ABBOTT, JEAN

The Perils of POLST

POLST-paradigm documents have become an important part of advance care planning (ACP) in the past 10-20 years. They are used as a mechanism for translating patient values and wishes regarding the scope of end-of-life care into physician orders to be honored across institutions, in the event people are unable to express wishes for themselves. With experience, providers, patients and families have started to identify challenges to initiating and interpreting POLST documents. Research and anecdotal experiences have suggested that the most effective uses of POLST are to avoid unwanted transport to the hospital with a downturn in health and unwanted CPR or intubation in emergency situations. Several problems with the form have been identified: inappropriate distribution of POLST documents to "well" adults in their 60s and 70s, incomplete forms, and confusions in surrogate designation. Of greatest distress to providers are seemingly inconsistent choices within the POLST document, and inability of the care team to interpret global choices (comfort vs. limited vs. full treatment options) in light of specific documented requests regarding antibiotics, pulmonary support, etc. The need to understand the intent of POLST choices and engage in ongoing conversation in the face of the particularities of the actual situation remains, and is an essential element if healthcare providers are to understand and honor patient conduct of the end of life. This discussion will review progress and new perils of the POLST.

Jean Abbott, MD, MH, is a board-certified Emergency Medicine physician and faculty member at the University of Colorado since 1985. She has a Masters of Humanities from CU and is a longstanding member of the University of Colorado Hospital Ethics Committee and the Ethics Consult service. She focuses lectures and writing on clinical consultation, and end-of-life issues through the Center for Bioethics and Humanities. She is currently helping create the ethics content for the new CU Palliative Care Master's Program, and also teaches and facilitates Advance Care Planning conversations through community presentations.

ABBOTT, JEAN

The Notion of Advance Directives: Headway or Hazard?

The scope of written advance directives (ADs) has expanded in recent years to include healthcare directions to surrogates and healthcare professionals for anticipated loss of motor skills (e.g. ability to drive) or decisional capacity due to dementia, frailty or severe mental illness. Advantages of such planning can include decreased stress on surrogates, protection of resources and protection of the public itself. Prospective planning, however, may fail because people can't imagine either the personal or medical context of future events. Written ADs may thus not represent the person's values or best interest at that future time. Current proposed uses of written ADs in a variety of situations will be reviewed and those challenges examined in this presentation.

Jean Abbott, MD, MH, is a board-certified Emergency Medicine physician and faculty member at the University of Colorado since 1985. She has a Masters of Humanities from CU and is a longstanding member of the University of Colorado Hospital Ethics Committee and the Ethics Consult Service. She focuses lectures and writing on clinical consultation, and end-of-life issues through the Center for Bioethics and Humanities. She is currently helping create the ethics content for the new CU Palliative Care Master's Program, and also teaches and facilitates Advance Care Planning conversations through community presentations.

Megan Prescott (co-author) is a nephrology social worker for the University of Colorado Hospital Acute and Home Dialysis Units and lead for the Ethics Consult Service. Through her dialysis experience, she has developed a deep interest in end-of-life and other ethical challenges. She has served on the National Council of Nephrology Social Workers (CNSW) Executive Committee and the Editorial Board of the Journal of Nephrology Social Work.

BATTIN, MARGARET PABST (WITH BREGJE ONWUTEAKA-PHILIPSEN AND AGNES VAN DER HEIDE)

Updating the Evidence about Physician-Assisted Dying and the Impact on Vulnerable Groups

In the early 2000s, as debates over the legalization of physician-assisted dying were raging, a team of researchers from the US and The Netherlands set out to examine "slippery slope" warnings made in statements by many medical associations and other entities—for instance, that legalization would pose risks to "vulnerable populations" (American College of Physicians, 2005) and that "physician-assisted suicide … would be difficult or impossible to control" (American Medical Association, 1996, 2005). We examined data from Oregon and the Netherlands, the two jurisdictions in which assisted dying was legal at that time, concerning 10 groups identified in the literature as "vulnerable": the elderly, women, the uninsured, people with low educational status, the poor, the physically disabled or chronically ill, minors, people with psychiatric illnesses including depression, people with stigmatized diseases like AIDS, and racial and ethnic minorities. We concluded that for 9 of 10 of these groups (all except AIDS) there was no evidence of disproportionate impact. On the contrary, the available data showed that "people who died with a physician's assistance were more likely to be members of groups enjoying comparative social, economic, educational, professional, and other privileges."

That study was published in 2007, and received wide notice in the global press. Now, a decade later, we plan to update that study, based on annual reports and other studies from Oregon and data from the Netherlands that will become available in spring 2017. Data from other US states and European countries where physician aid in dying is legal may also be included. This presentation will provide an update of the data, addressing as the main question: has the evidence for, or against, the risk of a "slippery slope" changed?

Margaret Pabst Battin, MFA, PhD, is Distinguished Professor of philosophy and medical ethics at the University of Utah. She has authored, co-authored, edited, or co-edited some twenty books, including "Ethics in the Sanctuary," "Drugs and Justice," and "The Patient as Victim and Vector: Ethics and Infectious Disease." She has worked on end-of-life issues throughout her academic career, and has published fiction, articles, and essays in two collections, "The Least Worst Death" and "Ending Life," as well as a comprehensive historical sourcebook, "The Ethics of Suicide: Historical Sources," coupled with an online Digital Archive, http://ethicsofsuicide.lib.utah.edu. She has held the Spinoza Chair at the University of Amsterdam Medical Center and testified in Carter v. Canada. Her current projects include a book on large-scale reproductive problems of the globe, "Sex & Consequences," and work on challenging assumptions in urban design.

Agnes van der Heide, MD, PhD, is a researcher at the department of Public Health of Erasmus MC, University Medical Center Rotterdam, the Netherlands. She has performed studies on epidemiological, clinical, ethical and public health aspects of end-of-life care and decision making, at a local, regional, national and an international scale. She has published in renounced international medical journals about the frequency, characteristics and developments in the practice of euthanasia, assistance in suicide, palliative sedation and other end-of-life decisions, and many other topics. Currently, she is involved in studies on new developments in end-of-life decision making, advance care planning and integrated palliative care.

Bregje Onwuteaka-Philipsen is professor of end-of-life research at VU University Medical Center in Amsterdam, the Netherlands. She leads the research line 'public health at the end of life' at the department of public and occupational health. Main themes of this research line are palliative care, advance care planning, and end-of-life decision-making. Furthermore, she is the chair of the VUmc Expertise Center for Palliative Care in which all care, educational and research activities in the field of palliative care come together. She has ample experience in leading and participating in national and international research. She has been involved in the Dutch nationwide monitoring of euthanasia and other end-of-life decisions and euthanasia regulation that takes place every 5 years since 1995, and has published in renounced international journals on this and other end-of-life related topics.

BERNHEIM, JAN

Palliative Care Including Euthanasia. Responses to Fundamental Criticisms of the Flemish-Belgian Model of Integral End-of-Life Care

BACKGROUND - The Belgian model of 'integral' end-of-life care consists of legally ordained access to (demand-driven) palliative care (PC) and to euthanasia. As a first worldwide, the Flemish professional PC organisation has embraced euthanasia. However, a host of foreign critics have declared the Flemish-Belgian-model concepts of 'integral PC' and 'palliative futility' to contradict the very fundamentals of PC.

AIMS - To analyse their essentialistic objections.

RESULTS - First, some critics wrongly dismiss empirical evidence as epistemologically irrelevant in a normative ethical debate. The disregarded facts are that in the euthanasia-permissive Benelux countries since the de-penalisation of euthanasia, carefulness of decision making at the end of life has improved and there have been no major adverse 'slippery slope' effects.

Next, rejecting euthanasia because its prevention was a founding principle of PC ignores scientific and historical developments.

Further, excluding euthanasia from PC departs from the PC tenets of patient-centeredness and 'total care' by prioritizing caregivers' values over patients' values.

Also objectionable is many critics' canonical adherence to the WHO definition of PC which relies on intention, a notoriously poor criterion to judge actions.

Intellectually rejecting the Belgian model also has practical adverse consequences: marginalisation of PC in euthanasia-permissive jurisdictions, continuation of clandestine practices and problematic palliative sedation until death. Also, some patients will shun PC services that exclude euthanasia and will receive suboptimal PC treatment in non-specialised settings, where moreover euthanasia will tend not to be practiced in the PC spirit of 'total' care. Together, these clinical consequences are likely to lower the overall quality of end-of-life care.

CONCLUSION - Doctrinal arguments against the Belgian model are flawed and reject a plurality of respectable views on decision making at the end of life. By marginalizing PC in euthanasia-permissive countries, they also entail serious risks of undesirable practical consequences, both clinical and at the level of public health.

Jan Bernheim, MD, PhD, is a medical oncologist and professor of medical ethics who started out studying cell death and eventually studied patient end-of-life issues. In 1979 he co-founded the first palliative care organisation in continental Europe and the European Study Group for Quality of Life, whose first chairperson he was. His testimony on the Belgian experience of 'comprehensive palliative care' including euthanasia was judged 'persuasive' in Canadian legal proceedings.

BLACK, ISRA

Adolescent Capacity to Refuse Life Prolonging Medical Intervention and Transformative Experience

This paper takes a novel approach to the vexed issue of adolescent capacity to refuse life prolonging medical intervention (LPMI). In a number of English cases in which adolescents have sought to refuse LPMI (Re E, Re S, Re L), judges refer to a lack of relevant life experience as a ground for decision-making incapacity, in particular a lack

of phenomenological or what it is like experience in respect to dying. Using philosopher L.A. Paul's work on transformative experience, we advance that adolescents ought not to be held incompetent to refuse LPMI on phenomenological grounds.

Decisions issuing in dying and death seem to involve epistemically and personally transformative experiences. Most (including adults) lack access to the information relevant to assigning values to the outcomes of such experiences, including the refusal of LPMI. Because assigning a value to outcomes is a requirement of decision theory – the legal test for capacity under the Mental Capacity Act 2005 is decision-theoretic, and the Gillick test arguably also – it seems to follow that few (if any) individuals are capable of making an instrumentally rational decision in respect of refusing LPMI. Yet, no adult in the reported cases has been held incompetent to refuse LPMI on phenomenological grounds. Indeed, such a requirement was deprecated in Re MB. We advance therefore that consistency requires either 'levelling up' the capacity test for adults, which is both undesirable and impractical, or 'levelling down' the test for adolescents. Therefore, if we much accept differential treatment between adults and adolescents, it must be on other (reasonable) grounds.

Isra Black holds a Lectureship in Law at the York Law School, The University of York. Isra's research covers and combines healthcare law and philosophy. He has a particular substantive interest in end of life issues.

Lisa Forsberg (co-author) is a Postdoctoral Fellow in Practical Ethics at the Rotman Institute of Philosophy at the University of Western Ontario.

Anthony Skelton (co-author) is Associate Professor in the Department of Philosophy at the University of Western Ontario and Associate Director of the Rotman Institute of Philosophy.

CHANDLER, JENNIFER

Organ Donation in the Context of MAiD: Ethics, Law and Policy

With the start of MAiD in Canada, we now face the question of how organ donation should be or should not be integrated with MAiD. The opportunity to donate in this context may offer psychological comfort to the donor and life-saving benefit to recipients, and yet there are challenges related to the risk that vulnerable patients may feel pressure to consent. This risk may also arise in a different way if directed donations are accepted in this context, as patients may decide to seek MAiD in part to benefit a friend or family member. In addition to issues related to the autonomy and well-being of the donor, there is also a possibility that recipients and physicians may also object to involvement in these cases, raising issues about what information should be disclosed to recipients, as well as issues about how to handle conscientious objection by physicians.

Jennifer Chandler is a Professor of Law and holder of the Bertram Loeb Research Chair at the University of Ottawa's Faculty of Law. She teaches mental health law and torts and runs an interdisciplinary discussion group entitled "Mind Brain Law." Her ethico-legal and qualitative empirical research addresses ethical and legal issues at the cutting edge of advances in biomedical science and technology, with a focus on the brain and mind, and on organ donation and regenerative medicine. She has published widely in legal, bioethical and health sciences journals and is the co-editor of the recent book Law and Mind: Mental Health Law and Policy in Canada (2016).

CIRUZZI, MARIA

To Live and Let Die. Withholding and Withdrawing Life Sustaining Treatment in Argentina: From Therapeutic to Judicial Obstinacy

The technological development has improved different techniques that allow to keep biological life far beyond experience. The need to establish boundaries to protect certain rights (autonomy, dignity, quality of life), the duty to avoid bad consequences (therapeutic obstinacy, abandonment of a patient), and the active role that the patient and her family has in the medical relation nowadays, has made us questioned the way to deal with those conflicts. Decision making in this field has been challenging the best patient interest principle. Among those challenges there's fear of liability. At what point is this grounded?

Even though Argentina has a legal and bioethical framework that allows end of life decisions to be discussed and taken within doctor-patient relation, a recent research carried out at Civil and Criminal Courts in Argentina by a paediatric intensivist and a lawyer (partnership between the Bioethics Committee at the National Paediatric Hospital and Law School from University of Buenos Aires) along with a leading case from the argentine Supreme Court show that commonplace belief that Argentina is "an outlaw country".

We will try to show how fear of liability can lead to therapeutic obstinacy and can also end up in a self-fulfilling prophecy: asking a judge, about a medical decision that should have been decided between doctors and patient, according to legal and bioethical framework, opens the chance of legal scrutiny over doctors' decision. And, involving Courts in end of life decision making process when doctors and patient/family agree on the course to be taken is also risky: judicial obstinacy can really harm patient's dignity and shatter family's deepest and beloved feelings.

This paper will present the challenges that end of life decision making process brings to health team, patients and families at the crossroads of medicine, individual rights and legal approach.

Maria Ciruzzi, Lawyer, Bioethics Specialist, PhD in Criminal Law. University of Buenos Aires. Member of the Bioethics Committee at the National Paediatric Hospital Prof. Dr. Juan P. Garrahan. Member of the Bioethics Committee at the Medical Research Institute Dr. Lanari, University of Buenos Aires. Professor of Criminal Law and Bioethics, Law School, University of Buenos Aires. Researcher at Gioja Institute, Law School, University of Buenos Aires.

CLOSE, ELIANA

Not "Worth" It? Doctors' Perceptions of the Role of Resources in Futility Determinations

BACKGROUND - This paper is part of an Australian Research Council Linkage grant, which looks at how doctors conceptualize futile treatment at end of life, why they provide it, and the cost of doing so. One stage of the project involved qualitative interviews with doctors, exploring how they define futile treatment and the reasons they provide it. Doctors' definitions of futility centered on patient benefit, but some indicated that resources were also a factor they took into account.

METHODS - 96 semi-structured interviews with doctors in three tertiary public hospitals in Brisbane. The doctors had expertise in end of life care and came from emergency, intensive care, internal medicine, geriatric medicine, oncology, palliative care, renal, surgery, cardiology, respiratory and medical administration departments. Doctors were asked about the role of resources as a factor in deciding whether or not a treatment was futile or inappropriate. The convergent interviewing technique was used, designed to probe issues that are hard to define.

As the interviews progressed, doctors were questioned about points of convergence and divergence from themes in previous interviews.

RESULTS - Doctors had diverse views. Some said they never took resources into account when making decisions about futility as this conflicted with their duty to the patient. Others indicated that resources were relevant in some situations, especially when the cost of the treatment was high and the expected benefit was marginal or when the resource was scarce. There was some suggestion that the concept of futility could be used to mask a bedside rationing decision.

DISCUSSION - Rationing end-of-life care is ethically controversial. Some doctors consider resources as a factor in making decisions about futility, in some circumstances. This, coupled with the discomfort doctors expressed about acknowledging resource rationales, suggests the need for procedural mechanisms or formal policies to encourage allocative transparency and ensure consistency in decision-making.

Eliana Close is a PhD student at the Australian Centre for Health Law Research at the Queensland University of Technology and is Senior Research Assistant on an Australian Research Council Linkage grant examining futile treatment at the end of life from multidisciplinary perspectives. Eliana has a BSc in Psychology from the University of Calgary, and an MA in Law from the University of Oxford, where she studied as a Rhodes Scholar. Eliana has worked for Google, clerked at the Alberta Court of Appeal, and practised as a Crown Prosecutor. Her PhD is part of the NHMRC Centre of Research Excellence in End of Life Care.

DEHKHODA, AIDA

Consensus View on Assisted Dying for Dementia: A Delphi Study on Key Issues and Concerns

Irrespective of the agreements and disagreements on the issue of assisted dying around the world, euthanasia is only legalized in The Netherlands, Belgium, Luxemburg, Colombia, and Canada; and, physician assistance in dying is permitted in five American states (Oregon, Washington, Montana, Vermont, and California). In all these jurisdictions, one of the main requirements a patient needs to meet to be eligible for requesting assistance in dying is to be mentally competent. This requirement would typically exclude individuals suffering from illnesses that deteriorate their competency such as dementia. The number of people affected by dementia is growing hugely and is considered one of the main causes of disability and dependency among older people worldwide. It is one of the most prominent and fearful conditions for which an aging population has been seeking end-of-life solutions. Growing numbers of patients with dementia and the practical difficulty in following and actioning advanced directives for incompetent patients coupled with increasing advances in medicine and medical health has led to an extended life beyond an individual's ability to be involved in treatment decisions, and highlights the need to explore ways of protecting patients' will beyond the loss of their capacity. In a study to achieve that, we gathered twelve experts with knowledge and experience in end of life care and decision making to seek their views on the issue of assisted dying for people with dementia. We used a qualitative open-ended questionnaire using the Delphi methodology. In this discussion, we will discuss the process we undertook and some of the preliminary findings that sought to devise safeguards within which this special end-of-life decision is achievable for people with dementia.

Aida Dehkhoda is a Doctoral Candidate in Psychology at the University of Auckland, New Zealand. She received a B.S. degree in Clinical Psychology from the Allameh Tabatabaee University and the M.S. in Rehabilitation Counselling from the University of Social Welfare and Rehabilitation Sciences, Tehran, Iran. Her research focus has been in the areas of death and Dying; psychological/existential/spiritual crisis in terminal illnesses; end of life care and choices; and Assisted Dying. Aida is currently exploring end of life choices within the dementia context to identify major issues and concerns and ways forward under the supervision of Dr. Phillipa Malpas and Professor Glynn Owens.

DEMBO, JUSTINE

Considering MAiD in Severe, Refractory Mental Illness

Medical aid in dying (MAiD) legislation has recently been introduced in Canada, for capable patients with incurable conditions, experiencing enduring and intolerable suffering, and where their "natural death" is "reasonably foreseeable." The eligibility criteria in the legislation are narrower than those established by the Supreme Court of Canada in Carter v. Canada. These criteria are required by law to be reviewed in five years, and are also being challenged in a new case called Lamb v. Canada.

