</sup>, Wendy Lipworth<sup>5</sup>, Ian Kerridge<sup>5</sup>, Cameron Stewart<sup>5</sup>**

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4. *University of Melbourne, Australia*
5. *University of Sydney, Australia*

The growing prevalence of businesses selling autologous stem cell-based interventions (SCBI) to patients in Australia and other major healthcare markets have raised serious ethical and regulatory concerns. Key among these are concerns about how weaknesses in regulation have enabled the emergence of an industry that engages in aggressive marketing to patients in a manner that both exaggerates benefits and underplays risks. Yet little is known about how patients experience this marketing and their subsequent interactions with practitioners—particularly in the domestic context.

This paper addresses this gap and reports results from an exploratory study of Australian patients and their carers who have accessed or have considered accessing an autologous SCBI from businesses operating in Australia. Findings are drawn from two workshops conducted in 2016 with patients, carers and family members (22 participants) and 15 semi-structured interviews (conducted in 2017). Results indicate that patients' consideration of, and decision to undergo an autologous SCBI was shaped by five factors: illness experience, disillusion with current medical practice, unrealistic expectations, lack of reliable information from providers, and trust in the healthcare system and medical professionals. In light of these results, and recent changes to autologous cell product regulation in Australia, the paper concludes with suggestions for enhanced consumer awareness and the ongoing review of policy and regulation in this area.

id #931

## SYMPOSIA: Gene Editing Technologies: Refining our understanding of obligations and key concepts

**G. Owen Schaefer<sup>1</sup>, Tamra M Lysaght<sup>1</sup>, Markus Labude<sup>1</sup>, Vicki Xafis<sup>1</sup>**

1. *Centre for Biomedical Ethics, Yong Loo Lin School of Medicine, National University of Singapore, Singapore*

**Symposium Chair:** Tamra LYSAGHT

**Symposium Facilitators:** Owen SCHAEFFER, Markus LABUDE, Vicki XAFIS, Tamra LYSAGHT

This symposium focuses on two themes central to current considerations in gene editing technologies including the application of such technologies. The symposium comprises two 20-minute talks and two 20-minute discussion sessions following each talk. The first five minutes of the discussion sessions will be dedicated to one or two key questions on each of the topics and will elicit participants' anonymous responses via an online platform. We have successfully employed this format previously. The remaining 15 minutes will be used to discuss the issues documented via the online platform to promote debate on these challenges. A round-up session of 10 minutes will reflect on the discussions held.

The first paper draws on a recent controversial application of such technologies, which was condemned by the international research community. It asks us to consider what responsibilities the scientific community has when members become aware of planned applications of gene editing technologies.

The second paper examines the concept of 'social consensus' much referred to in reports and statements as a key condition under which heritable genome editing might be permissible. This paper aims to promote the exchange and refinement of views around the scope and nature of 'social consensus' and it highlights the unintended potential impact of promoting 'societal consensus' before heritable genome editing can proceed.

Symposium contributions will be acknowledged in publications arising.

id #1046

## Do physicians have a duty to report medical device adverse events in patients?

**Aminath Mariya<sup>1</sup>**

1. *Maldives Institute for Psychological Services, Training & Research (MIPSTAR), Male', Kaafu, Maldives*

Over the past decade, malfunctioning medical devices have caused thousands of incidents of patient harm and hundreds of deaths in Australia. Therapeutic Goods of Australia make it mandatory only for sponsors and manufacturers of medical devices to report adverse events. Between 2013 -2017, there were 16,696 medical device adverse events reported under the mandatory reporting

requirement. Adverse events reported voluntarily by physicians during the same period amounted to only 4% of total reported incidents. Physician's lack of motivation to report medical device adverse events negate the crucial nexus they form between the patient and the medical device industry. Australia's Charter of Health Care Rights identifies embedding of the patient's right to safe and high-quality health care in Australian health system as the principal objective of the Charter. Guided by the Hippocratic Oath, the primary goal of a physician is to ensure that through their patient-physician relationship this objective of providing a patient-centred health service which promotes patient safety while minimising or avoiding incidents of adverse events is achieved. The Charter places a duty on the physician to participate in existing patient safety systems; recognising the role of the physician in the advancement of healthcare to the wider community. This paper proposes to examine the role of physicians and analyse whether patients faced with medical device adverse events and the wider community at risk of harm from medical devices have a right to have physicians report such events to the regulatory body through an analysis of rights using a claim-right paradigm.

**id #1073**

### **Perversity, profits and paradoxical effects: how the production, use and control of information creates ethical complexities in the context of end stage kidney disease care**

**Dominique E Martin<sup>1</sup>, Jordan Parsons<sup>2</sup>**

1. Deakin University, Geelong, VIC, Australia

2. University of Bristol, United Kingdom

End stage kidney disease (ESKD) affects millions of people around the world, with many dying due to lack of access to kidney replacement therapies. The high cost of providing life sustaining treatment for ESKD in the form of dialysis or kidney transplantation imposes significant burdens on patients, their families and communities as well as governments. Efforts to address the public health challenges of ESKD depend upon collection of information via population surveillance, patient registries and economic analysis of healthcare systems that may be used to inform priority setting and resource allocation and to guide clinical decision-making at the individual and policy levels. In this paper we explore three examples to highlight the potential risks and benefits of the collection and use of information in specific contexts of ESKD care, and examine the ways in which data may foster ethical goals or, conversely, undermine them. First, we discuss how financial conflicts of interest may result in "cherry picking" of dialysis patients that disadvantages those with poorer health status. Second,

we discuss clinician concerns that disclosure of information about expensive treatment modalities in low income countries may be harmful to patients and their families. Third, we consider whether access to care should be conditional upon participation in public health surveillance initiatives. We argue that greater attention to the ethical implications of production, use and control of information in efforts to address the global burdens of ESKD is urgently needed if the goals of such efforts are to be achieved.

**id #1030**

### **International standards and remedies for organ transplant abuse**

**David Matas<sup>1</sup>**

1. *International Coalition to End Transplant Abuse in China, WINNIPEG, MANITOBA, Canada*

The paper would address the standards and remedies specific to organ transplant abuse, with China and prisoner of conscience victims as a case study.

The standards canvassed would be

- 1) the UN Protocol against Trafficking in Persons,
- 2) the Council of Europe Convention against Trafficking in Human Organs,
- 3) the OECD Guidelines for Multinational Enterprises
- 4) the Genocide Convention,
- 5) the Statute of the International Criminal Court, and
- 6) the UN Convention against Torture.

The remedies canvassed would be

- 1) the UN Human Rights Council
  - a) agenda item 4 (human rights situations that require the Council's attention)
  - b) Universal Periodic Review, and
  - c) specialized mechanisms,
- 2) the meeting of states parties to the relevant UN Protocol,
- 3) the implementation mechanisms of the relevant Council of Europe Convention,
- 4) an advisory opinion from the International Court of Justice,
- 5) a referral to the International Criminal Court,
- 6) a petition to the International Court of Justice,

- 7) state based
  - a) exercise of universal jurisdiction
  - b) Magnitsky type legislation
  - c) immigration bans and
  - d) mandatory reporting of transplant tourism,
- 8) cases presented to the OECD National Contact Points for Responsible Business Conduct,
- 9) the reporting to the UN Committee against Torture, and
- 10) institutionally based investigations into organ transplant abuse.

The presentation would assess the advantages and disadvantages of each remedy. The conclusion would be that there exists a range of options which those promoting respect for global bioethics and health law could engage to address international and cross border organ transplant abuse.

**id #1023**

## **On the multi-births of bioethics: US, Australia and New Zealand**

**Christopher Mayes<sup>1</sup>**

*1. Deakin University, Geelong Waurn Ponds, VIC, Australia*

Bioethics is commonly considered to have its roots in the United States. Uncritical histories, such as Albert Jonsen's *The Birth of Bioethics*, as well as critical histories, such as Renée Fox and Judith Swazey's *Observing Bioethics*, tell the story of bioethics as a US-centric endeavour. Those writing histories of bioethics in other national contexts also agree with the premise that bioethics began in the United States and was subsequently adopted in other locations. Even scholars critical of the whole bioethical enterprise, such as Roger Cooter or Alan Petersen, leave untouched the idea that bioethics was birthed in the United States. For these latter scholars, this partly serves their critique that bioethics is an imperial and hegemonic force that has produced a global bioeconomy that serves the interests of US-based multi-national companies.

This paper questions the assumption that bioethics has a single-origin in the United States to which all other national manifestations can be traced. This is not merely a parochial exercise or naïve denial of US-influence on the field. Rather, I argue that greater appreciation of the historical contingencies and conditions through which bioethics emerged in different national contexts can shed light on way problems and corresponding solutions are framed differently and draw on different conceptual tools. Furthermore, being attentive to these

historical differences can open up new ways of thinking about future challenges, especially in the face of a global bioeconomy.

**id #1013**

## **Phenomenology and artificial hearts**

**Pat T McConville<sup>1</sup>**

*1. Monash University, Murrumbeena, VIC, Australia*

New and emerging biomedical devices radicalise the relationship between worldly, material objects and the feeling, experiencing human subjectivities which make use of them. Rather than scaffolding native ways of understanding and capacities present in human subjectivity, some biomedical devices may be able to generate new and supplant antecedent, physiological ways of comporting to the world.

In this talk, I consider the phenomenological approach offered by Maurice Merleau-Ponty as a way of understanding this relationship and the structures of subjectivity.

I survey artificial hearts and other cardiac devices in terms of the straightforwardly bioethical issues they pose, such as ownership and incorporation of the device, dependence on healthcare professionals and technicians, anxiety about device failure, and responsibility and expanded decision-making power brought about by being able to adjust and switch off devices.

