Book of Abstracts

Organized Alphabetically by Abstract Category:

Ethics Labs
Ethics M&M Rounds
Poster Presentations
Pre-Conference Workshops
Standard Concurrent Sessions

*Conference cancelled due to COVID-19 pandemic*
Ethics Labs
Abstract Category: Ethics Lab
Primary Theme: Other Patient Values, ACP

Three Valuable Questions:
When / where has the tool been used?
For what purpose has it been used?
How has it been received by patients? HCPs?

Abstract: Advance care planning (ACP) has traditionally focused on the identification of a substitute decision maker (SDM) and the documentation of care preferences in an advance directive (AD). Evaluation data indicate that the types of preferences documented in ADs tend to be highly specific, such as which life-saving procedures one would want performed (e.g., mechanical ventilation), and that the ACP process is difficult for patients and not particularly effective at preparing SDMs for their future role. It is clear that alternate approaches are required.

The GVHT is a unique new instrument designed to bring together the patient and SDM to work through the process of understanding the patient’s fundamental values and how those values inform preferences regarding future care. The tool links simple questions in clear language to sketches, graphics, and a coloured Likert scale. The patient documents personal health-related values by addressing common changes in physical ability, cognitive ability, and quality of life that are not specific to one medical context; in a parallel version, the SDM is asked to anticipate how the patient would respond. Evaluation of the GVHT to date suggests that the tool is user-friendly, the health scenarios presented (e.g., pain management, physical disability, cognitive impairment, and living independently) are easily understood by most people, and that the process is helpful both to patients and SDMs.

We will begin the session by engaging the audience with a few key questions about Advance Care Planning. To facilitate this, we propose to use live polling software (Poll Everywhere) that invites participants to provide input into the discussion via their personal smart phones or tablets. The anonymized polling results can be shared with the audience in real time to inform the discussion.

Next, we will provide an overview of the GVHT and the recommended process for completion. All participants will be provided with a copy of the tool and asked to complete 2-3 sections, then encouraged to share their experience in completing the tool. We will offer feedback from research participants who completed the tool and feedback from use in a number of clinical scenarios.

Finally, we will engage participants in a discussion of the various possible uses of this tool for values clarification, advance care planning (ACP), goals of care (GOC) discussions, and in-the-moment treatment decisions. We will conclude by exploring ways the GVHT can be used to break down common barriers to ACP.

Author Names: Peter Allatt, Sinai Health; Shawn Tracy, Sinai Health
VSED: Another EoL option or unacceptable practice?
Mr. Peter Allatt, Sinai Health

Abstract Category: Ethics Lab
Primary Theme: Other End of Life

Three Valuable Questions:
What is VSED and how does it relate to other ELO treatment options?
Why do patients choose VSED?
What are the fundamental ethical issues?

Abstract: “Voluntary Stopping of Eating and Drinking (VSED) has been defined as the conscious, voluntary, and deliberate decision by a capable person experiencing intolerable suffering from a serious medical condition to intentionally refrain from receiving food or fluids by mouth with the primary intention to relieve suffering by hastening death.”

Although VSED is attracting more attention, there is little scientific research or data regarding frequency and outcomes are scarce. In Canada, there are almost no standards of practice or statute law, and only a few common law cases to date. In light of this vacuum, a number of critical questions have emerged: What are health care professionals (HCPs) to do when VSED is requested? Should HCPs participate in treatment of a patient who chooses VSED? If so, to what extent? Are there times when HCPs should not support VSED? Does support from HCPs aid and abet suicide? What if any weight should be given to a Ulysses contract? How does VSED relate to MAiD?

A brief overview will be provided. We aim is for a lively, interactive session. To engage the audience, we will employ live polling software (Poll Everywhere) that invites participants to provide input into the discussion via their personal smart phones or tablets. Participants will be encouraged to share their opinions and experiences through a sampling of questions from a Knowledge, Attitude, and Practice (KAP) survey. Real-time polling results (anonymized) will be presented and used to direct discussion. Lab participants will also be presented with our proposed inclusion/exclusion criteria for HCP-supported VSED and our recommended decision-making process. Participants will have an opportunity to discuss the appropriateness and utility of both tools. Finally, we will examine the appropriateness of HCP-supported VSED in a country that permits Medical Assistance in Dying (MAiD).

Throughout the session, the facilitators and participants will co-create a crowd-sourced list of the clinical, ethical, and legal complexities and challenges that arise during discussion. This list could serve as an initial roadmap for future research and policy development regarding VSED.

Author Names: Peter Allatt, Sinai Health; Jordan Pelc; Shawn Tracy, Sinai Health
Practicing Healthcare Ethicist Engagement in a Scoping Review of Outcomes Reported in Clinical Ethics Consultations
Dr. Jennifer Bell, University Health Network

Abstract Category: Ethics Lab
Primary Theme: Theories and methodology in bioethics

Three Valuable Questions:
1. Which additional stakeholder groups should have input into determining the relevant outcomes domains?
2. What are the necessary components of a clinical ethics consult intervention?
3. What are some ways we can reliably measure the identified outcome constructs?

Abstract:
*Note: This Lab may be most appropriate for practicing healthcare ethicists, although all members of the bioethics community are welcome to participate.

Theme and purpose:
Clinical ethics consultations (CEC) can be complex interventions, involving multiple methods, stakeholders, and ethical values in conflict. Despite longstanding calls for rigorous evaluation of CEC, scientific progress has been limited. The Medical Research Council (MRC) has developed guidance for evaluating the effectiveness of complex interventions. Applying the MRC framework can help advance the transparency and scientific rigour of CEC. A first step is to understand the outcomes measured in evaluations of CEC in healthcare settings.

We conducted a scoping review of the literature to identify and map the outcomes reported in primary studies of CEC evaluations. Review findings demonstrated diversity of CEC in terms of method, ethical issue identified, and referrers/clients served. Studies varied according to participant type, sample size, institutional characteristics, study design, and research methodology. Outcomes reported in CEC evaluations were mapped across conceptual domains, including psychological outcomes, process factors, healthcare utilization, clinical documentation, and quality.

According to Arksey and O’Malley (2005), stakeholder engagement can “inform and validate findings from the main scoping review” (p. 23). The purpose of this Ethics Lab is to engage members of the bioethics community, with a focus on practicing healthcare ethicists, in a review of our preliminary findings. Objectives include capturing participants’ agreement/disagreement with the outcomes and conceptual domains identified, discussing the relative importance of each outcome, and identifying next steps for stakeholder engagement and planning scientifically rigorous efficacy trials of CEC.

Draft agenda:
1. Introduce the research question and scoping review methodology, including stakeholder engagement (5 min)
2. Review preliminary study findings – description and narrative overview of identified outcomes and conceptual domains (15 min)
3. Discussion (60 min)
   a. Seek agreement/disagreement on each outcome domain, and identify any important gaps in outcomes
   b. Discuss the relative importance of each outcome and/or conceptual domain
   c. Refine the narrative overview
   d. Brainstorm additional opportunities for stakeholder engagement and research collaboration
4. Wrap-up (5 min)

Learning objectives: Participants will learn: 1) the basics of scoping review methodology and stakeholder engagement; 2) the most prevalent outcomes evaluated in primary studies of CEC in healthcare settings; 3) gaps in evidence; and 4) future research opportunities to inform the scientific advancement of CEC.

Output:

This Ethics Lab will enhance our understanding of the scoping review findings, identify gaps in evidence, and inform opportunities for further stakeholder engagement and analysis. Additional outputs include the potential to establish research collaborations for planning future scientifically rigorous efficacy trials of CEC.

Author Names: Jennifer Bell, University Health Network
Decision-making on unfunded therapies in public healthcare organizations
Mr. Michael Campbell, Trillium Health Partners

Abstract Category: Ethics Lab
Primary Theme: Other Unfunded Therapy

Three Valuable Questions:
1. How might parts of this policy template translate to similar issues such as unfunded medical devices?

2. What are the accountability and dispute resolution structures for decision-making?

3. How can I tailor this policy to be appropriate for my organization’s structures, resources, and decision-making processes?

Abstract: *Note: This Lab is designed for participants from organizations that intend to permit the provision of unfunded therapies in some form; it will not be a debate on whether this practice should be permitted altogether.*

Theme and purpose: When a new medical therapy is approved for use in Canada, the provinces and territories must decide if the therapy will be publicly funded. At times, Health Practitioners may believe that a patient could benefit from a therapy that has been approved by Health Canada but is not funded by their province or territory (or a therapy that is under review by a provincial/territorial approval body and a decision has not yet been made). In other cases, the therapy may be approved elsewhere (e.g., US, Europe) or in Canada, but not for the indication that the Health Practitioner requires for their patient. Options for patients to receive the therapy in these situations may include self-pay, private insurance, personal fundraising, compassionate access programs, hospitals absorbing costs, and more. However, administering unfunded therapies in publicly-funded healthcare organizations raises ethical questions about fair access to treatments and allocation of public resources.

This Ethics Lab will produce a policy template that will support fair and consistent decision-making when a treatment is proposed by a Health Practitioner and the treatment and/or the ancillary costs of a treatment are not publically funded (e.g., nurses and chair time to administer chemotherapies). Participants will be provided with a structured draft policy template at the Lab. We will then examine key decision points including the relevant ethical principles and criteria, and several implementation issues. This interactive session will use real-time anonymous electronic online polling to incorporate participants’ opinions to construct the template. While we will focus on oral and intravenous oncology medications, much of the content may apply to other unfunded therapies.

Agenda:
1. Introduction to the issue and the draft policy template (10 mins)
2. Key decision points (75 mins)
   A) Scope of policy (10 mins)
   B) Criteria for permitting the provision of unfunded therapies (25 mins)
   C) Accepting referrals from other organizations (5 mins)
   D) Accepting requests initiated by patients (10 mins)
   E) Administering patient’s own therapies (10 mins)
   F) Absorbing costs of therapies and/or the ancillary costs of providing therapies (7.5 mins)
   G) Stakeholder inclusion in decision making (7.5 mins)
3. Summary and conclusion (5 mins)

Learning objectives: Participants will learn: 1) The salient elements of a policy to address the provision of unfunded therapies 2) The relevant ethical principles and values that underlie the key decision-making points, 3) How to tailor the policy to their organization’s structures, resources, and decision-making processes.

Output: The Lab will produce a policy template which participants can tailor for their organization. The template will include the necessary conditions that must be met to provide unfunded therapies, an algorithm/procedure for fair decision-making, and a delineation of appropriate roles and responsibilities of physicians, staff, and patients.

Author Names: Michael Campbell, Trillium Health Partners; Rosalind Abdool, Trillium Health Partners; Sally Bean, Sunnybrook Health Sciences Centre; Jennifer Bell, University Health Network; Julija Kelecevic, Hamilton Health Sciences
Ethics case studies for humanitarian innovation
Dr. Dónal O'Mathúna, The Ohio State University

Abstract Category: Ethics Lab
Primary Theme: Public health ethics

Three Valuable Questions:
Does humanitarian innovation raise novel ethical issues beyond those of research ethics?

What are the most common types of ethical challenges that arise in the different stages of humanitarian innovation and how are they typically addressed?

What training in ethics is typically provided to humanitarian innovators?

Abstract: Introduction: Humanitarian crises abound globally following disasters and/or conflict. The responses to such crises involve interventions and programs that are constantly being evaluated and changed. Obrecht and Warner (2016) define humanitarian innovation as “an iterative process that identifies, adjusts and diffuses ideas for improving humanitarian action.” Such innovation can include research studies which require ethics approval, but some innovation does not satisfy strict definitions of research. Such projects may lack the sort of ethical oversight research projects receive. At the same time, innovation projects raise ethical issues as they can involve unstable settings, vulnerable populations, experimental aspects, etc. To help resolve the unique ethical tensions that arise in humanitarian innovation, the Humanitarian Innovation Fund (HIF) and Elrha, a global charity that focuses on research and innovation in the humanitarian sector, funded our research group to produce a set of ethics resources for humanitarian innovation. Among these resources is a set of ethics cases studies which has been developed to provide opportunities for those involved in humanitarian innovation to identify, explore and discuss ethical issues and hence develop skills in ethical decision-making.

Objectives: These are: (1) to give participants an opportunity to explore and discuss ethical issues in humanitarian innovation, and (2) to identify additional ethical issues in the cases which provide insight into the ethics of humanitarian innovation.

Methods: The Lab will provide participants with three case studies which has been developed for this session. Each will focus on an ethical issue arising at different stages in humanitarian innovation. HIF uses a model of humanitarian innovation involving six stages which will be described to participants (http://higuide.elrha.org/toolkits/get-started/innovation-process). This description provides a useful map to identify various types of ethical issues. Participants will be divided into small groups and given 20 minutes to discuss the first case. The case as distributed will highlight an ethical issue in one of the six stages and participants will be asked to discuss this. Then they will be asked to identify other ethical issues that could arise at other stages in the innovation process. Each group will be asked to describe these additional issues and how they might be resolved. The second and third cases will be discussed in similar ways. The first case focuses on conflict of interest and reputation issues arising from a humanitarian organization working with a commercial company with technical expertise but no humanitarian experience. The second focuses on unanticipated developments with an innovation which lead to problems within the community where it was developed. The third focuses on questions around whether or not an innovation should be developed in a particular settings given the level of insecurity which currently exists.

Outputs: The outputs collected will be short written summaries from each small group of the additional ethical issues identified in each case, and an evaluation of the usefulness and credibility of the case studies developed for this Lab. These insights and evaluations will contribute to revisions of the case studies which will be shared with all participants after the conference.

Author Names: Dónal O'Mathúna, The Ohio State University; Gautham Krishnaraj, Humanitarian Health Ethics Research Group; Matthew Hunt, Humanitarian Health Ethics Research Group; Rachel Yantzi, Humanitarian Health Ethics Research Group; John Pringle, Humanitarian Health Ethics Research Group; lydia kapiriri, McMaster University; Lisa Schwartz, Humanitarian Health Ethics Research Group
Ethics M&M Rounds
**Abstract Category:** Ethics M&M rounds  
**Primary Theme:** Other Substance Use and Harm Reduction

**Three Valuable Questions:**
1. What is the evidence for harm reduction approaches in acute care?
2. Where have harm reduction approaches been implemented in hospitals in North America?
3. Why should hospitals provide harm reduction care, and what might this include?

**Abstract:** In this presentation we describe a situation involving Amanda, a fictional person admitted to a General Internal Medicine unit at an academic teaching hospital in a major urban centre. Amanda reported she was injecting street fentanyl both on and off the unit. She frequently missed her antibiotic doses for her infective endocarditis and would be absent from the unit for multiple hours at a time. Early in her admission, Amanda overdosed in the hospital washroom but was revived after her partner administered naloxone. The staff reported that they discovered needles hidden in the mattress of Amanda’s hospital bed, which created safety concerns for Amanda, staff, and her visitors. Upon admission, Amanda stated that she wanted to start on opioid agonist therapy (namely buprenorphine-naloxone), but there was no follow up on this request. Some staff are concerned that Amanda is going to inject drugs into her peripherally inserted central catheter (PICC line). Other staff report that they spend a disproportionate amount of time providing care to Amanda, which they argue is unfair to other patients. Many staff believe Amanda “does not want to get better”.

We describe the process the interprofessional team took to address this situation, including involving the hospital’s bioethicist. We also describe how the team adopted a harm reduction philosophy and approach to Amanda’s care, and how harm reduction, based in values such as respect for persons, compassion, and non-judgment, can improve the safety and quality of care for people who use drugs who are admitted to hospital.

**Author Names:** Daniel Buchman, University Health Network; Claudia Barned, Centre for Clinical Ethics - Unity Health Toronto; Josee Lynch, University Health Network; Andrea Sharp, University Health Network; Leigh Chapman, Toronto Overdose Prevention Society; Josephine Lau, Fred Victor Consumption and Treatment Services
Abstract Category: Ethics M&M rounds
Primary Theme: Ethics and health policy

Three Valuable Questions:
1. How can point of care health care providers be supported to maintain compassion for persons experiencing homelessness while promoting appropriate acute care resource utilization?
2. Can addressing a healthcare system issue with hospital emergency resources contribute to harming patients?
3. What is the hospital's responsibility to the health of persons experiencing homelessness?

Abstract: Persons experiencing homelessness continue to increase despite federal, provincial, and local commitments to prevent and end homelessness. Despite above seasonal winter temperatures, there are an average 5-7 individuals experiencing homelessness who are sleeping in the Emergency Department (ED) waiting room. Not all individuals have registered for medical care. Those who have registered will defer their place in queue to sleep longer. Other public spaces throughout the hospital are also slept in. Limited overnight community accommodations, restricted access to shelters of violent or intoxicated persons, lack of accessible health care resources, autonomous choice to sleep rough, and siloed approaches contribute to this issue.

ED staff have a variable approach to managing individuals sleeping in the waiting room and feel both moral and legal obligations in their approach. Current practice allows individuals to use this space for sleeping until 6:00 when they are provided with a bus ticket and told to leave. Previously identified violent behaviour presents concern for safety of staff and patients waiting for medical care. Hospital food, clothing, linens, and taxi vouchers are distributed. Healthcare providers in the ED feel unsupported in their approach to a community and organizational issue.

Addressing the issue will require both local and community engagement from the hospital. Taking a zero-tolerance approach is utilitarian and will not support individuals or the care providers. Allowing liberal use of the space for sleeping poses a safety risk. An approach that considers both perspectives will be required.

Author Names: Launa Elliott, London Health Sciences Centre
Case Study of Alexa: Ethical Considerations when Using Artificial Intelligence (AI) Devices in a Clinical Setting
Dr. Dianne Godkin, Trillium Health Partners

Abstract Category: Ethics M&M rounds
Primary Theme: AI and Ethics

Three Valuable Questions:
1. What concerns does the use of AI devices such as Alexa raise in a hospital environment?
2. How do we support the autonomy of patients and improve their quality of care without jeopardizing the confidentiality of other patients and staff?
3. What safeguards need to be in place to use this technology transparently and safely?

Abstract: This case study explores the use of Alexa, an AI device, in a patient’s room to support communication with family members and to improve access to care. The patient had a condition that limited her mobility and she was unable to use a call-bell to signal assistance from nursing staff. Alexa was set up by her children (without knowledge of staff) so that the patient could request that Alexa phone her children. Calls to her children served two purposes: 1) to enhance communication with her children and improve patient’s quality of life; and 2) to inform her children when she needed assistance. If she needed assistance, her children would subsequently call the nursing station on her behalf.

Use of the AI device raised a number of ethical questions and concerns related to autonomy (supporting the patient’s independence), confidentiality (of the patient’s information, other patients’ information, and staff information), quality of care (timeliness), and equitable access to resources (not all patients with similar needs had access to an AI device).

Members from the ethics and privacy departments, alongside the patient’s care team, were involved in the resolution of this case. Due to concerns about data collection and storage, the privacy department required that use of the device be discontinued. To compensate for this loss, several strategies were put in place to ensure the patient received timely care and could communicate with her children. However, questions remain about whether or not banning AI devices is the most ethically justifiable response.

Author Names: Dianne Godkin, Trillium Health Partners; Rosalind Abdool, Trillium Health Partners; Eoin Connolly, Trillium Health Partners
Abstract Category: Ethics M&M rounds
Primary Theme: Other Ethics and end-of-life care

Abstract: When children are divided regarding end-of-life decisions, understanding what their parent, our patient, would have wanted can be extremely challenging. This M&M round will review a withdrawal case in the Intensive Care Unit that unfortunately had to involve the Ontario Public Guardian and Trustee due to a family divided. Following a brief review of the case, this discussion will explore the values and beliefs of the multiple stakeholders: the patient, the children who were all equally weighted substitute decisions makers, and the healthcare team. The successes of the case as well as an exploration of opportunities for improvement will be shared. There will be space for all participants to share similar situations and learn from the collective experiences. This M&M round will explore questions such as: Is there an optimal way to manage family expectations in the ICU? Does prolonging these challenging cases contribute to unrealistic expectation setting, or does it allow time for understanding and acceptance? Should a utilitarian approach be taken in order to maintain a respectful environment? When should the Ontario Public Guardian and Trustee be called? Should the tolerance level for erratic behaviour from family members be raised at end-of-life? How should care be provided to other patients and families during these situations while maintaining privacy and confidentiality? How should video recordings be managed during and following a withdrawal of care? Etc.

Author Names: Rosanna Macri, Humber River Hospital; Phyllicia Lafreniere, Humber River Hospital
Poster Presentations
Abstract:

When a patient’s behaviour within a clinical setting is disruptive or potentially injurious, it can result in significant chaos, or worse. Health care providers sometimes employ “patient contracts” in an effort to remediate patient behaviour and restore predictability to the clinical encounter. By signing these documents, as is often required to continue receiving care from a given provider, patients promise to bring their behaviour in line with the expectations of the provider, hospital or clinic. Academic literature on the use of patient contracts is scant and the ethical nature of this practice is ripe for consideration.

A contract is a legal document through which one party agrees to do something, or to refrain from doing something, in exchange for a benefit provided by the other party. Through agreement, mutual promise and the protection of law, the aim of a contract is to provide certainty. Contract law reflects an ethical framework designed to determine which kinds of promises formed under which circumstances should result in a person being held to her promise or being required to pay damages to compensate for a breach.

Given that patient contracts are almost certainly never created under the conditions required for valid contract formation, I refer to these documents not as contracts but rather as PCs. The use of PCs has important implications for patient autonomy, and may result in the miseducation of vulnerable people about contractual relationships. Referring to documents that do not meet the ethical requirements for contracts (namely mutual advantage, absence of undue influence, and certainty of terms) as contracts invokes the authority of law where it does not exist. Moreover, PCs effectively compel patients to make promises they may be ultimately unable to keep, which may lead to feelings of shame. Finally, PCs perpetuate the notion of the “difficult patient” as only the “difficult patient” would have a PC in her file.

The reality of clinical life must not be ignored; at times, patients do behave in ways that are offensive and perhaps even incompatible with the peaceful functioning of the clinic or hospital. It is autonomy-enhancing for patients to be made aware of the potential consequences of their behaviour so that they have an opportunity to change. Rather than having behaviourally disruptive patients sign illegitimate contracts, however, more egalitarian approaches should be explored. All patients might be provided an outline of expectations and potential consequences for non-compliance, to be signed only as an indication of having been read and understood. Regardless of approach, patients should be encouraged to ask for support in meeting behavioural expectations if they feel that compliance may be a challenge.

Author Names: Alexandra Campbell
La trajectoire de vie : un outil de soutien à la discussion pour les consultations en éthique clinique
Mrs. Vanessa Chenel, CIUSSS de l'Est-de-l'Île-de-Montréal

**Abstract Category:** Poster Presentations

**Three Valuable Questions:**
Quel est l’apport d’une telle trajectoire aux consultations en éthique clinique?

Comment est-ce que cet outil peut prendre vie en clinique en dehors des consultations en éthique?

Comment pourrait-on évaluer l’impact de l’utilisation de cette trajectoire sur la facilitation de la résolution des situations cliniques complexes?

**Abstract:**

**Introduction**

Les conseillers en éthique peuvent être appelés en consultation lorsque des situations cliniques complexes nécessitent un nouveau regard sur le malaise en place. Dès lors, cet exercice éthique requiert de dresser un portrait complet de la situation, incluant une explicitation des valeurs sous-jacentes afin de convenir des différents scénarios possibles. Cependant, cet exercice n’est possible que via un langage et des repères communs.

**Problématique**

Différents cadres ont été développés pour soutenir la réflexion quant à la trajectoire de soins des usagers dans plusieurs contextes (i.e., maladies chroniques, maladies graves, fin de vie). Par exemple, le cadre sur les soins palliatifs au Canada propose une stratégie pour une transition optimale entre la prise en charge de la maladie et les soins palliatifs, avec, en exergue, l’importance de la discussion sur les différentes options. Par ailleurs, en ce qui concerne les personnes atteintes de la maladie d’Alzheimer, la participation des aidants est primordiale à l’établissement du traitement optimal de leur proche. La compréhension de leur perception est donc essentielle.

L’examen de ce que constitue un traitement pour ces aidants a permis de définir leur représentation en termes d’efficacité recherchée (stabilisation, ralentissement ou guérison de la maladie), de nature des attentes (visée préventive, symptomatique ou curative) ou encore d’impact attendu (cognitif, fonctionnel ou comportemental). Or, afin de dénouer une situation complexe en éthique clinique, aucun outil ne permet de soutenir les discussions d’un point de vue global, ni n’intègre l’ensemble des aspects à considérer (i.e., valeurs, projets de vie) permettant de mettre en évidence des objectifs de soins et services réalistes afin d’établir un plan d’intervention optimal.

**Méthodes**

Cette trajectoire découle de l’analyse du déroulement des consultations au CIUSSS de l’Est-de-l’Île-de-Montréal lors des rétroactions entre les conseillères en éthique. Il synthétise de manière structurée les principales thématiques généralement abordées. Ce cadre conceptuel a été discuté et retravaillé avec les membres du Comité d’éthique clinique et organisationnel.

**Résultats**

À cette fin, une trajectoire de vie avec les niveaux de soins en trame de fond est proposée comme référentiel en renfort aux différentes situations complexes rencontrées en consultation. Axé sur l’explicitation des valeurs en tension et centré sur le meilleur intérêt de l’usager, cet outil permet de mettre en perspective les projets de vie, les objectifs de soins ainsi que la nature appropriée et proportionnée des soins et services.

**Discussion**

Dans une visée participative et interactive, cet outil met l’emphase sur l’importance de la discussion dans les situations complexes où les conflits de valeurs peuvent être à l’origine des tensions sur les objectifs de soins et services. Tout en sensibilisant de manière pédagogique à l’arrimage entre ces aspects, cette trajectoire encourage le dialogue des intervenants et professionnels entre eux, et facilite celui avec les usagers et leurs proches.

**Conclusion**

Sans formaliser l’ensemble du processus de consultation en éthique, cette trajectoire de vie centrée sur le meilleur intérêt de l’usager constitue un point d’ancrage visuel pour soutenir les discussions sur les objectifs de soins et vise à clarifier ce qui constitue une offre de soins et services appropriés en contexte.

**Author Names:** Vanessa Chenel, CIUSSS de l'Est-de-l'Île-de-Montréal; Manon Joyal, CIUSSS de l'Est-de-l'Île-de-Montréal; Nora Sfihi, CIUSSS de l'Est-de-l'Île-de-Montréal
An Ethical Application of Virtual Reality in Research for Clinical Decision Making
Ms. Dorothyann Curran, The Ottawa Hospital

Abstract Category: Poster Presentations
Primary Theme:

Three Valuable Questions:
How does research play a part in ethical clinical care?
How can clinicians make decisions for changes in practice with the weight of research papers that exists and with inconclusive recommendations?

Abstract:
Health care providers (and patients) anticipate a progressive positive change with treatment implementation, but the acceptance of a grey area of unknown impact is often the final outcome. This impacts the ethical obligation that providers have to patients to offer them the best care. In rehabilitation, the use of virtual reality to assess and treat diverse patient populations is increasing in practice. The opportunity exists for the contribution of virtual reality to inform ethical clinical decision-making in this health care context. Using technology as a research tool to examine empirical measures of function can give health care providers the information they require to then make clinical practice decisions or to encourage practice change on a larger scale. Our example is a pilot study looking at patients who have persisting symptoms post concussio to understand the differences between people who have visual symptoms requiring prism glasses and those who do not. The use of prism glasses is becoming more common in the treatment of persisting visual deficits following concussion, but the actual impact of these glasses is unclear, both in terms of what symptoms they are acting upon and the need for long term use by patients. This project highlights the implications of a using virtual reality technology to inform normative health care decision-making for a specific patient population and discusses the opportunities to enhance ethical clinical decision making for best treatment options.

Author Names: Dorothyann Curran, The Ottawa Hospital
Dignity and a Child's Best Interests
Dr. Andrew Helmers, Department of Critical Care Medicine, the Hospital for Sick Children

Abstract Category: Poster Presentations

Three Valuable Questions:
Why do we need to reconceptualize the best interests standard?

How do we evaluate best interests in pediatric medicine?

How do we mediate conflict regarding best interests?

Abstract: Background
In the face of ever-expanding technological solutions in paediatric critical care, "should we?" is often a more challenging question to answer than "can we?". The best interests standard is often invoked for the former question in paediatric decision-making, yet it is flawed and suffers from inconsistency in its conceptual basis, variability in its enforcement and an inability to stand for more than a measure of the minimum in practice.

Objectives:
An ethics-based analysis of the best interests standard is undertaken, with a case put forward for an improved framework that incorporates a rigorous conception of dignity; the implications of this framework for paediatric medicine are explored, in particular its potential for improved guidance in the face of a growing technological imperative.

Methods:
"Dignity" is analyzed as the key to a framework for the best interests standard; this analysis is grounded in virtue ethics, building a method to evaluate care decisions in a manner inclusive of both harm-avoidance and human flourishing.

Results:
A new framework for understanding and applying the best interests standard in paediatric medicine is articulated with two principles with which to test decision-making. The “defence principle” asks "Is the proposed therapy or omission something we ought to defend the child from by virtue of the significant harm posed?", while the “promotion principle” asks "Does the proposed therapy or omission promote the child's dignity according to a reasonable understanding of human flourishing?". Further, implications for dignity as a constructive force are explored and contrasted with the narrower focus of current conceptualizations. Consideration of dignity demands that the public pursue all those things (inclusive of social determinants of health) that enable human flourishing – shelter, food, education and so forth; thus, this new conception of best interests may in turn inform values adopted for consequentialist considerations such as resource allocation in healthcare provision.

Conclusions:
As medical technology becomes increasingly complex while minimizing physical harm, dignity becomes a new criterion to gauge whether the application of a given technology is an affront to or a window for promotion of a particular child's flourishing. This ensures a whole-person consideration of best interests, rather than one overly focused on minimizing harm or achieving a merely physiologic solution.

Author Names: Andrew Helmers, Department of Critical Care Medicine, the Hospital for Sick Children
Integrating a care ethics perspective into the use of assistive care robots with older adults
Ms. Rachel Hewitt, Memorial University of Newfoundland

Abstract Category: Poster Presentations

Three Valuable Questions:
1. If one agrees that robots performing caring tasks is substandard, are they still not preferential to a crisis for care resources caused by lack of or low paid and emotionally-burnt out human carers?
2. What is the next direction for ethical research into socially assistive robotics technology?
3. What role should SAR developers play in contributing to discussions around the ethical implications for the design and use of such technology?

Abstract: Assistive healthcare robots have garnered much interest as a solution to alleviate the dearth of formal and informal caregivers available to assist an ever-increasing number of older adults. Much of robotics research is committed to the position that such technology is a much more effective intervention than relying on further human caregivers. This paper assesses the claims made by robotics developers in relation to the actual capacities of these technologies to meet the care needs of older adults. Referencing the works of scholars of care, I demonstrate that caring ought to be understood holistically. All caring tasks, including seemingly mundane and ‘easy’ ones, intrinsically create space for addressing evolving or conflicting care needs. Thus, those providing care ought to possess the qualities and capabilities that not only allow them to appreciate the same caring comforts, but enable them to have the ability to make the appropriate judgements for resolving the complexities intrinsic to the caring process. In considering the literature for socially assistive robots (SARs), I contend that these technologies have a limited reciprocal means of communication and interaction with their users. Consequently, I argue this precludes SARs from exercising the appropriate caring capacities to complete caring tasks well. Furthermore, SARs are unable to contextualize these tasks within the broader care context in order to incorporate evolving care needs and any possible practical constraints to the provision of care. I contend that if we uphold that persons ought to be treated as ends in themselves, introducing a technology that presents the possibility of removing opportunities for communication and moral solidarity with one’s fellow human beings should be at least somewhat ethically concerning.

Author Names: Rachel Hewitt, Memorial University of Newfoundland
NEUROWEARABLES: MANAGING INCIDENTAL FINDINGS AND ADVERSE EVENTS
Ms. Nicole Minielly, Neuroethics Canada, Division of Neurology, Department of Medicine, University of British Columbia

Abstract Category: Poster Presentations
Primary Theme:

Three Valuable Questions:
1. Is oversight over the DTC neurowearable industry adequate today?
2. If there was more oversight over the DTC neurowearable industry, who would or should be responsible for that oversight?
3. How can ethicists work with industry to encourage the implementation of the proposed recommendations?

Abstract: INTRODUCTION:
Wearable technologies are predicted to be a $31 billion-dollar industry by 2021 (Kaul and Wheelock, 2016). A sub-type of wearable technologies called neurrowearables that record from and stimulate the brain has become increasingly common on the consumer marketplace (Coates McCall et al., 2019). The open market utilization of these devices follows the medical and research uses for which they were developed – dating as far back as 1929 for neurorecording with electroencephalography (Berger, 1929) and more recently for non-invasive neurostimulation with transcranial direct-current stimulation (Nitsche and Paulus, 2000).

Policies surrounding incidental findings (unexpected findings revealed by a device) and adverse events (negative events caused by device use) are standard in the research and clinical landscape, especially following a long history of research on incidental findings in neuroimaging (Illes et al., 2002). However, neurowearable company policies surrounding incidental findings and adverse events are largely unexplored in the direct-to-consumer (DTC) space.

PURPOSE:
(1) Characterize incidental finding and adverse event policies through semi-structured interviews with representatives whose companies are selling neurowearables in the open marketplace or hoping to do so.
(2) Offer practical recommendations for the DTC neurowearable industry.

METHODS:
Using an existing database (Coates McCall et al., 2019) and snowball sampling, we contacted 41 company representatives. We engaged with a total of 12 participants: 8 from recording device companies (e.g., EEG); 3 from stimulating device companies (e.g., tDCS); and 1 from a stimulating and recording device company (e.g., EEG + tDCS). Interviews were transcribed, and qualitative methods were used to develop a coding strategy that was tested for reproducibility and applied to describe responses and identify emergent themes.

RESULTS:
Interviews highlighted that there are no standard data collection or management policies across the DTC neurowearable industry. One incidental finding was revealed by a participant. Adverse event occurrences were reported by 7 participants. Management strategies for incidental findings and adverse events were scarce and inconsistent.

CONCLUSION:
Four industry strategies for managing incidental findings and adverse events in DTC neurowearables that are grounded in practical ethics principles can promote responsible innovation in neurotechnology and consumer protection and trust. These strategies involve:

1. Minimizing data collection where possible. Increasing data security when data minimization is not possible.
2. Standardizing incidental finding and adverse event management procedures.
3. Articulating reporting and management policies on neurowearable product labels.
4. Reconsidering the classification of neurowearable devices as health devices and follow relevant regulatory guidelines.

REFERENCES:

Author Names: Nicole Minielly, Neuroethics Canada, Division of Neurology, Department of Medicine, University of British Columbia; Judy Illes, Neuroethics Canada, Division of Neurology, Department of Medicine ; Viorica Hrincu, Neuroethics Canada, Division of Neurology, Department of Medicine, University of British Columbia
Canadian Immigration Policy and it’s Unintentional Disregard of Refugee’s Human Rights
Ms. Monika Noble,

Abstract Category: Poster Presentations

Abstract: Introduction: The world is currently experiencing a global refugee crisis, with the United Nation’s High Commissioner for Refugees (UNHCR) finding that by the end of 2018, 70.8 million people were forcibly displaced worldwide. As Canada was found to have resettled the largest number of forcibly displaced people during 2018, and if the number of forcibly displaced peoples continues its upward trend, Canada’s immigration and refugee systems will be placed under much more strain. On paper, Canada presents a welcoming environment for these people, and has on multiple occasions committed to protecting the rights of vulnerable populations. However the reality is that various situations arise during this process that create barriers which perpetuate trauma and disregard the human rights of refugees and asylum seekers.

Methods: A systematic review of the Canadian Refugee Immigration system was conducted in order to properly grasp the mechanisms involved in a refugee’s immigration process. The processes were then analyzed using the human rights based approach to ethics, in order to evaluate the process’s respect (or lack thereof) of refugee and asylum seeker human rights. Sources that provide first hand testimony of refugees and asylum seekers were used to support claims of processes ignoring human rights, and alternatives were identified.

Findings: The author identified two main issues during this process. A refugee’s access to healthcare and the insurance provided to them demonstrate a lack of support for their right to physiological safety and healthcare, and the threat and use of detainment creates situations in which a refugee’s right to safety and overall health can be ignored. Both of these issues contribute to retraumatization of an already vulnerable population. Furthermore, there is no reason for these issues to continue to plague the refugee immigration system as promising alternatives already exist. In addition to the argument that these policies should be changed in order to respect a refugee’s human rights, further arguments include the fact that Canada is doing very little compared to other countries in regard to providing healthcare, and that alternatives to detention (such as directed places of residence or intermittent reporting to authorities at set intervals) already exist and have been highly suggested by the UN and other advocacy organizations.

Conclusion: While alternatives to traumatizing policies and practices currently exist, the Canadian government must make an effort to integrate these potential solutions and evolve current immigration policy to reflect their commitment to protecting the human rights of refugees and asylum seekers. Adopting these measures would greatly improve refugee’s mental and physical health and ensure that their human rights and need for physiological health and safety are respected throughout the immigration process.

Author Names: Monika Noble
Patients with schizophrenia and their experiences with legally mandated treatment, a systematic review of qualitative studies
Ms. Joanne Plahouras,

Abstract Category: Poster Presentations

Three Valuable Questions:
Which types of legally mandated treatment were included in this review?

How can patient autonomy be improved for patients who are legally mandated to receive treatment?

Is there an association between quantitative treatment outcomes and qualitative patient experiences?

Abstract: Background: Schizophrenia is a chronic and heterogeneous psychiatric disorder that affects approximately 1% of people globally. Schizophrenia involves emotional, cognitive, and behavioral dysregulation. It is a leading cause of disability globally.

Patients with severe forms of psychiatric illness, including schizophrenia, may be legally mandated to receive treatment. Laws and regulations for legally mandated treatment vary regionally and globally. In general, someone can be legally mandated to receive treatment for a psychiatric condition if they pose a risk to themselves or others. In Canada, there exists 12 Mental Health Acts, which equates to almost one separate act per province and territory.

Rates of legally mandated treatment are increasing and patients with schizophrenia are more likely to undergo involuntary treatment than patients with other forms of mental illness. Although studies have evaluated treatment outcomes for patients who were legally mandated to undergo treatment, the literature regarding patients’ attitudes towards their involuntary treatment is limited.

Objective: To describe the experiences of patients with schizophrenia and related disorders who were legally mandated to undergo psychiatric treatment.

Methods: Four databases, CINAHL, EMBASE, MEDLINE, and PsycINFO were searched for key words, text words, and medical subject headings related to schizophrenia, legally mandated treatment, and patient experience. Reference lists of each of the included studies were searched to identify additional publications. Studies where 50% of more of participants had a diagnosis of schizophrenia or schizoaffective disorder were included. Qualitative studies that reported on the experiences of patients who underwent any form of legally mandated treatment were included. A thematic analysis, where study results were categorized under two broad themes of positive and negative patients’ experiences was completed. Additional subthemes were identified. The quality of each of the included studies was assessed.

Results: The database search identified 4008 abstracts. Searching the reference lists of included studies identified 5 additional citations. Eighteen studies with 401 participants were included in this systematic review of qualitative studies. Each publication explored slightly different aspects of patients’ experiences with variations of legally mandated treatment. Seventeen of the included studies used interviews and one used a questionnaire to evaluate patients’ experiences. All studies, except for one, were rated as high quality. Results were categorized under the two broad themes of positive and negative patient experiences. Patients were satisfied when their autonomy was respected, and dissatisfied when it was not. Patients often recognized that their treatment was beneficial, but also disliked a lack of communication and information regarding their treatment.

Significance: Undergoing legally mandated treatment is a complex and variable process. Research has traditionally focussed on clinical and quantitative treatment outcomes. Thus, this study provides insight into the qualitative aspects of patients’ experiences with legally mandated treatment. Recognizing these opinions and experiences can lead to better attitudes towards treatment for patients with schizophrenia and other psychiatric illnesses. Understanding patients’ experiences may improve patient-provider relationships and lead to increased treatment compliance, and as a result, better treatment outcomes.

Author Names: Joanne Plahouras; Shobha Mehta; Daniel Buchman, University Health network; George Foussias; Daniel Blumberger; Jeff Daskalakis
Deconstructing the relationship between free will and addiction: A systematic review on tools assessing voluntariness
Ms. Marianne Rochette, Pragmatic Health Ethics Research Unit

Abstract Category: Poster Presentations

Three Valuable Questions:
1. Are there overlaps between the constructs that were characterized in this study?
2. Might there be theoretical overlaps that differ from the empirical overlaps?
3. What interesting findings about voluntariness emerged from the study?

Abstract: Scholars in different disciplines have debated whether individuals with an addiction are capable of making free decisions about their substance of use. Several scholars have described addiction as a “disease of the mind”, which raises questions about the state of one’s decision making abilities in the context of addiction. The literature on this topic is divided into different research paradigms based on construct, operationalization and scales. The aim of our study was to capture the most important features of the different scales and constructs assessing voluntariness in the addiction empirical research. To address this goal, through a systematic search, we identified and reviewed psychometric scales that have been used to characterize decision making in an addiction context. Using a scoping review methodology, Medline and PsycInfo databases were searched using 16 volition-related constructs as keywords (for example, voluntariness, self-efficacy, impulsivity and self-restraint) and drug use-related terms as subject headings (for example, addictive behavior and opioid-related disorders). From the articles gleaned, we examined the conceptual and methodological limitations of the scales and assessed the scope of the scale dimensions of each constructs. We observed that some constructs were absent from the literature: compulsion, choice behavior, willpower, among others. We present a synopsis of the major findings of our review and describe the data extraction strategy employed.

Author Names: Marianne Rochette, Pragmatic Health Ethics Research Unit; Claudia Barned, Centre for Clinical Ethics - Unity Health Toronto; Eric Racine, Pragmatic Health Ethics Research Unit, Institut de recherches cliniques de Montréal
Speech-Language Pathologists’ Experience of Moral Distress: By narrowing the scope, can we identify prevention strategies?
Ms. Stephanie Somers, London Health Sciences Centre

Abstract Category: Poster Presentations

Three Valuable Questions:
1. Do the survey results demonstrate a difference in the experience of moral distress between acute care speech-language pathologists and other healthcare providers?

2. How have the survey results informed individual clinician practice and organizational change?

3. Do preventative and coping strategies common amongst the nursing profession apply to acute care speech-language pathologists?

Abstract: Background:

Acute care speech-language pathologists (SLPs) are experts in the neuroanatomy and physiology of communication and swallowing. We are skilled in the assessment, diagnosis, and intervention of acquired speech, language, voice and swallowing disorders. SLPs providing services to the adult neurogenic population in an acute care setting routinely evaluate and treat patients with communication and swallowing disorders resulting from stroke, traumatic brain injury, brain tumors and neurodegenerative diseases. As clinicians, we frequently convey upsetting news pertaining to patients’ communication and swallowing diagnoses and prognoses and are often required to prescribe strict texture recommendations or advise nil per os (NPO) in the setting of significant risk for aspiration. Patients and their families look to the SLP for clinical guidance on their swallowing function and safety, and in turn SLPs are expected to provide timely, evidence-based and individualized management plans. In situations where SLPs are routinely unable to provide their patients with timely, efficacious care as the result of socioeconomic, institutional constraints, the end result can be moral distress.

This presentation will describe the incidence and impact of moral distress on speech-language pathologists at an acute care teaching hospital in southwestern Ontario, a practice area that has been under-reported in the literature. This data will be followed with a brief review of common recommendations to staff experiencing moral distress, suggesting where these fail to address the common scenarios identified by SLPs. Finally, acknowledging that moral distress in the hospital setting is unavoidable, this presentation will consider how honing in on very specific case scenarios may in fact lead to better prevention strategies.

Methods:

To identify the incidence of moral distress and its individual and institutional impact, a 10-question pilot survey was developed and disseminated to the SLP department, as well as the front-line staff at large, on our 59-bed inpatient Clinical Neurosciences Unit in the summer of 2018.

Results:

Of the 170 staff who received the electronic survey, 66 responded and more than 25% of the respondents were SLPs. Staff reported experiencing moral distress at a rate of every few months when a perceived unethical decision was made, often related to institutional conflict (73%), end of life decisions (65%), and time pressure (63.5%). The impact of frequent moral distress was varied, including poor quality of sleep (54%) and mental health (50%).

Conclusion:

These results deepen our understanding of the prevalence and impact of moral distress on healthcare workers, and contribute to our awareness of its influence on the profession of SLP, especially. Data was as well used to inform a larger, organization-wide survey, and provide strategies to identify, mitigate and better cope with moral distress moving forward.