Lamb v. Canada argues that the criteria should be expanded to include patients whose natural deaths are not "reasonably foreseeable." Some will oppose this notion altogether, and others who support it may still argue against allowing MAiD for patients with refractory mental illness in the absence of a somatic condition. It is therefore crucial that we discuss whether current legislation is too restrictive regarding severe, refractory mental illness.

First, I discuss how the "reasonably foreseeable" criterion contradicts the spirit of Carter v. Canada, and discriminates against patients with mental illness. Second, I examine the biases in how people view the subjective experience of suffering in mental versus physical illness. Third, I address the concern, expressed by many psychiatrists, that allowing MAiD goes against their fundamental training to prevent suicide at all costs; I argue that suicide prevention and MAiD are not mutually exclusive. Fourth, I argue that many individuals with refractory psychiatric illness can be capable with respect to decisions about MAiD. I will also include a discussion of rationality, "living death," personhood, and misconceptions about vulnerability. Ultimately, I argue that the current legislation should be broadened to include patients with refractory mental illness, and that it is feasible to implement appropriate safeguards to protect the "vulnerable" in either direction.

Justine Dembo is a Canadian psychiatrist currently working in Los Angeles as the Medical Director for Reconnect Integrative Trauma Center, and in private practice, specializing in OCD. She completed her MD and residency at the University of Toronto. She researches medical aid in dying, and is a member of the Joint Centre for Bioethics MAID task-force, the Ontario Shores MAID working group, the Physician Advisory Council at Dying with Dignity Canada, and the Medical Advocates' group for Compassion & Choices. She has conducted capacity assessments in Canada for MAID, and is the consultant for capacity assessments at a hospice in San Diego

DIERICKX, SIGRID

Euthanasia for People with Psychiatric Disorders or Dementia in Belgium: Analysis of Officially Reported Cases

BACKGROUND - Assisted dying for people who are not terminally ill, such as those suffering from psychiatric disorders or dementia, is legal in Belgium under strict conditions but remains a controversial practice. This study aims to report on the trends in prevalence and number of euthanasia cases with a psychiatric disorder or dementia diagnosis in Belgium and demographic, clinical and decision-making characteristics of these cases.

METHODS - We analysed the anonymous databases of euthanasia cases reported to the Federal Control and Evaluation Committee from the implementation of the euthanasia law in Belgium in 2002 until the end of 2013. Only those with one or more psychiatric disorders or dementia and no physical disease were included in the analysis.

RESULTS - We identified 179 reported euthanasia cases with a psychiatric disorder or dementia as sole diagnosis. These consisted of mood disorders (N=83), dementia (N=62), other psychiatric disorders (N=22) and mood

disorders accompanied by another psychiatric disorder (N=12). The proportion of euthanasia cases with a psychiatric disorder or dementia diagnosis was 0.5% of all cases reported in the period 2002-2007, increasing from 2008 onwards to 3.0% of all cases reported in 2013. The increase in the absolute number of cases is particularly evident in cases with a mood disorder diagnosis. The majority of cases concerned women (58.1% in dementia to 77.1% in mood disorders). All cases were judged to have met the legal requirements by the Committee.

CONCLUSION - While euthanasia on the grounds of unbearable suffering caused by a psychiatric disorder or dementia remains a comparatively limited practice in Belgium, its prevalence has risen since 2008. If, as this study suggests, people with psychiatric conditions or dementia are increasingly seeking access to euthanasia, development of practice guidelines is all the more desirable if physicians are to respond adequately to these highly delicate requests.

Sigrid Dierickx holds a master's degree in Sociology (2013, Ghent University) and Health Care Management and Policy (2014, KULeuven). In September 2014 she joined the End-of-Life Care Research Group (Vrije Universiteit Brussel & Ghent University) as a junior researcher. Her research focuses on the Belgian euthanasia practice.

DOMBRECHT, LAURE

The Research Protocol of a Post-Mortem Survey on End-of-Life Decisions in Stillbirths, Neonates and Infants

BACKGROUND **-** The death of a child either before or shortly after birth is frequently preceded by an end-of-life decision (ELD). Population-based studies of incidence and characteristics of ELDs in neonates and infants have rarely been studied and ELDs made in the foeto-infantile period (>22 weeks of gestation up until one year old) including both neonates and stillborns are non-existent. This despite the fact that important information is missing when decisions made before birth are overlooked. Our study addresses this currently missing evidence about and insights in ELDs in stillbirths, neonates and infants.

STUDY DESIGN - First, a new and encompassing framework was constructed in order to conceptualise ELDs in the foeto-infantile period. Next, a population-based mortality follow-back study in Flemish residents (Belgium) was set up with physicians who certified death certificates of stillbirths from 22 weeks of gestation onwards (limit of viability), and infants under the age of one. Two separate (stillbirths vs neonates), thoroughly pilot tested and validated questionnaires were developed. Both include questions on ELDs and preceding decision-making processes. For each certified death the corresponding questionnaire is sent out to the certifying physician. Inclusion aims at 320 stillborns and 375 neonates. Anonymity of the child, parents and physician is ensured by means of a rigorous mailing procedure involving a lawyer as intermediary between death certificate authorities, physicians and researchers. Approval by several physician associations, ethical and privacy commissions was obtained.

DISCUSSION - The protocol of this ELD study in stillbirths, neonates and infants is based on previous ELD studies in neonates, children and adults in Belgium, the Netherlands and other countries hereby ensuring a dependable anonymity procedure that can be applied in other countries. This will be the first research to study ELDs over the entire foeto-infantile period on a population level. Reliable incidence rates of these ELDs can contribute to the development of a uniform practice in perinatal care.

Laure Dombrecht is an experimental psychologist and doctoral researcher at the End-of-Life Care Research Group of Ghent University and Vrije Universiteit Brussel (VUB). She has a master's degree in experimental and theoretical psychology. She started her PhD in October 2015. Her doctoral research project focusses on end-of-life decisions in stillbirths, neonates and infants in Flanders.

DOWNAR, JAMES

Carter vs. Rasouli - Why was One Supreme Court Decision Right and the Other Wrong?

Two recent landmark decisions by the Supreme Court of Canada in the cases of Rasouli and Carter have dramatically changed the medicolegal landscape of end-of-life care in Canada. Each case involved a consideration of personal autonomy and the proper role of medical care in prolonging or shortening a life when some consider that life to be marked by suffering or poor quality. In the Carter case, the interests of patient autonomy and reducing suffering appeared to be aligned, and the court opted to allow patients to request medical aid in dying when they had intolerable suffering. In the Rasouli case, the interests of autonomy and reducing suffering appeared to be opposed to one another, and the court decided that life-sustaining measures could not be withdrawn without consent, even if the medical team felt that these measures were potentially causing suffering to no benefit for the patient. In this presentation, I will review and critique the core ethical considerations of these two Court decisions, and explore the complex relationship between the value of life, autonomy, and the medical standard of care.

James Downar is a Critical Care and Palliative Care Physician at the University Health Network and Sinai Health System in Toronto, and an Associate Professor in the Department of Medicine at the University of Toronto. He has a Master's degree in Bioethics from the Joint Centre for Bioethics at the University of Toronto. He is the chair of the Postgraduate Education Committee of the Canadian Society of Palliative Care Physicians, and the chair of the Ethical Affairs committee of the Canadian Critical Care Society. He has authored more than 50 peer-reviewed publications and is an Associated Medical Services Phoenix Fellow for 2016-17. His research interests include communication and decision-making for seriously ill patients and their families; palliative care for the critically ill; and palliative care for noncancer illnesses.

EAST, JAMES

Conversations About CPR - Professional Judgement or Autonomy?

The College of Physicians and Surgeons of Ontario recently adopted policy 6-16, which effectively requires Physicians to obtain consent to withhold CPR in the event of a cardiac arrest, even if they feel that CPR wouldn't be beneficial to the patient. Physicians could be compelled to provide CPR by default or if a previous discussion with the patient led to a "full resuscitation" order. This policy made the implicit assumption that typical conversations about resuscitation meet the standard necessary for informed consent for a treatment plan that includes CPR in essentially all circumstances.

From an autonomy-focused perspective, this assumption is problematic. Physicians often fail to meet the standards of informed consent for treatments, and CPR presents unique challenges that make obtaining informed consent essentially impossible. In particular, the context in which CPR is provided, the components, risks, benefits and alternatives are often oversimplified or not explained. The general population is almost universally aware of CPR and has important misunderstandings and overly optimistic expectations for its effectiveness and the implications of withholding it.

Yet, there are problems using the medical standard of care to resolve conflicts about withholding CPR. Outcomes of CPR are unpredictable and vary according to demographics, comorbidities and even location within the hospital. Judgments of futility are often not explained or supported by clear rationale, a requirement for establishing the standard of care. Policies that reference consent or medical judgment as the ultimate authority overlook the flaws in each approach, and the lack of existing mechanisms to properly establish a patient's interests or the standard of

care in a timely fashion. They ignore the role of compromise approaches (e.g. time-limited trials of aggressive care for ambiguous cases). Policies should work to enforce a shared understanding and conflict resolution process but not at the absolute loss of professional judgement.

James East is a Critical Care resident at the University of Toronto with a background in General Internal Medicine from the University of Toronto, and a personal interest in medical error in practice and communication around end of life planning.

ELIOTT, JAKLIN

'You're Going to Die. How Would You Like to?' Timing Discussions of End-of-Life Treatment Preferences

Despite endorsement and promotion of advance care planning (ACP), uptake remains low, partially due to lack of consensus about precisely when discussions about ACP should occur. Most research implicitly or explicitly attributes the widespread failure to undertake ACP to deficits, whether these be in patients, families, doctors, healthcare systems, or society. What is often overlooked is that ACP is a complex interpersonal, socially-constructed and socially negotiated process, encompassing multiple meanings around sensitive constructs. As part of a larger study on decision-making at the end of life, we conducted interviews with 51 patients with cancer (28 aware of their predicted death) with 26 attending family members. Here we discursively analyse their accounts of when discussions about end-of-life treatment preferences should occur. We demonstrate how different understandings of autonomy, being a good patient, family member, or doctor, and of emotion, disease, and death variably supported arguments that patients (sometimes regardless of their desire to do so) should complete ACP, sometimes earlier, sometimes later—but not now. The presence of often un-articulated, variably interacting, complex sets of discourses informing ACP may help explain why, despite widespread agreement in theory, uptake in practice remains low. Based on our analysis, we suggest strategies that might enable patients, families, and doctors to undertake ACP in ways that are compatible with highly-prized personal and social values, thus improving outcomes for all.

Jaklin Eliott, PhD, BA (Hons Psych), is a Senior Lecturer and Program Coordinator with the Counselling and Psychotherapy Graduate Program, and Post-graduate Coordinator in the School of Public Health at the University of Adelaide. She employs qualitative methodologies to examine how people talk or write about their experiences and perceptions of health-related issues, considering the social and ethical implications of different ways of understanding for individuals, carers (personal and professional), and society in general. Her research interests include policy and practice pertaining to medical decision-making, cancer, the end of life, hope, alcohol, and Complementary and Alternative Medicines.

EVENBLIJ, KIRSTEN

Conceivability of Performing Euthanasia in Cases of Psychiatric Disease, Dementia or Being Tired of Living

INTRODUCTION - In 2002, the Dutch Act on Termination of Life on Request and Assisted Suicide was enacted legalizing euthanasia and physician-assisted suicide (EAS) if the specific 'due care' criteria are met. In this act, no restrictions are mentioned relating to the cause of suffering other than that it must originate from a medically classifiable condition. However, EAS in patients with a psychiatric disease, dementia or patients who are tired of living (without severe morbidity) is rare. Research from 2011 showed that in case of an EAS request of a patient with a somatic disease, a large majority of the Dutch physicians found it conceivable that they would perform EAS and over half had ever done so. Physicians were significantly less likely to find EAS conceivable in a request from

patients with a psychiatric disease, dementia or who are tired of living (ranging from 18% to 40%) and even less physicians had ever granted a request from these patients (ranging from 1 to 3%).

AIM - Five years later, EAS in patients suffering from causes other than cancer or other severe diseases is still highly controversial, and gained even more attention in the public and professional debate. Therefore, we aim to determine the status quo on whether Dutch Physicians can conceive of granting requests for EAS in patients with cancer, another physical disease, a psychiatric disease, dementia or patients who are tired of living, and to evaluate whether physician characteristics are associated with conceivability.

METHOD - A cross-sectional survey, similar to the one in 2011, was conducted. A questionnaire was mailed to a random sample of 2500 general practitioners, clinical specialists and elderly care physicians working in the Netherlands. Data was collected in 2016.

RESULTS - The response rate was 51%. Results are not available yet, but will be presented at the congress.

Kristen Evenblij works as a PhD student at the VU University Medical Center at the department of Public and Occupational Health in Amsterdam, the Netherlands. She participates as a researcher in the Third Evaluation of the Dutch Euthanasia Law. Before working as a PhD student, Kirsten studied Health Sciences at the VU University Amsterdam. In 2013 she received her bachelor's degree. Subsequently, she studied the research master's programme Global Health at the VU University Amsterdam where she received her Master's degree in 2015.

EVENBLIJ, KIRSTEN

Experiences of Psychiatrists with (Granting) Requests for Euthanasia in Patients with Psychiatric Diseases

INTRODUCTION - in 2002, the Dutch Act on Termination of Life on Request and Assisted Suicide was enacted, legalizing euthanasia and physician-assisted suicide (EAS) if the specific 'due care' criteria are met. According to this act, suffering must originate from a medically classifiable condition; this can include psychiatric suffering. A survey among psychiatrists in 1995 showed that in that year, 320 requests for EAS were done by Dutch patients with a psychiatric disease of which around 2-5 were granted by a psychiatrist. In 2008, a similar survey estimated a number of 500 requests of which about 30 were granted. It is known that EAS in psychiatric patients is reported increasingly to Euthanasia Review Committees: from 2 cases in 2008 to 56 cases in 2015. At the same time EAS in patients with a psychiatric disease is still highly controversial and Dutch psychiatrists seem reluctant to grant requests for EAS. However, it is unknown how the experiences of psychiatrists have evolved since the earlier surveys.

AIM - To provide insight in the experiences of psychiatrists with (granting) requests for EAS in patients with a psychiatric disease and their reasons for either or not granting such requests.

METHOD - A cross-sectional survey was conducted among psychiatrists providing care for patients with a psychiatric disease. A questionnaire was mailed to a random sample of 500 psychiatrists. Addresses were obtained from a national databank of registered physicians (QuintilesIMS). Inclusion criteria were: (1) working as a psychiatrist in patient care for the last year; (2) working in the Netherlands; (3) working with adult patients. The questionnaire was similar to ones used in the surveys in 2008 and 1995. Data were collected in 2016. Two reminders were sent.

RESULTS - The response rate was 49%. Results are not available yet, but will be presented at the congress.

Kirsten Evenblij works as a PhD student at the VU University Medical Center at the department of Public and Occupational Health in Amsterdam, the Netherlands. She participates as a researcher in the Third Evaluation of the Dutch Euthanasia Law. Before working as a PhD student, Kirsten studied Health Sciences at the VU University Amsterdam. In 2013 she received her bachelor's degree. Subsequently, she studied the research master's programme Global Health at the VU University Amsterdam where she received her Master's degree in 2015.

FOTI, ANDRÉA

Regulating MAID: The Medical Regulatory Perspective

From the release of the Carter decision to the finalization of the federal legislation and beyond, Medical Regulatory Authorities (MRAs) across Canada have played a key role in regulating Medical Assistance in Dying (MAID).

MRAs engaged early in regulating MAID, acting in advance of legislation to develop standards and policy based on the Carter decision to guide physicians and to ensure the public's interests were protected. MRAs' work continued beyond these initial activities, with efforts undertaken to assist provincial and federal government in forming legislation and policy direction, and to ensure its own policies and standards for physicians were revised to keep pace with shifting requirements as the federal legislation was finalized. MRAs work continues further in regulating physician compliance with legal and policy expectations regarding MAID and responding to queries, concerns and complaints regarding MAID.

This presentation will provide an overview of MRAs role in regulating MAID, with an emphasis on the work of the College of Physicians and Surgeons of Ontario, Canada's largest MRA (14M population, 40 000 physicians).

The presentation will:

- Provide a broad high level summary of the relevant policy and standards MRAs across Canada have developed in relation to MAID.
- Focus in detail on policy and other resources developed by the CPSO to assist physicians and the public, with some emphasis on the CPSO's position relating to managing physician conscientious objections.
- Offer a practical perspective on the key areas of challenge with respect to compliance and access to MAID that have come to the CPSO's attention since the federal legislation was enacted in June 2016.

Andréa Foti is Manager of the Policy Department at the College of Physicians and Surgeons of Ontario. She oversees the development and review of all formal policies of the CPSO, along with formal CPSO positions on a range of issues in the health regulatory landscape. She holds a law degree from the Schulich School of Law at Dalhousie where she earned a specialization in health law and policy from the Health Law Institute. She also holds a master's degree in Medical Ethics and Law from King's College, University of London, UK and is a member in good standing with the Law Society of Upper Canada.

FOURNIER, VERONIQUE

End of Life Regulation and Recent Evolutions in France

In France, as in many other countries, debate has raged for many years about whether or not a "right to die" should be open. Regularly, the question resurfaces when a specific clinical case makes the headlines, and re-emerges as an important and controversial societal as well as political issue.

A first legislation, which explicitly regulated end-of-life medical decisions, was passed in 2005. It maintained the prohibition of active assistance in dying for healthcare professionals, but introduced a legal injunction to refrain

from medical futility. The recommendation was to let death occur and never do anything with the intention of hastening it. As such, it has been said that the intention concept was the one that has been settled as the "cornerstone" of the law. The law also introduced the right for patients to write advance directives, designed to give doctors indications as to patients' wishes, although they were not binding at this stage.

Seven years later and because of new presidential elections, the issue was open again. A large democratic consultation took place that lasted for three years and instigated many harsh and controversial disputes. Some asked that active assistance in dying become explicitly authorized, while others strongly resisted. At the end, in February 2016, a political compromise was finally found and a new law was adopted. The main changes introduced by the new regulation all consisted in reinforcing patients' rights, even if it did so far as to open a right to active euthanasia. Advance directives became binding and a possibility to ask for deep and terminal sedation at the end of life has been opened, under certain conditions. Moreover, explicit references to the intention concept disappeared from the law.

We will propose a critical analysis of the new regulation, nourished by the learnings coming from the clinical grounds that we are in good position to observe, as the leader team of the National Center for Palliative Care and End-of-Life.

Veronique Fournier is the President of the French National Center for Palliative Care and End of Life.