I also introduce some of the more intimately phenomenological complications they may entail, such as explicit biotechnological representation of bodily states which are usually felt, the loss of cardioceptive and metaphorical resources to understand and explain one's emotional state, and the link between the heartbeat and subjective temporality which may be threatened by non-pulsatile heart devices.

**id #950**

## **Air pollution disasters: legal issues associated with the provision of personal protective interventions (facemasks)**

**Fiona McDonald<sup>1</sup>, Claire J Horwell<sup>2</sup>**

*1. Queensland University of Technology, Brisbane, QLD, Australia*

*2. Department of Earth Sciences, Durham University, Durham, United Kingdom*

Globally, air pollution is the 9<sup>th</sup> highest cause of morbidity and it has been estimated that exposure to particles < 2.5 µm in diameter caused 8.9 million

deaths in 2015. Particulate pollution comes from several sources, including volcanic eruptions, dust-storms, fires and urban emissions. Protecting populations from harmful levels of exposures to particulates is a globally-significant health issue. One intervention to reduce exposure, while measures are being taken to reduce air pollution where this is possible, is facemasks. This presentation analyses whether there is or may be a legal duty on government agencies to warn and/or to distribute facemasks for community use during air pollution crises in disaster (for example, the 2015 South East Asian haze crisis that led to an estimated 100,000 deaths) or non-disaster contexts (high levels of air pollution due to vehicular and industrial pollution). The presentation will analyse European and international human rights law, with reference to the right to life and the right to respect for private and family life, and the torts of negligence and breach of statutory duty to analyse whether there is or may be a duty of care to warn and/or to provide facemasks in disaster or non-disaster contexts. It will also examine liability issues should a decision to distribute facemasks be made, including the expected standard of care.

**id #963**

### **“This is uncharted water for all of us”: Views of Victorian hospital staff about voluntary assisted dying from a survey of 7 health services.**

**Rosalind McDougall<sup>1</sup>, Marcus Sellars<sup>2</sup>, Barbara Hayes<sup>3</sup>, Mark Tacey<sup>3</sup>, Bridget Pratt<sup>1</sup>, Karen Detering<sup>2</sup>, Anastasia Hutchinson<sup>4</sup>, Cade Shadbolt<sup>1</sup>, Courtney Hempton<sup>5</sup>, Rosemary Aldrich<sup>6</sup>, Melanie Benson<sup>7</sup>, Jeffrey Kirway<sup>8</sup>, Michelle Gold<sup>9</sup>, Lisa O’Driscoll<sup>9</sup>, Danielle Ko<sup>10</sup>**

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3. *Northern Health, University of Melbourne, Australia*
4. *Deakin University, Geelong, Australia*
5. *Monash University, Melbourne, Australia*
6. *Ballarat Health Services, Ballarat*
7. *Peninsula Health, Melbourne*
8. *Eastern Health, Melbourne*
9. *Alfred Health, Melbourne*
10. *Austin Health, Melbourne*

Implementing voluntary assisted dying (VAD) is a sensitive and morally contested issue in healthcare organisations. This paper reports findings of

a mixed methods survey of clinical staff in seven health services in Victoria, conducted in the planning period between the passing of the state’s Voluntary Assisted Dying Act in November 2017 and the June 2019 start date.

The survey investigated clinicians’ level of support for the legislation, their willingness to participate in VAD-related activities, and their reasons. Text data was collected on the challenges anticipated and supports required.

5160 clinicians from seven health services responded to the anonymous online survey, making this the largest dataset of Victorian clinicians’ views on voluntary assisted dying to date.

Overall, there were high levels of support for the legislation with some variation across sites and roles. Support was highest amongst nursing staff and lowest amongst medical specialists. However, support for the legislation did not directly translate to willingness to participate in VAD-related activities.

Respondents anticipated a range of challenges for all types of individual practitioners in their work, but also a set of challenges for hospitals, health services and health systems in attempting to integrate VAD into existing healthcare structures.

The findings informed implementation decisions at the hospitals involved and provide an important baseline for future research on VAD in Victoria. The data offers significant insights into clinicians’ ethical decision-making when voluntary assisted dying becomes legal in their home state.

**id #975**

### **Is voluntarily stopping drinking and eating a form of suicide?**

**Andrew McGee<sup>1</sup>, Franklin Miller<sup>2</sup>**

1. *Australian Centre for Health Law Research, QUT Faculty of Law, Brisbane, Queensland, Australia*
2. *Weill Cornell Medical College, Medical Ethics, New York, New York, USA*

Background: A competent patient has the right to refuse foods and fluids even if the patient will die. The exercise of this right, known as voluntarily stopping eating and drinking (VSED), is sometimes proposed as an alternative to physician assisted suicide. In earlier work on this issue, we claimed that even if we classify VSED as a form of suicide, there are good grounds for rejecting the view that doctors making a patient comfortable are assisting suicide.

Methods: In this presentation, we will focus instead on the different issue about whether VSED really is a form of suicide. We approach this question by looking first at how the refusal of artificial nutrition and hydration has been held, both in medical ethics and the law, not to be a form of suicide and then we ask

whether the same arguments apply to VSED.

Results: We claim that the only ground for resisting the classification of VSED as a form of suicide is a normative one to do with avoiding certain *connotations* associated with the word 'suicide'. These include connotations of mental illness or depression, the stigma attached to the expression 'committing suicide' and, possibly, claims made by some stakeholders that the legalisation of assisted suicide is incompatible with policies aimed at reducing the rates of suicide in many jurisdictions. We examine whether these connotations provide a sufficiently robust reason for refusing to classify VSED as a form of suicide. We then examine whether there are alternative grounds for the distinction.

id #989

### **Between the anecdotal and the universal in assessing genomic data sharing practices: a scenario-based methodology for analysing complex landscapes**

**Rebekah McWhirter<sup>1</sup>, Lisa Eckstein<sup>1</sup>, Christine Critchley<sup>2</sup>, Ruthie Jeanneret<sup>1</sup>, Rachel Hay<sup>1</sup>, Don Chalmers<sup>1</sup>, Jane Nielsen<sup>1</sup>, Margaret Otlowski<sup>1</sup>, Dianne Nicol<sup>1</sup>**

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Sharing of genomic and associated data is becoming an essential component of clinical practice and biomedical research. The advantages for accelerating the diagnostic, preventive and therapeutic benefits are widely acknowledged, and genomic data sharing is increasingly encouraged by journals and funding bodies. Genomic data sharing raises a range of legal and ethical issues, but grappling with them presents a significant challenge given the extreme diversity in data sharing practices: from defined sharing of individual data for clinical purposes, to broad-scale public sharing of research data, to uploading of data from direct-to-consumer tests by community members. Most commentary to date has discussed data sharing issues in broad terms, but the debate can only progress if we identify and engage with more granular details grounded in jurisdictional and contextual specifics. Yet the sheer scale of the genomic data sharing universe can overwhelm this attention to detail, leaving a gap between the anecdotal and the universal. To overcome this gap, we developed an empirical approach to producing a set of representative scenarios that capture the diversity of current and anticipated genomic data sharing practices and allows legal and ethical analysis of the key issues at a granular level. The specificity of this approach provides a strong foundation for developing useful and relevant regulatory recommendations, and is potentially of benefit in other

areas with similarly complex landscapes.

id #1050

### **Is that really the case? An analysis of 'fact-based' arguments of Victorian politicians during the 2017 voluntary assisted dying debate**

**Rebecca Meehan<sup>1</sup>, Lindy Willmott<sup>1</sup>, Ben White<sup>1</sup>, Katrine Del Villar<sup>1</sup>**

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Australian parliamentarians have been debating law reform on voluntary assisted dying (VAD) for decades with more than 50 bills tabled since 1993. While these reform attempts have almost universally failed, we are now faced with a different reform environment. Victoria passed the *Voluntary Assisted Dying Act* in November 2017, legislation will be tabled in Western Australia later this year, and Parliamentary Committee reviews are under way (or completed) in Queensland, South Australia and the Australian Capital Territory.

Individual views on VAD are typically informed by a person's moral stance on the topic (based on their personal values), and their understanding of the practical implications of allowing VAD (based on evidence). This is also the case for our politicians. Politicians can legitimately have different moral stances on the topic of VAD. However, if politicians are deciding whether or not to support reform based on their perceptions of how VAD regimes actually operate, and associated effects of introducing legislation, it is critical for the evidence that they are relying on to be accurate.

This presentation reports on whether the assertions of fact made by politicians during the Victorian debates can be supported by evidence. The authors have analysed Hansard of the second reading debate for the Voluntary Assisted Dying Bill 2017 in the Victorian Legislative Assembly to identify the 'fact-based' claims, and have examined the evidence to determine whether those claims can be supported. We hope this analysis will inform further parliamentary debates, and encourage politicians to pursue evidence-based reform.

id #1001

### **WORKSHOP: What is, and isn't, anti-psychiatry -- and why it matters in 2019**

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We are three psychiatrists from different parts of the world, with rather different clinical and academic roles. In this session, we aim to develop a working definition of “anti-psychiatry”, and to consider its present relevance and impacts on clinical practice and public mental health.

We have chosen a recent publication by the UN Human Rights Council to focus discussion; the UN Special Rapporteur’s 2017 Report (1) is highly critical of the contemporary role of psychiatry around the world and has attracted commentary from us (2,3) and others. Drawing on examples from the Report, we will engage the audience in considering the extent to which the Rapporteur’s views may be considered “anti-psychiatry”. We plan to extend the discussion by including concepts of social vs biological causation, psychiatric treatment models, stigma and human rights abuses experienced by those with mental illness.

1) UN Human Rights Council (2017) Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.

