JUST EVIDENCE?

20th Annual
Canadian Bioethics Society Conference
June 11 –14, 2009
Hamilton, ON Canada

McMaster University

Hamilton Health Sciences

http://fhs.mcmaster.ca/bioethicsconference

Acknowledgements/Remerciements
The planning committee gratefully acknowledges contributions by the following:/ Le comité organisatuer remercie chaleureusement les donateurs suivants:

McMaster University
Inspiring Innovation and Discovery

CIHR IRSC

Hamilton Health Sciences

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Letter of Welcome from Conference Co-Chairs

Welcome to the 20th annual Canadian Bioethics Society conference, and welcome to Hamilton! We are delighted to have you with us, and look forward keenly to a rich round of sharing, both intellectual and social. We are especially touched that notwithstanding tough economic times and the particular challenges the outbreak of 'flu has presented to you in your professional capacities, you are here nonetheless, supporting the Society and the important work of the conference.

As some of you may remember, when we advertised the "Just Evidence?/Quelle preuve pour les decisions justes?" theme last year, there was some consternation over the meaning of the topic. We are happy to say that in interpreting the theme participants have shown much imagination and creativity! The program encompasses the local and the global, the clinical, the policy and the legal, the theoretical, the religious, the scientific and the philosophical. Our keynotes represent the best of national and international scholarship, and will challenge us at the level of understanding and of practice. We will be called to reflect on distributive justice, and to set goals for engagement in just practices; we will affirm the merit and challenge the limits of the received views on evidence; we will hear of successes and challenges in aboriginal health care and gender justice; and this year in particular we will share our perspectives on the norms of ethical research.

As always, there are many people without whose help this conference would not have taken place. CIHR, the Public Health Agency of Canada, and the Ontario Ministry of Long Term Care offered us generous financial support, as did McMaster University. Anonymous reviewers across the country offered their time and expertise to vet the abstracts, and colleagues at McMaster and Hamilton Health Sciences supported the venture with their volunteer activities. Pre-conference planners, local and distant, gave the Program 'added value', as always. The student organizing committee oversaw the selection of winning student papers, and managed the details of the student events, while an energetic and efficient group of local student volunteers presented themselves to welcome, guide and help to make things run smoothly. Our most heartfelt thanks must go to Terry Martens, our superb administrative assistant, Lucy Langston, our super-efficient, cheerful and willing research assistant, and Joan Balinson, our knowledgeable conference planner. Finally, thank you to all of you, the delegates, without whom the rooms would echo and the deficit would overwhelm!

Elisabeth Gedge Lisa Schwartz

CBS President's Welcome

I would like to wish you all a most warm welcome to the 20th Annual Canadian Bioethics Society (CBS) Conference, *Just Evidence* (June 11th-14th, 2009). Our colleagues at McMaster University and Hamilton Health Sciences are to be commended for bringing us together to address ethical issues around evidence-based knowledge, clinical care, health law, health policy and health related research. They are also to be commended for inviting discussions of justice in relation to global, local, and clinical contexts.

As you can see from the Conference Program, the 2009 Planning Committee--under the leadership of Dr. Lisa Schwartz and Dr. Elisabeth Gedge--has done an outstanding job of recruiting an impressive array of keynote speakers as well as an impressive array of individual presenters to address the Conference theme. Further, the two Pre-Conference Workshops ("Professional Issues in Clinical Ethics: Working Conditions and Professionalization", "Global Health and Ethical Responsibility" and "Health Policy Ethics: Cultivating a Growing Field in Canada") will offer significant contributions in their respective areas; both of which are breaking important new ground. We owe the Planning Committee members and the Conference's generous local, provincial, and national sponsors a great deal for making it possible for us to meet in Hamilton.

The richness of the Program we have all been invited to share in is, I think, a testament to our maturity and diversity as a society. For two decades the CBS has brought together Francophone and Anglophone colleagues from a variety of disciplines who engage in ethics work--including research, consultation, education, and clinical practice--in many facets of biomedicine and health policy as well as health care delivery. The CBS now enters its third decade well poised to fulfill our Vision: *To be the leading bioethics collaborative forum in Canada working towards advancing the health and well-being of people in Canada and other countries.*[1]

With best wishes to all,

Paddy Rodney, RN, MSN, PhD

President, Canadian Bioethics Society

PS Don't forget to put the 21st Annual Canadian Bioethics Society Conference in your calendar for June 2010—it will be held in Kelowna, British Columbia.

[1] *CBS Vision 2012: Strategic Plan.* This Strategic Plan was accepted at the Canadian Bioethics Society Conference in 2007 in Toronto. The full document can be found in the October 2007 issue of the CBS Newsletter (Vol. 12, Number 2, pp. 4-5). This CBS Newsletter can be retrieved at http://www.bioethics.ca/october 2007.pdf

Welcome Students!

Lucy Langston, Gina Freeman and Meredith Schwartz are honoured and pleased to welcome you to Hamilton, Ontario for the 20th Canadian Bioethics Society Conference and Pre-Conference! Did you know that Hamilton was the first city in Canada to install electric streetlights? Electric streetlights were first installed in Hamilton in 1883, one year before Montreal and Toronto. Hamilton is also known for being the home of the first Tim Horton's, opened in 1964. Hamilton is the eighth largest city in Canada. Nearly one-quarter of Hamilton's population is foreign-born, which makes Hamilton the Canadian city with the third highest proportion of foreign-born citizens after Toronto (44%) and Vancouver (38%). We hope you will enjoy the conference and your time in this exciting city.

We have planned many exciting student events for this conference:

- *T-Shirt Sales* – We will continue the student fundraising efforts by selling CBS t-shirts throughout the conference. Proceeds from t-shirt sales go to expanding and supporting student programs like the Travel Bursary. These shirts look great and are a fantastic way to show your proud membership in the Canadian Bioethics Society.
- *The Information Table* - The conference will be hosting an information display table. Here you will find a mixed bag of items: journals, texts, information about the student activities, a sign-up sheet for the Student-Mentor breakfast, material about the CBS as well as local information, to name just a few.
- *Student Meet & Greet* – Come and enjoy yourselves at the Honest Lawyer a great bar conveniently located next to Hamilton Convention Center and get (re)acquainted with the other students attending the conference. Relax outside on the patio or mix it up with a spot of air hockey or table soccer.
  Thursday June 11, 5:30-7:00 PM Location: Honest Lawyer, 110 King St W, Hamilton.
- *Student Business Meeting* – Have your voice heard on important student programs and issues. Do you have any ideas for new student programs? Do you want to hear more about the new graduate and undergraduate student programs that Gina and Meredith have proposed? Then come out to the business meeting where we will discuss student issues! The Graduate Student Representative elections will be held at this time. Come out and make your vote count!
  Friday June 12, 7:30-8:30 AM, Room 314
- *Student Mentor Breakfast* – An opportunity to have breakfast with prominent bioethicists to discuss current issues, research, careers and more. A great networking opportunity that received rave reviews last year. You won't be disappointed. It is not too late to sign up for this event! Please see the registration desk for details.
  Saturday, June 13, 7:30-8:30 AM, Chedoke A/B
- *Student Evening Social* – An opportunity to let your hair down and relax over a great meal of Lebanese food with other students. From here it's a short walk to a great selection of nightlife in Hamilton's Historic Hess Village.
  Saturday, June 13, 7:00-10:00 PM Location La Luna Lebanese Restaurant, 306 King Street West, Hamilton ON.

We hope you will come out, meet your fellow students, enjoy Hamilton's nightlife, network with students and fellow delegates, and immerse yourself in all this great conference has to offer! Don't forget to support your fellow students by checking out their interesting presentations scheduled throughout the conference.

We would like to thank all of the students from across Canada who helped to make this conference a guaranteed success! We would especially like to thank the chair of the student abstract competition, Kiran Pohar Manhas, and the student abstract selection committee: Tamara Adler, Stephane Ahern, Camille Assemat, Emily Bell, Renaud Boulanger, Samantha Copeland, Michael Da Silva, Simona Efanov, Nathalie Egalite, Olusegun (Segun) Famure, Cynthia Forlini, Jonathan Lear, Patricia Mariller, Ghislaine Mathieu, Diego Silva, Maxwell Smith, Raphaëlle Stenne, Scott Stevens, Mark Weir, McFee Yang, Amélie Zonato. We would like to say an extra special thanks to Samantha Copeland, Scott Stevens, and Mark Weir who were willing to take on extra work to ensure the abstracts

were reviewed in time. We received 50 abstracts for the student competition this year, so choosing only 7 was extremely difficult. This year the student abstract competition awards go to:

Jason Behrmann, Université de Montréal

Isabelle Chouinard, University of Calgary

Michelle Cleghorn, University of Toronto

Julie Cousineau, Université de Montréal

Cynthia Forlini, Institut de recherches cliniques de Montréal

Spencer Hey, University of Western Ontario

Danaë Larivière-Bastien, Université de Montréal

Come out to the student business meeting on Friday June 12, 2009 from 7:30-8:30 AM to meet these students and congratulate them as they receive their awards.

A Message to Undergraduate Students

Highlights for undergraduate students at this years conference include the Student Meet and Greet (a great place to meet other students interested in bioethics, many at the graduate level), the Student-Mentor Breakfast (where you can strike up a conversation with an established bioethicist over coffee), and the student social (a chance to have dinner with other students interested in bioethics).

Currently, Meredith and Gina are working on programs to help engage undergraduate students in the Canadian Bioethics Society. The proposed programs are created with the aim of enriching the undergraduate experience. We've discussed including an undergraduate symposium at the annual conference, ways to make the conference more affordable for undergraduate students, and adding an undergraduate abstract competition. If you are interested in these programs, want to learn more, or have some ideas of your own for undergraduate student programs, please come to the student business meeting on Friday June 12, 2009 from 7:30-8:30 AM to discuss!

All three of us hope you have a great time in Hamilton and at the 20th annual Canadian Bioethics Society Conference.

Sincerely,

Meredith Schwartz
PhD Student, Dalhousie University Department of Philosophy
Canadian Bioethics Society, Graduate Student Representative

Gina Freeman
Undergraduate Student, University of Calgary
Canadian Bioethics Society Undergraduate Student Representative

Lucy Langston
MA Student, McMaster University Department of Philosophy
Chair, Canadian Bioethics Society McMaster Student Conference Committee

Committees

Planning Committee
Lisa Schwartz (Co-Chair)
Elisabeth Gedge (Co-Chair)
Terry Martens (Conference Co-ordinator)

Student Committee
Lucy Langston (Student Committee Chair 2009)
Meredith Schwartz (Grad Rep)
Gina Freeman (Undergrad Rep)
Brynna Loppe
Mazen Zehairi
Nicole Martins Ferreira
Talene Thomasian

Communications & Marketing
Oliver Klimek
Michael Wilson
Claudia Emerson
Myra Leffler

Social Committee
Andrea Frolic
Jennifer Ranford

Abstract Committee
Michael Coughlin
Barb Jennings
Suzette Salama

Pre Conference Committee
Karen Szala-Meneok
Mita Giacomini

About Town Event & Meeting Planners
Joan Balinson

Referees

Thank you to the following people for reviewing the abstracts that we received. Without their hard work and dedication this program would not have been possible.

Blair, Henry
Sunnybrook Health Sciences Centre

Cline, Cheryl
Queens University

Emerson, Claudia
McLaughlin-Rotman Centre for Global Health

Giacomini, Mita
McMaster University

Gildner, Alina
McMaster University

Griener, Glenn
University of Western Ontario

MacDonald, Michael
W. Maurice Young Centre for Applied Ethics, UBC

McDonald, Chris
St. Mary's University

Nisker, Jeff
University of Waterloo

Peterson, James
McMaster University

Schofield, Giles
St. Joseph's Hospital, Hamilton

Simpson, Christy
Dalhousie University

Upshur, Ross
Sunnybrook Health Sciences
Joint Centre for Bioethics Toronto

Willison Don
Ontario's Public Health agency

Breslin, Jonathan
North York General Hospital

Doucet, Hubert
Université de Montréal

Flynn, Jennifer
Memorial University

Gibson, Jennifer
Joint Centre for Bioethics, Toronto

Glass, Kathleen
McGill University

Hardingham, Laurie
Joint Centre for Bioethics, Toronto

Maurer, Daphne
McMaster University

Neshi Nathoo, Al-Noor
Provincial Health Ethics Network (Alberta)

Pawluch, Dorothy
McMaster University

Salama, Suzette
McMaster University

Schuklenk, Udo
Queens University

Singleton, Rick
Eastern Health

Weijer, Charles
University of Western

Canadian Bioethics Society
Twenty Annual Business Meeting
Hamilton, Ontario
Friday, June 12, 2009
Main Room, Chedoke AB
12:00 – 1:30
(Lunch & Beverages provided)
Canadian Bioethics Society

AGENDA

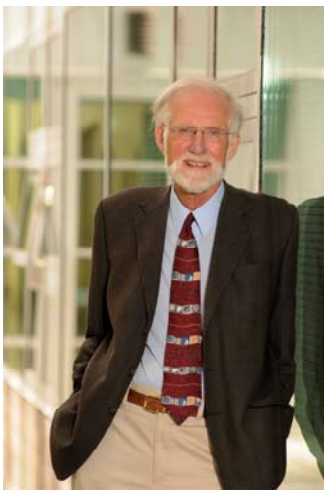
1)	Report of the President - Welcome - Award announcement - CBS membership	(P. Rodney)
2)	Implementation of the Visioning Process	(P. Rodney)
3)	20th CBS Annual Meeting Update	(L. Schwartz)
4)	Treasurer's Report	(B. Jiwani)
5)	Report of the Communications Officer	(S. Page)
6)	Executive Subcommittee report:	
	(a) CBS e-Journal	(G. Cleret de Langauant)
	(b) Website/logo Update	(A. Nathoo)
7)	Report of the Nominating Committee & Election	(A. Nathoo)
8)	Report of the Student Representatives	(M. Schwartz, G. Freeman)
9)	Ethics Initiatives:	
	(a) Peer Support Network for Bioethicisits	(L. Hardingham/G. Webster)
	(b) Practicing Healthcare Ethicists Exploring Professionalization	(A. Frolic, C. Cline)
10)	21th CBS Annual Meeting in Kelowna, BC	(L. Sawchenko)
11)	Call for the 22st CBS Annual Meeting Location	(P. Rodney)
12)	Motions from the Floor	(P. Rodney)
13)	Other New Business	
14)	Adjournment	

Lifetime Achievement Award

Michael McDonald

Lifetime Achievement Award

The CBS Lifetime Achievement Award is given annually to an individual whose demonstrated scholarship and/or leadership has contributed significantly to health care ethics in Canada. The Committee is pleased to announce that this year's recipient of the CBS Lifetime Achievement Award is Dr. Michael McDonald. Please join us at the award ceremony at noon on Saturday June 13, as Dr. Michael McDonald reflects on his experience with in the Canadian Bioethics Society.



Michael McDonald PhD – Maurice Young Chair of Applied Ethics.

Michael McDonald occupies the Maurice Young Chair of Applied Ethics in the W. Maurice Young Centre for Applied Ethics at the University of British Columbia. He served as the Centre's founding director.

McDonald's current research is focused on ethical issues in health research. McDonald's research and teaching can be located at the intersection of theory and practice in health care, business and professional life, politics, and other aspects of everyday life. He has written on such topics as the ethics of research involving human subjects, cross-cultural ethics, community rights, professional ethics, and the place of ethics in contemporary society. He continues to play a leadership role in the development of a significant Canadian capacity in applied ethics.

General Information

Theme

The theme of **Just Evidence** will raise ethical issues around evidence based knowledge, clinical care, health law, health policy and health related research. Topics may raise justice in global or clinical ethical issues in evidence based knowledge.

Meeting Objectives

The conference includes invited speakers and refereed papers presented as plenary sessions, topic oriented presentations and workshops. It provides a forum for presentation of current findings and emerging ethical problems.

About the Canadian Bioethics Society

The Canadian Bioethics Society is a non-for-profit organization. It is forum for professionals to share ideas relating to bioethics and to explore solutions to bioethical problems. The Society promotes the teaching of bioethics at all levels of post-secondary and continuing education. The Society also promotes research and publication in bioethics and encourages the dissemination of information and bioethics.

Simultaneous Translation

Headsets are available for use at sessions held in Chedoke A/B. Headsets will be available at the registration desk.
Thursday June 11, 5:00 – 10:00 p.m.
Friday June 12, 8:30 a.m. – 5:30 p.m.
Saturday June 13, 8:00 a.m.– 6:00 p.m.
Sunday June 14 8:30 a.m. – 1:00 p.m.

Headsets can be returned at any of the times or following the last session on Sunday at 1:30 p.m.

PLEASE NOTE EACH DELGATE IS PERSONALLY RESPONSIBLE FOR THE RETURN OF THEIR RECEIVER AND HEADSETS. DRIVERS LICENCE OR SOME FORM OF ID WILL BE HELD IN EXCHANGE FOR THE HEADSETS. FAILURE TO DO SO WILL RESULT IN A CHARGE OF APPROXIMATELY $400.00

Information Table

The conference will be hosting an information display table. Here you will find various items including journal, texts, material about the CBS as well as local information.

Plan now to attend

The next *Canadian Bioethics Society* Conference

2010 Conference Theme
"Voices of Communities"
Venue: Delta Grand Okanagan Resort, Kelowna, BC
Date: June 8 -12, 2010

Enjoy a *Latin* evening in the garden ...

...At The Royal Botanical Gardens

Evening Events:
6:00-7:00 pm Reception (cash bar)
7:00 pm Dinner
8:00 pm Entertainment: Salsa Lesson with Choreographer Victoria Slager
8:30-11:30pm Music and Dancing with the Juan Carlos Band
Transportation provided to and from the RGB on a 1950's Replica Trolley. It will pick up passengers in front of the Sheraton Hamilton Hotel at the following times 5:45, 6:15, 6:45. Show your dinner ticket to board. Return trips from the RBG to the Sheraton start at 10:00 pm, with shuttles leaving every 30 minutes until 11:30 pm.

DRIVING DIRECTIONS: King Street West to Bay Street North. Bay Street North to York Boulevard. Left on York Blvd,continue past, Locke and Dundurn Streets. Continue on York Blvd bearing right over three bridges. Royal Botanical Gardens is on the right hand side-- approximately a ten minute ride depending on traffic.