FRIESEN, PHOEBE

The Shift Away From 'Suicide' Talk: Incorporating Voices of Experience

Within discussions of expanding options for individuals at the end of their lives, there has been a push away from using the term 'physician-assisted suicide' and a move towards using the terms 'death with dignity', 'physician aid in dying', and 'medical assistance in dying'. Debates over the appropriateness of this shift have surfaced within proponents of aid in dying legislation. Those in favour of the shift argue that it is necessary to create a distance between the practice of medical assistance in dying for the terminally ill and the highly stigmatized act of suicide. Those against insist that one should call the act what it is and that to shroud it in another name is both imprecise and dishonest. This paper does not offer an argument for either side of this debate, but instead works towards exploring the ethical questions raised by the proposed act of distancing medical suicide from other forms of suicide. The methodology involves an exploration of qualitative literature that gives voice to those who have attempted suicide without medical intervention and those who are thinking about ending their lives with the help of a physician. These interviews with individuals who have thought about ending their lives are placed side by side, and their similarities and dissimilarities are highlighted. This allows for the mutuality of their suffering to come into view, but also allows for the differences in what motivates them to consider ending their lives to appear. In light of this qualitative data, the question of whether it is appropriate to abandon the term 'physician-assisted suicide' in favour of less stigmatized terms is revisited, and reasons drawn from the voices of those who have considered ending their lives are offered, both in favour of and against the shift.

Phoebe Friesen is a PhD Candidate in Philosophy at the CUNY Graduate Center in New York City. Her work focuses on issues within philosophy of psychiatry, especially those intertwined with questions related to philosophy of science and bioethics. She works as a Research Associate at the Division of Medical Ethics at NYU Medical Center, as an Ethics Fellow at Icahn School of Medicine at Mt. Sinai, and a Teaching Fellow at Baruch College. She is also a volunteer researcher at two outpatient programs for early psychosis in New York City, and is writing a dissertation on the placebo effect.

FRITSCH, RYAN

Law Reform and Improving the Last Stages of Life: Preliminary Research Findings from Ontario Consultations

The Law Commission of Ontario's Improving the Last Stages of Life project considers how the law shapes the rights, choices, and quality of life for persons who are dying and those who support them. The LCO has identified and will be consulting on 13 specific consultation issues: consent and advance care planning; access to justice for communities with unmet needs; the public health approach; transitions between care; resolving health care disputes; withdrawing and withholding treatment; palliative sedation therapy; planned deaths at home; caregiver and family needs; medical assistance in dying; cultural and religious needs; supports for professionals; and improving practice tools.

During this session, project head and LCO research lawyer, Ryan Fritsch, will report on preliminary findings from our Ontario-wide consultations, and the results of the LCO's consultation survey on the thirteen issues above. Following Ryan's presentation, session attendees will have the opportunity to discuss the findings, and potential law reform recommendations, which the LCO will release in its follow-up interim report.

Ryan Fritsch is a Research Lawyer with the Law Commission of Ontario. He is experienced in teaching, litigating, and leading community and corporate social justice initiatives as a Toronto-based health law, human rights, and administrative law lawyer. He is a sessional professor in mental health law at the University of Windsor Faculty of Law, and former legal counsel to the Psychiatric Patient Advocate Office.

GANZINI, LINDA

Twenty Years of Experience with Physician-Assisted Death in Oregon

The Oregon Death with Dignity Act, which legalized physician-assisted death (PAD) for competent, terminally ill patients, was enacted twenty years ago. This law allows a competent, requesting terminally ill patient to receive a prescription for a lethal medication from a physician for the purposes of self-administration. This talk will review research on the experiences of health care professionals, family members and requesting patients with the law.

Since enactment of the law, 991 Oregonians have died by lethal medication, a slow increase to 4/1000 Oregon deaths. People who die by PAD are more likely to have a college education; 2% lack medical insurance. Studies of physicians and hospice workers who have cared for requesting patients, family members and patients themselves all point to the importance of staying in control, not being dependent on others, maintain self-sufficiency and not burdening family. Negative views on the future are an important predictor of continued interested in PAD, but depression and lack of social support are less common than anticipated. Some patients with potentially treatable depression have accessed prescriptions and not received a mental health evaluation. Ninety percent of patients who die by PAD in Oregon are hospice enrolled and hospice referral and provision of nonjudgmental support are the most effective interventions that may result in patients changing their mind about PAD. Among those whose family member requested PAD, whether or not the patient accessed a lethal prescription had no influence on subsequent depression, grief, or mental health services use; however, family members of Oregonians who received a lethal prescription were more likely to believe that their loved one's choices were honored and less likely to have regrets about how the loved one died. Family members of Oregonians who requested PAD felt more prepared and accepting of the death than comparison family members.

Linda Ganzini, MD, MPH, is a psychiatrist at Oregon Health and Science University, where she is a Senior Scholar at the Center on Ethics in Health Care and Director of the Geriatric Psychiatry Fellowship Program; and at VA Portland Health Care System, where she is Director of Consult-Liaison Psychiatry and Associate Director of the Health Services Research and Development Center of Innovation.

GIROUX, MICHELLE

Medical Aid in Dying: An Update from Québec

The presentation will provide us the opportunity to present an update on the application of the legislation on end of life care adopted in the province of Québec, in June 2014, which came into force December 10, 2015. The focus will be on medical aid in dying and different issues that have been raised since the implementation of the legislation.

First, the federal legislation adopted in June 2016 provides different criteria to access medical aid in dying. End of life is one of the criteria in the Québec legislation, whereas it is a reasonably foreseeable death in the federal legislation. Can these two approaches be reconciled?

Second, the presentation will also address the role of the Commission de controle created in Québec by the same legislation. We will look at the legal process that has been put in place by the legislation to ensure the monitoring of medical aid in dying and to some statistics from the first reports that have been published to illustrate the discussion.

Third, the issue related to the application of the conscience clause to refuse to provide medical aid in dying will be also looked at. Health professionals in some institutions showed reluctance to deliver medical aid in dying. Can this be reconciled with the principles of the law?

More generally, the discussion will include a comparative analysis of the situation in the rest of Canada and abroad.

Michelle Giroux, LLL (Ottawa) MA, Medical Law and Ethics (London, UK) is Full Professor at the Faculty of Law, Civil Law Section, at the University of Ottawa and Member of the Québec Bar and of the Interdisciplinary Research Laboratory on the Rights of the Child and of the Centre for Health Law, Policy and Ethics at the University of Ottawa. Professor Giroux is a specialist in family and persons law, medical law and bioethics. She was on the panel of legal experts appointed by the government of Québec to implement the report of the Select Committee on Dying with Dignity. Since September 2015, she is a member of the Law Commission of Ontario Advisory Group for the Project on Improving the Last Stages of Life.

GREEN, LAURA

"Rock, Paper, Scissors" – Ideologies of End of Life Care for Older People in Hospital

In this paper I draw upon the theory of Pierre Bourdieu (1990) in order to explore issues raised by an ethnography of older peoples' end of life care in an acute hospital setting. Three ideologies of care are considered: rescue, rehabilitation and release. I illustrate through a consideration of Bourdieu's theory of cultural and social capital that negotiating ethical issues at life's end is influenced by power dynamics between professions and disciplines, and that the dominate ideology within the hospital is one of rescue. The care environment is further shaped by broader societal ideals about the purpose of hospital based medical care, the role of life-prolonging interventions, and the withdrawal of curative treatments. These perspectives will be illustrated using three examples from the field notes that exemplify clashing ideologies of care. The first relates to a dispute about a percutaneous

endoscopic gastronomy (feeding tube). The second example illustrates the diminishing role of the physician as natural death approaches and the resultant interprofessional dissonance. The final example illustrates the potential for harm that can result from attempting to rescue a dying person. I conclude by suggesting that ethical conflicts at the end of life can be understood within a broader context of socially informed values relating to aging and mortality.

Laura Green is a nursing lecturer in palliative and end of life care and is currently undertaking a doctorate under the supervision of Professor Jan Oyebode and Dr. Andrea Capstick, which is an ethnography of older peoples' suffering at the end of life in a hospital in the United Kingdom. Her background is as a community nurse, hospice nurse and latterly as a Clinical Nurse Specialist in Palliative and End of Life Care.

GREEN, STEFANIE

Medically Assisted Deaths on Vancouver Island – The First Year

BACKGROUND - On June 16th 2016 Bill C14 was passed by Parliament and it achieved Royal assent on June 17th and became law. Medical Assistance in Dying (MAiD) in Canada ceased to be illegal if it was explicitly requested by the patient and that patient met the criteria laid down in C14. We have completed a review of the cases of assisted deaths that have taken place in Vancouver Island in the first six months since this occurred.

METHODS - Case Review. All records from each MAiD death on Vancouver Island have been submitted to the Vancouver Island Health Authority (VIHA) working group on MAiD for review. We analyzed the data for demographics, trends, and also for signs of gaps in data collection and service availability.

RESULTS: There were 72 MAiD deaths in the six-month period. This is approximately 2% of the total deaths in that time (7100 expected deaths in 2016/17) (1). The number of MAiD deaths per week is probably rising. The gender distribution is even. MAiD deaths took place in home (64%), acute care (21%), hospice (12%), and residential/complex care (3%). Underlying conditions were neoplasm (57%), organ failure (25%), neurodegenerative (11%). others (7%). 69 (96%) deaths were by intravenous route, 3 (5%) by oral (though one of these progressed to IV after a previously agreed time by which death had not occurred). Age range was 49-96. 25% of MAiD deaths were expedited and took place within the 10-day 'period of reflection'.

Stefanie Green, MDCM CCFP, spent 10 years in general practice and another 12 years working exclusively in maternity and newborn care. She sought and received background education in The Netherlands and began working in Medical Assistance in Dying, becoming one of an initial handful of physicians who started providing MAiD care in Canada on day one. She was pivotal in starting the Canadian Association of MAiD Assessors and Providers (CAMAP) and enjoys educating both the public and her peers about MAiD. She is on clinical faculty at the University of Victoria and the University of British Columbia.

GUBITZ, GORDON (WITH LIANA BRITTAIN, TIM HOLLAND, MATTHEW KUTCHER, ROBYN MACQUARRIE, AND LIANNE YOSHIDA)

Medical Assistance in Dying (MAiD) – Early Experiences and Practical Considerations in Nova Scotia and PEI (Panel)

Medical Assistance in Dying (MAiD) became legal in 2016, resulting in immediate requests from patients to access this service. The medical profession and other allied professionals protected by the legislation (pharmacists and nurses) have found themselves 'catching up' ever since – not only with their own thoughts, opinions, and questions about MAiD, but also with respect to developing high-quality, legally-compliant professional practices,

while at the same time finding on-the-spot answers to many pragmatic "how to" questions underlying the provision of this important new service. In Nova Scotia, a core of 7 MAiD physicians has been working with our Health Authority to develop our MAiD-related processes and documentation. In this symposium/workshop, we will take MAiD from the theoretical to the practical, by providing an overarching review of the status of MAiD in our province since the service became available. We will address practical aspects of MAiD delivery, including documentation, protocols, medication, the logistics for in-hospital and community-based procedures, billing, and the need to develop collaborative relationships with pharmacists and nurses. We will also speak about our early challenges (and solutions), and will reflect upon some of our 'experiences from the trenches,' and discuss the impact that they have had upon us. We will also (if possible) include the perspectives of both the patient seeking MAiD, and the surviving families, as these perspectives are vitally important if we are to improve the care that we provide.

Gordon Gubitz is an Assistant Professor of Neurology at Dalhousie University, in Halifax, Nova Scotia. He was born in Calgary, Alberta (Gemini, Sagittarius rising), and obtained his MD at McMaster University in Hamilton, Ontario. He completed training in Adult Neurology at Dalhousie, followed by a Stroke Fellowship in the Department of Clinical Neurosciences in Edinburgh, Scotland. Dr. Gubitz works as an attending physician on the CDHA Acute Stroke Unit in Halifax, and is the Director of the Outpatient Neurovascular Clinic. He is also involved in stroke-related research, and medical education. He is the Program Director for Adult Neurology at Dalhousie. Dr. Gubitz became a Medical Assistance in Dying (MAiD) provider shortly after federal legislation was passed that legalized the process in Canada in 2016. In this role, he provides MAiD to eligible people in Nova Scotia, and has helped to develop and refine the protocols and documentation underpinning MAiD service delivery. He is also involved in MAiD-related education for medical learners (students, resident doctors, and medical practitioners), and is in the initial stages of developing a research protocol to evaluate the experiences of the families of those who have undergone MAiD

Liana Brittain lives in a century old Acadian farm house, on the Northumberland Strait in PEI, with her two loyal companion dogs. She is committed to her dual role as both MAID and chronic pain advocate. Before his death, her husband, Paul B. Couvrette, asked her to use his story to help educate the medical community and the public at large about MAID, as an end of life choice. Liana has willingly taken on that task. While living on the island, Liana has continued to show her art in numerous venues and devoted time to writing a book that chronicles the first eighteen-years of her journey with chronic pain. In addition, she is working on the development of a chronic pain, self management program that is peer guided and self assessing. Liana worked as an elementary school teacher for thirty-two years before medical problems forced her into early retirement. Later, she trained as a program facilitator and worked helping others develop the strategies necessary to live with chronic pain.

Tim Holland completed a degree in philosophy and psychology. He then began study at Dalhousie medical school in 2007 and completed a residency in family medicine in 2013. He currently divides clinical time equally between Emergency Medicine in Truro, Nova Scotia and Family Medicine. Dr. Holland's family medicine time is equally divided between Refugee Health (at the Newcomer Health Clinic in Halifax) and First Nations Health (at the Sipekne'katik Health Center in Indianbrook, Nova Scotia). He began providing Medical Assistance in Dying (MAID) in July 2016. As of July 2017, he has participated in ten cases. He was also elected as Chair of the Committee on Ethics for the Canadian Medical Association (CMA) in 2016. Since that time the Committee has finalized an updated policy on Medical Assistance in Dying for the CMA. He also sat on Doctor's Nova Scotia's MAID working group in 2015 and 2016 which helped develop some of the provincial infrastructure and policy around MAID.

Matthew Kutcher, MSc, JD, MD, is a general practitioner and hospitalist in Summerside, Prince Edward Island, where he divides his time between the Harbourside Collaborative Health Centre and the Prince County Hospital. He is a member of the Provincial Clinical and Organizational Ethics Committee and was the first physician to provide MAID in the Province of Prince Edward Island. Dr. Kutcher completed a master's degree in Neuroscience & Psychology at Dalhousie University. He then completed a law degree at the Schulich School of Law (Health Law and Policy specialization), where he was awarded a Schulich scholarship, the J.S.D. Tory writing award and graduated with the Health Law Institute prize. After law school, he completed his medical degree at Dalhousie Medical School

and his primary care residency at the University of Toronto. He returned to the East Coast in January 2017 with his wife Martha and daughter Ruby. Dr. Kutcher has published widely on both medical and legal topics. He is a dedicated educator with a keen interest in the interactions between system level health law and policy and the day-to-day delivery of health care in Canada.

Lianne Yoshida has been a family doctor for 18 years. She has a general family practice and works as an abortion provider in Halifax, NS. She has been involved in MAiD since it was legalized last year and has done several assessments and procedures. She is a member of CAMAP (Canadian Association of MAiD Assessors and Providers) and the MAiD Resource Group at the College of Family Physicians of Canada.

HABETS, MICHELLE

Elderly Who are Ready to Give Up on Life and the Right to Autonomy

The Dutch government aims to create a new legal framework to assist elderly in dying who, in their own judgment, have no perspective in life anymore. In contrast to the Termination of Life on Request and Assisted Suicide (Review Procedures) Act of 2001, which is based on the principle of compassion, a new preliminary law will have as core the 'right to autonomy', according to the Minister of Health. While the government will start working on designing this new law, the Supreme Court of the Netherlands is due to rule in March this year in the case of an assisted suicide by a family member of a woman who felt her life was completed. Both the legislator and the judicial system are thus preparing to decide on the legality of assisted suicide outside of the current legal framework. In this study we will mainly focus on the plans of the legislator to create a new exception to the prohibition on assistance in suicide (art. 294). We will attempt to clarify the government's interpretation of the concept of autonomy, and its implication.

This is important, because due to the ambiguity of the concept, the debate can get muddled. This is especially the case when aid is needed for people to perform their autonomous wish. Moreover, laws on euthanasia are in point of fact a shared concern of the public. In addition, we will discuss whether being autonomous requires a basic level of goods, in which case the austerity measures in elderly care, may cause freedom from interference to fall short of what is needed to protect elderly who are tired of life.

Michelle Habets works as a postdoctoral research associate on the project "Doctors and lawyers dealing with Death and Dying" at the Erasmus University of Rotterdam. Her background is in biology and philosophy. She completed her PhD (very good) in evolutionary biology in the Lab of Genetics at Wageningen University in 2008. Subsequently, she worked as a postdoc at the University of Liverpool, and subsequently studied "Healthcare Ethics and Law" at the University of Manchester. In 2016 she finished her PhD in medical ethics at the University Medical Center in Utrecht on the ethics of translational pluripotent stem cell research.

HAGENS, MARTIJN

Demedicalised Assistance in Suicide

INTRODUCTION - In the Netherlands, people with a wish to die can seek counselling to end their own life outside the medical context. We answer the question which people seek this demedicalised assistance in suicide (DAS), and what trajectories to DAS they take.

METHODS - The first - quantitative - study analysed date from counsellors facilitated by Foundation De Einder about people receiving DAS in 2011 and 2012 (n=595). The second - qualitative - study analysed date from in-depth interviews with people who receive(d) DAD from these counsellors (n=17).

RESULTS - The quantitative study showed that more than one third of the people seeking DAS had no current wish to end life, and almost two thirds did not request physician assistance in dying (PAD). While more than half of the people received information on how to end life, 13% had ended life themselves, primarily by ingesting self-collected lethal medication.

The qualitative study showed there were three trajectories that led people to see DAS. People with current suffering seek DAS because they were unable to obtain PAD. People anticipating possible prospective suffering either sought DAS as a back-up for when PAD would not be possible in due time, or preferred DAS as a result of valuing self-determination, independence, and own responsibility.

CONCLUSION - Results from the quantitative study can be explained by distinguishing two different groups of people that seek DAS. One group seems to be looking for a peaceful death to escape current suffering. Another group seems to be looking for reassurance in anticipation of possible prospective suffering.

Results from the qualitative study show that, while PAD is the preferred option in two of the three trajectories, obtaining PAD is uncertain and not always possible. To keep the physician involved, openness in patient-physician communication on assistance in dying is important, also about possibilities outside the Dutch PAD law.