2) Dharmawardene V, Menkes DB (2019) Responding to the UN Special Rapporteur’s anti-psychiatry bias. *Australian and New Zealand Journal of Psychiatry* 53:282-283

3) Cosgrove L, Jureidini J (2019) Why a rights-based approach is not anti-psychiatry. *Australian and New Zealand Journal of Psychiatry* 53:503-504

**id #1085**

## **Advance care planning in a multi-cultural family-centric community: A qualitative study of healthcare professionals’, patients’ and caregivers’ perspectives**

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*Context:* Advance care planning has been shown to improve end-of-life care but

it was developed in the USA and most research has been conducted in western communities.

*Objectives:* We aimed to study the attitudes and perceptions of patients with life limiting illnesses, informal caregivers, doctors, nurses and medical social workers regarding advance care planning in a multi-cultural family-centric community.

*Methods:* We conducted an explorative qualitative study, using focus groups and individual in-depth interviews. We used purposive sampling techniques to recruit 61 adults (15 doctors, 13 nurses, 5 medical social workers, 15 patients and 13 caregivers) from multiple healthcare settings across the country.

*Results:* The participants are genuinely anxious about the implementation of advance care planning. They had positive and negative expectations of advance care planning. Many were confused about the legal framework for healthcare decision-making and expected advance care planning to be of limited value because family members, rather than the patient, were usually the key decision-makers.

*Conclusion:* A nuanced approach to advance care planning which considers the family network is required in multi-cultural family centric communities. Policies should be reconciled to create a more consistent message that respects patients, the family, and is legally coherent. Further research could focus on adaptations of advance care planning to promote its acceptance in such communities.

**id #1078**

## **Next-of-kin consent to research in WA: a conflict between law and ethics**

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Law and ethics are two disciplines which are intimately linked. The divergence between them causes conflict in the medical research setting. This can lead to frustration among clinicians who are aiming to provide the best options to their patients and improve care. In Western Australia (WA) there is a current conflict in medical research caused by a lack of support within the *Guardianship and Administration Act 1990* (WA) to rely on next-of-kin consent for research.

Medical research ethics in Australia is based on the Principles Based Framework developed by Beauchamp and Childress. This approach requires the balancing of various ethical principles including autonomy and justice. It highlights the value of informed consent and individual autonomy. However, it stresses that autonomy must be balanced against access to research benefits and promoting

benefit for vulnerable patients.

In Western Australia there is a strong appetite to conduct research in contexts where the participant may lack the capacity to consent. This includes research in dementia, the ICU, emergency setting, stroke patients and mental health. However, current legislation in WA does not allow for research to be conducted without informed consent of the participant themselves as there is no legislative support for next-of-kin consent to research. This means that within the public health setting no research is being conducted in populations with impaired capacity to consent. This paper explores this conflict in WA and highlights concerns with this risk-averse interpretation of state legislation.

**id #1049**

## **Private Lives and Public Goods: The ethics of consent to the use of personal data on public social media platforms in research**

**Eleanor Milligan<sup>1</sup>, Kim Madison<sup>1</sup>**

*1. Griffith University, Nathan, QUEENSLAND, Australia*

Increasingly people are sharing personal information on publicly accessible social media platforms such as Twitter and Facebook. Consequently, researcher interest in using social media data is increasing as this data provides important and real time insights into the full gamut of human interests, including insights into health and wellbeing that may promote knowledge that is of public interest. The dynamic nature of social media data can prove beneficial for society; for example, being able to study trends in human activity that could result in timely and effective public health intervention and promotion.

Many researchers assume the use of such 'public' data is ethically unproblematic, as the person posting has freely chosen to place their views into the public domain. However, the use of social media data in research can present unique ethical concerns for researchers, institutions, and the ethics committees that are tasked with ensuring that research projects are conducted in line with accepted standards of ethical practice.

This paper discusses the ethical use of social media data in research, drawing on advice provided in the National Statement on Ethical Conduct in Human Research 2007 (Updated 2018), the Griffith University Research Ethics Manual, social media platform policies, privacy legislation and the latest academic literature. It will also consider the differences in types of 'publication' and outline practical approaches to seeking consent to research which draws upon social media data collected across a range of popular social media platforms

for use in research which is of public benefit.

**id #1020**

## **Conscientious and non-conscientious objections to Voluntary Assisted Dying**

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*2. Monash University, Victoria*

Whilst conscientious objections remain contentious in the bioethics literature, they are widely accepted by health practitioners, easily raised and protected by law. The new Victorian Voluntary Assisted Dying (VAD) legislation protects the right of health practitioners to refuse to participate in VAD and allows that doctors with a conscientious objection are not obligated to discuss or provide information on VAD, provide assessments or referrals. However, it is not clear what constitutes a conscientious objection, and what kind of reasons might distinguish between a justifiable conscientious objection and an abuse of this entitlement, such as a refusal to treat based on preference, prejudice or power imbalances.

A survey of staff attitudes to VAD at our health service, found that approximately 80% of the participating workforce (n=1624) supports VAD and only 8% hold personal ethical, philosophical or religious beliefs that would prevent them from being involved in providing access to VAD. However, 79% of participants indicated that they would only be involved in VAD given the option for conscientious objection, and staff willingness to be involved decreased significantly for hands-on interactions such as witnessing and assisting with VAD.

Our results suggest that some objections to providing VAD may not be true conscientious objections, but rather less morally weighty preferences, such as an aversion to providing services. In this paper, we consider the justification and limits of conscientious and non-conscientious objections with reference to medical practitioners' understanding of conscientious objections and our own recent research findings about attitudes to VAD.

id #1005

## **WORKSHOP (60 minutes): Research classification in bioethics: What should it be FoR?**

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Research in Australia and New Zealand is subject to the Australian and New Zealand Standard Research Classification (ANZSRC). This is a set of three classifications for measuring and analysing research: (i) the type of activity; (ii) the socio-economic objective, or SeO; and (iii) the field of research, or FoR.

Anyone who has submitted a grant or lodged a paper in their institution's repository will have been asked to provide these classifications. These then filter through to research quality assessment, such as which panel a grant application is allocated to, or what disciplinary norms should be used when assessing research outputs.

There is much for bioethicists to like about the ANZSRC. Some of the SeOs are explicitly relevant to our research. There are also FoR codes specific to bioethics, which puts us at an advantage compared to some other countries. And yet, the ANZSRC is also a source of frustration...

After a decade of operation, the ANZSRC is currently under review. In that time, we have seen significant changes to bioethics research, not least the greater use of empirical methods.

At this workshop, we will discuss how the ANZSRC can best serve bioethics. Focusing on FoR codes, we will ask:

- Do the current FoR codes work for bioethics? Why or why not?
- Do we need new FoR codes for bioethics? If so, where should they sit?
- Should FoR codes be used to determine who assesses our research? If not, then what?
- How can the ANZSRC best account for interdisciplinarity?

id #1008

## **What is the ethical value of genetic kinship? A critical interpretive review.**

**Ainsley Newson<sup>1</sup>, Jane Williams<sup>1</sup>, Rosalind McDougall<sup>2</sup>**

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Assisted Reproductive Technologies (ARTs) can allow people to have children who are genetically related to one or both intending social parents. Debate is ongoing on whether emerging ARTs such as mitochondrial donation should be used. One reason such ARTs are sought, over other potentially less risky options, is that they enable genetic kinship.

While the ethical value or disvalue of having genetic kinship between parents and children influences much scholarship in bioethics, there has been surprisingly little critical engagement with relevant ethical arguments. We contend that with regards to ARTs in particular, the ethical value of genetic kinship is often asserted or implied, but less frequently defended.

We undertook a critical interpretive review of bioethics and related literatures to identify and assess arguments about the ethical value of genetic kinship. Unlike systematic reviews, critical interpretive reviews aim for *critical engagement* with *key ideas* expressed in the literature, rather than to identify and analyse all relevant literature on the topic. One advantage of this approach is that it can assist in the development of theory as well as presenting existing scholarship.

This presentation will have four parts. First, we will describe the methods and processes used in our review. Second, we will describe the normative arguments we identified in the literature and the shape of the literature as a whole. Third, we will discuss our critical interpretation of these arguments. Finally, we will comment on how debates over the ethical value of genetic kinship might usefully progress in the future.

id #913

## **From substitute decision making to supported decision making in psychiatry**

**Giles Newton-Howes<sup>1</sup>, Sarah Gordon<sup>1</sup>**

1. *University of Otago, Wellington, New Zealand*

Recognizing the rights of all people to make their own decisions in health is an increasingly important cornerstone upon which western medicine is based. For most people, most of the time this fundamental tenet of any healthcare interaction is unchallenged, in large part because decision making capacity is assumed. However, this is not always the case in psychiatric practice. Mental Health legislation can deny people the right to make their own decisions (even irrespective of decision-making capacity) and enable others to make decisions

about an individual's treatment that are then enforceable, compulsorily (substitute decision-making).

Since coming into force, the Committee of the Convention on the Rights of Persons with Disabilities (CRPD) has clarified the interpretation of the CRPD. This includes that substitute decision-making regimes are prohibited by the CRPD and that States parties' are obliged to replace substitute decision-making regimes with supported decision-making regimes. This is a radical step away from current psychiatric practice. Much of the response of academia has been critical of the Committee's interpretation. Recognising the need for change to occur at all levels, the University of Otago **'World of Difference'** teaching and research team has implemented a programme\* to support psychiatric trainees to identify personal and organisational strategies to reduce substitute decision-making and promote supported decision-making. Through the paper we will present progress made and barriers faced with implementing this significant shift in practice.

\* Funded through the Like Minds, Like Mine programme, which is led by the Health Promotion Agency.