Royal Botanical Gardens
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CANADIAN BIOETHICS SOCIETY
SOCIÉTÉ CANADIENNE DE BIOÉTHIQUE

Pre-Conferences

CHEPA
Health Policy Ethics: Cultivating a Growing Field in Canada
Date: Thursday June 11, 2009, 8:00 a.m. – 4:00 p.m.
Location: McMaster University Campus Council Chambers Gilmour Hall GH111 1280 Main Street West, Hamilton, Ontario L8S 4L8
Planner: Mita Giacomini

Global Health Ethics in Research
Date: Thursday June 11, 2009, 9:00 a.m. – 3:30 p.m.
Location: McMaster University Campus 1280 Main Street West, Hamilton, Ontario L8S4L8
Planners: Genevieve Dubois-Flynn, James Dwyer

Professional Issues in Clinical Ethics: Working Conditions and Professionalization
Date: Thursday June 11, 2009, 8:00 – 4:00 P.M.
Location: Hamilton Convention Centre
Planners: Michael Coughlin, Cheryl Cline

PROGRAM

Program at a Glance

Thursday June 11, 2009

0800	CHEPA Pre Conference Health Policy Ethics: Cultivating a Growing Field in Canada 8:00 – 4:00 McMaster Campus
0900	Global Health Ethics in Research Pre Conference 9:00 – 3:30 McMaster Campus Professional Issues in Clinical Ethics: Working Conditions and Professionalization Pre Conference 8:00 – 4:00 Hamilton Convention Centre
17:00	Student Meet & Greet Registration and Headphone Distribution
1900	Welcome
1930	**Plenary – Maude Barlow** "*Can Science Solve the Global Water Crisis?"*
2100	Opening Reception

Friday June 12, 2009

0730	Breakfast, Student Business Meeting, Neuroethics, Nurses interested in Ethics, Regional and National Ethics Resource Network
0900	**Plenary - Jerome Wakefield** "*The Loss of Sadness: Are We Misdiagnosing a Normal Human Emotion as a Mental Disorder?"*
1000	Nutrition Break and Poster Viewing
1030	Concurrent Sessions
1200	Annual General Meeting Luncheon
1400	Plenary - Panel Discussion on Ethics in Evidence Based Medicine
1530	Nutrition Break and Poster Viewing
1600	Concurrent Sessions
1900	Evening Social Event Royal Botanical Gardens

Saturday June 13, 2009

0730	Breakfast, Student Mentor Breakfast
0900	**Plenary - Bernard Keating** *"Squaring the circle: reconciling evidence and equity"*
1000	Nutrition Break and Poster Viewing
1030	Concurrent Sessions
1200	Lunch and Lifetime Achievement Award
1330	**Plenary – Aboriginal Health Issues Panel Discussion** *"Aboriginal Health & Justice – Still A Ways To Go!"*
1500	Nutrition Break and Poster Viewing
1530	Concurrent Sessions

Sunday June 14, 2009

0730	Breakfast
0900	**AMS Lecture: Rosemarie Tong** *"Feminist Methodology and the Evidence-based Medicine Debate"*
1000	Nutrition Break
1010	Feminist Approaches to Bioethics Workshop
	Public Health Agency Canada Workshop
1130	**Challenge Set for the Future of Bioethics Sue Sherwin**
1230	Closing Remarks and Farewells

Conference Schedule
Thursday June 11, 2009

08:00 – 16:00	Health Policy Ethics: Cultivating a Growing Filed in Canada	***Council Chambers GH111 McMaster University***
08:00 – 16:00	Professional Issues in Clinical Ethics: Working Conditions and Professionalization	***Hamilton Convention Centre***
09:00 – 15:00	Global Health and Ethics Responsibility McMaster University,	***The Great Hall, Faculty Club***
17:00 – 17:30	Student Meet & Greet	
18:00 – 18:45	Registration, Headset Distribution	***Chedoke Foyer***
19:00	Opening Remarks and Welcome	***Chedoke A/B***
19:30 – 21:00	**Plenary Session Maude Barlow "Can Science Solve the Global Water Crisis?"**	***Chedoke A/B***
21:00	Reception Chedoke	

Friday June 12, 2009

07:30 – 08:30	Registration	***Chedoke Foyer***
07:30 – 08:30	Breakfast	***Chedoke C***
07:30 – 08:30	Neuro Ethics meeting	***Webster A***
07:30 – 08:30	Nurses Interested in Ethics	***Webster C***
07:30 – 08:30	Regional and National Ethics Resource Network	***Webster Lounge***
07:30 – 08:30	Student breakfast Meeting	***Room 314***
09:00 – 10:00	**"The Loss of Sadness: Are We Misdiagnosing a Normal Human Emotion as a Mental Disorder?" Dr. Jerome Wakefield**	***Chedoke A/B***
10:00 – 10:30	Nutrition Break and Poster Viewing	
10:30 – 12:00	**CONCURRENT SESSIONS**	***Chedoke A/B***

C01 Long Term Nurses' Responses to Moral Distress: Perceptions of Support Amidst Ethical Challenges
Author(s): Marie Edwards, Susan McClement, Laurie Read
C02 Title: The Need for Homecare Ethics Capacity: Evidence from the Community Ethics Network OutreachProject
Author(s): Kimberley Ibarra, Renaud Boulanger, Frank Wagner
C03 Titre: Ethique clinique et soins dans la communaute
Auteur(s): Maria Bouzidi, Michele Clement, Eric Gagnon, Marie-Helene Deshales

Webster A

C04 Title: Exploring Uncharted Territory: Mapping the Ethical Terrain in Consent Narratives of Patients with Implantable Cardioverter Defibrillators
Author(s) P.H. Strachan, S. Carroll, L. Schwartz, S deLatt, H.M. Arthur
C05 Title: Navigating the Ethical Space of Imaging Genetics: Clinical Translation of Neuropsychiatric Research
Author(s): Daniel Z. Buchman, Judy Illes
C06 Title: Just Evidence in assessing risk in emerging health care products
Author(s): Janice Graham

Webster B

C 07 Title: Are Explanatory Trials Ethical?
Author(s): Kirstin Borgerson
C08 Title: Production and Application of Evidence: Some Issues
Author(s): Joy Mendel
C09 Title: What Evidence? Or Evidence of what?
Author(s): Kristiann Allen, Jamie Flamenbaum

Webster C

C10 Title: The Ethics of Expert Authority in Evidence-Based Preventive Medicine
Author(s): Anita Ho
C11 Title: Shadows of Doubt: The Use and Medicine of Evidence-Based Medicine
Author(s): Anna Gotlib, Sorava Gollop
C12 Title: Evidence and Uncertainty: Challenges for Ethics
Author(s): Marika Warren

Webster Lounge

C13 Title: Bringing Culture to the Core: A Plan for Expanding the Core Competencies of Clinical Ethicists
Author(s): Thomas Foreman, Shawn Winsor
C14 Title: Spiritual Care Chaplaincy in Relation to Ethics: friend or foe?
Author(s): Philip D. Crowell
C15 Title: Goals of Care Designations: Fundamental change in joint decision-making about care
Author(s): Eric Wasylenko

Room 314

C16 Title: **Ethical Issues Surrounding Alpha-Thalassemia in Pregnancy**
Author(s): Susan Albersheim
C17 Title: Ethical questions arising out of nursing care for women experiencing spontaneous and therapeutic abortions
Author(s): Anne Simmonds, Joanne Louis
C18 Title: Ethical Care for Infants with Conditions not Curable with Intensive Care
Author(s): Bethan Everett, Susan Albersheim

Albion A

C19 Title: Ethical and social challenges in the field of deep brain stimulation: Perspectives from Canadian practitioners
Author(s): Emily Bell, Bruce Maxwell, Ghislaine Mathieu, Abbas Sadikot, Mary Pat McAndrews, Eric Racine
C20: Canadian Medical Device Regulations: the Case of Deep Brain Stimulation (DBS)
Author(s): Ghislaine Mathieu, Eric Racine
C21: Title: Reproductive Choice and the Ideals of Parenting
Author(s): Elisabeth Gedge

Albion B

C22: DNRC: Why Unilateral Orders Won't Fly
Author(s): Peter Allatt, Andrea Frolic
C23: Rituals, Death, and the Moral Practice of Medical Futility
Author(s): Shan D. Mohammed, Elisabeth Peter
C24: End of Life Decision Making: Whose goals count?
Author(s): Neil M. Lazar

Albion C

C25: How organ transplantation is represented in Quebec newspapers?
Author(s) *Andrée Duplantie, Claire Faucher, Dan Nicolau, Hubert Doucet, Marie-Chantal Fortin*
C26: Ethical Issues in Organ Donation: Views of Recent Immigrants and Health Professionals
Author(s): Wendy Austin
C27: Reducing the Weight Given to Family Distress in Organ Donation Decision-Making
Author(s): Robert L. Muhlnickel

Room 202

C28: A Philosophy of Technology Perspective on James Rachels' Attack on The Distinction between Killing and Letting Die
Author(s): *James Gerrie*
C29: Where Angels Fear to Tread; Proxy Consent and Novel Technologies
Author(s): *Monique Lanoix*
C30: Posthumans and Present Evidence: Exploring Future Enhancement
Author(s): Jason Marsh

Room 203

W01: Teaching Ethics to Medical Students: Achieving Effectiveness through Relevant Content and Respecting the Adult Learner
Author(s): *Dan Reilly*

12:00 – 13:30	AGM Luncheon	***Chedoke A/B***
13:30 – 15:00	**Ethics in Evidence Based Medicine Panel**	***Chedoke A/B***
15:00 – 15:30	Nutrition Break and Poster Viewing	
15:30 – 17:30	**CONCURRENT SESSIONS**	

Chedoke A/B

C31 Titre: L'anonymat des dons de gamètes et d'embryons: quelle justice, pour qui?
Auteur(s): *Julie Cousineau*
A01Titre: La valorisation des produits et résultats de la recherche: réflexion sur quelques aspects éthiques
Auteur(s):*Michel Bergeron, Isabelle Boutin-Ganache et Simon Hobeila*

Webster A

C32: Aggressive Discharge Planning
Author(s): Alister Browne
C33: Developing an Island Wide Clinical Ethics Program: Evidence and Reality
Author(s): Veronica Morris, Janet Storch, Bernadette Pauly
C34: The Murky Intersection between Clinical & Organizational Ethics : a Hybrid Case Taxonomy
Author(s): *Sally Bean*

Webster B

C35: **Public Engagement: a vehicle to enhance justice in wait list management**
Author(s): Rebecca Bruni
C36: The Ethics of Autism : responding to Barnbaum and colleagues
Author(s): Barbara Russell
C37: Health Care Justice Debate: May a hybrid view be the answer ?
Author(s): *Gilbert, F., Hurst, S.,*

Webster C

C38: "Evidence-based ethics": An examination of conceptual problems and implications
Author(s): *Rose Geransar, Glenys Godlovitch, Brian Forzley, Allen Dong, Anna Zadunayski*
C39: Technology and clinical judgement in evidence-based medicine
Author(s): *Isabelle Chouinard; Glenys Godlovitch*
C40: The Ethics of the Free-Rider: Are They Really Riding for Free?
Author(s): *Talene Thomsian*

Webster Lounge

C41: Ethics Review of Minimal risk and multisite qualitative studies: perspectives from two Canadian studies and the new Tri-Council Policy statement
Author(s): *Constance Deslauriers, Emily Bell, Nicole Palmour and Eric Racine*

C42: Social Justice in the Clinical Context: Using Charter Rights as a Framework for Healthcare Priority Setting
Author(s): *David Vitale and Randi Zlotnik-Shaul*

C43: A Closer Look at Contract Research Organizations (CROs) in the Canadian Context
Author(s): *Nina Preto*

Room 314

C44: Entitlement and implantation; resistance and expectation – reflections on biomaterials, disability, and social norms
Author(s): *Kevin Reel*

C45: Scientists' and regulators' perspectives on the ethical issues of stem cell research
Author(s): *Holly Longstaff, Michael McDonald, Nina Preto, Darquise Lafreniere, and Cathy Schuppli*

C46: Meanings and Understandings of Language Used in Researching Evidence for a Genetic Basis of a Clinical Condition
Author(s): *Justin Morgenstern and Jeff Nisker*

Albion A

C47: Citizens' Perspectives on Pandemic Influenza in Canada: Findings from the CanPREP Collaboratory
Author(s): *Ross E.G. Upshur on behalf of the CanPREP Team*

C48: The Social Justness of Insite: Insight into Insight from a Public Health Ethics Perspective
Author(s): *Pam Kolopack*

C49: The Limitations of Public Engagement in Canadian Policy-Making Regarding Assisted Reproductive Technologies
Author(s): *Elise Smith*

Albion B

W02: Bioethicists' Reflections on Proposed Changes to the TCPS (Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans
Speakers: Panelists: Françoise Baylis (Dalhousie University), Jocelyn Downie (Dalhousie University), Jonathan Kimmelman (McGill University), Michael McDonald (University of British Columbia), with input from Susan Zimmerman (Executive Director, PRE) and Norman Frohlich (Chair, PRE). Moderator: Susan Sherwin

Albion C

C50: Learning from patient: A case study of non compliance in patients with HIV associated Tuberculosis
Author(s): *Katherine Duckworth & Elizabeth Oduwo*

C51: Evidence-based assessments of competency
Author(s): *William Harvey*

C52: Competence, Paternalism and Risk
Author(s): Ian Wilks

Room 202

C53: Ethical issues in the treatment of bariatric patients
Author(s): *Peter Allatt and Kathy Carlin*

C54: Defining physiological mechanisms and policy responses for social injustice and health inequalities
Author(s): *Jason Behrmann, Robert-Paul Juster*

C55: Permission to Override Patients' Wishes
Author(s): *Eldon Soifer*

Room 203

C56: Social Justice and International Medical Travel for Reproductive Health Care
Author(s): *Gillian K. D. Crozier*

C57: Traveling Right: Ethical Issues in Medical Tourism
Author(s): *Jeremy Snyder*

C58: From Obligations to Inform to Duties to Warn
Author(s): *Lori Luthur, Lisa Schwartz, Matthew Hunt, Chris Sinding, Laurie Elit, Lynda Redwood-Campbell, Naomi Adelson, Jennifer Randford, Lucy Langston*

Saturday June 13, 2009

07:30 – 08:30	Breakfast	
07:30 – 08:30	Student Mentor Breakfast	***Chedoke A/B***
09:00 – 10:00	**Plenary Session: Bernard Keating "Squaring the circle: reconciling evidence and equity**	***Chedoke A/B***
10:00 – 10:30	Nutritional Break and Poster Viewing	
10:30 – 12:00	**CONCURRENT SESSIONS**	

Chedoke A/B

C59 Titre : Réflexion éthique sur la prise en charge des toxicomanes à l'hôpital
Auteur(s) : *Marie-Eve Bouthillier, Delphine Roigt, Élodie Petit, Marie-Josée Potvin*
C60: Informed Consent and Professional Interpretation Services
Author(s): *Elizabeth Abraham, Kyle Anstey*
C61 Titre: Utilisation de la médecine personnalisée en transplantation rénale: De nouvelles preuves scientifiques pour une plus juste attribution des organes?
Auteur(s): *Dion-Labrie, Marianne; Fortin, Marie-Chantal; Hébert, Marie-Josée; Doucet, Hubert.*

Webster A

C62: The Tyranny of Evidence in Medicine
Author(s): *Wayne Rosen*
C63: Evidence based medicine as a threat to individually appropriate care? Ethical concerns raised by family physicians
Author(s): *Vikki A Entwistle, Ian S Watt, Alex Barratt, Penny Lockwood, Lyndal Trevena*
C64: Keeping Evidence-Based Knowledge About Medical Error From Patients and the Public: An Ethical and Legal Conundrum
Author(s): *Joan A Gilmour*

Webster B

C65: Rights, Risks and Smoking: how 'denormalisation' mediates patient-provider interactions in primary case settings
Author(s): *Kirsten Bell, Jennifer Bell, Lucy McCullough, Amy Salmon, Michele Bowers*
C66: Milk: a neglected ethical issue
Author(s): *Angus Dawson*

Webster C

C67: **Quality public engagement in health policy making: An emerging framework for effective deliberation**
Author(s): *Michelle Cleghorn and Douglas K. Martin*
C68: Chaoulli, wait lists, and somatic solidarity
Author(s): *Lynette Reid*
C69: Here Come The Judge
Author(s): *Rick Singleton*

Webster Lounge

C70: The questionable ethics and science of experimental trials for evaluating 'black box' health ad policy interventions
Author(s): *Mita Giacomini*
C71: The Role of Pregnant Women in Medical Research: Does the systematic exclusion of pregnant women from being non-therapeutic research subjects protect or harm?
Author(s): *Lucy Langston*

C72: Presumed Consent: Red Herring or White Knight?
Author(s): *Linda Wright, Maxwell Smith*

Room 314

C73: Narrative as Evidence?
Author(s): *Debbie Rolfe*
C74: Ethics Blogs: Pedagogy, Public Outreach, and Professional Discourse
Author(s): *Chris MacDonald, Nancy Walton*
C75: Facebook and research: New challenges in research ethics
Author(s): *Nancy Walton, Chris MacDonald*

Albion A

W03: Shaping a Canadian Agenda for Research Ethics
Author(s): *Michael McDonald*

Albion B

C76: Fostering empathy and moral imagination in biomedical ethics teaching
Author(s): *Bruce Maxwell, Éric Racine & Alena Buyx*
C77: Medical Students' First Clinical Experiences of Death
Author(s): *Emily Kelly, Jeff Nisker*
C78: Just Accommodation in Canadian Healthcare Education
Author(s): *Jason Millar*

Albion C

C79: Moral distress and moral climate within the interdisciplinary ambulatory cancer care team environment
Author(s): *L.A. Martin, P. Rodney, and E. Serrano*
C80: Is Ambulatory Care Ethics Unique?
Author(s): *Moji Adurogbangba, Laurie Hardingham*
C81: Doing Taboo Work: Nurses' Experiences of Caring For Women Having Second Trimester Pregnancy Terminations For Fetal Anomalies Through Labour Induction
Author(s): *Susan E. Bishop*

Room 202

C82: Just evidence in an unjust world: The case of pharmacogenomics research in the current global context
Author(s): *Catherine Olivier*
C83: On Flying to Ethics Conferences : Climate Change, Justice, and Responsibility
Author(s): *James Dwyer*
C84: Uneven distribution of road traffic injuries and deaths across the Kenyan population: A social justice and political appraisal
Author(s): *Jacquineau Azetsop*

Room 203

W04: Case discussion of ethics in conditions of disaster and deprivation: learning from health workers' narratives
Author(s): *Lisa Schwartz, Matthew Hunt, Chris Sinding, Laurie Elit, Lori Luther, Lynda Redwood-Campbell, Naomi Adelson, Jennifer Ranford, Lucy Langston*

12:00 – 13:30 **Lifetime Achievement Award:** *Dr. Michael McDonald* ***Chedoke A/B***

13:30 – 15:00 **Aboriginal Panel "Aboriginal Health & Justice – Still A Ways To Go!"** ***Chedoke A/B***

15:00 – 15:30 Nutrition Break and Poster Viewing

15:30 – 17:30 **CONCURRENT SESSIONS**

Chedoke A/B

C85 Titre: Éclairer le débat public et la prise de décision gouvernementale Une consultation du Commissaire à la santé et au bien être sur les enjeux éthiques du dépistage prénatal de la trisomie 21
Auteur(s): *Isabelle Ganache, Sophie Bélanger, Ghislaine Cleret de Langavant*

C86 Titre: Diversité culturelle en éthique de la recherche, quelques enjeux du consentement libre et éclairé
Auteur(s): ***Danielle Laudy, Flore Gangbo, Marius Kêdoté***
C87 Titre : Prévention de la Transmission Mère-Enfant du VIH/SIDA au Bénin, A quoi consentent les femmes enceintes?
Auteur(s): *Marius Kêdoté*
C88 Titre: La modélisation de la décision dans la théorie des jeux : quelques exemples d'application pour la bioéthique
Auteur(s): *Yanick Farmer*

Webster A

C89: Ethics Change in Healthcare: What is our Burning Platform?
Author(s): Jonathan Breslin, Jennifer L. Gibson
C90: An Advocacy Role for NSHEN : Ethics Evidence and the Accreditation Process
Author(s): *Marika Warren and Christy Simpson*
C91: Ethics and evidence: exploring the role of public engagement in health technology assessment
Authors(s): *Yvonne Bombard, Les Levin and Tanya Khan*

Webster B

C92: Contributing to global health: An ethics framework for guiding international partnerships
Author(s): *L. d'Agincourt-Canning, T. McElroy, R. Armstrong*
C93: An exploration of the moral experience of Canadian healthcare professionals in humanitarian work
Author(s): *Matthew Hunt*
C94: "Playing God because you have to": Canadian health professionals' experiences of rationing care in humanitarian and development work
Author(s): *Christina Sinding, Lisa Schwartz, Matthew Hunt, Laurie Elit,Lynda Redwood-Campbell, Jennifer Ranford*