Martijn Hagens graduated as MSc in Social and Development Psychology from the University of Amsterdam in 2007. In 2012, he started as a junior researcher at the EMGO+ Institute at the VU University Medical. While demedicalised assistance in suicide is his main research interest, he also worked on several other projects in end-of-life care, e.g. voluntarily stopping eating and drinking, the pilot project 'palliative home care among GPs in Amsterdam' and the Dutch report about elderly people and a self-chosen death. Currently he continues his research focussed on understanding trajectories for assistance in dying outside the medical context.

HENRY, BLAIR

The Evolving Role of Palliative Sedation in the Area of MAID

This presentation will outline our current level of understanding - as it relates to both the areas of consensus and remaining contention, surrounding the ethics and practice of palliative sedation in Canada. This summary will be based on a contemporary review of policies and guidelines enacted over the past decade.

An additional analysis will be conducted using a literature review of the experiences and trends noted in how palliative sedation is used in countries that have had legalized assistance in dying legislation enacted for several years.

A comparison will be made of the current Canadian practice in light of the current issues being faced in other jurisdiction to identify areas of potential concern regarding the future use of palliative sedation in Canada.

Blair Henry is a Senior Ethicist with Sunnybrook Health Sciences Centre and North York General Hospital. He holds a Doctorate of Bioethics from Loyola University in Chicago, and he is an Assistant Professor in the Department of Family and Community Medicine at the University of Toronto. He was a member of the CSPCP working group that developed a Canadian Framework for the use of Continuous Palliative Sedation. He has presented locally and internationally on this topic, has consulted on the creation of PST policies for several organizations, and has published on topics related to palliative sedation.

IFTENE, ADELINA (WITH CRYSTAL DIELEMAN AND DAVID HOOEY)

End-of-Life Issues in Canadian Prisons (Panel)

During the last decade, the Canadian prison demographic shifted dramatically. Since 2005, the people considered "older" (i.e. 50+) increased to 25%, which is more than a doubling. Canadian correctional systems are thus faced with new challenges: chronic illnesses, disability, mental illnesses experienced by the elderly, and indeed, terminal illnesses.

In this panel, we will explore the challenges that the increasing number of terminally ill bring to the federal correctional system, as well as the quality and quantity of end-of-life care available in correctional facilities. This panel will bring together an interdisciplinary group well versed in prison matters, but from different backgrounds: a representative from the Office of the Correctional Investigator (i.e. the prison ombudsman); and two independent researchers specializing in prison issues (i.e. a health science scholar and a legal scholar).

Through case studies, empirical data, and health and legal analyses of the current standards of care in prisons, we plan on addressing the following questions:

- What type of end-of-life care is currently available in the federal correctional prisons and what are these individuals' release options?
- How are the community health care standards applied in the correctional setting in general, as well as in the particular context of terminally ill individuals?
- If there is a gap between the community health standards and the prison services available, how will this impact the implementation of assisted death legislation for prisoners?
- What are the steps needed in order to make assisted death an option for incarcerated individuals? When and how should such an option be available?

Adelina Iftene is an Assistant Professor at Schulich School of Law, Dalhousie University. Her main research and teaching interests are criminal law and procedure, prison law and prisoners' rights, sentencing, evidence, and human rights. Adelina has received her PhD in law, from Queen's University. He dissertation, focusing on the aging of the prison population and its legal consequences, is currently under contract with University of Toronto Press and will be available as a book. Other publications based on this work can be found at https://ssrn.com/author=2640651. In addition to scholarly work, Adelina has been actively engaged in numerous policy and volunteer projects surrounding prisoners' rights, rehabilitation and reintegration, both at federal and provincial levels. She is currently a member of the Prison Law Advisory Committee of Legal Aid Ontario and of the Dementia Justice Advisory Committee, and a member on the executive board of the Canadian Prison Lawyers Association. Adelina is also volunteering as a prison book club facilitator with Book Club for Inmates at Nova Prison for Women in Nova Scotia.

Crystal Dieleman worked as an occupational therapist with the Correctional Service of Canada for 10 years before taking up an academic position in the School of Occupational Therapy at Dalhousie University in 2006. She worked primarily with incarcerated men who have mental health problems as they prepared to make the transition from prison back to community life. She completed her BSc(OT) at Western University and an MSc and PhD in Rehabilitation Science at Queen's University. Her research uses critical theory and mixed methodologies for naturalistic inquiry of the intersection of health and criminal justice. Her past research has examined how mental health care in a prison-hospital is subordinated to correctional and security priorities, the impact of social determinants of health in the criminalization of mental illnesses, and the role of occupational therapy with people residing in correctional halfway houses. Her current scholarly work is examining end of life care in prisons, the impact of criminal record checks on occupational engagement and community participation, staff attitudes and

perspectives about sexual activity among forensic mental health clients, and evaluation of therapeutic and specialty courts. She is an active member of the Dalhousie Health Law Institute and the East Coast Prison Justice Society.

David Hooey, MA (Saint Mary's University), is Director of Policy and Research at the Office of the Correctional Investigator. He is responsible for drafting reports, public communications, correspondence and policy reviews of issues affecting federally sentenced offenders. He joined the Office in February 2009. Prior to that, he worked at the Privy Council Office (Security and Intelligence) and the Department of Public Safety (International Affairs).

JAMESON, KIM

Patients with Parkinson's Disease, Caregivers', and Healthcare Providers' Perspectives of Advance Care Planning for End-of-Life Care

Advance care planning (ACP) has been shown to support patients in making future healthcare decisions and lower healthcare costs at end-of-life (EOL). Nonetheless, recent studies indicate that communication of ACP and implementation within the Canadian healthcare system remains inadequate. This presentation focuses on findings from a qualitative research project on the psychosocial and relational factors that impact patients with Parkinson's disease willingness to engage in advance care planning (ACP) for their end-of-life (EOL) care. It compares health care providers' (HCPs), patients' and family members' views towards ACP barriers, as well as their recommendations to enhance supportive advance care decision-making practices. Semi-structured individual and joint interviews with 20 patients with Parkinson's disease, their caregivers, and health care providers (e.g. neurologists, general practitioners, nurses, and social workers) were conducted in a Western Canadian city. Interpretive description methodology informed an inductive thematic analysis of the findings and constant comparative techniques were employed to explore patterns of ACP experiences across and between datasets. Through triangulation of data sources, this study compares how patients and their caregivers, as well as patients who live alone or without care networks, engage in ACP regarding future EOL care pertaining to such issues as: placement planning, pain management, artificial nutrition and hydration, and life prolonging treatment/interventions they might consider at end-of-life. The study explores barriers and facilitators, including health system factors (e.g. access to services, communication and information provision) and psychosocial factors (e.g. impact of emotional distress and/or family support, or lack thereof), participants feel hinders or supports them to engage in advance care planning for end-of-life. Findings from this study aim to generate person-centered practice recommendations on who, how and when to engage Parkinson's disease patients and caregivers in advance care planning for end-of-life care.

Kim Jameson is a clinical ethicist at Vancouver Coastal Health. She holds a Master of Arts degree in philosophy, specializing in applied ethics, and is currently a PhD Candidate at the University of British Columbia's (UBC) W. Maurice Young Centre for Applied Ethics. Her dissertation research project focuses on Parkinson's disease patients', family caregivers', and clinicians' perspectives of advance care planning for end-of-life care. Kim is also involved in an ongoing CIHR funded project "Supportive Decision Making for Diverse Populations" and has been a volunteer ethicist for the UBC behavioural and clinical research ethics boards since February 2013.

KIM, OLIVER

Trying and Dying: Are Some Wishes Better?

In 2015, both chambers of the US Congress considered two legislative proposals related to care at the end of life. One proposal passed the House of Representatives as part of a larger package, and this proposal paralleled a "right to try" movement. The other proposal failed to be amended into a larger package being debated by the Senate, and this proposal would have assisted in advance care planning efforts with seniors.

While these two pieces of legislations are unrelated, it is striking how easily the "right to try" passed as part of a larger bill while at the same time, a very modest proposal on the periphery of the "right to die" debate did not. And in state legislatures across the nation, such efforts are even more dramatic: "right to try" bills have passed in several states while "right to die" proposals have not seen even a fraction of the same success. With the anti-regulatory Trump Administration potentially considering an FDA commissioner with a libertarian bent, stakeholders wonder if there will be an administrative push for a federal "right to try."

This proposal will discuss the legal underpinnings of both "rights" and the current policy debate over each. This debate says a lot not only about politics in the United States but also our policies around end-of-life decision-making. While we want a society that values life, we also want a society that empowers individuals to make their own decisions, particularly about their health and well-being.

Oliver Kim has over fifteen years of legislative and policy experience at the state and federal level. He served as a senior advisor to a US Senator and the deputy director for the Special Committee on Aging. Additionally, Oliver was legislative director for Planned Parenthood Federation of America. Today, he is a policy consultant and the executive director of Cross-Border Health, a non-profit that fosters policy exchanges between the United States and Canada. Oliver received his BA at Indiana University, JD at the University of Minnesota, and LLM at Georgetown Law Center.

KIRSHENBAUM, ARI

Physicians' Perceptions of Aid in Dying in Vermont

The objective of our study was to collect data on physicians' attitudes regarding medical aid-in-death (AID). Act 39 legalizes the practice of medically assisted death in the state of Vermont, and this act was implemented by the state legislature in 2013. Since then, there has been a lack of data surrounding physicians' attitudes towards AID. An electronic questionnaire was made available to physicians affiliated with the University of Vermont Health Care system. The questionnaire was designed to address three primary issues, these being: (1) To what degree are physicians involved in AID; (2) how well informed are they regarding the policies and procedures stipulated in Act 39; and (3) what is their level of approval regarding the policies and procedures pertaining to AID in Vermont. Other questions were included to evaluate correlates with the three aforementioned issues, such as gender, medical specialty, religious affiliation and geographical location (urban vs. rural). The results thus far indicate general support for AID, and trends are emerging regarding specific indicators of support and knowledgeability of the policies and procedures of Act 39.

Ari Kirshenbaum, PhD, is a professor at a small liberal arts college. His research career has been devoted to the field of psychopharmacology. He recently became interested in palliative-care, and his initial and current focus is on medications and policy issues regarding physician aid-in-dying. He lives and teaches in Vermont where recent legislation has made medical assistance for dying possible.

KITZINGER, CELIA

Withdrawing Life-Prolonging Treatment from Patients in Vegetative or Minimally Conscious States in England and Wales

In England and Wales it is commonly assumed that court applications are required before clinically assisted nutrition and hydration (CANH) can be withdrawn from patients in permanent vegetative or minimally conscious states - even if there is consensus between family and clinicians. This talk will cover the history and current practice associated with CANH-withdrawal from patients in prolonged disorders of consciousness and will draw on our interviews with 75 family members, dozens of clinicians, and our case studies of recent court cases, to develop a socio-legal analysis of the ethical, social and medico-legal issues involved. Our research shows that the apparent requirement for a court application before CANH-withdrawal in England and Wales has the following consequences:

- Contrary to case law post-Bland, feeding tubes are widely seen treated as default practice and basic care - even when other ceilings of treatment are in place (DNACPR, no return to ICU, no intravenous antibiotics etc.).
- Clinical team may abdicate responsibility for best interests decision-making about feeding tube, believing that this can only be decided by a court.
- It is rare to find 'best interests' discussion about feeding tubes – families often not aware of possibility of withdrawal (especially for MCS-patients). Clinicians are reluctant to engage with law and uncertain how to navigate legal processes – there is a tendency to delay court application, to view it as a 'last resort' and to hope that P will die by other means.
- When clinicians raise CANH-withdrawal there is often significant concern from families ("barbaric", "cruel", 'lethal injection preferable'). When families raise CANH-withdrawal they've been told by clinicians 'we don't do that here' or even 'that's murder'.
- Singling out withdrawal of CANH as requiring a court application adds to already heavy symbolic freight of feeding tube withdrawal and acts as a deterrent to CANH-withdrawal from PVS/MCS patients.

Celia Kitzinger is Co-Director (with Professor Jenny Kitzinger) of the Coma and Disorders of Consciousness Research Centre based at the Universities of York and Cardiff. They have jointly produced an online multi-media resource for families of people in vegetative and minimally conscious states, which is also widely used for professional training. This resource (available here: http://www.healthtalk.org/peoples-experiences/nerves-brain/family-experiences-vegetative-and-minimally-conscious-states/overview) won the British Medical Association prize for Information on Ethical Issues (2015). They also work more broadly on promoting understanding and uptake of end of life planning tools.

LAWSON, DEBORAH

Should Medical Input be Required in Completion of Advance Care Directives?

The Victorian Government recently introduced new advance care planning legislation which, amongst other things, permits people to make legally binding advance care directives (ACDs). Previously, legislation allowed for only the refusal of (and not consent to) medical treatment in advance by people with current medical conditions. When the law comes into effect in 2018, people will be able to give legally effective consent to or refusal of medical treatment in advance of losing capacity, and in advance of having a medical condition.

The law requires that an ACD is witnessed by two people, one of whom must be a medical practitioner. The Bill, as originally drafted, required that ACDs be witnessed by two people, one of whom had to be an 'authorised witness' – a broader category of professional witness that included people authorised to witness affidavits and medical

practitioners. During the debate, the Bill was amended to restrict the category of professional witnesses to medical practitioners only, "as a strong safeguard to ensure that advance care directives will only be made by people who understand the potential consequences". There were differing views as to whether medical input should be required as part of the ACD making process. Some groups submitted that requiring involvement of a medical practitioner may increase the likelihood that people understand the effect of their directives, a position ultimately supported in Parliament. However, restriction of professional witnessing responsibilities to medical practitioners only was opposed by other agencies, including lawyers' associations.

This presentation uses a cross-jurisdictional approach to discuss the purpose and role of the professional witness in completion of ACDs. The presentation draws upon competing considerations of autonomy and the principles underpinning consent laws to discuss the extent to which autonomy is enhanced or diminished by requiring involvement of a medical practitioner in completion of ACDs.

Deborah Lawson is a PhD-qualified lawyer with the McCabe Centre for Law and Cancer, whose work focuses on legal issues that impact on experiences and outcomes for people affected by cancer and those who care for them, including end of life law, consent to medical treatment, and regulation of healthcare providers. Deborah has undergraduate degrees in law and philosophy from the University of Otago (NZ), and is a member of the Law Institute of Victoria's Elder Law and Health Law Committees, the Royal Women's Hospital Human Research Ethics Committee and the Palliative Care Research Network of Victoria's Research Advisory Group.

LAWSON, DEBORAH

Voluntary Assisted Dying: The Proposed Framework for Victoria, Australia

In December 2016 the Victorian Government announced that it would prepare a Bill to legalise voluntary assisted dying, in response to a Parliamentary Committee Inquiry into end of life choices. A discussion paper was released for consultation in early 2017, with the Government committing to introduce legislation in the second half of the year.

The question of whether or not assisted dying should be lawful is relevant to many in the cancer community, including people affected by cancer, whether through a personal diagnosis, or as family members, carers and health professionals. In all jurisdictions that have legislated for assisted dying in some form, cancer patients have comprised the largest group of patients to access assisted dying (Emanuel et al. (2016)).

This presentation provides an overview and analysis of the key features of the proposed framework, with a focus on elements of particular interest to the cancer community, including eligibility criteria, the request process and oversight and monitoring.

The presentation will also discuss: the importance of increasing palliative care resourcing and availability; resources required to support informed end of life decision-making for people affected by cancer; support required for cancer clinicians to understand and use the law, including provision for conscientious objection; and opportunities for effective monitoring and evaluation that go beyond capture of numbers and compliance with requirements to incorporate qualitative measures, including the experiences of patients, families, and health professionals.

Deborah Lawson is a PhD-qualified lawyer with the McCabe Centre for Law and Cancer, whose work focuses on legal issues that impact on experiences and outcomes for people affected by cancer and those who care for them, including end of life law, consent to medical treatment, and regulation of healthcare providers. Deborah has undergraduate degrees in law and philosophy from the University of Otago (NZ), and is a member of the Law Institute of Victoria's Elder Law and Health Law Committees, the Royal Women's Hospital Human Research Ethics Committee and the Palliative Care Research Network of Victoria's Research Advisory Group.

Sondra Davoren (co-author) is a senior legal policy advisor with the McCabe Centre for Law and Cancer. Her work focuses on the role of law in the delivery of cancer treatment and supportive care. She is a member of the World Cancer Research Fund International's Policy Advisory Group. Sondra has previously worked as a legal advisor at the Victorian Legal Services Board and in multi-party litigation. Sondra has a Bachelor of Laws and Bachelor of Arts from the University of Canterbury (NZ) and the University of Sheffield (UK) and is currently undertaking a Masters of Law at the University of Melbourne.

LEVIN, BETTY WOLDER

The Cultural Construction of End of Life Issues in Biomedicine: Anthropological Perspectives

For the last 50 years, rapid developments in medical technology have generated challenging questions about the care of patients at the end of life for medical, legal and other professionals, for patients and families, and for other members of society. Through time, after clarifying the application of traditional standards, or developing new cultural understandings, the resolution of some previously difficult issues now seem unproblematic. Yet for other decisions, situations or individuals, uncertainty or different views about tend of life practices continue to cause distress.

In this presentation, a model developed based on ethnographic research in neonatal intensive care units in the United States will be described. It can be used to analyze clinicians' treatment decisions for newborns and for older patients. It can help to elucidate ways that the cultural construction of factors such as characteristics of patients, of treatment choices and of the goals of care have changed over time, and can also help to identify contemporary variations in views about the care of specific patients.

To illustrate, in the 1920s, when many people believed withdrawing treatment was euthanasia, some physicians were afraid to start aggressive treatment believing that once started, treatments could not be stopped. More recently, variations in the cultural construction of death have led to differences in clinical practices for organ retrieval. Today, virtually all people who work in biomedicine accept "brain death" definitions for death, yet some families and cultural groups do not accept such definitions. During the past few years, this has led to highly publicized problematic cases in both the United States and Canada.

Better understanding of the nature of cultural variations in views can lead to better communication about end of life care.

Betty Wolder Levin is a Professor of Community Health and Social Sciences at the City University of New York Graduate School of Public Health and Health Policy. She received her PhD in Sociomedical Sciences with a concentration in anthropology from Columbia University in 1986. She has conducted ethnographic and survey research on decision making in neonatal intensive care, the development of hospital-based palliative care units and other perinatal, pediatric and end of life issues. She is an active member of the NY Presbyterian Hospital Pediatric Ethics Committee.

LEWIS, PENNEY

Should Assisted Dying Require the Consent of a High Court Judge?