Author Names: Stephanie Somers, London Health Sciences Centre
Improving Equity for Hospitalized People who Inject Drugs by Supporting Harm Reduction and Transitions to Community
Ms. Karen Throndson, Winnipeg Regional Health Authority

Abstract Category: Poster Presentations

Three Valuable Questions:
1. What barriers did you encounter with this project?

2. How have staff responded to utilizing harm reduction approaches in hospital?

3. How do you deal with health care providers that support abstinence as the only option for patients?

Abstract: Ongoing pressures for intensive care beds and futility of care have contributed to tensions within our organization regarding optimal treatment for people who inject drugs. Increasing episodes of violence towards staff have acted as a catalyst for policies, strategies and initiatives to ensure staff safety; however, these actions have additionally limited visitation and patient movement. These actions have further emphasized “otherness” and fostered stigma and harm towards people who inject drugs. In an effort to bridge the gap between staff and patients and recognizing the less than optimal hospital experience the Bridge to Home Project was developed to promote improved provider/patient relations while at the same time working to optimize addiction care and treatment. This poster presentation aims to share our learnings and tools from project and hospital initiatives aimed at improving the patient journey.

Our project targeted multiple areas for improvement including a Guideline of Care for Patients Who Use Substances and a subsequent harm reduction pilot in which patients can receive injection materials to ensure access to clean supplies. Educational sessions for staff to help facilitate therapeutic conversions with appropriate tools and language to support a Harm Reduction approach. We also partnered with the Addictions Foundation of Manitoba so that patients in hospital could access counselling services from addiction specialists and begin the conversion around harm reduction or treatment options.

In addition, patients hospitalized with an injection related infection are being interviewed following discharge to gain a better sense of discharge information, community supports, and programs that are needed for those leaving hospital in an effort to try to decrease re-admissions and promote harm reduction and/or treatment.

Marginalized populations such as people who inject drugs are vulnerable to poor health outcomes related to reluctance to seek medical attention related to stigma and discrimination. Improving the care experiences of people who inject drugs is imperative if we are to treat infections in a timely manner prior to the development of severe cardiac complications. With this patient population come challenging treatment decisions, but when care providers know supports and treatment can be accessed in the community decisions can be made more confidently and with greater emphasis on the patient’s goals and desires.

Author Names: Karen Throndson, Winnipeg Regional Health Authority; Katarina Lee-Ameduri, St. Boniface Hospital/University of Manitoba; Shelley Marshall, Winnipeg Regional Health Authority; Sarah Gilchrist, St. Boniface Hospital; Emily Hyde, St. Boniface Hospital; Jacqualynn Persona, Resource Assistance for Youth; Linda Lawson, Community IV Program; Brett Hiebert, St. Boniface Hospital; Leighton Knapp, St. Boniface Hospital; Karen Martin, City of Winnipeg; Rick Lees, Main Street Project; Erin Knight, Health Sciences Centre; Dave Grift, Addictions Foundation of Manitoba
The Competing Demands of Organizational vs Clinician Priority Intervention Criteria in an Acute Care Centre
Ms. Jeanne Webber, London Health Sciences Centre

Abstract Category: Poster Presentations

Abstract: Allied health care professionals including occupational therapists, physiotherapists, social workers, and speech language pathologists, are routinely tasked with prioritizing referrals based on organizational needs and program specific standards. Although some variation may present itself between professional groups, a consistent theme emerges prioritizing these organizational claims over clinician values and judgement. Access, flow, and timely patient discharge is consistently positioned as the first priority of allied health care professionals providing frontline care. Clinicians are faced with the conflict of accommodating a hierarchy of organizational needs at the expense of their clinical judgement.

Across disciplines, imminent patient discharge, budget constrictions and resource limitations are identified as central considerations, superseding clinicians’ capacity to assess patient need and provide timely, meaningful, and effective treatment. Clinician time and intervention may not be allocated to the patients who could most benefit from the intervention, but rather to the patient most likely to leave hospital as a result of intervention. Do these organizational standards allow opportunities for clinical and professional judgement or are these only theoretical concepts scarified to the demands of a government funded, national health care system? Does the need for timely access and flow supersede the professional values of the health care provider?

The determination of priority intervention criteria in acute care has been criticized as inefficient, intuitive and lacking evidence based, analytical approaches to intervention. Organizational and program specific tools have been developed with the goal of standardizing the way in which referrals are prioritized. However, these tools are often developed to address a single criteria or value in priority setting, such as resource allocation, patient access or budgetary constraints. Further these tools do not allow for clinical discretion and can lead to an experience of moral distress for the health professional whose values are subsumed to the overarching needs of the organization.

Using institutional ethnography as a tool to examine how the texts of priority intervention criteria setting, this paper will argue that a comprehensive approach to priority setting which allows for stakeholder participation and clinical judgement will mitigate the experience of moral distress of allied health professionals in acute care settings and imbed fairness and consistency into the priority setting process. Institutional ethnography seeks to investigate the connections between different levels of interactions; namely the everyday experiences of people in particular settings and across multiple sites; the organization of those settings and the translocal processes of administration, governance and control.

Author Names: Jeanne Webber, London Health Sciences Centre
Pre-Conference Workshops
Abstract Category: Preconference Workshops (June 3, 2020)
Primary Theme: AI and Ethics

Three Valuable Questions:
1) What are the ethical challenges and opportunities related to AI, ML, and precision medicine in paediatrics?
2) How are these challenges and opportunities the same or different than those presented by other health technologies?
3) How are these challenges and opportunities the same or different than those arising in adult care?

Abstract: The New Kids on the Block: Healthcare AI, Precision Medicine, & Paediatric Bioethics

Proponents of artificial intelligence (AI), machine learning (ML), and precision medicine (PM) all promise the delivery of better care for children but the technology is still novel and without a consistent framework for proper evaluation. When decisions about non-capable young people rely on us acting in their best interests, we have greater reason for caution and anticipation of potential ethical challenges.

Here we propose the 8th Annual Paediatric Bioethics Preconference Workshop focused on the theme of the main conference. This preconference workshop provides an invaluable opportunity to consider the conference theme through the lens of paediatrics – preparing attendees to bring the paediatric lens to discussions throughout the main conference.

This year’s theme focuses on novel technologies and the role of the bioethics community with respect to these technologies. Are we or should we be - activators, inhibitors, or facilitators with respect to AI, ML, and PM? Where are the best places for bioethics to be situated in the lifecycle of these technologies from their conceptualization, evaluation, to application? What are the familiar tools and frameworks we have at our disposal and what are the novel challenges we will have to unpack?

In this proposal, we describe this lifecycle from our vantage point at The Hospital for Sick Children (SickKids) where our institution has adopted these technologies as part of our strategic plan for clinical care hospital-wide. We will explore some of the ways in which we have engaged with the computer scientists, senior management, and clinical staff on these technologies. We hope to engage with attendees for any similar experiences they have with respect to novel technologies to explore opportunities for more broadly defining the role of paediatric bioethics.

This year, the proposed workshop will include three 45-minute didactic sessions instead of five in order to make more time for meaningful interaction between participants. The remaining time will be devoted to small group discussion focused on both the issues identified by speakers and issues identified by participants.

References

Learning objectives
1. Explore the ethical issues that arise in the context of AI, ML, and precision medicine from our vantage point at a hospital prioritizing these technologies in clinical care and research.
2. Identification and discussion of strategies for engaging or providing ethical context for novel technological applications in paediatrics.
3. Identify opportunities for collaboration with attendees – (research, scholarship, policy development, advocacy, consultation support).

Agenda (schedule can be adjusted to the normal 3 hour time slot if necessary):
8:30-8:45: Welcome and introducing the pre-conference workshop – Randi Zlotnik Shaul
8:45-9:00: Artificial Intelligence, Machine Learning, Precision Medicine 101 - Melissa McCradden
9:00-9:35: Bias and values in AI: what’s new, what’s not – James Anderson
9:35-9:45: Questions
9:45-10:40: Clinical actionability: the motivation for applying machine learning in paediatric care - Mjaye Mazwi, Roxanne Kirsch, Mary Campbell, Lauren Chad
10:40-10:50: Questions
10:50-11:30: Precision medicine and decision-making in paediatrics – Melissa McCradden
11:30-12:00: Questions, opportunities for collaboration and wrap-up - Randi Zlotnik Shaul

Author Names: James Anderson, The Hospital for Sick Children; Mary Campbell, The Hospital for Sick Children; Lauren Chad, The Hospital for Sick Children; Roxanne Kirsch, Department of Critical Care Medicine, the Hospital for Sick Children; Department of
Formation des professionnels de la santé en décision partagée basée sur des pratiques réflexives, une réponse aux enjeux éthiques en rapport avec les technologies de l'information en santé

Mrs. Ndeye Diouf, Canada Research Chair in Shared Decision Making and Knowledge Translation

Abstract Category: Preconference Workshops (June 3, 2020)
Primary Theme: Public health ethics

Three Valuable Questions:
1. quels sont les types d’acteurs qui seront impliqués dans le développement d’une telle formation?
2. Connaissiez-vous des projets développés dans d’autres pays et qui pourraient vous inspirer?
3. Quel est l’ancrage éthique que vous allez promouvoir dans la diffusion des connaissances issues de ce projet, en lien avec les TIC?

Abstract: L’autonomie du patient dans le continuum de soins est fortement encouragée dans les systèmes actuels de santé. Les technologies de l’information et de la communication (TIC) devraient jouer un rôle important dans cette dynamique d’autonomisation du patient. En effet, les TIC facilitent l’ouverture d’un espace de discussion entre les patients mais surtout entre eux et les professionnels de la santé. Si elles sont bien encadrées, les TIC peuvent contribuer au désengorgement des urgences et à la réduction des coûts en santé. Néanmoins, la santé numérique pourrait conduire à divers contrastes. Par exemple, au lieu de faciliter une démocratie sanitaire, elle pourrait entrainer des effets non désirables dans les rapports de soins. Cela dit, qu’on perçoive cette évolution comme indispensable ou contraignante, il n’en demeure pas moins qu’elle soulève de vastes questions d’éthiques liés aux enjeux sociaux et juridiques de pratique ou de politiques, autour de ce que signifie être un patient. Ainsi, l’encadrement de l’utilisation croissante des TIC dans le domaine de la santé devrait tenir compte des dites questions de sorte à offrir au patient des soins qui répondent à ses attentes, et ceci dans sa plus grande dignité. C’est dans cette logique que notre équipe de recherche s’est penchée sur la valorisation de la prise de décision partagée (PDP) dans les pratiques en santé. La PDP est un processus dans lequel un professionnel de la santé et un patient s’engagent dans une dynamique d’exploration des différentes options qui permettent de prendre une décision éclairée en lien avec la santé. Ces options, quelle que soit la source d’information, devraient être basées sur des données probantes. L’importance de la PDP dans le rapport de soins entre les patients et les professionnels de la santé n’est plus à prouver. Cependant, des limites de différentes natures persistent dans son implantation. Par exemple, le regard du professionnel de la santé sur le patient, essentiellement guidé par l’idée selon laquelle sa condition de santé est source de vulnérabilité physique et sociale ne permet pas de considérer ce dernier comme un partenaire de soins à part entière. Ce qui entraine la non prise en considération du patient comme un être social, doué d’intelligence et apte à prendre soin de son existence. Face à cette conception, les interventions en santé s’ancrent dans une vision biomédicale, laissant en rade les facteurs sociaux, politiques et éthiques. Cela expliquerait pourquoi la dynamique de soins s’opère jusque-là dans un rapport essentiellement paternaliste. Or, l’exposition croissante du patient à d’autres sources d’information telles que l’espace numérique favorise le développement de son expertise et de son autonomie. Ce qui pourrait déclencher des rapports conflictuels avec certains professionnels de la santé qui voient leur autorité menacée. En plus, le partage de l’information par l’ère numérique faciliterait la surinformation et par conséquent la mésinformation en santé. Pour faire face à ces limites, nous suggérons que la PDP soit implantée dans une dynamique qui favorise à la fois le développement des compétences du patient et la gestion des enjeux liés à la surinformation qui nuisent à la qualité des soins. La réflexivité est grandement utilisée dans des interventions comme les formations en santé. Elle est un processus métacognitif qui se produit avant, durant et après des situations, qui crée une meilleure compréhension de soi-même et des situations de sorte que les rencontres futures soient mieux orientées. Une formation en PDP basées sur des pratiques réflexives permettrait aux professionnels de la santé de mieux appréhender les changements qui s’opèrent dans leurs milieux de pratique, de questionner leur jugement face aux patients et d’adapter leurs interventions. Nous examinerons le rôle des pratiques de soins sous cet angle concret, normatif et pédagogiques en polarisant notre attention sur la complexité du processus de création de nouveaux rôles pour le patient. Notre projet est implanté dans les organisations de soins de santé et services de première ligne au Québec qui fournissent le premier point d'accès au système de santé, des soins pour la plupart des problèmes de santé, une continuité et la coordination des soins fournis par tous les niveaux. Le projet est développé à travers une approche d’application des connaissances intégrée qui nécessite une participation significative des utilisateurs des connaissances (ex. patients et professionnels de la santé). Ce qui donne sens à notre projet d’organiser un atelier lors de ce congrès en bioéthique. Un atelier qui sera développé selon un processus récursif facilitant un va et vient entre les différentes étapes de réflexion sur le projet en vue de réadapter les actions prises. En effet, cet atelier permettra de partager avec les participants de nouvelles stratégies qui permettent d’ouvrir une perspective de valorisation du savoir expérimental du patient dans l’offre de soins tout en tenant compte des enjeux actuels induits par les avancées technologiques qui entourent les pratiques en santé. Plus spécifiquement, au sortir de cet atelier, les participants seront en mesure de 1. Cerner les enjeux de l’implantation d’approches centrées sur le patient telle que la PDP dans l’ère actuelle du développement des TIC en santé; 2. Comprendre comment l’introduction des pratiques réflexives dans la formation des professionnels de la santé pourrait être un moyen de prendre en charge les considérations éthiques, sociales et politiques qui entourent les offres de soins actuelles et 3. se familiariser avec des stratégies qui permettent de développer des approches intégrées d’application de connaissance en santé.

L’atelier se tiendra selon l’agenda suivant :
Présentation des participants : 15 mn
Présentation des objectifs pédagogiques : 5 mn
Présentation du projet : 35 mn
Ouverture d’une première série de questions, ouverture au partage d’expériences avec les participants : par exemple dans le cadre de projets similaires : 20 mn
Pause : 15 mn
Présentation d’un exercice réflexif sur la stratégie de mise en œuvre : 5 mn
Réflexion de groupe sur la stratégie (y compris l’identification de barrières et facilitants de l’implantation d’un tel projet (support de travail selon les initiatives du groupe) : 30 mn
Plénière et ouverture à d’autres questions : 40 mn
Synthèse et conclusion : 15 mn

Author Names: Ndeye Diouf, Canada Research Chair in Shared Decision Making and Knowledge Translation
Standard Concurrent Sessions
If we can, you must: evidence, bias, and moral legitimacy in paediatric care
Dr. James Anderson, The Hospital for Sick Children

Abstract Category: Standard Concurrent Session
Primary Theme: Other Ethics and the philosophy of medicine

Three Valuable Questions:
1) What is the relationship between epistemic authority and moral authority in paediatrics?

2) What is an example of contextual bias undermining evidentiary justification in health care?

3) Can you give examples of scientism, dualism, and elitism in medicine?

Abstract: Capable adults may refuse treatment, even when it is contrary to their best interests. A substitute decision maker may refuse treatment on behalf of an incapable adult that would otherwise be in their best interests if they have previously (and capably) indicated they do not want such treatment. In paediatric care involving incapable children, by contrast, it is impermissible for parents to make such decisions; some treatments are morally obligatory. Very young people (e.g., neonates) lack prior capable wishes, values, or preferences related to medical care. Decisions, thus, are dictated by the best interests standard.

The best interests standard is indexed to clinical criteria: prognosis with or without treatment, and the effectiveness of the treatment proposed. But arguments based on these criteria are only as strong as their evidentiary base. In situations where clinicians and parents disagree about the plan of care for an incapable child, discretion is largely a function of the quality of the available evidence: when it is low, parental discretion is high; when it is high, parental discretion is low. Epistemic authority translates directly into moral authority.

But evidential quality varies enormously across health care. Some conditions are the focus of intensive research efforts, others languish in relative obscurity. Some clinical specialities are well supported by research funding, others are not. Some groups of people are well studied, while others are excluded or ignored. This variability itself varies over time. Some of this variation is best explained by factors outside human control (e.g., some conditions continue to elude our best efforts at understanding and intervention). But some of it is best explained by contextual bias that shapes discovery: general social biases like sexism, racism, and ageism; and biases particular to medicine like scientism, dualism, and elitism.

Bias in the ‘context of discovery’ can undermine evidential justification. Since the moral authority of clinicians is based in large part on epistemic authority derived from the evidentiary basis of their recommendations, bias also undermines the moral authority of medical judgment. This is of particular concern in paediatrics where, as explained above, epistemic authority often translates directly into moral authority. Bias, perceived or actual, threatens to undermine trust in medicine in general, and in paediatrics in particular.

In this presentation, I will explore these issues through the lens of a fictional case involving a neonate. I will show how different sorts of bias in the context of discovery work to undermine the quality of evidence supporting treatment recommendations or illegitimately foreclose options that would otherwise be available to parents and their children. I will conclude by calling for efforts to bolster the moral legitimacy of clinical science. On the one hand, we must acknowledge the effects of bias and work to minimize their effects. On the other hand, recognizing that bias will always be with us, we must develop procedural (e.g., transparency about bias during consent) and political solutions (e.g., stakeholder engagement) that will mitigate its worst effects.

Author Names: James Anderson, The Hospital for Sick Children
Adapting and Implementing the Serious Illness Care Program in the Hospital Setting: Surprises, Successes & Challenges
Ms. Sandra Andreychuk, Hamilton Health Sciences

Abstract Category: Standard Concurrent Session
Primary Theme: Other Ethics and Quality Improvement / communication

Three Valuable Questions:
How does this method of communication differ from the traditional way of communicating with patients and families?
How do you know that patient feel more prepared to engage in conversations with their health care providers?
How to you sustain this way of communicating in a busy acute care unit when clinician time is so limited?

Abstract: As a person enters into the final phase of their life there is a risk that they may lose their ability to participate in care planning. Too often, discussions about goals of care with patients who have serious illness (or with their families) happen days, or sometimes only hours, before death. As a result, patients who have life-limiting illness may not receive goal-consistent care in the final months or years of life. The aim of the Serious Illness Care Program (SICP) is to achieve more and better conversations about goals of care with patients who have serious illness, and to start these conversations earlier in their illness trajectory. This program was developed for use in the ambulatory care setting, and has was adopted to the acute care setting, tested for feasibility and evaluated to determine if it improve patient clinician conversations leading to the creation of a care plan that aligned with patient health preferences. This early communication strategy offers patients an opportunity to explore their goals, fears and worries, sources of strength, critical abilities, tradeoffs and family supports. Early integration or high quality conversations can result in a person’s ability to maintain their autonomy, even if they lose their ability to speak on their own behalf.

Sharing of information gives health care professionals a deeper understanding of the human side of a person versus the disease which brought them into hospital. Through this collaborative approach of information sharing health care professionals can recommend care plans which align with patient health preferences, taking the guess work out of care planning when critical decision-making is required. Research has also shown that early conversations about goals of care are associated with: enhanced goal-concordant care; improved quality of life; higher patient satisfaction; better patient and family coping; eased burden of decision-making for families; more and earlier hospice care; fewer hospitalization; and improved bereavement outcomes.

This presentation present data from the feasibility study and explore the experience of an inter-professional team who has undertaken a quality improvement initiative to adapt and implement the SICP on a Medicine and Intensive Care Unit at an acute care centre. The learning Objective is to understand the surprises, successes and challenges experienced when adapting and implementing value based conversations with critically ill patients and their substitute decision makers within the hospital setting.

Author Names: Sandra Andreychuk, Hamilton Health Sciences; Marilyn Swinton, McMaster University; John You, McMaster University
Responding to Preferences for Indefinite Intensive Care
Dr. Kyle Anstey, Alberta Health Services

Abstract Category: Standard Concurrent Session
Primary Theme: Theories and methodology in bioethics

Three Valuable Questions:
1. How are ethical analyses of futility in intensive care prone to qualitative bias?
2. What are shortcomings of ethical analyses that do not give appropriate moral consideration to quantitative judgements?
3. How can ethical analysis accommodate quantitative considerations related to patient trajectory?

Abstract: Substitute Decision-makers sometimes wish patients to be subject to indefinite intensive care admissions despite the medical team’s judgment that such treatment is almost certainly of no benefit to the patient. Related disputes are increasingly heard by courts and health profession tribunals, and often the subject of clinical ethics consultations. While clinical ethicists can play an important role in clarifying related ethical issues including quantitative and qualitative futility, I argue that ethics analyses tend to be qualitatively biased in a way that may inappropriately limit their recommendations for managing these difficult cases. These biases often stem from legitimate concerns about displacing normative discourse with statistically-derived empirical evidence. However, there remains a need to give appropriate moral consideration to medical judgement about the patient’s critical care trajectory. When issues are combined together, there may remain an irreversible downward trajectory in which the patient’s physiological ability to survive outside ICU can no longer be achieved. Related medical judgments need not be about whether the interventions are worth it, but whether they work. A failure to incorporate these quantitative considerations in ethical analysis encourages “slow” plans of treatment at the decision-maker’s insistence. These plans over-emphasize immediate point-in-time interventions without regard to judgements about the trajectory and the patient outcomes at the end of the slope. There needs to be continued debate about appropriate primary outcome measures. However the primary outcomes are defined, ICU treatment is the means to achieve them, not the end itself.

Author Names: Kyle Anstey, Alberta Health Services
Artificial Intelligence in Assisted Reproductive Technologies
Ms. Marisa Araújo, Lusíada University - North (Porto)

Abstract Category: Standard Concurrent Session
Primary Theme: Ethics, perinatality and procreation

Three Valuable Questions:
1. The potential of AI in ART?
2. Ethical issues that AI arises in ART?
3. Guidelines to offer an ethical framework that can guide the use of AI in ART?

Abstract: After millions of years of human evolution, modern biotechnology provides us the tools to "control" the being of our children. Biotechnological solutions are changing the way in which people understand fertility, parenthood, reproduction and, at the end, family.

The "old" family stereotype lost the monopoly of the creation of familiar relations and new families emerge through laboratory within scientific dynamics.

The increasing diversity of family forms has, now, a new cycle related to (Michel Foucault’s) “biopower”. Test tube families are, more than ever, a growing reality in a new biotechnological era and new ethical and legal issues arise considering the different ART solutions and the new tools of AI. There is a need to establish "repronational” strategies and frameworks, since it has a direct influence in our, and next generations’, private lives, and in the community and the society we are building.

Also, the need to adapt the world in accelerated transformation, improve each person’s characteristics to better adjust to new and more extreme environmental conditions, ensuring an improved quality of life, enhancing the opportunities that may reasonably aspire including in a future society where humans are co-inhabiting with the beings of AI.

We are at the absolute threshold of human creation so, therefore, this is a moment of distress, and the shift from human nature to post-human nature, as Buchanan puts it. It is essential a balanced composition of the conflicting interests in this frontier debate where human nature and human dignity lay at risk. Human rights have a direct impact in this matter increasing the complexities of the issue.

Hubin talks about the principle, he called, the “Responsibility for Dependent Life”, and, in the global arena where we now stand, the issues related to cross-border ethical-legal issues are increasing and reaching out for areas typically related to domestic interest.

The future is today and, quoting Hawking “our future is a race between the growing power of our technology and the wisdom to use it”.

We have analysed the different AI intelligence tools in the biotechnological solutions science provides to reproduction and some of the different ethical and legal issues that they arise in a new comprehension of fertility, and, at the end, family, delivered by AI tools.

Author Names: Marisa Araújo, Lusíada University - North (Porto)
CREATING FAMILIES IN LABORATORY: BIOETHICAL LIMITS
Ms. Marisa Araújo, Lusíada University - North (Porto)

Abstract Category: Standard Concurrent Session
Primary Theme: Ethics, perinatality and procreation

Three Valuable Questions:
1. The concept of family.
2. "Reprogenetics" autonomy vs. identity.

Abstract: The increasing diversity of family forms has, now, a new cycle related to (Michel Foucault’s) biopower. Test tube families are, more than ever, a growing reality in a new biotechnological era.

Biotechnological solutions, based in a consumer-relation, are changing the way in which people understand fertility, parenthood, reproduction and, at the end, family. The old stereotype lost the monopoly of the creation of familiar relations and new families emerge through laboratory.

Within scientific dynamics, human gametes, embryos, enhancement procedures, surrogates are in the global market, and not confined within the frontiers of one State. The different legal solutions that each country provides to ART intensify the “fertility tourism” around the globe, it produces children whose legal status, and citizenship may be uncertain, and (can) create a (human) commoditization in this new bio-contracts.

Parent-child relationships are closely connected with personhood, particularly with personal identity. However, in this new parameter how do we recognize and validate the identities of people and families formed through emerging technologies? In addition, if, in doing so, we change our core definitions of family. What is a mother? What is a father? What does it mean to be a human?

The aim of our work is to set the ethical and legal criteria to, considering the different ART solutions, establish repronational strategies and frameworks.

Author Names: Marisa Araújo, Lusíada University - North (Porto)
Is Community Benefit Enough to Avoid Exploitation in Big Data Research?
Dr. Fareed Awan, McGill University

Abstract Category: Standard Concurrent Session
Primary Theme: Research Ethics

Three Valuable Questions:
Is the Community Benefit Model better than other alternatives?
Given a relational view of exploitation, what sort of framework would avoid exploitation in big data research?

Abstract: Recently, McCoy, Joffe, and Emanuel have argued that exploitation is a central ethical challenge of big data research, because concerns about privacy and consent fail to address the wider outcomes of data sharing. The value of extensive patient data to private and public interests is significant, both for health outcomes and financial reasons. One serious ethical challenge raised by the prospect of patient data sharing is exploitation. Exploitation is frequently regarded as a problem of unfair distribution, where one party benefits unfairly over another.

Given that such sharing is increasingly common, McCoy et al. argue that the proper balance between the potential promise and possible ill-effects of big data research is a framework that explicitly avoid exploitative outcomes. Their Community Benefit Model of fair allocation purports to be an anti-exploitation mechanism which would give community stewards authority to take in benefits (primarily monetary benefits) and distribute them in a way that achieves a fair outcome.

The Community Benefit Model is promising, but limited given another compelling interpretation of exploitation. An alternative to distributional accounts of exploitation treat exploitation as a feature of unequal relationships, where one party instrumentalizes this inequality for benefit. From this perspective, the Community Benefit Model raises three serious issues. First, the authority of community stewards to receive benefits on behalf of individuals is problematic. How to legitimately identify the scope of the community is difficult: possible solutions are arbitrary, vague, or ethically suspect. Second, there is the problem of reciprocity, given that stewards working for community benefit might work in opposition to those whose data is shared. The Community Benefit Model might expropriate individuals’ data as a community resource. And finally, there is a systemic objection. Given that large and powerful interests are the ones doing the data sharing, shifting the distributional concerns about exploitation to stewards and away from powerful interests, governmental authority, and individual interests. Taking exploitation as primarily distributional and not relational obscures the problems of authority, reciprocity, and the systemic objection. A relational view of exploitation clarifies the difficulties involved in avoiding exploitation in big data research.

Author Names: Fareed Awan, McGill University
Hope and the Wish to Die
Mrs. Ariane Bakhtiar, York University

Abstract Category: Standard Concurrent Session
Primary Theme: Theories and methodology in bioethics

Three Valuable Questions:
Can your novel notion of deliberative hopelessness be applied to cases of palliative care and medical assistance in dying? If deliberative hopelessness can be transformed into hopefulness through a narrative process, is the goal to treat the patient who wishes to die? What are the limitations of the MacCAT for determining competency?

Abstract: Should we be giving the depressed access to medical assistance in dying (MAiD)? Does that not seem counterintuitive given that suicidality is a central feature of the psychopathology of depression? Even following the legalization and growing acceptance of MAiD for those with incurable and unbearable physiological ailments in Canada, the question of assisted suicide and mental illness remains controversial and provocative. This paper defends the position that allowing MAiD for the mentally ill is justified because some people who experience hopelessness as a result of grievous and irremediable major depressive disorder are competent. However, given that hopelessness is also a notable feature of depression, this project differentiates multiple forms. After all, it could be said that the hopeless, suicidally depressed person is not expressing a genuine wish to die, it is their “depression talking” and, as such, the wish to die ought to be disregarded insofar as it is evidence of compromised decision-making capacity (the medical assessment of capacity determines mental competency needed for MAiD). Thus, an assessor in capacity in MAiD cases should be able to differentiate depressive hopelessness, which is a symptom of depression, from “deliberative hopelessness”, which is a rational response to the verifiable irremediability of an illness causing grievous suffering. In doing so, the assessor can determine that some depressed persons are competent and that their wish to die ought to be considered seriously.

To demonstrate that individuals with irremediable and grievous depression are competent, this paper explores the novel concept of deliberative hopelessness which builds on the standard assessment tool for capacity known as the Macarthur Competency Assessment Tool (MacCAT). Deliberative hopelessness is an indicator for capacity insofar as the depressed person experiences hopelessness as a result of reflecting on the reality that they have tried and failed various treatments for a considerable amount of time and can no longer bear the burden of their suffering. It is not hopelessly “giving up” common in depressive thinking, but a reasonable acceptance of facts regarding one’s condition. The challenge is that the capacity assessor must be able to differentiate pathological hopelessness from deliberative hopelessness. Given that acknowledging and listening to a competent depressed person’s story will help them regain hopefulness because their wish to die is taken seriously, considering a patient’s biography in capacity assessments may be helpful for distinguishing forms of hopelessness. That is, once deliberative hopelessness becomes an experience of hope in the patient who is considered for MAiD, it becomes a simpler task for the capacity assessor to differentiate hopelessness as a reasonable response to the burden of suffering and hopelessness as symptom. The reason, only deliberative hopelessness can be positively influenced by the narrative process. Indeed, hopelessness related to symptomology like depressive hopelessness can become worse when a patient is given access to MAiD. Thus, deliberative hopelessness is a strong indicator for capacity if it can transform into hopefulness. This is not hopefulness as blind optimism but as courage felt toward the undeniable reality of their mental illness and wish to die.

Author Names: Ariane Bakhtiar, York University
Abstract Category: Standard Concurrent Session
Primary Theme: Public health ethics

Three Valuable Questions:
1. What are the dominant discourses used amongst substance use treatment providers when talking about the legalization of cannabis in Canada?
2. Has legalization significantly impacted those with lived experience of addiction?
3. How can bioethicists mobilize findings about stakeholder perceptions about the legalization of cannabis?

Abstract: Since the passing and implementation of Bill C-45 in Canada, researchers have sought to understand the perceptions of cannabis use, its short term and long-term effects, among other ethical, legal and social impacts. Despite this renewed effort to understand all things cannabis, few studies have explored how people perceive the legalization of cannabis, and the impact it may have. This study examines the perceptions of two stakeholder groups: those with lived experience of addiction, and addiction clinicians/substance use treatment providers. Thirty-two semi-structured in-depth interviews were conducted amongst these two groups; 16 substance use treatment providers from Quebec and 16 people from Ontario, Quebec and British Columbia with lived experience of addiction shared their perspectives. Themes related to legalization as being overdue, as an avenue for the economy to grow, as having no impact on use or accessibility were salient among those with lived experience, and themes related to harm reduction, substance and retail regulation, and a lack of proper educational and public health messaging prior to legalization were prominent amongst substance use treatment providers. Overall, core themes related to legalization as a political agenda, as an avenue to normalize cannabis use, as a more useful system than criminalization, and as a false signal that cannabis is benign were raised. Research aimed at better understanding the perceptions and experiences of those directly impacted by the legalization of cannabis (e.g. health professionals and cannabis users) may improve cannabis misuse prevention efforts and inform policy decisions as we begin to understand more about the health and social effects of cannabis use.

Author Names: Claudia Barned, Centre for Clinical Ethics - Unity Health Toronto; Eric Racine, Pragmatic Health Ethics Research Unit, Institut de recherches cliniques de Montréal
Abstract Category: Standard Concurrent Session  
Primary Theme: AI and Ethics

Three Valuable Questions:
1) What types of protocols including AI might an REB review?

2) What are the existing methods and recommendations for REBs reviewing a biomedical research protocol including AI?

3) What are transferable lessons from non-health related AI applications that might be relevant?

Abstract: Artificial Intelligence (AI) is the ability of computers to mimic specific aspects of intelligent human behavior such as problem-solving, reasoning, and recognition. AI applications in healthcare are under rapid development. For example, in 2018 the Food and Drug Administration approved the first AI clinical algorithms to aid in clinical decision-making involving the diagnosis of diabetic retinopathy and wrist fractures. In these two examples, AI applications supplement rather than replace clinical judgment.

Ethicists, particularly those working in academic teaching hospitals, often sit on institutional Research Ethics Boards (REBs). Given the rapid development of AI technologies through relatively new intersections between biomedical research and the technology industry, REBs must be prepared to provide research ethics review for research submissions including AI. Existing methods may be insufficient to provide sufficient oversight. Indeed, regulating bodies in both the US and Canada are developing specific regulatory processes for certain types of AI health technologies.

In a report issued in 2018 by the Wellcome Trust on the Ethical, Societal & Political Challenges of AI in Health outlined the following 5 types of use cases for AI: 1. process optimization 2. pre-clinical research 3. clinical pathways (e.g. algorithms) 4. patient facing applications (e.g. smart homes and robotics) and 5. population level applications. Of these 5 types of use cases, nearly all could fall under the auspices of an REB at varying governance levels.

The majority of AI-related ethics guidance documents to date have outlined recommended principles that should guide decision-making around AI applications. However, there is little concrete information on how to operationalize these principles, particularly within the research ethics context. The aim in this presentation is to share the results of a scoping review to summarize the range of existing ethics-based approaches for assessing AI clinical applications and augment extant work to provide robust recommendations to REBs on reviewing biomedical research protocols that include AI.

Author Names: Sally Bean, Sunnybrook Health Sciences Centre; Blair Henry
AI-Powered Domotics and Gerontechnology for Supporting Seniors’ Independent Living: How New Monitoring-Based Technologies Can Help with Capacity Assessment While Protecting Privacy
Dr. Jean-Christophe Bélisle-Pipon, Harvard Law School

Abstract Category: Standard Concurrent Session
Primary Theme: Ethics and health technology assessment

Three Valuable Questions:
• How can we balance the infringements of privacy through gerontechnologies with the (more traditional and current) ones in long-term care facilities?
• Other than legal capacity assessment, could you provide other examples of direct benefits for seniors?
• Are high-tech solutions really necessary to respond to seniors’ needs in terms of autonomy and dignity?

Abstract: Canada’s population is not getting younger. Seniors now outnumber children (5.9 million seniors versus 5.8 million aged 14 or younger). This has a major impact on government priorities and actions to maintain seniors active and capable of living independently at home. Besides the high costs of long-term housing and care, living at home is associated with better quality of life, greater satisfaction and sense of dignity. Unfortunately, Canada’s record on home care services is weak. The advent of new home-based technologies powered by artificial intelligence (AI) can be salvific to support senior’s life when their capabilities decline. It is only a matter of time before health technology assessment (HTA) agencies are tasked with routinely evaluating the deployment within the healthcare system of these types of domotics (AI-based and robotic technologies to support home activities) and gerontechnology (elders-specific assistive technologies). These home-based intelligent solutions can help slow down age-related decline as well as remotely monitor and help manage care chronicity and continuity of living at home. In addition to assessing clinical benefits and cost-effectiveness, HTA must include a broad understanding of the ethical, legal and social implications. One of them being that gerontechnologies might provide to courts pivotal data for better assessing capacity. Decline in capacity looms large over seniors. This represents an important milestone in a person’s life. Once passed, it often signifies the end of independent living and the need to be legally represented for some or all decisions concerning one’s person and/or property. Be it through sensors, robotic pets, telemedicine and all the wonders of the Internet of things, the collection, use and disclosure of personal data by third parties could also help capacity assessors. These clinicians and social workers would greatly benefit from having a more comprehensive understanding of a person’s behavior. For instance, data may indicate that technological support allows a senior to remain autonomous even with declining faculties, thereby sometimes eliminating the need for legal protection. However, seniors may experience important privacy and intimacy intrusions, far greater than what they would undergo under current capacity assessments (seniors are not yet daily tracked from their beds to the kitchen and bathroom). New monitoring-based technologies pervading seniors’ home environments might very well help maintain their independence with regards to everyday activities and be cost-effective for public and private insurers, however we call for greater critical examination of these data-intensive intelligent systems. Both HTA agencies and courts have a role to play in developing acceptable limitations to privacy (i.e., avoid unduly collecting and sharing sensitive information). The former must consider and monitor the full range of privacy implications in authorizing and recommending data-intensive intelligent gerontechnology solutions. The latter must be prepared to interpret these data to support the ability to live independently, value all spheres of residual autonomy and make sure that this new stewardship is in individuals’ interest. We stress that, for fulfilling the full promises of domotics-based gerontechnology, respect for seniors’ dignity and rights is essential.

Author Names: Jean-Christophe Bélisle-Pipon, Harvard Law School; Anne-Isabelle Cloutier, McGill; Louise Ringuette, Université de Montréal
AIship, Artificial Intelligence, Arts and Bioethics. An Art/Science Exhibition to Interest the General Public on the Relational, Identity and Affective Dimensions of AI in Health
Dr. Jean-Christophe Bélisle-Pipon, Harvard Law School

Abstract Category: Standard Concurrent Session
Primary Theme: AI and Ethics

Three Valuable Questions:
1. How can such project help unravel and engage the public in reflecting on complex issues, like AI, to the general public?
2. What did the work of the duos allow us to explore?
3. What can a multidisciplinary approach bring to the ethical gaze on AI? What are your lessons learned? Are there best practices to follow and pitfalls to avoid?

Abstract: The increasing introduction of artificial intelligence (AI) technologies in healthcare is anticipated to transform the basic notions of caring, treating, diagnosing, and curing. This looming impact deserves a deeper focus as AI technologies are becoming more autonomous and are spreading at a very fast pace into the healthcare system (e.g., carerobots, intelligent care management tools, expert systems diagnosis, precision medicine interventions). As scholarship develops on these issues, there is a need to engage the public in reflecting on them because of the larger repercussions on society as a whole, in affecting peoples’ identities, relationships, and care experiences. While many citizen consultation initiatives are taking place around the world, there is clearly a need to raise awareness and provide a space for reflection, introspection and contemplation of the issues that AI can pose to our lives and relationships. To address this need and put forward the reflection on the new relationships and identities emerging from the use of AI, we organized a scientific and artistic exhibition entitled “AIship: the New State of Being”. Held in Montréal from September 2019 to January 2020, the exhibition presented the result of the collaboration between leading bioethicists and international artists, who were tasked to spark the interest of the general public on the ethical, legal and social issues of the introduction of AI in health. Therefore, five duos (each composed of one bioethicist and one artist) worked on “AIship”, a new term we coined from artificial Intelligence (AI) and the suffix “-ship” which means “the fact or state of being” through the production of a series of artworks and essays. Thus, based on the work of the duos, the public was engaged in reflecting on questions such as: Should we develop emotions towards robots? Will the distance between patients and their human healthcare providers grow? How will the automation of routine interventions affect patients? What about the feeling of being increasingly seen as biomedical data instead of as a person? Is AI solving more problems than it may generate? In this talk, we will present the work that have been done thought the exhibition and a series of mediation activities focusing on the work of each duo. We will also discuss duos’ approaches to AIship, be it through the lens of physician-patient relationships, responsible innovation, ecological perspectives, robots’ actual capacity to have and express empathy, and data-monitored wellness withal. Over 1,500 peoples visited “AIship: the New State of Being”, making it the most visited exhibition in the history of the Centre d'exposition de l'Université de Montréal. As aesthetics and ethics may both resonate with individuals’ sensitivity and allow approaching difficult moral subjects more easily than conventional academic dissemination, the exhibition created a safe space for fostering reflection on emotionally charged issues calling for public positioning on the socially transformative aspects of AI and its ethical implications.

Author Names: Jean-Christophe Bélisle-Pipon, Harvard Law School; Nathalie Vourino, Université de Montréal; Virginie Manus, AIship
Reflections on physicians’ interactions with industry and on the physician as innovator
Dr. Cécile Bensimon, Canadian Medical Association

Abstract Category: Standard Concurrent Session
Primary Theme: Other Ethics of new technologies (i.e., Medical ethics as it relates to interactions with industry)

Abstract: Background The CMA Guidelines for Physicians in Interactions with Industry (Guidelines) provide physicians in Canada with direction on how to appropriately manage interactions with industry and uphold their ethical and professional commitments to patients and the public. Interactions with industry, and indeed the nature of industry itself, are becoming increasingly complex and are raising new ethical concerns as new technologies, relationships, and industries are introduced into medicine. Last updated in 2007, the Guidelines required substantive revision and greater clarity to reflect the rapidly evolving nature and scope of conflicts of interests, types of physician-industry relationships, and the increasing scope and role of industry in medicine. Objective Our objective is to present the results of the ongoing revision of the CMA Guidelines, in particular background research that informed the revision, including scoping reviews of relevant academic and professional literature as well as key informant interviews. Findings & Conclusion Guidelines governing physician-industry interactions have traditionally centred on interactions with pharmaceutical and device manufacturers. Increasingly, information technology-based industries are entering the medical landscape and physicians are themselves initiating biomedical start-ups. To contend with novel forms of industry involvement, governance of physician-industry interactions requires both aspirational and prescriptive direction to guide ethical decision-making to uphold the wellbeing of patients and the public while also supporting medical innovation.

Author Names: Cécile Bensimon, Canadian Medical Association; Ana Komparic, University of Toronto
What does it mean to be a brain (disease)? Pain, addiction, and neurotechnologies
Dr. Daniel Buchman, University Health Network

Abstract Category: Standard Concurrent Session
Primary Theme: Neuroethics and neuroscience

Three Valuable Questions:
1) Does the BDMA/chronic pain account for public health contributions to addiction/chronic pain?
2) What are some positive aspects of medicalization?
3) What are evidence-based approaches to reduce either addiction stigma or chronic pain stigma?

Abstract: Since the late 1990s, key opinion leaders from organizations such as the National Institutes of Drug Abuse (NIDA) have promoted the idea that addiction is a chronic relapsing brain disease. Proponents argue that conceptualizing addiction as a brain disease enhances the capacity for the study of the neurobiology of behaviour, in turn promising improved and targeted interventions. Moreover, proponents argue that medicalization decreases the burden of stigma surrounding substance use disorders, which have long been held as moral failings (Fraser et al. 2017). Similarly, recent advances in neuroimaging have encouraged some scientists, clinicians, and people living with pain to advocate that chronic pain is a disease of the brain—much in the same way, and for the same reasons, as that of addiction (Tracey and Bushnell 2009). While a brain disease framing of chronic pain is controversial, such efforts can be linked closely to global brain initiatives as well as recent funding opportunities through agencies such as NIH that encourage the identification of brain-based biomarkers for chronic pain, themselves arguably part of a larger socio-historical shift toward rendering interiority visible through biotechnologies. All of this has taken on a new urgency in the context of the current opioid overdose crisis. But if the rhetorical and institutional shifts surrounding chronic pain indeed parallel those of addiction, some caution might be warranted. The “saturation” of the brain disease model of addiction (BDMA) is arguably as indebted to its socio-historical moment as it is to any helpful outcomes or advances from the model itself (Hellman 2018), and carries with it the burden of unintended consequences, not the least of which is a different, rather than mitigated, form of stigma.

In this presentation, we trace the parallels between the BDMA and the notion of chronic pain as a brain disease, offering an ethical analysis of the scientific, institutional, and rhetorical forces that have contributed to its framing. We then go on to examine and critique the implicit concepts of personhood embedded within the brain disease framing—concepts of identity and agency that are intertwined with presumptions about technology, progress, objectivity, evidence, and their place within a neoliberal political rationality. By foregrounding this critique within a feminist materialist STS theoretical framework, we go on to describe what might be the foundation for a more generative model of personhood, one that does not ignore the material and biological, but also holds space for invisibility, subjectivity, and multiplicity.