Webster C

W05: Palliative Sedation Workshop: Stakeholder Engagement to Inform National Guideline Development
Author(s): *Victor Cellarius, Blair Henry, and Sally Bean*

Webster Lounge

C95: The Impact of Medical "Evidence" Regarding Prenatal Screening on Legal "Evidence" Regarding Wrongful Birth and Resulting Normative Implications
Author(s): *M. Pioro, R. Mykitiuk, J. Nisker*
C96: Consent for prenatal scanning and suggestions for best practice: a viewpoint from Sri Lanka
Author(s): *NTW Wijeratne, D Rodrigo, H Dodampahala*
C97: Rescuing Prenatal Screening from the (Ethical) Quagmire
Author(s): *Victoria Seavilleklein*

Room 314

W06: Qualitative Ethics Research: Evidentiary Needs and Directions
Author(s): *Leigh Hayden, Andrea Frolic, and Mona Gupta*

Albion A

C98: Who is the research subject in cluster-randomzied clinical trials?
Author(s): *Andrew McRae*
C99: Equipoise, Experimental Design, and Inferential Strength
Author(s): *Spencer Phillips Hey*
C100: Extending Equipoise to Phase 1 Trials: A Bridge Too Far?
Author(s): *James A Anderson; Jonathan Kimmelman*

Albion B

C101: Health-care Professionals' Perceptions of Nutritional Genomics
Author(s): *Mark Weir; Karine Mori; David Castle*
C102: Conceiving the post-Prozac Self
Author(s): *Samantha Copeland*

C103: **Paediatric Advance Care Planning: Evidencing the Birth of a Paediatric Goals of Care Designation Policy in the Calgary Health Region**
Author(s): *Anna Zadunayski, Glenys Godlovitch, Sharron Spicer*

Albion C

C104: Masking mental health information within the electronic health record: considerations raised in a regional ethics consultation
Author(s): *Connie Mahoney, Stacey Page, Susan Rich, Roxanne Rowan, Information Management*

C105: Use of data from the electronic health record for health research – current governance challenges and potential approaches
Author(s): *Don Willison*

C106: Ethical Use of RFID Technology in the Surveillance of People and the Tracking of Things in Healthcare Deliver
Author(s): Michael J.Wilson

Room 202

C107: The Use of Meconium Testing : A Regional Health Authorities Response to a Growing Practice
Author(s): *Sarah Gebauer, Lynne Palmer, Bashir Jiwani*

C108: Authentic Research Relationships to Improve Aboriginal Health
Author(s): *Julie Bull*

C109: Ethical and social challenges in healthcare for adolescents and young adults with cerebral palsy
Author(s): *Danaë Larivière-Bastien, Eric Racine*

C110: Culturally Sensitive Obstetrical Care for Canada's Aboriginal Women Living in Urban Centres
Author(s): *Robyn MacQuarrie*

Room 203

C111: The Dependent Adult Donor : A Challenge for Canadian Health Law and Health Policy
Author(s): *Brian R. Forzley, Anna C. Zadunayski, Rose Geransar, Isabelle Chouinard, Allen Dong, Glenys Godlovitch*

C112: Does high-fidelity simulation facilitate staff preparation for the ethical and clinical care of patients and families in Donation after Cardiac Death (DCD)?
Author(s): *Barb Jennings, Maggie Zeman, Dianne Norman, Barb Flaherty*

C113: Can Ethics Really Be Taught? An Ethics Education Agenda for A Canadian Regional Health Authority
Author(s): *Bashir Jiwani, PhD, Sarah Gebauer, MA*

Sunday June 14, 2009

07:00 – 08 :30	CBS Executive Meeting	***Webster A***
07:30 – 08:30	Breakfast	***Chedoke A/B***
09 :00 – 10 :00	**Plenary Session Feminist Methodology and the Evidence-based Medicine Debate** Rosemarie Tong	
10:00 – 10:15	Nutrition Break	
10:15 - 11:30	**PHAC Workshop**	***Chedoke A/B***
10:15 – 11:30	**FAB Workshop** Robyn Bluhm: *'Incorporating patient values' and relational theories of autonomy* Kirstin Borgerson: *Feminist epistemology and the ethics of uncertainty in medicine* Maya Goldenberg: *An ethics of evidence: feminist considerations* Rebecca Kukla: *No evidence-based medicine without evidence: the paradox of pregnancy exceptionalism*	***Webster A***
11:30 – 12:30	**Plenary Session Challenge for the Future Susan Sherwin**	***Chedoke A/B***
12:30 – 13:00	**Wrap Up**	

PLENARY SESSIONS

Plenary Speaker
Opening Public Address

Date: Thursday June 11, 2009 7:00 p.m.

Title: Can Science Solve the Global Water Crisis?

The world is running out of fresh, clean water. The global crisis threatens all humanity and all species. Yet political leaders everywhere, armed with the belief that science and technology will solve the crisis, are acting as if it is a temporary and "fixable" threat. Maude Barlow has studied the so-called technological miracles such as nanotechnology, toilet to tap recycling, and desalination and argues that they cannot replace conservation, source protection and good public policy.

Speaker: Maud Barlow

Maude Barlow is the National Chairperson of the Council of Canadians and Senior Advisor on Water to the President of the United Nations General Assembly. She also chairs the board of Washington-based Food and Water Watch and is a Councillor with the Hamburg-based World Future Council. Maude is the recipient of seven honorary doctorates as well as many awards, including the 2005 Right Livelihood Award (known as the "Alternative Nobel"), and the 2008 Canadian Environment Award. She is also the best selling author or co-author of 16 books, including the recently released *Blue Covenant: The Global Water Crisis and The Coming Battle for the Right toWater*.

Plenary Speakers

Plenary Session

Date: Friday June 12, 2009 9:00 – 10:00 a.m.

Title: "The Loss of Sadness: Are We Misdiagnosing a Normal Human Emotion as a Mental Disorder?"

Speaker: Jerome Wakefield

Jerome C. Wakefield, PhD, DSW is University Professor, Professor of Social Work, and Professor of the Conceptual Foundations of Psychiatry, as well as Affiliate Faculty in Bioethics and in the Center For Ancient Studies, at New York University; and Lecturer in Psychiatry (Clinical Phenomenology Division, Biometrics Unit) at Columbia University College of Physicians and Surgeons. A licensed clinical practitioner, he has previously held faculty positions at University of Chicago, Columbia University, and Rutgers University. He holds two doctorates, in social work and philosophy, and a masters degree in mathematics with a specialization in logic and methodology of science, all from University of California at Berkeley. He is the author of over 150 publications appearing in journals in psychiatry, psychology, philosophy, psychoanalysis, and social work. His scholarship focuses on the conceptual foundations of the mental health professions, especially the concept of mental disord er and the validity of DSM diagnostic criteria. He is author with Allan Horwitz of "The Loss of Sadness: How Psychiatry Transformed Normal Sorrow into Depressive Disorder" (Oxford, 2007), named best psychology book of 2007 by the American Association of Professional and Scholarly Publishers. He is currently at work on a book on Freud's case of Little Hans.

Plenary Session
Date: Saturday June 13, 2009 9:00 – 10:00 a.m.

Title: "Squaring the circle: reconciling evidence and equity"
Bernard Keating

Professor Keating teaches catholic biomedical ethics and bioethics. In addition to teaching at the faculty of Théologie et Sciences Religieuses at Université Laval, he is also responsible for teaching ethics to students of the faculties of Pharmacie and Médecine Dentaire. His most recent work is on the ethics of research, ethical problems related to the development and commercialization of drugs and on the nourishment and artificial hydration of patients in permanent vegetative state.

Plenary Speakers

Plenary Session Associated Medical Services Canadian Bioethics Society Lecture

Date: Sunday June 14, 2009 9:00 – 10:00 a.m.

Title: "Feminist Methodology and the Evidence-based Medicine Debate"

Rosemarie Tong

Rosemarie Tong is Distinguished Professor of Health Care Ethics in the Department of Philosophy and Director of the Center for Applied and Professional Ethics at UNC Charlotte. Receiving her PhD in Philosophy from Temple University in 1978, she has come to be internationally known for her contributions to feminist thought and bioethics. Dr. Tong has authored and co-edited thirteen books, including *Ethics in Policy Analysis* (1985), *Controlling our Reproductive Destiny: A Technological and Philosophical Perspective* (1994), *Feminist Approaches to Bioethics* (1996), *Linking Visions: Feminist Bioethics, Human Rights, and the Developing World* with Ann Donchin and Sue Dodds (2004), *New Perspectives in Health Care Ethics: An Interdisciplinary and Crosscultural Approach* (2007) and *Feminist Thought: A More Comprehensive Introduction* (2008 3rd edition). She has also published over one hundred articles on topics related to feminist theory, reproductive and genetic technology, biomedical research, global bioethics, aging, and healthcare reform.

Since coming to UNC Charlotte, Dr. Tong has greatly expanded the University's role and visibility in promoting the Center for Professional and Applied Ethics. Her efforts have brought many noted academics as well as civic and professional leaders to UNC Charlotte as participants in various speakers' series, workshops, and seminars. A sought-after speaker, she regularly delivers addresses for leading institutions and organizations internationally as well as nationally. Her most recent speaking engagement were in Beijing and Croatia. Dr. Tong is the immediate past Chair of the American Philosophical Association's Committee on the Status of Women, Chair of the Institutional Review Board's Conflict of Interest Committee at Chesapeake Research, Inc., and was Co-chair of the NC Institute of Medicine's taskforce on Pandemic Influenza in 2006-2007. She is an executive board member of the International Network for Feminist Approaches to Bioethics, the Association for Practical and Professional Ethics, the U.S. Women's Bioethics Project, the Executive Forum of Charlotte, and the North Carolina Biotechnology Center. Currently, Dr. Tong's research is focused on ethical issues in long-term care, cognitive enhancement and genetics.

Date: Sunday June 14, 2009 11:30 a.m. – 12:30 p.m.

Title: Challenge for the Future

Speaker: Susan Sherwin

Susan Sherwin is University Research Professor Emerita in the Departments of Philosophy and Gender and Women's Studies at Dalhousie University. She is an elected Fellow of the Royal Society of Canada (1999) and of the Canadian Academy of Health Sciences (2007). Her principal areas of research and teaching are in feminist theory and health ethics, and in the intersection of these two fields. She won the 2006 Killam Prize in Humanities and the 2007 Lifetime Achievement Award from the Canadian Bioethics Society. Her books include *No Longer Patient: Feminist Ethics and Health Care* (1992) and *The Politics of Women's Health: Exploring Agency and Autonomy* (1998, with the Feminist Health Care Ethics Research Network).

Panel on Ethics and Evidence Based Practice

Moderator: Dr John Watts
Professor and the Associate Chair, Education in the Department of Pediatrics
McMaster University and a neonatologist
McMaster Children's Hospital
Roman Jaeschke MD:
Clinical Professor, Department of Medicine McMaster University,
General Internal Medicine and Intensive Care, St. Joseph's Hospital
Wayne Rosen MD:
Department of Surgery, University of Calgary, Peter Lougheed Hospital
Mona Gupta MD:
Psychiatrist at Women's College Hospital, Toronto
Lonny J. Rosen LLB:
Specialist in Health Law, Gardiner Roberts

Aboriginal Panel on

"Aboriginal Health and Justice...Still a Ways to Go"

Moderator: Marilyn Wright
Pat Mandy
Chief Executive Officer,
Hamilton, Niagara, Haldimand, Brant Local Health Integration Network
Ruby Jacobs,
Director of Health Services
Six Nations
Matilda Lee Styres
Aboriginal Patient Navigator,
Hamilton Health Sciences Juravinski Cancer Centre

THANKSGIVING ADDRESS OF THE LONGHOUSE PEOPLE

THE PEOPLE:
We have been given the duty to live in harmony with one another, and with other living things. We offer thanks that this is true.

MOTHER EARTH:
We offer thanks to our Mother Earth. All that makes us strong and alive comes from you. We are all like children as we walk upon you. You nourish us and all living things.

WATER:
We offer thanks to the water for our well-being. You quench our thirst. You give strength for plants and animals and for many medicines.

PLANTS:
We offer thanks to the plant life. Within you is the energy that sustains many life forms. You give us food, medicine, and beauty.

TREES:
We offer thanks to the trees of the forest. You give us shelter and fruits of many kinds. Your beauty is ever-changing.

ANIMALS:
We offer thanks to our animal brothers. You are still living in your hidden places and we see you sometimes. You give us food, clothing and beauty.

BIRDS:
We offer thanks to the winged creatures, you remind us to enjoy our life cycle.

THE FOUR WINDS:
We offer thanks to the four winds. We listen and hear your voices as you blow above our heads. Always you bring strength. You come from the four directions.

THE SUN:
We offer thanks to Brother Sun as you travel across the sky you nourish Mother Earth. You give us warmth, energy and light. Your cycle changes, to allow all life forms to be reborn with every sunrise…is a miracle.

GRANDMOTHER MOON:
We offer thanks to Grandmother Moon. We see your face shine for us at night. Your cycle provides new life on Mother Earth.

THE STARS:
We offer thanks to the stars. You are helpers for Grandmother Moon. You make the sky shine at night and we admire your glowing beauty.

THE CREATOR:
We offer thanks to the Creator. You have prepared all these things on Mother Earth for our peace of mind. We see that all things are following your teachings. All together, we give thanks to you, the CREATOR.

ABSTRACTS

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C22 Allatt, Peter	DNRC: Why Unilateral Orders Won't Fly
C53 Allatt, Peter	Ethical Issues in the treatment of bariatric patients
C09 Allen, Kristiann	What Evidence? Or evidence of what?
C100 Anderson, James	Extending Equipoise to Phase I Trials: A Bridge Too Far?
C26 Austin, Wendy	Ethical Issues in Organ Donation: Views of Recent Immigrants & Health Professionals
C84 Azetsop, Jacquineau	Uneven distribution of road traffic injuries and deaths across the Kenyan population: A social justice and political appraisal
C34 Bean, Sally	The Murky Intersection between Clinical & Organizational Ethics: a Hybrid Case Taxonomy
C54 Behrmann, Jason	Defining physiological mechanisms and policy responses for social injustice and health inequalities
C19 Bell, Emily	Ethical and social challenges in the field of deep brain stimulation: Perspectives from Canadian practitioners
C65 Bell, Kristen	Rights, Risks, and Smoking: how 'denormalisation' mediates patient-provider interaction in primary care settings
C81 Bishop, Susan	Doing Taboo Work: Nurses' Experiences of Caring For Women Having Second Trimester Pregnancy Terminations For Fetal Anomalies Through Labour Induction
C92 Bombard, Yvonne	Ethics and evidence: exploring the role of public engagement in health technology assessment
C07 Borgerson, Kirstin	Evidence-Based Medicine and the Collapse of the Research/Practice Distinction
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C03 Bouzidi, Maria	Éthique clinique et soins dans la communauté
C89 Breslin, Jonathan	Ethics Change In Healthcare: What is our Burning Platform?
C32 Browne, Alister	Aggressive Discharge Planning

C35 Bruni, Rebecca	Public Engagement: a vehicle to enhance justice in wait list management
C05 Buchman, Daniel	Navigating the Ethical Space of Imaging Genetics: Clinical Translation of Neuropsychiatric Research
C108 Bull, Julie	Authentic Research Relationships to improve Aboriginal Health
C39 Chouinard, Isabelle	Technology and clinical judgement in evidence-based medicine
C67 Cleghorn Michelle	Quality public engagement in health policy making: An emerging framework for effective deliberation
C102 Copeland, Samantha	Conceiving the post-Prozac Self
C31 Cousineau, Julie	L'anonymat des dons de gametes et d'embryons: quelle justice, pour qui?
C14 Crowell, Philip	Spiritual Care Chaplaincy in Relation to Ethics: friend or foe?
C92 d'Agincourt-Canning	Contributing to global health: An ethics framework for guiding international partnerships
C66 Dawson, Angus	Milk A Neglected Ethical Issue
C41 Deslauriers,Constance	Ethics review of Minimal risk and multisite qualitative studies: perspectives from two Canadian studies and the new Tri-Council Policy statement
C61 Dion-Labrie, Marianne	Utilisation de la médecine personnalisée en transplantation rénale: De nouvelles preuves scientifiques pour une plus juste attribution des organes?
C50 Duckworth, Katherine	Learning from patient: A case study of non compliance in patients with HIV associated Tuberculosis
C25 Duplantie, Andrée	How organ transplantation is represented in Québec newspapers?
C83 Dwyer, James	On Flying to Ethics Conferences: Climate Change, Justice, and Responsibility
C01 Edwards, Marie	Long Term Care Nurses' Responses to Moral Distress: Perceptions of Support Admist Ethical Challenges
C63 Entwistle, Vikki	Evidence based medicine as a threat to individually appropriate care? Ethical concerns raised by family physicians
C18 Everett, Bethan	Ethical Care for Infants with Conditions not Curable with Intensive Care
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C111 Frozley, Brian	The Dependent Adult Donor: A Challenge for Canadian Health Law and Health Policy

C85 Ganache, Isabelle	Consultante en éthique, Agente de recherché et de planification socioéconomique, Commissaire adjointe à l'éthique
C107 Gebauer, Sarah	The Use of Meconium Testing: A Regional Health Authorities Response to a Growing Practice
C21 Gedge, Elisabeth	Reproductive Choice and the Ideals of Parenting
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C28 Gerrie, James	A Philosophy of Technology Perspectives on James Rachels' Attack on The Distinction between Killing and Letting Die
C70 Giacomini, Mita	The questionable ethics and science of experimental trials for evaluating 'black box' health and policy interventions
C37 Gilbert, F.	Health Care Justice Debate: may a hybrid view be the answer?
C56 Gillian, K.	Social Justice and International Medical Travel for Reproductive Health Care
C64 Gilmour, Joan	Keeping Evidence-Based Knowledge About Medical Error From Patients and the Public: An Ethical and Legal Conundrum
C11 Gotlib, Anna	Shadows of Doubt: The Use and Misuse of Evidence-Based Medicine
C06 Graham, Janice	Just evidence in assessing risk in emerging health products
C51 Harvey, William	Evidence-based assessments of competency
C99 Hey, Spencer Phillips	Equipoise, Experimental Design and Inferential Strength
C10 Ho, Anita	The Ethics of Expert Authority in Evidence-Based Preventive Medicine
C93 Hunt, Matthew	An exploration of the moral experience of Canadian healthcare professionals in humanitarian work
C02 Ibarra, Kimberley	The Need for Homecare Ethics Capacity: Evidence from the Community Ethics Network Outreach Project
C112 Jennings, Barbara	Does high-fidelity stimulation facilitate staff preparation for the ethical and clinical care of patients and families in Donation after Cardiac Death (DCD)?
C113 Jiwani, Bashir	Can Ethics Really Be Taught? An Ethics Education Agenda for a Canadian Regional Health Authority
C87 Kêdoté, Marius	Prévention de la Transmission Mère-Enfant du VIH/SIDA au Bénn, A quoi consentent les femmes enceintes?
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C48 Kolopack, Pam	The Social Justness of Insite: Insight into Insight from a Public Health Ethics Perspective