A consensus has recently developed within the British Parliamentary debate over the legalisation of assisted dying that the consent of a High Court judge should be required as part of a future regulatory regime. In this paper I question the basis of this consensus, arguing that it is neither evidence-based nor, as has been suggested, required by the decision of the Supreme Court in Nicklinson. A large majority of requests for assistance in dying in permissive regimes come from persons who are dying of cancer. Using this typical request, I evaluate the extent to which a prospective judicial approval requirement would meet the likely legislative goals of respecting autonomy, protecting the vulnerable and responding compassionately to unbearable suffering. I conclude by proposing that if a substantive case for prospective judicial approval is to be made, it would be more convincing if applied to persons who are not expected to die in the near future.

Penney Lewis studied mathematics, law and philosophy in the US, Canada and the UK, where she is Professor of Law and co-Director of the Centre of Medical Law and Ethics at King's College London. In the area of medical law, her research focuses on end of life issues including advance decision-making, refusal of treatment and withdrawal of life-sustaining treatment. She is the author of a number of articles and briefing papers on assisted dying and her monograph Assisted Dying and Legal Change was published in 2007 by OUP. She is a member of the Human Tissue Authority, the Health Research Authority's National Research & Ethics Advisors' Panel, and the Clinical Ethics Committee of St Christopher's Hospice, and was a member of the UK Donation Ethics Committee from 2010 until its demise in 2016.

MACDONALD, SUSAN

Developing and Implementing a Medical Assistance in Dying Curriculum in a Family Medicine Residency Program

INTRODUCTION/OBJECTIVE - In 2016, medical assistance in dying (MAID) was legalized in Canada. Medical educators are presently challenged with determining how most effectively integrate MAID into residency curricula. The purpose of this study was to determine family medicine (FM) residents' and their family physician faculty preceptors' perceptions of MAID, willingness/readiness to learn and teach about MAID, and recommendations for curricular content and faculty development (FD).

METHOD - Using mixed methods and purposive sampling, an anonymous online survey was distributed to FM physicians and residents (N=134). Thematic analysis, and descriptive and inferential statistics were used to analyze the data.

RESULTS - The findings demonstrate that preceptors were significantly more confident, competent and comfortable than residents in explaining and discussing MAID with colleagues and patients ($p<0.05$). However, residents were more willing to actively participate in administering MAID to patients than preceptors ($p<0.05$). Seventy-two percent of respondents believe it important to integrate MAID into core curriculum, with preceptors who were non-conscientious objectors (CO's) to MAID being statistically more likely to believe it should be included in the residency curriculum ($p<0.05$). The curricular elements deemed most important included advanced care/end-of-life planning (76%), technical aspects (73.4%), and regulations/ethical issues (56%).

CONCLUSIONS/IMPLICATIONS - There is a need for MAID education. Developing a MAID curriculum will bridge the competency gap self-identified by faculty and resident respondents. Patients' access to compassionate end of life care can be improved through training that increases both faculty and residents' comfort and competence in the topic of MAID. It is important that FD sessions be developed to educate and support both faculty who are

MAID proponents and those who are COs, so as to allow residents to learn about appropriate care for patients requesting MAID from all preceptors.

Susan MacDonald is Associate Professor in Department of Family Medicine, Queens University (Kingston, Canada), where she has her family practice. She has a MHSc (Bioethics) from University of Toronto (Joint Center Bioethics). Her main focus of teaching is in ethics, at the undergraduate medical student and residency levels.

MARTIN, STEVIE

The Human Rights Implications of the Blanket Ban on Assisted Suicide in England and Wales

My presentation will consider the law on assisted suicide in England and Wales and its compatibility with the rights to life and private life enshrined in Articles 2 and 8 (respectively) of the European Convention on Human Rights ('ECHR').

The Suicide Act 1961 (UK) contains a blanket prohibition on assisting suicide. Human rights challenges to the prohibition before the courts (domestic and the European Court of Human Rights ('ECtHR')) have consistently failed to secure a change to the law, the most recent rejection of change being the resounding defeat of an amending bill in the House of Commons in late 2015. The need to protect vulnerable individuals and the fear that any relaxation of the law will lead to a slippery slope has pervaded both the political and judicial debate. Given the decision of the Canadian Supreme Court in Carter and a new legal challenge to the Suicide Act 1961, it is a propitious time to revisit the law on assisted suicide in England.

My presentation will analyse whether the successful arguments in Carter, (that the Canadian prohibition on assisted dying infringed Charter rights) are likely to be successful in English domestic courts and/or the ECtHR. Reference will be made to domestic and ECtHR jurisprudence, including the Grand Chamber's decision in Lambert v France, with a view to demonstrating that s 2 of the Suicide Act 1961 is incompatible with Article 2 of the ECHR.

This presentation will also demonstrate, by reference to evidence from jurisdictions permitting assisted dying, that the justifications proffered by the UK before the ECtHR and by various members of the House of Commons to justify the blanket ban (particularly the right to life of vulnerable individuals) are flawed and insufficient to justify the ongoing interference with Article 8 ECHR.

Stevie Martin, LLM (First) (Cantab); Grad Dip Legal Practice (Griffith University); LLB (First) (Griffith University); BSc (Psychological Science) (Griffith University) is a PhD student and Teaching Associate at the Faculty of Law, University of Cambridge. Her doctoral research concerns the human rights implications of the blanket ban on assisted suicide in England and Wales.

MASON, BARBARA

Caregiver Perspectives of Palliative and End of Life Care for Individuals at end-stage dementia in Newfoundland and Labrador: A Qualitive Phenomenological Perspective

Much research into dementia focuses on caregiver burden, financial costs to health care systems, pathology of and cures for the disease. However, there is a gap in the literature examining the quality of death for individuals at end stage dementia, specifically as it relates to palliative and end of life care (PEOLC).

Individuals with dementia present with a unique set of circumstances that make it difficult to assess if the individual is nearing the end of his/her life. Impaired cognition, ineffective communication capabilities and co-morbidities are some issues that impact the ability of providers to determine impending end of life for dementia patients. Current research indicates that indicators of impending death for this population are often misinterpreted as behavioural issues associated with the disease, prompting the development of scales to help identify pain and impending end of life. Research also suggests that this population faces specific barriers to PEOLC, that they receive more invasive and aggressive life sustaining treatment, less comfort care, and are in longer phases of pain and suffering due to non-control of pain. It has been suggested that dementia requires a dementia specific approach to PEOLC, including chronic and terminal palliation. If the PEOLC needs of individuals at end-stage dementia are not being met, the impact of such inadequacy could affect the dignity and quality of life for both the individual and their families.

Familial caregivers of deceased individuals who were at end-stage dementia participated in this research. The methodology that was used was selected because the reality of a phenomenon is derived from the fact that it is subjectively experienced. The phenomenological approach is one that focuses on the uniqueness of individual experiences and meanings. This is important to the study of PEOLC among individuals with dementia because a familial caregiver's subjective experience of PEOLC may differ from what is thought to exist by professional caregivers. Resource allocation, principles of justice, non-maleficence and beneficence, and discriminatory health care practices experienced by people at end-stage dementia are just some of the topics that unfolded. This research demonstrates how easy it is for people at end-stage dementia to fall through the cracks with relation to PEOLC; the ethical question is why.

Barbara Mason is a Masters of Health Ethics candidate at Memorial University. Research interests include PEOLC, dementia care, elder abuse, and seniors' mental health, structural discrimination and social citizenship. Awards include the Law Foundation of Newfoundland and Labrador Legal Research Award and The Barrowman Community Health Travel Award. Practicum experience in adult acute ethics, long term care ethics, administrative ethics, mental health ethics, clinical ethics and research ethics.

MCCANN, ADAM

The Politics Behind the Law on Assisted Dying

Public support to legalise assisted dying is increasing in most Western liberal democracies. Yet directly elected officials, unless judicially compelled to do otherwise, appear as keen as ever to evade the issue.

A political 'strategy' to avoid such a polarizing issue is unsurprisingly useful for re-election interests. This paper argues it may also, in particular instances, be useful for policy output. This claim presupposes three things: (i) it challenges us to accept that when it comes to the legal policy on assisted dying, a wide gap between stated objectives and actual policy results will not in itself invite punishment at the polls; (ii) it recognises that policy framing and the role of powerful interest groups will determine political action/inaction; and (iii) it demands that supporting the judiciary to effect legal change, without taking due account of policy framing and the role of

powerful interest groups, risks undermining the long-term authoritative issuance and social efficacy of the law on assisted dying.

This paper offers all three of the above via a comparative critical analysis of the politics behind the law on assisted dying in England, France, Switzerland, and the Netherlands. In light of this analysis, brief remarks are made on the recent judicially inspired amendments to the Canadian Criminal Code allowing for medical assistance in dying.

Adam McCann is a Lecturer in Medical Ethics and Law, and Criminal Law at the University of Exeter. His main research focus is on the legal framework surrounding end-of-life medical decisions in the context of broader governance and political theories. Adam holds a PhD in law (2016) from the University of Groningen, with a dissertation on: "Assisted Dying in Europe: A Comparative Law and Governance Analysis of Four National and Two Supranational Systems." He has published with Kluwer Law, Brill Publishers, Eleven International Publishing, and Cambridge University Press. Adam has also contributed to The Irish Times and has appeared on national radio discussing the law on assisted suicide. In January 2017, he was appointed one of the editors of the European Journal of Comparative Law and Governance.

MCDONALD, FIONA (WITH CHRISTY SIMPSON)

Ethical Issues: MAID and its Provision in Rural and Remove Settings

In this paper we examine the ethical implications of providing (and of not providing) medical assistance in dying (MAID) in rural and remote settings. As a matter of equity it is important for Canada to consider the ethical implications of MAID on and for rural residents and rural based health professionals, as, according to Statistics Canada, in 2011 at least 19 percent of the Canadian population resides in very rural or remote areas. In addition to the logistical issues around the provision of or access to MAID, it is well recognised that in rural settings the nature of the relationships between community and health professionals and health professionals and patients can have a different quality than the relationships between communities, patients and health professionals in urban settings. The different quality and intensity of these relationships in rural settings may give rise to potentially different issues or to recognised issues (e.g. confidentiality or stigma) being experienced more acutely. In previous work, we have argued that both approaches to ethics and health policies are often developed in urban settings by predominantly urban based or focused ethicists, policy-makers, health professionals and others. Therefore approaches to ethics or health policies may overlook, under-recognise or incompletely address ethical issues that may arise in the delivery of health care services in rural settings. Drawing from our work on rural health care ethics, we analyse the ethical issues associated with the provision (or lack thereof) of MAID in rural areas. We then critically analyse policies in respect of MAID that have emerged from the provincial and territorial governments, colleges of physicians and other health professionals and key stakeholder groups to see whether and how these documents address rural issues.

Fiona McDonald is a Senior Lecturer in the Faculty of Law at Queensland University of Technology and is a member of QUT's Australian Centre for Health Law Research. She is an Adjunct Associate Professor at the Department of Bioethics at Dalhousie University. Her research interests include rural health care ethics.

Christy Simpson is an Associate Professor and Head of the Department of Bioethics at Dalhousie University and an Adjunct Associate Professor in the Australian Centre for Health Law Research at Queensland University of Technology. Her research interests include rural health care ethics.

MORRISON, KATHRYN

Medical Aid in Dying for Mature Minors: Re-interpreting the Problem of Decisional Capacity

Should mature minors be eligible for medical assistance in dying (MAID)? In 2016, the Canadian criminal code was modified to permit MAID, which controversially limited eligibility to adults over 18 years of age. This eligibility restriction was motivated by concerns that permitting MAID harms mature minors by mistakenly attributing decisional capacity to them. The ethical matter of whether mature minors have decisional capacity is commonly framed empirically, asking at what age we develop decisional capacity; however, scientists are divided on the question. Cognitive scientists and psychologists estimate full decisional capacity to develop as early as 14 years old and as late as 25 years old.

Rather than ask when we develop decisional autonomy, a useful approach that is seldom considered, is to frame the problem as a normative question in ethics and law: when should minors be treated as having decisional capacity? In this paper, I will consider how the reframing of this question impacts our understanding of autonomy – particularly in ways that reinterpret informed consent to MAID. In Part A, I will elaborate on the distinction between the development of decisional capacity and its attribution to moral agents. The implications of this distinction on preserving autonomy will be considered in Part B by applying it to mainstream conceptions of autonomy. In Part C, factors particular to MAID and mature minors will be analyzed, including vulnerability to manipulation, unjust deprivation of a future, and the limits of parental responsibility. I find that examining the MAID and mature minor problem in terms of the attribution of decisional capacity lends far better to legislative and policy development, and is highly applicable outside medicine. For instance, it presents more compatibility with the problem of youth criminal responsibility.

Kathryn Morrison is a PhD student at the University of Waterloo. Having entered into UW's new Applied Philosophy program, she has researched bioethics in both academic and clinical environments. Most recently, Kathryn completed a clinical placement at Sunnybrook Health Sciences Centre, helping to develop health policy on medical assistance in dying.

MUTCHERSON, KIMBERLY

End of Life Care at the Beginning of Life

In the U.S., abortion is a battleground. While the abortion debate may not be a typical lens through which to consider law, ethics, and policy surrounding death and dying, new tactics in the fight against abortion may change that. A new entry into the legal part of the battleground is an attempt in Texas to require abortion providers to bury or cremate fetal remains after miscarriages or abortions. Supporters of the bill claim that its purpose is to provide “dignity” to unborn infants. It, of course, is not new for abortion foes to argue for the personhood of a fetus, but if there is to be a coming wave of legislation targeting how to deal with fetuses in life and death, it is worthwhile for those who advocate for abortion rights to think critically about how and whether to incorporate concepts about dignified death into the abortion realm. First, this paper contemplates the possibilities of legislation and regulation claiming to provide dignity in death to fetuses, including fetal pain or fetal burial laws. Second, it considers the ways in which abortion providers already consider these issues in their practices, especially those who perform abortions later in the second trimester, but do so as a way to serve the interests of pregnant women and, perhaps, their partners, rather than to benefit a terminated fetus. For instance, some facilities allow women to view, touch, and perhaps even hold terminated fetuses to provide closure, especially when termination is chosen because of fetal anomalies that are incompatible with life. Third, the article argues that it is possible to continue to accord respect to terminated fetal life without doing so in a way that compromise abortion access for women who terminate their pregnancies.

Kimberly Mutcherson is Vice Dean and Professor of Law at Rutgers Law School where she teaches Family Law, Bioethics, Babies, & Babymaking, Torts, and South African Constitutional Law. Her scholarly work encompasses family and health law and uses health law topics to study the relationship between families and the state. She writes on issues related to reproductive justice, with a particular focus on assisted reproduction and its relationship to how the law understands family.

OKNINSKI, MICHAELA

A Comparative Analysis of Voluntariness in the Netherlands and Oregon Physician-Assisted Dying Laws

Euthanasia and physician-assisted suicide (E/PAS) remain fiercely debated topics in many jurisdictions globally. This is especially the case in Australia, where discussions on E/PAS dominate social and political discourse and E/PAS Bills are a common feature in both State and Federal parliaments. Although there are myriad complex issues contained within the E/PAS debate, discussions concerning how to adequately regulate and control the provision of E/PAS dominate the existing scholarly literature. Yet despite the breadth of academic discussion E/PAS, there exists a paucity of research into the elements of a voluntary decision and, importantly, how voluntariness is interpreted and applied in practice. The requirement that a decision for E/PAS be voluntary is a pivotal legal requirement in all jurisdictions that have legalized E/PAS. However, little is known concerning how this test operates.

This paper will provide a comparative statutory analysis of the requirements for a voluntary decision in a request for E/PAS in the Netherlands and Oregon, U.S.A. Official reports released by the Regional Review Committee (Netherlands) and the Oregon Public Health Authority will be considered. Moreover, judicial consideration of the elements/parameters of a voluntary decision will be discussed where applicable. Key findings of this comparative statutory analysis will provide insight into how voluntariness is determined in these key jurisdictions, identifying potential limitations with a test for voluntariness in practice. Recommendations for a more robust test will be posited. This research may be of benefit to jurisdictions like Australia, where legalization of E/PAS is a recurrent issue.

Michaela Okninski is a 2nd year PhD candidate at Adelaide Law School, the University of Adelaide, Australia. She holds LLB/LP (Hons) qualifications from Flinders University, Adelaide, South Australia. Her research interests include euthanasia and physician-assisted suicide; consent to and refusal of medical treatment; refusal of curative medical treatment for minors. She has authored and co-authored several publications in peer-reviewed journals.

PARENT, BRENDAN

Medical Aid in Dying in New York State: Physician Attitudes and Impact of Framing Bias

This presentation will offer a summary and analysis of an empirical investigation of the attitudes of health care professionals towards medical assistance in dying (MAID) in New York State. The project consists of two components, a traditional direct question survey as well as a short vignette survey, using a between subjects design. The project has two aims: (1) Collect data that can inform the reception of a MAID bill that is currently under review in the State; and (2) explore the way in which the presentation of information on MAID can impact attitudes. While there is already substantial evidence supporting the fact that framing effects can significantly impact the likelihood of individuals to express support for MAID, there has been no investigation of how framing effects may impact individuals' support for particular restrictions or safeguards related to MAID. This project seeks to fill this lacuna by directly asking one group of participants to rate their support for particular restrictions and safeguards (e.g. minimum age, concurring physician, terminal illness) in a traditional online survey, while collecting

data from a parallel participant group through a short vignette survey. The latter will offer vignettes that vary the presence of these restrictions and safeguards (e.g. below 18 and over 18, with or without the agreement of a concurring physician) and will ask respondents to rate the ethical and medical acceptability of the proposed situations. It is anticipated that there may be a difference between which restrictions are seen as morally relevant within the survey and within the vignettes. During the presentation, data from the two components will be presented side by side, in order to illuminate how framing effects can impact what one sees as a morally relevant restriction related to MAID, and will be situated among findings in the moral psychology literature.

Brendan Parent, JD, is the founding Director of Applied Health at the NYU School of Professional Studies, which offers curriculum to assist healthcare professionals refine their ethical decision making skills in clinical contexts. As an affiliate in the division of Medical Ethics at the NYU Langone Medical Center, he teaches Bioethics in the Practice of Medicine to second and fourth year medical students. He also teaches Clinical Ethics and Advanced Intro to Bioethics in the Master program at the NYU Center for Bioethics. Parent is also COO of the NYU Sports and Society think-tank.

PARKER, MALCOLM

Fine Lines and Dr. Syme: Intention, Palliation and Death Causation in Regulation and Law

In early 2016, the Medical Board of Australia (MBA) received a mandatory notification concerning Dr. Rodney Syme, from the GP of a patient who had also consulted Dr. Syme. He had told the GP that Dr. Syme was to assist him to end his life. The MBA considered that Dr. Syme's apparent intention constituted a significant departure from accepted professional standards under the relevant regulatory legislation, as it presented a serious risk to the patient. It imposed the following condition on Dr. Syme's medical registration:

> "Dr. Rodney Syme is not to engage in the provision of any form of medical care, or any professional conduct in his capacity as a medical practitioner that has the primary purpose of ending a person's life."