**id #1086**

## **From Eugenics to Human Gene Editing: Ideology and Engineering Life in China in a Global Context**

**Jing-Bao Nie<sup>1</sup>**

*1. University of Otago, Dunedin, Otago, New Zealand*

Gene editing technologies such as CRISPR-Cas9 (invented in 2013) have the capacity to alter the world forever through altering the genetic make-up of humankind. The announcement by a Chinese scientist in late November 2018 of the birth of the world's first gene-edited babies sparked outrage across the world. Among numerous ethical issues, editing heritable germline genomes of otherwise healthy embryos for natural resistance to HIV constitutes an effort of positive eugenics, i.e. not treating disease but enhancing genetic features. This paradigm case of scientific misconduct has its roots in the widespread practice of *yousheng* (eugenics) in China and in the nation's pursuit of science superpower status. Eugenics has long been a global phenomenon, and the engineering and instrumentalising of human life is a fundamental feature of global modernity. This presentation will offer a socio-ethical inquiry into how the ideologies of sinicised social Darwinism, nationalism and scientism have shaped the Chinese authoritarian model of human genetic engineering in a global context.

**id #936**

## **Puberty suppression for non-binary young people: clinicians' practices, views and decision making**

**Lauren Notini<sup>1</sup>**

*1. Melbourne Law School, University of Melbourne and Biomedical Ethics Research Group, Murdoch Children's Research Institute, Carlton, VICTORIA, Australia*

Approximately half of transgender or gender diverse youth identify as gender non-binary (not entirely/exclusively male or female). Some clinicians have reported that some non-binary youth request ongoing puberty suppression to prevent development of secondary sex characteristics. These requests are controversial, as puberty suppression for transgender or gender diverse youth has typically only been discussed as the first of a two-stage hormonal treatment pathway, rather than standalone treatment. Ethical issues associated with puberty suppression for non-binary youth remain under-explored. This study aimed to explore how Australian clinicians working with transgender or gender diverse youth navigate these complexities and view and make decisions about puberty suppression for non-binary youth.

Semi-structured interviews were conducted with clinicians. Inductive content analysis was used to identify content categories from the data. While clinicians expressed concerns about the potential physical, cognitive and psychosocial harms of blocking puberty long-term, many were also concerned that asking non-binary youth to choose a puberty could also cause psychosocial harm. Given the current lack of evidence and professional guidance, clinicians could benefit from evidence-based ethical guidelines for making these complex decisions. Such guidelines could support clinicians and improve decision-making and outcomes for patients and families.

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id #1035

## **Aristotelian medical virtues, Christian medical virtues, and end-of-life decision making**

**Justin Oakley<sup>1</sup>**

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In 1847 the AMA advised physicians that they have a “sacred duty” to “minister...hope and comfort to the sick; that, by such cordials to the drooping spirit, he may smooth the bed of death, revive expiring life, and counteract the depressing influence of those maladies which often disturb the tranquillity of the most resigned in their last moments”. This was directed not only at Christian physicians but at *all* American physicians, who were encouraged to instil hope in dying patients, whether or not the patient had any religious affiliation. The virtue of medical beneficence is no longer understood to include a preparedness to instil hope in the dying - doctors have learned from experience that this does not serve patients’ best interests. Both secular and Christian accounts of medical virtues have thus become more evidence-based, and have developed more inclusive approaches to the best interests of patients generally. Aristotelian accounts of medical virtues emphasise the importance of doctors developing practical wisdom, in fine-tuning virtuous dispositions to hit their targets. Such accounts are more empirically informed than previously, in drawing on empirical studies of factors – like the prevalence of certain cognitive biases in clinical practice – that divert virtuous dispositions from their targets. How might Christian accounts of medical virtues draw constructively on such studies? And, might Aristotelian accounts of medical virtues learn important lessons from Christian approaches to medical virtues? In this presentation I critically compare these two approaches to medical virtues, in the context of end-of-life decision making.

id #983

## **Sharing Health-related Data for Precision Medicine: An Exploration of Ethical Concerns in Singapore**

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Precision Medicine (PM) is gaining prominence in many healthcare sectors with its promise of tailoring disease treatment and prevention to individual factors such as genetics, lifestyle and environment. Central to the development of PM are databanks with health-related information that is stored and readily shared between researchers and authorised healthcare providers. PM’s success will depend on a large proportion of the population contributing biological samples and consenting to share de-identified health information about themselves. As it is not feasible to obtain specific consent each time these data are accessed, participants’ trust in data security and governance systems will also be critical. Understanding what oversight mechanisms might affect participation in PM programmes can assist with the design of trustworthy governance systems.

This presentation reports on preliminary findings from five focus groups conducted in Singapore between May-June 2019, which aimed to explore the ethical concerns Singaporeans may have about participating in a proposed PM programme and how policymakers might address these concerns. Discussion topics centred on (i) concerns about the risks of data sharing and re-identification, (ii) which authorities or institutions Singaporeans trust to safeguard their data and its uses, and (iii) distribution of benefits from PM. Preliminary findings suggest Singaporeans are likely to trust certain government agencies to safeguard the data and distribute benefits; more so than the private sector. However, there may be confusion about which agency to trust, and the limitations of de-identification and consent. Results of this research will inform the design of a survey and Citizen Juries.

id #948

## **Decision making and consent: Helping patients make informed decisions about their care**

**Kanny Ooi<sup>1</sup>**

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Obtaining consent before treating patients is a key part of medical practice. Ideally, the doctor helps the patient understand their condition and treatment options, and the patient helps the doctor understand the patient’s values, preferences and goals. In this way, they work together to decide the best way forward.

In reality, the decision-making and consent process can be fraught. Reasons include cultural and language barriers, doctors using technical terms, and talking past their patients. Patients feel rushed if there is little opportunity to reflect and ask questions, and when signing forms is seen as the end goal. In a public hospital, the doctor who obtains consent may not necessarily be the same doctor who provides the treatment.

This presentation will highlight key aspects from the Medical Council of New Zealand's statement on informed consent. It was updated in September 2019 after consulting widely with a number of stakeholders including our Consumer Advisory Group. Key changes include more emphasis on shared decision-making, involving the patient's family (where appropriate), and discussing the option of not treating where this is viable. There is also more guidance on delegating care to other health care professionals, obtaining the patient's consent beforehand if a medical student or clinical observer attends a consultation, and when a patient under anaesthesia needs more investigation and treatment than they have consented to. Ultimately, our statement is about how doctors can communicate more effectively and support their patients to make informed decisions that lead to better (health) outcomes.

id #999

## Formulating an Ethics of Pharmaceutical Disinvestment: A Critical Interpretive Review

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There is growing interest among pharmaceutical policymakers in how to “disinvest” from subsidised medicines. This is due to both the rapidly rising costs of healthcare and the increasing use of accelerated and conditional reimbursement pathways which mean that medicines are being subsidised on the basis of less robust evidence. It is crucial that disinvestment decisions are morally sound and socially legitimate, but there is currently no framework to facilitate this. We therefore conducted a critical interpretive review of the bioethics literature in order to identify ethical principles and concepts that might be relevant to pharmaceutical disinvestment decisions. We searched the databases PubMed, MEDLINE/EMBASE, CINAHL, the Cochrane Library, Google Scholar, PsychINFO and Sociological Abstracts using terms related to disinvestment and ethics in November 2018. One reviewer appraised candidate publications and extracted data. Articles were then analysed thematically until no new ethical principles or concepts were emerging, and results were refined by discussion amongst the authors. Included papers pointed to a number of key ethical considerations—both procedural and substantive—

that need to be considered when making pharmaceutical disinvestment decisions. These principles do not, however, provide practical guidance so we present a framework outlining how they might be applied to different types of disinvestment decisions. We also argue that even the most rigorous ethical reasoning may be overridden by moral intuitions and psychological biases and that it is important not to assume that disinvestment will be a socially or politically feasible solution to the problem of unsafe, ineffective or low-value care.

id #1004

## International transfer of health data: individuals' privacy concerns and the role of the law

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Increasing international collaboration in health research raises new challenges for privacy and data protection laws relating to health data.

Advocates of ‘open science’ promote sharing medical data and benefits resulting from medical research with the international community as a desirable international norm. International instruments such as the OECD Privacy Guidelines and the Council of Europe Convention 108 approach international transfer of data, including health data, as something which should be not only allowed but encouraged. Free flow of health data, while enhancing the quality of research and benefits made available to the public, presents difficulties in meeting the expectations of persons who contribute their data to these endeavours. Privacy protection is particularly challenging where sensitive health data moves between jurisdictions with non-harmonised data protection regimes. A survey of Australian attitudes to privacy points to high levels of concerns regarding personal data being transferred to other countries. Concerns identified with regard to sharing medical data generally, particularly apprehensions of loss of control and lack of trust, may be magnified when medical data is transferred internationally.

This paper examines the manner and degree to which Australian privacy and data protection law addresses these concerns and compares the Australian law to approaches of the GDPR and other jurisdictions with regard to international transfer of health data. Based on this examination, the paper interrogates the ‘dual role’ of the law, ensuring free flow of data while protecting the privacy rights of individuals, and draws conclusions regarding the key factors directing its evolution.

id #932

## Cause of death under VADA17: unethical obfuscation or beneficent legal fiction?

**Malcolm H Parker<sup>1</sup>**

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Under Victoria's *Voluntary Assisted Dying Act 2017* (VADA17), registered medical practitioners responsible for either a person's medical care immediately before death (usually the coordinating medical practitioner) or examining the body of the deceased person, and who believe or know the person was the subject of a voluntary assisted dying (VAD) permit, must notify the Registrar of Births, Deaths and Marriages and the Coroner that:

- the person was the subject of a VAD permit;
- the person either self-administered or had administered to them, or did not self-administer or have administered, the relevant VAD substance; and
- the disease, illness or medical condition was the grounds for the person to access VAD.