C71 Langston, Lucy	The Role of Pregnant Women in Medical Research: Does the systemic exclusion of pregnant women from being non-therapeutic research subjects protect or harm?
C29 Lanoix, Monique	Where Angels Fear to Tread: Proxy Consent and Novel Technologies
C109 Larivière-Bastien, Danaë	Ethical and social challenges in healthcare for adolescents and young adults with cerebral palsy
C86 Laudy, Danielle	Diversité culturelle en éthiique de la recherché, quelques enjeux du consentement libre et éclairé
C24 Lazar, Neil	End of Life Decision Making: Whose goals count?
C45 Longstaff, Holly	Scientists' and regulators' perspectives on the ethical issues of stem cell research
C58 Luther, Lori	From Obligations to Inform to Duties to Warn
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C30 Marsh, John	Posthumans and Present Evidence: Exploring Future Enhancement
C79 Martin, L.A.,	Moral distress and moral climate within the interdisciplinary ambulatory cancer care team environment.
C20 Mathieu, Ghislaine	Canadian Medical Device Regulations: the case of Deep Brain Stimulation (DBS)
C76 Maxwell, Bruce	Fostering empathy and moral imagination in biomedical ethics teaching
C98 McRae, Andrew	Who is the research subject in cluster-randomized clinical trials?
C08 Mendel, Joy	Some Ethical Issues in the production and application of clinical evidence
C79 Millar, Jason	Just Accommodation in Canadian Healthcare Education
C23 Mohammed, Shan	Rituals, Death, and the Moral Practice of Medical Futility
C46 Morgenstern, Justin	Meanings and Understandings of Language Used in Researching Evidence for a Genetic Basis of a Clinical Condition
C33 Morris, Veronica	Developing an Island Wide Clinical Ethics Program: Evidence and Reality
C27 Muhlnickel, Robert	Reducing the Weight Given to Family Distress in Organ Donation Decision-Making

C82 Olivier, Catherine	Just evidence in an unjust world: The case of pharmacogenomics research in the current global context
C95 Pioro, M.	The Impact of Medical "Evidence" Regarding Prenatal Screening on Legal "Evidence" Regarding Wrongful Birth and Resulting Normative Implications
C95 Preto, Nina	A Closer Look at Contract Research Organizations (CROs) in the Canadian Context
C44 Reel, Kevin	Entitlement and implantation; resistance and expectation – reflections on biomaterials, disability and social norms
C68 Reid, Lynette	Chaoulli, wait lists, and somatic solidarity
C73 Rolfe, Debbie	Narrative as Evidence?
C102 Rosen, Wayne	The Tyranny of Evidence in Medicine
C36 Russell, Barbara	The Ethics of Autism: responding to Barnbaum and colleagues
C97 Seavilleklein, Victori	Rescuing Prenatal Screening from the (Ethical) Quagmire
C17 Simmonds, Anne	Ethical Questions arising out of nursing care for women experiencing spontaneous and therapeutic abortions
C94 Sinding, Christina	"Playing God because you have to": Canadian health professionals' experiences of rationing care in humanitarian and development work
C69 Singleton, Rick	Here Comes the Judge
C49 Smith, Elise	The Limitations of Public Engagement in Canadian Policy-Making Regarding Assisted Reproduction Technologies
C57 Snyder, Jeremy	Traveling Right: Ethical Issues in Medical Tourism
C55 Solfer, Eldon	Permission to Override Patients' Wishes
C04 Stratchan, Patricia	Exploring Uncharted Territory: Mapping the Ethical Terrain in Consent Narrations of Patients with Implantable Cardioverter Defribrillators
C40 Thomsian, Talene	The Ethics of the Free-Rider: Are They Really Riding for Free?
C47 Upshur, Ross	Citizens' Perspectives on Pandemic Influenza in Canada: Findings from the CanPREP collaboratory
C42 Vitale, David	Social Justice in the Clinical Context: Using Charter Rights as a Framework for Healthcare Priority Setting
C75 Walton, Nancy	Facebook and research: New challenges in research ethics
C12 Warren, Marika	Evidence and Uncertainty: Challenges for Ethics
C90 Warren, Marika	An Advocacy Role for NSHEN: Ethics Evidence and the Accreditation Process

C15 Wasylenko, Eric	Goals of Care designations: Fundamentals change in joint decision-making about care.
C101 Weir, Mark	Health-care Professionals' Perceptions of Nutritional Genomics
C96 Wijeratne, NTW	Consent for prenatal scanning and suggestions for best practice: a viewpoint from Sri Lanka
C52 Wilks, Ian	Competence, Paternalism and Risk
C105 Willison, Don	Use of data from the electronic health record for health research – current governance challenges and potential approaches
C106 Wilson, Michael	Ethical Use of RFID Technology in the Surveillance of People and the Tracking of Things in Healthcare Delivery
C72 Wright, Linda	Presumed Consent: Red Herring or White Knight?
C103 Zadunayski, Anna	Paediatric Advance Care Planning: Evidencing the Birth of a Paediatric Goals of care Designation Policy in the Calgary Health Region

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A01 Bergeron, Michel	Réflexion sur l'intégrité au Coeur de l'activité de recherché
W05 Cellarius, Victor	Palliative Sedation Workshop: Stakeholder Engagement to Inform National Guideline Development
W07 FAB	*Bluhm:* 'Incorporating patient values' and relational theories of autonomy
	Borgerson: Feminist epistemology and the ethics of uncertainty in medicine
	Goldenberg: An ethics of evidence: feminist considerations
	Kukla: No evidence-based medicine without evidence: the paradox of pregnancy exceptionalism
W06 Hayden, Leigh	Qualitative Ethics Research: Evidentiary Needs and Directions
W03 McDonald, Michael	Shaping a Canadian Agenda for Research Ethics
W08 PHAC	Public Health Agency of Canada Topic TBA
W01 Reilly, Dan	Teaching Ethics to Medical Students: Achieving Effectiveness through Relevant Content and Respecting the Adult Learner
W04 Schwartz, Lisa	Case discussion of ethics in conditions of disaster and deprivation: learning from health workers' narratives
W02 Sherwin, Susan	Bioethicists' Reflections on Proposed Changes to the TCPS (Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans).

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P01 Affleck, William	Informed Consent for Functional Neuroimaging
P15 Axler, Renata	Marketing A Better World the Many Meanings of Benefits
P13 Bombard, Yvonne	Evidence of Genetic Discrimination Experiences Among Individuals
P08 Chapple Sarah	The Experience of Working Age Adults in Residential Care
P05 Cox, Kelly	Impact of Parents Receiving Individualized Feedback on Results
P11 Geransar, Rose	Rethinking The Meaning and Significance of Consent in the Context of Tissue
P06 Gibson, Barbara	Assessment of Childrens' Capacity to Consent for Research
P03 King, Judy	An Ethical Framework
P04 Kotecha, Jyoti	A Canadian Primary Care Chronic Disease Sentinel Surveillance
P09 Krahn, Timothy	Justice & Autism Balancing Public Investments In Research Futures
P07 McClimans, Leah	The Ethical Significance of Patient-Reported Outcome Matters
P16 Mitchell, Ian	Cystic Fibrosis Screening Do We Help or Cause Harm
P02 Reilly, Dan	Elective Caesarean Section
P12 Rodrique, Catherine	Controversies Updates and Dilemma in the Ethics of Care and Research
P10 Vanderbyl, Brandy	Internet Marketing of Dietary Supplements for Alzhiemers' Disease
P11 Willison, Don	What Do Academic Healthcare Facilities Tell Their Patient's About Research Uses of Health Information in Their Custody?

Abstract Presentations

C01 Title: Long Term Nurses' Responses to Moral Distress: Perceptions of Support Amidst Ethical Challenges.

Author(s): Marie Edwards, Susan McClement, Laurie Read

Moral distress has been identified as an important issue in nursing. Andrew Jameton's (1993) early writing on this topic distinguished between initial moral distress--the feelings people experience when faced with situations where values conflict -- and reactive moral distress--the feelings people experience if they do not deal with that initial distress. Limited research exists examining nurses' experiences of and responses to initial moral distress. This is particularly true as regards nurses working in long term care settings. The ability to support nurses in dealing with initial moral distress is predicated on first understanding their experiences of it. To redress this gap in the literature, an interpretive descriptive study was conducted to examine and describe: a) the ways nurses respond to initial moral distress in their work in long term care; and b) nurses' perceptions regarding interventions and resources that have assisted or could assist them to respond effectively to this distress. Audio-taped interviews were carried out with fifteen registered nurses working in long-term care. Interviews were transcribed and data analyzed using qualitative techniques articulated by Giorgi (1985). In this presentation, three aspects of the study findings will be explored: i) the types of ethical challenges in their work that caused nurse participants to experience moral distress; ii) participants' perspectives on the availability of, and need for, 'safe places' to discuss ethical issues and conflicting values; and iii) participants' perceptions of the role of the health care team, management, and ethics committees in contributing to or mitigating moral distress.

C02 Title: The Need for Homecare Ethics Capacity: Evidence from the Community Ethics Network Outreach Project

Author(s): Kimberley Ibarra, Renaud Boulanger, Frank Wagner

As the number of patients cared for in their home increases, the ethical dilemmas encountered by community healthcare workers become ever more complex. To meet growing need for ethics capacity in the community health and support sectors, the Community Ethics Network (CEN) was launched in 2005 by a number of homecare and community health service is a desire to foster ethical decision-making, essential for good organizational practices, such as due process for resource allocation. As a result, the CEN is instrumental in both reducing the moral distress experienced by community healthcare workers and increasing the quality of care received by patients. In July 2008, the CEN embarked on a quality improvement project to ensure that, three years after its launch, it continued to me the needs of its 35 members. Using an outline survey and semi-structured interviews, data was collected on 1) members' perspectives of ethical issues in community healthcare, 2) current capacity to respond to these issues, and 3) ideas for future directions of the Network. The aim of this presentation will be to share quantitative and qualitative data from this quality improvement project and provide insight into how to develop integrated, accountable, and sustainable ethics networks in the emerging LHIN environment. Finally, by providing an overview of the unique ethical dilemmas faced by community healthcare workers, the presentation will shed light on gaps and areas of priority for building ethics capacity in community healthcare.

C04 Title: Exploring Uncharted Territory: Mapping the Ethical Terrain in Consent Narratives of Patients with Implantable Cardioverter Defibrillators

Authors: *P.H. Strachan, S. Carroll, L. Schwartz, S. de Laat, and H.M. Arthur*

In recent years, implantable cardioverter defibrillators (ICDs) have been increasingly used in Canada for primary and secondary prevention of sudden cardiac death (SCD). During a minor operative procedure, these devices are implanted under the skin and their lead wires placed to continuously monitor the heart rhythm. If a life threatening arrhythmia is detected, a shock is fired to defibrillate the heart, and thus prevent SCD. Little is known about what information patients' value when considering an ICD. We undertook a multicenter study to explore consent narratives of patients who have accepted an ICD for primary prevention. Patients who had the device implanted were interviewed 2-4 weeks following the procedure to explore issues they considered relevant to their consent. Patients' descriptions of information they sought and were given about the related to the device and its implications were collected and analyzed. Our findings to date suggest that patients primarily focused on prevention of SCD. This paper will explore the information that is largely missing from patient accounts and is related to implications for living with the device: for instance, possible device recalls, follow-ups, lifestyle adjustments, and particularly, end of life issues. The focus of our discussion will be on navigation of the ethical terrain that is reflected in these aspects of the consent narratives. Finally, issues about if and how additional information could enrich consent discussions for ICD for primary prevention will be considered. Findings of this study have significance for best practices, informed consent processes, patient education, health service providers and health policy makers.

C05 Title: Navigating the Ethical Space of Imaging Genetics: Clinical Translation of Neuropsychiatric Research

Author(s): *Daniel Z. Buchman, Judy Illes*

The new field of *imaging genetics* is emerging as a powerful approach to the study of functional genetic variations and associated brain responses in neuropsychiatric disease. The approach involves identifying a meaningful variation in the sequence of a candidate gene with predictable effects at the neuronal level. Imaging genetics may thus allow for improved abilities in disease differentiation and identification of clinical findings detected incidentally in research. Although the dual technology capability is relatively new, future demand may raise issues of resource allocation in healthcare settings, and the commodification of scientific knowledge in the private sector. While ethical, legal and social issues (ELSI) as they apply separately to genetics and neuroimaging have received significant academic attention, only recently has there been an exploration of the ELSI space that they collectively occupy. We build on recent efforts by Tairyan and Illes[1] who suggest that the combination of imaging and genetics calls for special attention to potentially qualitatively new ELSI issues.

Our proposed model extends their thinking to address the potential implications specifically in the clinical translation of neuropsychiatric research. It is unknown, for example, how knowledge constructed from imaging genetics may impact a patient's sense of agency, responsibility for symptoms, and perceptions of health and illness. Further, it is unclear how the cumulative knowledge may impact the recovery process and orientation towards treatment. The new model provides a fluid trajectory as opposed to discrete time points for examining how patients may negotiate the relationship between themselves, their genes, and their brains.

Reference Tairyan K, Illes J. Imaging genetics and the power of combined technologies: A perspective from neuroethics. Lancet Neuro 2009; in press.

C06 Title: Just Evidence in assessing risk in emerging health care products

Author(s): Janice Graham

The Canadian Health Products and Food Branch has been undergoing regulatory modernization: a project to revamp a regulatory framework designed in the 1920s, updated sporadically, and now recognized as incapable of meeting the regulatory implications raised by rapidly emerging biotechnologies (such as those associated with recombinant DNA, nanotechnology, xeotransplantation, stem cells, synthetic technologies). Along with changing technological landscapes, the framework is intended to address growing trends and pressures for public participation in technology governance. These demands – to keep pace with evolving technologies and to heed participatory pressures – post often-conflicting views of what is legitimate evidence in evidence-based risk regulation. Using ethnographic methods (participation observation, document analysis, and interviewing) with HPFB regulatory scientists and policy analysts, this report attempts to contribute to regulatory best practices by 1) examining the determination of different forms of evidence in risk regulation regimes; 2) addressing an under-theorized area: empirical studies of risk regulation. I show that HPFB modernizing strategies allow, epistemologies into the evidence base. I suggest that by approaching different types of evidence in a balanced manner, the evidence base itself might be made more robust in cases where uncertainty precludes easy decisions. A symmetrical multiple epistemologies can begin to address the decline in trust of regulatory decisions brought about by highly publicized product withdrawals and exacerbated by the close relationship between regulator and industry.

C07 Title: Evidence-based Medicine and the Collapse of the Research/Practice Definition

Author(s): Kirstin Borgerson

Franklin Miller and Howard Brody argue that medical therapy and medical research were fundamentally distinct and give rise to different ethical obligations (2003). The achievements and shortcomings of evidence-based medicine (EBM) provide grounds for questioning this proposed distinction. First, the primary aim of EBM has always been greater integration of medical research of medical research into clinical practice; physicians are advised to consult research evidence in order to provide ethical, and optimal, patient care. Advocates of EBM also encourage researchers to pay attention to the needs and goals of patients. Even if it were the case that, era of global evidence-based practice this is simply no longer the case.

Second, drawing on the shortcomings of EBM, critical analysis of EBM over the past seventeen years have persuasively demonstrated that the EBM hierarchy of evidence is problematic. Critics have argued instead for methodological pluralism in medicine. If we pay closer attention to the plurality of research methods available to medical researchers, including case studies, qualitative research, bench research and n-of-1 trials, the clear distinction between research and practice collapses. Research is no longer always generalized, done on groups of patients, or focused exclusively on future benefits. Drawing on the lessons gained from close attention to the literature on evidence-based medicine, I argue that a strict research/practice division shortchanges both the epistemological dimension of medical practice and the practical dimensions of medical research.

C08 Title: Production and Application of Evidence: Some Issues

Author(s): Joy Mendel

Some ethical issues in the production and application of clinical evidence Evidence based medicine (EBM) was originally devised as a method to link the results of scientific trials to medical practice. EBM provides the benefit of ensuring, at least in the short term, an acceptable level of efficacy and risk. That EBM may compromise consent to treatment through limiting choice has also been raised. Approval mechanisms for new therapies favour those with an evidence base. The therapies truly advantaged by EBM however, are often those which are translatable into marketable commodities. Even where some market potential exists for new therapy, marketing agendas, approaches to drug company R & D, and regulatory requirements for new treatments, will naturally lead to the greater availability of therapies into which a heavy investments have been made. While the availability of research funding is implicated in the development of new therapies, rethinking the levels if evidence, particularly for treatments already in wide use in the community, may promote broader choice. Arguments from the perspectives of autonomy, beneficence and justice can support the goal of maximizing he range of available treatments.

Evidence is frequently employed beyond the medical encounter. Among other applications, evidence frames some health policies, determines clinical care pathways, and arguably, shapes health care budgets. It has also been suggested that evidence will increasingly became a feature of medicolegal cases. Issues have been raised from the scientific perspective in relation to reliability and generalisability of evidence. Applying evidence outside the clinical practice of medicine should be approached with caution.

C09 Title: What Evidence? Or Evidence of what?

Author(s): Kristiann Allen, Jamie Flamenbaum

Bio-ethics has a long history of concern for research and the protection of the human subject. More recently, attention has been paid to the notion of 'evidence' as an ethical concern. In particular the rapid rise of the field of evidence-based medicine (EBM) has prompted ethical discussions of adequacy and quality of evidence for decision making as well as the use of best evidence as a moral imperative for treatment decisions.

Despite bio-ethics' analytical lens turning toward 'evidence' however, there has been little discussion of evidence as a construct in itself. Taking inspiration from the fields of Medical Anthropology and of Science Studies, we argue that 'evidence' as a product of the socio-cultural activity known as scientific research, can itself be viewed as socially constructed.

We do not debate the existence of facts in science. Rather, categorizing facts as 'data', and in turn analyzing and interpreting these is a process in which value judgements are embedded and thus taken for granted.

Whereas it is by now well recognized that the notion of 'truth' in scientific discourse is value-laden and thus debatable, we argue that the use of the 'evidence' has come to replace 'truth', but has not yet been problematised in the same way.

We therefore suggest that a critical understanding the process of evidence construction is an ethical imperative when research results are used for decision-making.

C10 Title: The Ethics of Expert Authority in Evidence-Based Preventive Medicine

Author(s): Anita Ho

This paper explores the underlying assumptions and values that shape the epistemic and ethical deliberations of evidence-based preventive medicine (EBPM). Expert based panels and committees, such as the Canadian Task Force on Preventive Health Care and the United States Preventive Services Task Force, review the scientific evidence for the preventability of various conditions to assess whether certain types of interventions should be introduced into communities or clinical practice. Recommendations of these expert panels have become standard reference tools for primary care clinicians.

Expert panels for EBPM often pride themselves for focusing on evidence rather than consensus, and for being objective by placing greatest weight on randomized clinical trials, critical appraisals, meta-analyses, and systematic reviews, which are some methods that tend to minimize biased results. While applauding these panels' emphasis on using sound medical evidence in making intervention recommendations, this paper argues that the choice of these standards and the recommendations based on such standards are far from value neutral. This paper begins with a discussion of the notions of expert and expertise, with a particular focus on how dissent and uncertainties are handled. As evidence is open to various interpretations, embedded in EBPM are assumptions about how science/epidemiology works, how expert status is determined, the expert's own biases and preferences, and values the society chooses to prioritize. This paper explores those underlying assumptions and values, and cautions any dogmatic acceptance of expert authority under the disguise of value neutrality.

C11 Title: Shadows of Doubt: The Use and Medicine of Evidence-Based Medicine

Author(s): Anna Gotlib, Sorava Gollop

Evidence-based medicine has been praised by many as the way to ensure the best possible patient care. While it remains a valuable tool in closing the gap between research and practice, we propose two serious worries about its methods and effects on clinical practice. First, we claim that evidence-based medicine is potentially harmful to patient care when combined with the profit imperative of United States-style HMOs. Indeed, when the provision of care is predicated on the existence of resource-intensive studies required for evidence-based medicine, the results are morally troubling: The lack of certain randomized controlled trials is taken by HMOs as grounds to deny insurance coverage for non-controversial, but evidence-based "untested," procedures which meet standards of care, leading to the withholding of often necessary care. Secondly, we suggest that a wholesale reliance on evidence-based medicine would be harmful to the physician's ability to engage in patient-centered care grounded in the unique needs of individual patients. Although physicians treat diverse populations, there is a risk that any given population is not represented in evidence-constituting trials. And while we do not dispute the need for practitioner familiarity with relevant studies in his or her field, we take this knowledge by itself to be too general to allow a simple extrapolation of data to cases. Although we do not take these two worries to be dispositive, they are sufficiently serious to warrant careful and thoughtful discussion about the appropriate scope of evidence-based medicine.