In late 2016, this condition was set aside by the Victorian Civil and Administrative Tribunal (Syme v Medical Board of Australia (Review and Regulation) [2016] VCAT 2150). The Tribunal's focus was necessarily restricted to the disciplinary question of whether Dr. Syme's conduct posed the kind of serious risk that required an interim but immediate action condition on his registration.

This turned on (1) accepting Dr. Syme's stated intention as being prepared to provide nembutal to the patient to palliate his psychological suffering through giving him confidence and control, and not that the patient would ingest the Dr.ug; (2) asserting that the MBA conflated the lethal effect of Nembutal, if ingested, with the stated subjective intention of Dr. Syme; and (3) accepting that patients who do in fact take such a Dr.ug do so by independent, voluntary decision, often after a significant lapse of time.

No doubt patients in such cases benefit psychologically from the possession of nembutal. But the idea that the purpose and intention is that it be possessed but not used, raises theoretical, practical and legal questions that are explored in the paper.

Malcolm Parker is Emeritus Professor of Medical Ethics at the University of Queensland (UQ), having been the inaugural Head of the Discipline of Medical Ethics, Law and Professional Practice in the School of Medicine at UQ. He was a GP for over thirty years, and inaugural president of the Australasian Association of Bioethics and Health Law. He served on committees of the Medical Boards of Queensland and Australia, and was a director of the Postgraduate Medical Council of Queensland. He has published internationally in philosophy of medicine, bioethics, medical ethics, health law, and medical education, including on end-of-life issues.

PASMAN, ROELINE

What Characterises Complex Euthanasia Consultations? Experiences of SCEN-Physicians

BACKGROUND - Consultation of an independent physician is a requirement for due care in Dutch Euthanasia law. SCEN (Support and Consultation on Euthanasia in the Netherlands)-physicians are trained to provide such consultations.

OBJECTIVE - What characterises a complex consultation according to SCEN-physicians?

METHODS - Postal questionnaire to all 694 registered SCEN-physicians in 2015 (response 78.7%). Closed and open questions were asked about their most complex consultation they had as SCEN-physician in 2015. In total 484 SCEN-physicians described such a case. Answers to open questions were categorized. Main diagnosis of most complex cases in 2015 were compared to main diagnosis of all 'last' cases (complex or not) described in 2014.

RESULTS - In complex consultations the main diagnosis was most often cancer (33%), followed by 'old age' (11%), psychiatric disorder (10%) and dementia (9%). Main diagnosis from 'last' cases described in 2014 was more often cancer (71%) and less often 'old age' (4%), psychiatric disorder (2%) and dementia (1%). Looking at all diagnoses/disorders and problems present, 74% had a somatic disorder, 29% had psychosocial or existential problems, 28% had 'multiple ailments related to old age', 21% had a psychiatric disorder and 15% had dementia. Most mentioned aspects why SCEN-physicians experienced this case as complex concerned patient characteristics (80%), such as no short term life-threatening disease or problematic communication with patient, judgement of requirements for due care (41%), such as difficult to estimate suffering, aspects concerning family of the patient (26%), such as some family-members not being ready for euthanasia yet, and aspects concerning other professionals (23%) such as experiencing pressure from the treating physician.

CONCLUSION - Consultations are experienced as complex by SCEN-physicians due to different aspects related to the patient, family or other professionals. Complex cases more often concern patients with old age, dementia and psychiatric disorders.

Roeline Pasman has a Master in Sociology and a PhD in Medical Social Sciences on the topic of 'forgoing artificial nutrition and hydration in nursing home patients with dementia.' She supervises PhD students in their research focused on palliative care and medical decision-making at the end of life in all health care settings, in different patient groups and about several topics, such as advance care planning, participation in decision-making, dignity at the end of life and euthanasia/assisted suicide. She uses both qualitative and quantitative research designs.

POPE, THADDEUS

Medical Futility Dispute Resolution Options in the United States: Law and Ethics Fundamentals

Medical futility conflicts over life-sustaining medical treatment (LSMT) occur frequently in ICUs across the United States. Fortunately, these disputes can usually be prevented. With better communication and better documentation of patients' end-of-life treatment preferences, there are fewer conflicts. After all, most patients do not even "want" LSMT in these situations. Moreover, to the extent that futility disputes do continue to arise, they can almost always be resolved informally within the hospital.

Only around 5% of futility conflicts remain intractable. Most of these can be resolved through "surrogate replacement." The clinician may not be able to obtain consent to stop LSMT from the current, authorized surrogate. But the clinician can often "replace" that surrogate with a new surrogate who will provide consent. But as recent Ontario cases illustrate, there are limits to this approach. Some surrogates cannot be replaced. For

example, a surrogate, often for religious reasons, may make the very same treatment decision that the patient would have made for herself.

In these cases, the clinician may want to take "unilateral action" and stop LSMT without patient or surrogate consent. I outline three main legal approaches that the United States' fifty-six jurisdictions have taken with respect to unilaterally withholding or withdrawing LSMT:

1. One state affirmatively permits clinicians to stop LSMT without consent.
2. Some states (e.g. NY, ID, OK) categorically prohibit clinicians from stopping LSMT without consent.
3. Most states provide vague and uncertain guidance about whether clinicians may stop LSMT without consent.

Thaddeus Pope, JD, PhD, uses the law both to improve medical decision making and to protect patient rights at the end of life. He works: (1) to balance liberty and public health, (2) to assure adequate informed consent, and (3) to develop fair internal dispute resolution mechanisms. Specific topics include medical futility, advance directives, ethics committees, and brain death. He explores these issues in over 125 publications in: leading medical journals, law reviews, bar journals, nursing journals, bioethics journals, and book chapters. Pope coauthors the definitive treatise The Right to Die: The Law of End-of-Life Decisionmaking. And he runs the Medical Futility Blog, which has over 2.5 million page-views.

POPE, THADDEUS

The Under-Examined End-of-Life Option: Hastening Death by Voluntarily Stopping Eating and Drinking (VSED)

A majority of U.S. states are exploring the expansion of patient liberty at the end of life. Most of this attention has been focused on medical aid in dying. In contrast, far less examined and far less considered is another exit strategy: voluntarily stopping eating and drinking (VSED).

I have four objectives for this presentation:

1. Compare the legal and clinical distinctions between VSED, on the one hand, and medical aid in dying and withholding or withdrawing life-sustaining treatments, on the other hand.
2. Describe four legal foundations of a patient's right to contemporaneous VSED.
3. Understand the challenges and risks for families and clinicians in implementing an "advance" VSED decision for a now incapacitated patient.

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POSTMA, LISELOTTE

Advance Directives Requesting Euthanasia in the Netherlands

The Dutch Termination of Life on Request and Assisted Suicide (Review Procedures) Act came into force in 2002. Based on this act, euthanasia, although a criminal act, is justified if performed by a physician complying with specified due care requirements and the physician has notified a municipal pathologist. Fulfilling these due care requirements, seems to be relatively unproblematic when it concerns competent patients with a somatic, medically classifiable illness, whose suffering is unbearable and without prospect of improvement. However, legal and practical challenges regarding euthanasia still exist.

Currently, one of the problematic issues in the Netherlands is the significance of a written advance directive concerning patients with dementia. Although section 2 (2) of the Act allows physicians to honour a request for euthanasia from patients (ages 16 or over) lacking mental capacity, based on a directive drawn up at a time the patient was still competent, the due care requirements apply 'mutatis mutandis' ('to the extent allowed for by the actual situation'). Uncertainty exists about the interpretation of the wording.

The legislative history and case law do not seem to provide enough guidance for a careful and practical application of an advance directive for patients lacking capacity. Therefore, the Ministry of Health, Welfare and Sport published a 'guide' in December 2015 to provide further clarity, but misconceptions are still present among the public as well as physicians.

In this presentation, the current situation will be outlined focusing on the question how the due care requirements can be met in case of an advance directive concerning patients with an advances stage of dementia. The legal position of a written advance directive in such a situation is complex and in need of assessment.

Liselotte Postma, MA, LLM, is a researcher at the department of Criminal Law of the Erasmus University Rotterdam and Ph.D. fellow in the collaborative research project "Doctor and lawyers dealing with death and dying" between Erasmus School of Law and the Erasmus Medical Center in Rotterdam. She holds a Master in Criminal Law (cum laude) and obtained a Master in Modern History and International Relations from the University of Groningen (cum laude). Her Ph.D. dissertation examines the legal status and practice of written advance directives requesting euthanasia in the Netherlands.

PRONK, ROSALIE

Psychiatrists' Views on Physician-Assisted Suicide and Psychiatric Patients: A Qualitative Study

The Netherlands is one of the few countries in the world where euthanasia and assisted-suicide (EAS) are legalized under certain conditions. The physicians that end the life of competent patients who suffer unbearably from an irreversible illness are not punishable when he or she acts in accordance with criteria of due care. The law does not state that the patient needs to suffer from a terminal illness, which means that psychiatric patients can request the termination of their own life, and have their request granted. This has been the case since 1994, when Dr. Boudewijn Chabot was found guilty of intentionally assisting in his patient's suicide, but received no punishment for doing so. Since then, an increasing number of patients with a psychiatric disorder request EAS, which has led to much debate amongst the public and medical profession.

The study that will be presented was part of the third evaluation of the 'Termination of Life on Request and Assisted Suicide (Review Procedures) Act'. The aim of this study was to find an answer to the question what the experiences and views of psychiatrists in the Netherlands on EAS and patients with a psychiatric disorder are. In order to answer this question, we conducted in-depth interviews with 16 psychiatrists from the Netherlands that

hold different views on the subject. Questions regarded their experiences, their views, bottlenecks, the criteria of the law, the End-of-Life Clinic, the Dutch mental health care system and the relation between suicide and EAS. The results of this qualitative study are not available yet, but will be presented at the congress.

Rosalie Pronk holds a bachelor's degree in Psychology and bachelors and masters degree in Philosophy. She currently holds a PhD position at the AMC Amsterdam. The focus of her study is physician-assisted suicide and psychiatric patients. She is currently working on the third evaluation of the Dutch Euthanasia Act, where she focuses on EAS and psychiatry. After completing this study, she will focus on the experiences of psychiatric patients on the EAS.

RICHARDS, BERNADETTE

Advance Care Planning in Australia: Aspirational or Practical?

In September 2011 the National Framework for Advance Care Directives was released in Australia, and in the preamble it is described as an 'aspirational document' setting out goals for which policy and practice should aim. Some of the core aims of this document included greater adoption of advanced care planning in the community, mutual recognition across state boundaries, treatment plans reflecting patient preferences and a broad base of support for advance care planning. The overarching goal being the implementation of personal preferences at the end of life.

South Australia was one of the first jurisdictions to answer the call and introduce an Advance Care Directives Act 2013 (SA). The aim of the legislation was to, amongst other things, empower 'individuals to give directions in relation to their future health care, residential and accommodation arrangements and personal affairs'. A driving principle behind the legislation was the implementation of personal preferences. This presentation will consider the aspirations behind the advance care planning scheme in Australia with a particular focus on the South Australian Act. It will provide an overview of the legislation and challenge the practical implementation of the national 'aspirations' and suggest that whilst this is a good first step, it fails to provide practical guidance because it fails to realistically engage with individual preferences.

Bernadette Richards is an Associate Professor at the Law School, University of Adelaide and her research focus is on the area of medical law and ethics with her work sitting at the nexus of ethics and the law in the context of medical treatment, with a particular emphasis on medical treatment. She is currently exploring issues around Advance Care Planning (and is a CI on an NHMRC Partnership Grant exploring the issue) and access to innovative treatment. She is currently Chair of the Southern Adelaide Clinical Human Research Ethics Committee and a member of the NHMRC Embryo Research Licencing Committee. She is also President of the Australasian Association of Bioethics and Health LAW (AABHL).

RIVAS, ROBERT

A New American Threat to Open Discussion of End-of-Life Issues

In American law, the crime of "assisting in a suicide" is unique in punishing the assistance in an act that is itself not an offense. In 39 states, any "assistance" in another person's death is punishable by a substantial prison term no matter whether the "victim" is competent, terminally ill, imminently dying, and acting with the fully informed support of all of her loved ones and health care practitioners. It is no defense that the "victim" rationally sought to terminate irremediable suffering.

Until now, these laws were understood to punish tangible assistance, not mere speech. In 2016, however, a leading right-to-die organization, Final Exit Network, was convicted in Minnesota of "assisting" in a "suicide" even

though the organization's "exit guides" - by every account - committed no physical act to "assist," but only gave information, education, and emotional support to the "victim" of the crime. The Minnesota precedent, which could be cited in support of similar holdings in other jurisdictions, poses a serious threat to the American right-to-die groups, all of which provide some sort of person-to-person counseling about end-of-life choices. Moreover, the precedent threatens health care practitioners, potentially creating a mine field of their confidential communications with patients who seek information about end-of-life options. It could produce a chilling effect on private conversations among family members when a loved one is dying.

This paper will explain the history and development of the widespread American state laws against "assisting in a suicide" and show how the new Minnesota rule evolved and threatens to create new ethical and legal hardships across the United States. At the time of the conference, the author will be arguing these issues in either the Supreme Court of Minnesota or the Supreme Court of the United States in an effort to reverse the Minnesota decision.

Robert Rivas, JD, is an attorney based in Tallahassee, Florida who has been litigating end-of-life issues in courts across the United States since 1996. At this time he is general counsel for the nationwide volunteer group Final Exit Network. In 2012 he persuaded the Supreme Court of Georgia to declare that state's law on assisting in a suicide unconstitutional in violation of First Amendment-protected free speech rights. Since then he has been litigating in Minnesota trial and appellate courts against that state's efforts to make it a crime to give information about how one may lawfully hasten death to terminate irremediable suffering.

RODNEY, PATRICIA

Challenges in End of Life Care and Medical Assistance in Dying: Towards a Relational Ethics Approach

While the implementation of Medical Assistance in Dying (MAID) rolls out across Canada, there remain long-standing and serious inequities in access to resources for appropriate health and health care throughout acute care, home care, long term care, and palliative care. Inequities are especially pronounced for Indigenous peoples, those with mental health challenges, those who are impoverished, those who don't speak English/French, those living in rural/remote areas, and older adults. Despite significant work to support better end of life decision making through initiatives such as advance directives, too many patients still experience what they would consider to be over-treatment at the end of their life, and/or a lack of access to supportive and palliative care resources. The impacts on patients (suffering), families (grief), and health care providers (moral distress) is significant (Rodney, 2016). In this paper I argue that current challenges in access to health care in general and palliative care in particular mean that MAID may not be a meaningful 'autonomous choice' for many Canadians. Health care professionals, ethicists, and academics/policy makers across Canada must argue for sufficient supportive health care/palliative resources so that MAID does not become a default. I further argue that a relational ethics approach, where patients are understood as embedded in power-laden layers of context (from individual through to family, community, organizational, provincial and national levels) allows us to interrogate the complexities of MAID and end of life care. I close by pointing to implications for empirical and theoretical inquiry in ethics, and to implications for health policy work at all levels. I also point to implications for the education and support of health care professionals and ethicists.

Patricia (Paddy) Rodney, RN, MSN, PhD, is an Associate Professor at the University of British Columbia (UBC) School of Nursing and a Past President of the Canadian Bioethics Society. She is also a Faculty Associate with the W. Maurice Young Centre for Applied Ethics at UBC, and a Research Associate with Providence Health Care Ethics Services. Further, she serves as an ethics consultant for the BC Provincial Advisory Panel on Cardiac Health. Dr. Rodney's current research and publications focus on end-of-life care for seriously ill older adults and the moral climate of health care delivery.

ROONEY, WILLIAM

Are Concerns About Irremediableness, Vulnerability, or Competence Sufficient to Justify Excluding Psychiatric Patients from MAID

This presentation is based on an upcoming journal article co-authored with Professor Udo Schuklenk and Professor Suzanne van de Vathorst.

Some jurisdictions which have decriminalized assisted dying (like Canada) exclude psychiatric patients on the grounds that their condition cannot be determined to be irremediable, that they are vulnerable and in need of protection, or that they cannot be determined to be competent. We review each of these claims and find that none have been sufficiently well-supported to justify a ban on psychiatric patients' access to assisted dying.

Some authors have criticized assisted dying for psychiatric patients by highlighting allegedly problematic practices in those countries which allow it. We addressed recent evidence from the Netherlands, showing that these problems are either misrepresented or have straight-forward policy solutions. Even if one finds such evidence troubling, other jurisdictions need not adopt every feature of the Dutch system.

The central thrust of this presentation is that proponents of banning assisted dying for psychiatric patients ignore alternatives to their proposal, including an assisted dying regime with additional safeguards or consultations.

William Rooney is a fourth-year undergraduate philosophy student at Queen's University who has primarily worked under Professor Udo Schuklenk. William's research seeks to determine the necessary features of a responsible MAID regime. In addition to this focus, he is currently working on a piece investigating the Canadian legal justification supporting MAID for psychiatric patients, and another piece on the limited moral justification for certain forms of conscientious objection.

RUTHERFORD, JODHI

The Influence of Doctors in the Australian Assisted Dying Debate

With over 50 failed attempts at law reform in the last 25 years, Australian jurisdictions are so far resisting the international trend towards legalised assisted dying. While polling regularly shows in excess of 70 percent of the broader population support assisted dying laws only 38 percent of Australian doctors support the practice, according to a 2016 survey by peak professional body, the Australian Medical Association.

Notwithstanding ongoing debate as to the level of doctors' opposition, doctors' concerns about legalised assisted dying are contextually critical to the debate. Research shows the significant influence of doctors and/ or their professional associations on the process of law reform. There is also evidence that a positive or neutral attitude of doctors towards assisted dying is a key precursor to legislative reform.

The influence that doctors wield in the assisted dying debate is frequently acknowledged, but rarely in focus. There is an implicit understanding that doctors' opinions matter; they are key stakeholders in the field and they hold final responsibility for many end-of-life treatment decisions. Doctors are given an explicit lead role in assisting death, under legislation in both the Australian and international jurisdictions.

This paper aims to improve awareness of the under-examined influence of doctors in the Australian assisted dying debate. It will explore the extent to which doctors' attitudes are important by locating the sources of their power. It unpacks the significant legally mandated role for doctors in both the overturned Northern Territory legislation and the multitude of various bills in many Australian States and Territories. It examines the position of trust that

doctors enjoy in their professional context. It agrees with an implicit assumption from critical legal studies that the law is a political construct formed by those with power, to acknowledge doctors' influence on the legislative process.

Finally, it suggests that designing an Australian assisted dying regime which accommodates doctors' concerns about assisted dying, might contribute to eventual law reform.