Author Names: Daniel Buchman, University Health Network; Suze Berkhout, University Health Network
The Neuro-Specific Human Rights Bill - http://chng.it/pkCvhRMS
Mr. Shad Budge,

**Abstract Category:** Standard Concurrent Session  
**Primary Theme:** Neuroethics and neuroscience

**Abstract:** The Neuro-Specific Human Rights Bill - http://chng.it/pkCvhRMS

Rapid advancements in human neuroscience and neurotechnology open unprecedented possibilities for accessing, collecting, sharing and manipulating information from the human brain. Such applications raise important challenges to human rights principles that need to be addressed to prevent misuse or unintended negative consequences. This proposal assesses the implications of emerging neurotechnology applications in the context of the human rights framework and suggests that existing human rights are not sufficient to respond to these emerging issues. After analysing the relationship between neuroscience and human rights, we identify four new neuro-specific human rights that will be vital in the effort of protecting the human brain.

The right to cognitive liberty is the right of individuals to use emerging neurotechnologies as well the protection of individuals from the coercive and unconsented use of such technologies. The right and freedom to control one’s own consciousness and electrochemical thought processes is the necessary substrate for just about every other freedom. Cognitive liberty is necessary to all other liberties, because it is their neuro-cognitive substrate. As such, cognitive liberty resembles the notion of ‘freedom of thought’ which is usually considered the essential justification of other freedoms such as freedom of choice, freedom of speech, and freedom of religion. Cognitive liberty is a conceptual update of freedom of thought that takes into account the power we now have, and increasingly will have to monitor, manipulate, and alter cognitive functions.

The right to mental privacy aims to protect any bit or set of brain information about an individual recorded by a neurodevice. This right would protect brainwaves not only as data but also as data generators or sources of information. In addition, it would cover not only conscious brain data but also data that is not under voluntary and conscious control. Finally, it guarantees the protection of brain information in absence of an external tool for identifying and filtering that information.

The right to mental integrity will provide a specific normative protection from potential neurotechnology-enabled interventions involving the unauthorized alteration of a person’s neural computation and potentially resulting in direct harm to the victim. For an action to qualify as a threat to mental integrity, it has to: (i) involve the direct access to and/or manipulation of neural signaling (ii) be unauthorized –i.e. must occur in absence of the informed consent of the signal generator.

The right to psychological continuity can be seen as a special neuro-focused instance of the right to identity. What the right to psychological continuity aims to prevent is the induced alteration of neural functioning. The right to psychological continuity will protect the mental substrates of personal identity from unconscious and unconsented alteration by third parties through the use of invasive or non-invasive neurotechnology.

These rights must be enacted into law as absolute rights.

All credit for the Neuro-Specific Human Rights Bill belongs to Dr. Marcello Ienca and Dr. Roberto Andorno. Excerpts from their paper https://lsspjournal.biomedcentral.com/articles/10.1186/s40504-017-0050-1 have been used.

**Author Names:** Shad Budge
Ethics in Conversation: Responding to Requests for Non-Beneficial Treatment
Dr. Andrew Butler, Centre for Clinical Ethics

Abstract Category: Standard Concurrent Session
Primary Theme: Other Clinical Ethics

Three Valuable Questions:
(1) What is the meaning of ‘non-beneficial treatment’?

(2) What are the similarities and differences between the main categories of non-beneficial treatment?

(3) How should clinicians respond to requests for non-beneficial treatment?

Abstract: Difficult conversations are routine in the healthcare context. Sometimes these involve delivering bad news, negotiating challenging family dynamics, or explaining complex medical information. But surely some of the most challenging conversations for healthcare teams are those in which patients, families, or substitute decision-makers request – or even demand – interventions or treatments which the team regards as inappropriate or non-beneficial.

There are many different reasons why a healthcare team may regard a requested treatment as non-beneficial for a given patient. The team may judge that the treatment is medically futile given the patient’s particular circumstances; the treatment may be an instance of so-called “complementary” or “alternative” medicine which the team regards as ineffective in general; or it may be an untested and unproven therapy found on the back pages of the internet. Regardless of the details of the cases, however, these requests for non-beneficial treatment pose some common challenges for healthcare teams. They can strain a team’s relationship with patients and families by imposing demands that the team is unable or unwilling to meet; they can lead to complex conflicts between both the values and empirical judgments of teams, patients, and families; and they call for sophisticated communication skills to work through tensions and disagreements.

Although much has been written in bioethics on the subjects of medical futility, unproven therapies, and complementary and alternative medicines, comparatively little has been said about the ethics of responding to requests for non-beneficial treatments in general. With that in mind, this paper aims to explore some different ways of conceiving the idea of non-beneficial treatment, and to propose some general strategies and guiding principles for responding ethically to requests for treatments which healthcare teams view as non-beneficial.

Generally, I argue that healthcare teams should not be hesitant to express their views clearly and explicitly when confronted with requests for treatments which they regard as non-beneficial. However, I also argue that special emphasis should be placed on clearly communicating to patients and families the grounds for these judgments. In particular, teams should be careful to distinguish between the empirical, epistemological, and evaluative assumptions at play when judging a requested treatment to be non-beneficial. I argue that it is only by being forthright about the way that these assumptions are expressed in clinical judgments that healthcare providers can respond ethically to requests for non-beneficial treatments, while also preserving and strengthening relationships between healthcare providers, patients, and their families.

Author Names: Andrew Butler, Centre for Clinical Ethics
A Reflexive Equilibrium Ethics for Autonomous Vehicles
Dr. David Černý, Institute of State and Law if the Czech Republic, Institute of Computr Science of the Czech Republic

Abstract Category: Standard Concurrent Session
Primary Theme: AI and Ethics

Abstract: Rapid progress in autonomous vehicles’ technology makes the need for an ethically sound guiding algorithm increasingly pressing. There is an obvious external utilitarian justification for introducing AV into daily traffic, but no consensus has been reached as to which ethical system is best suited for dealing with potential crash situations. In this contribution I set out to present a hybrid ethical system based on three pillars: i) empirical testing of moral intuitions of potential users of the AVs, ii) utilitarian considerations, iii) deontological considerations. My overall aim is to show that we have to reach a state of reflexive equilibrium between utilitarian and deontological considerations, based on empirically (moral intuitions) determined threshold separating deontological realm of decision making from a higher level (relative to the distribution of harm) of decision making governed by utilitarian ethical considerations.

Author Names: David Černý, Institute of State and Law if the Czech Republic, Institute of Computr Science of the Czech Republic
Creating a Specialized Decision-Making Body for Guardianship Matters: A Path to Explore for a Better Protection of Vulnerable Seniors
Ms. Anne-Isabelle Cloutier, McGill

Abstract Category: Standard Concurrent Session
Primary Theme: Other Health Law & the Elderly

Three Valuable Questions:
1. Are there existing jurisdictions in Canada or abroad with similar specialized decision-making body?
2. Apart from the creation of such specialized decision-making body, what other initiatives could be put in place to better protect the interest, rights and residual autonomy of vulnerable adults in need of protection?
3. Is there a risk that we trivialize or appear to be trivializing the importance/gravity of legal protection’s consequences in one’s life if we move away from traditional court settings towards a more informal approach?

Abstract: In Québec, when an adult is no longer able to take care of himself or administer his property due to illness, disability, age-related impairment, etc., the legislator has created protective regimes designed to provide him with a legal representative or adviser, depending on how incapacitated he is. This allows for the protection of his person and/or the administration of his property.

Instituting protective supervision has far-reaching human and legal consequences. The protected person sees the exercising of his civil rights considerably reduced or even eliminated. The choices and decisions he can make are also considerably affected. It is therefore not surprising that this loss of autonomy has been described as a distressing period, often experienced as “the mourning of a part of himself.”

To promote and protect the well-being of vulnerable adults, the legislator has clearly stated that any decision concerning a person in need of protection must be in his interest, be respectful of his rights, safeguard his autonomy and be in accordance with the presumption of capacity. The rigorous application of these key principles allows the person subject to protective measures to be treated as a human being in his own right and to realize himself even though his mental capacities might be impaired. However, the current application of the law in this field, both by legal and health professionals, is too often in conflict with these key principles.

In this talk, I explore how the creation of a specialized decision-making body could remedy to criticisms and observations made in recent years by lawyers, health professionals and academics regarding the neglect of these key principles.

I highlight the dissonance between practice and key principles that should guide it. I mention how the importance of the courts’ role as the ultimate guardians of the fundamental rights is often undermined by their high deference to medical and psychosocial assessments—which are often conducted in a context that is not conducive to valuing residual capacity. I also discuss how the underuse of tutorship and the negligence of the person’s residual decision-making autonomy often result in an undervaluation of the protected adult’s residual capacity.

I suggest that the creation of a specialized decision-making body could be an interesting path to explore for ensuring that vulnerable adults are appropriately protected when protective supervision is instituted. Such specialized body—nurturing multidisciplinary expertise, having an educational mission, having better configured courtrooms and being inquisitorial—could be better adapted to protect vulnerable adults’ interests, rights, and residual autonomy.

Author Names: Anne-Isabelle Cloutier, McGill
A case study in collaborative, cross-domain sharing and multi-omic analysis of infectious disease data: ReCoDID
Mrs. Katelyn Cullen, Institute on Ethics & Policy for Innovation

Abstract Category: Standard Concurrent Session
Primary Theme: Public health ethics

Three Valuable Questions:
1. What are the strengths/weaknesses of a federated cloud-based platform?

2. What are the ethical concerns of using a federated cloud-based platform to share data?

3. How do we ensure benefit sharing in a federated cloud-based platform model?

Abstract: Despite widespread global commitments to sharing data in research, salient ethical concerns continue to act as barriers to routine sharing amongst researchers in the public health landscape. Ramifications of such hesitancy are displayed during health emergencies, such as the 2015-2016 Zika virus epidemic and the 2013-2016 Ebola virus epidemic, where difficulties with rapidly sharing health data resulted in increased incidence rates and lives lost.

The Reconciliation of Cohort Data in Infectious Diseases – ReCoDID – Consortium aims to facilitate personalized medicine approaches to infectious disease research through fair and equitable data sharing and robust data analysis. ReCoDID brings together multidisciplinary teams from four continents to develop an integrated, sustainable platform for the sharing, synthesis and analysis of clinical epidemiological data, and high-dimensional (HDL) omics data that is derived from infectious disease related cohorts. This platform will be a federated cloud-based model with a tiered-permission system in place. In such a model, researchers may upload their data to the cloud repository, maintaining legal data ownership and controlling who has access to which parts of the data. This allows cohorts in low- and middle-income countries, with few computational resources, to facilitate the analyses of their data through the pooling of resources without sending it abroad. This collaborative process, led by cohorts, helps to circumvent the limitations of traditional data sharing models wherein the outsourcing of data can lead to concerns of exploitation, inequity, lack of reciprocity, and ambiguity in ownership, among others.

One key aspect to the success of the project is an understanding and responsiveness to the political, ethical, administrative, regulatory, and legal (PEARL) barriers to data sharing. While cloud-based technology and machine-learning can facilitate data sharing and analysis from a technical standpoint, in many ways the conventional challenges of sharing data that involve issues of distrust, inequality between high resource and low resource settings, and questions surrounding data ownership remain and compel us to find novel ways of addressing them. This presentation will provide early insights into the PEARL barriers of sharing data as they pertain to ReCoDID and the considered ethical responses.

Author Names: Katelyn Cullen, Institute on Ethics & Policy for Innovation
Abstract Category: Standard Concurrent Session
Primary Theme: Ethics and information technology or social media/networks

Three Valuable Questions:
What are best practices for citing and drawing from digital sources of these kinds?
What ethical problems are associated with lurking practices for professionals?
How can we better foster spaces within our professions to better invite these conversations into professional spaces?

Abstract: Online conversation platforms like Twitter can generate important counternarratives to received knowledge in health practices and research. These platforms offer opportunities for conversations that reveal patterns of failure or exclusion in health practices, and raise important opportunities for reevaluating standards of care and practices of inclusivity. For example, conversations focused around hashtags like #TransDocFail and #WhatDisabledPeopleKnow have identified shortcomings in care of trans and disabled people respectively. Easily accessible, these platforms serve as important knowledge bases for projects of building more inclusive health practices by revealing narratives that only infrequently get raised in professional settings. The medical and health professions stand to gain invaluable perspectives on inclusive practices through these digital health narratives and conversations.

However, little guidance exists on professional best practices for engaging in these conversations for the purposes of learning and building action. Given that many participants in these conversations do not necessarily intend to be read by a professional audience, and that many participants may be identifiable by information attached to conversations, we are in need of more conversation on ethical conduct in lurking. This presentation offers preliminary remarks toward an ethics of lurking, drawing from contemporary research in the field of digital epistemology. No background knowledge will be assumed.

Author Names: C Dalrymple-Fraser
Disability in the World Professional Association for Transgender Health’s Standards of Care: Limitations and Recommendations
Dr. C Dalrymple-Fraser

Abstract Category: Standard Concurrent Session
Primary Theme: Other Transgender Health Ethics, Disability Health Ethics

Three Valuable Questions:
Is the WPATH SOC an appropriate venue for these recommended changes?

How does recognizing unique difficulties faced by disabled trans people impact health delivery in my field?

What social factors are important to consider in disabled trans care beyond increased sensitivity to contraindications and personalized care plans?

Abstract: The World Professional Association for Transgender Health Standards of Care (WPATH SOC) for the Health of Transsexual, Transgender, and Gender-Nonconforming People seeks to “provide clinical guidance for health professionals to assist transsexual, transgender, and gender-nonconforming people” across medical and health fields.

This presentation discusses the role of disability in the WPATH SOC (7th Edition). More precisely, since the current WPATH SOC make only one direct mention of disability, this presentation focuses on the absence of disability from discussions of trans care. Drawing from experience and testimonial evidence from disabled trans people, this presentation argues that a more comprehensive WPATH SOC needs to account for the unique difficulties faced by many people at the intersections of trans and disabled identities and health care. The presentation concludes with brief recommendations toward building more comprehensive and nuanced training and practices around trans health in general.

Author Names: C Dalrymple-Fraser
Abstract Category: Standard Concurrent Session
Primary Theme: Public health ethics

Three Valuable Questions:
How do we appraise unnecessary or inappropriate care? Are deep learning technologies currently positioned to actually reduce bias in care settings, or are they irrelevant to the discussions at hand? In what specific ways are the technical report’s recommendations particularly vulnerable to worries about inequalities?

Abstract: In 2017, The Canadian Institute for Health Communication (CIHC) and Choosing Wisely Canada (CWC) published a technical report on unnecessary care in Canada. Adding to continually growing research on the topic, the report found that up to 30% of tests, treatments, and procedures in Canada are potentially unnecessary. Such unnecessary care, they caution, may lead to possible exposures to harm, unwanted patient stress, inappropriate treatments, increased burden and queues, and waste of time and medical resources. That report, alongside subsequent research and public health campaigns, encourage Canadians to do their parts to reduce apparently unnecessary care. As deep learning technologies continue to improve in diagnostic accuracy, speed, affordability, and availability, concerns about overtesting and overdiagnosis are set to face new challenges in the coming years.

This presentation offers a different challenge to current trends in reducing apparently inappropriate testing and diagnosis, which intersects with issues in new technologies. In particular, I argue that such reduction efforts need to carefully account for national systemic inequalities in access to treatment and care. Potential patients who already face difficulties accessing care and treatment due to systemic or professional biases are positioned to face additional barriers to health access given movements to reduce testing and diagnosis. The 2017 report and related publications make no explicit reference to demographic inequalities or exemptions. Drawing predominantly on recent research in feminist epistemology of medicine and on public patient testimonies, I argue for a more critical and cautious approach to reducing apparently unnecessary care. I conclude the presentation with tentative remarks on the potential role of deep learning technologies to ameliorate these inequalities, while supporting the general reductions recommended by the CIHC/CWC report. No background knowledge will be assumed.

Author Names: C Dalrymple-Fraser
"Other Dimensions": Examining the Incorporation of Ethical Aspects and Patient Perspectives in HTA
Dr. Deirdre DeJean, CADTH

Abstract Category: Standard Concurrent Session
Primary Theme: Ethics and health technology assessment

Abstract: Health technology assessment (HTA) is the systematic evaluation of properties, effects or impacts of health technologies and interventions, including their intended and unintended consequences. Despite a conventional focus on clinical and economic evidence, there is growing recognition—in Canada and internationally—of other elements needed to comprehensively assess a health technology. These include the technology’s intended use and how effectively or expensively it serves that purpose, but also other effects such as non-health outcomes, effects on care processes, social organization, distribution of benefits and burdens, etc. In recent years, researchers and HTA agencies have thus given more serious consideration to incorporating social values and ethics into HTAs, and to patient-focused HTAs that incorporate patients’ values, needs, preferences, and lived experiences.

In this critical analysis, we reflect on our collective experiences participating in, conducting, and overseeing the incorporation of qualitative and ethics research evidence within HTA in Canada. In addition, we draw on conversations with HTA researchers and methodologists who have similarly been involved in early work developing approaches for addressing social values and patient perspectives. Finally, we examine published and grey literature describing the evolving rationales and methods for incorporating these elements into the HTA process. The purpose of this analysis is to explore efforts to incorporate these distinct but often overlapping elements—ethical aspects and patient and social aspects—into HTA, and to draw lessons for how this incorporation might be strengthened in future work.

We begin by comparing and contrasting the challenges faced when incorporating these elements into the HTA process. For example, both ethical aspects and patient aspects encounter tensions with the traditional focus of HTA agencies on clinical and economic evidence, and perceptions that these elements may introduce biased sources of evidence into what should be a technocratic process. Similarly, criticisms that these considerations could politicize what should be a solely evidence-informed process abound. We reflect on varying efforts to develop methodologies for incorporating these aspects. Several different ethical approaches have been promoted for the examination of ethical aspects in HTA (e.g. principlism, casuistry, wide reflective equilibrium, coherence analysis). Likewise, there are many mechanisms for incorporating patient aspects (e.g. qualitative evidence syntheses of patient perspectives, invited submissions from patient groups, patient member participation on committees). We argue that the ongoing epistemological dominance of “verifiable facts” in HTA has favoured research-based approaches that more closely parallel traditional HTA review methods, hence the comparatively accessible uptake of qualitative evidence syntheses to elicit patient perspectives. Finally, we reflect on external pressures that have mobilized the incorporation of ethical aspects and patient aspects in HTA, and describe how the political backdrop of the HTA landscape has advanced the need to include patient voices in the process in particular.

We conclude by offering strategies for pragmatic methods for incorporating both ethical aspects and patient aspects, drawing examples of what has flourished and what has faltered in HTA, and by making suggestions for how to create space for continued and enriched considerations of both of these crucial elements in the HTA process.

Author Names: Deirdre DeJean, CADTH
Performing Pediatric Autonomy: Culture, Capacity, and Compliance
Dr. Carey DeMichelis, Vanderbilt Center for Biomedical Ethics and Society

Abstract Category: Standard Concurrent Session
Primary Theme: Other Pediatrics; Diversity; Indignity

Three Valuable Questions:
Do you think the reason a young person gives for refusing treatment changes assessments of their capacity?

Would using age as a heuristic for capacity change the dynamics you describe here?

Can you talk more about how the possibility of parental coercion fits into your dichotomy of capacity and compliance?

Abstract: This paper explores adolescent autonomy and the “capacity to consent” to biomedical treatment. I ground the discussion in a case study of an 11-year-old Mohawk girl who attempted, along with her family, to refuse chemotherapy in favor of Haudenosaunee healing practices. Drawing on four years of ethnographic field work, I consider the culturally particular performances that this young person was expected to enact in order to be found capable of making her own medical decisions. Attending to the intersection of capacity and compliance, I argue that young people who face systemic discrimination in health care institutions may be more likely than other patients to be understood as incapable of participating in medical decision-making. Thus, this paper exposes the infrastructure which regulates “choice” in Canadian pediatric healthcare – who is seen as capable of choice, which choices can be made, which choices cast doubt on a person's ability to choose.

Author Names: Carey DeMichelis, Vanderbilt Center for Biomedical Ethics and Society
Artificial Intelligence, Therapeutic Relationship and Mental Health Care: A scoping review
Dr. SAUMIL DHOLAKIA, GERIMEDRISK, McMaster University

Abstract Category: Standard Concurrent Session
Primary Theme: AI and Ethics

Three Valuable Questions:
1. From the literature reviewed in the scoping review, are there any new themes apart from those influencing empathy, trust and physical/psychological contact that you saw emerging?

2. The descriptive themes are the take home message of the presentation. What are the normative themes, or are there any normative themes emerging?

3. What are the implications of your study in terms of policy, especially in context of the 'digital first' thrust by the provincial government?

Abstract: Therapeutic relationship in health care is a necessary and many a times, a sufficient platform to provide care to people with mental health needs. This platform traditionally has a human interface of a congruent therapist and a client in need, with implicitly normative boundaries of empathy, variable degree of physical/psychological contact and Trust. Artificial Intelligence (AI) and their applications in the field of mental health care have the potential to influence therapeutic relationship in unique yet unknown and unexplored ways.

This presentation aims to answer the critical question: “What are the ways in which AI and its applications influence the field of therapeutic relationship in mental health care”? I present the results of a scoping review mapping the terrain of therapeutic relationship at the intersection of various AI applications like robotics, machine learning, artificial neural networks, natural language processing, affective computing, virtual reality and augmented reality in the diagnostic, preventive, therapeutic and rehabilitative domains of mental health care.

The scoping review follows the 5-step model of formulating the research question and operationally defining its central elements and then locating the studies on Medline, Embase, PsychInfo, SCOPUS, IEEE Xplore, Google Scholar, ACM (association of computer machinery) databases through an iteratively designed and peer reviewed search strategy. We used the search strategy to select and evaluate academic literature in accordance to predefined inclusion and exclusion criteria and map emerging themes at the intersection of AI, therapeutic relationships and mental health care. We analyzed the themes against the research question to generate narratives as outcomes.

Furthermore, the presentation explores the emerging themes from the included 84 academic papers of the scoping review using an ethics of care lens. In so doing, this presentation prompts the stakeholders involved in design, implementation, utilization and regulation of AI in the mental health care field, to reflectively contemplate: “What are the emerging values and the value trade-offs which stake-holders are making at this intersection? More importantly, how is care getting defined at the intersection of AI, therapeutic relationship and mental health care”?

Author Names: SAUMIL DHOLAKIA, GERIMEDRISK, McMaster University; Jay Shaw, Women's College Hospital; Jennifer Gibson
Ethical design and artificial intelligence: a review and proposed framework for health
Mr. Joseph Donia, University of Toronto

Abstract Category: Standard Concurrent Session
Primary Theme: AI and Ethics

Three Valuable Questions:
How should I as an ethicist try to collaborate with designers based on your findings?

Who do you mean by ‘designers’ anyway?

What would this mean when a health care organization is procuring AI, so hasn't been involved in designing it?

Abstract: Emerging digital technologies such as artificial intelligence (AI) not only mediate everyday human practices and engagement with the world, but are also rapidly re-creating new social and economic orders that characterize contemporary global life. The speed at which these changes have occurred, and the lack of adequate response at either the national or global policy level, has inspired renewed interest in the literature on ethics and values in design (E+VID). These “ethics-first” approaches generally focus on clarifying the normative dimensions of design, and outlining strategies to more strongly incorporate ethical decision-making throughout the design process. Only recently, however, has attention been devoted to comparing these approaches on their practical and normative characteristics, and very little attention has been paid to their application in health-related AI. The purpose of this session is to present a review of E+VID approaches that have appeared in the academic literature, underscoring in particular the central importance of attending to designer agency and normative strength for such approaches to be meaningfully employed in the context of AI for health.

Our approach in this project was framed by a highly specific objective: to identify approaches to E+VID that have been proposed and discussed in the literature, and to assess those approaches for their normative strength and assumptions about designer agency. In this way, our approach to identifying relevant publications was informed by purposive sampling. This process uncovered 17 E+VID approaches, ranging from normatively “weak” approaches to normatively “strong” approaches. Normatively weaker approaches included ‘value-sensitive design’, which emphasizes identifying and incorporating the values of the local design team throughout the design process. Normatively stronger approaches include ‘design justice’, which is concerned with how the design process distributes risks, harms, and benefits among different groups in society.

We conclude by discussing the strengths and limitations of normatively “strong” versus “weak” approaches, and suggest that design ethics in health care must consider a particularly complex range of institutional realities that surround the practice of health-related design. We suggest there are four influences on the practice of design in health care that require close attention. First, the epistemic privilege of evidence-based medicine; second, the complexity of organizational relationships within health systems; third, the complicated relationship between the payer, the provider and the patient (i.e., the payer is not the one receiving services); and fourth, existing public beliefs about surveillance and public health. We conclude with recommendations for how E+VID in health-focused AI can inform more ethical applications of AI, including in specific cultural and policy contexts around the world.

Author Names: Joseph Donia, University of Toronto; Jay Shaw, Women's College Hospital; Jennifer Gibson
In the absence of guidelines and regulations: the need for scientific virtues in health research
Dr. Jeff D'Souza, Institute on Ethics and Policy for Innovation

Abstract Category: Standard Concurrent Session
Primary Theme: Public health ethics

Three Valuable Questions:
1st Question: What grounds or justifies the particular seven scientific virtues proposed in the presentation? Could these virtues differ based on geography, culture, or the novel technology under consideration?

2nd Question: Who is responsible for fostering these scientific virtues? Does it fall on just individuals, or is there a role for national regulatory bodies, academic institutions, teachers, scientists, and workplaces as well? What would successful fostering of the scientific virtues look like?

3rd Question: How likely are such scientific virtues to be fostered among researchers, scientists and members of the research community, and what impact are they likely to have on ensuring the proper use of powerful technological innovations in healthcare? How do the scientific virtues proposed differ or what value do they add to existing codes of conduct for responsible research?

Abstract: Powerful technological innovations in healthcare – such as the use of genome editing to prevent disease or neurological enhancements – typically take place prior to the existence of ethical regulations or guidelines governing the proper use of them. The time lapse between the two can be long, resulting in extended periods of time where powerful healthcare technologies are left unregulated. During this phase, camps tend to emerge with inhibitors calling for the cautious and judicious use of new technologies until all the important details have been worked out, while activators call for the expedited, yet responsible introduction of novel technologies with the goal of improving health outcomes urgently. While this debate is taking place, it is often up to those who created the new technology, and those aware or capable of utilizing it to ensure that the new intervention is not misused, but appropriately applied in socially and ethically responsible ways.

The absence of guidelines or regulations governing powerful technological innovations in healthcare presents two challenges: (1) finding a way to get researchers, scientists and members of the research community to more thoroughly think through the potential impacts and likely uses of their innovations on society and the environment, and (2) figuring out how to motivate them to act in socially and environmentally responsible ways, amidst potentially competing interests, such as financial gain, fame, or career advancement.

The answer to these two challenges, I contend, is rooted in fostering a particular set of virtues in the scientific community aimed at encouraging members of the research community to more thoroughly think through the potential impacts of their technological innovations on society and the environment, and motivating them to act in socially and environmentally responsible ways.

In the first section of my presentation, I illuminate the challenge of developing timely guidance and regulatory frameworks for powerful technological innovations in healthcare, and turn to some examples to illustrate the extent to which things can go badly when there is insufficient guidance governing powerful technological innovations in healthcare. In the second section, I advance seven scientific virtues – justice, honesty, humility, courage, purposefulness, respect, and service – aimed at minimizing the misapplication of technological innovations in healthcare, especially during the early phase, where guidelines and regulations are non-existent. In the final section, I conclude by demonstrating how the scientific virtues work in practice, and show how they would have prevented one of the most significant misuses of an emerging healthcare technology in the 21st century: the gene editing of human babies.

Author Names: Jeff D'Souza, Institute on Ethics and Policy for Innovation
TransLife: Development of a smartphone app to predict and improve rates of suicidal ideation among transgender persons
Dr. Alex Dubov

Abstract Category: Standard Concurrent Session
Primary Theme: Ethics and health technology assessment

Abstract: Background: Transgender people have an extremely high prevalence of suicidal ideation and suicide attempts. In the US, the lifetime prevalence of suicide attempts among this group is estimated to be as high as 41.0%, compared to 4.6% in the general population. Despite this disproportionately high prevalence of both suicidal ideation and suicide attempts in trans population, research is limited on factors that account for variability in suicide risk and associated mental health concerns in this population.

Specific Aims: In this presentation we will report on the mHealth suicide prevention phone app TransLife designed with the help of transgender people (focus groups at St. John’s clinic Los Angeles and consultations with transgender health providers at Mount Sinai NYC). The app will provide transgender people with resources intended to promote resilience and cope with minority stressors. Additionally, the app will allow researchers to collect longitudinal data that will be used to create a comprehensive model outlining the process and series of psychosocial mechanisms leading to suicidal ideation in transgender people.

Materials and Methods: We will present the beta version of the app together with results of focus group discussions. In addition to the main feature of the app – structured mood tracking, the users of TransLife can access a variety of resources addressing mental and physical health, housing and employment, legal questions, and ways of reporting violence. The app connects users to a community of peers and local resources including pre-vetted healthcare providers and community rated transgender friendly services. Mood tracking allows users to record their mood and track health activities (sleep, energy, etc.) to identify patterns in their mental health. Researchers will be able to use these entries to create a large training dataset. This dataset will be analyzed using deep neural networks and time series analysis to develop a deep neural net classifier for early detection of suicidal risk. Given a series of mood entries the model will predict likelihood of the next entry being worse or suicidal.

Results: There are several mood logging apps and CBT mHealth interventions developed for general population. These interventions are not tailored for trans people, they do not address stressors unique to trans people, and they were not designed to collect longitudinal data to be analyzed by a deep neural network.

Conclusions: There is a need for an mHealth intervention designed with the input from transgender community and tailored to the specific needs of this community to address high rates of suicidal ideation.

Author Names: Alex Dubov
Ethical Tensions in Practice: An Examination of Competing Allegiances
Dr. Evelyne Durocher,

Abstract Category: Standard Concurrent Session
Primary Theme: Other Ethics in health and social care practice

Three Valuable Questions:
1. Is it possible that some of these tensions are not ethical in nature but are rather merely situations that arise in one's role as a health and social care practitioner?
2. How might practitioners go about resolving such tensions?
3. How might socio-political contexts contribute to such tensions?

Abstract: Background. Healthcare professionals in all domains have long been recognized to experience ethical challenges in practice in light of diverse agendas embedded in practice contexts. The prevalence and increasing complexity of ethical challenges are alarming, as these have shown to have negative implications for individuals of all health and social care disciplines such as moral distress as well as professional burnout and attrition. Despite potentially serious implications, little work has been done to examine how various allegiances in practice can set up ethical tensions.

Purpose. In this paper we present findings of an exploratory study examining conflicting allegiances in occupational therapy.

Method. Using collective case study methodology (Stake, 2006) we examined the phenomenon of ethical tensions in practice as reported by seven occupational therapists practicing in different settings in Southwestern Ontario, Canada. The data were analyzed inductively within and across the cases.

Findings. Ethical tensions were seen to arise in ways that highlighted competing allegiances in the occupational therapists perceived roles and contexts. These included tensions between allegiances to 1) respect for client autonomy and safety concerns; 2) client values and therapist values; 3) colleagues, clients, and regulatory college mandates; 4) therapists’ values and employer directives; and 5) clients and regulatory college mandates.

Implications. The findings open a discussion informing how practice settings can better facilitate health and social care directed at responding to patient needs while also meeting the various demands imposed on practitioners.

Author Names: Evelyne Durocher; Elizabeth Anne Kinsella
Ubuntu Philosophy and the Consensus Regarding incidental findings in Genomic Research: A Heuristic Technique
Dr. C.O EWUOSO, University of Johannesburg, South Africa

Abstract Category: Standard Concurrent Session
Primary Theme: Ethics and genomics

Three Valuable Questions:
1) Why is Ubuntu philosophy a better ethical for supplementing research guidelines than existing ethical approaches?
2) Is a harmonized approach to research result management across research settings practicable?
3) In the absence of consent, does this ethical theory support an ethical duty to return significant incidental findings?

Abstract: This study adopts a heuristic technique to argue the thesis that a set of guidelines rooted in the African philosophy of Ubuntu can usefully supplement current research guidelines, and be of assistance in the implementation of the consensus to return some Incidental findings (IFs) discovered in genomic research, thereby contributing towards clarifying the ancillary obligations owed participants, advancing the field of ELSI (by providing exposure to the under-represented African perspective on the ethical, legal and social issues of genomics), and the clinical goal of genomic research.

The consensus regarding IFs is that there is an ethical obligation to return individual genetic incidental findings that meet the threshold of analytic and clinical validity, have clinical utility and actionable, provided that research contributors have not opted out from receiving such information. This study outlines the hurdles that may hinder the integration of this consensus in mainstream practice, and show how an ethical theory from the global south may be used to supplement current ethical theories to address the same.

Obviously, much work also remains to flesh out the specific ancillary duties of the stakeholders in research. But what this study accomplishes is to demonstrate that the philosophy of Ubuntu is a useful ethical theory capable of supplementing current ethical approaches in contributing towards the much needed harmonized approach to research result management across borders, and the effective implementation of the consensus around IFs.

Author Names: C.O EWUOSO, University of Johannesburg, South Africa
Towards the Co-production of Ethical Practice in Big Data Research with Minors
Ms. Danica Facca, Western University

Abstract Category: Standard Concurrent Session
Primary Theme: Research Ethics

Three Valuable Questions:
1. Do you think research with minors that involves the generation and/or collection of digital data presents unique ethical challenges?
2. If a minor generates digital data through their parent’s phone, whose data is it?
3. In what ways can researchers strive to co-produce ethical practice in research with minors which uses digital data collection methods?

Abstract: Background: Much has been written about the ethics of conducting research with minors, due in part to the novelty of ethical issues that emerge when conducting research with this population. Similarly, much has been written about the ethics of conducting research that collects digital data, again, due in part to the novelty of ethical issues that emerge when digital data, typically big data, is involved in research. While emerging digital health technologies offer researchers new avenues to collect real-time behavioural data, little is known about current ethical dimensions, considerations, and challenges that are associated with conducting digital data collection in research with minors. As such, this presentation will report the findings of a scoping review which explored existing literature to canvass current ethical issues that arise when using digital data collection in research with minors. A multidisciplinary research team was established to undertake the review, with expertise in computer science, digital health, ethics, law, and public health.

Methods: Scholarly literature was searched using electronic academic databases (Scopus, PubMed) for articles that provided explicit ethical analysis or presented empirical research that directly addressed ethical issues related to digital data collection used in research with minors. After screening 1,156 titles and abstracts, and reviewing 73 full-text articles, 20 articles were included in this review. The articles were thematically coded for key ethical themes through multiple iterative discussions held among study authors.

Results: Themes which emerged across the reviewed literature included: consent, data handling and ownership, children’s data rights, observing behaviours that may result in risk of harm to participants or others, private versus public conceptualizations of data generated via social media, and gatekeeping. The review revealed that there is a degree of uncertainty which invariably exists with regards to the ethics of research that involves children and digital technology. Yet, we conclude that no ethical issues have been raised in this context that are unique relative to existing ethics literatures on research with minors and research using digital data collection. Instead, we found that a perception of ethical novelty exists in this area given what some argue constitutes a form of ‘hypervigilant gatekeeping’ that arises with the use of digital data collection methods in research with this population.

Conclusion: Conducting research that involves the collection of minors’ digital data involves a degree of uncertainty that appears inevitable given the evolving ways in which digital data is produced, particularly among younger generations. This has led to increased ethical scrutiny of such research. The literature reviewed suggests that this uncertainty can often lead to the preclusion of minors from otherwise important lines of research inquiry. While uncertainty warrants ethical consideration, increased ethical scrutiny and restricting the conduct of such research raises its own ethical challenges. We conclude by discussing the ethical merits of co-producing ethical practice between researchers and children as a mechanism to proceed with such research while addressing concerns around uncertainty.

Author Names: Danica Facca, Western University; Maxwell Smith, Western University; Jacob Shelley, Western University; Dan Lizotte, Western University; Lorie Donelle, Western University
Ethical Challenges in End-of-Life Care with Patients Facing Structural Vulnerabilities: Developing a ‘close to practice’ approach to ethics
Ms. Karen Faith, Joint Centre for Bioethics

Abstract Category: Standard Concurrent Session
Primary Theme: Other Ethical challenges faced in palliative care for patients with structural vulnerabilities

Three Valuable Questions:
1) What are the particular ethical challenges faced by clinicians?
2) What approaches to ethical reasoning could be relevant in this area of clinical practice?
3) What existing resources, ethical reasoning are clinicians currently utilizing to face these significant challenges?

Abstract: Researchers have begun to examine barriers that limit access to quality end of life care for patients who experience homelessness, mental illness, alcohol or drug use stemming from early experiences of trauma, social, economic, racial and/or political inequalities.1,2,3 Much of this research was intended to not only examine structural influences and their impact on patients at end of life, but also how the approach and practices of palliative care providers are challenged and shaped as a result of a “constellation of sociopolitical, economic, cultural and historical forces” .4 People living with structural vulnerabilities are likely to have a significantly shorter life span, will suffer at a younger age from chronic conditions normally seen in older patients, and are also more likely to have a history of trauma and/or abuse.1,5 Many people with structural vulnerabilities mistrust formal health care settings in which they or members of their communities have experienced bias, discrimination, or stigmatization. Such mistrust can result in avoidance of traditional health care settings until such time as health problems and symptoms become unbearable.2-5 Despite such pressing health issues, it has been found that most people who face structural vulnerabilities will remain focused—out of necessity—on the day to day struggle to survive. Reimer-Kirkham et al 4 concluded in their examination of social justice considerations pertaining to equity informed palliative care, that “palliative care tends to discount the needs of those who can be characterized as doubly vulnerable” ( p 294).

The case of “Alex” (a hypothetical case drawn from real experiences from the field) will be used in this session to illustrate the kinds of clinical and everyday ethical challenges experienced by community based palliative care providers whose patients have faced long term difficulties like homelessness or unstable housing, drug and/or alcohol use, poverty and discrimination. The objective of this concurrent session is to explore some of the complex ethical challenges that palliative care providers face in providing end-of-life care to this population of patients, and to highlight the need for a more nuanced and ‘close to practice’ 7 approach to ethics.

REFERENCES:


Author Names: Karen Faith, Joint Centre for Bioethics; Naheed Dosani, Palliative Education and Care for Homeless (PEACH) ; Daniel Buchman, University Health Network
Emerging Health Technologies and the Moral Distress of Non-Medical Providers: A Qualitative Investigation
Dr. Sophia Fantus, University of Texas at Arlington

Abstract Category: Standard Concurrent Session
Primary Theme: Other moral distress and emerging health technologies

Three Valuable Questions:
1. What are the practical implications of moral distress on patient care as non-medical providers are not directly involved in providing interventions?

2. A shift in the culture of the institution seems like an unattainable short-term goal. How could this strategy be broken down into smaller, shorter-term and more attainable plans of action?

3. Emerging health technologies are not going anywhere, so what are some implications for education? How can we train future hospital social workers, chaplains, patient liaisons and other allied health professionals to work within the confines and limitations of such practices? Does this change the role of the profession, professional values and ethics, or dialy responsibilities?

Abstract: Developments in emerging health technologies may afford unique opportunities to facilitate the care of older adults, introducing novel ways to prognosticate, diagnose, and treat. Although such technologies may offer patients newfound hope of receiving life-transforming interventions, potential hurdles ought to be identified and explored. Hospitals are currently facing escalating resource burdens across departments and fields of discipline in an effort to maintain beneficial healthcare services for a rapidly aging population. Issues related to length of stay, readmission rates, and sustainable care plans are influencing effective patient care. In turn, emerging health technologies may introduce further barriers to the provision of exceptional care. In particular, health technologies may expend internal and external healthcare resources through expensive tests and interventions, further treatment options, and the inevitability of longer life spans. The problem here is that such issues may disproportionately place burdens on non-medical providers of healthcare teams. Allied health professionals’ competencies are in identifying and integrating social determinants of health to present a comprehensive understanding of a patient’s clinical picture; social workers, chaplains, and patient liaisons assume responsibility to address psychosocial barriers and implement practical solutions to resolve issues associated with healthcare resources. Accordingly, health technologies may have unintended consequences on non-medical providers and, consequently, heighten experiences of moral distress.

The purpose of this presentation is to report on findings from a qualitative study that explored sources of moral distress for non-medical providers and concerns associated with the growing demand of physicians and nurses to treat an aging population. Through the use of directed content analysis, semi-structured interviews (30-75 minutes) were conducted at a U.S.-based hospital with social workers (n=15), chaplains (n=10), and patient liaisons (n=4). Participants were asked to elucidate experiences of moral distress and to reflect on the implications of moral distress to patient care. Findings indicate that moral distress, as it relates to emerging health technologies, occurs in: (1) clinical practice, whereby requests are made for non-medical providers to convince patients to agree to new treatment plans or interventions, (2) internal hospital constraints that place restrictions on patient care and accessible resources, (3) financial supports and community-based resources that negatively impact available discharge plans, treatment options, and long-term care plans, (4) structural conditions that impose unrealistic expectations from management, and (5) impediments to code status, hospice, or palliative care conversations with patients at end of life.

This presentation will conclude by focusing on institutional approaches that may assist in mitigating experiences of moral distress and the novel ways clinical ethicists might assist. Strategies include: (1) shifts in the culture of the institution to appreciate and value non-medical providers, (2) clinician education about resource allocation and the roles and responsibilities of non-medical providers, (3) internal programming to support interdisciplinary communication and foster cohesiveness, and (4) funding and resource development to support investment and mentorship for non-medical providers. Findings may inform future practice and policy recommendations to protect non-medical providers from undue burdens as the inevitable emergence of health technologies in hospitals continues to expand.

Author Names: Sophia Fantus, University of Texas at Arlington; Steven Moore, University of Texas at Arlington
Abstract Category: Standard Concurrent Session
Primary Theme: Public health ethics

Three Valuable Questions:
1. Were there any noticeable differences between the participants based on location of practice or age?

2. Given the role of the adolescent patient in choosing treatment, what were their reasons for preferring antidepressants?

3. How might the introduction of OHIP+ impact the prescribing of antidepressants to adolescents.

Abstract: The use of antidepressants in the paediatric population has increased dramatically in recent years. There are a number of concerns with prescribing antidepressants to the paediatric population, foremost of which is the questionable evidence of their safety and effectiveness in “off-label” use. Joan Busfield’s theory of pharmaceuticalisation tries to explain why this is the case; suggesting physician’s roles as “gatekeepers” for pharmaceutical products is weakening. I used Busfield’s theory to frame the analysis of this qualitative study of primary care physicians and paediatricians who treat adolescent depression. I conducted qualitative interviews with 11 primary care physicians and 2 paediatricians and used Thematic Analysis to analyze my data. The major finding of this study was that Busfield’s theory is inadequate to explain the rise of antidepressant prescribing in adolescent depression. I provide an alternative explanation that primary care physicians and paediatricians prescribed antidepressants for depression in youth when it was decided upon through shared decision-making with the patient. Given the subjective nature of depression, and the lack of any objective testing to judge severity or improvement of depression, participants considered choosing treatment as a process of “trial and error”, and considered patient involvement in decision-making important to the treatment process. This finding challenges Busfield’s account of pharmaceuticalisation, and indicates that her theory may need to be refined for clinical situations where there is a lack of strong evidence for pharmacotherapy.

Author Names: Julian Ferguson
Is Bioethics Action-Centred?
Dr. Jennifer Flynn, Memorial University

Abstract Category: Standard Concurrent Session
Primary Theme: Theories and methodology in bioethics

Three Valuable Questions:
What does Iris Murdoch say about moral philosophy?

Could what she says apply to bioethics?

Does bioethics focus too heavily upon action and choices between possible actions?

Abstract: Is Bioethics Action-Centred?

Philosopher and literary figure Iris Murdoch criticized the moral philosophizing of her day as overly focused upon action and choices between possible actions. In my paper, I explore this criticism and the extent to which it applies to contemporary bioethics. The argument presented in the paper is two-fold. First, I maintain that contemporary bioethics does in fact fall prey to much of Murdoch’s criticism. Second, I argue that while bioethics’ practical emphasis might explain and justify action-centered tendencies, there is nonetheless something important lost in the focus on action and choice.

I begin with a look at the criticism itself, connecting it to other, similar criticisms of moral philosophy. In short, Murdoch’s worry about the moral philosophizing of her time was that a focus on action and choice rules out of consideration much of what is of moral significance (Murdoch 1956). There are connections between this criticism and criticisms of moral philosophy put forth by Elizabeth Anscombe (Anscombe 1958). There are also connections to criticisms that moral philosophy succumbs to scientism (i.e., that it models itself too closely after scientific exploration and discovery).