C12 Title: Evidence and Uncertainty: Challenges for Ethics

Author(s): Marika Warren

Patients frequently expect certainty from their health care providers, health care providers often expect certainty of themselves, and both groups have expressed discomfort with explicit acknowledgement of uncertainty in the context of medical decision-making. One response has been to turn to evidence to increase certainty, and while research evidence does have the potential to reduce uncertainty it just as often increases uncertainty or cannot provide any greater certainty for patients or providers as to what approach to take in a particular clinical uncertainty will cause the patient harm in the form of distress or will result in a loss of trust in the health care provider and thereby diminish the patient-provider relationship.

The focus of this presentation, then will be how to appropriately communicate clinical uncertainty and its relationship to evidence in the process of medical decision making. This includes uncertainty regarding the appropriate course of treatment, the patient's diagnosis, the significance of a particular test result, or patient's diagnosis, the significance of a particular test result, or the patient's prognosis. There are two main questions: (1) How can uncertainty be communicated and acknowledge in an ethically appropriate way? And (2) What is it ethically necessary to communicate regarding uncertainty in the decision-making process? I.E. given the requirement that consent be informed, how much uncertainty must be communicated to meet that requirement? The particular use of informed consent for presymptomatic genetic testing will be examined in addressing these questions, but the discussion applies to decision-making in a range of contexts.

C13 Title: Bringing Culture to the Core: A Plan for Expanding the Core Competencies of Clinical Ethicists

Author(s): Thomas Foreman, Shawn Winsor

This presentation will expand the ASBH competencies to include, alongside ethical analysis, consensus building and facilitation, *cultural competence* as an essential skill needed to conduct ethics consultation in the increasingly culturally diverse institutions in which many Western clinical bioethicists find themselves practicing today. While the ASBH recognizes that "advanced skills" in this area are useful in some ethics consultation, they see this as residing in other hospital professions (e.g., social workers and chaplains) who they recommend be brought into consultations because of this expertise.

Cultural competence in this context can be defined as, "having the ability to interact effectively with people of different cultures [… and comprising] four components: (a) Awareness of one's own cultural worldview, (b) Attitude towards cultural differences, (c) Knowledge of different cultural practices and worldviews, and (d) cross-cultural Skills. Developing cultural competence results in an ability to understand, communicate with, and effectively interact with people across cultures".* However, we will argue that cultural competence is not a specialized body of knowledge and process skill independent of the consultation process but a corpus so critical to effective cross-cultural clinical ethics consultation that it must also be a core competency for the Clinical Ethicist and not resident in an adjunct participant. Accordingly, it is no longer adequate to simply have knowledge of multicultural issues; the Clinical Ethicist must be skilled in cultural competence.

Training in cultural competence is now commonplace, particularly in healthcare[2] and is designed to address the specific pedagogical needs of its learners. We will outline a training module in cultural competence tailored to the unique needs of clinical ethicists for their work in consultation. This module will include components addressing formal knowledge acquisition, reflective practice, and strategies for life-long learning.

*Mercedes Martin & Billy Vaught (2007). "Strategic Diversity & Inclusion Management" magazine, pp. 31-36. DTUI Publications Division: San Francisco, CA.

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C14 Title: Spiritual Care Chaplaincy in Relation to Ethics: friend or foe?
Author(s): Philip D. Crowell
The recent Hastings Center Report (Nov-Dec 08) entitled "Can we measure good chaplaincy?" seeks to describe what modern spiritual care chaplaincy is doing and its intentions relative to healthcare and ethics services. This paper will examine these issues and cover a significant area neglected in these articles concerning consultation by looking at two cases. The first, dealing with a devote Sikh couple requiring "everything" be done for their "dying" newborn in the NICU, and the second case involving a Christian fundamentalist couple trying to decide if they will terminate a pregnancy after being informed by medical genetics that they have a baby with lethal anomalies.
This paper will look at the "ethics of responsibility" as a shared language for clinical ethicists and clinical spiritual care chaplains. I suggest that there are significant differences between the disciplines, however, chaplaincy is a friend to clinical ethics even though it approaches ethics in a different mode. For example, spiritual care in speaking the language of religion with religious patients and families is able to move toward a more appropriate patient center focus and opens up a space for the ethics conversation, since for the religiously devout the ethical is discovered in the religious beliefs. Margaret Urban Walker asserts that ethicists in the health care setting should be regarded less as expert engineers, than as skilled architects creating **"**moral space**"** within which healthcare people can air their bafflement and their convictions. Likewise, the spiritual care provider creates "a spiritual space" where the personal meaning of events can be explored as well as "moral space" for patients to express their doubts and beliefs.

C15 Title: Goals of Care Designations: Fundamental change in joint decision-making about care
Author(s): Eric Wasylenko
Important difficulties may arise as part of complex decision-making regarding care interventions, locations of care and general directions of care. These difficulties arise in any health care setting in Canada, and often result in need for ethics consultations or deliberation.
This paper addresses one of the root causes that results in impasse between providers and care recipients when determining courses of action, namely the language used, and focus on, Levels of Care, Do Not Resuscitate (DNR) Orders, and Code Levels.
The paper describes a novel approach, rooted in ethics principles, for decision-making and communication amongst provider teams and with patients and families. The product resulting from inclusive conversation is codified medical Orders called Goals of Care Designations. This language and process has replaced Code Levels and DNR Orders within our health system.
The confluence of expertise provided both by health care experts and by patients and their families results in a mutually agreed upon direction of care grounded in both physiologically appropriate and person appropriate interventions and care plans.
The new approach, which has just been implemented throughout all sectors of the Calgary Health Region, is expected to provide a fundamental shift in decision-making activity. This shift may provide a foundational pillar to assist resolution of the current Canadian conundrum surrounding the question "Who gets to decide?".

C16 Title: Ethical Issues Surrounding Alpha-Thalassemia in Pregnancy

Author(s): Susan Albersheim

In Canada, the fetus has no legal status, and the pregnant woman decides about any interventions on behalf of the fetus. Fetal interventions are increasing though outcome data may not yet be available. With some rare conditions, such as Alpha Thalassemia, with Hemoglobin Bart's Hydrops Fetalis, there is scant evidence that intrauterine transfusion will alter the fatal outcome. Yet, in one case, which we will describe, Haematologists advocated for fetal transfusions despite the skepticism of other specialists (e.g. Obstetricians, Neonatologists, Ethicists) involved, and the ambivalence of the parents. Several ethical issues were at stake:

(i) Is life with a severe chronic illness always in the best interest of a child?

(ii) When there are considerable attendant risks (e.g. due to the underlying conditions or fetal interventions; future ability for pregnancies; family burden caring for a child with chronic illness), can treatment be refused?

(iii) When physicians differ in their views about treatment, who should decide what treatment should be offered?

(iv) Is aggressively treating what is generally considered a lethal condition a reasonable use of resources?

(v) Is it reasonable to expect other children in the family to be transplant donors or to have another pregnancy for that purpose?

We conclude that when there is a lack of evidence about outcomes this should be considered innovative therapy. Due to scientific, ethical and legal concerns this requires undertaking a full consent process that delineates all potential adverse and unknown outcomes, and thorough medical scrutiny before any interventions are offered.

C17 Title: Ethical questions arising out of nursing care for women experiencing spontaneous and therapeutic abortions

Author(s): Anne Simmonds, Joanne Louis

Social discomfort persists around the issue of abortion and pregnancy loss. Underlying this discomfort is the philosophical debate regarding fetus-as-person. With advances in technology, the gap between the gestational age of viability and the time for second trimester terminations is closing. Although nurses are actively involved in the care of women undergoing spontaneous and therapeutic abortions, we rarely take the opportunity to consider our role in shaping societal discourse around abortion. In addition, we question the role that nurses play in structuring care in order to control the woman's experience and our own response.

In this presentation, we will use clinical examples from our experiences as nurses working in an abortion clinic and high risk antepartum unit to explore ethical issues that arise out of caring for women undergoing spontaneous and therapeutic abortions. We will also examine the implications for our clients and ourselves and society in general.

C18 Title: Ethical Care for Infants with Conditions not Curable with Intensive Care

Author(s): Bethan Everett, Susan Albersheim

One of neonatology's most contentious issues is the offering of intensive care and aggressive resuscitative measures for infants diagnosed as having conditions that carry extremely poor prognoses. Historically, even when parents have protested termination of intensive care, there has been consensus amongst neonatologists that resuscitation is not indicated when there is a diagnosis of an imminently lethal condition. However, unilateral decision-making by physicians has recently come under close scrutiny by regulatory bodies, the courts and bioethicists. The tension is to negotiate the provision of care based on best interests without usurping parents' general authority to make decisions for their children.

In this paper, by discussing the life and death of Baby Smith, we take up the questions of what is appropriate care for infants with imminently lethal conditions not curable with intensive care; and on what basis, at what processes should be in place to ensure that parents' decision-making authority remains intact and, at the same time, physicians maintain their moral integrity by not doing things that are against their conscience/

We conclude that once it is certain that an infant's diagnosis of a lethal condition will not permit life outside of intensive care, and the appropriate steps have been taken to work towards integrity-preserving moral compromise, it is morally justifiable for neonatologists to refuse to continue to impose intensive care and to ask society, through the courts, to join in these difficult decisions.

C19 Title: Ethical and social challenges in the field of deep brain stimulation: Perspectives from Canadian practitioners

Author(s): Emily Bell, Bruce Maxwell, Ghislaine Mathieu, Abbas Sadikot, Mary Pat McAndrews, Eric Racine

Background: Deep brain stimulation (DBS) is an approved neurosurgical intervention for motor disorders such as Parkinson's disease and essential tremor. DBS is an invasive and expensive procedure and there are emerging uses of DBS in psychiatry (e.g. depression) creating important ethical and social challenges needing further examination. We have explored Canadian healthcare provider perspectives of ethical and social issues in neurostimulation.

Methods: Healthcare providers working in Canadian DBS surgery programs were interviewed and completed questionnaires to identify and characterize ethical and social issues in neurostimulation for motor disorders and in its extension to psychiatric conditions.

Results: Issues such as managing patient expectations and psychosocial outcomes in patients are amongst key concerns expressed by providers. For example, providers emphasized the urgent need to convey realistic expectations of the potential of DBS surgery given contradictory public information "[The patients] have to know that this is not a cure for the disease, this is something that you are improving their care but you are not actually going to cure them". With respect to the second issue, providers warned about the complexity of managing psychosocial adjustment after surgery and its implications on personal identity, "(…) people have been used to a certain type of role, the sick role. And you more or less remove this from them and that could cause problem adapting to this new role". Other issues identified include resource allocation and public understanding. Our study shows the importance of addressing ethical issues in DBS proactively and collaboratively across neurosurgery programs.

C20: Canadian Medical Device Regulations: the Case of Deep Brain Stimulation (DBS)

Author(s): Ghislaine Mathieu, Eric Racine

Background: DBS is an approved and effective neurosurgical intervention for motor disorders such as Parkinson's disease. The literature shows promising results to extend DBS to other disorders (e.g., depression, epilepsy). Existing and emerging uses of DBS lead to ethical, legal, and social issues ranging from the management of patient expectations prior to surgery to personality and identity changes after surgery (Bell, Mathieu and Racine, under review). The policy and regulatory issues of DBS have not been well characterized and analyzed. Nonetheless, current practices suggest important challenges in matters of DBS device approval, such as clinical trial design, emission of patents, and off-label uses.

Methods: To provide a comprehensive overview of current and emerging policy and regulatory issues regarding DBS, we performed an extensive literature review of clinical trials and ethics discussion using PubMed, the USPTO database, the FDA and Health Canada regulations and report decisions, market studies, and business reports of key DBS manufacturers. We also use data from an ongoing Canadian qualitative study of healthcare providers involved in the care of neurostimulation patients.

Results and discussion: Our results suggest that there are important regulatory and policy gaps in matters of governmental oversight and regulatory approval. Once a medical device is approved, no further approval is necessary to use it in an off-label manner (Alpert, 2007). Also, further examination needs to be done about clinical trials and post-market surveillance, to ensure that DBS treatments be based both on science and balancing harms, benefits, and economic costs (Graham, 2008).

C21: Title: Reproductive Choice and the Ideals of Parenting

Author(s): Elisabeth Gedge

The expressivist argument against prenatal genetic diagnosis for disability (PGD) maintains that PGD constitutes an affront to persons with disabilities (Parens and Asch, 2000). When expressivism targets individual reproductive choice it is often judged implausible because reproductive choice is typically motivated by personal circumstances rather than political sentiments. However, in "Where is the sin in synecdoche?" (2005) Asch and Wasserman make a persuasive case for criticizing the individual choice to use PGD to determine disability. They argue that basing reproductive choice on a finding of disability is a case of synecdoche, "the uncritical reliance on a stigma-driven inference from a single feature to a whole future life." According to them, parenting is unique amongst intimate relationships. Whereas increased selectivity is appropriate when choosing a romantic partner, for instance, prospective parents should aspire to an ideal of "unconditional devotion" in keeping with, and conducive towards, the goods of family life.

Although Asch and Wasserman's argument supports the moral objection at the heart of expressivism, its valorizing of unconditional maternal love and its emphasis on the distinctiveness of the parental relationship is at odds with some important lines of feminist ethical reasoning. Amy Mullin (2006) has recently argued for the importance of analogizing parenting to friendship and of challenging the emphasis on the moral uniqueness of pregnancy. Likewise, Rebecca Kukla has shown how the idealization of the maternal figure in public discourse can politicize reproduction and jeopardize the personal goods of reproduction. In this paper I explore the tension between Asch and Wasserman's account of the ideals of parenting and feminist theoretical unease with the moral exclusivity of the reproductive role.

C22: DNRC: Why Unilateral Orders Won't Fly

Author(s): Peter Allatt, Andrea Frolic

In 2008 Ontario implemented the Do Not Resuscitate Confirmation Form (DNRC form), a vast improvement over earlier forms used exclusively for intra-facility transfer. The DNRC form, which applies everywhere, including in the community, ensures that paramedics and EMS will not initiate resuscitation for a patient in cardio-respiratory arrest. A patient with a DNRC form will be treated palliatively.

Physicians completing the form must choose between two conditions. The second is problematic.

The physician's current opinion is that CPR will almost certainly not benefit the patient and is not part of the plan of treatment and the physician has discussed this with the capable patient or the substitute decision-maker when the patient is incapable.

The authors will argue that this condition represents a unilateral order, untenable both ethically and logistically. They will present arguments for not using this condition in the prehospital setting.

C23: Rituals, Death, and the Moral Practice of Medical Futility

Author(s): Shan D. Mohammed, Elisabeth Peter

Medical futility is often defined as providing inappropriate treatments that will not improve disease prognosis, alleviate physiological symptoms, or prolong survival. This understanding of medical futility is problematic because it rests on the final outcome of procedures, which are often narrow and only medically defined. In this paper, Margaret Urban Walker's "expressive-collaborative" model of morality is used to examine how certain critical care interventions that are considered futile actually have broader social functions surrounding death and dying. By examining cardiopulmonary resuscitation (CPR) and technological procedures found in intensive care units (ICU) as moral practices, we show how so called futile interventions offer ritualistic benefit to patients, families, and healthcare providers, helping to facilitate the process of death and dying. As moral practices, CPR and ICU measures help mediate the problem of responsibility for death, dissipate the sense of ambiguity from the dying body, establish a social script for letting go, and realize a space for grieving. This work offers a new perspective on the ethical debate concerning medical futility and provides a means to explore how the social value of certain acute care treatments may be as important in determining futility as medical scientific criteria.

C24: End of Life Decision Making: Whose goals count?

Author(s): Neil M. Lazar

In Manitoba, according to the College of Physicians & Surgeons of Manitoba Statement No. 1602, life sustaining treatments should only be employed if a minimum goal of treatment is realistically achievable. Key outcomes used to judge 'realistically achievable' surround a focus on cerebral function such that the patient will not be left in a persistent vegetative state. In Ontario, common practice is to involve the patient or their surrogate in defining the value of these outcomes strictly from the patient's perspective. Two cases will be presented to illustrate the importance of incorporating patient values when developing a patient centred care plan. Factors that might lead to discounting patient values when defining goals will be explored. Effectively managing surge capacity has entered the literature as one example of when community interests should probably trump individual patient interests. Doctors risk losing the trust of their present and future patients if they put community interests ahead of their own patients' interests too quickly.

C25: How organ transplantation is represented in Quebec newspapers?

Author(s) *Andrée Duplantie, Claire Faucher, Dan Nicolau, Hubert Doucet, Marie-Chantal Fortin*

Background : News media are a key source of health information for the public. No study has examined how organ transplantation (OT) is depicted in the newspapers. Analysis of press coverage in transplantation will inform us on how public perceive OT. This better understanding of press media coverage can help transplant professionals to address expectations and misconceptions of patients seeking a transplant and open a dialogue with journalists and the public on OT.

Purpose : The aim of this study is to analyse Québec press coverage on OT.

Methods : Throughout Eureka database, we retrieved 948 newspaper articles published between January 1st 1995 and December 31 2008. These articles were published in 8 Québec daily newspapers.

Results : Our preliminary results show that the most cited organ transplantation was heart transplantation (51% of all articles). The keywords found more frequently were the following: life/human, death/dying, specialist/physician, certainty, research, success and hope. Only few articles dealt with technical and negative connotation keywords, such as organ allocation, immunosuppressive drugs, compliance and uncertainty. Further content analysis will be undertaken and presented

Conclusion : Our preliminary analysis shows that the most cited organ transplantation, i.e. heart transplantation, in Québec newspaper articles is the less performed. Also, it appears that the theme of OT success is more popular than failure in the Québec newspaper. This might contribute to a public idealization of transplantation.

C26: Ethical Issues in Organ Donation: Views of Recent Immigrants and Health Professionals

Author(s): Wendy Austin

Organ and tissue transplantations are increasingly considered the solution for a number of serious and life-threatening health conditions, resulting in a larger number of people who would benefit by a transplant. Key to the success of any transplantation program is not only the availability of organs and tissues donated for transplantation but also those donated for research. Faced with this evidence, many policymakers have grappled with how to best narrow the gap between available organs and potential recipients and researchers. To date, several Private Member's Bills have been recently proposed to address the donor shortage. Should these Bills be adopted, significant changes to the method of procuring organs and ensuring informed consent will result. Beyond the ethical issues that currently exist with organ donation, the proposed changes have the potential to create new ethical challenges for healthcare professionals working in this specialty area and potential donors alike.

This paper presents findings from a Canadian pilot-project that explored ethical issues in organ donation as perceived by recent immigrants and healthcare professionals. The findings from three groups of recent immigrants to Canada (African-Francophonie, Mandarin-speaking Chinese, and Spanish-speaking Latin Americans), as well as health professionals working in the area of organ procurement, will be presented.

C27: Reducing the Weight Given to Family Distress in Organ Donation Decision-Making

Author(s): Robert L. Muhlnickel

In several countries, standing policies give family members the authority to decide whether to donate the organs. Family members are given this authority when the dead person has not indicated a preference about organ donation and, in the U. S., family members are given the authority to refuse organ donation when the dead person has communicated a preference for donation.

One of the most frequently cited reasons for giving family members this authority is that family members experience distress at the loss of a loved one, and refusing to comply with the family members' preferences would increase their distress. Family members' distress is considered a reason for a moral policy: family members' distress is judged to outweigh the benefit to potential recipients of donated organs. This judgment reflects the intuitive view that distress at the loss of a family member is severely harmful to those experiencing the distress, and that the severity of the harm justifies complying with the family members' preference despite the deaths and decreased quality of life of potential transplant recipients.