Jodhi Rutherford is an Australian lawyer and mediator who teaches in the Faculty of Law at Queensland University of Technology in Brisbane. She is currently pursuing her PhD with the Australian Centre for Health Law Research. She receives funding through the Australian National Health and Medical Research Council to support her research into assisted dying law reform as part of QUT's Centre for Research Excellence in End of Life Care.

SAUL, PETER

ACP Without Paper: Adventures in Cyberspace

Evidence from a recent meta-analysis showed that only complex advance care planning (ACP) interventions were effective in determining treatments subsequently received. ACP in these settings was multi-stage or iterative. (Brinkman-Stoppelenberg 2014)

We undertook a series of projects in NSW, Australia to determine if complex ACP interventions could be replaced by a web-based coordination of end of life care extending over the last year of life. This system, called MyNetcare, is accessible by the full health care team including State Ambulance, and by the patients and carers, all of whom can view and contribute. Patient self-assessment and preferences are recorded and updated.

The project went through several phases: community meetings, data gathering, setting up the IT platform then making this accessible across the local health system including general practice. In a parallel eHealth project with NSW Health we also converted existing documents into an IT format to avoid scanning and uploading.

This paper describes the challenges in unflinching detail when it emerged that State Ambulance had no internet access, 90% of our patient cohort had no computer, over 50% were already fully dependent on a carer, and all the GP practices had a different IT provider. Two years in, we have valuable insights to share.

Peter Saul is a Senior Intensive Care Specialist in Newcastle, NSW Australia. He has been working with NSW Health for 20 years developing guidelines on advance care planning and end of life decision-making. He is Clinical Lead of the MyNetcare and the eMR2 eHealth End of Life projects.

SELLER, LORI (WITH VERONIQUE FRASER)

A Year in Review: The Who, When, Why and How of Requests for Medical Aid in Dying in Quebec

In response to the December 2015 legalization of medical aid in dying (MAID) in Quebec, regulatory bodies issued practice guidelines. Physicians were instructed to ensure that prior to choosing MAID patients are offered the opportunity to receive all the palliative care required by their state of health, and that MAID be used only in exceptional circumstances and as a last resort. In spite of the above guidance, it is not yet known when and how requests for MAID are being approached by patients and clinicians in practice. Even prior to the introduction of MAID, ineffective communication about dying and end-of-life care has been well documented. Recent studies have shown that patients often receive a significant number of interventions at the end-of-life, sometimes despite

limited medical benefit. There is no available data on how requests for MAID fit into the broader context of end-of-life discussions in Canada.

We conducted a one-year retrospective chart review of all requests for MAID at two urban teaching hospitals to explore the relationship between routine end-of-life care practices with the timing of requests for MAID. This presentation will provide preliminary results from this study, including (1) socio-demographics of patients requesting MAID, (2) characteristics of requests that were and were not completed, and (3) how requests for MAID are situated within end-of-life care. We will examine how current practice aligns with professional practice guidelines and provincial and federal law. Understanding when and how requests for MAID fit into the broader context of end-of-life care practices has the potential to provide insight into a new and controversial medical practice as well as end-of-life care planning and practices more generally.

Lori Seller is an ethics advisor at the Centre for Applied Ethics, McGill University Health Centre.

Veronique Fraser is an ethics advisor at the Centre for Applied Ethics, McGill University Health Centre.

SHAPIRO, MICHAEL

Euthanasia by Organ Donation

We offer an ethical analysis to support the concept of euthanasia by the process of organ donation. Organ donation can now be carried out by the technique of Donation after Circulatory Death (DCD, or DCDD), where life-sustaining therapy (e.g., artificial ventilation or inotropic support) is removed, the patient dies as determined by cardiopulmonary arrest, and organs are then recovered. There have been ethical concerns about DCD donation because of the short time interval between "death" and organ recovery, and uncertainty about whether the person is, in fact, dead. One solution to this issue is to do away with the requirement that the patient be dead before recovery (the "dead donor rule"). We maintain that there is little difference ethically by the active removal of ventilator support and active euthanasia, which, in any case, is legal in a number of countries, including, recently, Canada.

The decision to either withdraw life-sustaining therapy, or for euthanasia, should be made by the patient, family and healthcare team, irrespective of the patient's desire, or the medical potential, for organ donation, and without participation by the organ procurement organizations, transplant surgeons or others involved with donation. Once it is determined that euthanasia is appropriate for the patient, there is no ethical distinction between euthanasia, pronouncement of the patient, and recovery of organs or euthanasia accomplished in an anesthetized patient by the organ recovery itself. Additionally, there would be significant utilitarian benefit because of the potential for much greater organ recovery (e.g., heart) from the heart-beating donor.

We recognize the potential for significant objections to this proposal, from the transplant community and others, but believe this approach would maximize patient autonomy as well as utility.

Michael Shapiro is a transplant ethicist and kidney-pancreas surgeon. He has been involved in organ donation, transplantation and bioethics for over 30 years. He has chaired the US OPTN/UNOS Ethics committee, and participated on the ASTS and TTS Ethics committees. He has been a part of policy development concerning DCDD organ donation. His current scholarly interests are related to the intersection between the determination of death and organ donation. He is actively involved in the training of young surgeons.

SNIJDEWIND, MARIANNE

Expert Views on Developments in the Practice of Physician-Assisted Dying in the Netherlands

BACKGROUND AND AIMS - Euthanasia and physician-assisted suicide (EAS) have been legally regulated in the Netherlands since 2002. Our study aims to describe important developments in the field of EAS since the enactment of the law according to experts of the field with a focus on the question if euthanasia has become a normal practice.

METHODS - A qualitative study with semi-structured in-depth interviews was conducted. We interviewed 12 experts in the field of EAS in the Netherlands, these included ethicists, policy advisors, health law jurists and researchers.

RESULTS - The respondents mentioned that EAS has become a more discussible topic than it was before. They describe an increased emphasis on the notion of self-determination and avoidance of suffering. They were not in agreement whether or not the pressure to perform EAS towards physicians had increased. They mentioned the extensive debate on EAS based on psychiatric suffering or cognitive decline; while physicians are still very hesitant to perform EAS in these cases, the general public has a more liberal point of view and supports this option in general. The start of the End-of-Life Clinic - an initiative to help patients whose request for EAS was rejected by their own physician - was also seen as an important development. The respondents said that most developments contribute to EAS becoming an overall accepted practice in the Netherlands. Still, considering an actual individual request of EAS remains something out of the ordinary for physicians.

DISCUSSION AND CONCLUSION - Our study shows an increased acceptance of EAS in general, but a gap between physicians and the public when it comes down to supporting more uncommon reasons to request EAS. Does this gap have implications for the practice of EAS? Can the End-of-Life Clinic bridge this gap or only widen it further? How do these issues relate to medicalization and normalization?

Marianne Snijdewind is junior researcher based in Amsterdam, both at the AMC - department of medical ethics - and VUmc - department of public and occupational health. She has participated as researcher in the second evaluation of the euthanasia law in the Netherlands and in the evaluation of the first year of the End-of-Life Clinic. Currently she is conducting a project 'Is euthanasia on its way of becoming normal medical treatment?'

STEFFEN, LLOYD

The Ethics of POLST

Distinct but related to Advance Directives is POLST (physician orders for life-saving treatment), a portable actionable medical order designed to facilitate conversations between health care professionals and patients. The purpose of POLST is to complete the process for identifying patient wishes with respect to care in end-of-life conversations. Research indicates that patients have difficulties understanding POLST forms, and ethical issues have arisen over POLST. Does POLST improve communications as intended and facilitate acquiring informed consent? Since POLST does not require that a patient be terminally ill before directing the withholding and withdrawing of life-sustaining care, does POLST represent a paradigm shift in care as some Roman Catholic mecial professional have suggested? This paper will offer that POLST may run into some practical problems due to seemingly persistent and expected communications issues around critical illness and end-of-life issues, but that POLST is aimed at a morally worthy end, that of facilitating informed consent and supporting patient autonomy. The “paradigm shift” critique of POLST will be examined and challenged.

Lloyd Steffen is a professor of Religion Studies, University Chaplain and Director of both the Center for Dialogue, Ethics and Spirituality and the Prison Project at Lehigh University. Author or editor of eleven books, his most recent books are Ethics and Experience: Moral Theory from Just War to Abortion and The Ethics of Death: Religious and Philosophical Perspectives in Dialogue, co-written with Dennis Cooley.

TARSNEY, PREYA (WITH DEBJANI MUKHERJEE AND GAYLE SPILL)

Reframing Hope: A Rehabilitation Perspective on End of Life Care (Panel)

"Aren't we really just rearranging deck chairs on the Titanic?" This question was posed at a recent ethics Rounds about "shifting hope" that highlighted the case of a young-adult patient with a life-limiting condition who was receiving care in the rehabilitation setting to improve his functional status. This case evoked discussion about what it means to hope at the end of life. More specifically, while hope is not written into the treatment plan for rehabilitation inpatients, hope is certainly part of the equation and factors into the clinician-patient relationship at the end of life. The complexities of varying definitions of hope among multidisciplinary team members, as well as the patient and family, also complicates the dynamics in the rehabilitation setting. Given that rehabilitation is hard work with expectations of some benefit to the patient, what is the role for "hope" in rehabilitation at the end of life? And how can we work with patients to provide care that is effective and compassionate but also fosters realistic hope?

In this panel presentation three clinical ethicists who hail from different disciplinary backgrounds will draw on their experiences with hope and end of life issues in the rehabilitation setting. First, a physiatrist/clinical ethicist, will look at the relationship between goal setting and hope in rehabilitation and how we can create realistic hope at the end of life. Second, a clinical psychologist/clinical ethicist will explore the cognitive and emotional aspects of hope and how individual factors and context impact the ways that hope may work in this setting. Third, a lawyer-ethicist, with experience in conflict-resolution, will discuss relevant skills and techniques for negotiating and reframing hope at the end of life.

Panelists are all faculty in the Donnelley Ethics Program at the Rehabilitation Institute of Chicago (RIC) which has been a long-standing ethics program focused on disability ethics, rehabilitation ethics and clinical ethics. All panelists have privileges to perform ethics consultations at RIC and have faculty appointments at the Northwestern Feinberg School of Medicine in Chicago, IL as well.

Preya Tarsney, JD, is a Bioethicist in the Donnelley Ethics Program at the Shirley Ryan AbilityLab (formerly Rehabilitation Institute of Chicago) and a Lecturer in Physical Medicine & Rehabilitation at Northwestern University Feinberg School of Medicine and Faculty Lecturer at the University of Chicago, MacLean Center for Clinical Medical Ethics. Preya received her law degree from the University of Virginia, School of Law and her BA in Bioethics and Political Science from the University of Michigan. Preya completed her clinical ethics fellowship at the MacLean Center for Clinical Medical Ethics at the University of Chicago. Prior to entering the world of medical ethics, Preya practiced law for over six years in both the private practice setting (Sidley Austin LLP) and in-house (then Abbott Labs) where she specialized in commercial litigation and health care litigation. Preya's scholarly interests include informed refusals, negotiation and mediation in rehabilitation and clinical ethics, and best practices in ethics consultation.

Debjani Mukherjee, PhD, is the Director of the Donnelley Ethics Program at the Shirley Ryan AbilityLab (formerly the Rehabilitation Institute of Chicago) and an Associate Professor of Physical Medicine and Rehabilitation & of Medical Education at Northwestern University's Feinberg School of Medicine. Dr. Mukherjee is a licensed clinical psychologist and her scholarship and practice are informed by over 25 years of clinical experience, working in 8 hospital settings (in Buffalo; Boston; Urbana; Chicago; Paris, France; and Kolkata, India). She received her BA from Cornell University, her MA and PhD from the University of Illinois at Urbana-Champaign, and she completed two years of postdoctoral fellowship at the MacLean Center for Clinical Medical Ethics at the University of Chicago. Dr.

Mukherjee's clinical focus and research interests are in psychosocial adjustment to disability, the impact of emotionally demanding cases on healthcare providers, medical decision-making, and ethical dilemmas posed by neurological impairments. She has lectured and published on topics ranging from ethical considerations in international traumatic brain injury research to an innovative model of clinical ethics consultation. She is currently the section editor of the Ethics/Legal column of the American Academy of Physical Medicine and Rehabilitation's journal PM&R.

Gayle Spill, MD, is an Assistant Professor in the department of Physical Medicine and Rehabilitation at the Northwestern University Feinberg School of Medicine, an Attending Physician specializing in Cancer Rehabilitation and a Bioethicist in the Donnelley Ethics Program at the Shirley Ryan AbilityLab (formerly the Rehabilitation Institute of Chicago). Dr. Spill received her medical degree from the Robert Wood Johnson Medical School (now Rutgers Medical School) and completed her residency in Physical Medicine and Rehabilitation at the Rehabilitation Institute of Chicago, Northwestern University. Dr. Spill completed her clinical ethics fellowship at the MacLean Center for Clinical Medical Ethics at the University of Chicago. Dr. Spill's scholarly and clinical interests include rehabilitation for patients with advanced cancer, prognosis disclosure and brain tumor rehabilitation.

TEN CATE, KATJA

Dutch GP's Views on Good Dying and Euthanasia

BACKGROUND - In the Netherlands euthanasia or assisted suicide (EAS) is neither a right of the patient nor a duty of the physician. Beside the legal requirements, physicians can weigh their own considerations when they decide on a request for EAS. In a former qualitative study with Dutch general practitioners (GPs) aimed at getting a better picture of the considerations that play a role in practice when GPs have to decide on a request for EAS, we found three main types of considerations. (1) Perceived legal criteria, (2) individual interpretations of the legal criteria, and (3) considerations unrelated to the legal criteria. Examples of considerations of this 3rd type are: the family should agree to EAS, the patient's attitude must reflect resignation, or conflicts must be resolved. We hypothesized that this type of considerations reflects GPs' views on what 'good dying' entails. That is the reason we set up a new qualitative study to explore the relationship between GPs' views on good dying, their own role in that and their views on EAS.

METHOD - In-depth interviews with 20 Dutch GPs from various regions in the Netherlands.

RESULTS - Results are not available yet, but will be presented at the congress.

We suspect that the results of our study can feed the ethical discussion on the possible tension between a physician's own views on death and dying, and the views and preferences of his patients. When fixed ideas on good dying make considerations as 'no unresolved conflicts' or 'enough resignation' influence the decision to grant a request for EAS or not, this poses questions from an ethical and professional point of view.

Katja ten Cate studied Medicine and Applied Ethics. Currently she works as a PhD-student at the department of General Practice, section Medical Ethics, of the Academic Medical Centre Amsterdam, on a qualitative research project aimed at gaining more insight in the considerations that play a role in Dutch (general) practice for physicians that have to decide on requests for euthanasia and assisted suicide. Professor Van de Vathorst, professor 'quality of the end of life and dying', supervises her.

VAN DER HEIDE, AGNES

An International Perspective on Patient Preferences in the Decision-Making of Continuous Sedation Until Death

BACKGROUND - Guidelines encourage physicians to discuss the decision-making of continuous sedation until death with the patient and obtain consent. This study describes how patient preferences were taken into account in the various stages of decision-making of continuous sedation.

METHODS - Qualitative interviews with 26 physicians, 30 nurses and 24 relatives (involved in the care for 24 patients with cancer who received continuous sedation prior to death in Belgium, UK, and the Netherlands) exploring the decision-making process of the use of sedation prior to death.

RESULTS - Although the overarching goal of providing comfort was similar in all cases, there was a large variety in the timing and the extent to which patient preferences for the use of continuous sedation at the end of life were taken into account in the decision-making process, especially in the initiation and decision phase of continuous sedation. On one end of the spectrum, the decision-making was more patient-directed where physicians predominantly only evaluated whether and when the patient fulfilled the medical criteria. This was predominantly the case in case descriptions from Belgium and the Netherlands. On the other end of the spectrum, the decision-making was primarily clinical and physician-driven. These cases were especially present in the UK, where the decision-making was a more gradual process. Our data suggests that this variety can be explained by the clinical context (e.g. whether or not the patient was still competent, or an acute exacerbation of symptoms necessitated the use of sedation), specific preferences for or against the use of continuous sedation of the patient, relatives or the healthcare professional, and cultural-legal factors.

CONCLUSION - The large differences in the role of patient preferences in the decision-making of continuous sedation stress the difficulties of patient, relatives and clinicians when faced with refractory suffering at the end of life.

Agnes van der Heide, MD, PhD, is a researcher at the department of Public Health of Erasmus MC, University Medical Center Rotterdam, the Netherlands. She has performed studies on epidemiological, clinical, ethical and public health aspects of end-of-life care and decision making, at a local, regional, national and an international scale. She has published in renounced international medical journals about the frequency, characteristics and developments in the practice of euthanasia, assistance in suicide, palliative sedation and other end-of-life decisions, and many other topics. Currently, she is involved in studies on new developments in end-of-life decision making, advance care planning and integrated palliative care.

Lenzo Robijn (co-author) is a junior researcher at the End-of-Life Care Research Group of the Vrije Universiteit Brussel (VUB) and Ghent University in Belgium. Lenzo obtained a predoctoral Fellowship from the Research Foundation Flanders (FWO). His research focuses on the practice of palliative sedation and more specifically on the development, validation and effectiveness of clinical practice guidelines for palliative sedation in nursing homes aimed at improvement of care delivery by general practitioners.

VAN DE VATHORST, SUZANNE

Euthanasia in Advanced Dementia: The Use of Advance Directives

If an advance directive can substitute an oral request for euthanasia, this could be useful when patients are unable to make an oral request. However there are some theoretical issues, put forward by ethicists, regarding the validity of such an advance directive, either related to the concept of response shift, or related to the continuity of identity. In practice, doctors too are reluctant to act upon such an advance directive, partly based on the same moral questions, partly because they argue killing incapacitated persons is always morally wrong. The Dutch law allows for euthanasia based on an advance directive, but only if all other due care criteria are met.

I will present some Dutch cases of euthanasia in advanced dementia, both contested and uncontested, and address the concerns voiced by doctors and ethicists.

Suzanne van de Vathorst, MD, PhD, is a professor of end-of life issues at the Amsterdam Medical Centre (University of Amsterdam), works as an ethicist at the Erasmus MC in Rotterdam, is a former member of the Dutch Euthanasia Committees, and is involved in various research projects on end-of-life issues.

VAN DE WETERING, VEERLE

A Grey Area Between Palliative Sedation and Euthanasia

According to law and professional regulations, euthanasia is the deliberate act of ending a patient's life, at the explicit and serious request of the patient (article 293 Dutch Criminal Code); whereas palliative sedation is the deliberate act of reducing consciousness of a patient in the terminal phase of life. Euthanasia and palliative sedation therefore seem to be clearly defined and distinguishable.