I go on to suggest that much of bioethics is susceptible to Murdoch’s general critique. That is, I suggest that bioethics does for the most part focus upon action, to the detriment of other morally significant aspects of human life. Bioethics’ practical emphasis might explain its action-centered tendencies. However, there is nonetheless something important lost to bioethics in the focus on action and choice. To illustrate what can be lost, I discuss what I take to be two exceptions to this emphasis upon action: Rosalind Hursthouse’s work on abortion (1991) and Michael Sandel’s work on genetic engineering (2009). This paper addresses the general question of what is the proper sphere of bioethics, and speaks to the issue of what sort of subject we take bioethics to be.

References


Author Names: Jennifer Flynn, Memorial University
Abstract Category: Standard Concurrent Session
Primary Theme: Ethics and information technology or social media/networks

Three Valuable Questions:
How would healthcare providers weigh the benefits of engaging audiences online with data privacy concerns of using SM?

Knowing what we know about data privacy and surveillance today, is it ethical for healthcare providers to engage with the public on SM?

What are some ethical ways that health providers can engage online with patients?

Abstract: In Canada, 94% of adults have at least one social media (SM) account, creating vast amounts of personal data every day. The business model of SM corporations, such as Facebook and YouTube, is built upon using artificial intelligence (AI) to collect and aggregate this data, creating detailed profiles of each user. Details of users’ behaviour, such as shopping habits, socio-economic status, political opinions and health information, is monetized using targeted advertisements and shared with third parties, including advertisers, researchers and insurers, without the knowledge or explicit permission of the SM consumer. Personal attributes including age, ethnicity, sexual orientation, and health-related behavioural information are used to target specific users and discriminate against others. Facebook’s lack of transparency regarding their privacy and surveillance practices has been called into question from recent scandals, such as the Cambridge Analytica scandal, and more recently with the Canadian and Ontario human rights commissions regarding job discrimination.

The promise of big data from PHI on SM purports more personal medicine, disease prediction and prevention, and is already employed by federal agencies in Canada. The Public Health Agency of Canada has used PHI on SM to predict suicidal activity in rural communities. Despite the rapid uptake of the technology, there remains a dearth of research on the ethical, social and legal implications of collecting and analyzing PHI from SM. Most users, as well as health providers, are unaware of the level of surveillance and privacy risks they encounter when patients share PHI on SM. Data gleaned from SM can be easily re-identified to users, and can be sold by SM corporations and mobile applications to unknown actors. Grundy et al. found that location and prescription drug lists of app users were shared by 79% popular medical applications, and 71% distributed data to third parties. This is concerning, as sensitive PHI requires additional legal and ethical protections.

Research has shown that users are unable to judge the privacy risks to their PHI unless they are made acutely aware to whom and when it is disclosed. Previous work has shown that when users and health providers engage on SM, some believe their health data has the same legal protections as an electronic medical record (EMR). Other research has found that most users ‘just clicked agree’ when encountering an SM privacy policy, spending less than one minute reading it. The authors found that users were dismayed when informed what the policy entailed.

There is a critical need to assess the potential risks and unintended consequences of data privacy issues facing healthcare providers and users. In this presentation, I will examine the social, ethical and legal implications of data privacy and surveillance on SM in a public health context. Using a socio-technical lens, I argue that the use of emerging AI technologies in public health, such as SM, and the associated data privacy implications, warrants in-depth critical analysis prior to widespread adoption in Canadian healthcare.

Author Names: Lyndsay Foisey, Western University
Ethical Aspects of Health Artificial Intelligence
Ms. Sara Gerke, Harvard University

Abstract Category: Standard Concurrent Session
Primary Theme: AI and Ethics

Three Valuable Questions:
1. How will the use of health AI interface with the principles of informed consent?
2. How can we ensure that health AIs are safe and effective and mitigate biases?
3. How can we properly balance data privacy of individuals with health AI innovations?

Abstract: Health Artificial Intelligence (AI) has enormous potential to improve health care. Some health AIs have already been cleared or approved by the FDA, such as IDx-DR, an AI diagnostic system for the eye disease diabetic retinopathy, OsteoDetect, an AI software designed to detect wrist fractures, and BrainScope TBI (model: Ahead 500), an AI that helps in the diagnosis of concussion and mild traumatic brain injury by providing results and measures. In the context of health and research, it is expected that AI will be increasingly applied in four areas: 1. Clinical Applications (e.g., imaging, diagnostics, and AI-assisted or autonomous robotic surgery); 2. Patient/Consumer Use (e.g., health AI apps, fitness trackers, and chatbots); 3. Research and Development Process (e.g., higher efficiency of clinical trials); and Workflow Optimization (e.g., the reduction of costs and the training of clinicians). However, even though health AI is already transforming health care and will continue to do so, it also raises several ethical issues such as informed consent to use, bias, and data privacy.

This presentation will first briefly explain what AI is and give some examples of the current and potential future applications of AI in health care. It will then focus on the ethical aspects of health AI and discuss four key issues: 1. Informed Consent to Use; 2. Bias, 3. Transparency and Trust, and 4. Data Privacy. Questions that will be discussed include: To what extent do clinicians have a responsibility to educate their patients around the complexities of health AIs, including the kind of data inputs and the possibility of shortcomings in the data that is being used? How can we best reduce biases such as contextual and unconscious biases or biases in the training data? How can we promote transparency and trust among stakeholders, especially patients and clinicians, which are crucial for a successful implementation of health AI in clinical practice? How can we adequately protect the privacy of individuals while facilitating health AI innovations? Among other things, it will be concluded that stakeholders, especially AI makers, should consider the ethical issues at the earliest stages of the development process of health AI-based products. The goal should be “ethics by design” – rather than after a product has been designed and tested.

Author Names: Sara Gerke, Harvard University
Standardizing Substitute Decision-Making Identification and Documentation in a Healthcare Setting
Dr. Dianne Godkin, Trillium Health Partners

Abstract Category: Standard Concurrent Session
Primary Theme: Other clinical/organizational ethics; quality improvement

Three Valuable Questions:
1. How were staff knowledge levels evaluated? What methods did you use?
2. Are you confident that staff identified the correct SDMs?
3. What was the content of the education that staff members received?

Abstract: The law in Ontario mandates that substitute decision-makers (SDMs) are required to make treatment decisions for people who lack decisional capacity. Even if a patient is capable at the time of presentation to a hospital, there may come a time when an SDM(s) is needed (e.g., if a patient experiences delirium or is anesthetized). Thus, it is important when a patient arrives at the hospital to confirm who the patient’s SDM is or would be according to the hierarchy outlined in the Health Care Consent Act. If the patient is capable and indicates that they would want someone other than the person identified as highest in the hierarchy to be their SDM, the patient can at that time be encouraged to appoint an attorney for personal care. Not knowing the correct SDM may result in ethical, legal and practical issues such as undermining the patient’s autonomy, violating the law, and delaying treatment, all of which may negatively impact patient outcomes.

At a large community/academic hospital, a quality improvement project was initiated to standardize the process for identifying and documenting the SDM (hereafter, the ID-SDM project) using non-electronic patient health records. Following the initial success of the project on the first two pilot units, this process was further tested at another community-based hospital in both electronic and non-electronic patient health records environments.

The objective of the ID-SDM project was to optimize correct identification and documentation of the patient’s SDM. A target to increase the rate of documentation of SDMs to 20% above baseline was established. Baseline data was collected from cardiac surgery and rehabilitation/geriatric pilot units at the first hospital and from a nephrology outpatient unit, regional bed unit, and complex transitional care unit at the second hospital. The project involved development of a documentation form and selection of a designated location for the form in patients’ health records by a working group of key stakeholders and included engagement with patients/family members. Staff education, mini-audits, unit champions, check-ins and FAQ sheets supported the process.

Chart reviews were conducted at baseline, three months and one-year following implementation. Baseline rates of documentation ranged from 0% to 53%. At three months post-implementation, rates had increased to a range from 52% to 100%. At the one year mark, documentation rates on the two pilot units at the first hospital were 46% and 66%; the one year results at the second hospital are not yet available.

The ID-SDM project increased healthcare providers’ confidence in SDM identification. Staff reported the form was quick and easy to use. The results exceeded the goal of increasing ID-SDM to 20% above baseline. Support from unit champions and ongoing reminders helped to motivate and sustain change. The SDM form assisted healthcare providers in meeting their ethical, legal and professional obligations. This session will highlight key learnings from implementing this quality improvement project.

Author Names: Dianne Godkin, Trillium Health Partners; Michael Campbell, Trillium Health Partners; Rosalind Abdool, Trillium Health Partners
The Capacity of Bioethics to Assess Emerging Health Technologies
Dr. Matthew Grellette, Institute on Ethics and Policy for Innovation, McMaster University

Abstract Category: Standard Concurrent Session
Primary Theme: Ethics and health technology assessment

Three Valuable Questions:
1. What, precisely, could be done to plug the gaps in bioethical analyses of emerging health technologies?

2. Is the distinction between bioethics and the ethics of emerging technology ultimately sustainable?

3. Should bioethicists be bothered to provide a full and comprehensive analysis of a given health technology, or should they be satisfied with offering a less-than-comprehensive domain specific analysis?

Abstract: Ethicists who specialize in assessing emerging technologies sometimes write as though the moral insights contained in traditional bioethics will not translate into questions about their subject. Martin Peterson, for example, asserts that “(t)he moral problems faced by engineers dealing with new or existing technologies are quite different from the moral problems faced by doctors and nurses working in hospitals and biomedical research units.” My aim in this presentation is to explore whether skepticism about the value of bioethical contributions to discussions about emerging technologies is warranted.

I will begin by briefly delineating the study of bioethics, in order to show that this discipline is concerned with significantly more than just ‘the moral problems faced by doctors and nurses working in hospitals and biomedical research units’. In particular, I will highlight the numerous times that bioethicists have grappled with moral issues raised by emerging technologies, i.e. cloning, genetic selection, xenotransplantation, etc. Yet, I will also acknowledge that the mere fact that bioethicists have engaged with questions about emerging technology does not entail that their contributions were conclusive. The bioethical perspective may, after all, represent too limited a purview of analysis for assessing new technologies, or it may exclude the use of certain pertinent theoretical tools, etc.

In order to determine whether this is so, I will briefly elucidate the concept of an emerging technology. I will then argue that the ethical assessment of such phenomena must occur via one of four different analytical modes, each of which comes with certain distinctive success conditions. In short, these are a prospective mode, concerned with assessing an emerging technology’s potential uses and effects; a retrospective mode, concerned with assessing a technology’s de facto uses and effects; an institutional mode, concerned with questions of governance and social licence; and a participatory mode, concerned with questions that pertain to the development process itself, usually raised by engineers, funders, etc.

In the remainder of the presentation, I will seek to determine whether bioethical thought is adequately attuned to the all the different modes of assessing emerging technologies, such that it can satisfy the success conditions of each of these various endeavors. Here I will argue that, while bioethics provides many of the tools necessary to successfully assess the merits of an emerging health technology, there are some gaps in its coverage. For example, contemporary bioethical thought does not provide adequate forecasting techniques to support accurate prospective analyses, nor does it include the sorts of non-medical role-based analyses that would be required by certain participatory inquiries. I will, therefore, conclude that, although contemporary bioethics can contribute much to the analysis of emerging technologies, there are some specific areas where it must be supplemented. In this way, I will have taken some first steps towards determining the capacities and limits of modern bioethical thought to contribute to the assessment of emerging health technologies.

Author Names: Matthew Grellette, Institute on Ethics and Policy for Innovation, McMaster University
Towards responsible implementation of intelligent monitoring technologies in institutional care
Dr. Alisa Grigorovich, KITE Research Institute - UHN

Abstract Category: Standard Concurrent Session
Primary Theme: AI and Ethics

Three Valuable Questions:
1. What are the potential benefits of implementing intelligent monitoring technologies and for whom?
2. What are the potential risks of implementing intelligent monitoring technologies and for whom?
3. What social and institutional mechanisms will need to be developed to mitigate risks and to build trust?

Abstract: Amid growing awareness of errors and harms in institutional care settings (e.g. hospitals, nursing homes), artificial intelligence and other types of monitoring technologies are increasingly advocated for improving the safety and quality of care. The discourse around the use of these technologies has been dominated by enthusiasm about their “transformative potential” to improve health care quality, safety, and effectiveness of care. Yet, there have also been concerns regarding “irresponsible innovation,” including that “failed” technologies may further threaten the sustainability of the health care system. Given the potential impact of such technologies on patients, providers, and systems, there is a pressing need to reflect on the values that underpin interest in implementing monitoring technologies, and how these values can be (re)aligned with the public good. Our purpose here is to contribute to broader efforts across science and technology studies to question the dominant assumptions that underpin development and implementation of monitoring technologies, focusing on their ethical, social, and policy implications. Our review suggests there is limited and inconsistent empirical evidence regarding promised improvements, and evidence that they may introduce new types of risks that may undermine otherwise good intentions with the use of these technologies.

Author Names: Alisa Grigorovich, KITE Research Institute - UHN; Pia Kontos, KITE Research Institute - UHN, University of Toronto
Abstract Category: Standard Concurrent Session
Primary Theme: Neuroethics and neuroscience

Three Valuable Questions:
If partaking in a moral bio-enhancement can be described as a 'pre-commitment contract', how is this agreement with your 'future-self' distinct from an agreement to sell yourself into slavery? Might we suffer morally relevant losses by taking away our freedom to make regrettable decisions? How do ethical concerns about moral bio-enhancement differ from ethical concerns about cognitive enhancement, and in which ways are they similar?

Abstract: Debates on the ethics of human enhancement are often centred on concerns of fairness. Critics assert that by improving ‘positional goods’ (e.g. height), enhancements place non-users at a disadvantage. There is, however, one subset of human enhancement that does not warrant these same concerns: moral bio-enhancement. These enhancements are characterized by the biomedical manipulation of human motivation to generate conduct that is deemed moral or virtuous. They have the potential to benefit non-users by making individuals less impulsive, less aggressive and more cooperative. Due to their inability to effectively appeal to concerns of fairness, proponents of the anti-enhancement position have focused on concerns of identity in their moral evaluations, positing that possible benefits of the enhancement would be outweighed by the loss of personal identity that would ensue. In this paper, I respond to these critics by focusing on the compatibility of autonomy and enhancement. I argue that the voluntary use of moral bio-enhancement is consistent with a ‘higher-order moral trait’ or ‘second-order desire’ to improve one’s moral dispositions, eliminating so-called threats to identity. Further, I argue that arguments in favour of the coercive use of moral bio-enhancement cannot overcome identity concerns, limiting the ethical use of moral bio-enhancement to instances of consent.

Author Names: Jennifer Guiho
Abstract Category: Standard Concurrent Session
Primary Theme: AI and Ethics

Three Valuable Questions:
1.) What is the role of patients in shaping public-private partnerships around ethical and responsible AI?

2.) Does the nature of the healthcare/health data organization in question (e.g. a hospital in isolation as opposed to an existing data trust such as Ontario’s Institute for Clinical and Evaluative Sciences or the UK's National Health Service) pose unique considerations for a partnership?

3.) How do AI partnerships differ from other P3s in healthcare (i.e. infrastructure, maintenance, equipment/devices, etc.) What are the lessons that can be learned from other P3s?

Abstract: Background: The responsible deployment of artificial intelligence (AI) has rapidly become a cause of concern across industries. In healthcare, AI shows promise for improving the administration and quality of care for physicians and patients alike. However, with the excitement of these promises comes a large number of ethical concerns and risk for many organizations, healthcare providers, and patients. In recent years, several technology companies have been attempting to enter healthcare through both business-to-business and business-to-consumer/patient applications. Through these applications, companies are able to access patient data and could opaquey use this data in other aspects of their business (e.g. advertising). As such, many of these same companies have also been faced with ethical scandals, causing concern to both healthcare decision-makers and patients (namely on the infringement of patient autonomy and right to privacy).

The increasing push for healthcare organizations to operationalize AI has created ethical concerns for many healthcare decision-makers to find a balance between innovation and risk. The limited academic literature to inform decision-making by health practitioners around best practices to form industry partnerships has made these concerns increasingly difficult to identify and navigate. Here, we introduce a framework of questions and concerns as guidance for healthcare stakeholders to consider while co-designing and deploying a responsible healthcare AI solution at the public-private boundary.

Methods: We produced a literature synthesis based on a rapid search of databases (Scopus, Medline, Embase) and grey literature that describes partnerships between healthcare and various organizations in the technology sector, including news articles, business case studies, and organizational white-papers. We included over 50 articles in our synthesis.

Results: The outcome of our work produces a series of questions to be asked by healthcare decision-makers when evaluating a proposal for a public-private partnership to create AI solutions, grouped into four key themes. 1) What is the value generated from the proposed partnership? (i.e. benefits and drawbacks of choosing to deploy the AI system, the necessity of private sector expertise/resources, value and goal alignment between parties, broader societal implications as they relate to equity and justice) 2) What governance concerns exist by nature of this partnership? (i.e. data governance, organizational governance, deployment governance, liability, participation) 3) What technical concerns exist by nature of this partnership? (i.e. privacy, security, reliability, audit/compliance) 4) What risk mitigation measures need to be considered when forming this partnership? (i.e. the use of silent trials to validate software effectiveness before full-fledged deployment, differences in perceived and assumed risk between parties)

Significance/Future Directions: This work provides a tool for healthcare decision-makers to navigate the creation of a partnership with industry who may otherwise lack knowledge of AI and its deployment challenges. Our next step is to conduct a qualitative study to provide insights on the questions we posed by characterizing the elements of a successful partnership through semi-structured interviews of experts in healthcare, business, and software engineering who have actively faced these issues in practice.

Author Names: Vinyas Harish, MD/PhD Program, Faculty of Medicine, University of Toronto; Nuwan Perera, integrate.ai; Anita McGahan, Rotman School of Management, University of Toronto; Sunit Das, Division of Neurosurgery, University of Toronto; Laura Rosella, Dalla Lana School of Public Health, University of Toronto


**Abstract Category:** Standard Concurrent Session  
**Primary Theme:** Ethics and health policy

**Three Valuable Questions:**  
Are there professional guidelines for physician or nursing actions when caring for children during a violent intruder incident?  
What must hospitals do to keep healthcare workers secure from violence?  
How does a duty to care apply to "code white" situations? Is this analogous to a duty to care during a violent intruder incident?

**Abstract:**  

**Background:**  
The American Medical Association published its first Code of Ethics in 1847, containing this exhortation: “When pestilence prevails, it is their duty to face the danger, and to continue their labours for the alleviation of suffering, even at the jeopardy of their own lives”. This early articulation of a duty to care has shaped the professional identity of healthcare workers over the decades. Such a commitment to the care of patients even in the face of personal endangerment has been scrutinized largely in the context of infectious diseases, prominent recent examples being Ebola virus disease (EVD), pandemic influenza and severe acute respiratory syndrome (SARS). Yet the tension inherent in this duty is also encapsulated in images of first responders rushing to their death in Manhattan on September 11, 2001, and by headlines describing patients abandoned in the wake of Hurricane Katrina in 2005. An emerging contemporary challenge to this duty to care is the increasing incidence of armed individuals who enter healthcare facilities intent on destruction. Such incidents provoked renewed examination of the philosophical underpinnings of a duty to care. While there is a paucity of literature exploring this from the paediatric medicine perspective, this discipline’s dedication to particularly vulnerable patients is well-positioned to challenge and further clarify the claims of duty in the face of personal threat.

**Objectives:**  
The objectives of this study are threefold: first, to review the history of and extant ethical propositions concerning a duty to care; second, to analyze the ethical considerations unique to a duty to care in the face of violence; and finally, to analyze how those ethical considerations might be clarified in the Paediatric context.

**Methods:**  
Narrative review of literature relating to a duty to care, coupled with novel ethical analyses as per the objectives noted above.

**Findings:**  
There is extensive literature describing how a duty to care has been articulated and codified since it first appeared in the 1847 AMA Code of Ethics – this duty is inconsistently conceptualized from a philosophical standpoint, ranging from supererogatory to utilitarian considerations, and its translation into health policy has been lacking. There is a lack of literature, professional codes, or policies that specify the duty to care in the context of violence within a hospital. A framework to translate this duty into health policy is thus outlined, addressing the duty to care from the individual, institutional and societal perspectives. The concept of solidarity is employed to highlight the necessary role of hospitals (and the broader public) in anticipating and mitigating violence faced by patients and healthcare workers; this empowers healthcare workers to undertake personal or professional duties of care, analogous to the empowerment afforded to healthcare workers by appropriate pandemic preparedness. The paediatric context aptly illustrates the need for and utility of this framework in building health policy for vulnerable persons who are particularly at-risk due to developmental factors.

**Author Names:** Andrew Helmers, Department of Critical Care Medicine, the Hospital for Sick Children; Roxanne Kirsch, Department of Critical Care Medicine, the Hospital for Sick Children; Department of Bioethics, the Hospital for Sick Children
Artificial Intelligence and Real Relational Impact: The Case of Automated Health Monitoring for Older Adults
Dr. ANITA HO, University of British Columbia; UCSF

Abstract Category: Standard Concurrent Session
Primary Theme: AI and Ethics

Three Valuable Questions:
1. How may socio-relational conditions affect older adults’ decisions regarding using AI health monitoring?
2. How may the normative lens of relational autonomy address socio-relational and structural issues arising in AI health monitoring?
3. How can health administrators and policy makers prevent digital divide, healthcare disparity, and senior isolation in the era of AI health monitoring?

Abstract: Artificial intelligence (AI) has been touted as an innovative alternative or enhancement to in-person monitoring. Continuous monitoring of older adults' health-related activities, altered behavior patterns, disease progression, and adverse events (e.g., falls) through computer vision allows remote collection, automated de-identification, and sharing of key health data. Such monitoring aims to facilitate early detection, self-management, clinical decision-making, and continuity of care between clinic visits, potentially preventing acute deteriorations or serious injuries. In particular, AI monitoring may provide family and professional caregivers real-time information and alerts, thereby supporting older adults to live in their communities safely while reducing caregiver burden.

Nonetheless, health monitoring at the dawn of AI is socio-politically and relationally complex. AI health monitoring is often developed without explicit consideration of important ethical aspects, potentially compromising people’s autonomy, well-being, and equitable access. Through the normative lens of relational autonomy, this presentation will explore how socio-relational conditions may affect older adults’ decisions regarding using AI health monitoring. It will critically assess intersecting ethical issues at various socio-relational levels that may affect how older adults may decide on AI health monitoring. At the individual and family levels, this presentation will explore the social conditions affecting older adults’ ability to choose according to their values and goals. Moreover, older adults and family caregivers may have intersecting but divergent considerations regarding in-person versus AI monitoring based on their different social locations. Family caregiving is deeply symbolic, but sometimes also fraught with gender equality and justice concerns. Automating health monitoring may affect families’ relational identities and potentially redefine norms and (gender) role expectations. As some older adults’ capacity to (withdraw) consent to continuous observation may gradually decline, relational autonomy concerns abound when family members with different considerations may be consenting on their behalf.

At the organizational and health system levels, this presentation will explore how administrators and policy makers must balance human resource and cost considerations in exploring efficient and effective ways to provide safe care for our aging population. It will also consider how AI monitoring may change privacy norms for care workers, who may be indirectly surveilled. At the societal level, this presentation will explore how AI home monitoring practices may blur the line between private and health information and the corresponding ethical implications, and whether investment in AI monitoring may affect governments’ workforce planning. The presentation will conclude by exploring how to ensure that AI monitoring would not intensify the digital divide, healthcare disparity, senior isolation, and ageism.

Author Names: ANITA HO, University of British Columbia; UCSF
Ethical Management of Incidental Findings in Emergency Care: A Critical Interpretive Literature Review
Ms. Renata Iskander, McGill University

Abstract Category: Standard Concurrent Session
Primary Theme: Other Ethics in Healthcare Practice

Three Valuable Questions:
1) According to the literature, what is the current understanding about and state of IFs in ED settings?

2) Based on the literature, what are the ethical and professional obligations of ED healthcare professionals for identification, disclosure, and management of IFs?

3) What are the ethical challenges of IFs in ED settings that require research and policy reform?

Abstract: Incidental findings (IFs) are findings discovered during medical testing (e.g., blood tests, genetic tests, imaging) that are unrelated to the primary purpose for which a test was sought. Some IFs constitute new knowledge that have implications for patient autonomy and welfare. IFs found in emergency departments (EDs) are difficult to manage because of the fast-paced and crowded environment, with one study reporting that of 392 patients with IFs, 122 had no follow-up and 242 had no electronic record of the finding. Currently, there are no literature reviews that explore IFs in the ED setting. A critical interpretive literature review was conducted to explore what the literature shows about current practices regarding identification, disclosure, and management of IFs in EDs, and to identify ethical challenges that require research focus and policy reform. The search strategy included ‘incidental findings’ AND ‘emergency’ and derivatives, retrieving 12,021 studies from databases including PubMed, PubMed Central, Scopus, and Web of Science, as well as handsearching and reference list searching. Following screening, 97 studies were included that fit the eligibility criteria adequately discussing incidental findings in ED settings. Data was extracted, analyzed using descriptive statistics, and then critically interpreted to capture key ideas. Of 97 included articles, 75 have relevant empirical data. Of the 75, most literature (89%) presented the frequency of IFs in EDs, with approximately one-quarter of studies reporting the prevalence to be under 10% and the highest reported prevalence being 97%, with an average frequency of 33%. Of the 75 studies with relevant empirical data, only 29% explored the rates of reporting of IFs in documentation or discharge summaries. Of these 22 studies, the average reporting rate was 42%, which means that more than half of IFs were not documented. Most (84%) did not report on patient disclosure rates or follow-up rates, but when reported, patient notification rates were as low as 0.2% with an average of 15% over 12 studies. Many articles described IFs as being an “abnormality”, “unrelated”, not previously known, or found while conducting a test for a different purpose. One study defined IFs as “not pertinent to the immediate patient care in the emergency department”. Empirical studies included in the review did not address ethical principles or patient preferences on disclosure. The literature revealed suggestions to manage IFs in EDs, including implementation of automatic feedback or alert mechanisms, clarification of responsibilities within treating teams, protocols and evidence development, enhanced patient communication and discussion, and improvements to reporting and patient documentation and follow-up practices. Test results by letter were noted as insufficient because patients are unable to ask questions. Authors suggest further research on optimal follow-up recommendations to alleviate patient and physician distress. The literature on IFs in EDs focuses too narrowly on frequency, with ad hoc suggestions for practice, research, and policy changes to improve IF management. Numerous factors, including crucial knowledge gaps, contribute to inadequate management of IFs arising in EDs. This research will draw from the literature to identify ethical challenges and develop research and ethics informed guidance.

Author Names: Renata Iskander, McGill University; Carolyn Ells, McGill University
Abstract Category: Standard Concurrent Session  
Primary Theme: Other Death Investigation Bioethics  

Three Valuable Questions:
1. What impact would Death Investigation Bioethics have? 2. What are the next steps to have this subdiscipline recognized? 3. Why now?

Abstract: Despite being understood as an important topic for the practice of medicine, bioethics did not really become a standard in institutions and among medical professions until bioethics as a field of academic inquiry was established in the 80’s. In many ways, the field of bioethics is now considered mature in that it has moved beyond a topic of medical education to include professionalization of bioethicists, along with its own journals, and sub-specialties. Yet today, biomedical ethics largely remains centered on the ethics of clinical medicine. The focus in clinical ethics is largely centered on the physician-patient relationship and about just distribution of access of clinical care for individual patients. Due to recent medical advances, clinical ethics has been pushed to consider end of life issues, such as brain death; however, the discussion abruptly ends here despite the fact that medical practice extends beyond life. This absence is highlighted in the paucity of frameworks, conceptual theories and models in diverse areas of medical practice to the exclusion of the unique ethical dilemmas that arise in medicolegal death investigations. Further, importing these ethical concepts will not suffice in death investigation and the direct application of these frameworks, such as principilism, is dubious (e.g. considering the role of patient autonomy). The authority of death investigation falls directly under the law and this statute gives pathologists the ability to perform medicolegal autopsies without the authorization of surviving family members. This fundamental pillar of death investigation directly contrasts clinical ethics, wherein autonomy is paramount in day-to-day decision-making.

Similarly, pathologists have written virtually no literature and certainly no systemic work or metareflection on the ethical dilemmas that arise during a medicolegal death investigation. This paucity of academic work by pathologists may be due to a number of causes. First, pathologists are laboratory-based physicians that determine the cause and effect of death and disease through autopsy. They are stereotyped as basement dwellers, removed from direct patient care, working with only the dead. This may shelter pathologists from broader ethical scrutiny. Second, there is some reluctance and lack of awareness by those who work in death investigation to engage in bioethics, in part because the moral status of dead bodies is controversial. Third, many pathology residency programs have inadequate or no training in pathology ethics. Hence, there is no model or demonstration of incorporating ethics into medicolegal practice.

There is a need for a new subdiscipline in bioethics wherein researchers, academics, bioethicists, pathologists and allied workers should examine and analyse ethical dilemmas that uniquely occur once a person dies by appealing to moral philosophy. This process will create ethical norms in death investigation that are currently lacking. This presentation will justify the need for a new field of ethics, entitled Death Investigation Bioethics, define and contrast Death Investigation Bioethics from Thanatology, highlight the ethical issues in Death investigation and how this contrasts to clinical medicine, discuss the barriers and enablers to develop this applied area of ethics.

Author Names: Rebekah Jacques, London Health Sciences Centre & Western University
“The slightly biased slot machine”: AI technology using public genomic data for drug discovery
Ms. Esha Joshi, University of Toronto

Abstract Category: Standard Concurrent Session
Primary Theme: AI and Ethics

Three Valuable Questions:
1. How should researchers make an effort to be more inclusive when recruiting participants for their studies?
2. What is the best way to facilitate sharing of genomic data across institutions while maintaining privacy of participant data?
3. What is the best way to create standardization or regulations when using AI for drug discovery?

Abstract: Pharmaceutical and biotechnology companies spend a large percentage of their capital towards drugs discovery and identifying novel therapeutic candidates, only for a small percentage of their efforts to succeed. Many start-up companies have set out to revolutionize the drug discovery process by using novel artificial-intelligence technology in conjunction with large repositories of genomic and transcriptomic data. Specifically, deep-learning algorithms can aggregate publicly available genomic data, extract patterns from the millions of data points (on gene function and expression, variant data etc.) and then screen for potential pathogenic mutations that underlie diseases(s) where therapies are few to none. By identifying these potential targets, companies can accelerate the process of experimentally validating these candidates and significantly reduce the time and costs associated with drug development.

While this technology holds immense benefit in deciphering and leveraging large amounts of genomic data in the drug discovery process, are we making sure the datasets being analyzed are appropriate to use? Around 80% of the genomic data that is publicly available is biased and over-represents persons of European ancestry (Kessler et al., 2016, Bustamante et al. 2011). Determination of which variants are pathogenic has been considerably more difficult in people of non-European ancestry and the lack of population-specific pathogenicity information has largely contributed to this. The algorithms being trained on these biased datasets may in turn apply this same systemic bias to questions it is asked. In the context of drug discovery, these algorithms could end up identifying pathogenic mutations specific to particular populations as novel therapeutic candidates. The failure to detect these systemic biases in the training data used to develop these algorithms, that is then propagated into pharmacotherapeutic advances, could exacerbate current disparities in disease treatment availability and efficacy amongst different ethnic populations (Fiscella., K & Sanders, M.R., 2016).

While efforts are being made to capture greater genetic diversity within these databases, empirical research evaluating the biased outcomes of AI should be done concurrently. Some recommendations for areas of evaluation include: (1) testing algorithms using multiple different genomic data sources to reveal systemic biases, and (2) assessing outcomes of algorithms tested on current genomic datasets improved through methodological substitution of missing data, a statistical method called imputation. This, along with cross-collaboration, interdisciplinary development teams, and crowd-sourcing data will drive advancement of AI in drug discovery to be both profitable and equitable.

References

Author Names: Esha Joshi, University of Toronto
Framing ethical concerns about CRISPR gene drives in the news media
Dr. Kalina Kamenova, Canadian Institute for Genomics and Society

Abstract Category: Standard Concurrent Session
Primary Theme: Ethics and genomics

Abstract: Gene drives based on the CRISPR-Cas9 gene editing system are a powerful genetic engineering method that defies the laws of Mendelian inheritance by allowing genetic dominance of specific traits and their spread at an enhanced rate in nearly 100 percent of the next generation. While this technology offers great promise for agriculture, conservation and public health, the ecological risks and impacts of introducing species modification directly into the environment are difficult to forecast. This paper examines the media coverage of gene drive technology between 2016 and 2019, focusing on how science journalists frame key bioethical concerns arising from the deployment of gene drives for the prevention and elimination of deadly vector-borne diseases such as malaria, Lyme disease, Zika and dengue fever. It undertakes content analysis of print and online news reports to identify major trends in framing the technology, its potential benefits and risks for human health and the environment, and the evolution of media representations. The results show a considerable emphasis on uncertainty and risks in media representations, with scientific and bioethical experts being the strongest voice in providing authoritative statements about CRISPR-Cas9 gene drives as a high-risk technology.

Author Names: Kalina Kamenova, Canadian Institute for Genomics and Society
Abstract Category: Standard Concurrent Session
Primary Theme: Ethics and health policy

Three Valuable Questions:
1. What happens if DAPs are working in a non-democratic country where equity is not a recognised value?

2. You recommend that there should be a framework to guide ethical policies among DAP organization, how feasible might this be? What would the motivation for DAPs to buy into this?

3. Did the respondents talk about the other competing values such as efficiency? How do they balance these with equity?

Abstract: Equity and social justice are ethical values that have become increasingly important in health policy and systems decision making. The concept of equity has different meanings for different people when used in health policy. What counts as just or fair to one person or group looks inequitable to another. The wide range of meanings afforded to the concept of equity—and the challenges posed with weighing up these meanings—is one of the things this paper explores, based on the views of development assistance partners in low income countries. Development Assistance Partners (DAPs) have significant influence on health policy and healthcare in low-income countries (LIC) since they contribute the resources needed to support the health systems. While they initially focused on the most efficient, effective ways to support health systems, there is an increasing focus on equity and social justice in the DAP operations.

This paper, based on forty-two in-depth interviews with development assistant partners (DAP) involved in health system priority setting (PS) in low-income countries (LIC), explores the degree to which equity is a consideration in the DAP decision making processes in relationship to LIC health systems. This paper considers both (a) the explicit attention played to equity, and (b) the degree to which equity is implicitly present within other criteria decision making criteria. We also discuss ways in which equity might be more meaningfully incorporated into the PS process.

Results show that stakeholders struggle to both define and apply the concept of equity. They do not list it among their core criteria. Other criteria—particularly evidence and cost-effectiveness—are seen as more immediate and therefore more important. Even when the importance of equity is acknowledged, stakeholders struggle to determine between groups marginalized by factors such as gender, age, geography, income, and culture. Further, respondents suggested that equity is often not pursued for its own sake, but rather to meet specific requirements set by funders—or, worse yet, to avoid being seen to further entrench inequities.

Hence, more attention must be paid to the criterion of equity in the health policy decision making processes. In particular, DAPs need to build greater awareness of how equities manifest, so that they can better address the needs of underserved communities. Furthermore, there is need for the development of an internationally recognized, cross-sector framework for articulating and operationalizing equity-based policies. Further research needs to focus on developing an evidence base to support equity-based health policies.

Author Names: Lydia kapiriri, McMaster University
Global and National Perceptions of Development Assistance Partners’ Legitimacy

Dr. lydia kapiriri, McMaster University

Abstract Category: Standard Concurrent Session
Primary Theme: Public health ethics

Three Valuable Questions:
1. Did the DAPs think legitimacy was important to their activities? How did they talk about the relevance of their legitimacy?

2. There are several frameworks for evaluating legitimacy e.g. Slim et al. Why did you use the framework for analysis that you used? What contributions did it make to the legitimacy literature?

3. It’s surprising that the perceptions of the national respondents were similar to those of the DAPs, can you talk about some of the reasons for these findings?

Abstract: Development assistance partners (DAPs) are playing an increasingly critical role in supporting health systems in low and middle income countries (LMICs). While some of the literature has justified this role in terms of equity and social justice, there is a body of literature that questions the legitimacy of some of the roles that have been assumed by DAPs in LMICs. In particular, some of the DAPs actions have been questioned on basis of their legitimacy. While legitimacy is widely discussed in the literature, legitimacy may be particularly important when talking about healthcare priority setting and resource allocation. This is because these decisions have direct impact on individuals’ health and health outcomes. In such cases, it is important that both the decisions and the people making these decisions are perceived as legitimate by those who are most impacted by the priority setting decisions. When DAPs are perceived to be legitimate, it enables them to exert power through either voluntary or quasi-voluntary compliance and makes it possible for them to receive international, national, and local support for their interventions. However, determining the legitimacy of a DAP and the sources of that legitimacy can be complicated.

The overall aim this paper is to discuss the reported legitimacy of DAPs from the perspectives of the DPAs and Uganda health policy makers, based on Brechenmacher & Carothers (2018) framework.

This was a qualitative study involving key informant interviews with 102 respondents (Forty-two from the Global level and sixty from the national level). Global respondents were sampled from seven different types of international organizations representing bilateral organizations, financing institutions, public private partnerships, not for profit organizations, National health institutes and foundations. National respondents included health policy makers at the national and sub-national levels.

Legitimacy was discussed extensively by respondents at the global and national levels. Surprisingly there was consistency in the sub-themes legitimacy from both respondent groups. Most of the respondents thought that the legitimacy of the DAPs was dependant on how they work with their LMIC partners. These respondents were more likely to perceive a DAP as legitimate depending on the degree to which they worked collaboratively with the host LMICs, with the least collaborative DAPs being perceived as illegitimate stakeholders in priority setting. The other themes that emerged from the analysis were related to who the DAPs were; with some organizations, (such as the bilateral organizations) were deemed more legitimate. Other indicators of legitimacy were associated with the kind of activities or services or programs they engaged in.

Brechenmacher & Carothers (2018)’s principles provided a robust framework for discussing the legitimacy of DAPs. Most of the respondents realised and talked about the legitimacy in terms of the degree to which DAPs work collaboratively. However, DAPs need to work on the additional sources of legitimacy so as to strengthen their legitimacy. Brechenmacher & Carothers (2018)’s principles can be used to guide DAPs who desire to further bolster their legitimacy.

Author Names: lydia kapiriri, McMaster University
A Phenomenological Hermeneutic Resolution to the Principlist-Narrative Bioethics Debate
Dr. Chandra Kavanagh, Memorial University of Newfoundland

Abstract Category: Standard Concurrent Session
Primary Theme: Theories and methodology in bioethics

Three Valuable Questions:
How does narrative provide us with a basis for agreement about what is best to do in terms of bioethical decision making?

Does teaching bioethics using context (such as case studies) mislead us about morality?

Must we choose between principlism and narrative bioethics?

Abstract: Narrative approaches to bioethics and principlist approaches to bioethics have often been presented in fundamental opposition to each other, and this is rightly the case when it comes to the most radical versions of each position. However, I argue that a phenomenological hermeneutic approach to the narrative versus principlist debate finds a compromise between both positions that maintains what is valuable in each of them. The project begins by exploring the diversity of perspectives contained under the heading ‘narrative bioethics’. I utilise the five categories of narrative bioethics found in Hilde Lindemann Nelson’s Stories and Their Limits: Narrative Approaches to Bioethics to highlight the profound differences that divide various narrative bioethical approaches. Despite these differences, I argue for five crucial similarities that bind together narrative bioethics as a coherent school of thought. These similarities include the following: arguments in favour of the ethical relevance of particularity, the view that epistemological value exists in first-person experience, the belief that the narrative form has a generative capacity within moral education rather than serving in a merely illustrative role, a shared critique of principlist approaches to bioethics for being unjustifiably reductive and finally, the shared claim that irreducible and incommensurable narratives are possible.

These five defining commonalities are also points of contention for principlists such as John Arras, who object to the logic and arguments that comprise the narrative bioethical position. Unlike narrative bioethicists, who argue that the narrative form serves as the fundamental ground that makes ethics articulable, the principlist argues that abstract concepts or maxims serve as the foundation of ethics. Arras presents a counter-argument to each of the five commonalities characteristic of narrative bioethics. In response to the position that particularity is ethically relevant, he argues that no manner exists to determine which particular cases are ethically relevant and which are not, without a prior set of governing principles that determines ethical questions. In response to the claim that there is epistemological value in first-person experience, he provides counterexamples, such as false consciousness and self-delusion that throw into question the epistemic accuracy of this type of experience. In response to the argument for the generative capacity of narrative, he reduces it to an illustrative device that can help us to learn ethical principles but that stands as fragmented, unrelated stories without those principles. In response to the critique that the principlist view is unjustifiably reductive, Arras responds that in the end, narrative approaches to bioethics also require a set of principles to make moral determinations. Finally, he argues that the dedication of narrative ethics to irreducible and incommensurable narratives means that a narrative bioethical approach requires an endless investigation before a moral decision can be made, and even after such an investigation, there may be no clear way forward when it comes to moral action.

Author Names: Chandra Kavanagh, Memorial University of Newfoundland
**Abstract Category:** Standard Concurrent Session  
**Primary Theme:** Ethics and health policy

**Three Valuable Questions:**
1. How are data trusts different than traditional data governance models in health research and health care, and what advantages do they offer?

2. Who should be the beneficiary of a health data trust?

3. How will trustees be chosen? Considering the professional duties imposed on them - who will be willing to take this burden?

**Abstract:** Artificial Intelligence (AI) researchers and companies are hungry for access to health data (clinical, imaging, and bioinformatics) to train medical algorithms and ultimately improve patient care. In broader policy debates, data trusts have been proposed as a strategy to facilitate access to personal data, while also protecting the interests of data subjects and other stakeholders. Modeled from legal trusts, data trusts clarify who is meant to benefit from data sharing, and may provide legal recourse against trustees in the case of irresponsible data management. Data trusts are expected to enhance data security and privacy, as well as rebalance power between individuals and data controllers. This can reassure both data generators and data providers to make data available for research and innovation. The data trust debate can shed light on how AI intensifies ethical, legal and commercial pressures on researchers and health care organizations responsible for health data. First, data trusts highlight the importance of defining a clear legal framework for governing data resources, including the purpose of establishing the trust and key stakeholder relationships. Researchers’ and hospitals’ intentions, by contrast, are often vague: is health data an asset to be commercialized, sensitive information to be protected, or a public resource meant to be stewarded? Second, data trusts highlight the importance of trustees being legally independent from data generating organizations, and their duties to avoid conflicts of interest. Such conflicts have already emerged where hospital leaders have financial relationships with AI companies accessing data, or withhold data access in the hopes of extracting some of the “anticipatory” value of AI applications. Furthermore, it is unclear how establishing a “new” legal entity will immediately strengthen trust, which takes time to build. Data trusts also have evident limits. First, the analogy from traditional trusts is incomplete, since data trusts cannot clearly assert ownership rights over personal data. This raises serious ethical concerns about accountability and privacy as soon as the trust releases data to researchers and companies. Second, data trusts still struggle to define who is supposed to benefit from the data trust. Are beneficiaries the AI researchers seeking to use data, the data subjects who provide data, or society in general (who presumably benefits from scientific insights and innovation)? The resulting vague definitions of beneficiaries and fiduciary duties raise enforceability concerns. Third, data trusts seek high-level legal relationships and recourse; they provide little practical guidance about day-to-day governance or technical needs. Health data resources still need detailed access governance to ensure only authorized parties access data for approved purposes. There is also an increasingly complex range of technical models for providing access, which involve important trade-offs between security and researcher freedom. It remains to be seen if the trust-gap in health research and health-care is sufficiently large to merit the adoption of data trusts in healthcare.

**Author Names:** Kristina Kekesi-Lafrance, McGill University; Adrian Thorogood
Will homeless people benefit equitably from the high-tech innovations in health care?

Dr. Julija Kelecevic, Hamilton Health Sciences

Abstract Category: Standard Concurrent Session
Primary Theme: AI and Ethics

Three Valuable Questions:
How health care system can bridge the inequalities in services provided for homeless individuals?

How health care professionals and leaders can engage homeless individuals in creating common framework for use of AI and other advance technologies?

How to create relationships between health care and other sectors that provide services that can positively affect health outcomes for the homeless individuals?

Abstract: Although we are currently witnessing fundamental economic and social transformations, people do not experience the impact of these transformations equally. Some of the most significant applications of artificial intelligence (AI) have been achieved in health care; however, many of the innovations have been limited to societies which researchers have easy access to material wealth and finances, and the benefits of this work are not spread equitably. One of the groups that we may need to consider when discussing AI in health care are homeless individuals. The challenges that this group faces when interacting with health care system are numerous and their health outcomes are comparably worse than in the population with stable housing. The ethical challenges in delivering care for homeless people have not been explored in great depth. Some of the recent research findings like Dr. Stergiopoulos' study (2019) about the home first approach, and others outlined that the improvement of health outcomes for homeless people may result by the use of low tech interventions, like rent supplements and structured access to mental health support services. With the growing access to developing technologies and overall, easier access to newer, shiner things, there is a lingering question: are these potentially beneficial social goods that may result in better health outcomes being equitably distributed?