This paper reviews recent empirical research on grief after the loss of a loved one that challenges the intuitive view that grieving is a severe harm to the griever. Empirical studies of classify grief responses as *common*, consisting of an intense response of several months followed by recovery of pre-loss emotional and psychological state; *resilient*, in which the griever maintains relatively stable patterns of emotional state and social functioning, and *complicated*, in which the griever experiences clinically significant depressive responses for at least six months.

The empirical literature on grieving shows that for most grievers, the distress that accompanies the loss of a loved one is relatively short in duration and is less emotionally and functionally disruptive than in the intuitive view. Relatively shorter duration and lower levels of emotional and functional disruption indicate that grieving is less harmful to the griever than the intuitive view suggests.

The implication for moral policy regarding organ donation is that we should give less weight to the putative distress of family members. If the harm to family members is actually less than the intuitive view suggests and the benefit to transplant recipients is much longer-lasting then there is less reason to comply with family members' preferences regarding organ donation than is usually believed.

C28: A Philosophy of Technology Perspective on James Rachels' Attack on The Distinction between Killing and Letting Die

Author(s): *James Gerrie*

Influential American ethicist James Rachels has argued that since both removing life-sustaining treatment and physician assisted suicide aim at the same end, hastening death to limit suffering, there is no critical ethical distinction between them. This conclusion can only be drawn by ignoring the recent work of philosophers of technology on what is known as the non-neutrality thesis and the wealth of data on the complex social impacts of technologies that twenty years of the growing field of history and sociology of technology have discovered. According to the non-neutrality thesis, any act requiring the use of a technology will inevitably contribute to the creation of some negative social or environmental effects that cannot be separated from the good effects sought in that technology's ordinary use. This thesis has led the supporters of what has come to be called the Science and Technology Studies (STS) movement to advocate for two specific ethical obligations regarding ethical decision-making involving the use of technologies. First, we have an obligation to consider and support careful empirical investigation of the social and environmental impacts of our choices to use specific technologies. Second, we must include in our analysis at least a preliminary consideration of possible impacts based on what we have already learned about the effects of relevantly similar technologies. My paper will explain in more detail the recent discussions around and defenses of the non-neutrality thesis and these two proposed moral obligations and show how Rachels' defense of physician assisted suicide ignores these obligations.

C29: Where Angels Fear to Tread; Proxy Consent and Novel Technologies

Author(s): *Monique Lanoix*

The bleak prognosis for individuals suffering from severe disorders of consciousness (DOC) has resulted in the therapeutic neglect of such patients according to Fins (2003). Some physicians and researchers take the study of DOC to be a moral imperative (Schiff, 2005) and perceive novel technologies, such as Deep Brain Stimulation (DBS), as offering potential therapeutic benefit. However, in their study of the law and ethics of research and treatment of severe traumatic brain injuries, Tovino and Winslade (2005) conclude that until physicians can predict research outcomes and convey these predictions to surrogates, patients with DOC will continue to be at risk of therapeutic failures.

In this paper, I discuss the risk of therapeutic illusion (Thomas, 1978) in the context of DBS for surrogates of individuals with severe DOC. It is usually agreed that surrogates may fall victim to therapeutic illusion because of their lack of understanding of the scientific evidence in addition to their emotional attachment to the patient. Therefore, efforts are directed at improving the transfer of knowledge from physicians and researchers to surrogates. However, I make the case that therapeutic illusion is also informed by the burden of on-going care for the patient which surrogates must face, and that physicians and researchers often fail to apprehend the implications of this on-going care for surrogates. Instead of focusing consent solely on knowledge transfer, I put forward that an ethic of responsibility (Walker, 1998) captures more comprehensively the hazards facing surrogates and can provide sustained support for the decisional process.

C30: Posthumans and Present Evidence: Exploring Future Enhancement

Author(s): Jason Marsh

Many bioethicists interested in the ethics of human enhancement have turned their attention to future bio-technologies – including radical forms of cognitive enhancement (genetically selecting the IQ and impulse control levels of children) and life extension (substantial life increases). Although there are many ways in which we currently enhance ourselves, these bioethicists suspect that human biology may soon be fundamentally transformed as to render us posthuman.

Naturally, there are sceptics and those who would simply have us focus on present research. So what is the evidence for the claim – call it imminence – that such technologies may be soon upon us? The answer is typically taken to be two-fold: first, we have positive empirical grounds for thinking that fairly radical technologies could easily emerge in the next ten to thirty years; second, we have inductive grounds for thinking technologies which seem farfetched are often just around the corner.

My task is to evaluate these claim, and whether they are sufficient to justify a growing body of ethical literature on future enhancement issues. My conclusion is that although neither claim is (presently) up to the task of justifying imminence, two other overlooked factors can justify philosophical work on these topics: the first has to do with relationship between scientific research and ethics; the second has to do with transhumanism, big picture ethics and epistemic modality.

C34: Aggressive Discharge Planning

Author(s): Alister Browne

In any health care system in which demand exceeds supply—which means any typical public health care system—patients cannot always get the care they want or need when they want or need it. It is also unrealistic to suppose that it will ever be otherwise. But if sub-optimal care is to be our destiny, we must plan how it is to be delivered. Such planning has already taken place at the admission and treatment stages of health care, where wait lists, triage, and rationing are standard fare, and I contend that similar planning should go into the discharge phase. Public health systems commonly have large wait lists for admission that are accompanied by an undesirable level of mortality, morbidity, and discomfort. To lower this level, patients must be admitted more rapidly. But if the capacity of hospitals cannot be expanded, this can only be done by increasing (as the current word is) "throughput," and that means that patients in hospital have to be discharged more quickly. It is becoming common for hospitals to discharge patients to "alternative levels of care." I will argue that if hospitals can further reduce overall morbidity, mortality, and discomfort by discharging patients to inferior levels of care, they should do so. Hospitals will not have a comprehensive plan for the delivery of sub-optimal care until such aggressive discharge policies are in place, and unless hospitals have such a comprehensive plan, they will not provide patients with the very best care resources will allow.

C35: Developing an Island Wide Clinical Ethics Program : Evidence and Reality

Author(s): Veronica Morris, Janet Storch, Bernadette Pauly

Evidence of the need for clinical ethics support has been identified in health care ethics research, in organizational standards and by health care practitioners. There are a growing number of potential models for the development of clinical ethics programs with variations on the biomedical expert model. However, there is limited evidence available about best approaches and practices as to design and delivery of clinical ethics programs. In this presentation, we will outline the development and implementation of a Vancouver Island Wide clinical ethics program that prepared and engaged 20 peer based ethics resource people to provide ethics consultation throughout the Vancouver Island Health Authority in British Columbia. The program was developed through a unique health authority- university partnership and was based on an understanding of ethics as integral to everyday practice, a pragmatic approach to integration of ethical theory and the development of practical wisdom in ethics consultation. The program was launched in August 2008 and preliminary evaluation data will be presented to illustrate the initial successes and ongoing challenges in developing and sustaining this clinical ethics program. Considerations and recommendations for the development of clinical ethics programs nationally will be discussed.

C36: The Murky Intersection between Clinical & Organizational Ethics : a Hybrid Case Taxonomy

Author(s): *Sally Bean*

The current trend categorizes ethical challenges as clinical or organizational based on the type of issue. Despite this common issue-based methodology, empirical studies demonstrate that no clear line can easily be delineated between clinical and organizational ethics. Technological innovations in end-of-life treatments, for example, often spawn value differences amongst parties at both levels, thereby complicating an already classically difficult issue in health care. I refer to issues that contain elements of both clinical and organizational issues as *hybrids* and propose a new taxonomy to characterize hybrid cases. The primary goals are to 1) systematize thinking about the origin, scope, and context of ethical issues and 2) identify a prioritization process such the content of the ethical challenge drives the process instead of the traditional binary issue-based choice which fails to capture the complexity of hybrid situations.

C37: **Public Engagement: a vehicle to enhance justice in wait list management**

Author(s): Rebecca Bruni

Background: Scholars and government reports have argued there is a need for public input to enhance justice in priority setting (ps). Typically the public do not have a direct role in ps, but we know public engagement can enhance the procedural justice and the legitimacy& fairness of ps. This study focuses on public engagement in a key ps context that plagues every health system around the world: wait list management.
Objective: To determine why, how & where to involve the public in a wait list ps initiative.
Methods: Three studies were conducted:1) a case study to describe and evaluate ps of the Ontario Wait Time Strategy (OWTS); ps was evaluated using 'accountability for reasonableness'; 2) telephone interviews with a population of Ontarians to describe views on public involvement, ps and the OWTS; 3) synthesis and analysis of public emails sent to the OWTS email address.
Results: Interviews with OWTS officials reveal minimal involvement of the public. Stakeholders propose there is opportunity to involve the public in OWTS ps. Interviews with citizens and email analysis suggest support for public engagement in OWTS ps. The public can be involved through:1) shared decision making, 2) the communication strategy, and 3) feedback/appeals.
Conclusion: There is ample opportunity to involve the public in a wait list strategy. Increased public engagement in the OWTS will enhance the procedural justice, the legitimacy and fairness of the strategy.

C38: The Ethics of Autism : responding to Barnbaum and colleagues

Author(s): Barbara Russell

Autism is generally recognized as a seriously impairing mental disorder or condition. Effective and/or short-term therapies remain elusive. The significant personal and financial burden of providing multidimensional, developmental care has prompted some groups of parents to sue provincial health plans on the basis of contravening the Canadian Charter of Rights and Freedoms. To date, however, no court has ruled that the lack of provincial reimbursement qualifies as indefensible discrimination.
In newly published The Ethics of Autism (2009), Barnbaum and colleagues argue provocatively in favour of the concept of "autistic integrity." Conclusions flowing from this concept include the claim that alleviating autism, developing preventive diagnostic measures, and offering remedial treatments are not as mandatory as currently held. This paper begins with an explanation of the evidence offered for creating such a concept. The consequences of this concept for those with this diagnosis, their parents, and healthcare providers will then be explored. Finally, the evidence will be critiqued in terms of whether it is theoretically sound or not and the implications that follow from this critique.

C39: Health Care Justice Debate: May a hybrid view be the answer ?

Author(s): *Gilbert, F., Hurst, S.,*

Equity has a large importance in the health care system discussion. Despite the fact that equity is a key concern, there might not necessarily be a unique justifiable theory of justice used by physicians. Which philosophical position of equity is right for physicians in the allocation of health care resources debate? The normative philosophical literature suggests four traditional approaches to resolve the equity's dilemma: 1) Desertism 2) Egalitarianism, 3) Prioritarianism, 4) Sufficientism. However, newly arrived in the debate, and empirically support by previous research, a hybrid concept of equity that mix the four traditional views seem to be employing by physicians while justifying their decisions in the context of limited resources. Such a concept may, on the face of it, seem too complex to be applied in clinical care. However, empirical data suggest that physicians do indeed use a hybrid concept of equity when making allocation decisions.

The purpose of this paper is to complete the normative literature of the four major philosophical conceptions of distributive justice by examining whether a hybrid view can be considered theoretically robust, and whether it may help physicians in their practice. The paper uses a neuroethical dilemma to analyse the normative literature.

C40: "Evidence-based ethics": An examination of conceptual problems and implications

Author(s): *Rose Geransar, Glenys Godlovitch, Brian Forzley, Allen Dong, Anna Zadunayski*

It has become commonplace to cite evidence as critical to applied ethics. In recent years, there has been an increasing push for evidence in the health-policy contexts, particularly when considering governance approaches for newly emerging or evolving technologies. This has been framed pragmatically as an example of "evidence-based ethics" (hereon, "EBE"). However, the concept and meaning of "EBE" has received little analysis and the phrase is often used in ways that indicate misunderstandings regarding the nature of the normative decision-making process and the structure of ethical arguments. For example, the application of "EBE" often blurs the distinction among normative, applied and descriptive ethics. Arguably, appeal to evidence also frequently commits the naturalistic fallacy and presupposes a hard fact-value distinction. Little attention has been paid to the philosophical literature in examining this concept. In the first part of this paper, we explore the concept of evidence and the epistemic role that it is thought to play by those who advocate for "EBE" approaches. In doing so, we use examples from the philosophical literature to highlight the key role of human values in the production, selection and interpretation of evidence. In the second part of the paper, we argue that ill-considered and/ or mere reliance on "evidence" in policy contexts in the interests of transparency and accountability paradoxically undermines and obscures the normative premises that are necessarily parts of the policy making process, and in that respect fails to meet the goals of transparency and public accountability in this context.

C41: Technology and clinical judgement in evidence-based medicine

Author(s): *Isabelle Chouinard; Glenys Godlovitch*

It can be argued, in principle, that the practice of evidence-based medicine (EBM) is ethical in that it provides the foundation for a health care system that provides standardised care to all patients. Practiced as it was intended, EBM not only relies on current evidence but it takes into account clinical judgement and patient preferences. Several factors, including the focus on what constitutes appropriate evidence, has resulted in a shift where evidence is now the central component of EBM and where clinical judgement and patient preferences have lesser authority in medical decision-making.

The most recent developments in EBM practices further threaten the fragile balance among its three components. An often-cited criticism of EBM involving the absence of guidance on how to incorporate research findings into clinical practice is being addressed through what are considered improvements to clinical practice: sophisticated computerised order-entry systems. Such systems rely on clinical prediction rules that guide clinicians through diagnostic critical pathways based on the latest and most recently available research evidence. In this context, clinicians are no longer required to keep up to date with research evidence, nor are they required to be able to interpret these research findings. Effectively, improvements of this type are leading to the gradual extinction of the role of clinical judgement in medical practice.

This paper will examine the ethical impact of the most recent movements in EBM, particularly technological advances that are viewed as an improvement to clinical practice, and their effects on patient care.

C42: The Ethics of the Free-Rider: Are They Really Riding for Free?

Author(s): **Talene Thomsian**

The “free-rider” problem occurs when some agents do not bear a fair portion of the risks or sacrifices necessary to obtain group benefits; the free-rider benefits at the expense of others in the group. A notable medical example deals with vaccinations for communicable diseases. Agents who do not vaccinate themselves (or alternatively their families) gain the benefits of living relatively risk-free, if the group as a whole remains disease free, without taking the small, but real, risks associated with vaccinations. This occurs once the group has achieved “herd immunity:” once a certain percentage of the population is disease free, its spread is essentially stopped. There exist, however, many reasons why people abstain from vaccinations, and some cite doubt about their effectiveness, or unacceptability of risk. This paper will first explore the moral implications of the free rider problem along the gradient of those who deny to those who defend the effectiveness and necessity of vaccinations. Second, it will explore the struggles to reconcile competing evidence - to even assess the moral implications of the free rider problem assumes that there are real benefits. This presents a unique case in regards to coercion, since in the free-rider situation, agents inevitably gain benefits; from the point of view of proponents, it creates an unfair advantage. This added dimension is important, for it makes central the assessment of agents’ reasoning. In contentious situations, such as when a new disease threatens the population, the morality associated with vaccination depends on whose evidence counts.

C43: Ethics Review of Minimal risk and multisite qualitative studies: perspectives from two Canadian studies and the new Tri-Council Policy statement

Author(s): *Constance Deslauriers, Emily Bell, Nicole Palmour and Eric Racine*
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According to the 1998 and 2008 Tri-Council Policy Statement (TCPS) all research involving human subjects requires review by a Research Ethics Board (REB). Both versions of the TCPS adopt a proportionate approach to ethics review capturing the principle that "as the risk to participants increases, so should the level of scrutiny in assessing the research and the level of expertise involved in the review process" (TCPS, 2008). Both versions also emphasize the responsibility of each institution for REB review for multi-jurisdictional research. Many have already drawn attention to the complexity, variations and inconsistencies in requirements for application and approval by different REBs, which create important practical, legal, and ethical challenges for investigators. We draw on our experience with two recent multisite Canadian qualitative studies to illustrate some of these important challenges. The first study required 15 REB submissions investigated the REB process for Canadian neuroimaging research based on interviews and an online questionnaire. The second study required 7 REB submissions and examined through interviews and a questionnaire, ethical and social issues that neurosurgical teams face with the use of neurostimulation devices. We report substantial differences in: approval decisions, requirements for informed consent forms, delays, expectations regarding local principal investigators, and specific challenges for the evaluation of minimal risk qualitative research. Our experience supports both from a scientific and ethical standpoint the need to move beyond the model of "independent review by several single REBs" to other models identified in the 2008 TCPS such as multi-institutional REBs and reciprocal REB review.

C44: Social Justice in the Clinical Context: Using Charter Rights as a Framework for Healthcare Priority Setting

Author(s): *David Vitale and Randi Zlotnik-Shaul*

This presentation will address the social justice tradeoff between equity and efficiency in the allocation of scarce resources, with an innovative twist – it will include a normative framework grounded in the values of the Canadian Charter of Rights and Freedoms and constitutional jurisprudence to assist healthcare decision-makers in the allocation of healthcare resources.

Resource allocation and/or priority setting continues to be a highly debated issue in health policy and health-related research. As evidenced by the 2008 "Paediatric Surgical Wait Times" recorded by the Ministry of Health and Long-Term Care, wait times alone can have devastating consequences for those unable to access needed resources and services in a timely fashion. Moreover, public demand/need for treatment often exceeds available resources. As such, healthcare decision-makers are frequently faced with complex prioritization choices.

Research in this area clearly establishes a range of social values prioritized by Canadians. Questions remain as to (1) how we should determine which social values, in addition to cost-effectiveness, should inform allocation and prioritization decisions; and (2) how we should balance these social values against cost-effectiveness?

These questions will be addressed drawing insights from the values entrenched in Canadian constitutional law. Specifically, we will present and actively engage with the audience on analysis related to equality (s. 15) under the Charter as well as analysis related to the balancing of competing values under s.1. This presentation will provide a social justice analysis for application as a framework in the clinical health care context.

C45: A Closer Look at Contract Research Organizations (CROs) in the Canadian Context

Author(s): *Nina Preto*

Over the past 10-15 years, academic health centers (AHCs) have lost a significant percentage of their industry funded clinical studies to commercial contract research organizations (CROs). CenterWatch, a key source of data and statistics on the pharmaceutical industry, suggests that while AHCs held roughly 63% of industry sponsored clinical projects in 1994, this had fallen to a mere 23% by 2006 with independent community-based CROs capturing the remaining 77%. Despite their key role in this major shift towards the commercialization of clinical trials, there has been little focus on CROs in the academic literature. Based on an extensive review of the relevant industry and medical literatures, as well as the limited broader academic literature on CROs, this paper describes these organizations that have emerged to meet the needs of the pharmaceutical industry and now dominate the outsourcing market. The relationship between CROs and industry sponsors, which in some cases is transitioning away from a contractual approach towards a partnership model, is also discussed. In addition, some of the key ethical challenges associated with the move of clinical trials out of the academic setting and into the community are also canvassed. These include, among others, questions related to the role and use of private research ethics boards and the often limited training in research and research ethics of private practice physicians and their staff who conduct trials in the community based investigative sites. This discussion is set against an overview of the regulatory context within which CROs function in Canada.

C46: Entitlement and implantation; resistance and expectation – reflections on biomaterials, disability, and social norms

Author(s): *Kevin Reel*

Following on from a request to introduce bioethics to undergraduate engineering students, the author himself was introduced to the field of biomaterials – one in which ongoing development has made possible technologies for restoring or improving the functional performance of many people with disabilities arising from illness, injury or aging.

This paper presents some reflections arising from the teaching encounter, considers the nature of biomaterials, elaborates a variety of the ethical issues they present, and explores the pressure felt by some to avail themselves of the interventions made possible through these materials to ‘correct’ disabilities.