The Registrar of Births, Deaths and Marriages must record that VAD was the *manner* of death, but that the *cause* of death was the notified disease, illness or condition. The Coroner must treat such cases as *non-reportable* deaths. These attributions/descriptions require that the death is in accordance with the VADA17.

These requirements reflect the recognition that VAD is only available to people who are already dying, as strictly defined by VADA17, and hence that their death should not be regarded as unexpected or avoidable. Nevertheless, opponents of VAD argue that recording the cause of death as the relevant disease or condition obfuscates the real cause of death, in order to rationalise and facilitate unethical legislation like VADA17. The argument is deployed in continuing resistance to further enactments of VAD.

The paper critically appraises this argument.

id #839

## PrEP in Prisons: An ethical approach to HIV harm-reduction in incarcerated populations

**Jordan Parsons<sup>1</sup>, Chelsea Cox<sup>2</sup>**

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2. *Schulich School of Law, Dalhousie University, Halifax, Nova Scotia, Canada*

Pre-exposure prophylaxis (PrEP) as a means of reducing the risk of HIV infection in high risk individuals is commonly discussed in relation to men who have sex with men (MSM). Other high-risk populations, such as prisoners, are frequently side-lined. We argue that in the global fight against HIV and AIDS, it is important that the potential of PrEP as a HIV harm reduction intervention in prisons is recognised. Existing interventions to reduce the spread of HIV in prisons, such as needle exchanges, focus on reducing harm from intravenous drug use only. PrEP would be effective against HIV infection through both intravenous drug use and condomless sex, both of which are significant factors in the increased risk of infection in prisons.

Firstly, we highlight how objections to needle exchanges are not applicable to PrEP provision: condoning drug use; the weaponisation of needles; and poor uptake. We also demonstrate that ethical objections to PrEP provision generally, such as risk compensation and poor adherence, do not stand when considering PrEP provision for incarcerated individuals. Finally, we argue that the ethical issues raised by the question of post-incarceration access are not strong enough to block this policy due to the significance of the increased risk of HIV infection prisoners are at. In doing so, we demonstrate the lack of substantive objections to the introduction of PrEP as an HIV harm reduction intervention in prisons and call for further consideration in both academic and policy circles of PrEP's potential outside of the MSM community.

id #1014

## When is it in the interests of permanently cognitively impaired patients to forego dialysis?

**Jordan Parsons<sup>1</sup>**

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Dialysis is not curative, and there has long been concern over its liberal provision. When acting as a bridge therapy to transplant the value is clear. However, organ shortages mean clinicians recommend for dialysis patients with no realistic prospect of a kidney transplant.

Things get more unclear when patients lack capacity to consent. When dialysis' benefits are unclear it is difficult to conclude the course of action in the best interests of an incapacitated patient. If physicians are predisposed to dialysis as the default for patients with renal failure, discarding conservative care, cognitively impaired patients may receive unsuitable treatment as a result of clinician bias.

There are myriad reasons to deem dialysis not in the best interests of a mentally

incapacitated patient, mostly relating to quality of life. For certain patients, such as those who are elderly and have dementia alongside several co-morbidities, it may not even be life-extending. Then there is the issue of the burden on the patient's family/carer(s), which itself raises the important question of whether it is ethically justified to account for this.

This project employs an empirical bioethics approach of reflexive balancing. Interviews with patients, families, and healthcare staff provide necessary insight, enabling consideration of when it is and is not appropriate for a permanently cognitively impaired patient with ESKD to begin dialysis. The resulting moral framework will be able to assist nephrologists in such decisions, minimising any mistreatment of renal patients lacking capacity.

**id #914**

### **Cautious paternalism in psychiatric ethics**

**Neil Pickering<sup>1</sup>, Giles Newton-Howes<sup>1</sup>, Greg Young<sup>2</sup>**

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2. *CCDHB, Wellington*

We wish to advance the case for psychiatrists and other health care professionals to pursue a cautious paternalism where their patients make decisions which might be regarded as extremely harmful to themselves. This approach is in contrast with the process approach to decision making capacity judgments. The process approach does not allow judgments about decision making capacity of patients to be based upon judgments about the outcomes, values or beliefs basis of their decision making. It rules these out on two grounds: first that a process account of decision making is able to account for all aspects of decision making; and second that any other approach is normatively questionable, allowing as it must some unwarranted degree of restriction of liberty.

We endorse the alternative view that process accounts cannot adequately capture all aspects of decision making capacity, and embrace the view that inevitably judgments about the content of decisions must be made by psychiatrists in capacity assessment. Given that such judgments are inevitable if any judgement of capacity is to be made at all, we deny that such judgments must be normatively questionable or liberty restricting.

**id #955**

### **HeLEX symposium on health data and the limits of the law: 'Conceptual incoherence': are data breach notification laws fit for healthcare contexts?**

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In Australia, legislation mandating notification of data breaches to those affected came into force early in 2018. A separate breach reporting scheme has been enacted for Australia's integrated electronic health record 'My Health Record'.

Data breach notification laws originated in the US, form part of the General Data Protection Regulation in the EU and are proposed for New Zealand (Privacy Bill 2018). Mandatory breach notification is commonly justified on the basis that it enables individuals affected by the loss or theft of personal information to take steps to minimise their risk of harm. These laws are also purported to improve the security practices of organisations holding personal data, motivated by a newfound fear of publicity if a breach were to occur. However their application in the health context is problematic. It is not obvious how someone subject to a breach of personal health data might, once notified, take steps to reduce their consequent harm. Nor is it clear that the health sector is adopting enhanced security practices in response to the new laws.

In this paper I will provide an overview of what Mark Burdon described as the 'conceptual incoherence' of data breach notification law, examining their application in the healthcare context. I will analyse the drivers for the introduction of these laws, and their complexity in operating across a federated, public/private health system overlaid by the 'My Health Record' in Australia. I will draw conclusions about the laws' fitness for purpose in the digital health context.

1. Burdon, Mark, Bill Lane and Paul von Nessen, 'Data Breach Notification Law in the EU and Australia – Where to Now?' (2012) 28(3) Computer Law & Security Review 296, 302.

id #1066

## **SYMPOSIA: 'Overt and covert recordings in healthcare' contexts: Digitally-enabled overt consultation recording in Australia: an analysis of legal concerns**

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Audio-recording doctor-patient consultations for later use by patients has been adopted and researched since the 1970s, particularly in oncology and paediatric care. There is evidence that patients who listen to a recording of their consultation have better recall and understanding of information about their condition and treatment; and feel more empowered to participate in their healthcare. Patients can use the recordings to share healthcare information with family, friends and other clinicians.

Technologies such as smartphones and telehealth make it easy for patients to record their consultations. It has been posited that in a future, fully-integrated and personalised healthcare system, such recording will be commonplace. In Australia, the Peter MacCallum Cancer Centre is leading the field, piloting a consultation recording app called 'Second Ears', which relies upon the consent of both parties for the recording.

While health professionals see the benefits in recording medical information discussed with their patients, they also express curiosity or concern about how the law deals with these new modes of recording when consent is provided, particularly regarding medico-legal liability (especially if the recording is taken out of context), and the ownership, security, storage and sharing of digital files. This paper will critique the Australian legal landscape applicable to consultation audio recordings. It will focus on their evidentiary use; and their likely impact on litigation rates. It will also examine how healthcare providers can promote patients' use of recordings to share information with family members whilst restraining their broader distribution via social media.

id #812

## **Device Representatives in the Clinic: Help, hindrance or liability?**

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Medical devices play an important role in the continued improvement of healthcare, yet they can be complex and are increasingly high tech. This technical complexity represents both their strength and their weakness. The strength is self-evident- the potential for improved quality of patient care and cutting-edge treatment, the weakness is more complicated. One dimension of this weakness can be summarised in the question: How can clinicians keep pace with rapid technological change and product turnover, and make informed decisions about whether to use one device rather than another? The introduction of medical device representatives (MDRs) into the clinical environment has been industry's response to this question. The role of MDRs raises a number of regulatory issues that will be the focus of this presentation. These include : patient consent, the outsourcing of expertise, potential conflicts of interest (commercial versus clinical), harm to professionalism, dependence on MDRs and the risk of stifling innovation through overregulation. In short, does the insertion of device representatives into the clinical relationship represent a help, a hindrance or a liability?'

id #951

## **More-than-human solidarity in practice: Insights from a veterinary school about One Health and its promotion**

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3. *Department of Clinical and Diagnostic Sciences, Faculty of Veterinary Medicine, University of Calgary, Calgary, Alberta, Canada*

The partnership at the centre of this manuscript revolves around what we call 'more-than-human solidarity.' By this term, we mean acts that are motivated by a desire to help humans in the first instance yet also that implicate non-human beings, and vice versa. In particular, we examine a partnership between a veterinary school and a charity that exists to enhance low-income people's physical, mental, and social well-being. Through this partnership, the charity periodically hosts free veterinary clinics. Even as the veterinarians and veterinary students duly examine people's pets, these pop-up clinics aim to help both people and their pets -- simultaneously and symmetrically. To delve

into the ethical and sociological implications of subsidized veterinary services, and to assist with program planning, we conducted several in-depth interviews with veterinarians. Based on these interviews and our own reflections, we invite more scholarship on the cultural, economic, and political influences that influence the health of both human and non-human beings.

**id #1075**

## **SYMPOSIA: Gene Editing Technologies: Refining our understanding of obligations and key concept: Silence and Complicity in the Case of the First Gene-Edited Babies**

**G. Owen Schaefer<sup>1</sup>, Markus Labude<sup>1</sup>, Vicki Xafis<sup>1</sup>**

*1. Yong Loo Lin School of Medicine, National University of Singapore, SINGAPORE, Singapore*

Soon after the 2018 case in China where the first babies were born with DNA deliberately edited by the now-notorious He Jiankui, it was revealed that several scientists in other countries had been informed of the experiment, and were even told when pregnancy was first achieved. However, the international community only became aware after the children were born. The backlash against He was immediate, with widespread condemnation of the experiment as unethical due to concerns about safety, efficacy, lack of necessity, consent and oversight. While at least one other pregnancy was reportedly ongoing, the study was shut down and He is under investigation.