In this presentation, we plan to examine the concepts of justice and transparency in relation to the access and the use of AI and other advance technologies for improving health outcomes in homeless individuals. Further, we plan to use case studies to illustrate the facilitators and barriers between the low and high tech approaches in providing care for the homeless individuals. We will examine tensions between the perceived social good of the new technologies and the anecdotal mistrust that homeless people may have about the power structure in health care Finally, we will devise a framework that is more inclusive around engagement of as end-users of AI and other innovative technologies using as an example of homeless patients who we service in our organizations.

References:

Author Names: Julija Kelecevic, Hamilton Health Sciences; Kevin Rodrigues, University Health Network
Advance Care Planning for Patients with Heart Failure: An Exploration of Relational Autonomy in the Context of Future Care Decision Making
Ms. Tieghan Killackey, University of Toronto/University Health Network

Abstract Category: Standard Concurrent Session
Primary Theme: Ethics and health policy

Three Valuable Questions:
1. How might these findings be transferable to other populations or contexts?
2. What other models of decision making exist that may guide further development of ACP?
3. What is the role of self-trust in the ACP process, or in autonomy more broadly?

Abstract: Background: Advance care planning (ACP) is the process of understanding and sharing personal values and goals to ensure people with serious illnesses receive medical care that is consistent with their preferences. With the increasing number and complexity of medical options available to patients, ACP is regarded as a means of preserving individual autonomy. Despite significant public awareness and interventions developed to increase participation in ACP, this practice remains severely under-utilized by those who are chronically ill. This gap in practice highlights the need for further understanding of how patients, families and healthcare providers (HCP) understand their autonomy in relation to the process of ACP.

Research Objectives: The aim of this research was to gain an understanding of how patients, families and healthcare providers (HCP) understand, experience and express their autonomy in the process of ACP.

Design: A critical qualitative multiple case study.

Methods: Patients with advanced heart failure (HF) were purposefully recruited from two study sites; cases were constructed using data from 19 semi-structured interviews with seven patients, eight caregivers, and nine HCP. 25 hours of observational data, field notes and document analysis were also used to build the cases, resulting in a total for 537 pages of data. Constructions of autonomy were developed using within and across-case analysis, guided by the concept of relational autonomy.

Results: There were three key findings that resulted from this study. First, ACP is understood as external to treatment decision-making within the current biomedical landscape, with a specific focus on the power of the legal model and therefore, signing a “Do Not Resuscitate” (DNR) document is one of the only methods for patients to exercise their autonomy. Second, the experience of autonomy in advanced heart failure is incongruent with the dominant individualistic approach and instead, is a relational experience that is based on trust and self-trust. Finally, ACP is influenced by interpersonal relationships and responsibilities as well as interpersonal and social power dynamics.

Conclusion: Although ACP is considered a practice that preserves individual autonomy, interpersonal, institutional and societal level relationships were all heavily influential in supporting this practice in the context of advanced illness. Future research and practice endeavours should consider the advancement of ACP (and the enactment of autonomy) within the contexts of institutional, social, and interpersonal relationships.

Author Names: Tieghan Killackey, University of Toronto/University Health Network; Elizabeth Peter; Jane Maciver; Shan Mohammed
Abstract Category: Standard Concurrent Session
Primary Theme: AI and Ethics

Three Valuable Questions:
Are there ethical issues associated with the presence of tech and AI companies in health and public health?

In what ways are ethics and governance issues associated with AI and tech companies similar or different to those associated with other industries in health (e.g., pharmaceuticals)?

Do the bioethics and business ethics literatures conceptualize the ethics and governance of AI companies in health differently, and if so, what are the potential implications?

Abstract: While the private sector has long been involved in health care and public health, advances in information technologies and artificial intelligence (AI) are increasingly attracting new industries and private sector entities into health care and public health. The increased private sector presence and ongoing public-private interactions in health raise ethical and political questions about the legitimate scope, ends and responsibilities of private stakeholders and institutions as they relate to health care and public health, both within and across nation states.

This presentation sets out to identify ethical issues that arise from private sector involvement—particularly in the technology and AI space—in health care and public health, and considers how non-state actors are implicated in and may contribute to health care and public health. In other words, rather than primarily asking what the ethical obligations of states are in regards to regulating AI and technology companies involved in health care and public health, the presentation focuses on the obligations of private entities themselves.

The first part of the presentation reviews existing accounts of the ethics and governance of technology companies within the bioethics (including public and global health ethics) literature, as well as in business ethics. Next, the presentation turns to considering whether the ethical issues associated with technology companies involved in AI research, development, and implementation are analogous to or different from those associated with industries (e.g., pharmaceutical and device manufacturers) that have traditionally been the focus of ethics guidance concerning industry in health care and public health. The presentation ends with a reflection on the merits and limitations of bridging the bioethics and business ethics literatures for informing ethical analysis and guidance concerning private sector involvement in health, and especially with respect to companies involved in AI development and implementation in health care and public health.

Author Names: Ana Komparic, University of Toronto
Developing ethics resources to support humanitarian healthcare innovation: perspectives of key stakeholders

Mr. Gautham Krishnaraj, Humanitarian Health Ethics Research Group

Abstract Category: Standard Concurrent Session
Primary Theme: Other Ethics and Humanitarian Innovation

Abstract: Introduction: In humanitarian settings such as conflict or natural disaster, innovation can be as important as regular programmatic activities or research conducted to inform response, and sometimes it can be difficult to distinguish from either of these. Obrecht & Warner (2016) define humanitarian innovation as “an iterative process that identifies, adjusts and diffuses ideas for improving humanitarian action”. At once experimental and responsive, innovation can be a welcome immediate response to an unresolved problem, but it can lack the oversight of research and the reliability of established evidence-based practices. To help resolve the unique ethical tensions that arise in humanitarian innovation, the Humanitarian Health Ethics Research Group (HHE) is collaborating with the Humanitarian Innovation Fund (HIF) and Elrha, a global charity that focuses on research and innovation in the humanitarian sector, to produce a set of ethics resources for humanitarian innovation. Principles rooted in bioethics can be a useful guide for innovations that aim to improve outcomes for people affected by humanitarian crises, particularly given the rise in biometric data use, artificial intelligence, and other novel health technologies by humanitarian organizations. The goal of this study is to explore humanitarians’ experiences and challenges with innovation, identify best principles for practice, and to begin defining humanitarian innovation from an ethical standpoint.

Methods: We employed an interpretive description methodology (Thorne, 2016), conducting key stakeholder interviews, recruiting through a purposive snowball sampling method, and engaging in concurrent analysis that was organized using QSR’s NVivo12 software. A total of 40 (24-16 M/F) individual, semi-structured interviews were conducted over five months. Interviews were conducted by a single researcher, in-person or on skype, and lasted 60-120 minutes in duration. Participant profiles included representatives from the UN system, international and local NGOs, government, and academia, with varying degrees of engagement with and understanding of humanitarian innovation processes.

Results: Interview participants had varying definitions and levels of comfort with ethics (usually citing Red Cross principles, and “do no harm”/non-maleficence) and innovation as concepts and practices. Some viewed innovation as a highly formalized process that carried Western cultural connotations and implicated bureaucratic processes, while others saw it as little more than the quotidian problem solving inherent to working in humanitarian contexts. Perceived barriers to transparent, ethical innovation included rigid funding structures, limited definitions of impact and failure, and a generally low appetite for risk (given the increased vulnerability of people affected by crises). Experiences of ‘successful’ innovation were often linked with highly participatory processes, where communities were engaged in a meaningful way at critical stages of the innovation process. Participants expressed strong interest in having guiding ethical principles for innovators in the humanitarian space, presented in a format that is accessible, interactive, and responsive to the changing realities of humanitarian practice.

Next Steps: HHE is actively integrating these reflections with the results of a scoping literature review, with the aim of producing and piloting a toolbox of humanitarian innovation ethics resources. The aim is to have these resources publicly available later this year through the Humanitarian Innovation Fund.

The Imperative Role for the Ethics of Care in Discussions on Disability and Personhood as Related to Autism Spectrum Disorders
Ms. Taylor Lakusta-Wong, Loma Linda University

Abstract Category: Standard Concurrent Session
Primary Theme: Neuroethics and neuroscience

Three Valuable Questions:
1. In a given scenario, how might you determine if autism is a disorder, not a disorder, or both?
2. Could you further explain what it might look like to apply care ethics in a clinical setting?
3. You mentioned a connection between personhood and autism—could you provide more specific examples of this?

Abstract: Autism Spectrum Disorders (ASD) encompass a spectrum of neurodevelopmental disorders characterized by altered communication and behaviors. But the neurodiversity movement poses the question, “Is autism truly a disorder?” The medically assumed answer is “Yes”: in many cases, the functional impairment is debilitating. Redefining autism as a non-disorder may thus limit access to therapies which have great potential to improve quality of life, rendering the classification all the more important. Yet, in cases where autism does not manifest as a clear medical disorder, individuals with autism simply demonstrate neurological differences that are not inferior but do not meet social expectations. Defining autism as a disorder in these cases may thus be perceived as disrespectful to the personhood of such individuals. While both perspectives on autism are well represented in the literature, these perspectives do not adequately account for the connection between neurodiversity and personhood. This paper addresses the issues raised by the neurodiversity movement with a focus on the relationship between autism and personhood. We promote a moderate perspective in which autism is simultaneously conceptualized as a disorder and not a disorder. This perspective acknowledges the full spectrum of autism, while differentiating between medical and social constructs of disability. We promote the ethics of care, which affirms an individual’s subjective experience and relationships, as an appropriate framework for addressing the needs of those affected by autism. Consequently, the application of the ethics of care at the levels of clinical intervention, policy making, and social understandings, is an appropriate response to the ethical challenges addressed by the neurodiversity movement.

Author Names: Taylor Lakusta-Wong, Loma Linda University; Alex Dubov
When going home is "treatment": Capacity, consent, and substitute decision-making in the context of a complex community discharge
Mr. Dave Langlois, Centre for Clinical Ethics, Unity Health Toronto

Abstract Category: Standard Concurrent Session
Primary Theme: Other Clinical Ethics

Three Valuable Questions:
1. For unrepresented patients without known family members, the Public Guardian and Trustee (in Ontario) is the statutory substitute decision-maker of last resort regarding treatment. Would the PG&T be willing to consent to a plan of treatment involving discharge, given that they typically do not and cannot make discharge decisions?

2. What does or should determine whether a patient's discharge should be managed as a treatment decision, rather than simply as a typical discharge?

3. What would or should happen if a patient's substitute decision-maker refused to consent to a patient's discharge (where the discharge is being handled as part of a plan of treatment)?

Abstract: In Ontario and some other jurisdictions, the prevailing healthcare laws concerning informed consent and decision-making capacity provide little guidance for managing complex discharges. When a medically stable patient is discharged from the hospital to return to the community, this discharge is generally understood not to be a treatment decision. If a person’s community discharge is not a treatment decision, it is not subject to the structure provided by consent and capacity legislation (e.g., Ontario’s Health Care Consent Act). And for complex legal reasons, other statutes that might first appear relevant (e.g., the Substitute Decisions Act) are often inapplicable in the most challenging circumstances. As a result, healthcare practitioners generally cannot make legally authoritative determinations about a patient’s capacity with respect to discharge and, relatedly, decisionally impaired patients have no legal substitute decision-makers regarding discharge. In typical discharges, where clinicians have minimal concerns about their patients’ decision-making, or where decisionally impaired patients are sufficiently supported by friends and family, the absence of a legal structure is unproblematic. In complex cases, however, the absence of a legal structure can create profound moral distress for clinicians.

Responses to this problem have fallen into two categories. In the first category, in an effort to respect the parameters set by the law, some authors have endorsed eliminating any consideration of patients’ capacity regarding discharge (Chidwick, et al. 2013, 45). This approach, while a reasonable response to the extant legal framework, may come with a considerable downside: failing to appreciate and address the full ethical complexity of discharging socially isolated individuals with decisional impairments. In the second category, in an effort to address the perceived legislative lacuna, some authors have endorsed conducting capacity assessments about discharge decisions and adopting local practices for informal substitute-decision-making about discharge (Abdool, et al. 2015). However, because these practices are arguably inconsistent with the prevailing laws, they raise concerns about professional practice, institutional liability, and patients’ rights.

In our session, we consider and reject these approaches and, as an alternative, propose a novel strategy that falls between these two extremes. Controversially, we argue that many complex discharges from hospital—even for medically stable patients—may appropriately be conceived of as treatment decisions. When a patient’s discharge should be one aspect of a broader plan of care that will extend into the community, that total plan, including the discharge, should be subject to the typical legal standards of informed consent to treatment. Accordingly, if a patient is incapable of making this decision on their own behalf, the decision should be made by their appropriate legal substitute decision-maker for treatment.

This approach has been developed and put to use through a collaboration between hospital-based healthcare providers, community care providers, and bioethicists. Our presentation will include an analysis of a deidentified case in which we successfully (albeit imperfectly) employed this strategy in Toronto, and will include insights from the patient’s hospital MRP (a nurse practitioner), transition planner (a nurse), community care coordinator (an occupational therapist), and the consulting bioethics service.

Author Names: Dave Langlois, Centre for Clinical Ethics, Unity Health Toronto; Christy Konietzny, Unity Health Toronto; Sharon Mulsant, Unity Health Toronto; Jamie Robertson, Centre for Clinical Ethics, Unity Health Toronto; Steve Abdool, Centre for Clinical Ethics, Unity Health Toronto; Tanya Poon, West Community Care Team, Toronto Central Local Health Integration Network
Can Artificial Intelligence Save the Substituted Judgment Standard?
Mr. Dave Langlois, Centre for Clinical Ethics, Unity Health Toronto

Abstract Category: Standard Concurrent Session
Primary Theme: AI and Ethics

Three Valuable Questions:
1. What are alternatives to the SJS? If we abandon the Substituted Judgment Standard, then on what basis could we make decisions on behalf of an incapable person?

2. Suppose we had truly perfect knowledge about what an incapable person would choose for themselves if they could. Are you saying that this would still not be of any value in substitute decision-making?

3. Is your argument also a criticism of advance healthcare directives (e.g., "living wills")? If not, why not?

Abstract: According to the Substituted Judgment Standard (SJS), the primary obligation of an incapable patient's substitute decision-maker is to make the decisions that the patient would make if she were capable (Buchanan and Brock, 1990). For example, when deciding whether to continue or discontinue life-sustaining treatments for a critically ill patient, the SJS requires that the patient’s proxy make her decision on the basis of a counterfactual judgment about what the patient would decide for herself if she could. If the patient would (if capable) wish to continue treatment, then treatment should be continued; if the patient would (if capable) wish to discontinue treatment, then treatment should be discontinued. The SJS is now a widely accepted part of the modern Western bioethical tradition, and it is enshrined in many jurisdictions’ laws concerning substitute decision-making. The SJS is standardly regarded as an uncontroversial corollary of the moral requirement to respect the autonomy of persons.

Although the SJS has become ubiquitous, it has been subjected to some philosophical scrutiny, primarily on epistemic grounds. Some critics have proposed that the counterfactual question embedded in the SJS is not a useful and meaningful question, because it is not one to which proxies could reliably know the answer. On this line of thought, the SJS is flawed because it doesn't provide an epistemically practicable standard. In support of this line of criticism, some recent empirical research has suggested that proxy decision-makers are, indeed, quite poor at accurately representing the would-be wishes of their wards (Newman et al., 2012).

In this paper and presentation, I consider whether artificial intelligence and emergent cognitive-mapping technologies might provide practical and epistemic support to the SJS. In the near future, we will have the ability to use personalized patient data and inputs (whether propositional or cognitive), paired with complex computer models, to make reliable counterfactual judgments about what would be an incapable patient’s current wishes (if they were capable). One might see these technologies as closing a small gap that has, thus far, prevented the SJS from being fully actualized.

Against this attractive conclusion, however, I argue that artificial intelligence and cognitive-mapping technologies offer no support to the SJS. In fact, I propose that considering how technologies could be used to answer the counterfactual question embedded in the SJS helps to reveal a stark conceptual problem within the standard itself. The SJS rests on a misunderstanding of the nature and source of the moral authority derived from a person’s autonomous choice. Drawing on historical and contemporary authors’ work on the nature of autonomy—from Kant to Korsgaard—I will argue that it is only actual choices and willings, and not hypothetical or potential choices and willings, which carry moral authority and require respect. As a consequence, we should abandon the SJS and fundamentally reconsider the ethics of substitute decision-making.

Author Names: Dave Langlois, Centre for Clinical Ethics, Unity Health Toronto
Abstract Category: Standard Concurrent Session
Primary Theme: Ethics, perinatality and procreation

Three Valuable Questions:
What types of regulations would Canada need in place prior to offering these transplants?

Is payment for uterine transplantation more ethically acceptable given the basic needs of many individuals are not met and thus should not be subsided by health care dollars?

Ought we limit further subsidized medical interventions in Canada when Canadians seek medical interventions abroad?

Abstract: 2012 ushered in a new wave of successful assisted reproductive technologies when the first successful uterine transplants began in Sweden through the harvesting of uteri from live donors. Eight years later there have been two successful live births that have resulted from the use of cadaver donors, both of which occurred in the US.

While uterine transplantation has consistently fallen in the purview of research worldwide there has been a failure to identify appropriate regulation for when uterine transplantation is no longer research. At the current rate of progression, it is reasonable to foresee uterine transplantation will become like many other assisted reproductive technologies, a pay for play model.

Given that it is highly unlikely uterine transplantation will flourish in the Canadian context due to significant restraints such as limited surgical units, lack of training and lack of funding, it is foreseeable that Canadians may choose to venture to the US to seek uterine transplantation.

The purpose of this presentation is to elucidate ethical questions surrounding potential medical tourism, but additionally is meant to highlight the current regulatory structure in the US. Congress enacted the National Organ Transplant Act (NOTA) in 1984 and while NOTA did not initially address uteri as a governed organ when HHS asserted jurisdiction over VCA’s in 2014 uteri were governed. Importantly, this is inconsistent with the governance of most assisted reproductive technologies (ARTs) in the US. There is currently only one federal act that regulates ARTs – the Fertility Clinic Success Rate and Certification Act. Instead the American Society of Reproductive Medicine (ASRM) and its affiliate organization, the Society for Assisted Reproductive Technology (SART) provide non-binding governance documents in order to help “regulate” ARTs. This poses the question of whether uterine transplantation will be governed by typical organ donation practices or whether it ought to be governed by the free market that all other ARTs are subject to.

Additionally, when these individuals return to Canada, they are the responsibility of the Canadian health care system, which poses other questions of obligations associated with cost and potential future interventions.

Author Names: Katarina Lee-Ameduri, St. Boniface Hospital/University of Manitoba
One and Yet, Many: Judaism, Genetics and the potency of pre-natal CRISPR manipulation
Ms. Yoelit Lipinsky.

Abstract Category: Standard Concurrent Session
Primary Theme: Ethics, perinatality and procreation

Three Valuable Questions:
1) How can we accommodate religious tradition without potentially harming a patient?
2) How can we reduce harm and potentially integrate CRISPR and other genetic technology?
3) Can religious ethics help us establish protocols, policies and boundaries as technology progresses?

Abstract: Judaism is an endogamous culture. Often, this results in significant genetic mutations during reproduction. As a result, Ashkenazic Jewry (Jews from Eastern Europe) have created a plethora of genetic testing options for young couples. This has proven successful; rates of Tay-Sachs have significantly decreased since the introduction of these services. Although genetic screening is vital for the Jewish community, there is tension surrounding the progression of such testing including sex selection, genetic enhancement and the CRISPR technologies.

However, Judaism is a pro-natalist religion. Nowhere is there more apparent than the State of Israel. As such, there have been several significant cases brought before courts of law in which more aggressive genetic testing and selection was permitted expressly due to religion. Indeed, this paper will seek to not merely explore the Judaic principles surrounding genetic screening and testing. Rather, this paper will drive the dialogue further. Judaism is perhaps more lenient and progressive in sanctioning genetic medicine than previously believed. Indeed, the religion may wholeheartedly embrace CRISPR while the secular ethics community is more hesitant of the technology. How can we balance religious and secular ethics when so much is unknown? Whether and how can we make scientific progress in an ethical manner?

Author Names: Yoelit Lipinsky
Equitable AI in Healthcare: What Do We Mean?
Ms. Jillian Macklin, University of Toronto

Abstract Category: Standard Concurrent Session
Primary Theme: AI and Ethics

Three Valuable Questions:
1) What were the similarities and differences in equity concepts across the multi-disciplinary field of AI (eg. computer science vs public health vs ethics, etc).

2) What does this work mean for future AI research?

3) What are the most tangible areas of AI design, development, and implementation to tackle equity?

Abstract: Background: Equity is widely recognized as a key guiding principle for ethical AI. The CIHR Institute of Public and Population Health’s new Equitable AI Initiative “recognizes the importance of ensuring equity is built into AI research from the start” because “only through prioritizing equity can we ensure health solutions benefit everyone”. However, as we plan toward a research program for equitable AI, we are facing questions about what equitable AI means in practice for health research. On the one hand, there are different, and often competing, conceptions of equity (e.g., equal outcomes vs. equal access); on the other hand, different AI methods may lead to different equity-related outputs. As a result, it is not always clear where research teams should focus their efforts or how emerging research programs should plan and set priorities to advance health and social equity. To bridge this gap, we synthesized what is currently known about equity-informed AI to gain a better understanding of its conceptual, normative and practical dimensions.

Methods: We produced a literature synthesis based on a rapid literature search (Scopus, Medline, Embase), as well as articles amongst our circle. We extracted equity concepts from 47 articles and created a concept map.

Results: Five key equity concepts were constructed: Equal Benefit (AI is equitable if AI’s development produces social and economic benefit for all by reducing social inequalities and vulnerabilities, either form the utilitarian, egalitarian, or minimax view), Equal Access (AI is equitable if availability and access to AI fundamental resources, knowledge, and digital tools are guaranteed for all), Structural Equity (AI is equitable if it is designed and trained so as not to create, reinforce, or reproduce discrimination based on social, sexual, ethnic, or cultural differences, among others), Representativeness (AI is equitable if AI works to minimize or eliminate bias in datasets and seeks active participation of, and meaningful consultation with, a diverse community from the start), and Algorithmic Fairness (AI is equitable if algorithms have been thoroughly studied to understand priorities and trade-offs between equal machine performance and accuracy for all groups). We define these concepts, relate them to one another, and discuss how these different concepts conflict in practice.

Significance/Future Directions: This work synthesizes a better understanding of equity for the purposes, processes, and products of AI research in healthcare. It helps inform future priorities in AI research, guide research practices, train research personnel, and inform decision makers and AI designers. This work highlights the need for research teams to discuss their concepts of equity and the trade-offs needed to be made with different equity outputs in practice. Our next step is to engage local research teams who are using AI methods in their population to clarify the equity-related issues and questions they are facing in the design and conduct of AI health research and to canvas the practical steps they are taking to address these issues.

Author Names: Jillian Macklin, University of Toronto; Jennifer Gibson
Abstract Category: Standard Concurrent Session
Primary Theme: Ethics and health technology assessment

Abstract: Humber River Hospital (HRH) is one of Canada’s largest regional acute care hospitals, serving more than 850,000 people in the northwest Greater Toronto Area (GTA). Canada’s first fully digital hospital, HRH provides both in-patient and out-patient care. HRH has implemented several digital technologies to support patient care. In September of 2019, in partnership with General Electric Healthcare Partners, HRH was the first in the world to launch clinical analytic applications inside the hospital’s Command Centre to strive for excellence in patient care and work toward being a high reliability hospital. The new clinical applications integrate standardized early warning systems, predictive analytics, real-time information from multiple digital systems, and professional expertise, to provide early alerts for patients with conditions that make them more vulnerable to risks of adverse events. Other forms of technology offered at HRH are applications such as MyHumber Health which is a platform that allows patients to access their own health information and test results. HRH has also invested in technology tools for specific patient groups. For instance, in 2014 HRH purchased Pepper, a social humanoid robot that helps provide support to sick children and their families and can greet and guide patients in the hospital. HRH also has an integrated bedside terminal in each room that works as a telephone, television, radio, computer, and offers a number of patient resources and videos. Further technological investments seen throughout HRH are Ascom phones, robotics in pharmacy, lab, operating room and many others. Although there are multiple ethical concerns associated with emerging health technologies, this exploratory review is focused on how patient values, wishes and beliefs can be included in their care using technology. Since 2011, Humber River Hospital has also been an early adopter of Advance Care Planning (ACP). HRH understands the importance of patient engagement in their health and recovery. Resources were developed in accordance with the SpeakUp Canada materials encouraging patients to think about, talk about and share their wishes, values and beliefs for future personal and health care, understanding that this is extremely important to patient care. One of the first steps in ACP is to verify or identify a substitute decision maker (SDM) in the event that a patient becomes incapable of making a healthcare decision. Given the technological advancements in patient care, there are opportunities to share patient values and wishes associated with their care, and at a minimum, consistently and clearly indicate a patient's SDM on the their medical record. Through a fulsome analysis of the technologies HRH currently employs, technological opportunities will be identified and tested to encourage these important ACP conversations, and ultimately enhance patient care.

Author Names: Rosanna Macri, Humber River Hospital
What Lies Beneath: The Underlying Ethics of Vaccine Hesitancy and Potential Lessons for Communicating with the Hesitant Parent

Ms. Juhee Makkar

Abstract Category: Standard Concurrent Session
Primary Theme: Public health ethics

Abstract: The World Health Organization (WHO) has identified vaccine hesitancy as one of the top ten threats to global health in 2019 (2019). Continuing outbreaks of vaccine preventable diseases have created a sense of urgency and concern for health care providers who must counsel parents on the appropriate course of action for their children. Despite credible evidence supporting the benefits of immunization, some parents remain steadfast in their refusal to vaccinate or are, at the very least, ambivalent about the practice. Organizations such as the College of Family Physicians of Canada (CFPC) and the Canadian Paediatric Society (CPS) have recently issued practical clinical guidance for physicians on how to advise vaccine-hesitant parents. Recommendations include the use of presumptive and motivational interviewing techniques, story telling, and open and honest communication that builds trust (MacDonald, Desai, & Gertein, 2018; Shen & Dubey, 2019). However, these recommendations lack a more detailed exploration of the values and beliefs held by vaccine hesitant parents, which may influence decision-making.

A few research studies suggest that vaccine hesitancy has a distinct moral component; that is, a parent’s ethical viewpoint can contribute to his or her attitude towards vaccination (Amin et al., 2017; Rossen, Hurlstone, Dunlop, & Lawrence, 2019). These studies speculate that by appealing to the values held by vaccine hesitant parents, it may be possible to increase vaccine uptake (Amin et al., 2017, p. 877; Rossen et al., 2019, p. 27). Vaccination messaging that addresses the underlying moral concerns of parents is presented as an issue with potential for further exploration.

Ethical frameworks can assist in categorizing the values held by vaccine hesitant parents such that patterns begin to emerge; it may become clear that certain moral concerns conflict or are particularly relevant when addressing vaccine hesitancy. An ethical analysis of existing literature on the beliefs and values of vaccine hesitant parents may also reveal commonalities in thought between clinicians and parents, which can be a useful starting point for conversation about negative attitudes towards vaccination.

In this paper I will conduct an ethical analysis of research literature on the connection between moral belief and vaccine hesitancy. This may in turn identify which moral concerns or ethical principles are the most relevant for the vaccine hesitant parent. If supported by the evidence, I will then offer recommendations for how the ethical principles identified in the above exercise can be translated into a possible communication strategy for clinicians.

REFERENCES


Author Names: Juhee Makkar
An ethical response to the development of transplant technology
Mr. David Matas

Abstract Category: Standard Concurrent Session
Primary Theme: Ethics and health policy

Three Valuable Questions:
1. Should reporting by health professionals to health administrators of transplant tourism and transplant abuse be statistical only or should the reporting include information which identifies patients?

2. In light of the evidence of transplant abuse in China, should foreign transplant professionals ostracise or engage with Chinese transplant professionals to attempt to effect reform?

3. To what extent can professional ethics be effective in combating cross border organ transplant abuse?

Abstract: The development of transplant technology raises ethical issues which did not exist before transplants were possible. In particular, the development of transplant technology allows for the possibility that innocents will be killed for their organs. That possibility requires an ethical response. As transplant technology develops, the threat of transplant abuse becomes more acute and the need to develop an appropriate ethical response becomes more dire.

There is persistent and credible evidence that prisoners of conscience in China have been and are being killed on an industrial scale for the organs. Primary victims are practitioners of the spiritually based set of exercises Falun Gong and Uyghurs.

The Transplantation Society, the international association of transplant professionals, developed in 2006 a policy on interaction between Chinese and foreign transplant professionals, in light of the then evidence of Chinese transplant abuse. The Canadian Society of Transplantation and the Canadian Society of Nephrologists developed in 2010 an elaborate and sophisticated ethical response to cross border transplant abuse and transplant tourism which focuses specifically on patient counselling.

The issue of compulsory reporting from health professionals to health administrators has been addressed across a wide spectrum of health issues, but not squarely anywhere in the area of transplant tourism and transplant abuse. Research protocols for anti-rejection drug testing in China to avoid complicity in organ transplant abuse have been developed by some pharmaceutical companies, but not by public bodies. The 1964 World Medical Association Declaration of Helsinki on ethical principles for medical research involving human subjects does not address transplantation specifically.

The paper would first of all present a summary of evidence about transplant abuse in China as a background factual setting for a presentation on the ethical issues posed. The paper would then go through the four sets of ethical issues generated by this factual setting - patient counselling, interaction with Chinese transplant professionals, reporting by health professionals to health administrators of transplant abuse and transplant tourism, and research.

For patient counselling, the paper would consider the extent to which the Canadian standards could be internationalized. For interaction with Chinese transplant professionals, the paper would consider the extent to which The Transplantation Society standards need to be updated, elaborated or modified.

For reporting by health professionals to health administrators of transplant abuse and transplant tourism, the paper would consider the advisable forms and locus of reporting mechanisms. For research, the paper would address how the standards developed by pharmaceutical companies can be transformed into health policy.

The paper would further consider how the Declaration of Helsinki principles could be made applicable particularly to transplantation research. Finally, the paper would attempt to suggest how all of the four sets of ethical issues arising out of transplantation technology could be addressed globally and comprehensively.

Author Names: David Matas
A Defense of the Less-to-Lose Principle for Gene-Editing Research
Dr. Eric Mathison

Abstract Category: Standard Concurrent Session
Primary Theme: Research Ethics

Three Valuable Questions:
1) What is the correct way to identify research subjects?
2) How much weight should the ability to consent be given in selecting research subjects?
3) When gene-editing research can be conducted on subjects with different diseases, which diseases should be researched first?

Abstract: In an editorial last year, Julian Savulescu and Peter Singer propose a translational pathway for human genome editing. On their view, researchers should first focus on catastrophic single gene disorders that are fatal in the neonatal period and for which there is no current cure before researching less-severe diseases. Thus, Tay-Sachs is a better candidate for gene-editing research than Huntington’s, as babies suffering from the former will die within the first few years of life, whereas those with Huntington’s usually experience no negative symptoms until middle age. Savulescu and Singer propose that research on the former is more justified because those with Tay-Sachs have “less to lose”. The editorial nature of their proposal means that they do not explore this point.

In this paper, I defend and explore the implications of the less-to-lose principle. It holds that, when all else is equal, research should be conducted on subjects who will experience the smallest loss of expected welfare, where ‘expected’ includes both the magnitude of the loss and the likelihood of the loss occurring.

The less-to-lose principle is controversial when applied to different classes of research subject. Many believe that research should be conducted on subjects with the capacity to consent whenever possible. For instance, according to the Helsinki Declaration (para. 28), it is impermissible to conduct research on incapacitated subjects if the research could instead be conducted on capacitated subjects. This is true regardless of the potential consequences to the subject: i.e., even if a capacitated subject faces much greater potential for harm than an incapacitated subject, it is still preferable to conduct the study on the capacitated subject. Capacity is a trump.

I argue that the Helsinki Declaration gets it wrong and that the less-to-lose principle explains why. While there is a reason to choose the capacitated subject for research when all else is equal—i.e., when the subjects face the same expected consequences—the Declaration over-emphasises capacity. This is true both when choosing between different diseases for the same type of research (i.e., studying the effectiveness of gene-editing on diseases), and also when choosing subjects with the same disease. Thus, contrary to the Helsinki Declaration, it is better to research on infants with a severe form of ornithine transcarbamylase deficiency than on adults with a less severe form. This change in priorities explains the wrongness of the research that led to Jesse Gelsinger’s death.

Consent is a crucial condition of ethical research on capacitated subjects, but capacity to consent should not have the trumping power afforded to it by the Declaration. Put another way, the risk of harm to the Huntington’s subject is much greater than the risk to the Tay-Sachs subject, so even though the adult can give consent and the infant cannot, we ought to conduct research on the infant if the expected research contribution is the same (and if other conditions for ethical research are met). Acceptance of the less-to-lose principle therefore warrants a significant change in research priorities.

Author Names: Eric Mathison
Brain Injury and the “Reverse Turing Test”
Dr. Richard Maundrell, Lakehead University

Abstract Category: Standard Concurrent Session
Primary Theme: Neuroethics and neuroscience

Three Valuable Questions:
Since consciousness is poorly understood, can we trust neurophysiological "markers" of consciousness?

Would a test for consciousness bring us up against the reverse inference problem (i.e. drawing inference from correlate of consciousness to consciousness itself)?

Should the diminished consciousness of the profoundly brain-injured have moral standing?

Abstract: The presence of attentional awareness is difficult to assess in patients who cannot respond to motor commands. In recent years, fMRI has been used to interact with patients in the unresponsive waking state. However, it can be impracticable to get seriously brain-injured patients out of an ICU and into an MRI. It would be helpful to have a bedside test for consciousness.

Electroencephalograph (EEG) technology is a non-invasive means of monitoring cortical activity, but an EEG readout is informationally complex, subject to electromagnetic interference, and difficult to interpret - even for experts. In June of 2019, The New England Journal of Medicine published the results of a clinical study involving the application of EEG in detecting cortical response to spoken motor commands in otherwise unresponsive patients. The analysis of EEG data in the study was performed by machine learning technology developed to recognize electrocortical markers of consciousness. This AI enhancement of an old technology shows promise, but how far can we trust machine learning to help us make critical treatment decisions? Should such technology be deployed in the determination of neurological death?

Author Names: Richard Maundrell, Lakehead University
Fixing bias with math?: minding the 'fairness' gap
Dr. Melissa McCradden, The Hospital for Sick Children

Abstract Category: Standard Concurrent Session
Primary Theme: AI and Ethics

Three Valuable Questions:
1. How can bioethicists engage with the development of clinical ML tools to minimize the risk of exacerbating bias?

2. What is the gap between fairness in ML predictions and real-world fairness?

3. How can we bring a bioethics lens to engage with computer scientists developing these tools and the clinicians who intend to use them?

Abstract: The worry that pernicious bias (i.e., reflecting social inequality) may be exacerbated with the use of machine learning (ML) has been recognized by bioethicists and computer scientists alike. The ‘Fair ML’ field is actively developing solutions that researchers hope will produce fairness for patients by virtue of engineering fair predictions. These solutions are increasingly marketed by tech companies as a way to ‘correct for’ existing biases, including those in medicine.

Recently, Obermeyer and colleagues unearthed racial discrimination in a widely used USA-based algorithm automatically referred patients to a complex care management program (Science, 2019). The shocking part for many was that algorithm was purportedly ‘neutral’. Developers, aware of potential racial bias, removed ‘race’ from the dataset and focused on total healthcare expenditures per patient as a proxy for medical need.

Obermeyer’s group revealed that when broken down by race, a black patient had to be twice as sick as a non-black patient to have the same cost expenditure and thus automatic referral to the program. This example highlights the serious implications of naively correcting for bias through algorithmic fairness solutions.

Currently, there is a lack of ethically-grounded guidance on promoting ‘fair’ predictions when the data reflects unfairness. This presentation will outline a set of considerations and practical points for bioethical engagement in the problem of bias in clinical ML. Through algorithmic fairness, we will explore the gap between fairness of predictions and fairness in outcomes. We begin by describing the range of ‘algorithmic fairness’ solutions and explore their limitations epistemically, empirically, and ethically.

The main epistemic limitation of algorithmic fairness is that it assumes the relationship between the extent of bias’s impact on a given health outcome and one’s protected identity is mathematically quantifiable. The reality is that social and structural factors confluence in complex and unknown ways to produce health inequalities. With respect to any specific task, it is difficult to untangle the complex relationships between potentially influential factors and which ones are ‘fair’ and which are not to inform their inclusion or mitigation in the model’s design.

Empirically, when attempting to control for the effects of bias within an ML model we may unintentionally obfuscate persistent inequalities. Effectively the algorithmic solution creates a prediction that is based on relationships that do not map onto the real-world. As such, seeing fairness only through the predictions can make us ignorant to the real-world unfairness. Moreover, the clinical accuracy of the model will suffer and ultimately become unhelpful to clinicians.

Bioethics provides a critical lens to help computer scientists and clinicians work through these challenges from the stage of conceptualization to clinical integration. Importantly, there are opportunities to use ML to bring the bias problem to the forefront of medicine. Considerations to inform ML solutions include: 1) identifying values at stake for a particular task; 2) explore competing justifications for options about how the ML problem is formulated; 3) identifying opportunities for transparency to inform clinical decision-making; 4) advocating for inclusion of under-represented stakeholders.

Author Names: Melissa McCradden, The Hospital for Sick Children; James Anderson, The Hospital for Sick Children; Mjaye Mazwi, The Hospital for Sick Children; Shalmali Joshi, Vector Institute for Artificial Intelligence
Reinvent the wheel? Situating healthcare machine learning in the research ethics pathway
Dr. Melissa McCradden, The Hospital for Sick Children

Abstract Category: Standard Concurrent Session
Primary Theme: Research Ethics

Three Valuable Questions:
1. What do members of research ethics boards need to know to evaluate clinical machine learning?

2. How can we promote evidence-based application of ML tools in healthcare?

3. What is familiar and what is really novel about clinical ML?

Abstract: There is an apparent lack of authoritative guidance for effective, ethical oversight for healthcare machine learning (ML), both for ML solutions developed within academic healthcare institutions and those from industry. As narratives consistently appeal to ML’s novelty, innovativeness, and unique methodology, proponents often argue it is ill-fitted to research review processes. It is essential to identify the novel challenges posed by ML to develop a consistent, rigorous review process to evaluate models.

Here we describe a proposal for a ML pipeline for healthcare institutions, divided into three stages: 1) exploratory ML research; 2) the ‘silent trial’; 3) clinical evaluation. These stages each have ML-specific considerations but can be grounded in existing concepts in research ethics.

The (1) exploratory ML research involves retrospective analysis of health data collected for clinical purposes, which fits under current Tri-Council Policy Statement (TCPS)-2 specifications for ‘secondary use of data’. A departure from this precedent is the lack of a priori hypotheses. Common practice in ML is to avoid making assumptions about the data, the relationships between variables, and the possible tasks in order to avoid assumptions that could prompt a biased analysis of the data. A general method is that the research team works with the data, testing a huge variety of potential models to look for tasks that can be of clinical value.

Some argue that quality improvement (QI) is better suited for ML, since ML is intended to improve care of individuals, is not protocol-driven, requires iterative modifications, is often not generalizable, and is not independent from routine medical care. However, the ethical underpinning of QI is the optimization of established interventions that are known to be in patients’ best interests. There is a well-recognized gap in performance accuracy in a retrospective database versus real-time (the ‘AI chasm’ [Keane & Topol, 2018]). Therefore, performance in stage (1) is insufficient justification for assuming good performance in real-time, and so prospective research is critical and parallels with QI do not apply.

Clinical evaluation initially involves a (2) ‘silent trial’, where the model predicts for real patient cases but independent from the clinical team. A research team assesses predictions against the clinical course/outcomes to establish the clinical accuracy. The silent trial thereby informs clinical equipoise - the ethical underpinning for conducting medical research. Because ML accuracy in retrospective data is entirely disconnected from clinical accuracy, equipoise cannot be established until the silent trial. Once the silent trial has generated sufficient uncertainty about whether the model is superior to the current standard, we have ethical justification for conducting clinical research.

The second phase of clinical evaluation involves a (3) prospective clinical trial where the model is analogous to any medical intervention. The central question is whether the model can independently influence patient outcomes, requiring a comparison between patients whose care is informed by the ML model versus those whose care proceeds as per the current standard. Through this pathway, ML models can be assessed to the same level of scrutiny as any other evidence-based medical practice.

Author Names: Melissa McCradden, The Hospital for Sick Children; James Anderson, The Hospital for Sick Children; Anna Goldenberg, The Hospital for Sick Children; Randi Zlotnik Shaul, The Hospital for Sick Children; Lauren Erdman, The Hospital for Sick Children; Elizabeth Stephenson, The Hospital for Sick Children
Ethical Considerations in the Antenatal Management of Preterm Labour at Borderline Viability
Ms. Virginia McLaughlin, Alberta Health Services

Abstract Category: Standard Concurrent Session
Primary Theme: Ethics, perinatality and procreation

Three Valuable Questions:
Three questions:

1. How can obstetrical and neonatal teams clarify the substantive values inherent in the antenatal management of preterm labour at borderline viability?

2. How might teams approach decisions around interventions?

3. How should providers and teams make decisions around antenatal interventions?

Abstract:
Preterm labour, particularly at borderline viability, results in a series of clinical judgements and decisions about the benefits and risks of antenatal interventions including medical management, monitoring, and timing and mode of delivery. There are occasionally different views on these interventions within the multidisciplinary team.

To achieve greater team consensus on antenatal interventions, it is important to name and clarify the substantive and procedural values underlying the management of threatened preterm labour.

Substantive value tensions may relate to different perspectives on the ethical obligations providers have to both to the pregnant person and to the fetus. Debates about the moral status of the fetus are well represented in the discourse surrounding termination of pregnancy, including work that that emphasizes the moral significance of the interconnected relationship between the pregnant person and the fetus (Cannold, 2001). This view of interconnection is relevant yet seldom applied to antenatal and obstetrical interventions in the context of preterm labour.

Clinical interventions seek to achieve beneficial or desirable ends and to avoid negative outcomes (death, morbidity, trauma). How a healthcare professional assesses benefits or harms of interventions depends on whether the pregnant person and fetus are assessed in isolation or as an interconnected unit. Medical professionals may offer a range of meaningful clinical interventions to the pregnant person that look to optimize that individual’s health outcomes and the health outcomes of the fetus. This may include interventions that are done for the benefit of the fetus, but confer little or no direct medical benefit to the pregnant person (example; magnesium sulfate for neuroprotection and antenatal corticosteroids for lung maturation (Ladhani et al, 2017)).

A more straightforward, but still important consideration is that these decisions often involve moments of important communication within and between separate obstetrical and neonatology teams, who in turn may independently communicate with the pregnant person. Procedurally, careful attention therefore needs to be given to consistent, respectful and clear professional communication.

References:


Author Names: Virginia McLaughlin, Alberta Health Services
Abstract Category: Standard Concurrent Session
Primary Theme: Other Medical aid/ assistance in dying and hospice palliative care

Three Valuable Questions:
1.) What should hospices that are interested in allowing MAID consider to minimize challenges and maximize opportunities?
2.) What is the relationship between the perception of hospice workers towards MAID and the dying process?
3.) What is the relationship/difference between MAID and palliative sedation within the hospice setting?

Abstract: Background:
The recent introduction of medical aid in dying/medical assistance in dying (MAID) to the Canadian healthcare landscape has created a new treatment option for the management of suffering in patients with chronic and/or terminal illnesses. By adopting this role MAID has been placed on a collision course with hospice palliative care.

However, many in the hospice palliative care community have criticized MAID, going so far as to argue that it is incompatible with the hospice palliative care approach. This argument has gained traction when applied to stand-alone hospices, with Quebec legislation allowing hospices to opt out of providing MAID, and British Columbia’s Delta Hospice Society engaging in a public standoff with the provincial government on whether MAID should be allowed within hospices. Canadian hospices outside of these provinces have also decided not to offer MAID.