An examination of example cases where individuals have embraced or rejected bioengineered technological intervention potentially offers some support to the ‘social model’ of disability – highlighting the extent to which we all depend on engineered environments and ubiquitous assistive devices to function in our daily lives.

The reflection concludes with its application to better understanding the refusal by some people of certain healthcare interventions that might be seen by their health care team to be in their ‘best interests’.

C47: Scientists' and regulators' perspectives on the ethical issues of stem cell research

Author(s): *Holly Longstaff, Michael McDonald, Nina Preto, Darquise Lafreniere, and Cathy Schuppli*

This paper discusses the methods and preliminary results of research currently underway at the University of British Columbia's W. Maurice Young Centre for Applied Ethics (CAE). The study is part of a larger Canadian Stem Cell Network (SCN) project entitled "The Stem Cell Research Environment: Drawing the Evidence and Experience Together".

The overall objectives of this study are to (1) identify the main ethical issues associated with stem cell research and (2) develop a web based ethics education module for the stem cell research community. We have introduced an ethics user-oriented "needs assessment" to accomplish these goals. This assessment includes focus groups and interviews with stem cell researchers and trainees, REB members, and others. The SCN community will also be invited to participate in a novel NERD web survey (developed at CAE) to confirm assessment findings.

Preliminary results indicate that scientific SCN members come to the field with limited ethics training and receive little ethics education on the job. They are deeply concerned about public misperceptions of science and the potential harm that ethics rules may have on human subjects and animals. Most agree that stem cell research is of special concern to many because of its powerful potential and promise. Many call for a more holistic understanding of the ELSI context as well as more transparency, consistency, and efficiency in the ethics review process. While emphasis on certain ethics related topics varied across groups, participants agreed on the importance of research ethics for all areas of stem cell research.

C48: Meanings and Understandings of Language Used in Researching Evidence for a Genetic Basis of a Clinical Condition

Author(s): *Justin Morgenstern and Jeff Nisker*

Meanings of researchers and understandings of potential research participants regarding language used in looking for evidence of a genetic basis for clinical conditions may differ, as terms used in genetics research are not commonly employed outside of genetics and genetic concepts are often complex. A gap between these meanings and understandings would threaten both the informed choice process and the validity of the research findings (i.e. if demographic data or survey responses were inaccurate). This study explores language as it relates to informed consent in research documents of CIHR and Genome Canada funded human genomics projects, including information letters, consent forms and grant applications. Qualitative content analysis was performed supported by the analysis NVivo7™ software. The major themes that emerged were: A) complexity and variability in the description of genetic phenomena; B) novel and intricate portrayals of family; C) language of new classes of illness; D) combinations of previously distinct concepts; E) unintentionally pejorative language; F) personification of genetic concepts; G) need for and use of definitions and explanations; and H) our inability to maintain the authenticity of qualitative data and present it anonymously. Woven through these overarching themes were themes related to language that may confuse and language that may cause harm. Through examples from the informed choice documents, this paper will present how these themes emerged and explore how discrepancies in meanings and understandings influence both informed choice and valid research.

C49: Citizens' Perspectives on Pandemic Influenza in Canada: Findings from the CanPREP Collaboratory

Author(s): *Ross E.G. Upshur on behalf of the CanPREP Team*

Infectious disease outbreaks such as the SARS crisis and pandemic influenza raise a host of complex ethical questions. What are the obligations of healthcare providers in a pandemic and what are the reciprocal obligations of the healthcare system to healthcare providers? How should limited resources be allocated in a pandemic? And how should information be communicated to the public during a pandemic and who should lead the public dialogue? The answers to these questions will have significant implications for the building and maintenance of public trust, for the process of public engagement, and for the protection of persons with special needs.

To date, the pandemic plans that have been developed largely reflect the views of policymakers, administrators, and health professionals. What are the views of the Canadian public on these ethical issues? There has been very little public engagement. To address this knowledge gap, we assembled a multi-disciplinary team that includes citizen groups as well as health researchers, practicing clinicians, policy developers, program administrators, research users, professional associations, and regulatory bodies.

The CanPREP team has conducted a national survey and townhall meetings across Canada. Our objective was to elicit public perspectives on: a) the goals of pandemic planning, and b) key pandemic planning issues such as healthcare providers' duty to care, resource allocation, the use of restrictive measures, and Canada's role in a global outbreak. In this presentation, we report key findings of our national study and discuss the implications for the complex ethical questions currently posed by pandemic influenza.

C50: The Social Justness of Insite: Insight into Insight from a Public Health Ethics Perspective

Author(s): *Pam Kolopack*

Insite is North America's first legally sanctioned medically supervised safe injection site. Insite provides persons who use illicit injection drugs with sterilized injection equipment as well as physical space to allow them to inject their own pre-obtained drugs under nursing supervision. Located in Vancouver's Downtown Eastside (DTES), Insite was established as a public health initiative primarily in response to the DTES' escalating incidence of HIV/AIDS. Recent estimates suggest that more than one-third of the DTES' 16 000 residents use injection drugs among whom 30-40% are also HIV positive—an HIV incidence considered "explosive" as it is comparable to what is found in many developing countries.

Since opening its doors in September 2003, Insite has operated at near capacity and its services have been accessed by more than 8000 unique individuals; however, its existence is currently at stake. This spring, Stephen Harper's Government will appeal last year's British Columbia Supreme Court decision granting Insite the right to "remain open indefinitely". The federal government, who holds the authority to allow Insite to operate legally, no longer intends to permit harm reduction initiatives, like Insite, that do not require persons to stop or reduce their use of injection drugs. Should Insite be allowed to operate indefinitely? In this paper I will explore the ethicality of Insite from a public health ethics perspective, in particular from the perspective of Baylis, Kenny and Sherwin's recently articulated relational approach to public health ethics, an approach that includes considerations concerning relational autonomy, social justice and relational solidarity.

C51: The Limitations of Public Engagement in Canadian Policy-Making Regarding Assisted Reproductive Technologies

Author(s): *Elise Smith*

The policy-making process for Assisted Reproductive Technologies (ART) in Canada, going back to the Royal Commission in 1993, has been officially grounded (and justified) through the use of public consultations, including opinion surveys, consensus conferences, and ultimately interest group and public commentary on draft policies. The resulting legislation, the Canadian Assisted Human Reproduction Act (2004), prohibits certain activities, notably human cloning and the commercialization of gametes. It also establishes a regulatory body responsible for licensing and inspection of ART procedures and related research. The literature in bioethics recognizes public engagement as a legitimate (even ideal) democratic instrument of policy-making. Canadian policy-makers have thus claimed that ART regulations are justified or in keeping with a 'public consensus' on 'socially unacceptable' practices. However, this claim is tenuous at best since policy opinions of both the key stakeholders and the lay public are diverse and fluctuate over time. This presentation analyzes the use of public engagement in the Canadian policy-making environment and tests the claim that policy-makers achieved 'public consensus' in 2004. First, I explore the theoretical rationale behind public engagement, and more precisely the move from the expert-driven model of policy-making to public engagement in Canadian health and science policy-making; then, I examine the policy context of ART in Canada that gave impetus to a focus on public involvement. Finally, I conclude with a short critique of the effectiveness of public engagement efforts and point out their limitations in achieving the ideal of 'public consensus' regarding the Assisted Human Reproduction Act.

C52: Learning from patient: A case study of non compliance in patients with HIV associated Tuberculosis

Author(s): *Katherine Duckworth & Elizabeth Oduwo*

HIV/AIDS associated Tuberculosis is a challenging illness for patients and the healthcare teams involved because patient autonomy will collide with the very strict treatment guidelines laid out by health authorities for the treatment of Tuberculosis and for HIV/AIDS. Patients who require healthcare for HIV/AIDS associated Tuberculosis often come from marginalized groups. Standard practices in healthcare may push marginalized groups further to the periphery. In this paper, we discuss the case of Jarry, a patient with HIV associated Tuberculosis. He is a self sufficient 23 year old young man with an immigrant background. Jarry was diagnosed with HIV in his early teens and has been on Highly Active Antiretroviral Therapy for 8 years, consistently following his treatment plan. After a diagnosis of Tuberculosis, he was quarantined in hospital to remain there for at least 4 months. Unfortunately, he is not responding to HAART and it is unlikely he will recover. Jarry does not want to be in hospital and wishes to self administer his medication at home. The healthcare team has labeled Jarry a "non-complaint" patient advising and informed him of the consequences. Yet, they are emphatic to his situation and have always offered him compassionate care working hard to preserve his autonomy. Through Jarry's case study, we learn how healthcare practices may push individual cases to the margins of healthcare. We take the evidence in our discussion to inform our healthcare practice and to develop an alternative but median model for care that is inclusive towards marginalized groups.

C53: Evidence-based assessments of competency

Author(s): *William Harvey*

To date there have been no philosophically and ethically acceptable analyses of assessments of mental competency. The concept of mental competence as analyzed in the current literature is faulty, primarily because the analyses fail to accommodate the normative ethical nature of the concept and thereby the normative nature of assessments of competency. Hence, it is not surprising that an evidence-based analysis of competency assessments must fail insofar as the evidence presented for the determination of the conclusion is purely empirical. The ”categorial gap” between empirical statements and normative nature of competency determinations of mental competency is seldom recognized, much less crossed successfully. When the gap is recognized, the ethical basis provided is ethically unacceptable. In result, appeals to evidence-based assessments of mental competency are either confused or misleading.

C54: Competence, Paternalism and Risk

Author(s): Ian Wilks

Articulating standards of mental competence for medical decision-making has been a long-time subject of debate. One major area of disagreement is whether considerations of risk are relevant to this enterprise. Should a higher-risk medical decision require higher level of ability in the decision-maker? There is a concern that an affirmative answer will encourage paternalistic approaches to the notion of mental competence.

In this paper I support an affirmative answer against that concern. I emphasize the need to be clear about the *kind* of account we are offering for the notion of mental competence. (i) Say we are simply trying to provide an account which aligns well with our intuitive notion of competence. In that case, I argue, it is clear that considerations of risk are quite relevant to that notion. (ii) But on the other hand, say we are actually trying to stipulate the sort of account which will serve the needs of public policy in this area, even if the account does not align perfectly well with our intuitive notion of competence. In that case everything depends on how we style the account. It is possible to exclude considerations of risk and still evolve a paternalistic approach to competence. It is also possible to include such considerations and nonetheless evolve a safely non-paternalistic account. I pursue this latter possibility. I propose an account of competence which incorporates considerations of risk, and yet is free of paternalistic bias.

C55: Ethical issues in the treatment of bariatric patients

Author(s): *Peter Allatt and Kathy Carlin*

Health Canada has cautioned that the number of overweight and obese (bariatric) Canadians has dramatically increased over the past 25 years. WHO has a moniker for this epidemic: globesity. Globally, there are more than 1 billion overweight adults; of these, at least 300 million are obese. The risk of developing chronic disease, including type 2 diabetes, cardiovascular disease, hypertension and stroke, and certain forms of cancer is increased for those who are overweight or obese.

The majority of the literature on care for bariatric patients focuses on treatment regimens. Nursing literature addresses patient dignity and staff sensitivity. There is very little literature on other ethical issues.

This presentation will outline ethical issues raised in the care of bariatric patients. Special attention will be paid to concerns of justice. Issues to be discussed will include risk to healthcare providers, risk to patients, patient workload, access to equipment and services, and rationing of health care resources.

As the patient population becomes heavier, justice questions become more complex. Do bariatric patients have the same access to treatment as others? Do hospitals have an obligation to purchase special equipment for bariatric patients? Do hospitals have a right to refuse patients who exceed the weight limit on specialized equipment, such as CT and MRI scanners? Should all bariatric patients be treated in specialized hospitals? Should hospitals treating bariatric patients be allocated greater funding? Does and should the perception of the obese as having 'caused' their own problems have a role in determining their access to treatment?

C56: Defining physiological mechanisms and policy responses for social injustice and health inequalities

Author(s): *Jason Behrmann, Robert-Paul Juster*

Within numerous developed countries, population health measures have stagnated due to the emergence of health inequalities between socio-economic classes. The political philosopher, Norman Daniels, argues that one strategy to counter this stagnation in population health resides in 'flattening' the gradient between socio-economic classes, such as by the enactment of policies that promote equity through social justice. This presentation supports Daniels' theory by demonstrating a physiological link between social justice and health by merging his theory with allostatic load (AL) biomedical research. This presentation will also demonstrate that by quantifying AL, decision-makers can obtain methods to evaluate the efficacy of policies that promote social justice in terms of benefit in public health initiatives.

Allostasis refers to adaptive biological responses to acute environmental stressors (e.g., increased arousal when aggressed). Prolonged activation exerts strain, or AL, on these same systems via maladaptive recalibrations (e.g., hypertension) that increase susceptibility to various disease states. Conditions of chronic stress, such as socio-economic deprivation and social exclusion, concordantly increase in prevalence as one proceeds down the socio-economic ladder. This trajectory embedded within social inequalities is measurable using multiple allostasis biomarkers predictive of adverse health outcomes. By triangulating knowledge of health inequalities, social justice, and allostasis, this research provides further evidence that promoting social justice can improve population health. Furthermore, the tentative ability to minimize AL by interventions such as poverty alleviation, suggest that measuring AL at the population level could be a means to assess and prioritize public health policies that promote social justice and improve health.

C57: Permission to Override Patients' Wishes

Author(s): *Eldon Soifer*

Professionals in different aspects of health care seem to have differing degrees of permission to override the patient's wishes (or those of the substitute decision-maker). For example, even in cases in which the patient wants "everything done," surgeons may be allowed to refuse surgery on the basis that the patient is "not a good candidate." This may leave doctors in the non-surgical unit in the frustrating position of being required to treat the patient's symptoms aggressively, out of deference to the patient's wishes, even though they may believe that, in the absence of treatment of the underlying condition, such treatment will be of no real benefit to the patient. In this paper, I will argue that the surgeons' permission to refuse surgery may derive in part from underlying assumptions that are in need of more careful examination. For example, it might derive from a worry that surgery might kill, coupled with the problematic assumption that killing is significantly worse than letting die, or from some questionable assumptions about what makes a given treatment "futile". I will show how careful consideration of these underlying assumptions could point to a need for changes in the differing degrees of permission to override patients' wishes.

C58: Social Justice and International Medical Travel for Reproductive Health Care

Author(s): *Gillian K. D. Crozier*

International medical travel – defined as (prospective) patients crossing international borders to seek medical goods or services – is on the increase around the globe. This trend highlights important questions about global justice and economic development, with particular concern for equitable access to health care. But in many discussions regarding the legitimacy of various instances of international medical travel, debate tends to focus narrowly on economic questions about how to maximize access and otherwise optimize the allocation of scarce medical resources. (Consider, for example, recent discussions about the ethics of buying and selling kidneys and liver lobes.) However, even if sufficient observational support were available to resolve these empirical debates, other under-explored ethical questions remain. Specifically, more attention needs to be paid to the ways in which international medical travel entrenches or alleviates additional, more subtle, barriers to equality for various marginalized groups in both the 'source' and the 'destination' countries. This paper expands upon work done for the World Health Organization's Department of Ethics, Equity, Trade and Human Rights on the ethical dimensions of international medical travel. In particular, it critically examines the ethics of international medical travel for reproductive goods (e.g., oocytes) and services (e.g., surrogate mothers), in order to highlight some of the subtler – yet potentially more profound – implications that the growing trend of international medical travel has for social justice. The analysis will be informed by insights from feminist bioethics and the work of Powers and Faden (2005), Storrow (2006, 2008), Young (2006), and Sherwin (1998, 2008).

C59: Traveling Right: Ethical Issues in Medical Tourism

Author(s): *Jeremy Snyder*

Individuals from wealthy countries increasingly travel to the developing world to seek out medical services. This process, often called 'medical tourism', is driven by: 1) the relative affordability of these services (primarily for tourists from countries with privately funded healthcare); and 2) long waiting times for and rationing of medical services (primarily for tourists from countries with publicly funded systems). Medical tourism has been praised for allowing developing world countries to increase revenues, improve their health infrastructure, increase tourism, and help retain domestic health workers. However, critics charge that medical tourism may undercut access by the poor to scarce medical resources if these resources are used to cater to the needs of wealthy tourists.

In this paper, I first discuss when and why medical tourism is unethical. While medical tourism is not inherently unethical, I argue that it can: 1) reduce access to health care among the poor in host countries for medical tourism; and 2) exacerbate inequity in the provision of healthcare in host countries. Second, I discuss who should be held morally responsible when medical tourism is developed in an unethical manner. I argue that government officials, both in the host countries and source countries for medical tourists, should be held responsible for failing to develop and enforce restrictions on medical tourism that will protect the poorest members of the host countries. Moreover, medical tourists are themselves morally culpable for participating in and perpetuating a process that serves to harm the poorest members of developing world countries.

C60: From Obligations to Inform to Duties to Warn

Author(s): *Lori Luthur, Lisa Schwartz, Matthew Hunt, Chris Sinding, Laurie Elit, Lynda Redwood-Campbell, Naomi Adelson, Jennifer Randford, Lucy Langston*

The concept of informing patients of their diagnosis, prognosis and treatment typically relates to notions of autonomy, consent, and standards of care within the doctor –patient relationship. A duty to warn typically relates to notions of privacy and confidentiality. Personal health information should typically not be disclosed to third parties, even at-risk third parties, unless the individual (about which the information relates) provides consent or as provided by law , that is, where a serious risk of harm can be avoided. But how is the individual able to provide consent, if the information, seemingly in his “cultural best interests” is not disclosed? As evidenced from interviews gathered through a CIHR funded study *entitled Ethics in Conditions of Disaster and Deprivation: Learning from Health Care Worker’s Narratives*, individuals with HIV are often not told of their disease because of village stigmatization and lack of resources to provide ongoing counselling and/or treatment. The notion of averting harm suggests that treatment is available. The difficulty in the scenarios considered is that treatment is typically unavailable or unavailable for extended periods of time. As well, due to limited resources, counselling and education are also unavailable or woefully inadequate. Cultural concerns of stigmatization seem to trump avoidance of risk of harm. It is suggested that further consideration be given to instituting an obligation of disclosure to minimize the spread of disease and risk of harm. To be clear, an obligation means that failure to do so may result in professional liability. Although the burden may seem onerous, in such circumstances it may be satisfied by appropriate counselling. Appropriateness of counselling – to the patient only or to the patient’s family and appropriate community/village would also have to be considered.

C62: Informed Consent and Professional Interpretation Services

Author(s): *Elizabeth Abraham, Kyle Anstey*

Despite the positive impact of professional interpretation services on health outcomes, these services are available to varying degrees depending on the policies of individual healthcare organizations. Many of these organizations encourage, but do not require the use of professional interpretation services, while discouraging but not prohibiting informal interpretation through untrained, bilingual staff or the patient's family members.

Focusing on the use of family members instead of professional interpreters, we discuss how the failure to mandate use of professional interpretation services leads to serious ethical issues in patient care: most notably, failings in obtaining informed consent to treatment and personal care. These stem from family members' frequent lack of proficiency in both languages; their lack of knowledge and training to competently interpret medical procedures and concepts; and their tendency to significantly filter the information provided to the patient. This filtering may also lead to a failure to disclose serious diagnoses to patients due to a family desire to "protect" them from negative information.

Family preferences against disclosure also present as an ethical issue when professional interpreters are appropriately utilized: In Canadian hospitals, it is not uncommon for family members to dismiss the hospital interpreter from visits where diagnosis or consent to treatment is the subject of discussion with a care provider. We outline strategies for health care professionals in responding to this dismissal, discussing it with family members and managing disclosure to patients.