This paper will explore a significant issue of professional ethics raised by this case: What responsibility do scientists and others have when learning of unethical experiments like these that occur at a separate institution in another country? If the international community were made aware sooner, the experiment might have been halted before it began, or at least the second pregnancy prevented. A WHO committee has proposed that all gene editing trials be registered, so proper monitoring can take place. However, such a system would likely take years to set up; in the meantime, there is not a clear reporting mechanism, other than tipping off international professional organizations or the news media. While such informal disclosures may have a salutary effect, there may be a need for more formal channels as the international scientific community deliberates over proposals to assist in monitoring applications of gene editing technologies.

**id #1034**

## **Student perceptions of learning about medical ethics in clinical case-based tutorials**

**Nicole Shepherd<sup>1</sup>, Iulia Oancea<sup>1</sup>, Ben Barry<sup>1</sup>, Sharon Darlington<sup>1</sup>**

*1. University of Queensland, St Lucia, QUEENSLAND, Australia*

Competition for time within medical curricula is fierce, therefore it is important to find an effective means of delivering ethics education. Students enjoy learning about ethics using realistic scenarios that allow them to explore aspects of clinical science, ethics and professional practice. In this presentation we report on student perceptions of learning about ethics through case-based learning sessions. First year medical students were surveyed in 2018 (n=37). Results showed they were confident in their ability to recognise and discuss ethical issues, but were frustrated with that the ethical aspects of the cases were underdeveloped and discussion was not supported by some tutors. In 2019, we introduced further training for tutors, developed new cases focusing on ethical issues, and a more explicit integration between lectures and case based learning sessions. The survey will be repeated with first year students in September 2019, and the results will be compared to evaluate the effectiveness of this approach. The findings will be relevant for medical educators and ethics teachers.

**id #938**

## **The limits of autonomy in advanced cancer and palliative care**

**Russell J Shute<sup>1</sup>**

*1. Calvary North Adelaide Hospital, North Adelaide, SA, Australia*

An increased focus on autonomy in the last half a century has resulted in necessary changes in the therapeutic relationship between patients and physicians but in an environment of rapid development and availability of cancer therapies in which patients expectations have changed partly due to increasing access to online information (including social media) and arguably an increased sense of entitlement for treatment the management of advanced cancer (including palliative care) can be compromised.

The author contends that cancer patients are often acting as 'consumers', that is there is a belief that there is a commodity or 'good' to be obtained within a market and a desire to access such a 'good' despite not necessarily understanding the complexity of action, side effects, costs or benefits. The

ultimate motivation for such action would appear to be life extension at all costs, especially in younger and wealthier patients, but there is evidence that this can undermine the provision of realistic and 'good' medical, especially palliative, care.

The proposal is that there are justifiable grounds to limit autonomy when patients or their families request the provision of futile and often expensive treatment that arguably complicates and worsens outcomes in advanced cancer. The talk is given by a Palliative Care clinician with a postgraduate qualification in bioethics and will include clinical vignettes demonstrating how care has been compromised by oncologists acquiescing to patients requests or demands for often expensive, and arguably futile, therapies.

id #960

## An attempt to articulate and apply 'coercion' as a mid-level principle in public health

**Diego S. Silva<sup>1</sup>**

1. *Sydney Health Ethics, University of Sydney, NSW, Australia*

The aim of this paper is to attempt to articulate, defend, and apply *coercion* as a mid-level principle in public health. This assumes that coercion can be right or good, which may help us articulate and justify the inherent coercive powers of public health.

*Coercion* as a mid-level principle denotes a commissive or omissive act by *P* toward *Q* to bring about an intended end, *x*, such that *P* reduces *Q*'s range of plausible and reasonable choices beyond *x*, and by extension, reduces the extent to which we hold *Q* responsible for *x* should *x* actualize. Crucially, the use of coercion means that there exists a choice or set of choices *y* that *Q* could make at some cost or penalty that would not exist but for the presence of the coercion itself.

Whether or not a coercive act is justified will rest on:

1. The argument in favour or against what constitutes 'plausible and reasonable choices' (i.e., whether the coercive act is right);
2. (i) who is the person or persons coercing, and (ii) whether they're coercing properly (i.e., whether the actors are the right actors to be coercing and whether they're doing so in a fair manner); and
3. Whether the power imbalance between the coercer, *P*, and coercee, *Q*, is right or fair in the first place.

The treatment of tuberculosis provides cases which will allow us to test the plausibility of using coercion as a mid-level principle (e.g., directly observed

therapy, involuntary isolation, etc.).

id #1036

## The significance of the decision in *PBU & NJE v Mental Health Review Tribunal* [2018] VSC 564: human rights perspectives on decisions about electroconvulsive therapy

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The Victorian Supreme Court decision of *PBU & NJE v Mental Health Review Tribunal* ("PBU") concerned an appeal to determine some specific issues under the *Mental Health Act 2014* (Vic) ("MHA"). The case clarified the test of capacity to be applied under the MHA, as well as the application of the 'no less restrictive way for the patient to be treated' test in the context of decisions about electroconvulsive therapy (ECT).

In PBU, the Victorian Supreme Court determined that a higher threshold than that outlined within the MHA was applied by the clinicians. It was emphasised that the legislation did not require that a person accepts or believes a diagnosis of mental illness to meet the statutory definition of capacity and that the application of a higher threshold of the capacity test was discriminatory and in breach of human rights principles. The Court held that a person's right to self-determination and protection from non-consensual medical treatment be prioritised above "best interests" judgments when making decisions about ECT. Importantly, decisions about ECT must be made not only on the basis of whether it is the least restrictive way of treating a person, but also after considering a person's views and preferences, even if the person lacks capacity. Consequently, decisions about ECT for persons who lack capacity must be made by the Tribunal.

We consider the significance of the decision in *PBU* in line with the Queensland *Mental Health Act 2016*, also with reference to Queensland's new *Human Rights Act 2019*.

id #1016

## The 'Myth' of Bambi: Idealising Nature and the Grim Reality of Wild Animal Suffering

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1. *University of Otago, Dunedin, Otago, New Zealand*

When we think about wild animals, it is easy to imagine that they live relatively good lives in nature because they are free. Films like *Bambi* and *The Lion King* paint an idyllic picture of the natural world, and while we know that the lives of wild animals contain many hardships, most accept that they have generally acceptable levels of welfare when left alone in nature. But when we look the population dynamics and most common life history strategies of wild animals we find that many – perhaps most – wild animals who come into existence lead very short lives which predominantly consist of suffering. This suggests that their welfare may be very poor, which has serious implications on how we conceive of our ethical attitudes toward helping wildlife. This talk will explore some of the reasons for why suffering might be so prevalent in nature, contrary to our intuitions. It aims to show that the commonly held belief about nature being 'happy' for its inhabitants is a scientific misconception, and that there is a serious gap in the way wildlife research has been carried out to date.

id #1080

## Ethical issues of social robots in medicine

Robert Sparrow<sup>1</sup>

1. *Monash University, VIC, Australia*

In this presentation, I will offer a survey of hopes and fears about the applications of social robots in medicine. What do social robots have to contribute to health care? And what should we be looking out for if we are worried about the ethics of their use? Enthusiasts for social robots have held out the prospect that they will help meet the social, informational, and emotional needs of people entering healthcare contexts as well gather data that may be used to diagnose disease and to promote and monitor public health. I will argue that this claim depends upon implausible assumptions about the capacities of robots and the institutional and economic imperatives operating in contemporary healthcare settings. I will also highlight important concerns about privacy, surveillance, and bias in big data, as well as the risks of over trust in machines, the challenges of transparency, and the ethics of "designing to deceive".

id #990

## "I just lied to a kid for eight hours ...": When parents ask clinicians to withhold information from their child

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Being open and honest with children about their medical condition and treatment is generally regarded as ethical best-practice in child and adolescent health care. However, this is not always straightforward in practice. One difficulty is parents asking clinicians to withhold information from their child. In this paper, we are presenting findings from a study about how paediatric clinicians think about and manage these situations where parents tell them not to give the child certain information. This presentation is based on interviews with 20 clinicians, in which nearly 50 instances were described.

Our findings show that clinicians find these situations particularly challenging. Broadly speaking, clinicians wanted to tell the child the information in question, and tended to try to persuade parents to allow this. Most, but not all, parents were reported to have eventually accepted their child being told. If clinicians agreed not to tell, it was generally a short term measure – they believed that it wasn't something that could be or should be sustained long-term. We discuss reasons clinicians gave in favour of telling the truth and what they understood to be parents' reasons for not telling. To finish, we also discuss a number of the nuances that are arising from thematic analysis of the data, which indicate that there are still aspects that are ethically murky. One of these is the use of euphemisms, or choice of words which could be seen as skirting or glossing over the issue.

id #900

## **No longer merely 'vulnerable' participants: a new focus on disability and disabled people in the National Ethics Advisory Committee standards for health and disability research**

**Hilary j Stace**<sup>1</sup>

*1. Victoria University of Wellington, New Zealand*

New Zealand has a health and disability system with health-related disability policy developed and implemented through the Ministry of Health, although 'disability' is a minor focus. In 2017 the National Ethics Advisory Committee and the Ministry of Health began a major review of the standards for bioethical research for Health and Disability Ethics Committees. A significant part of this process was the alignment of international bioethics principles with the principles of Te Ara Tika (guidelines for Māori research ethics developed from a Te Ao Maori worldview). However, disability still remained largely invisible although disabled people were no longer considered merely problematic 'vulnerable' participants. After questions were raised by members of the disability community an extra chapter on disability was co-developed through a participatory process with disabled people and disability researchers. This will also help New Zealand meet its obligations under the United Nations Convention on the Rights of Persons with Disabilities whereby research with and by disabled people is vital and data urgently needed. The presentation will outline what happened.

id #956

## **HeLEX symposium on health data and the limits of the law: Health research and de-identified data: time to protect group privacy?**

**Mark Taylor**<sup>1</sup>

*1. University of Melbourne, Carlton, VIC, Australia*

The scale, digital nature and participatory model of new large-scale data initiatives creates challenges for the existing regulatory infrastructure. Traditionally health data governance, as it applies to personal health and genomic information, has focused on data that relates to people in identifiable form. This isn't good enough anymore. Not only is there increasing recognition of the enduring risk of re-identification but, even while de-identified, data has significance for individuals as members of groups.