That said, several hospices in Canada do offer MAID. There is little knowledge as to why some hospices have decided to integrate MAID into the care they provide, and others do not. Moreover, there has been little research as to the impact of allowing MAID within hospices on hospice workers and the care they provide. This study aims to address this knowledge gap by using qualitative description to identify the perspectives of hospice workers as to what opportunities and challenges MAID brings to hospice practice—envisioned here as the social activity undertaken by hospice workers in providing care within free-standing hospice institutions.

Methodology and methods:
This study utilized qualitative description and conducted focus groups and semi structured individual interviews with Canadian hospice workers at two hospice sites in Alberta and Quebec. The Alberta hospice site has allowed MAID within its walls, while the Quebec one has not. A total of nineteen participants were recruited. Given the interdisciplinary nature of hospice care, participants represented a range of hospice occupations. Participants were asked to discuss the opportunities and challenges MAID brings to hospice practice. Qualitative content analysis was applied to the data to generate categories, and the results from the two hospice sites were compared.

Results:
Preliminary results from the Alberta site indicate that participants view MAID as a disruption to hospice practice. Many participants described this disruption as having created a variety of challenges for hospice workers. However, a few participants perceived MAID as providing an opportunity to further hospice practice. These findings will be compared with that from the Quebec site, allowing researchers to see if predictions from the Quebec site regarding the impact of MAID on hospice practice indeed materialized at the Alberta site. The implications of these findings on the relationship between Canadian hospice practice and MAID will be discussed.

Significance:
This study hopes to better elucidate the impact of MAID on Canadian hospice practice. In doing so, this study hopes to provide policy makers and healthcare administrators with knowledge to help navigate the emerging relationship between Canadian hospice practice and MAID.

Author Names: James Mellett, McGill University; Mary Ellen Macdonald, McGill University
Abstract Category: Standard Concurrent Session
Primary Theme: Other Resource Allocation

Three Valuable Questions:
1. What stakeholder engagement methods pre & post guideline development were used, which were successful and why?
2. What feedback have patient and family advisors provided since implementation?
3. What are the lessons learned and recommendations for adopting a length of stay guideline in my own setting?

Abstract: This presentation will explore the complex issue of managing requests to extend length of stay for in-patients at a pediatric rehabilitation hospital and the development of a guideline to manage these requests fairly. Holland Bloorview Kids Rehabilitation Hospital is Canada’s largest pediatric rehabilitation teaching hospital and as such serves the local, provincial and, at times the national community. The hospital has a 75-bed inpatient capacity that is divided into three units: Specialized Orthopedic and Developmental Rehab, Brain Injury Rehab Team, and Complex Continuing Care. The allied healthcare team, the most responsible physician or the family can initiate requests for an extension to the length of a child's inpatient stay.

Many inpatient lengths of stay extension requests can be determined by consideration of medical stability, safety, and achievement of clinical goals. However the increasing complexity in the population of children and youth with congenital and acquired disabilities have led to an increasing number of extension requests combine with increasing demand for inpatient beds.

With the recognition of the need for a standardized way to consider requests and justify decisions, the process began to engage stakeholders in developing a Length of Stay guidance document. In addition to review of both internal and external polices, relevant law and literature, a working group (front line clinicians who are members of the hospital’s Bioethics Forum, a Family Leader, an Operations Manager and the Bioethicist) was formed. Multiple stakeholder engagement activities were conducted including interactive case-based clinician sessions (more than nine disciplines were represented with more than 35 individuals attending over two sessions), an ongoing drop-in feedback thought activity (which sought feedback from youth-aged inpatients, parents of inpatients, administrators and frontline staff), as well as consultation with the hospital’s Bioethics Forum.

After the guidance document was drafted, communication to key stakeholders of the changes began. All information sessions were delivered in person to allow for questions and any clarifications. These information sessions also allowed the Bioethicist to answer questions about the stakeholder engagement activities and highlight where how that input had been incorporated. After a short trial period that allowed for initial user experience changes to be made the guidance document was disseminated.

This presentation will explore the journey of engaging stakeholders to inform the development of a length of stay extension request guidance document and the ethical principles used to create a standardized way to consider and justify the extension decisions.

Author Names: Dolly Menna-Dack, Holland Bloorview Kids Rehabilitation Hospital
Abstract Category: Standard Concurrent Session
Primary Theme: Ethics and genomics

Three Valuable Questions:
Should all patients be told of secondary findings, or is this program of better use if only patients who are attempting to concieve are notified?

Given the relationship between STRs and disease severity should all patients be notified or only high risk patients.

Should low risk carriers be notified, this news may be harmful to some who are unlikely to develop a secondary illness or those who are unlikely to have an affected child?

Abstract: Arguments of actionability are often made when determining if secondary findings of whole genome or whole exome sequencing (WES/WGS) should be reported. The American College of Genetics and Genomics (AMCG) maintains a list of 56 genetic mutations or variants, known as secondary findings, that are reported to patients. Decisions to report or include a gene on this list are largely predicated on medical actionability. The AMCG defines actionability as evaluating penetrance, intervention efficacy, risk/benefits of intervention and current knowledge of the gene in question. This definition is inadequate as it does not allow for genetic anticipation, nor does it consider issues of procreative beneficence. The exclusion of monogenetic disorders caused by short tandem repeats (STRs) from the secondary findings list highlights the insufficiency of the current AMCG secondary findings list and the inadequacy of the current definition of medical actionability.

Monogenetic diseases such as Fragile X, Friederichs’s Ataxia and Myotonic Dystrophy types 1 and 2 are caused by STRs in non-coding regions of DNA which interfere with gene expression. STR related disease severity and penetrance are positively correlated with increased numbers of STRs. The discovery of STRs found in a WES/WGS presents an opportunity for report of secondary findings, as there are individuals whose genome contains a higher than normal number of STRs but are phenotypically normal. In these premutation carriers the number of STR repeats can increase in subsequent generations, increasing the likelihood of disease in the offspring of a premutation carrier. By reporting STR status to a patient, actions including preimplantation genetic diagnosis can be used to prevent passage of disease to offspring; this is not considered in the current definition of actionability. The exclusion of genetic anticipation in the current AMCG secondary report highlights that not all the implications of a secondary finding, or their actionability, are considered.

Additionally, some STR related diseases increase a premutation carriers’ risk for developing secondary conditions. Phenotypically normal woman who carry STR premutations responsible for Fragile-X syndrome often suffer from primary ovarian insufficiency. This is a treatable, thus actionable, condition. Patients made aware of their premutation status can pursue fertility preservation options, such as oocyte or embryo cryopreservation.

In the authors opinion, diseases related to STRs satisfy the AMCGs secondary findings list inclusion criteria, when a more expansive definition of medical actionability is applied. STR related monogenetic diseases are well studied and data related to penetrance, risks/benefits of treatment and current knowledge are thoroughly documented. Depending on the disease, premutations may be actionable for the proband and genetic anticipation can provide valuable information for individuals who have or wish to have children. Medical actionability is a shifting concept, increasing the scope of actionability to include treatment of premutation caused illness and the prevention of disease in offspring can improve outcomes. This redefinition ultimately allows a premutation carrier to seek treatment and make medically relevant decisions for themselves and potential offspring.

Author Names: Joshua Moise-Silverman, McGill University
Counterstories, Narrative Repair, and Rewriting the Harmful Stereotypes of Mental Illness

Mr. Andrew Molas,

**Abstract Category:** Standard Concurrent Session  
**Primary Theme:** Ethics and health policy

**Three Valuable Questions:**  
How do we implement narrative medicine in mental health care?  

How do we address the reliability of the narrator in first-person narratives?  

How do we train caregivers to engage with narrative?

**Abstract:** In my paper I discuss the role of narrative in guiding our moral response towards supporting persons living with schizophrenia. Drawing on Lindemann’s concept of counterstories and narrative repair, I argue that a narrative ethical approach shifts the stigmatizing attitudes surrounding mental illness towards an attitude of inclusiveness and care. I demonstrate how counterstories repair identities that have been damaged by harmful master narratives that depict persons with schizophrenia in dehumanizing ways and how a narrative ethical approach strengthens relationships of care to support patients in their recovery from mental illness. I begin by introducing the concept of master narratives and discuss how master narratives influence our interactions with others. Master narratives play a key role in the social construction of persons and their identities. But because master narratives are often established and sustained by groups with high social privilege, the problem with master narratives—and, relatedly, stigma and stereotypes—is that they depict persons belonging to marginalized groups in negative and limiting ways, and this imposed identity influences how we perceive and treat members belonging to these marginalized groups. Given how master narratives impose a harmful identity which negatively impacts the lives of persons living with mental illnesses, it is necessary to shift the conversation of how mental illness is viewed and understood. I argue that one way to achieve this aim is through counterstories. Counterstories are stories written from the perspective of a person belonging to a marginalized group. Counterstories resist an oppressive identity and replace it with one that commands moral respect from those belonging to more socially dominant groups. Counterstories repair identities damaged by oppression by altering the oppressors’ perception of the marginalized group and by altering an oppressed person’s perception of herself in virtue of belonging to that group. By replacing the master narrative with a narrative that showcases the person’s strengths and capabilities, counterstories constitute an individual’s identity in an active way. The process of telling one’s story contributes to the restoration of that person’s identity and self-worth. Drawing on numerous autobiographical accounts of persons with schizophrenia, I argue that these narratives are important for the author herself because it provides her with a contextual framework to make sense of her experiences and explore hidden or implicit meaning behind those experiences. Moreover, these narratives can help support other patients by providing hope and the realization that they are not alone in their suffering. But engaging with the narratives of others can help this process as well. I argue that engaging with their narratives in a caring manner humanizes the person and this relational approach to ethics allows caregivers to better understand how their lived experience with schizophrenia impacts their life. Through this direct engagement with the experiences of others, I argue that caregivers can broaden their understanding of mental illness and learn ways to improve the therapeutic options available to better support individuals in their recovery. And through this collaborative approach, the master narrative and the harmful stereotypes of schizophrenia can be rewritten.

**Author Names:** Andrew Molas
Abstract Category: Standard Concurrent Session
Primary Theme: Public health ethics

Three Valuable Questions:
1. Should concerns about the effects of PrEP on solidarity among MSM be weighed in the decisions of MSM about whether or not to take PrEP given its well documented beneficial effects on their physical health?

2. Should we really take into account the view of older gay, bisexual, and queer men on HIV, and PrEP in particular, given that these views are based on their emotions and experiences, not the medical facts of PrEP use among MSM?

3. How would this approach to an emerging medical technology in terms of solidarity apply to other cases? Is this approach useful in other cases where concerns about solidarity are not as obvious, like cases where the technology is being used by a less well defined social or political group?

Abstract: In this paper, I focus on the concept of solidarity in the ethics of pre-exposure prophylaxis (PrEP) as HIV prevention among men who have sex with men (MSM). Solidarity is a concept that is increasingly being used in bioethics, especially feminist bioethics, in order to understand the broader effects of emerging medical technologies on individuals as well as communities (Sherwin, 2008; Sherwin & Stockdale, 2017). I use the recent academic work on solidarity to analyze and contextualize the ethics of PrEP in terms of solidarity within gay communities in North America. Although the AIDS epidemic and early AIDS activism necessitated solidarity among MSM, including the formation of groups like Gay Men’s Health Crisis and ACT UP, this solidarity is being threatened today by new developments in HIV treatment and prevention and new developments in society more broadly, including the successes of the gay rights movement, which are eroding the foundations of this solidarity. Therefore, I highlight two challenges that PrEP presents to solidarity among MSM and the normative implications of these challenges. First, PrEP exposes differences in sexual moralities among MSM by reinforcing widespread social and political objections to its use based on its effects on safe sex, promiscuity, and the stereotyping of gay, bisexual, and queer men in society. These objections to PrEP centre on the risks associated with condomless sex, the recent changes in sexual and romantic relationship structures, and the strategy of the gay rights movement respectively. Second, PrEP highlights differences in intergenerational views by exposing how the legacy of the AIDS epidemic affects the views of HIV among MSM from different generations. The deep divisions exposed by PrEP within gay communities along generational lines and lines of sexual morality demonstrate a clear threat to solidarity. These challenges raise important questions about the use of PrEP as HIV prevention among MSM today because of the specific critical and historical context of its use in North America. First, there are epistemological questions about how to weigh the testimony of survivors of the AIDS epidemic against MSM who feel marginalized and alienated by established gay culture. Second, there are ethical questions about whether to take community damage into account in thinking about how to advocate, advertise, and promote PrEP. Finally, I explain how responding to these challenges can actually build, or rebuild, solidarity within gay communities. I consider the kinds of opportunities that PrEP provides for building, or rebuilding, solidarity among MSM and within gay communities around new understandings of non-traditional sexual behaviour, non-traditional sexual and romantic relationships, and intergenerational differences. For example, if MSM discuss their views on sexual morality and their experiences of HIV with each other more openly, then they can begin to understand how to better relate to each other. Understanding how PrEP challenges solidarity among MSM helps us account for the social and political dimensions of this emerging medical technology as well as the specific social and political effects of PrEP on communities of MSM and gay, bisexual, and queer men in North America.

Author Names: Michael Montess, York University
Abstract Category: Standard Concurrent Session
Primary Theme: Research Ethics

Three Valuable Questions:
1. On what basis does an individual’s anti-mortem wishes and preferences exert a claim on iPSC researchers after their death?
2. What considerations ought to guide a surrogate decision-maker who is approached for consent to the excision of dermal fibroblasts for future unspecified research?
3. Is it plausible to harmonize iPSC research ethics norms across countries, research cultures, and legal jurisdictions?

Abstract: Induced pluripotent stem cells (iPSCs) are a powerful tool for research into neurodegenerative diseases such as ALS (amyotrophic lateral sclerosis), Parkinson’s disease, and Alzheimer’s disease (AD). iPSC research in AD is of particular relevance to countries with an aging population like Japan, Italy, Germany, the United States, and Canada. However, ethical issues unique to iPSC research in AD remain under-explored in the bioethics literature. One area of moral concern that would benefit from greater attention is the ethics of collecting, storing, and using somatic cells from decisionally-vulnerable adults and the deceased for use in iPSC studies. Two sub-groups are of special interest to researchers: (a) individuals with late-onset AD or other dementias and (b) individuals without dementia whose cells may be of value as “super-controls” post-mortem. Many individuals in the first group will be decisionally impaired when consent or re-consent to research is required and none in the second group can consent after death. While international and domestic research norms encourage the inclusion of decisionally-impaired adults in limited circumstances, the Canadian regulatory framework includes a collection of consent/capacity and information privacy laws that often lack clarity on when proxy consent to non-therapeutic research is permitted. A cautious interpretation of Ontario’s Health Care Consent Act and relevant case law, for example, might conclude that proxy consent for non-therapeutic iPSC research with decisionally impaired adults is impermissible. This interpretation would exclude many individuals with late-onset AD from participating in iPSC research even if the individual’s personal values were highly compatible with such research. Meanwhile, use of postmortem tissue is governed by a separate set of regulations. These regulations could allow the use of tissue in iPSC research from a deceased individual whose antemortem values were highly incompatible with iPSC research in AD. The way forward for iPSC science requires that Canada and the international stem cell community map the technology’s research ethics terrain and elaborate research norms specific to the needs of iPSC study contexts, somatic cell donors, and the public. This presentation seeks to define the unique moral space of iPSC research in AD, explore the moral basis of current guidance on proxy decision-making for non-therapeutic research in Canada, and identify candidate concepts for inclusion in normative guidance on iPSC research. In addition, I argue three related positions: (1) decisionally-impaired AD patients and the deceased have interests, (2) these interests can be served or violated through proxy consent to donation of their tissues to iPSC research; and (3) these interests ought to be a central concern to REBs and others responsible for oversight of iPSC research in Canada and elsewhere. Finally, I make the case that a donor’s personal values ought to guide proxy consent decisions for iPSC research in AD.

Author Names: Rika Moorhouse
Abstract Category: Standard Concurrent Session
Primary Theme: Other Ethics Program Delivery, Community and Rural Ethics

Three Valuable Questions:
Have the LHIN community partners expressed their preferences for ethics service delivery?
What characterizes community service providers, and how do they fit into health care delivery?
Which ethics support structures are most applicable to this new partnership?

Abstract: The ethical issues which arise in hospital follow patients upon discharge to the community. Yet small general hospitals, long-term homes, home care organizations and community service providers (CSPs) have less access to ethics support, despite experiencing similar rates of challenging ethical issues. In particular, the ethical issues arising among CSPs have become more complex due to scarce resources, more diverse communities, a lack of regulatory support, and increasingly complex health and social service systems. CSPs would benefit from access to standardized, accessible and sustainable ethics support.

A challenge in providing CSPs with ethics support lies in determining its structure. Traditionally, ethics support structures are designed to meet the needs of large tertiary academic hospitals. Structures include hiring a practicing health care ethicist, establishing an ethics committee, creating policies and procedures around key ethical challenges in an organization, and adopting an ethics framework as a standardized approach to addressing ethical questions. Many of these practices are incompatible with the needs of CSPs, or are not feasible to meet the demand of numerous and diverse providers.

As a result of smaller local partners seeking the ethics services of a successful ethics program in a large academic hospital, a new partnership has started to provide CSPs in a Local Health Integration Network (LHIN) with ethics support. As part of this work, the ethics program has conducted a needs assessment survey of CSPs in the LHIN to determine what ethical challenges arise in the community. This scoping review complements the needs assessment survey by investigating how to deliver ethics services to meet the needs of our partners.

The purpose of the scoping review is to determine the current literature on community ethics service delivery; including ethics support structures, targeted ethical issues, and the benefits and challenges of service delivery. The scoping review follows the PRISMA statement, as well as a 5-step approach outlined by Arksey and O’Malley. Relevant studies were curated from Web of Science, Scopus, and PubMed databases with a search statement sourced from the needs assessment survey as well as researching the LHIN CSPs. Inclusion criteria are papers published in English; from any year; on the subject of any/all community ethics services or ethical needs in the community. The following information was charted (1) study author, (2) year, (3) outcomes assessed and themes explored, (4) main conclusions and any other relevant information.

The scoping review reveals several key findings on ethics service delivery, as well as key findings about the nature of community ethics. The study concludes that, despite there being several structures to provide ethics support in the community, ethics support structures specifically for CSPs is limited. The scoping review includes two main limitations. Firstly, the scope of ethics service delivery models is ambiguous, especially with respect to community social services. It is unclear what ethics support ought to look like to such organizations. Secondly, search terms were informed by the needs of our partners, which may not be generalizable.

Author Names: Kathryn Morrison, Hamilton Health Sciences; Julija Kelecevic, Hamilton Health Sciences; Andrea Frolic, Hamilton Health Sciences
Against the Study of Children Whose Genomes have been Modified through Unethical Genetic Interventions
Dr. Timothy Murphy, University of Illinois College of Medicine

Abstract Category: Standard Concurrent Session
Primary Theme: Ethics and genomics

Three Valuable Questions:
1. What are the grounds for calling the 2017 intentional genetic modification of children unethical?

2. What’s to be gained from an ‘embargo’ against studying children who were genetically modified?

3. If immoral studies lead to results that might prove useful in advancing genetic research, shouldn’t those results be published?

Abstract: In 2018, a Chinese biophysics researcher reported using CRISPR-cas9 techniques and certain IVF procedures to knock out the presence of a certain gene sequence in two newborns. Some people are functionally immune to HIV because of a genetic trait that interferes with cellular infection, and the intentional genetic modification was intended to confer that immunity on the children. The researcher He Jiankui justified this intervention as a way of protecting the children from the medical and social risks of HIV infection. This intervention involved, however, a morally objectionable choice rooted not in an error (an action not going as planned) but in an intentional choice (deliberate deviation). At the very least, the intervention disregarded ethics advisories from key professional groups that have articulated standards for the clinical study of intentional genetic modification. In response to He’s genetic modifications, some critics have questioned the alleged justification for the intervention; they argue it is unnecessary given that there are other ways to protect against HIV infection. Additionally, it is arguable that this intervention involved only an ‘enhancement’ and therefore involved no urgent reason to bypass expected standards of conduct in research. Other critics focused on the exposure of the children to the unknowable health risks of the intervention. As important as these lines of criticism are, they are not the only ethical considerations at stake. Because of the novelty of the intervention, it may be tempting to study these children to identify the effects of the genetic modification. I argue that because of the unethical conduct involved, researchers should decline to study the children. Since any such efforts would involve the ‘fruit of a poisonous tree,’ researchers should exclude the children as subjects for symbolic reasons and for reasons of deterrence. Declining to study these children would signal in a strong way the impermissibility of interventions that disregard relevant professional advisories, that involve unknowable risks to health, and that disregard possible germline effects. Involving the children as subjects of research might only incentivize more unethical genetic interventions, if there is no obvious downstream ‘penalty’ for conducting morally doubtful research. Along the same lines, I argue that journals should ordinarily decline to publish results of the study of these children were any to emerge. However, if the children were to come forward as adults and offer themselves as research subjects, there might be justification for studying the effects of their genetic modification. Under such circumstances, any journal choosing to publish a study of those effects should at the very least accompany the report with an editorial or statement regarding the morally compromised circumstances of the original genetic modification. But unless the parties most affected by this intervention agree to serve as research subjects, and do so as adults, it seems morally preferable to leave them unstudied, regardless of any loss of possibly useful scientific results.

Author Names: Timothy Murphy, University of Illinois College of Medicine
Data Sharing Between Regulatory Bodies, Health Care Organizations, and Unions: The Potential for Fostering Shared Responsibility for Ethical Practice
Dr. Lynn Musto, Trinity Western University

Abstract Category: Standard Concurrent Session
Primary Theme: Ethics and health policy

Three Valuable Questions:
What are some of the potential ethical conflicts with sharing data across organizations?

How does ‘managerialism’ contribute to concealing unethical practice?

What are some suggestions for how the regulatory bodies, health care organizations, and unions can move towards collaboration and shared responsibility for upholding fiduciary responsibilities, while maintaining their different, and sometimes opposing, mandates?

Abstract: Violations of fiduciary responsibilities to society occur within and across professions and agencies. Some high profile examples include the airline industry (Boeing), the automobile industry (Volkswagen), financial institutions (ENRON), and health care (Mid-Staffordshire Trust). Health care professionals and their regulatory bodies/professional associations have particular fiduciary responsibilities to ensure that their actions in relational contexts of caring for others are directed towards upholding bioethical principles such as beneficence and nonmaleficence, and, at the aggregate level, social justice. In situations where health care professionals engage in activities that cause harm to individuals and groups, responsibility for action is usually addressed within the realm of individual professional agency. However, health care professionals act within complex sociopolitical and organizational contexts.

In this paper we examine a particularly troubling case of Canada’s first known healthcare serial killer, a nurse who intentionally caused the injury and/or deaths of fourteen patients (Gillese, 2019). The story of nurse Elizabeth Wetlauffer is an extreme case of malfeasance (and criminality) that went undetected within and across diverse regulatory and health care jurisdictions over a period of nine years. In our examination of the Wetlauffer case we will explore how the regulatory bodies, health care organizations, and unions -- operating within an overall political climate of ‘managerialism’ in health care -- contributed to the tragedies that unfolded.

It is our premise that in situations where accidental, and, in particular, deliberate harm to patients occur, health care leaders ought to examine and address the relational contexts that either allow such harm to continue, and/or create conditions that prevent and ameliorate individual malpractice. Technological advancements such as data analytics have potential to play a key role in preventing, deterring, and detecting intentional and nonintentional wrong doings by health care providers. A Public Inquiry into Long-term Care (LTC) was conducted to determine how Wetlauffer was able to commit numerous serious crimes in licensed and regulated LTC homes, over several years, without detection (Gillese, 2019). Recommendations from the Inquiry include utilizing data analytic models to identify facilities with a higher than expected number of deaths and analyzing aggregated data to detect patterns and atypical trends in patient deaths (Gillese, 2019). Having this information available to stakeholders would facilitate collaboration, cooperation, and communication within and between regulatory bodies, health care organizations, and unions to thwart the systemic vulnerabilities identified by the Inquiry into the Wetlauffer case.

We will conclude our paper by arguing that responsibility for upholding health care professionals’ fiduciary responsibilities is shared by individuals and organization across micro, macro, and meso levels of society. We will further argue that such preventative and ameliorative action requires a more robust approach to data collection, interpretation, and sharing within and across health care organizations and regulatory bodies/professional associations than currently exists.

Reference cited:

Author Names: Lynn Musto, Trinity Western University; Patricia (Paddy) Rodney, University of British Columbia; Melissa Moynihan, University of British Columbia
Becoming A Medical Assistance in Dying (MAiD) Provider: An Exploration of the Conditions that Produce Conscientious Participation
Ms. Allyson Oliphant, University of Western Ontario

Abstract Category: Standard Concurrent Session
Primary Theme: Other Medical Assistance in Dying (MAiD)

Three Valuable Questions:
what is the most determining factor in a clinicians decision to be a MAiD provider?

How do we create a system that supports clinicians to become MAiD providers?

How do you create a practice that is sustainable?

Abstract: The availability of willing providers of Medical Assistance in Dying (MAiD) in Canada has been an issue since a Canadian Supreme Court decision and the subsequent passing of federal legislation, Bill C14, decriminalized MAiD in 2016. Following this legislation, Hamilton Health Sciences (HHS) created a specialised, voluntary, interprofessional team called the Assisted Dying Resource and Assessment Service (ADRAS) to support access to MAiD for patients. This research utilized a qualitative, mixed methods approach to data collection, obtaining the narratives of providers and supporters of MAiD practice at HHS. This study occurred at the outset of MAiD practice in 2016, and one year later, once MAiD practice was established. Our study reveals that professional identity and values, personal identity and values, experience with death and dying, and organization context are the most significant contributors to Conscientious Participation (CP) for MAiD providers and supporters. The stories of study participants was used to create a model that provides a framework for values clarification around MAiD practice, and can be used to explore beliefs and reasoning around participation in MAiD across the moral spectrum. This research addresses a significant gap in the literature by advancing our understanding of factors that influence participation in taboo clinical practices. It may be applied practically to help promote reflective practice regarding complex and controversial areas of medicine, to improve inter-professional engagement in MAiD practice, and promote the conditions necessary to support moral diversity in our institutions.

Author Names: Allyson Oliphant, University of Western Ontario; Andrea Frolic, Hamilton Health Sciences
Success Rates for Anti-Cancer Drug Development Efforts in Pediatric Oncology
Ms. Elisabeth Oliviero, McGill University

Abstract Category: Standard Concurrent Session
Primary Theme: Research Ethics

Three Valuable Questions:
1) What is the clinical significance of approving a drug in children, since many drugs are that commonly used in standard treatment regimens to treat pediatric cancers are FDA approved in adults but not children (yet still work very well)?

2) Ethically speaking, how else could these base rates be useful, aside from physicians conducting pediatric cancer studies?

3) Registering clinical trials is not necessarily a widespread practice (though it is highly encouraged). What implication(s) does this reality have on the base rates that you presented?

Abstract: Introduction: Pediatric cancer drug development presents both ethical and logistical challenges: minors cannot provide informed consent and eligible patients are scarce. In adult cancer, only 1 in 20 treatments put into clinical testing ultimately graduate to regulatory approval. Little is known about corresponding graduation rates in pediatric cancers. In what follows, we set out to estimate the fraction of treatments in pediatric cancer trials that advance to later stages of development and/or clinical practice. Secondarily, we aim to probe which types of trial activities are associated with higher graduation rates, and what proportion of patients participate in trials testing treatments that advance to further research and care.

Methods: ClinicalTrials.gov was used to search and collect all pediatric anti-cancer drug trials that are registered on the database; key characteristics of trials were extracted, including indication type, drug type, and certain trial design features. We included trials that recruited cancer patients below the age of 21 and/or trials that were specifically indicated for pediatric malignancies. For each trial that met eligibility, “graduation status” (i.e., transition to a subsequent phase, a Children’s Oncology Group (COG)-supported trial, an FDA approval, and/or FDA label revision to include the relevant cancer indication within 6 years of trial launch) was determined for the drug-indication pairing by using the Drug Trials Visualizer – Beta v 0.17. Base rates were calculated for the number of trials and patients in these trials that led to a particular graduation event.

Results: We identified 468 trials for inclusion. This sample included 220 phase 1, 53 phase 1/2, 158 phase 2, 2 phase 2/3, and 35 phase 3 trials testing singular or combination therapies. These trials enrolled 44,401 patients. We calculated that 17.7% (18.9% patients) of treatments in phase 1 trials graduated to a phase 2 trial, 1.9% (3.1% patients) of treatments in phase 2 trials transitioned to a phase 3 trial, 3.2% (1.7% patients) of phase 1 and phase 2 trials transitioned to a COG-supported trial, 1.1% (0.79% patients) of all trials led to an FDA approval for pediatric cancer, and another 0.85% (0.29% patients) of all trials led to a revision in FDA labelling to include the pediatric indication of interest.

Discussion: Our results suggest that the greatest prospect of graduation occurs for phase 1 to phase 2 transitions, with graduation decreasing from phase 2 to FDA approval/label revision. Only a small percentage (3.2%) of phase 1 and phase 2 trials go on to be supported by COG (the world’s largest organization dedicated to pediatric cancer treatment) in subsequent studies. To supplement these base rates, a predictive model investigating which types of trials are associated with greater probability of graduation is being built; results will be presented at the conference. Information of pediatric cancer treatment graduation can serve implications relating to informed consent prior to trial participation. While clinicians may not know the definitive outcome for future innovative therapies, their recommendations can still convey an estimate of the likelihood of a patient’s participation advancing care for future patients.

Author Names: Elisabeth Oliviero, McGill University
Abstract Category: Standard Concurrent Session  
Primary Theme: Public health ethics

Three Valuable Questions:
1. Aside from relational autonomy, what other concepts about autonomy might be especially relevant to help redress inequalities in breast cancer diagnosis and mortality observed in Canada?
2. What are the enablers and barriers to implementing informed choice and shared decision making in clinical practice?
3. How might artificial intelligence challenge the concept of autonomy in Canada’s national breast cancer screening recommendations?

Abstract: Autonomy is a prominent issue in breast cancer in Canada. The breast cancer advocacy movement vociferously campaigned for informed consent to stop the once common practice of one-step biopsy-mastectomy; now, its members partner with the pharmaceutical industry to expand access to chemotherapy drugs and advise health care decision makers about cancer system reform. The most recent gain for autonomy has been the introduction of informed choice and shared decision-making in the Canadian Task Force on Preventive Health Care’s (CTFPHC) 2018 breast cancer screening recommendation.

This recommendation advises that scientific evidence and patient values and preferences all be considered in screening decisions. The shared decision-making process is committed to respect for patient autonomy and is relevant for breast cancer screening because there is a close trade-off between mammography benefits and harms that could be altered by patient values and preferences. The ethical imperative for shared decision-making in this context is to make mammography harms and benefits evident to patients in an effort for patients to evaluate them in discussion with their physician.

Not questioning, critiquing, and contesting the concept of autonomy in breast cancer screening recommendations is problematic because it limits the types of considerations that are able to legitimately bear on a breast cancer screening decision and the appropriateness of the resultant screening decision itself. As breast cancer screening is a public health intervention, the specific research questions were: 1. What concept of autonomy is operant in the CTFPHC’s 2018 breast cancer screening recommendation?; 2. What benefits and harms does this concept of autonomy confer for population health?; and 3. How might a relational account of autonomy support the population health aims of breast cancer screening programs?

In the CTFPHC’s 2018 recommendation, only a patient’s values and preferences regarding the scientific evidence presented by the physician to the patient about mammography benefits and harms are invited to impact informed choice. A patient is expected to be autonomous by rationally weighting only these benefits and harms for themselves and by themselves. This liberal notion of autonomy privileges some patients over others; namely, those who are able to understand scientific evidence, articulate their values and preferences, and arrive at a satisfactory screening decision with their physician. That fewer patients decide in favour of screening upon learning the benefits and harms of mammography might threaten the viability of population-based breast cancer screening programs.

Relational autonomy, which simultaneously holds the atomistic and social constructs of an individual in the moral imagination, bridges the public health and health care goals of screening by promoting positive liberty, balancing power between physicians and patients, distributing responsibility and agency, building trust in decision making, and addressing inequities in breast cancer incidence and mortality. The concept may enjoy wide acceptance given the relational framing of breast cancer in Canada. As disparities in breast cancer incidence and mortality have been observed in certain immigrant groups and some Indigenous populations in Canada, relational autonomy also invites non-Western accounts of autonomy to bear on breast cancer screening decisions.

Author Names: Manisha Pahwa, McMaster University
Equality of Opportunity, Natural Inequality, and Disability: Are genetic interventions in the service of egalitarian justice?
Mr. Matthew Palynchuk, McGill University

Abstract Category: Standard Concurrent Session
Primary Theme: Theories and methodology in bioethics

Three Valuable Questions:
What does this argument entail about future persons, such as embryos?

How does this argument handle those who defend equality of outcomes?

What does this argument mean for policies aimed at regulating the use and distribution of genetic technologies?

Abstract: The orthodox position among philosophers on the topic of genetic modifications of persons and the role of justice is that equality of opportunity demands, where possible, the elimination of disabilities like blindness, deafness, and cognitive impairments. In this paper, I argue that it’s not the case that equality of opportunity demands the genetic modification of persons with disabilities. First, when theorists think that this demand flows from equality of opportunity they mistakenly confuse opportunities with outcomes. The two outcomes they aim to produce by way of genetic interventions, that is, the inequalities these procedures redress, are so-called “natural inequalities” and inequalities in cognitive capacity. Secondly, I argue that these two outcomes are plagued with conceptual and practical issues and should not serve as a basis for requirements of egalitarian justice. In short, my claim is that the genetic modification of persons with congenital disabilities is not a requirement of justice since it does not follow from widely held conceptions of equality of opportunity, nor so the assumptions required to advance this claim, namely natural inequality, hold under analytical pressure.

The structure of my presentation is as follows. I first present some terminological clarifications and proceed to present the equality of opportunity argument for genetic intervention in its most basic form. I then delve into more precise articulations of equality of opportunity, namely, Rawlsian and Luck Egalitarian views. In regards to the former, I remain unconvinced that the elimination of disabilities, even quite radical cognitive disabilities, actually entails more egalitarian outcomes between persons. This is because people with a wide range of disabilities hold differential opportunity sets relative to their endowments, rather than, necessarily, unequal opportunity sets relative to their non disabled counterparts (just in virtue of the former’s disability). For luck egalitarians, it’s similarly unclear, so far as equality of opportunity for welfare is concerned, that people with disabilities are unequal, just in virtue of their disabilities, in attaining equal welfare levels.

The next part of this presentation is concerned with the belief that there are society- or context-independent inequalities between persons in virtue of their internal features, endowments, or abilities, or “natural” inequalities. This is indeed an important assumption for the egalitarian who holds steadfast to the requirement of genetic interventions because the inequality in question that the procedure is intended to mitigate or eliminate is a “natural” one and not a social one. I argue that we don’t have good reason to take on this assumption. I show that some arguments establish a very unorthodox interpretation of natural inequality, to the extent that few could hardly refer to it as such and fails to uphold the requirement I challenge in this paper. I then consider other conceptions of natural inequality, but fail to see how they provide a natural, rather than socially contingent basis upon which we make judgements about inequalities.

Author Names: Matthew Palynchuk, McGill University
Autonomy and Assisted Death: It’s Complicated.
Ms. Victoria Panwala,

Abstract Category: Standard Concurrent Session
Primary Theme: Ethics and health policy

Three Valuable Questions:
1) How does the concept of autonomy differ from other related concepts in the context of MAiD?

2) How do relational and contextual factors affect patients’ end-of-life care decisions?

3) How may policy makers and health care professionals best promote patients’ autonomy given the complex contexts of end-of-life desires?

Abstract: In 2016, Canada passed bill C-14 which legalized medical assistance in dying (MAiD) for individuals whose natural death is reasonably foreseeable and whose suffering is grievous and irremediable. An increasing number of jurisdictions in the US are also legalizing assisted dying. A major argument in favor of physician assisted death and various methods of such assistance centers on respect for patient autonomy. Nonetheless, divergent views on what autonomy means, how that intersects with and differs from other related concepts, the best ways to promote autonomy, and ethically appropriate limits to autonomy in the context of MAiD remain unclear. To elucidate the meanings and role that autonomy plays in MAiD decisions and professional practice, two methods were used. First, a qualitative analysis of 26 in-depth semi-structured interviews with palliative care providers was conducted in Vancouver, B.C. Transcripts were coded and thematic analysis was informed by content analysis with a focus on discussions of autonomy. Second, a scoping review using Arksey and O'Malley’s six-stage methodological framework was conducted to map the international literature on the meanings and roles that autonomy plays in justifying and providing various forms of assisted deaths. The semi-structured interviews and the scoping review generated several intersecting themes. First, autonomy is sometimes manifested in a desire to regain control over an illness which robs patients of a sense of well-being and power. Second, autonomy is understood as having the right to pursue assisted death as an insurance measure rather than a true desire to die of a certain way. Third, autonomy is related to but different from the concept of dying with dignity. Fourth, patient autonomy as a concept is ironically used to both justify and argue against assisted death. Autonomy is conceptualized both as an ideal, and a value which must be protected in order to allow for future autonomous decision-making. Relational and contextual factors such as ableism, sexism, and the increased power of medical professionals also beg the question of what respect for patient autonomy truly means in the context of MAiD. Our qualitative study and scoping review reveal that respect for autonomy is a complex and rich concept, requiring understanding of both individual and relational contexts. People’s desire for autonomy or concerns over losing autonomy in the future intersect with other considerations regarding not only one’s physical and emotional suffering but also relational environment. Knowledge of the unanticipated ways in which autonomy alters end-of-life decision making, including the use of assisted death as a “back pocket” option rather than a desire to hasten death, may help healthcare professionals to better support their patients as they make end-of-life decisions in the future. Further research is required on the varied reasons that patients pursue assisted death within the medical system, and within the Canadian cultural context in particular. Understanding patients’ motivations as they make end-of-life decisions will allow policymakers and health care professionals to promote patient autonomy, while simultaneously protecting the rights and dignity of vulnerable populations.

Author Names: Victoria Panwala; ANITA HO, University of British Columbia; UCSF; Soodabeh Joolaee; Joshua Norman; Christopher Ng
Medical Scribes, the Electronic Health Record and the Elephant in the Room
Ms. Tamara Perez,

Abstract Category: Standard Concurrent Session
Primary Theme: Ethics and information technology or social media/networks

Three Valuable Questions:
1. The physician’s ability to refer to the EHR and extract information quickly (via the scribe) provides them with the power of more information in the clinical encounter. While there are definite benefits to the clinician having more information on the patient’s medical history, what might be the downsides of this?

2. How do patients respond to the presence of a scribe during clinical encounters?

3. What might the impacts and consequences be of standardization and regulation of the scribe industry?

Abstract: Introduction:
Electronic Health Records (EHRs) can improve the efficiency of healthcare and facilitate continuity of care through enabling the collection and access to patient medical records. While 75% of Canadian physicians in 2014 reported using EMRs and 80.5% of US hospitals had at least a basic EHR system in 2017, it remains controversial whether these truly improve efficiency and streamline care, in part due to the increasing documentation burden on physicians and technological limitations of these systems. Physicians may spend half their work hours on the EHR, as well as time spent after hours, which interferes with physician-patient interaction, diminishes professional satisfaction and contributes to physician burnout, with negative implications for patient care. One solution to this growing documentation burden has been the use of medical scribes, which is relatively new in Canada.

Methods:
In this presentation, I provide a critical overview of ethical implications of the use of medical scribes, examining the impact of the presence of a medical scribe during patient-physician encounters, the implications of the medical scribe industry on the provision of healthcare and the use of the EHR, and questions of regulatory oversight for medical scribes, drawing from the limited literature on medical scribes and my own professional experience.

Discussion:
While working with a medical scribe offers many benefits for physicians, such as increased accuracy of medical documentation, decreased administrative burden, enabling the physician to devote their attention to the patient during the clinical encounter, as well as the evidence of increased work-related satisfaction, there are a number of ethical questions to consider. The presence of a third party during the clinical encounter may impact the information shared by the patient with the clinician and the dynamics of the patient-clinician relationship. Use of a scribe may modify documentation habits of clinicians, with important justice-related implications within a publicly funded healthcare system. Scribes’ vulnerable position working for and with clinicians will be examined, particularly given their responsibility to document information that is used for determining physician compensation. Furthermore, the use of medical scribes may slow progress on EHR improvements – as physicians delegate their documentation responsibilities to their scribes, their dissatisfaction with unwieldy and cumbersome EHRs may dissipate, slowing improvement to this crucial tool in clinical practice. Finally, the medical scribe industry is not formally regulated, relying on outside contractors to hire and train scribes. Scribing provides an incomparable learning opportunity for potential future healthcare workers, however scribes’ access to protected health information should raise questions of safety and regulation of the industry.

Conclusion:
Medical scribes are an adequate solution to the real challenges of physicians’ growing documentation burden. This being said, there is an urgent need to improve the EHR and come to a consensus on proper documentation practices for clinicians, which includes an examination of reimbursement structures that may promote superfluous documentation. Working with a medical scribe should be an option for clinicians, however this industry might benefit from regulatory oversight and standardization.

Author Names: Tamara Perez
What’s in a diagnosis? Explanations and Communication Regarding Medically Unexplained Symptoms in Primary Care.
Ms. Tamara Perez,

Abstract Category: Standard Concurrent Session
Primary Theme: Other Medically unexplained symptoms

Three Valuable Questions:
1. Why do medically unexplained symptoms fall under the purview of medicine? How do we identify and delimit which symptoms without objectifiable pathology medicine is responsible for?

2. How do improvements and innovation in medical technologies contribute to the presence of MUS? How might they help resolve MUS?

3. Is the notion of medically unexplained symptoms inherently reductionist and dualistic? Is it possible to move away from this way of thinking in medicine?

Abstract: Anomalous bodily sensations drive individuals to seek medical attention in search of explanations and relief of their symptoms. Using the scientific approach of the biomedical model, physicians may investigate these, and through clinicopathological correlation, often can provide an (actionable) explanation for them. Medical technologies, from the stethoscope to the MRI, provide the clinician access to the inner workings of the patient's body, allowing for the identification of pathology. While these tools have vastly increased in acuity in the last century, and while this approach allows for rigour and precision, its reductionism and disease-focus elide the patient’s illness experience, proving to be especially problematic when no pathological process is found that adequately explains the patient’s symptoms.

Up to two thirds of symptoms in primary care are medically unexplained, posing a particular challenge for physicians to explain and address. There is substantial evidence to indicate that patients with medically unexplained symptoms are not satisfied with the explanations they receive, which are often perceived as blaming and rejecting the reality of their symptoms. Medically unexplained symptoms (MUS) that follow a particular pattern or body system may be attributed a diagnosis, however this often does not lead to effective management nor do these patients achieve adequate quality of life. Physicians struggle to provide adequate, acceptable explanations to patients with MUS, and may rely on negative diagnostic tests or particular syndrome diagnoses as means of addressing the symptoms.

MUS are highly prevalent in primary care; however, they remain poorly managed and may compromise the patient-physician relationship. In this presentation, I discuss the inherent paradox and challenges of explaining medically unexplained symptoms, as well as the implicit mind-body dualism of MUS. I examine the use of diagnosis and reassurance with negative test results as a means of explaining MUS, and argue that these are not adequately responsive to the needs of people with MUS. Borrowing from phenomenology and an enactive approach to pain, I hope to elucidate an effective and acceptable means of communicating with patients about their symptoms that do not correlate to an underlying somatic disease.

Author Names: Tamara Perez
Dépistage prénatal et consentement à l’ère numérique: un enjeu majeur
Mrs. Chantale Pilon, Chaire de recherche du Canada Tier 1 sur la décision partagée et l'application des connaissances, Centre de recherche sur les soins et les services de première ligne de l’Université Laval (CERSSPL-UL)

Abstract Category: Standard Concurrent Session
Primary Theme: Ethics and health technology assessment

Abstract: La santé numérique a fait irruption dans le cadre d’un mouvement de « démocratie sanitaire », visant à défendre les droits du patient et à lui redonner du pouvoir face au monde médical. Bien que sa réalisation rencontre de nombreux défis, elle serait un terreau fertile pour soutenir une telle transformation. De fait, le déploiement des technologies de l’information et de la communication (TIC) contribue à l’essor d’une nouvelle pratique médicale et d’une relation plus éclairée entre le citoyen et sa santé, mieux contrôlée grâce à un accès facile à l’information en santé. Il favorise la démocratie sanitaire en permettant à l’usager de co-construire son parcours de soins avec les professionnels et de devenir partenaire « actif » de sa santé, aidé en cela par différents dispositifs numériques, offrant un contenu qui lui permet : d’élargir ses connaissances, de bénéficier de services et d’échanger avec les professionnels de la santé. Ces échanges accentuent la confiance dans le système en favorisant l’expression de demandes négligées et de réponses personnalisées. En ce sens, les TIC représentent une ressource féconde qui doit s’intégrer en complément d’information aux soins déjà offerts.