However, looking at these two practices more closely demonstrates that the distinction between seems to be more complicated. In this juridical literature study we look at the cut-off point between palliative sedation and euthanasia from a juridical point of view.

When euthanasia and palliative sedation are being outlined following three criteria: (1) the action of reducing the consciousness, (2) the intentionality of the act, and (3) the terminal phase of life in which this action has to take place, it appears that this does not lead towards a clear demarcation. First, both acts involve reducing a patient's consciousness. Second, article 293 of the Dutch Criminal Code also includes the conditional intentions, the deliberate acceptance of the chance, according to common experience, of the occurrence of consequences. This results in the conditional intention of ending someone's life in situations in which the physician is aware of the fact that, due to his act, the death of the patient can occur faster, even though this is not the predominant aim of his act. Third, there is uncertainty about the actual effect of palliative sedation on the length of a patient's life, even with the prerequisite of a life expectancy of no more than two weeks. In addition, it is unclear to what extent life expectancy can be estimated realistically.

Thus, a grey area exists between euthanasia as an act that falls outside of the normal medical domain and palliative sedation as a normal medical act. We conclude that the grey area itself is not the core of the problem, but the fact that lawyers invent more problems based on the classical doctrines than necessary, in any case from a medical perspective.

Veerle van de Wetering holds a BA in Law from the Erasmus University Rotterdam and the University of Vienna. She graduated (cum laude) from the Erasmus University in Rotterdam with a Master in Criminal Law. Her MA thesis investigated the legal difficulties of ending the life of severely disabled newborns. In 2015 she started a PhD

project at the Erasmus Medical Center in Rotterdam. Her research focuses on the practice of decision-making at the end-of-life in the light of juridical standards, among them the criminal code and the Termination of Life on Request and Assisted Suicide Act. In particular, Veerle van de Wetering investigates the possible existence of a grey area between palliative sedation and euthanasia. Next to her PhD, she is completing a Master's programme in Health Law at the University of Amsterdam.

WAINER, RAFAEL

Mapping Out the Implementation of Bill C-14 on Health Care Providers in British Columbia

In Canada, the recently passed Bill C-14 (MAiD) has brought colossal changes in the therapeutic relations between patients and health professionals that need to be mapped out to better understand not only the societal and health care impacts at the structural level but also the ramifications of the implementation of this new law at the micro-sociological level (that is, the everyday interactions between health care providers and patients). This presentation will be based on exploratory interviews to different health care providers over the summer of 2017, in anticipation of fellow funding via MSFHR. The objective of this research project is to examine how the implementation of Bill C-14 has affected health professionals supporting patients enduring dire conditions who request assistance with dying in their everyday professional praxis. This presentation will answer the following question: How does the implementation of Bill C-14 affect, modify, and re-shape the therapeutic relationship between health care providers, patients, and families in British Columbia? This research will provide new evidence not only to measure the expansion of MAiD in British Columbia but also the intensity of these changes in how health professionals see themselves practicing medicine in the new context of decriminalization of medical assistance in dying. This presentation will discuss provincial efforts to strengthen not only Palliative Care services for those patients close to the end of life but also test the hypothesis whether the implementation of Bill C-14 has created a two-tier process (professionals only doing MAiD vs. professionals only doing Palliative Care).

Rafael Wainer is a qualitative health researcher with a PhD in Anthropology (UBC) with a specialization on medical anthropology, pediatric cancers, palliative care and corporeal experience of medical treatments.

Jennifer Kryworuchko (co-author), PhD, RN, CNCC(C), is an Associate Professor with the School of Nursing (UBC). Her new line of research focuses on agency in decision-making, palliative care, structural barriers, and social vulnerability.

WASYLENKO, ERIC

Medical Assistance in Dying and Incarcerated Persons – Special Considerations?

Health of, and health care for, incarcerated persons is subject to declared principles promulgated in at least some countries, notably within the European Union and the United States, and several of the countries also have legalized medical assistance in dying. In some jurisdictions, responsibility for health care provision for incarcerated persons is incorporated into the formal health system. In other jurisdictions, the justice system partners directly with health providers in order to provide health services to incarcerated persons. Despite the recognized aging and chronic health challenges of prison populations, the standards for health care delivery have not generally contemplated assisted death within prison health programs. This leaves patients/prisoners subject to potentially discriminatory treatment arising from non-equitable access to a legitimized service that non-incarcerated persons can avail themselves of, within those jurisdictions. It also leaves health providers at the mercy of idiosyncratic policies, regulations and program provisions when faced with the vexing practical issues and ethical uncertainty at the intersection of prison health and assisted death. Further, incarcerated populations have been shown to have high rates of mental illness and drug addiction, two situations that impact on autonomous choosing precepts that

underlie many assisted death regulations. Together with the potentially unique coercive influences inherent in incarceration, assisted death considerations are therefore even more challenging to sort out.

This paper will explore: a) potential grounds for supporting differential access to assisted death between incarcerated and non-incarcerated individuals, considering specific vulnerabilities that are exposed by incarceration; b) potential arguments in favor of equitable access, considering principles such as equivalence; c) ethics considerations that health personnel might bring to bear in their deliberations with patients who are incarcerated and who may wish to consider medical assistance in dying; and d) ethics and policy considerations regarding modes of assisted death within this environment.

Eric Wasylenko is a palliative care physician and clinical ethicist. He currently advises the Health Quality Council of Alberta on health system ethics and policy issues. Eric recently served as Medical Advisor and Secretariat Chair with a team tasked to introduce legal, policy, practice and education supports within a Canadian province, in preparation for legalization and implementation of medical assistance in dying. He chairs the Ethics Consultative Group for the Public Health Agency of Canada, and holds academic appointments at the University of Calgary and the University of Alberta.

WASYLENKO, ERIC

Organ Donation and Assisted Death: Are There Special Ethics Considerations?

Medical assistance in dying is legal in a number of jurisdictions in the world, now including Canada. Organ donation provides putative benefits to potential recipients, and might, in the situation of deceased donor donation, provide some potential psychological (prior to death) and legacy (after death) benefits to donors. Many jurisdictions struggle to raise rates of organ donation while needy patients languish and sometimes die on wait lists for transplant. Some jurisdictions require that organ donation be considered and discussed with all patients who are close to death. The introduction of assisted death in a jurisdiction may uniquely affect particular organ donation and transplant program elements that were in place prior to the legalization of assisted death. Controlled death may be seen by some as an ideal mechanism to improve organ viability for transplant success. In some situations, the opportunity to donate may also influence decisions to undertake medical assistance in dying.

This paper will argue that there are special ethical issues that arise at the intersection of assisted death and organ donation decisions. Several circumstances are of particular interest for this paper: a) when a person asks for assisted death and also wishes to be an organ donor, especially in the situation of directed donations; b) when attending clinicians or organ transplant programs, as a matter of policy and practice, actively seek permission for organ donation from persons who are considering assisted death; and c) when organ transplant programs, as a matter of policy, deliberately exclude people who are seeking assisted death from participating in organ donation due to unresolved legal or ethical issues.

Policy makers will need to wrestle with the question that will be addressed in this paper - ought the fact of dying via assisted death matter for eligibility to be a donor or a directed recipient?

Eric Wasylenko is a palliative care physician and clinical ethicist. He currently advises the Health Quality Council of Alberta on health system ethics and policy issues. Eric recently served as Medical Advisor and Secretariat Chair with a team tasked to introduce legal, policy, practice and education supports within a Canadian province, in preparation for legalization and implementation of medical assistance in dying. He chairs the Ethics Consultative Group for the Public Health Agency of Canada, and holds academic appointments at the University of Calgary and the University of Alberta.

WHITE, BEN

Australian Doctors' Legal Compliance in Relation to Decisions About Withholding or Withdrawing Life-Sustaining Medical Treatment

This paper reports on whether, and to what extent, medical specialists in three Australian States (New South Wales, Victoria and Queensland) consider the law to be relevant when making decisions about withholding and withdrawing life-sustaining treatment from adults who lack capacity. It is based on a postal survey of seven medical specialties most likely to be involved in end of life care (response rate 32%, with 867 medical specialists of 2702 potential participants completing the survey).

The role of law was tested using a hypothetical scenario where a majority of respondents in each State said that they would provide treatment, despite the presence of an advance directive refusing such treatment. Of significance is that the relevant law being examined (complying with advance directives) is very different in Queensland than it is in New South Wales and Victoria. This provides a natural experiment to examine the impact of law on medical decision-making.

Despite this different law in Queensland, doctors made broadly the same decisions as doctors in the two other States. Queensland doctors also gave broadly the same reasons for their decisions (very few selecting legally correct options) as doctors from the other two States. The overall results (high levels of non-compliance with the advance directive) and the lack of variation by State (despite different law) gives rise to important questions about the role law plays in regulating end of life decision-making. More education and training about the law and its role is needed, particularly where the law is inconsistent with widely held expectations.

Ben White is a Director of the Australian Centre for Health Law Research at the Queensland University of Technology (QUT). His area of research focus is the law, policy and practice of end of life decision-making. Ben graduated with a University Medal in Law from QUT and won a Rhodes scholarship to complete a DPhil at Oxford University. He has worked as an associate at the Supreme Court, at Legal Aid Queensland and as the full-time Commissioner of the Queensland Law Reform Commission. He has undertaken a series of Australian Research Council funded studies examining law at the end of life and is an editor of the text 'Health Law in Australia'.

WIEBE, ELLEN

Experiences of Patients and their Support People with Medical Assistance in Dying in Canada

CONTEXT - Canada passed the Medical Assistance in Dying (MAiD) law on June 17, 2016. For the first time, Canadians have the right to be granted an assisted death in their own country.

OBJECTIVE - To explore the experiences and perspectives of Canadians who requested and were eligible for MAiD as well as the experiences of people supporting them.

METHODS - This was a qualitative study using semi-structured interviews and thematic analysis. Patients who had a consult about MAiD in a clinic in British Columbia and were found eligible, were recruited for the study. Semi-structured interviews were conducted by two family practice residents with patients and their support people to explore the wishes, fears, beliefs and experiences as they pursued, prepared for and in some cases reflected on MAiD. Basic demographics were recorded for context.

RESULTS - Twenty-three patient experiences were explored in interviews with 11 patients and 18 support people. Most patients had a malignancy, neurological disorder or organ failure. The major reason for requesting assisted death was a self-perceived unacceptable quality of life, most commonly due to loss of: autonomy, independence,

physical function and ability to communicate. Some patients expressed fear of future suffering and future disability. The support people included spouses, sons and daughters, and friends. All supported their loved one's decision, although some were initially opposed and some found it very hard. All 11 support people who were interviewed after the MAiD death, said that the death was peaceful. They valued that they could be present, prepared, and could say some final words.

DISCUSSION - The reasons patients in our study requested assisted death were similar to the findings in other countries, namely loss of autonomy and the ability to do the things they enjoyed. Their loved ones supported their decisions and valued the chance to be prepared and present.

Ellen Wiebe is a Clinical Professor in the Department of Family Practice at the University of British Columbia. After 30 years of full-service family practice, she now restricts her practice to women's health and assisted death. She is the Medical Director of Willow Women's Clinic in Vancouver and provides medical and surgical abortions and contraception. She developed Hemlock AID to provide consultations for doctors and patients about aid in dying and provides assisted death. She has published widely on women's health and now is researching the experience of assisted dying in Canada.

WIEBE, ELLEN

Reasons for Requesting Medical Assistance in Dying (MAiD) in Canada

BACKGROUND - Canadians have had the right to assisted dying since the Carter decision came into effect February 6, 2016 and the Medical Assistance in Dying (MAiD) law was passed on June 17, 2016. Our objective was to explore who is requesting and who is receiving assisted deaths and what their reasons are. This information is not being gathered by the oversight agencies, the provincial Coroner's offices. They collect forms for completed cases only. These forms provide diagnoses for eligibility for MAiD, but not the patients' reasons. Therefore, the only way to get this information is a retrospective chart survey.

METHODS - We did a chart survey of six physicians' practices during the first six months since the law was passed. These physicians were accepting referrals for MAiD and provided the majority of assisted deaths in BC during this time.

RESULTS - The six physicians did 282 assessments and 108 provisions of MAiD. The diagnoses listed included malignancies 36%, neurological diseases 34% and end organ failure 21%. Loss of autonomy was listed as first or second most important reason in 69% of completed cases, with loss of being able to do the things they enjoyed and illness-related suffering both listed in 51% of cases. In the cases that were assessed but not completed, 48% listed fear of future suffering in the top two reasons compared to the completed cases in which only 26% listed this reason.

CONCLUSIONS - The reasons Canadians request assisted dying are similar to those in other jurisdictions with legal assisted death; loss of autonomy is the most important reason followed by loss of ability to enjoy doing things and illness-related suffering. There was a higher percentage of patients with neurological diseases than reported elsewhere.

Ellen Wiebe is a Clinical Professor in the Department of Family Practice at the University of British Columbia. After 30 years of full-service family practice, she now restricts her practice to women's health and assisted death. She is the Medical Director of Willow Women's Clinic in Vancouver and provides medical and surgical abortions and contraception. She developed Hemlock AID to provide consultations for doctors and patients about aid in dying and provides assisted death. She has published widely on women's health and now is researching the experience of assisted dying in Canada.

WILKINSON, SUE

Advance Decisions to Refuse Treatment: Explaining Low Uptake in England and Wales

The Mental Capacity Act 2005 provided a statutory basis in England & Wales for Advance Decisions to Refuse Treatment. However, more than a decade later, only 3-4% of people have completed an Advance Decision. This is in stark contrast to a figure of around 20-30% in North America and parts of Europe, where polls suggest the figure for equivalent documents is around 20-30%. This paper attempts to explain the low uptake of Advance Decisions in England and Wales with reference to law, ethics, policy and practice. It is based on work with two British charities, Compassion in Dying and Advance Decisions Assistance (ADA). It draws on: (a) a research project analysing a sample of recorded calls to Compassion in Dying's telephone helpline; and (b) several years' experience with ADA offering 'writing clinics' to support people in writing Advance Decisions, and providing training on Advance Decisions for healthcare professionals.

My research found that almost half of callers to Compassion in Dying spontaneously raised the issue of practical barriers to making an Advance Decision, including: understanding the law; translating end-of-life wishes into a formal document; discussing the Advance Decision with doctors and other professionals; and ensuring its effectiveness. ADA 'writing clinics' suggest that people wanting to write an Advance Decision grapple with concerns including insufficient medical knowledge, possible conflicts with family members, and change over time. ADA training sessions reveal widespread ignorance and misinformation about Advance Decisions among healthcare professionals, and problems associated with the lack of a central registration system for the completed documents. It is suggested that uptake of Advance Decisions in England and Wales is unlikely to increase substantially through the efforts of small charities, without a more sustained programme of government involvement.

Sue Wilkinson is Honorary Professor at the University of York, UK and Co-founder of the charity Advance Decisions Assistance (ADA). She has published widely in the areas of gender, sexuality, health and qualitative methods. Her current research uses Conversation Analysis to help charities - such as Compassion in Dying and Dementia UK - improve their telephone helpline services. Her charitable work involves raising awareness of Advance Decisions to Refuse Treatment, supporting people in writing them, and training healthcare professionals in their use.

WILLMOTT, LINDY

Attitudes of Doctors on the Role of Law in End-of-Life Medical Practice: Empirical Findings from Australia

Patients who are approaching the end of their life are or can be a vulnerable cohort. The law has an important role in protecting this group of patients by ensuring that medical practice complies with the relevant regulatory framework. This imperative exists whether decisions are being made in relation to withholding or withdrawing potentially life-sustaining treatment (including from individuals who lack decision-making capacity), or physicians are providing pain and symptom relief (including when it is provided in circumstances that may result in the patient being sedated until he or she dies), or physicians are providing a patient with assistance to die as a result of that patient's request. The authors argue that when physicians practise in this field of medicine, they have an obligation to do so within the parameters of the law. In reality, this can be a challenge because laws can be complex and difficult to know and understand. And there is now evidence that doctors lack knowledge of the law in some of these areas. Physicians operate under increasing time constraints, and they will be prepared to invest time into learning about the law only if they believe that the law is worth knowing and that practising medicine in a legally compliant way is a desirable goal.

This presentation reports on research findings on doctors' attitudes about the role of law in one aspect of medical practice at the end of life: decisions to withhold and withdraw potentially life-sustaining medical treatment from adults who lack decision-making capacity. We argue that education is required for doctors to reconceptualise knowledge of the law as constituting an integral component of their clinical expertise.

Lindy Willmott is a Professor with the Faculty of Law at the Queensland University of Technology (QUT) and a Director of the Australian Centre for Health Law Research at QUT in Queensland, Australia. She researches in the area of health law, particularly end-of-life issues and is currently undertaking a number of empirical research projects funded by the Australian Research Council. She is also a Chief Investigator in a National Health and Medical Research Council funded Centre of Research Excellence on End of Life. Her empirical research focuses on end-of-life decision-making and the impact of law in the clinical encounter. Lindy is also the author of many text books and is one of the editors of the text 'Health Law in Australia'. She is formerly a member of the Queensland Civil and Administrative Tribunal and the Queensland Law Reform Commission.

YOUNG, HILARY

Against Advance Directives for MAID

The law decriminalizing Medical Assistance in Dying (MAID) does not provide for advance directives for MAID. This is despite widespread support for advance directives for MAID from the public, some academics, and the Special Joint Committee on Physician-Assisted Dying. There have been calls for statutory change to permit advance directives for MAID. My paper explores reasons why these calls should be resisted.

Reasons to allow advance directives for MAID include: respecting patient autonomy; not discriminating against those with diseases of the mind (since advance directives for MAID will generally involve those with dementia); and preventing people from taking their lives prematurely.

However, one reason not to allow advance directives for MAID is that the permissibility of MAID is grounded in intolerable suffering. Advance directives require people to anticipate at what point their suffering would become intolerable. Advance directives often relate to values, which persist (e.g. I don't want to be dependent on machines), but suffering is an experience, and people are generally not good at predicting how much or what kind of suffering they will find intolerable.

Another reason against advance directives for MAID relates to the moral consequences (for physicians and society) of the state-sanctioned killing of people who do not presently want to die. Those who lack capacity, and therefore must rely on advance directives, are those who no longer understand what death is or its consequences. They have no present wish to die because they have no ability to understand what that means. It is one thing to kill someone with capacity who conveys their present wish to die. It is another to kill someone who has no idea what MAID is and is not presently requesting it. Thus, even in permissive jurisdictions like the Netherlands, advance directives for MAID are virtually never respected.

Hilary Young is an Associate Professor in the University of New Brunswick's Faculty of Law. Her research areas relate primarily to health law (especially end of life legal issues and informed consent) and defamation law.