There is an increasingly urgent need to acknowledge the importance of group data and its appropriate control within the framework of health research regulation. Failure to do so will undermine trustworthiness in effective governance: compromising our ability to effectively regulate big data flows capable of fundamentally reshaping the conditions under which future generations will live and be judged.

The need to govern use and dissemination of de-identified health data is recognised by the Framework to Guide the Secondary Use of My Health Record System Data. With the first release of data under the Framework expected from next year, this presentation assesses its capacity to promote and pro group privacy risks and protect the public interest in not only health research but also individual and group privacy interests.

id #1068

## **SYMPOSIUM: 'Overt and covert recordings in healthcare' contexts: Patients taking photos, audio recordings and video in the health care context – when is it wrong and what can you do about it?**

**Mark Taylor**<sup>1</sup>

*1. University of Melbourne, Carlton, VIC, Australia*

There are anecdotal reports of an increase in the use of smartphones by patients, in various hospital settings, to capture still images, audio, and video. Images of others sharing the healthcare space may be captured, intentionally or unintentionally, and then published through social media. Scenarios range from patients capturing others as unwitting extras in family photos, covert capture of people or events intended to entertain friends, to pleas for help by live-streaming involuntary treatment in mental health inpatient units. We have yet to establish common understanding of when taking photos, audio, and videos is okay and who has responsibility for doing what in cases where it is not. This paper will explore the question of what constitutes a reasonable expectation of image and audio capture in the healthcare context and the responsibility, and liability, of health care providers and professionals in case of inappropriate taking and sharing. What responsibilities does a hospital or a health care professional have when recording is directly observed or reported to them? Can the use of recording devices be banned? How could such a ban be enforced? This paper will outline the steps that might be taken by a health care provider to address the risk of images or audio being captured inappropriately and the action that might lawfully be taken if a report is made.

**id #1056**

## **The development and future needs of guidance for the conduct of ethical research involving indigenous peoples in New Zealand and Australia: footnotes to Te Ara Tika in honour of the late Barry Smith**

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2. *Ngai Tahu Research Centre, University of Canterbury, Christchurch, New Zealand*

Over the last three decades, New Zealand, Australia and Canada have been travelling toward developing a coherent, consistent and respectful approach to human research ethics review for research that involves indigenous populations.

All three countries have grappled with similar histories and current developments so eloquently summarised in the introduction to chapter 9 of the Canadian Tri-Council policy and paraphrased here.

Research involving indigenous peoples has been defined and carried out primarily by non-Aboriginal researchers. The approaches used have not generally reflected indigenous world views, and the research has not necessarily benefited indigenous peoples or communities.

As a result, many indigenous people continue to regard research, particularly research originating outside their communities, with a certain apprehension or mistrust.

However, this landscape of research involving indigenous peoples is now changing. Growing numbers of indigenous scholars are contributing to research as academics and community members as researchers while communities are better informed about the risks and benefits of research.

In this presentation, we provide a brief account of the development of guidance for the ethical conduct of research involving indigenous peoples in New Zealand and Australia. We seek to identify matters of substance and process that remain in need of clarification in future developments of that guidance, for example, how are the subjects of research determined and when and how do researchers need to consult with indigenous participants?

1. Te Ara Tika: Guidelines for Maori Research Ethics: A framework for researchers and ethics committee members, 2010, Health Research Council, New Zealand
2. Guidelines for Ethical Research in Australian Indigenous Studies, 2012, Australian Institute of Aboriginal and Torres Strait Islander Studies

3. Ethical conduct in research with Aboriginal and Torres Strait Peoples and communities: Guidelines for researchers and stakeholders, 2018, National Health and medical Research Council, Australia
4. National Statement on Ethical Conduct in Human Research, 2018, National Health and Medical research Council, Australian Research Council, Universities Australia

**id #940**

## **The regulation of Surgical Innovation: A qualitative study**

**Alice Toms<sup>1,2</sup>, Giles Birchley<sup>2</sup>, Robert Hinchcliffe<sup>3</sup>, Richard Huxtable<sup>2</sup>**

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This paper presents preliminary results of a doctoral study exploring the regulation of surgical innovation. Numerous ethical concerns about surgical innovation have been raised that indicate a need for better regulation (Rogers et al., 2019). These include lack of accountability, harm to patients and conflicts of interest. The topic has entered public consciousness in response to new surgical procedures going wrong. Examples of this include the vaginal mesh implant, which caused long term harm to many patients, and the metal on metal hip replacement, which was surgically ineffective and required revision in many patients, whilst causing additional harm through metal toxicity.

Preliminary research to address some of these issues has been undertaken, including ongoing attempts to conceptualise surgical innovation and its attendant ethical issues. While this research is welcome, our systematic review of research on the topic suggests patient and surgical expert narratives have yet to be adequately explored.

To begin to understand how these groups view the current regulatory system, qualitative semi-structured interviews were conducted with two diverse samples – surgical patients and experts in surgical innovation (including surgeons and policymakers with practical/research interests in surgical innovation)- to explore their views and experiences. Interviews discussed how participants conceptualised innovation, their views on current ways of regulating innovation, and whether they believed regulation could be improved.

This paper presents the preliminary findings of a thematic analysis of these interviews and explores how these findings might inform the development of better regulation.

1. Rogers, W., Hutchison, K. and McNair, A. (2019). Ethical Issues Across the

**id #928**

## **Conscientious Defiance: Using moral courage for action rather than objection**

**Emma Tumilty<sup>1</sup>, Kathryn McAuley<sup>2</sup>, Tim Stokes<sup>2</sup>, Fiona Doolan-Noble<sup>2</sup>**

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The authors, healthcare professionals and bioethicists who collaborate on health system research, felt there was an undefined phenomenon occurring in practice. McAuley called it 'The Nike Clause' that is when faced in practice with a barrier that caused a moral dilemma, some health professionals' solution was to 'just do it', take the action thought to be the 'right' thing to do despite the barrier. We philosophized whether this had a positive relationship to moral distress and how prevalent it might be across different clinical settings given their varying constraints on professional autonomy and differing barriers to care. We felt that to explore this further a conceptual definition of what we now term 'conscientious defiance' was necessary. To that end, in this work, we outline the concept of conscientious objection and its key elements. Using these key elements, we then set out to define conscientious defiance, describing similarities and key distinctions. We discriminate our concept from previously defined terms such as "workaround" (Berlinger, 2016) and "civil disobedience" (as it relates to health) (Childress, 1985) and suggest that conscientious defiance is novel and important. We then discuss whether a health professional has a right to conscientious defiance under conscience protections, exploring the arguments for and against. Lastly, we suggest that empirical work is needed to further understand conscientious defiance in practice and its relationships to moral distress and moral courage. There will be important ethical considerations in investigating a phenomenon that may be considered unprofessional and we raise some of these.

1. Berlinger, N. (2016). *Are Workarounds Ethical?: Managing Moral Problems in Health Care Systems*. Oxford University Press.
2. Childress, J. F. (1985). Civil disobedience, conscientious objection, and evasive noncompliance: A framework for the analysis and assessment of illegal actions in health care. *The Journal of medicine and philosophy*, 10(1), 63-84.

**id #1124**

## **SYMPOSIA: What Can Deliberation Do in and for Bioethics?: Deliberation, disagreement, and common morality**

**Simon Walker<sup>1</sup>**

1. *Bioethics Centre, University Of Otago, Dunedin, OTAGO, New Zealand*

Deliberative methods are often used with the aim of identifying a consensus position that all parties can accept, irrespective of – or perhaps in the light of – the disagreements that are uncovered through the process. This aim reflects Habermas's view that people of divergent views will arrive at a common position by exchanging reasons in an idealised deliberative forum. It also broadly aligns with the Kantian idea that moral truths are discerned through reasoning and founded in a notion of common humanity that is based in our capacity to reason.

In 2018 a citizens' jury was conducted to learn whether a group of 15 New Zealanders thought the law should be changed to allow some form of euthanasia/assisted dying, having been informed about the issue, heard arguments, and having deliberated together. Rather than arriving at a consensus, the group become more polarized, with several changing their positions to either strong opposition or strong support. In this presentation I will outline what this citizens' jury involved, and then consider what such sustained or entrenched disagreement means for the Kantian or Habermasian view of morality. I will argue that while such disagreement may indicate a limit on our ability to resolve moral differences through exchanging reasons, it does not therefore negate the Kantian concept of humanity. Rather, the identification of such limits can itself be a 'humanising' process, and this affirms the overarching Kantian claim. I will close with some brief remarks on what this may mean for policy.