C’est pourquoi notre équipe a développé un outil d’aide à la décision numérique (OAD) lié au dépistage prénatal. De fait, si l’on vise l’autodétermination du patient, il importe de s’interroger sur son autonomie et son consentement, car l’aptitude du patient à comprendre l’information médicale délivrée a des répercussions sur sa conscience de faire ou non un choix, et donc sur la réalité de sa volonté. Or, dans le cadre du dépistage prénatal cette question s’avère problématique. L’insuffisance du temps disponible en consultation pour couvrir la question, la banalisation de l’offre présenté machinalement comme un test de routine ou une décision d’ordre médical, oblitèrent la dimension des valeurs des protagonistes, l’inclinaison à faire de l’acceptation une condition, etc. autant de facteurs qui affectent le processus discrétionnaire. Pourtant, un véritable consentement est nécessaire considérant les possibles répercussions sociétales de ces tests, qui tendent à réduire le nombre d’individus atteints d’une trisomie (tels que : la stigmatisation de la diversité humaine ou l’appauvrissement des ressources de soutien et d’intégration). En l’occurrence, il est permis de croire que l’utilisation d’un OAD numérique, apte à alimenter la discrétion en présentant de façon plus personnalisé les informations requises, les enjeux et les valeurs (au regard desquels la décision doit s’opérer) afin de permettre un consentement éclairé, serait une option prometteuse pour les cliniciens et les protagonistes.

Notre présentation se veut donc un effort de réflexion collective sur l’incidence (sur les individus, la population, la pratique médicale) et les divers enjeux (éthiques, pratiques, socio-politiques, économiques, etc.) entourant : a) les tests de dépistage prénatal, dont l’efficacité s’accroît sans cesse, b) l’importance du consentement éclairé et de la prise de décision partagée (PDP), c) la pertinence et l’intérêt de recourir au TIC pour offrir aux cliniciens et aux protagonistes un OAD numérique, cette ressource technologique simple, que nous examinerons sous ses aspects concrets, normatifs, fonctionnels et pédagogiques.

Author Names: Chantale Pilon, Chaire de recherche du Canada Tier 1 sur la décision partagée et l’application des connaissances, Centre de recherche sur les soins et les services de première ligne de l’Université Laval (CERSSPL-UL)
Comparing outcomes for capable and incapable patients with schizophrenia who were treated with electroconvulsive therapy, a chart review
Ms. Joanne Plahouras,

Abstract Category: Standard Concurrent Session
Primary Theme: Other Ethics - consent and capacity

Three Valuable Questions:
Why is there stigma surrounding the use of ECT?
Why did most patients in this study lack capacity to consent to treatment?
What are some of the ethical challenges associated with treated patients who lack capacity to consent to ECT?

Abstract: Background: Schizophrenia is a severe psychiatric illness affecting approximately 1 in 100 people and is a leading cause of illness burden worldwide. Individuals with schizophrenia experience hallucinations, delusions, disordered behavior, and impaired cognitive function.

A sizeable number of patients with schizophrenia do not respond to antipsychotic medications. In this circumstance, electroconvulsive therapy (ECT) is a safe and effective treatment. With ECT, electrodes are placed on the scalp and an electrical stimulus induces a therapeutic seizure. Patients are provided with muscle relaxants and anesthetics to reduce the risk of adverse events. Across the globe, approximately 1 million people are treated with ECT annually. ECT leads to remission in 50% of patients with schizophrenia.

Many patients with severe mental illness may lack capacity to consent to treatment. Treatment capacity is the patient’s ability to understand and appreciate facts relevant to their treatment. When an individual is declared incapable to consent to treatment, there is a rigorous legal framework to protect their rights, which often involves the appointment of a substitute decision maker (SDM) to provide informed consent for treatment decisions on their behalf.

Previous studies have compared clinical outcomes for capable and incapable patients who were treated with ECT. However, these studies were limited by small sample sizes and most patients were diagnosed with another illness other than schizophrenia.

Objectives: To describe how patients with schizophrenia who received ECT as incapable or capable patients differ with respect to short- and long-term outcomes.

Methods: A retrospective chart review of all inpatients with schizophrenia who received ≥ 1 acute course of ECT between January 2010 and December 2018 at the Centre for Addiction and Mental Health (CAMH), in Ontario, was completed. Short-term outcomes included clinical improvement, and whether incapable patients regained capacity and consented to further treatment with ECT. Long-term outcomes included receipt of subsequent acute course of ECT, maintenance ECT, and readmissions to CAMH.

Results: A total of 242 patients with schizophrenia were included. Of these patients, 165 (68%) were incapable and were treated with the consent of their SDM. A total of 7 (4%) incapable patients regained capacity, and 1 consented to further treatment with ECT. The mean clinical improvement score for incapable patients was 2.1, and 2.2 for capable patients. Incapable patients were treated with an average of 0.4 subsequent courses of acute ECT, compared to 0.3 subsequent acute courses for capable patients. A total of 97 (59%) incapable and 32 (42%) capable patients were treated with maintenance ECT. Seventy-two (44%) incapable and 34 (44%) capable patients were readmitted to CAMH within 6 months of discharge from hospital.

Significance: The large global burden of disease for schizophrenia, widespread use of ECT, and ethical challenges of treating patients who lack treatment capacity underscore the importance of this study. Despite the safety and efficacy of ECT, there remains much stigma on its use for patients who lack capacity to consent to treatment; thus, this study will inform clinicians, patients and their SDMs.

Author Names: Joanne Plahouras; Gerasimos Konstantinou; Tyler Kaster; Daniel Buchman, University Health Network; George Foussias; Jeff Daskalakis; Daniel Blumberger
What is a moral problem? A pragmatic proposal for “morally problematic situations”
Dr. Eric Racine, Pragmatic Health Ethics Research Unit, Institut de recherches cliniques de Montréal

Abstract Category: Standard Concurrent Session
Primary Theme: Theories and methodology in bioethics

Three Valuable Questions:
1. What differentiates a moral problem from other kinds (e.g., psychosocial, clinical) of problems in healthcare settings?
2. Why is it so difficult to establish whether a problem is a genuine moral problem in healthcare settings?
3. What is the role of ethics theory with respect to understanding and solving moral problems in healthcare settings?

Abstract: Bioethics activity – whether in the form of ethics consultation, scholarship or other – requires the identification of certain problems as moral problems. But what makes a given problem in the context of healthcare a moral problem? And what are the standards by which this problem should be understood and described as a full-fledged moral problem? There is considerable fluidity and vagueness about what constitutes a moral problem and how it differs from other types of problems, defying clear-cut, objective criteria for different reasons. 1. Competing ethics theories offer different identification criteria. 2. Different terms are commonly used (e.g., a dilemma, an issue, a question, a situation). 3. Everyday experience exhibits a wealth of wide-ranging moral problems. 4. Complex and multifaceted mechanisms of moral awareness are involved in the initial identification of moral problems.

In this talk, I would like to offer a set of operational concepts and principles bringing clarity to the nature of moral problems and offering an explanation for the unavoidable vagueness of the domain of morality, which needs to be acknowledged and worked with. First, I will succinctly introduce the topic of moral problem identification and its relevance to bioethics. This is a crucial first step to any subsequent conversation about a moral problem (or the neglect of that problem if it is not identified). Second, I will briefly explain how ethics (and bioethics) are grounded in the experiential domain of human morality but which stands apart from it and can call for radical changes to common morality to align it with human flourishing. Accordingly, moral problem identification needs to be subsequently guided by a critical, reflective, and constructive open-minded assessment of the actual nature of the problem at hand and its genuine connection to human flourishing. Third, I will present a taxonomy of different competing views on the nature of moral problems (e.g., as questions, as issues) and stress how the concept of “morally problematic situations” provides the most definitive and concrete account of what ethics is concerned with. I will resort to the resources of philosophical pragmatism to explain that ethics is grounded in the experiential and the contextual and needs ultimately to be serviceable to moral problem solving. In this light, philosophical pragmatism represents an orientation toward ethics theory, methodology and practice that stresses the instrumental role of ethics theory toward human flourishing, including our ability to identify moral problems (e.g., the inability to identify and understand moral problems can generate moral distress and harm). Fourth, I will present 7 attributes of morally problematic situations, thus providing a working definition which can be used to guide ethics consultations, ethics research, and policy-making. Although attendees may disagree on the proposal and its value and usefulness, I hope to at least engage the audience on the importance of fostering greater clarity about the nature of moral problems and their relationship to ethics theory, methodology, and practice.

Author Names: Eric Racine, Pragmatic Health Ethics Research Unit, Institut de recherches cliniques de Montréal
Dissolving the Conflict Between Black-Box AI and Patient-Centered Medicine
Mr. Travis Ramsay, Institute on Ethics & Policy for Innovation

Abstract Category: Standard Concurrent Session
Primary Theme: Ethics and health technology assessment

Three Valuable Questions:
Do medical practitioners have an obligation to defer to the verdicts of AI systems with superior accuracy and reliability? Can patients make informed decisions without knowledge of the internal decision-making processes of AI systems? Is it realistic to expect the processes of AI systems to be totally inscrutable?

Abstract: Artificial intelligence (AI) is an increasingly important technology across many domains, medical research and practice are no exception. It is likely only a matter of time before AI systems become more accurate and reliable than human practitioners at predicting disease occurrence, diagnosing disease, and determining optimal treatment strategies. There is no doubt that this will have a profound impact on the practice of medicine.

While increases in the accuracy and reliability of medical intervention are ostensibly a good thing, there is an emerging line of thought in bioethics literature that identifies a potential conflict or incompatibility between the use of advanced AI systems in medical decision-making and the prevailing attitudes about what constitutes an appropriate relationship between a medical practitioner and their patient. One example of this is a January 2020 article published in Philosophy & Technology in which Bjerring and Busch argue that black-box AI systems, i.e., ones with inscrutable decision-making processes, are in conflict with core ideals of patient-centered medicine. Arguments like this one highlight the concern that the use of AI in medicine could mean a reversion towards medical practice that is solely concerned with the elimination of disease and leaves little room for patient autonomy, individual values, and informed decision making.

The aim of this presentation is to show how we can dissolve the purported conflict between the use of black-box AI in medical decision-making and the practice of patient-centered medicine. This presentation will first provide the audience with a clear understanding of the concepts that are central to the debate. This will involve defining black-box AI (and distinguishing it from other forms of AI) as well as delineating the principles of patient-centered medicine. With these key concepts in hand I will proceed to unpacking why exactly some commentators think there is an incompatibility between these kinds of advance AI systems and patient-centered medicine. I will close by arguing that, in fact, no such incompatibility exists. Instead I will show that the use of black-box AI systems in medical decision-making can be entirely consistent with the principles of patient-centered medicine.

Author Names: Travis Ramsay, Institute on Ethics & Policy for Innovation
Fit at work, or fit to work? Apps for workplace health and wellness
Dr. Vardit Ravitsky, University of Montreal

Abstract Category: Standard Concurrent Session
Primary Theme: Ethics and information technology or social media/networks

Three Valuable Questions:
What are the greatest dangers posed by the use of health and wellness tracking apps by employers?

What is the regulatory status of health and wellness tracking apps?

In what ways are power imbalances relevant to the ethical challenges raised by health and wellness tracking apps?

Abstract: Many companies are establishing ‘Worker Health and Wellness Programs’ to help improve their employees’ health, wellbeing and productivity. Increasingly, such programs include the use of various health and wellness tracking apps, such as Fitbits, diet apps, fertility trackers or ingestible ‘smart pills’. While regulation in most countries draws a firm line between lifestyle and healthcare, in practice, it is often unclear whether these apps are covered by medical device regulation or whether they constitute consumer lifestyle products. Many of these apps are not used in routine clinical care, but they can be used in the workspace context. Companies use them as part of health and wellness programs. In some instances, employees have used wellness apps in their personal lives without being aware that these were sending health-related information to their employer.

Although monitoring of employees’ health is not particularly new, the latest innovations in data science raise novel ethical concerns. Digital practices have increased the breadth and depth of surveillance. The health monitoring of workers can be linked to other types of monitoring at the workplace (such as work performance monitoring). Health and wellness tracking apps and devices are designed to interact with other apps and can unobtrusively establish connections. The possibility of a spill-over of information gathered at work into the healthcare context and influencing medical treatment – and vice versa - thus increases.

Moreover, well-known ethical issues are intensified if self-acting devices such as smart pills are used in the workplace. These include concerns regarding meaningful and valid informed consent when using such apps against a background of asymmetrical power relationships between employer and employee; worries about covert (or even explicit) monitoring and surveillance of employee health to penalize workers for poor fitness or low adherence; issues of stigmatization and discrimination against, e.g., disabled employees; changes in workplace culture; dangers of manipulation; and many more. Such concerns can be particularly relevant in the U.S. context, where health insurance is largely the responsibility of employers, giving them strong incentives to monitor employee health and lifestyle to reduce costs, even when such monitoring violates principles of privacy and autonomy.

In this paper, we analyze the ethical issues that can arise from increased use of health tracking apps and other technologies in the context of employment. We consider examples from the US, Canada, Germany and Austria to illustrate how applications can fall through the cracks of current regulatory frameworks, offering little protection to employees. Based on our analysis, we propose that such lifestyle technologies should be regarded as a new class of medical device. We explore the conceptual foundations of what policy and regulatory frameworks for such devices ought to look like and close with recommendations for future policy making. Our aim is to enable a proactive approach to regulating novel kinds of medical devices instead of an ex post facto regulatory “repair shop”.

Author Names: Vardit Ravitsky, University of Montreal; Eva Kuhn; Barbara Prainsack; Alena Buyx
Comparing Vulnerability: Literature, Policy, Local Communities
Dr. Donya Razavi, McMaster University

Abstract Category: Standard Concurrent Session
Primary Theme: Other Ethics and vulnerability

Three Valuable Questions:
What do you believe is the role of bioethics and bioethicists in mediating vulnerable populations' participation in decision- and policy-making around AI and emerging health technologies?

What, if any, are the differences in how concepts of vulnerability can apply to emerging health technologies, AI, and the use of big data in HIC vs LMIC settings?

What, if any, unique challenges do you foresee in engaging vulnerable populations in decision-making about emerging health technologies, considering the complex nature of these rapidly developing technologies?

Abstract: Background/Issue: As the push towards the use of emerging technologies for health grows, bioethicists and policy- and decision-makers in health must consider that there is an absence of equitable programs and policies, particularly for vulnerable populations in both high-income country and low-and middle-income country contexts. Exclusion and alienation of vulnerable groups in all health system decision-making processes including the use of AI and other emerging health technologies can widen the gap between rich and poor, male and female, diseased and healthy, and ethnic & racial populations. Vulnerability has been defined in different ways and how the concept is understood has a bearing on who is targeted for health planning and programming.

Objectives: To compare the literature, Ugandan policy documents, and respondents’ perspectives about vulnerability, namely how vulnerability is defined, what it means to be vulnerable, and the potential impacts of experiencing vulnerability in participation for health sector decision-making.

Methods: This was a qualitative case study based on semi-structured interviews with decision-makers at the district & sub-county, and with women living in rural villages in Tororo District, Uganda. Data was collected between May 2017 and June 2017. QSR NVivo 12 software and conventional content analysis was used identify emerging themes.

Results:
There is general agreement between the literature, Ugandan policy documents, and our respondents on categories of vulnerable populations. These include orphans and vulnerable children (OVC), youth (particularly adolescent girls), the elderly, people with disabilities (PWD), people living with HIV/AIDS (PLWHA), people who are terminally ill, and women. However, definition of vulnerability, reasons for vulnerability, and experiences of vulnerability are not always well fleshed out. The ways in which the literature explains and examines vulnerability may not accurately reflect our respondents’ perspectives. Respondents identified factors that led to vulnerability including: lack of resources, lack of education, famine, dependency (economic, physical), lack of property ownership/land ownership, poverty, physical geography, disease and death, some of which are consistent with the literature. However, understandings of the experiences of vulnerable populations and impact of these vulnerabilities on health and participation in health sector decision-making varied based on whether the respondent was a decision-maker or a rural dwelling-women.

Conclusion:
The concept of vulnerability is nuanced. Who is considered vulnerable and what makes them vulnerable is defined differently by different stakeholders. Powerful stakeholders are responsible for using the available literature and evidence to develop policy documents and target programming to the needs of vulnerable groups. Without a context-specific understanding of vulnerability, health programming may not meet the needs of the target populations.

Author Names: Donya Razavi, McMaster University
Old technology, enduring controversy – What to do with anatomical drawings created by Nazi anatomists
Mr. Kevin Reel, Joint Centre for Bioethics

Abstract Category: Standard Concurrent Session
Primary Theme: Ethics and health policy

Three Valuable Questions:
- What similarities does this collection of anatomical drawings carry to other examples of unethically sourced knowledge?
- What are the particularly distinguishing features of this unethically sourced knowledge base?
- Who should ultimately decide what should happen with these images?

Abstract: Recent literature has discussed the problem of how to treat a useful information resource – exceptionally detailed anatomical drawings with a reprehensible origin. Created by Nazi anatomists during WWII, the drawings were made without consent, using dissections made from the bodies of prisoners. They are presented in an atlas of anatomy that has been republished multiple times since the end of the war, but without any acknowledgment of their highly unethical history.

Proposals have ranged from outright destruction of all the images in existence to various options for establishing an exhibition of them as a permanent memorial to the victims. More practically, some suggest that the images ought only to be consulted when all other possibilities are determined to be inadequate.

Complicating the issue is the fact that the drawings are valued highly for their comprehensiveness and accuracy. The drawings are often credited by contemporary surgeons and anatomists as unparalleled in their meticulous presentation of tissues and structures, and with enabling successful diagnosis and intervention in treating nerve-related disorders, in particular.

With digital technology and the internet, fully controlling the sharing and use of the images has become further challenging, if not impossible.

This paper presentation will explore the issues associated with this example of a valuable knowledge base derived from unspeakable actions.

Author Names: Kevin Reel, Joint Centre for Bioethics; Sally Bean, Sunnybrook Health Sciences Centre
Climate, Affluence and Morality - Do bioethicists, in particular, need to rethink our carbon emitting activities?
Mr. Kevin Reel, Joint Centre for Bioethics

Abstract Category: Standard Concurrent Session
Primary Theme: Public health ethics

Three Valuable Questions:
Is paternalistic restriction of autonomy (government intervention) justified?

Where does an individual start?

How does one retain a sense that there is hope to avert catastrophe?

Abstract: The evolving awareness of human impact on the planet presents a variety of insights about the devastating effects of the lifestyles to which we have become accustomed. This awareness is arguably leading to a consciousness regarding the use of plastic and the emission of carbon.

While both issues require the support of individuals, industry and government, reducing plastic is perhaps the easier to address. Policies and practices that dramatically reduce the use of plastic have been in place for decades in some societies. When given the option, most consumers will likely embrace plastic free choices fairly readily.

Addressing the use of carbon emitting fuels is arguably a more intractable challenge. While there is a growing consensus around the climate crisis, there remains significant resistance to making real changes – in government, in industry and in individuals. This is, lamentably, reflective of the profound extent to which fossil fuels make possible a vast array of essential human activities and endeavours in the world. In the most affluent parts of the world, many carbon emitting non-essential pursuits have become seen as entitlements in the minds of most – like holidays and leisure pursuits, as well as career related mainstays such as commuting and conference travel and networking.

In the face of the increasing evidence that our lifestyles may well be self-limiting in the medium term, many appear to choose to rely on a positivist faith in science to develop compensatory strategies and alternate energy sources and generation technology.

As a field experienced in supporting complex decision-making where interests conflict, do bioethicists carry any greater moral obligations in responding to the growing knowledge about the causes of climate change? What should this response look like?

With a nod to both the classic 1977 paper by Peter Singer and the pivotal book, Silent Spring, by Rachel Carson, this presentation asks what might help motivate significant behavioural and structural changes while there may still be an opportunity to avert catastrophic damage to the planet and the lives of those who call it home.

Author Names: Kevin Reel, Joint Centre for Bioethics
The Ethics of Accepting Financial Support Cannabis Industry: Implications for Healthcare Organizations, Medical Journals, and Universities
Dr. William Reisman, UWO

Abstract Category: Standard Concurrent Session
Primary Theme: Research Ethics

Three Valuable Questions:
1.) Should the framework for the relationship between academic institutions more closely resemble that of academic institutions to the tobacco industry or the pharmaceutical industry?

2.) Does a conflict of interest exist in accepting funding from companies that do not have any stake in the recreational or smoked marijuana industry?

3.) What disclosures should be required of researchers who accept industry funding be required when they submit research for publication.

Abstract: In 2019 after the legalization of Cannabis in Canada it was announced that University Health Network, University of Guelph, University of New Brunswick and the University of British Columbia, and the Lung Association of Ontario have accepted philanthropic and research funding from the cannabis industry. The medical cannabis industry is an emerging and potentially powerful research partner, however these partnerships raise the potential for conflict of interest issues.

Cannabis is a substance with promising medical applications but is not without health risks. Smoked cannabis contains many of the same types of volatile substances found in tobacco that are known to cause injury to the lung. Dependence has been reported as 25% of weekly users of cannabis, a lower figure than nicotine (67.3%) but higher than alcohol (15.6%). It is widely agreed that further research is needed to better determine the physical and mental health effects of cannabis as well as its potential medicinal applications, the question remains however how best to carry out this research.

The controversy regarding cannabis industry funding of medical research was highlighted following the publication of an article examining the effects of vaporized cannabis on exertional breathlessness in patients with chronic obstructive pulmonary disease. This article was published in the Annals of the American Thoracic Society (ATS) and involved research performed at McGill University. This research received funding from the company Tilray, a publically traded for-profit cannabis company. Tilray, through a subsidiary, also produces and sells recreational cannabis in a form that is intended to be smoked. As the ATS requires its authors to certify that no part of the research presented as been funded by tobacco industry sources, the question was raised as to why similar requirements are not put in place regarding cannabis companies.

This presentation seeks to: (1) examine what has been learned from past experience regarding conflict of interest matters when it comes to industry funding of research. Focus will be paid to lessons learned from tobacco-industry funded research and guidelines and policies that were developed in response; (2) Describe the state of industry funded cannabis research in Canada and the current guidelines and policies from the organizations such as the American Thoracic Society and the Canadian Thoracic Society; (3) Discuss ethical considerations when considering academic partnerships with the cannabis industry, with consideration additional issues that arise when collaborating with companies that have interests both in medical and recreational cannabis; (4) Make suggestions as to the framework for the policies of academic institutions and organizations regarding future partnerships with the cannabis industry.

Author Names: William Reisman, UWO; Robert Sibbald, LHSC
Sparing Some Change: Revisiting a Health System's Moral Responsibilities When Discharging Homeless and Vulnerably Housed Patients
Mr. Kevin Rodrigues, University Health Network

Abstract Category: Standard Concurrent Session
Primary Theme: Ethics and health policy

Three Valuable Questions:
1. How should we balance the needs of vulnerable patients who are occupying hospital beds, with upstream patients who are in need of beds?

2. What are an institution's moral responsibilities to homeless and vulnerably housed patients?

3. What would a "good" discharge from hospital look like, and consist of, for homeless and vulnerably housed patients?

Abstract: An alarming amount of people in Toronto and like urban centres across Canada, are struggling with vulnerable housing situations, and street and shelter living. It has been demonstrated that the lack of safe and stable housing can have significant health consequences. Homeless and vulnerably housed persons are among the most at risk groups, in terms of poor health outcomes (Hwang, 2001). However, approaches to the care of these individuals can often be fraught with bias and inconsistency.

When hospitals embark upon the discharge of homeless and vulnerably housed individuals, conflict and ethical dilemmas often arise. Literature that has looked at the nature of conflict at the time of a transitions from hospital, has generally not grasped the complexity that discharge to the street, shelter, or volatile housing situation poses. Recent commentary has focused on legal obligations of hospitals when facing conflict at the time of discharge (Chidwick et al., 2017). The trend of current inquiry, academically and at a policy level, has tended to examine what it is an institution can do under the law, but does not venture into what should be done for this population.

In our presentation, we will move beyond legal obligations, and explore the moral responsibilities and obligations of individuals and organizations. We will argue that solidarity with the most vulnerable in our system ought to be the guiding principle through which we view clinical dilemmas, policy, and institutional partnerships. There are certainly challenging system issues that arise when considering complex discharges - including the institutional responsibility to appropriately steward valuable, limited resources. That being said, we will explore what it means to be a hospital that serves a community, where inequities exist, and the burdens of illness and benefits of healthcare fall disproportionately. We will present a conceptual framework to revisit the relationship between provider and patient, and institution and community. Solidarity with our patients who live in shelters, on the streets, or in tenuous situations involves a revisiting of: how we interact with and treat these patients; our policies around discharge that have hereto been punitive in nature; and the partnerships we have with community organizations, government, and patient and cultural groups. We will argue that, at a time in our history where technological change is happening at light speed, changing the way that a hospital views it’s community and the moral obligations that it has to those least fortunate would make as profound a difference, yet it seems not to be moving along as quickly - if at all.

Author Names: Kevin Rodrigues, University Health Network; Julija Kelecevic, Hamilton Health Sciences
Don’t Worry, Be Happy: Considering the Ethical Implications of Mood Tracking Apps
Ms. Anna Rudkovska, Western University

Abstract Category: Standard Concurrent Session
Primary Theme: Ethics and health technology assessment

Three Valuable Questions:
1. What recommendations do the authors have for app developers?
2. Given that there is a shortage of psychologists/psychiatrists in Canada, can mobile apps serve as an alternative to therapy for hard to reach populations?
3. For individuals with pre-existing psychiatric conditions, do you see these apps being prescribed by their doctors?

Abstract: Among the plethora of applications (apps) available for both iPhones and Androids, mood tracking apps are an emerging health technology which aim to track, visualize, and augment mood through users’ daily recordings and reflections. These apps intend to improve users’ moods by providing insight into, and recommendations for, daily mood fluctuations. However, the current expansion and execution of these apps into digital distribution platforms warrants ethical consideration as unregulated personal data aggregation as well as lack of adequate planning in design and follow-up can result in catastrophic consequences for users.

Mood tracking apps can be categorized as either: 1) apps for the general public with aims to improve and maintain better moods; or 2) apps for individuals with pre-existing psychiatric conditions such as anxiety, depression, and bipolar disorder with aims to manage or improve symptoms. For the general public, mood tracking can increase well-being when conducted through apps offering guided meditation or mindfulness training. However, the extensive data aggregation characteristic of these apps is problematic. Firstly, users are asked to consent to data collection for information that seems unnecessary for mood tracking, like location tracking or access to a user’s camera and microphone. To date, there are no guidelines for regulating data collection and storage which may result in serious breaches in user privacy.

For individuals with pre-existing psychiatric conditions, mood tracking apps pose a unique set of challenges and dangers. While many apps claim to deliver effective interventions such as Cognitive Behavioural Therapy (CBT), developers provide little evidence to suggest that apps are designed by qualified professionals or by following an evidence-based protocol. Hence, apps targeted at individuals with psychiatric conditions tend to be imprecise in both monitoring and delivering interventions. For instance, eMoods, an app for tracking manic/depressive cycles for individuals with Bipolar Disorder, lets users rank depressive or elevated moods and automatically positions them as part of a depressive or manic cycle, instead of daily mood fluctuations. These classifications are misleading as manic/depressive cycles are distinct from simply feeling happy or sad during the day. Simply mislabeling moods as depressive/manic episodes can result in user distress. Additionally, apps like eMoods rarely provide any meaningful follow-up with their users, despite the importance and effectiveness of follow-up during in-person therapy. For those living with chronic psychiatric conditions, this lack of follow-up can result in harm, both self-inflicted and otherwise.

While many of the apps are free to download, thereby making them appealing for individuals unable to afford in-person therapy, most levy in-app purchases in order to unlock supplementary features or information which set up a cost barrier for users who may not be able to afford such purchases but rely on the app for mental health maintenance. For example, MoodTrack is free to download, but charges an addition $1 for any additional feature. In all, the emergence of mood tracking apps within Apple and Android App Stores begets the question: in the quest for emotional well-being, do mood tracking apps help or harm?

Author Names: Anna Rudkovska, Western University; Danica Facca, Western University
It's All Been Done: The Socio-Cultural Building Blocks of Epigenetics and Their Implications for Disability Theory
Ms. Katie Saulnier, McGill University

Abstract Category: Standard Concurrent Session
Primary Theme: Ethics and genomics

Three Valuable Questions:
How can we amplify the voices of disability theorists in emerging scientific fields?
How do we recognize the power imbalances that underpin which new ideas are amplified?
How can we foster a better working relationship between researchers in the sciences and social sciences?

Abstract: Although research at the intersection of genomics and developmental biology began broadly under the title of epigenetics as early as 1942 with the work of Conrad Waddington, the field in its current form appears in the 1990s, with a consensus definition on the phrase “epigenetic trait” being reached in 2008. This definition – a "stably heritable phenotype resulting from changes in a chromosome without alterations in the DNA sequence" – has also engaged the imaginations of ethical, legal, and social issues (ELSI) researchers, particularly because the epigenome, unlike one’s genetic code, is potentially both heritable and reversible. Epigenetics is becoming increasingly relevant to conceptions of justice in health, engaging questions of intergenerational justice, responsibility for both individual and public health, and access to prevention and treatment. In particular, bioethicists have expressed an interest in epigenetics as providing evidence on a molecular level for the deep interrelatedness between health outcomes and family and community environments.

The story of epigenetics as told by Conrad Waddington in 1942 was not just a story of an emerging science, but rather one that considered the deep links between the human body and its socio-cultural environment. Waddington’s work, which led to his characterization as “the last Renaissance biologist”, spanned palaeontology, population genetics, developmental genetics, biochemical embryology and theoretical biology. Interestingly, modern approaches to epigenetics exhibit a much starker divide between those who see it as changing the way we imagine the body, and those who see it as providing evidence for the importance of information gleaned from the social sciences. Indeed, despite being touted as helping to finally bridge the nature-nurture divide, bioethicists have expressed a concern that epigenetics will in fact serve to further entrench a molecularized understanding of the human body.

In this talk, I will look at the historical, social, and cultural ideas that underpin this debate around the significance and future directions of epigenetics. In particular, and in reaction to the noticeable absence of disability theory voices currently being amplified at the centre of these debates, I will discuss what epigenetics discourse is contributing to changing conceptions of the value of disabled bodies. I will show how the language of epigenetic harm and epigenetic deficits both stem from certain historical normative claims about the body and contribute in turn to a discourse that generates an alarming moral claim about “good” and “bad” epigenetic environments. To do so, I will draw attention to the problem of presumed objectivity in scientific research and demonstrate the degree to which many of the scientific presumptions made about epigenetics have emerged from historical conflict between a false binary of “nature” and “nurture” as foundations for human behavior and health. Finally, I will argue for the need to exercise extreme caution in the navigating conventions and power dynamics within the medical sciences as they shape the direction of emerging scientific fields, and show why this makes the exclusion of disability narratives from the epigenetics debate a particularly urgent concern.

Author Names: Katie Saulnier, McGill University
Crafting and Creating Human Beings: How to Respect Human Personhood
Ms. Olivia Schuman, York University

Abstract Category: Standard Concurrent Session
Primary Theme: Ethics, perinatality and procreation

Abstract: How do we show due respect toward people who don’t yet exist? Are we bound to the same standards for the uncreated as for the already living? What limitations and expectations does this impose on how we craft both the genomes and the environments of people who do not yet exist?

Because of the non-identity problem, certain decisions that are intended to benefit the quality of life of future persons results in simply creating a different person. This seems to undermine commendable efforts to benefit persons who are not yet created.

In order to circumvent this problem, I outline an account based on the work of David Velleman, which I call the Respect Argument. On this view, our correct moral relationship with future persons is to show respect to human personhood generally, rather than respect for any human individual in particular. A surprising outcome of this account is that the minimally acceptable standard for the intended life quality of an uncreated person is higher than the minimally acceptable standard for the actual quality of life of already existing persons.

In so far as human beings have inherent dignity, and thus they have lives that matter, we are obligated not to create human beings whose potential for flourishing is seriously endangered. Because a person is not harmed by never coming into existence, it is better not to create a person than to create someone with seriously damaged potential of ‘realizing their personhood’.

To illustrate, I look at four cases:

1. A person who chooses to become pregnant while taking a drug that will cause a severe disability in her fetus

2. A person who chooses to become pregnant while carrying a gene for a serious disability

3. A person who chooses to become pregnant while carrying a gene for a minor disability

4. A person who chooses to become pregnant with an anonymous donor

All of the resulting individuals have lives that matter and are valuable but also, arguably, face additional challenges in order to flourish. Thus, I outline several conditions that intended parents must meet in order for the creation of this child to meet the minimal standard for respecting human personhood.

However, I also caution against an overly perfectionistic standard for creating human lives. I draw on psychological literature on resilience and toxic stress to emphasize the many mitigating factors there exist that prevent negative or harmful circumstances from causing serious and permanent damage a person’s potential.

Finally, I consider what further implications this view of respecting personhood may have for persons we create with genetic enhancement and genetic therapy. At first glance, extending someone’s potential may not always be consistent with respecting human personhood, and I provide suggestions as to why that may be the case.

Author Names: Olivia Schuman, York University
The role of Big Tech in building Artificial Intelligence for health: An analysis from Global Health Ethics
Mr. Jay Shaw, Women's College Hospital

Abstract Category: Standard Concurrent Session
Primary Theme: AI and Ethics

Three Valuable Questions:
• Does Big Tech not already create public value?
• Would contributions from Big Tech to health care in Canada not create positive benefits?
• Are there not other ethical principles that should be considered when analyzing the ethical status of collaborations between Big Tech and health care?

Abstract: Artificial Intelligence (AI) is a general-purpose technology, and its potential applications in health care are numerous and diverse. As applications of AI to various domains of health care delivery are developed and implemented, large technology corporations with expertise in AI such as Alphabet (the parent company of Google) are positioning themselves to become central contributors to AI innovation for health. Collaborations between Alphabet companies and health care organizations have created public concern in Europe and North America, raising public awareness regarding the ethical issues associated with collaborations between extremely large and profitable technology companies (referred to herein simply as “Big Tech”) and organizations focused on delivering health care. Drawing on the literature on surveillance capitalism, in this paper we provide an ethical analysis of the nature of Big Tech’s involvement in advancing AI innovation for health care from a global health ethics perspective.

In this presentation, we focus in particular on the role of Alphabet (the parent company of Google) in developing collaborations that advance their strategic presence in health-related AI innovation. We provide a summary of Alphabet’s recent activities in health-related AI innovation, and outline three potential consequences of these activities. First, that Alphabet uniquely establishes access to data across public health issues, lifestyle, and health care records, thereby having access to virtually all data related to certain health-related phenomena. Second, that Alphabet acquires expertise in health care, thereby obtaining the necessary knowledge to produce AI technologies that are practically relevant in health care and economically viable in the market. Third, that Alphabet further entrenches its influence in government decision-making by hiring senior government employees into leadership roles in the company.

We suggest that public trust is a prerequisite to enable the role of Big Tech in health-related AI innovation, and that if Big Tech does not find a way to contribute to public value, then resistance from the public will grow. Drawing on the central value of solidarity to global health ethics, we outline how critiques of Big Tech often arise from the priority of solidarity and the focus on public value for the global population as a whole (as opposed to a select few stakeholders of a given corporation). We conclude by outlining the challenges faced by the bioethics community in a new market characterized by surveillance capitalism, and the implications of surveillance capitalism for ethics in health care environments.

Author Names: Jay Shaw, Women's College Hospital; Leah Kelley, Women's College Hospital
The Impact of Gene Editing on Our Understanding of Genetic Relatedness
Ms. Shelly Simana, Harvard Law School

Abstract Category: Standard Concurrent Session
Primary Theme: Ethics, perinatality and procreation

Three Valuable Questions:
1) What are the moral grounds for protecting the desire in having genetically-related children?

2) What are the implications of the potential “break” in relatedness between prospective parents and their future children?

3) Do genetic modifications have impact on the child’s identity? Are the modifications’ degree and kind crucial in determining whether there was a change in the child’s identity?

Abstract: In 2018, He Jiankui, a Chinese scientist, released a video announcing that he had “created” the world’s first genetically modified babies, engineered to protect them from HIV. In 2019, Denis Rebrikov, a Russian geneticist, announced his plan to become the second scientist to create genetically modified babies. Rebrikov’s goal is to treat inherited deafness.

Gene editing technologies are now allowing the editing of DNA with greater precision and safety than ever before. They are already used on plants and animals and their implementation in the context of human health is imminent. While the use of gene editing technologies in somatic cells is seen as falling under existing ethical frameworks, the use of these technologies to edit the DNA of the human germline (i.e., human embryos and gametes) raises much more complex ethical concerns. Germline gene editing would be heritable and passed on descendants, and it is therefore seen as raising unprecedented risks and requiring specific ethical and policy attention. As proved by the cases of the Chinese and Russian scientists, germline gene editing is quickly approaching and have far-reaching consequences; it is imperative that we address its potential impact.

Prospective parents may use gene editing technologies to prevent the transmission of a disease to the resulting child or to ensure that the child is resistant to a certain disease. One of the main justifications proposed in the literature for such use is allowing those parents to have a “genetically-related child” who is free of the disease in question. It is believed that when people are unable to reproduce by “natural” means, they should be able to use a variety of means of artificial assistance in reproduction, including gene editing technologies, in order to have a genetically-related child. For many people, so the argument goes, the desire to have genetically-related children is one of the strongest of human desires, and thus, deserves strong protection.

One interesting aspect of germline gene editing in this respect is that the new technologies have the potential to call into question the justification of “genetic relatedness” and the substantial weight that the interest in having genetically-related children has been given thus far. As future uses of germline gene editing may involve the modification of multiple genes, a critical question is being brought to the fore: at what point do genetic modifications have an impact on the “relatedness” of a child to its genetic parents? More specifically, do the genetic modifications’ degree (i.e., how many genes are being edited) and/or kind (i.e., which genes are affected) “break” this relatedness? In the presentation, we shall seek to tackle this unexplored territory.

Author Names: Shelly Simana, Harvard Law School; Vardit Ravitsky, University of Montreal
Time for a New Approach? Changing the Way We Think about Professional Boundaries in Therapeutic Relationships
Dr. Christy Simpson, Dalhousie University

Abstract Category: Standard Concurrent Session
Primary Theme: Other Clinical ethics - Professional boundaries

Three Valuable Questions:
1) What is the ethical issue(s) with how professional boundaries are currently framed (and taught) in health care?

2) In what ways might biases, such as an urban-based bias, influence how health care providers and others, such as ethicists, address issues related to professional boundaries as they arise in the care of patients?

3) What is the value of changing how we think and teach about professional boundaries, if the alternative framing presented is utilized?

Abstract: Establishing and maintaining professional boundaries with patients is understood by health professionals to be an important aspect of providing health care. Professional boundaries acknowledge the fiduciary nature of the patient-provider relationship and act as a safeguard from possible harm(s) for both patients and providers. Typical or traditional framings of professional boundaries have tended to emphasize the need for separation between personal and professional relationships, highlighting concerns when these relationships overlap. In rural and remote care settings, many health care professionals frequently find themselves in situations where it is not possible to fully separate personal and professional relationships. This creates moral distress as well as questions about whether one is still or can be a “good” health care professional when there are overlapping or dual relationships, which may potentially blur, or raise concerns about the ability to maintain, professional boundaries. This talk challenges the status quo framing of professional boundaries, in part by highlighting how both urban-based assumptions about health care practice and the nature of relationships has influenced what is expected of health care professionals. We argue that professional and ethical standards have as a core assumption the urban norm that health care professionals will, for the most part, be providing health care to strangers. In contrast, for many health professionals in rural areas, the presumption is that care will be provided to neighbors (broadly understood) - thus an overlap between the personal and the professional is an inevitable part of professional practice. In addition, overlapping relationships are often reported to be valued by patients and providers in rural and remote settings. Drawing on these and other insights from rural health ethics and rural health practice, this talk then proposes an alternative framing of professional boundaries – one which reflects a broader range of practice settings and relevant considerations for establishing and maintaining professional boundaries. Examples of strategies and approaches that rural health professionals employ to successfully and ethically navigate the complexities of overlapping personal and professional relationships will be shared.

Author Names: Christy Simpson, Dalhousie University; Fiona McDonald, Queensland University of Technology
Waiting to Live: Relational Suffering and the Potential for Healing in Paediatric Transplant
Ms. Kristina Smith, University of Toronto

Abstract Category: Standard Concurrent Session
Primary Theme: Other Suffering; Relational suffering; waiting; paediatric transplant; palliative care

Three Valuable Questions:
1. How is the distribution of suffering an ethical concern?
2. How do people suffer relationally with bigger social ad cultural structures?
3. How can healthcare providers support children and families through waiting?

Abstract: Within the fields of bioethics and medical research more broadly, pain is generally understood at the local, individualized level. That is to say, pain is something that happens within, and to, particular individual persons. Yet people do not simply experience pain, they also suffer greatly through illness processes. Suffering (generally understood as the experience of mental, emotional, and existential anguish) draws our attention to people’s relationships in the world with other ‘things’ that may be diminished, reduced, challenged, altered, or threatened through illness (such as the loss of one’s sense of self, personal relationships, cultural identities, physical abilities that allow one to move with other people, and other markers of social inclusion and status). By definition, then, suffering is relational. In this presentation, I unpack the concept and implication of relational suffering to the field of bioethics. Using the case study of children awaiting organ transplantation in Canada, I highlight both the distributional nature of suffering and how people suffer together in webs. Even more specifically, I discuss what ‘waiting to live’ does to children and others’ in the palliative care context, and the centrality of the waiting-suffering relationship in illness processes. Finally, I emphasize the need for health care practitioners to not only witness the suffering of their patients, but understand their role in the relational web of suffering and their social responsibility as practitioners.

Author Names: Kristina Smith, University of Toronto; Michael Atkinson
The Ethics of the Deep Freeze: Cryonics and the possibility of life after death
Ms. Kristina Smith, University of Toronto

Abstract Category: Standard Concurrent Session
Primary Theme: Ethics and health technology assessment

Three Valuable Questions:
1. Have cryonics institutes thought through or provided any information on what life after revival might look like for the cryo-revived person?

2. Are hospitals working with cryonics institutes? Do you think that they should be working with them at this stage?

3. What is the extent of testing that the institutes have done in order to assess the possibility of revival?

Abstract: Within the health, medical, and bioethics fields, discussions about life extension and life extending technologies are becoming increasingly prevalent. Globally, there seems to be a cultural movement towards attempting to “cheat” death (Kyslan, 2019). One topic that is largely under-explored as part of these conversations, however, is that of cryonics.

Originally introduced as an idea in 1962 by Robert C. Ettinger in The Prospect of Immortality, cryonics is the process of preserving a person’s body after they are declared dead, with the goal of reviving it through future scientific advances. More specifically, cryonics involves cooling a dead body to a liquid nitrogen temperature so that any further decay is halted; this process is also known as cryopreservation. The motivation behind this controversial practice is that if corpses can be preserved, then irreversible death may be preventable. It seems, then, that the particular appeal of cryonics lies in the possibility of reviving a body after death and curing it of any former terminal illnesses.

At this point in time, and unbeknownst to many, a number of adults’ and children’s bodies (as well as pets) have been successfully frozen in cryopreservation labs with the goal of them being revived at a future date. Although we are presently unable to revive them, the practical question of whether we can revive corpses is being explored. In addition to the practical question, however, it is also necessary to examine the bioethical implications of cryonics and the work being done to achieve its practicability. For instance, should we, as a society, seek to achieve immortality? If yes, then how many and what kinds of resources ought we assign to the preservation of dead bodies? Furthermore, should healthcare providers be required to care for and maintain dead bodies until a cryopreservation lab becomes involved (which would plausibly be required in the case of a hospital death) even if they object to the moral permissibility of cryopreservation? And if revival becomes a possibility, then what rights would these “new” members of our society have? What obligations would our society have to them, if any?

Given the unknown implications of immortality and the growing cryonics clientele, it is surprising that there has been minimal clinical and academic discussion about the practice and its bioethical implications. In order to shed light on this ethically complex topic, this presentation will initially review the history of cryonics and discuss where and how it is currently practiced. Next, we will pose several ethical questions/concerns and offer some preliminary remarks. Ultimately, the goal of this presentation is to promote a dialogue around the possibility of immortality and the practices that currently exist. Cryonics presents a unique case for the medical system and society, with the prospect of preventing a permanent death. It is necessary, however, to carefully consider the multi-dimensional impacts of suspending death, and how to mitigate potential negative outcomes.

Author Names: Kristina Smith, University of Toronto; Andria Bianchi, University Health Network
Modelling Ethical Standards of Health Equity in Public Health
Dr. Maxwell Smith, Western University

Abstract Category: Standard Concurrent Session
Primary Theme: Public health ethics

Three Valuable Questions:
1. What are the implications of adopting different interpretations of health equity for population health interventions?
2. How do different interpretations of health equity, grounded in accounts of justice, impact population health outcomes?
3. To what extent do modelling data about the effect of different interpretations of health equity on population health outcomes affect how we should pursue health equity in practice?

Abstract: Two key groups of researchers work in parallel on health equity. Epidemiologists work on describing health inequities and the effect that population health interventions might have on reducing those inequities. Ethicists, on the other hand, work on establishing the ethical standards that ought to be met when defining and operationalizing health equity. These ethical standards are informed by different accounts of justice (e.g., egalitarianism, sufficientarianism, prioritarianism, utilitarianism). Yet, a significant gulf exists between the research of epidemiologists and ethicists. This means that population health interventions may fail to target the most appropriate populations or the most ethically important health disparities, and might therefore fail to achieve the most ‘equitable’ health outcomes. At the same time, without empirically testing different ethical standards of health equity, ethicists may end up producing ethical guidance for the design and implementation of public health interventions that ultimately have undesirable (or less desirable) outcomes in practice. This empirical ethics study therefore sought to empirically model population-level interventions for diabetes according to distinct ethical criteria of health equity (e.g., ‘sufficiency’, ‘equality’) in order to understand the realistic consequences of adopting different ethical views about what health equity requires for public health. Through the case of diabetes and diabetes prediction models used at Public Health Ontario, the primary research question that this presentation addresses is: What differences and similarities do different ethical criteria of health equity reveal for diabetes outcomes among Canadian adults using the Diabetes Population Risk Tool?

Using the validated Diabetes Population Risk Tool (DPoRT), ten-year diabetes risk was calculated for respondents to the nationally representative 2015-16 Canadian Community Health Survey (n=67,867). The number of diabetes cases prevented or delayed was estimated across low, medium, and high education categories according to two ethical criteria: 1) ‘Equality’ (equalizing diabetes risk); 2) ‘Sufficiency’ (reducing diabetes risk below the DPoRT high-risk threshold (≥16.5), beyond which remaining inequalities are not considered ethically important). Hypothetical percent weight-loss interventions in overweight and obese individuals were modeled for each ethical criterion.

In total, 1,811,017 new diabetes cases were predicted for 2026. Education was inversely associated with baseline diabetes risk (risk ratio (RR)=1.68, 95% confidence interval (CI): 1.63,1.73; low compared to high education). ‘Equality’ was achieved by implementing 20% and 15% weight-loss interventions in low and medium education groups. ‘Sufficiency’ was achieved by a 14% weight-loss intervention in high-risk individuals; however, large social inequalities in diabetes remained in this scenario (RR= 1.52, 95%CI: 1.48-1.56; low compared to high education). These interventions resulted in 246,923 and 267,690 diabetes cases prevented or delayed, respectively.

This study quantifies how the choice of different ethical criteria, which both aim to ‘reduce diabetes inequities’, can have disparate effects on population-level diabetes outcomes. It is the first of its kind to illustrate how adopting different criteria of equity offered by public health ethicists could impact population health outcomes. As such, this study represents a promising program of research, the findings of which being poised to transform the ethical design of public health interventions which aim to ‘reduce health inequities’.

Author Names: Maxwell Smith, Western University ; Brendan Smith, Public Health Ontario
Third-Party Interpretation and the Release of Raw Genetic Data: A Clinical Perspective
Mrs. Cherith Somerville, University of Toronto

Abstract Category: Standard Concurrent Session
Primary Theme: Ethics and genomics

Three Valuable Questions:
1. How are TPI services governed, and are there any foreseeable changes to their current regulation?
2. What are conceivable ways in which the genomics community can appropriately educate and inform the public about the limitations regarding TPI tools and DTC tests?
3. What are the potential ethical implications regarding the raw genetic data release in the pediatric context?

Abstract: As genetic testing initiatives continue to advance, people will gain unprecedented (and legally mandated) access not only to their validated genetic test information but also to their “raw,” or uninterpreted, genetic data. This access will be granted through consumer genomics, genetic research endeavours, and in time, through clinical sequencing. The release of raw data is most widespread in the context of Direct-to-Consumer (DTC) testing, wherein customers are offered their genotype data which lacks sequence validation and is subject to a high rate of false positives. In pursuit of personally tailored information, customers may seek out unregulated Third-Party Interpretation (TPI) tools to navigate this raw genetic data, posing the risk of misinterpretation and unreliable health-related information. Consumer utilization of this DTC data is still under preliminary investigation. Recent studies have highlighted prominent concerns regarding TPI tool accuracy and reliability in addition to limited genomic literacy in the general population. Consumers receiving unsettling results following TPI use may experience undue psychosocial stress and seek out clinical confirmation of the variants. The result is a strain on clinical resources and increased financial burden on the healthcare system.

The Health Insurance Portability and Accountability Act (HIPAA) Privacy Rule amendments of 2014 granted people the legal right to obtain their laboratory test results, which includes raw genetic data containing unconfirmed and uninterpreted variants. However, limited research has been conducted on the downstream implications of raw genetic data release in the clinic. Documented issues have already arisen with DTC data release and could continually and predictably manifest within a clinical context. Patients attempting to understand their unvalidated data may utilize third-party analysis, leading to an increased return of uncertain and adverse results. A portion of those patients will then elect to have their results clinically validated, ultimately contributing to a drain on the healthcare system through the misallocation of resources. An additional ethical and legal concern surrounding clinical raw data release is the responsibility for patient harm during downstream interpretation of their raw data. It must be considered whether or not a clinical testing lab could be held liable for the release of unvalidated, potentially subclinical-quality, genetic data if the patient is harmed psychosocially or through unnecessary medical interventions following unregulated TPI use.

In my presentation I will frame the ethical discussion on raw genetic data release within a clinical context, exploring both the potential strains on the healthcare system and the resulting ethical and legal implications for TPI services and clinical testing labs. I will conclude by recommending the necessities for clear communication between the professional genetics community and end users of TPI services; both to understand consumer motivations behind the pursuit of TPI analysis and to educate about the reliability concerns of interpretation and data privacy. By addressing the complex and understudied facets of raw data issues, the professional genetics community can help to increase public awareness and reduce potential harms to TPI end users and the healthcare system.

Author Names: Cherith Somerville, University of Toronto
The Future of Ethics: An Aristotelian Approach to Moral Enhancement
Mr. Georgios Strempolis,

Abstract Category: Standard Concurrent Session
Primary Theme: Ethics and health technology assessment

Three Valuable Questions:
Why should we rely on Aristotle in order to approach the issue of moral enhancements?

Are moral enhancements a real issue that we are going to face over the next years?

Why would it be bad to rely on biotechnology in order to achieve moral excellence, if that will make the world a better place?

Abstract: Is moral excellence in need of an upgrade? Are we equipped to face a biotechnologically enhanced future if morality is not adapted to it? New biotechnological interventions offer us unprecedented control over our species’ evolutionary process by allowing us to make various biological enhancements. Some bioethicists insist that in addition to enhancing our biological capabilities (e.g. memory, strength, life expectancy, etc.), we ought to enhance our species’ moral capacities as well. Failing to adapt the ways to achieve moral excellence with the use of biotechnological methods for moral enhancements could potentially be dangerous in a world that prioritizes cognitive enhancements. Julian Savulescu is one bioethicist who supports this perspective and argues that we need to embrace biotechnological and genetic interventions as the new and improved way to achieve moral excellence. Savulescu’s position seems to be based on the idea that our moral capacities are biologically determined (i.e., that one can improve one’s moral character via neuropharmaceutical or genetic interventions).

In this paper, I argue that Savulescu maintains a rather simplistic conception of moral development that disregards the dynamic character of our moral understanding. And by failing to recognize the multifaceted and interconnected workings of the moral agent, we are in danger of undermining certain aspects of morality such as freedom and autonomy. Moreover, by giving into biological determinism, we accept that our morality is nothing more than a product of our biochemical or genetic composition; a composition that can be affected or completely altered by administering drugs and/or genetic engineering. In opposition to the idea that moral enhancement can be achieved via biotechnological and genetic interventions, I propose using Aristotelian moral philosophy as a better way to understand the issue of moral development. While the most common approaches to such matters usually stay within the utilitarian or the deontological schools of thought, I argue that we should not ignore the relevant insights that Aristotle provides us (both in regard to his views on morality as well as the perplexities of the human condition). Aristotle recognizes that everybody possesses certain natural moral dispositions (e.g. being just, being brave, etc.), and he also suggests that moral judgements do not solely depend on these natural dispositions. According to Aristotle, one’s moral development demands conscious and continuous personal efforts. These efforts require knowledge of what is good, the intention to act in accordance with what is good for its own sake, and for the action to proceed from a firm and unchangeable character. Despite the fact that Aristotle’s understanding of morality has a teleological end to it (where, the purpose of all human actions is eudaimonia), the moral agent still has the freedom to choose right over wrong, good over evil. It is this freedom of choice that makes Aristotle’s understanding of both morality and the human condition far more realistic and helpful than any biologically or genetically engineered moral excellence.

Author Names: Georgios Strempolis
Machine Oversight of Machine-learning: can Ethical Data Aggregation be Automated?
Mr. Adrian Thorogood,

Abstract Category: Standard Concurrent Session
Primary Theme: AI and Ethics

Three Valuable Questions:
What different types of ethical limitations and conditions may be imposed on health data sharing?

What does it mean to make data sharing policies and consents machine-readable, and what are the advantages?

For international consortia, what is the difference between harmonizing data sharing policy, and automating the enforcement of diverse data sharing policies?

Abstract: Effective training artificial intelligence and machine-learning algorithms (AI/ML) in medicine is dependent on access to multiple health data sources. The burden of data aggregation is typically left to researchers or research organizations, who must find, access, and curate these data sources, often with great cost and delay. Alternatively, data generators (namely researchers and healthcare institutions) can organize into consortia that bring together multiple datasets into a single “data commons”. One important barrier to establishing a data commons, especially internationally, is that different datasets tend to be subject to different ethical limitations and conditions on sharing. The traditional solution to this problem of “ethical interoperability” is policy harmonization, where a consortia establishes a single policy governing who may access data, for what purposes, and under what conditions. The International Cancer Genome Consortium, for example, has a single policy and process for sharing thousands of cancer genomes. This is a boon for researchers, who can access multiple datasets under a single set of rules and processes. It also makes life easier for data access committees, who only need to implement a single policy. But policy harmonization compromises re-use and integration of data in two ways. First, already-collected datasets may be governed by a more restrictive policy or consent than the data commons policy. These datasets cannot be included in the data commons, unless data generators are able to seek renewed consents or ethics waivers. Second, datasets governed by permissive policies or consents become subject to the comparatively restrictive policy of the commons, curtailing their re-use. An alternative, technologically driven solution has been proposed to avoid these compromises: machine-readable data sharing policy. In this automated solution, any dataset offering an ethical prospect of sharing/re-use can be deposited and semantically tagged with a data sharing profile. This profile is constructed from a standard set of computable terms, such as those defined by the Global Alliance for Genomics and Health’s Data Use Ontology. Research access requests can then be easily matched to all ethically available datasets. This automated solution promises to overcome the problems of entirely excluding restrictive datasets or curtailing re-use of permissive datasets, and to improve accountability for respecting patients’ consent even as data are shared worldwide. Implementations are being developed for the All of Us Project, a million-person US genomic research resource, and EU-CanSHare, an international network of cardiovascular research datasets. A number of preconditions must be satisfied, however, before this automated solution succeeds in creating more than a mere aura of responsible data aggregation. First of all, policy harmonization remains essential. Prospectively, researchers, hospitals and research ethics boards must strive to adopt straight-forward, transparent data sharing language that unambiguously maps to machine-readable standards. For already-collected data, existing consents must be carefully interpreted during the tagging process, and perhaps also renewed. Second, an international standard terminology and logic needs to be maintained for representing data sharing policy, that is flexible enough to capture variation across jurisdictions, but also simple enough to be commonly understood by data generators, data users, and patients themselves.

Author Names: Adrian Thorogood
Carebots, dementia care and respect for cultural diversity
Dr. Ryan Tonkens, Northern Ontario School of Medicine, and Lakehead University Centre for Health Care Ethics

Abstract Category: Standard Concurrent Session
Primary Theme: AI and Ethics

Abstract: Internationally, a lot of research is being done at the intersection of dementia care and robotics. The main reasons for this are (1) an increasing population of elderly people (and people with dementia), and (2) a relative shortage of human eldercare workers.

The moral implications of the development of robots in the context of dementia care change in light of consideration of different groups, and their particular values and needs. The main motivation for this presentation is to give consideration to a particular group of people, namely people living in rural and remote areas of Northwestern Ontario, in the context of the research, development and use of robotic systems/artificial intelligence in the care of people with dementia. In particular, I draw on recent empirical data regarding the prevalence and causes of dementia in Indigenous populations in Canada, in order to critically engage with the automation of dementia care, focusing in particular on the potential implications for such groups. This research aims to inform culturally sensitive healthcare robotics research.

Indigenous people are the fastest growing group of people with dementia in Canada (Petrasek MacDonald, Ward et al. 2018). However, most of the risk factors contributing to the prevalence of dementia in Indigenous people are modifiable (e.g. lifestyle, education, access to nutritious food, health literacy, etc.). Moreover, Indigenous Canadians are the fastest growing population demographic, and, because of location and/or socio-economic factors, may not have access to such cutting-edge dementia care technology. Indeed, many of them prefer to remain in the care of family/community. This suggests that groups of people such as this may not need or desire dementia care robots. Thus, resources being used to develop dementia care robots could be directed elsewhere, for example towards combatting ongoing epidemic rates of malnutrition, diabetes, youth suicide and substance abuse that plague many Indigenous communities. Indeed, investing resources into medical robotics may mean that (many) other (more pressing) concerns for Indigenous people in Canada do not receive the attention or resources that they require.

The development of robotic systems to aid with the care of people with dementia in Canada ought not to be a high-ranking priority in contexts where basic medical resources—including access to physicians, hospital beds, and medications—are not already provided for everyone that needs them.

The above facts suggest that much more needs to be done in order to coordinate these areas of medical robotics research in a manner that is ethically responsible and inclusive. Indeed, an important corollary of the argument presented in this paper is that the research and development of robotic systems for dementia care in Canada may not be consistent with certain aspects of the Truth and Reconciliation Commission’s Calls to Action (2015), in particular #19—the call for “the federal government, in consultation with Aboriginal peoples, to […] close the gaps in health outcomes between Aboriginal and non-Aboriginal communities”.

Author Names: Ryan Tonkens, Northern Ontario School of Medicine, and Lakehead University Centre for Health Care Ethics
Better birth control: Improving clinical and regulatory guidelines in the emerging pharmacogenomics era of hormonal contraception through a narrative ethics framework
Ms. Sarah Towle,

Abstract Category: Standard Concurrent Session
Primary Theme: Ethics and genomics

Three Valuable Questions:
1) How can clinicians balance harms and benefits of genetic screening for contraceptive use?
2) Given the complexity of genetic testing, how can we ensure that patients fully consent to screening if we cannot be sure that they understand what it means?
3) Moving forward, how can we facilitate patient-centred research on pharmacogenomics and hormonal contraception, given the ethically problematic past of birth control research and development?

Abstract: Hormonal contraception is considered one of the greatest pharmaceutical developments of the 20th century. It revolutionized family planning and treatment of menstrual disorders, and its contribution to the women’s liberation movement cannot be overlooked. But despite these benefits, the use of hormonal contraception has been plagued with adverse reactions, and calls continue to grow from patients for improved options. While clinicians have attempted to mediate more serious side-effects through patient history and routine monitoring, evidence now suggests that genetics and perhaps pharmacogenomics may hold the key to better birth-control prescribing.

Research has identified multiple genetic mutations responsible for increased risks of breast cancer, blood clots, hypertension, and even lowered drug efficacy in carriers who also use hormonal contraceptives. Though this correlation between adverse reactions and genetics keeps growing, regulations and clinical guidelines in North America are slow to catch up: genetic screenings in contraceptive users are still not clinically recommended, and both Health Canada and the U.S. Food and Drug Administration have identified only one hormonal contraceptive for pharmacogenomic biomarkers. However, this lack of options has not stopped patients or the consumer market from responding, with users assessing their own contraceptive risks through direct-to-consumer genetic testing and start-ups promising genetic screenings aimed at “personalizing the pill.”

With recent genetic advances, it is clear that hormonal contraception is on the cusp of entering the pharmacogenomic era. Regulations and clinical guidelines must change to meet the diverse needs of patients wanting safer birth-control options while also addressing the ethical and legal issues that a genomics approach to this field of healthcare may create. In this presentation, I will discuss my original research on this topic which includes a narrative literature review and thematic analysis of: existing studies, regulations and clinical guidelines, the consumer market, patient perspectives, and emerging ethical and legal tensions. I will conclude with a narrative ethics analysis of these issues, aiming to address ways forward for future genomic approaches to birth control prescribing and counselling. Women’s experiences have traditionally been suppressed in the development of hormonal contraception, and narrative ethics brings forward their voices as a guide towards resolutions. Pharmacogenomics holds much promise in the field of contraception, but future guidelines and regulations must carefully balance harms and benefits through patient-centred perspectives.

Author Names: Sarah Towle
Human rights and ethical issues regarding nursing care to persons with mental illness: a scoping review
Dr. Carla Ventura, University of Sao Paulo

Abstract Category: Standard Concurrent Session
Primary Theme: Ethics and health policy

Abstract: Background: People with mental illness are a vulnerable group, facing barriers in the exercise of political and civil rights, as well as in their ability to participate in public affairs. These people are subjected to stigma and discrimination, encountering restrictions in the exercise of their political and civil rights, and in their ability to participate in public affairs. Considering this scenario, mental health, ethics and human rights are key approaches to advance the well being of persons with mental illnesses.

Objectives: The study was conducted to review the scope of the empirical literature available to answer the research question: What evidence is available regarding human rights and ethical issues regarding nursing care to persons with mental illnesses?

Method: A scoping review methodology guided by Arksey and O'Malley was used. The human rights and ethical issues regarding nursing care to persons with mental illness were the central problem which motivated the development of this scoping review. The guiding question for the scoping review was identified as: "What evidence is available regarding human rights and ethical issues regarding nursing care to persons with mental illness?" Studies were identified by conducting electronic searches on CINAHL, PubMed, SCOPUS and Hein databases. Of 312 citations, 26 articles matched the inclusion criteria.

Results: The central theme which emerged from the selected literature was “Ethics and Human Rights Boundaries to Mental Health Nursing Practice”, which comprised the following subthemes: Nursing and mental illness: the limitation of autonomy and individuals rights; The value of dignity and the ethics of nursing care; Advocacy, informed consent, confidentiality, privacy and mental health nursing practice; Health services polices and legal aspects of psychiatric nursing practice and research. Protecting human being’s dignity is a fundamental value, although several studies inform that dignity is not always promoted within mental health services.

Discussion: Mental health policy affects human rights, and human rights violations affect mental health. Thus, the positive promotion of mental health and human rights are mutually reinforcing.

Conclusion: This review may serve as an instrument for healthcare professionals, especially nurses, to reflect about how to fulfill their ethical responsibilities towards persons with mental illnesses, protecting them from discrimination and safeguarding their human rights, respecting their autonomy, and as a value, keeping the individual at the centre of ethical discourse.

Author Names: Carla Ventura, University of Sao Paulo; Bruna Carrara, University of Sao Paulo; Emanuele de Brito, University of Sao Paulo
Abstract Category: Standard Concurrent Session
Primary Theme: AI and Ethics

Three Valuable Questions:
(1) If we should be aiming for grey box systems, as you argue, how do we determine what information can remain opaque and what information needs to be explainable?

(2) You say this presentation is in the context of radiology -- how would we transfer these arguments to other departments in the hospital / clinic?

(3) While theoretically it is good to have explainability, in practice shouldn't we really be primarily focused on producing the most powerful systems?

Abstract: The prospect of including artificial intelligence in clinical decision making is an exciting next step for some areas of healthcare. This presentation aims to outline what kind of artificial intelligence systems I believe we should want in radiology, specifically, by examining reliable “black box” systems, fully explainable systems, and “grey box” systems.

In general, I believe that healthcare applications require specific analyses of artificial intelligence, rather than being grouped with other applications. I think that this is the case because there are specific issues and considerations that are unique to the healthcare field and for which there are no close analogies in other fields – one prominent example is informed consent.

This presentation begins by examining current artificial intelligence systems as they appear in other fields. I refer to these in this project as “reliable systems”. This does not mean that these systems are 100% reliable all the time – rather, it is meant to capture the reliabilist background I believe is active in current black box artificial intelligence systems. The first section of the presentation demonstrates why these kinds of systems are ethically fraught for application in healthcare by examining a handful of unique features in healthcare decision making. This section also demonstrates why I believe that implementing these kinds of systems will instead set back the implementation of fuller artificial intelligence systems in healthcare due to the risks and problems that reliance on black box systems would cause.

In the second section of the presentation I compare reliable systems to explainable systems – both fully explainable systems and so-called grey box systems. The intention here is to show that reliable systems face significant problems that explainable systems do not (or, at least, do not to the same degree).

I then conclude with section three where I defend the claim that grey box systems are better for healthcare than fully explainable systems. I believe this is the case for several reasons, including: that healthcare already operates with some opacity, that there is already uncertainty in healthcare (so demanding full explainability is asking too much), and because we still need our systems to have some power if they are to be useful in application.

An additional benefit, I argue, is that grey box systems can come in a range of “shades”, rather than the stark all or nothing options presented in reliable systems or fully explainable systems. This customizability is a unique feature that could allow for greater application of artificial intelligence in healthcare, as tailored decision making systems could be incorporated into more nuanced areas of clinical practice.

Author Names: Jordan Wadden, University of British Columbia
Should the Definition of Consent Be Expanded in Reproductive Healthcare?
Mr. Jordan Wadden, University of British Columbia

Abstract Category: Standard Concurrent Session
Primary Theme: Theories and methodology in bioethics

Three Valuable Questions:
(1) Even if your proposal is ethically more justifiable, how can we implement this view of consent if the legal requirements for consent remain hyper-performative?

(2) If you're right that we should be looking for a performative view of consent, rather than a hyper-performative view, how do we determine where to draw the line regarding what counts as enough "performance"?

(3) Since healthcare is a specialty field, do the more general conceptions and views on consent in the broader academic literature even transfer to our situations?

Abstract: Sometimes there are cases in healthcare that lead us to question some of our fundamental concepts. In this presentation I want to explore two cases that I think open the floor for an examination of consent in healthcare.

The first case regards Peter Zhu, a 21-year-old Californian killed in a skiing accident. In February 2019 his parents won the right to extract sperm from their son’s body in order to have a grandchild. While Peter had talked about eventually wanting kids, he had not left written consent for his parents to extract his reproductive material to create a child in the event he passed prematurely. Because Peter had not consented to this process, the criticisms of this court decision rest on concerns regarding whose best interests are being served in creating a child from Peter’s reproductive material.

The second case happened in December 2019 and involves a woman in British Columbia who was denied the right to use her deceased husband’s reproductive material to make a sibling for their daughter. Mrs. and Mr. T had been in a long-term relationship before he died suddenly and had discussed many times having another child. Evidence was even provided to the court by several persons close to the deceased that he had wished to have more children with his wife. Unfortunately, because there was no written consent, legally Mrs. T cannot use her husband’s reproductive material no matter how much evidence is provided.

It seems to me that the verdicts in these cases are exactly backwards – the Zhu’s should not have been given permission to extract their son’s sperm, but Mrs. T should have been given permission. I think a reconceptualization of consent in medicine might have helped get us to the right results.

In the philosophy of consent, there are two primary theories: the mental view, in which consent refers simply to a particular state or mental action of the consenting agent, and the performative view, which conceives of consent as a public act. Currently, the medical application of consent appears to be hyper-performative. By this I mean that the only way to express consent that is legally binding is through a signature on a waiver or form. But we know that ethically informed consent is a process that is constantly evolving, and that a simple signature or written statement is not the be-all-end-all of consent and respect for autonomy.

In this presentation I am not suggesting that consent should be re-conceptualized as something like the mental view. I have issues with this view of consent in general, and in these situations I believe this view would be too easy to distort. Instead, I think a laxer performative view – one that is not hyper-performative – would be better for healthcare, at least for reproductive matters.

Author Names: Jordan Wadden, University of British Columbia
Generalizability, Transportability, and Artificial Intelligence in Healthcare
Mr. Jordan Wadden, University of British Columbia

Abstract Category: Standard Concurrent Session
Primary Theme: AI and Ethics

Three Valuable Questions:
(1) If the risk of generalizability and transportability is high in AI systems, why should we consider using AI in healthcare at all?

(2) If a system was able to identify generalizability problems but not identify transportability problems (or vice versa), would it still be ethical to use it in the clinic?

(3) How can we learn from an AI system after it has identified a pattern or a generalizability/transportability problem -- wouldn't this require healthcare professions understand the programming used in the system?

Abstract: Whenever someone publishes in medical research, one of the most important questions is whether this study would have come to the same result if it had been conducted on a different population. There are two ways a population could be ‘different’: either it could be a different sample from the same general population, or it could be a different sample from a non-overlapping population. These lead to two separate problems: the problem of generalizability and the problem of transportability, respectively. In this presentation I argue that any analysis of artificial intelligence in healthcare needs to be sensitive to both of these problems.

Generalizability is important because it is not practical to create a new trial for every treatment in a class of medication, nor is it practical to evaluate every possible sub-group of a test population. Additionally, it may be unethical to conduct trials of a similar treatment, or a different dose of the same treatment, in a new population. Continuing to test a treatment we know is harmful, or testing treatments we don't know about instead of using ones that already work, puts patients in direct harm and violates the biomedical principle of non-maleficence.

On the other hand, transportability can be more difficult. Medical studies generally remain vague regarding what ‘representative’ means in their claims that results are found in a representative population. This vagueness entails two questions to remove the uncertainty: (1) representative of what target population? and (2) representative of what characteristics in this population? Answering these questions gives an idea of who is external to the target population, which is necessary for delineating transportability concerns from generalizability concerns.

These problems are important when considering healthcare AI because the studies we have for various conditions would need to be used by the system to justify treatment for all patients. If a study doesn't properly generalize, we could instead be causing patients harm. Additionally, patient populations are not homogenous -- any one hospital can see newborns to the elderly, from a myriad of races, ethnicities, and cultures, in the same day. I argue that any AI system in healthcare would need to be programmed in such a way that it could learn potential patterns of diagnosis or patterns in the data that reveal generalizability and transportability concerns. If this approach is taken, I believe two benefits emerge: first, patients get better treatment because they're not being given something that won't help (and could instead harm), and second, we could learn from the system why the study doesn't generalize or transport to other populations.

Author Names: Jordan Wadden, University of British Columbia
“Woof Woof” Robotic Dogs at the Bedside: An Ethics Based Critical Interpretive Literature Review of Animal-Like Socially Assistive Robots
Ms. Ellie Wakabayashi, McGill University

Abstract Category: Standard Concurrent Session
Primary Theme: AI and Ethics

Three Valuable Questions:
1) How do design considerations impact the A.I. acceptability
2) Why is there a difference between animal-like and humanoid robotics
3) what specific unique dilemmas led to animal-like SARs

Abstract: Artificial Intelligence (AI) technology is being used for elderly care as a possible tool to empower elderly to live more independent lives with better quality of life in an institutionalized setting. Socially Assistive robots (SARs) are viewed as a promising technological development with the potential to mitigate the growing care recipient to caregiver disparity. Specifically, animal-like SARs have been developed for institutionalized elderly. Examples include AIBO - the robotic dog, PARO - the robotic seal, and JustoCat - the robotic cat among others.

Numerous ethical issues and implications of SARs are raised in the academic literature regarding a wide variety of SAR uses. The aim of this critical interpretive review was to identify and analyze ethical themes which have been raised in the literature specific to the use (or potential use) of animal-like SARs in elderly care. Particular attention was placed on the unique dilemmas that face the elderly and their caregivers in institutionalized care.

A literature review search in October 2019 of eight academic databases resulted in the identification of 14 publications. Two ethical categories of universalism and particularism were used to structure some of these identified articles. These normative theories did not reach a consensus and had various competing points. Interestingly, most articles were largely concerned with deception and who should feel guilt and responsibility for transgressions on individual autonomy. Another major theme was questions centered around how elderly autonomy could be respected while providing them with optional animal-like SARs.

The significance of this critical interpretive review is its discussion on the applied practicability of ethically-sound delivery of elderly care. The unique dynamic between animal-like SAR and institutionalized elderly would benefit from being analyzed to guide further application and guidelines.

Author Names: Ellie Wakabayashi, McGill University
Grandma’s pet seal is a robot called PARO?!: An introduction to PARO, a socially assistive robot, through a bioethics lens
Ms. Ellie Wakabayashi, McGill University

Abstract Category: Standard Concurrent Session
Primary Theme: AI and Ethics

Three Valuable Questions:
1) How does familiarity with different animals affect user perception
2) In what countries are animal-like SARs more readily accepted
3) What are the main barriers to animal-like SAR use

Abstract: Grandma’s pet seal is a robot called PARO?!:

An introduction to PARO, a socially assistive robot, through a bioethics lens

Abstract

Animal-like socially assistive robots (SAR) is an emerging field of elderly care and cross-disciplinary research. These robots are presented as companions to elderly living in institutionalized care. One of the most well known SARs is a robotic seal named PARO. It is a robot with five kinds of sensors: tactile, light, audition, temperature and posture. The robot also has the ability to behave in a way that the user prefers as if it had a personality. A search of the literature on PARO suggests that clinical research has found positive psychological effects (e.g. increased motivation and improved mood), physical effects (e.g. stress reduction) and social effects (e.g. encouraging communication). Other studies have tested to see whether PARO would inhibit anxiety levels or have neuropsychological effects. Despite the overall positive reception to PARO, there are various ethical discussions around the use of PARO for elderly care. Discussions around normative ethics concepts about PARO have great diversity and are didactically opposed in the same article.

In this presentation, I will 1) introduce PARO the robotic seal as a new innovative SAR used in elderly care, 2) present broad results that have been published about its use, and 3) discuss certain ethical themes that arise when PARO is used for institutionalized elderly.

The major ethical themes I will discuss involve: 1) the tension between deception and truth telling, 2) the inquiry whether counterfeit relationships are good relationships, and 3) the “target.” An exploration of whether PARO is ethically-sound could allow for greater interest in research on animal-like SARs in general. Future research should examine what complexities in institutionalized geriatric care could complicate how traditional ethics concepts such as relationships of “care” can understood.

Key words: Animal Assisted Artificial companions, Paro, Animal Assisted Therapy

Author Names: Ellie Wakabayashi, McGill University
Watch and Learn: Using Video Interviews in Ethics Education
Dr. Marika Warren, Dalhousie University Department of Bioethics

Abstract Category: Standard Concurrent Session
Primary Theme: Other Information technology and ethics education

Three Valuable Questions:
1. Which groups of health care providers are most likely to access the Fireside Chats?
2. How might you evaluate each Fireside Chat in a more specific way?
3. Which Fireside Chats have generated the greatest response? Why do you think that is?

Abstract: Technological advances have created novel ways of approaching ethics education. Not all of these approaches have been equally effective in our experience, but in this presentation we will describe one educational strategy that capitalizes on the ability to make videos available online and present an analysis of why it has been successful.

The popularity of using the telehealth system for education events resulted, for our jurisdiction, in its being limited to clinical purposes only. We used telehealth to provide hour-long, bimonthly ethics education sessions across the province, and when telehealth was no longer available we had to explore other options. We needed to find a way to reach individuals and groups who might not be able to travel to attend an ethics education event, as travel budgets were increasingly restricted and providers were finding it difficult to take the time away from their usual activities to participate in workshops and other educational activities.

Our experience was that participants in telehealth sessions who were not physically in the room where the session was being presented tended to approach telehealth education much as if they were watching a television broadcast. Based on this observation, our response to the removal of the telehealth option was to develop a video series dubbed “Fireside Chats”, with the name chosen to convey the friendly, accessible tenor that we wanted for the videos.

The objectives for Fireside Chats are:
*To ground discussion of ethical issues in realities of clinical practice
*To approach ethical issues from a place of curiosity, as opposed to presenting an argument
*To demonstrate constructive ways of engaging in ethical discussion
*To raise awareness around the range of ethical issues relevant in clinical practice
*To encourage further discussion and dialogue among health care providers
*To encourage health care providers to reflect on the relevance of the ethical discussion to their own practice

In this presentation we describe how we create these resources, the ways these resources are used, and the impact that they have had in providing ethics education in our context.

We begin with an outline of the strategy that we have used in designing the resource and outline the decision making process around how to achieve the objectives described above.

Next, we describe the production process. Key learning for us has been around how to respond to participants’ fears around appearing in a video recording. Through trial and error we have also settled on ways to help participants convey their points effectively. We will then turn to an analysis of the lessons that we have learned during this process, encompassing key learning about technical aspects, conceptual structure, addressing common challenges, and logistical considerations.

We conclude with a discussion of outcomes, including a description of how the Fireside Chats have been used by different groups, how we assess the effects generated by the Fireside Chats, and consideration of why these videos have been effective in our context.

Author Names: Marika Warren, Dalhousie University Department of Bioethics; Lisbeth Nielsen, Nova Scotia Health Ethics Network (NSHEN)
Abstract Category: Standard Concurrent Session
Primary Theme: AI and Ethics

Three Valuable Questions:
1. How is collaboration between bioethicists and computer scientists different from collaboration between any two disciplines?
2. If collaboration is going to be labour-intensive, where is the need to collaborate most pressing?
3. To what degree does creating a shared language depend on resolving the dispute regarding the way values are integrated into work in computer science?

Abstract: Terasse, Gorin, and Sisti argue in The Hastings Center Report that “[b]ioethicists should seek to collaborate with fields such as human-computer interaction and health care informatics to encourage the incorporation of ethical principles into discussions of online technological innovation.” Computer scientists agree; in The Communications of the ACM Grosz et al. describe how their program, dubbed Embedded EthiCS, “compensates for the reluctance of STEM faculty to teach ethics on their own by embedding philosophy graduate students and postdoctoral fellows into the teaching of computer science courses.”

This paper is a dialogue between a bioethicist and a computer scientist. We concur that collaboration between our disciplines is desirable. We argue, however, that it is much more easily said than done in part due to differences in approaches and assumptions between the two disciplines. We begin by cataloging some of the questions that invite collaboration between bioethicists and computer scientists. We then explore how disciplinary frameworks and perspectives can affect collaboration. We conclude that for collaboration to be successful and effective a consensus about the role of values in computing is necessary, as is foundational work to establish a shared understanding of key concepts and terms.

Individuals working in bioethics are trained in a variety of disciplines but there is a common appreciation of the complexity of the ethical questions that arise in bioethics and the need to be appropriately responsive to context. It is a truism in bioethics that the answer to many questions is “it depends”. In contrast, those trained in computer science are taught to decompose and abstract problems. For computer scientists, complexity is viewed negatively and is something to be abstracted away whenever possible. The objective in computer science is the discovery of techniques to improve computational performance, all with the end of determining an optimized way to achieve a desired outcome.

Collaboration between bioethicists and computer scientists is difficult in part due to disagreement regarding the degree to which values are reflected in the work of computer scientists. A computer scientist might ask, “What do you mean, values in computing processes? If you think about computing processes as a stick, then the same stick could be a hockey stick, a cane, or a club. The use to which that stick is put would be seen as having values attached, but not the stick itself.” The bioethicist might argue that values are deeply embedded in all domains of human activity and thus that algorithmic processes cannot be value neutral. Addressing fundamental disagreements is necessary if collaboration is to be mutually beneficial.

Additionally, some of the disciplines that train bioethicists do not emphasize collaboration. Computer scientists are trained to collaborate, but primarily with other computer scientists or individuals from related STEM disciplines. There has been collaboration between computer scientists and philosophers of logic, where there is a shared language. This does not exist between computer science

Author Names: Marika Warren, Dalhousie University Department of Bioethics; Alexander Brodsky, Dalhousie University Faculty of Computer Science
Abstract Category: Standard Concurrent Session
Primary Theme: Ethics and health policy

Three Valuable Questions:
How did Parliament fail to meet its stated goals for AHRA?

How can the concern about exploitation be refuted?

What is your vision for a more ethical and effective policy?

Abstract: After a long struggle to enact federal Canadian law in the area, the Assisted Human Reproduction Act (the “AHRA”) was passed in 2004. What had once been permissible – compensating a gamete donor for their time; inconvenience; and potential pain, suffering and risk – became criminal activity punishable by up to ten years in jail and/or a fine of up to $500,000. The justification lay in equating gamete compensation with the commodification of human tissues – an affront to human dignity – and to the exploitation of children, women, and men for commercial ends.

With this new law, Canada became one of the most restrictive jurisdictions in the world for gamete donation and is now almost completely dependent on imported gametes to meet its citizens’ needs. We believe this reliance on imported gametes because of the criminalization of compensation has hindered Canada’s ability to meet the goals Parliament set out in section 2 of the Act: prioritizing the health and safety of women and children, promoting human individuality and diversity, protecting patients’ rights and legally valid participation in treatment, and ensuring non-discrimination on the basis of sexual orientation.

We will explain in this paper how criminalizing compensated gamete donation in Canada has hindered Parliament’s legislative goals and harmed the very people that the AHRA intended to protect – in particular, donor-conceived people, and ova donors; how the doctrine of double effect, novelly used in a policy context, demonstrates that reasonable compensation to gamete donors is ethically permissible; why other jurisdictions have shown the prohibition to be ethically and legally unenforceable; and how donors and recipients can benefit from gamete donation policy and practices that permit fair compensation and are regulated as health and parentage matters, not criminal ones.

Author Names: Shawn Winsor, TRIO; Sara Cohen, D2 Law LLP
Thinking locally, Acting Globally: The Ethical and Legal Challenges of Proposed Global Egg Donor Recruitment Programs and What Is Required to Make These Programs Morally Permissible
Mr. Shawn Winsor, TRIO

Abstract Category: Standard Concurrent Session
Primary Theme: Ethics and health policy

Three Valuable Questions:
1. Why is global egg donor sourcing a growing practice around the world?
2. What are the ethical and legal concerns of global egg donor sourcing?
3. Can the practice be made ethical permissible and if so what is needed?

Abstract: The demand for ethnically diverse egg donors and the desire to lower operational expenses has led egg banks in the United States to expand donor recruitment practices to low- and lower-middle-income countries. As a consequence, unique ethical and legal challenges have emerged that include jurisdictional ambiguity created by competing legal frameworks that may place the health and rights of donors, donor-conceived children and their families at risk; uncertain access for the donor conceived and their families to health records or identifying records; and the tension created by a new healthcare market’s risk of exploitation against its promise of economic opportunity and financial recognition of new forms of health labor. We explain these challenges in the context of exploring whether global egg donor sourcing is ethically permissible. In conclusion, we will argue that the considerable potential harms may be ameliorated through robust management by stringent regulatory oversight. We will explore various models for such oversight including one modelled on existing international protocols to which participating countries must be signatories, and another modelled on an accreditation program.

Author Names: Shawn Winsor, TRIO; Aisha Lewis, California Cryobank; Sara Cohen, D2 Law LLP
How Chinese students evaluate the ethical and social issues in the applications of robots especially sex robots: a questionnaire study
Ms. Huihui You

Abstract Category: Standard Concurrent Session
Primary Theme: AI and Ethics

Abstract: Introduction: As the applications of robots coming onto markets apace that directly influence human private lives, the resulting ethical and social issues get into the focus of sex robots in particular. Sex robot (sexbot) is an anthropomorphic sex doll with artificial intelligence, and an artificial intelligence robot that can meet sexual needs. The present study focuses on the participants’ evaluation about how sexbots affect the shape of human intimacy and social behaviors in China. There were some empirical data about people’s attitudes of sexbots in some developed countries but in the absence of other views from developing countries.

Methods: This paper presented results via an online questionnaire, 473 college students (257 females and 216 males) indicted their attitudes towards sexbots. This was distributed to college students at Xiamen University in China in October 2019. The detailed results were reported from comparative and correlation analysis.

Results: Sexbots were the least popular application of social robots that participants would choose (35.9%). 70% of all respondents refused to have sex with the robot and women reported significantly more unwilling compared to men (81.3% vs 56.5%, p<.001). 78% of students who accepted the application of sexbots with varying different degrees (n=400) believed sexbots can help some special people as the primary reason. Sexbots can destroy the relationship between humans and make them more isolated (60%, n=407) was reported as the most frequent reasons for not accepting. Around half of participants disagree the application of sexbot brothels (51.4% women vs 42.1% men, p=.04) and child sexbots. 51% of students thought people who are married or in love having sex with robots can be regarded as cheating (62.7% women vs 36.6% men, p<.001). The respondents’ prediction to the acceptance of sexbots in China was rated lowest (7 point Likert scale, M=2.98) while the average rating results of the influences of Chinese traditional attitudes on the acceptance of sexbots (M=4.92) and the influences of sexbots on Chinese traditional morality (M=4.97) were the highest. A marginal effect was found that men being more accepted to sexbots (27.3% vs 14.8%, p<.001) while women being more against it (34.6% vs 21.8%, p<.001) as a result of filling out the survey.

Conclusions: We found that participants’ attitudes to sexbots were overall rather neutral and obtained marginally significant gender effect in this study with women less and men more inclined to accept sexbots, while the results could not sufficiently justify education, emotion state and beliefs do play a significant role. The rights of sexbots, the change of human intimacy and social behaviors and business models of sex industries, the mutual influences between Chinese traditional culture and sexbots were perceived as the most challenging ethical aspects. This study showed the ways of focusing on ethical issues and the importance of knowing how sexbots relate to human needs, and indicated the need to determine what stakes sexbots mean for society and what their use should be in China, thus help frame future ethical works for sexbots.

Author Names: Huihui You
Abstract Category: Standard Concurrent Session  
Primary Theme: Ethics and health policy

Three Valuable Questions:
What are the implications of ongoing definitional controversy for organ donation and transplantation?

What are the implications of these Ontario cases for the rest of Canada?

Can Canada sustain 2 sets of criteria to make a determination of death?

Abstract: While one might reasonably expect the question of how to define death to have been laid to rest in the earliest days of healthcare, in 2020 and contributed to by evolving life sustaining technology, this question remains a Canadian bioethics challenge. The form and substance of current ethical and legal debates surrounding the definition of “dead”, are informed by jurisdictional values. The spectrum of international engagement with this issue in part reflects approaches to reconciling or entrenching space for difference between scientific criteria and religiously informed criteria.

There have been legal challenges regarding criteria to be used in the determination of death in New York, California, and Michigan and a recent controversy in the UK. In the face of high profile cases within the United States, there is currently talk within the field of neurology of coming up with a unified definition of death. New Jersey and New York are the most accommodating American states to religiously grounded beliefs – with statutory support for ‘reasonably accommodating’ the patient’s religious objection to being declared dead by brain death.

A window into local implications of the lack of definitional consensus, is available through the two recent cases of Taquisha McKitty and Shalom Ouanoounou argued in Ontario courts. In both cases, the patients were declared dead using neurologic criteria in accordance with accepted medical practice. In each case family members obtained a temporary injunction prohibiting the hospital from discontinuing mechanical ventilation and somatic support based on their religious beliefs that define death as cessation of breathing and heart function. As a result, both brain-dead patients were maintained on technological - somatic support until cardiac arrest occurred.

One case is currently with the Ontario Court of Appeals, after the Ontario Superior Court ruled in favour of the existing Canadian guidelines for determining death using neurologic criteria.

Concurrently, advancements in technology such as the use normothermic regional perfusion, which involves reanimating the heart and circulation in the donor’s body after circulatory arrest and death determination, are challenging existing concepts of death that are based on the permanent cessation of circulation to the body (versus cessation of circulation specifically to the brain).

This presentation will discuss (1) the history of determinations of death in the face of evolving technology, (2) implications of technological innovation for law and clinical practice and (3) ethical dimensions for defining death in Canada - a country whose public narrative speaks of a mosaic aiming to respect distinct religious and cultural approaches to health.

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