**id #957**

## **HeLEX symposium on health data and the limits of the law: Adaptive governance: flexibility to counteract limits of traditional health data governance?**

**Tess Whitton<sup>1</sup>**

1. *University of Melbourne, Parkville, VIC, Australia*

Technological advances are driving increased data collection and use. New and increasing applications of data are exposing the limits of traditional approaches to law. Examples include the unknowns surrounding new uses of health data in the context of My Health Record, and the way current frameworks tend to

support an individualistic notion of data rights. Governance and particularly law, provides stability and consistency but in highly innovative spaces increasing ability to support flexibility is required.

There is reason to reconsider how we might govern in conditions of high uncertainty. Health data is sensitive. And how best to govern where there are conflicting ethical, moral and social issues is continual balancing act. Ethical, legal and social issues (ELSI) research is a well-known way that one might consider the issues which arise in respect of any innovation. Further, a new, and influential approach to health governance is responsible research and innovation. But these approaches provide little guidance as to how to translate this into practice. Flexible governance approaches contribute to answering whether governance can support these goals.

In this paper, I consider how adaptive governance might provide tools to navigate uncertainty. I argue that any efficient governance approach in this area, should be consistent with high level health governance approaches. Further, it must support processes facilitating flexibility to support technological innovation and human responses to it over time. I also consider the extent to which this approach may provide a means to address legal limitations.

**id #929**

## **Doctors' use of Unconventional Medicine and Emerging Treatments in Australia: Is Additional Regulation Required?**

**Miriam Wiersma<sup>1</sup>, Ian Kerridge<sup>1</sup>, Wendy Louise Lipworth<sup>1</sup>**

*1. The University of Sydney, Camperdown, NSW, Australia*

Doctors frequently use treatments that are outside the scope of standard practice and that have not (yet) been shown to be safe or effective according to the standards of evidence-based medicine. This practice, which may be thought of as clinical innovation, occurs across all areas of medicine and is extraordinarily diverse.

In most cases, clinicians innovate responsibly, and clearly have their patients' best interests in mind. But unfortunately, this is not always the case, as evident in doctors' use of autologous stem cell therapies for the treatment of dementia or motor neuron disease; IVF specialists' use of endometrial scratching or embryo glue to enhance implantation; and surgeons use of avant-garde surgical approaches of questionable validity.

These and other issues have recently been recognised by the Medical Board of Australia, which has launched a public consultation into "complementary and unconventional medicine and emerging treatments". The scope of the inquiry is broad—covering complementary medicines, innovative therapies

and experimental practice, as well as the unconventional use of approved medical treatments and devices. The primary aim of the consultation is to gather feedback about whether additional regulation of doctors' use of these treatments is necessary, and if so, what form this regulation could take.

In this presentation, we will discuss several key questions raised in the consultation paper, including those centered on definitional issues; outline and critique the strengths and weaknesses of existing regulatory mechanisms; and offer a series of ethically-informed recommendations to guide the governance of clinical innovation.

**id #1040**

## **SYMPOSIA: Prioritisation of Vaccination Groups in an Influenza Pandemic: Pandemic vaccination strategies: direct vs indirect protection**

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One aspect of planning for pandemic influenza is deciding who will be prioritised for scarce pandemic vaccine. Vaccine production cannot begin until the pandemic virus strain is identified and initial production will be insufficient to meet demand. While governments plan to vaccinate everyone who wants it, decisions must be made about who to vaccinate first. Many different strategies are suggested with different operational requirements and ethical characteristics; most involve prioritising the medically vulnerable, i.e. directly protecting those most likely to become seriously ill with pandemic influenza. An alternative strategy is to employ a vaccination distribution strategy that explicitly aims for population benefits rather than individual protection. This involves prioritising the vaccination of those groups most likely to spread pandemic influenza, such as primary school children, with the aim of indirectly protecting the population from infection. These distribution strategies differ markedly in how they distribute the benefits, burdens and risks of infection and immunisation across population at a time of public health emergency.

The aims of vaccination programs are value-based because they involve decisions about who and what is most important. In a pandemic, aims might include protecting vulnerable people, ensuring fair access, saving the most lives, protecting the most people, and maintaining social order. Taking into account the different barriers and facilitators for effective implementation,

we assess ethical justifications for and against direct and indirect protection strategies for pandemic influenza vaccine in light of these different aims in the Australian context.

**id #813**

## **Legalizing Assisted Death in New Zealand- Learning from the Canadian Experience**

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New Zealand's current "End of Life Bill Choice Bill" (EOLCB) sponsored by David Seymour, borrows heavily from the 2016 Medical Assistance in Dying (MAiD) legislation that legalized euthanasia in Canada. The MAiD legislation was developed relatively rapidly; a 2015 Canadian Supreme Court decision gave the legislature one year to legalize assisted dying in Canada. Novel, undefined terms and phrases are now being interpreted by Canadian clinicians and the Canadian courts. Examples include, what constitutes a "grievous and irremediable condition" and when is death "reasonably foreseeable"? The New Zealand EOLCB utilizes some of the same phrases and also shares some specific requirements. One of these is the requirement for the medical provider to remain in close proximity to the patient from administration of the lethal agent until the death. Questions arise from this requirement. Does requiring a provider to stay incentivize using the fast-acting intravenous route of administration? Does it trouble or upset the providers to be present to witness the death process?

This presentation will first identify provisions and terms of MAiD that are similar to the current EOLCB. Then media reports and academic literature regarding the Canadian experience with euthanasia from 2016 to 2019 will be reviewed. Finally, I will describe the study that I am conducting. In October 2019, I will interview twelve Canadian doctors about their lived experience of personally administering medications to hasten death under MAiD. This will be my first presentation of my impressions of the twelve first-hand accounts of the provider experience.

**id #905**

## **Bioethical Dilemmas in the area of Mental Health Care and Law: Involuntary Detention and Treatment of the Mentally Ill**

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Involuntary admissions and hospitalizations of mentally ill patients, present a medico legal, moral, social and mostly bioethical dilemmas for the western legal systems. Those are mostly due to the necessity to choose between conflicting principles of deprivation of personal freedom and autonomy of the mental patients vis-a-vis the necessity to preserve safety of society.

Some legal systems tend to rely more psychiatric evaluation - the medical model, however most western legal systems use the medico-legal model, by which the final decision regarding the terms of involuntary hospitalizations, is taken by mental health tribunals or courts

Many western legal systems have enacted special statutes for the treatment of the mentally ill patients.

However despite the statutory arrangements, there are still quite a few unsolved bioethical dilemmas which the different statutes cannot solve.

Such dilemmas are in the areas of the definition of dangerousness, the psychiatric disorders that are not defined by the DSM-V as psychiatric diseases, cases of psychiatric patients who refuses to take their psychiatric medications etc. Another set of bioethical dilemmas may concern the involuntary admissions of suicide attempters who may present psychiatric symptoms vis-a-vis the right of a person to end his/her life, as well as the dilemma of the "normal" suiciders.

The presentation shall address the bioethical dilemmas, both from academic as well as from practical point of view of a statutory tribunal of involuntary hospitalizations.

id #1069

## **An Ethics Framework for Big Data in Health and Research**

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### **on behalf of the SHAPES Big Data Ethics Working Group**

The topic of Big Data has been explored extensively in academic, technical, government, legal and private sector literature for many decades. The potential arising from the use of Big Data in health and research is widely recognised, as are the challenges posed in this fast-paced dynamic field.

Despite the wealth of literature, there is a lack of practical guidance in the form of a framework that considers ethical issues that arise from the use of Big Data in a variety of health and research contexts.

The *Ethics Framework for Big Data in Health and Research* (the Framework) addresses this gap and is intended for a wide-ranging professional audience: biomedical researchers; clinician-researchers; data scientists; policymakers; those involved in the governance of Big Data activities in health and research, including ethics committees and data access committees; and data controllers. Beyond the professionals who may find this resource helpful, the Framework may also be useful to lay people with an interest in Big Data, patients, and research participants.

The Framework itself comprises two main components: the articulation of relevant values and a decision-making process. This is then applied to six Domains employing big data: *Openness in big data and data repositories*; *Precision medicine*; *Real-world data to generate evidence about healthcare interventions*; *AI-assisted decision making in healthcare*; *Public-private partnerships*; and *Cross-sectorial big data*.

This paper presents details of the Framework structure and provides examples of how it can be applied to the various Domains.

id #1055

## **WORKSHOP (60 minutes): What are the responsibilities of the bioethicist in an age of political cruelty?**

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In an age of increasing human rights abuse, should bioethics be a discipline in which political neutrality is either possible or desirable? Here, we discuss the way in which bioethical work cannot be characterised as neutral. We begin with the proposition that even the choice of topics is a political decision, through which bioethicists allocate intellectual resources. On this basis we believe that within the field issues of political and social importance that have an impact on global populations should be prioritized, and that bioethicists should investigate and contribute to public policy and debate. Bioethics should be a normative discipline that seeks to make a difference, as well as being academically rigorous.

Our focus today concerns our professional duties to expose human rights violations and advocate for those who are subjected to deliberate cruelty, through discussion of three case studies where bioethicists have sought to bring to light violations of the right to health and acts of injustice, and what obligations might flow from this knowledge. We focus on the situation of asylum seekers in offshore detention, organ harvesting in China, and recent examples of obesity campaigns.

Deborah Zion: **On Beginning with Justice: Bioethics, Advocacy and the Rights of Asylum Seekers.**

Angus Dawson: **Good Bioethics, Academic Quality and Indifference to Making a Difference**

Christopher Jordens: **Cruelty as Political Theatre: Australia's system of Mandatory Immigration Detention**

Angela Ballantyne: **Indirect levers: reflections on how to achieve change**

Kathryn MacKay: **'Click with Compassion': Public Health Communication in a Cruel Age**

# NOTES

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# CONFERENCE VENUE FLOOR PLAN