C64: The Tyranny of Evidence in Medicine

Author(s): *Wayne Rosen*

Modern medical practice has become fixated on the concept of 'evidence'. Hardly a discussion occurs involving patient care in which someone does not refer to 'evidence' to justify decision-making. All aspects of medicine, including bioethics, are increasingly expected to provide 'evidence' to back up positions or decisions. This development is exemplified in the movement known as "Evidence-based medicine" and reflects, to a large degree, the general trend in society to demand substantiation for all decisions.

The concept of 'evidence', however, is frequently taken for granted by both physicians and the lay public. In this paper, I extend my previous analysis of the concept of 'evidence'. I argue, with use of examples, that the preoccupation with quantifying medical phenomena is frequently misleading and inaccurate. And I contend that 'evidence', especially as it pertains to medical practice, is very pliable and prone to different interpretations.

The failure to appreciate the malleability of 'evidence' and its susceptibility to individual and commercial interests, represents a deep threat to the integrity of patient care in medicine. In the final analysis, I contend that evidence-based medicine (EBM) is a deeply flawed methodology, which has been largely appropriated by commercial interests with pernicious effects on medical thinking and management.

C65: Evidence based medicine as a threat to individually appropriate care? Ethical concerns raised by family physicians

Author(s): *Vikki A Entwistle, Ian S Watt, Alex Barratt, Penny Lockwood, Lyndal Trevena*

In 2007-2008 we conducted semi-structured interviews with diverse family physicians or general practitioners (GPs) working in Australia (n=21) and Scotland (n=19). We explored GPs' thoughts about what makes for good quality care in general practice then asked particularly about 'evidence-based medicine' (EBM) and 'patient involvement in treatment decision-making'.

Few GPs spontaneously mentioned EBM as important for good quality care. When we asked about EBM directly, they acknowledged the importance of research for practice, but expressed various concerns about EBM as such. We focus here on ethical issues associated with the standardizing tendencies of evidence-based guidelines and clinical policies.

Most GPs associated EBM with the notion that some interventions are 'evidence-based' and 'should' be given when particular clinical indicators are present. Some GPs critiqued specific 'evidence-based' policies and recommendations, and some expressed uncertainty about the appropriateness of their own or others' use of evidence to persuade patients to accept or avoid particular interventions. The idea that EBM must be used with caution to avoid it resulting in individuals receiving inappropriate care was a strong theme in our data.

When we showed GPs Haynes et al's (2002) model of evidence-based clinical decision-making, they endorsed the approach this represented, but not all thought they practised EBM when their attention to individual patient circumstances or preferences led them to deviate from guideline recommendations.

Narrow understandings of EBM, reinforced by policies promoting evidence-based standards, threaten the provision of individually appropriate healthcare. GPs' concerns highlight the need for careful attention to their ethical implications.

Haynes RB, Devereaux PJ, Guyatt GH. Physicians' and patients' choices in evidence based practice. Evidence does not make decisions, people do. *BMJ* 2002; 324:1350.

C66: Keeping Evidence-Based Knowledge About Medical Error From Patients and the Public: An Ethical and Legal Conundrum

Author(s): *Joan A Gilmour*

Health care providers' ethical and legal obligation to disclose error to injured patients is clear. However, a countervailing impetus supports significant limits on disclosure. Patient safety advocates argue that there is an urgent need for accurate information about errors, so they can be investigated and effective strategies developed to prevent or reduce harm, and that confidentiality is essential to encourage disclosure. As justification, they rely on the public interest in making health care safer. All provinces and territories provide some legislative protection from disclosure ("qualified privilege") for certain types of information about critical incidents that harmed patients. However, non-disclosure has costs – to injured patients, professional governing bodies and institutions, courts, and the public. Further, empirical evidence that shielding information from disclosure increases error reporting is lacking. This paper will examine two aspects of questions about "just evidence": first, whether access to information and expert opinion about "what happened" to cause injury should be limited and under what conditions, and second, what the evidence is for and against qualified privilege rules that prohibit disclosure of relevant information. It will use examples such as the Newfoundland Commission of Inquiry on Hormone Receptor Testing, which could only access an expert report on the quality of laboratory testing after challenging the hospital's claim of qualified privilege in court, and succeeded only because the report fell outside the legislative definition of protected information. The paper will explore tensions between ethical and legal requirements of disclosure and secrecy, and propose ways to balance these conflicting interests.

C67: Will university students fell free to use prescription drugs as "cognitive enhancers"? Perspectives from a qualitative study

Author(s): C Forlini, E Racine

Background: There is mounting evidence that methylphenidate (MPH; Ritalin) is being misused by healthy university students to improve concentration, alertness, and academic performance, a phenomenon often described as "cognitive enhancement" (CE). One of the key concerns associated with the spread of the use of pharmaceuticals to improve cognition in healthy individuals is the degree of freedom they have to engage in or abstain from performance enhancement. However, it remains unclear whether CE is viewed as 1) an individual's autonomous decision; 2) the result of external coercion or 3) a combination of both scenarios. This qualitative study aimed to examine stakeholder perspectives on autonomy, informed consent, and coercion relating to non-medical use of MPH for enhancement purposes.

Methods: We examined the perspectives of three stakeholder groups (university students, parents of university students, and healthcare providers; n=65) during focus groups (n=9). The focus group content was coded systematically for statements relating to the autonomy of individuals, social pressure to succeed and feelings of coercion to engage in CE.

Results: Our study revealed that focus group participants had mixed opinions about whether the decision to use MPH for CE was autonomous or coerced. Stakeholder perspectives tended to reflect that despite beliefs in autonomous choice, students are subject to enormous social pressures that may ease the social acceptance of cognitive enhancement.

Conclusion: Our data indicate the need to understand perspectives of stakeholders and non-experts on key issues like cognitive enhancement to fully grasp moral insights in pluralistic societies and prepare sound public health responses.

C68: Rights, Risks and Smoking: how 'denormalisation' mediates patient-provider interactions in primary care settings

Author(s): *Kirsten Bell, Jennifer Bell, Lucy McCullough, Amy Salmon, Michele Bowers*

During the past decade, Canadian health policy has increasingly emphasised the need to de-stigmatise substance use in order to encourage timely access to health services. However, one major exception to this policy shift in responding to substance use as a public health issue is the tobacco control strategy of 'denormalisation' – a strategy that seeks to change social values and norms regarding tobacco use. The success of denormalisation efforts can be witnessed in the stigma presently attached to smoking (and smokers) by Canadian health professionals. There is growing evidence suggesting that some doctors discriminate against smokers when providing healthcare, and recent reports suggest that some doctors are choosing to withhold treatment from smokers unless these patients take action to quit smoking. The doctors who have taken such steps point to their frustration in dealing with 'self-inflicted' health issues and the growing demands placed on GPs in a healthcare system where supply does not meet demand and resources are already spread too thin. However, this emphasis on the individual responsibility for health disguises the fact that 'risk' behaviours such as smoking are increasingly confined to low socio-economic status (SES) groups and that smoking-related morbidity and mortality are heavily concentrated amongst these groups. Drawing on findings of a qualitative study exploring smokers' and doctors' perspectives on their interactions around tobacco use, this paper will explore the ethical and policy implications of denormalisation strategies and recent moves to frame healthcare as a privilege that smokers have negated the 'right' to access.

C69: Milk: a neglected ethical issue

Author(s): *Angus Dawson*

Milk from domesticated animals has been central to human diets for thousands of years. However, it has also long been known that it can carry risks to human health. For this reason, pasteurization was developed in the nineteenth century as a method of treating milk to reduce risks from various biological contaminants, including, but not limited to, bovine tuberculosis, listeria, e coli, salmonella, campylobacter and brucella. The risks to humans from these diseases vary, but they are real, and in some circumstances can result in hospitalization and even death. Some groups, such as children, pregnant women and those with weakened immune systems, are at greater risk than the general population. For this reason, pasteurization was introduced as a routine, effective, risk-free and legally enforced means of reducing these potential risks.

However, some people argue that it is their right to decide how much risk they are exposed to in the course of pursing their own lives. In this case, they argue that any risks of harm are small and are outweighed by the benefits of drinking raw (i.e. unpasteurized) milk. They argue that the state has no role in intervening to stop informed and competent citizens drinking raw milk if they wish to do so.

This paper explores the ethical arguments relating to this disputed issue, and focuses on discussions in Ontario following the recent prosecution of a farmer for selling raw milk.

C70: **Quality public engagement in health policy making: An emerging framework for effective deliberation**

Author(s): *Michelle Cleghorn and Douglas K. Martin*

Involving the public in health policy decisions that affect them is important to ensure the fairness and legitimacy that is sought by most policy makers. Health policies inevitably encompass value-laden judgments, and the public can offer a valuable perspective that otherwise would be missing – engaging the public can be thought of a type of "due diligence". When policy makers agree on the importance of public engagement and wish to engage the public, it may be implied that they wish to do it well or effectively. But, we need to know what is meant by effective public engagement. Currently, there is no theoretically-grounded and empirically-supported definition or operational standard of effectiveness in public engagement. Using a synthesis of the available literature, including lessons learned from initiatives around the world, and experiences from the Toronto Health Policy Citizens' Council, a preliminary framework has been devised which attempts to address this deficiency. The framework includes 25 elements that describe, concretely, good deliberation. It is structured into 'process' (developed into categories of 'group dynamics' and 'communication and information') and 'output' sections. More specifically, the framework looks at participant and facilitator characteristics, atmosphere, resource accessibility, and task definition features. Such a framework could help policy makers plan and evaluate the quality of their engagement initiatives and, ultimately, be more confident in using their findings in their policy development

C71: Chaoulli, wait lists, and somatic solidarity

Author(s): *Lynette Reid*

Robert Evans and others have highlighted the income redistribution effect of Medicare; in this light, the Chaoulli decision has been fairly criticized as a class-specific response to a policy of economic solidarity and social justice. I argue that, beyond economics, Medicare represents a policy of "somatic solidarity"— a form of solidarity dramatized in Simone Weil's extraordinary and fatal choice, while living and working with the Free French in London during World War II, to eat only the rations available to those in occupied France. In this paper, I delineate the notion of "somatic solidarity," and demonstrate that it places in doubt the common distinction between utility and sentiment as distinct foundations for solidarity. Medicare redistributes "external goods" (services and therefore money), but also entails that central human experiences will share common embodied features (place—the hospital; biology—the treatment or prophylaxis; time—the wait) across class distinctions. Somatic solidarity generates contradictory moral intuitions: we readily endorse the view that no one should suffer disease and death because of a lack of financial resources, but suspect that, for the well-off, foregoing care they could otherwise access would be, like Weil's gesture, supererogatory. The Supreme Court in effect endorsed the latter view in *Chaoulli*, arguing that constitutional guarantees of "security of the person" constitute a limit to laws enforcing somatic solidarity. This paper challenges the view that somatic solidarity is supererogatory under conditions of healthcare resource "scarcity," complementing the arguments of *Chaoulli* critics who represent the perspective of economic justice.

C72: Here Come The Judge

Author(s): *Rick Singleton*

In the past five years there have been a number of ethics consultations in Eastern Health that eventually made their way to court. The documents from the ethics consultations were called as evidence and the facilitators of the ethics consultations were called as witnesses.

This session will give an overview of the cases, the reasons why they went to court and lessons learned along the way. Some important factors are documentation, communication, quality initiatives, and the challenge to present ethical reasoning as evidence in an adversarial court system where the art of persuasion seems more relevant to the ethical principles and concepts.

In some cases there was strong challenge to the credibility of the ethics consultation service. There were challenges to the process, the competency of participants in the consultations, the selection of participants, and the point at which the ethics service was consulted. In some cases there was there was insistence that the ethics service ought to be more proactive and function more as ethics police than as a consultation service.

A portion of this session will be reserved for interaction and discussion regarding the potential to establish best practices for ethics consultation. A few trips to court give *Just Evidence* new meaning.

C73: The questionable ethics and science of experimental trials for evaluating 'black box' health ad policy interventions

Author(s): Mita Giacomini

The evidence decision making movement in health policy, following on the values of the evidence based medicine movement, has widely embraced the epistemological primacy of the randomized experimental trial for the evaluation of the effectiveness of health and policy interventions. While other methodologies are valued for answering other sorts of questions, the experimental trial remains the definitive arbiter of "what works" for clinical, administrative, and policy decision makers who rely on scientific evidence. This reliance is justified in the case of interventions whose mechanisms of effect are well understood. However, 'black box' interventions are those whose mechanisms are not well understood – or so complex that their variables and dynamics are not well accounted for in experimental designs. For these interventions, I will argue that even methodologically sophisticated randomized experimental trial evidence can seriously misguide clinical, administrative, and policy practice. Intercessory prayer provide an illustrative case of a 'black box' intervention in medicine that has been extensively subjected to the methodological rigours of randomized clinical trials and systematic reviews without due attention to basic theoretical issues. The resulting evidence of the effectiveness of intercessory prayer, although recognized and disseminated through the institutions of evidence based medicine, is deeply ethically and scientifically problematic in ways that remain largely unacknowledged by these same institutions. Lessons from this case are drawn for the evaluation complex and interdisciplinary interventions in health and policy, as well as for the decision making uses of experimental evidence concerning 'black box' interventions.

C74: The Role of Pregnant Women in Medical Research: Does the systematic exclusion of pregnant women from being non-therapeutic research subjects protect or harm?

Author(s): *Lucy Langston*

Pregnant women have been systematically excluded from participating in non-therapeutic research in Canada and the USA because they are defined as a vulnerable population and face more risk. This policy of systematic exclusion, despite intention to contrary, may however serve to harm pregnant women more than it helps. I consider two related arguments for the systematic inclusion of pregnant women into non-therapeutic drug research. Firstly, preventing pregnant women from being research subjects limits knowledge about treatment safety and dosage for pregnant women. Pregnant women have unique pharmacokinetic profiles, and as such to determine the efficacy and safety of therapeutic treatments for pregnant subjects on data collected from the non-pregnant invites the possibility of side effects and drug efficacy for pregnant women who seek medical treatment. Secondly, despite being labelled as vulnerable, pregnant women as a group fail to meet any of the common definitions used for populations deemed medically vulnerable. To label them vulnerable falsely implies that pregnant women as a group are less capable of making informed decisions and actively reinforces negative stereotypes of pregnant women. Pregnant women should only be excluded from being research subjects when the risk is greater than the possible benefits of the knowledge gained from answering the research question. Thus I argue for the systematic inclusion of pregnant women in non-therapeutic drug research to allow for both the development of a systematic body of knowledge about unique drug reactions in pregnant women and to allow pregnant women to make informed choices.

C75: Presumed Consent: Red Herring or White Knight?

Author(s): *Linda Wright, Maxwell Smith*

Canada continues to experience a shortfall between the number of organs available for transplantation and the number of people whose lives could be saved by organs. Evidence shows that rates of organ donation from deceased donors (ODDD) in Ontario are lower than those in the United States, several European countries, and some other Canadian provinces. Research continues into these disparities to find evidence of factors that affect organ donation rates and their degree of influence.

Spain, which boasts the highest rates of ODDD in the world, has a system of presumed consent (PC), otherwise known as opting-out. It is often suggested that a PC system leads to higher rates of ODDD than an expressed consent, opt-in system which is the model currently in place in Canada, the U.S.A. and the U.K. PC legislation has previously been rejected in Canada, but the debate continues as to the need to consider this approach in order to increase organ donation. The conflicting evidence of PC's role in ODDD includes a lack of direct correlation between PC legislation and increased rates of ODDD, suggesting that additional factors prevail. To identify success factors in increasing donation rates, this presentation will explore whether PC is a red herring or a white knight in the challenge to improve rates of organ donation. We will examine the evidence of PC's effects and ask if there is reason for additional ethical considerations, such as justice and solidarity, to inform our response to the call for PC legislation.

C76: Narrative as Evidence?

Author(s): *Debbie Rolfe*

The juxtaposition of science as truth and narrative as fiction misses the common element of both science and narrative as "a way of knowing" – distinctly different, but equally compelling and often complementary, especially in the field of health care, where the sick and the suffering are dependent not only on our competence but also on our compassion.

The author's reflective narrative, "Now and Then", about a patient relationship she encountered in her role as a medical social worker, and the layers of moral distress she experienced in the process, will be the focus of this presentation. The audience will be invited to consider the question of whether narrative constitutes evidence - and if so, of what nature?

The author will propose the idea that 'just' evidence occurs when science (empirical population based knowledge) and narrative (experiential individual based knowledge) recognize their fundamentally interdependent nature in the formulation of "truth" and subsequent best practices in patient-centered care.

C77: Ethics Blogs: Pedagogy, Public Outreach, and Professional Discourse

Author(s): *Chris MacDonald, Nancy Walton*

Ethics blogs – including bioethics blogs – play a unique role in the realm of public discourse. In some ways, blogs seem ill-suited for discussion of bioethics. By their very nature, blogs encourage quick, off-the-cuff commentary, rather than careful, thoughtful reflection. They also tend towards sensationalism, focusing on the hot topics of the day, rather than the "big" questions that have pervaded bioethics for years or decades.

As experienced ethics bloggers – with 5 years of combined blogging experience – we argue that these limitations are not fatal. In this presentation, we argue that ethics blogs have three distinct contributions to make.

First, ethics blogs have a role in pedagogy. Blogs can be (and sometimes are) assigned as required reading in university courses. In this role, good blogs bring informed commentary on the very latest bioethical issues into the classroom.

Second, ethics blogs have a role in public outreach and public education. When those with bioethics expertise write blogs, they expose an enormous audience to critical, scholarly reflection on the bioethics-related news stories of the day.

Third, ethics blogs serve an important and growing role in professional discourse. In bioethics and beyond (including especially in economics) blogs are rapidly becoming a place for scholars to try out new ideas, and to engage in real-time debates of a kind simply not possible in print journals.

In summary, we argue that blogging – especially when informed by scholarly or professional insight – constitutes a powerful new forum for bioethical debate and consensus-building.

C78: Facebook and research: New challenges in research ethics

Author(s): Nancy Walton, Chris MacDonald

Social networks such as Facebook are increasingly pervasive in our daily lives, and more and more researchers are realizing the potential of such networks as viable, virtual "sites" for the conduct of research. The use of these networks to advertise research studies, to recruit participants, to collect data and indeed to generate data poses unique ethical challenges.

While the issues themselves (e.g., consent, disclosure and confidentiality) are not unique to research conducted using social networks, the kinds of questions that are raised about these issues within this context are, in their particular form, unprecedented. Examples of questions that are raised include: Is it ethically problematic to mine a social network such as Facebook for demographic data on users with publicly accessible profiles? Should social networks be used to post recruitment notices? Are the privacy risks of participation in research different from the risks of membership in such networks itself?

The popularity of virtual social networks has resulted in new ways of thinking about confidentiality, privacy, and disclosure of personal information. While such networks encourage personal disclosure first with reflection on risk of disclosure later, ethical guidelines for research insist that reflection on risks and contemplation of privacy and confidentiality should precede disclosure.

Research ethics boards may be unprepared for these challenges. They must tackle a novel range of dynamic issues armed only with static guidelines and regulations, while at the same time remaining open to novel ways of conducting research and evolving ideas about how research is conducted.

C79: Fostering empathy and moral imagination in biomedical ethics teaching

Author(s): *Bruce Maxwell, Éric Racine & Alena Buyx*

It is generally accepted that one of the goals of healthcare training is to promote empathy in the emerging professional, where "empathy" refers to a trait of professional ethics consisting in appropriate responding to patients' and their kin's sufferings and misfortunes. Other times, the injunction to foster empathy is part of a critique of an overly rationalist approach to teaching biomedical ethics. In this connection, a number of prominent ethics educators have expressed the concern that a biomedical ethics pedagogy that focuses only on the analysis of ethical principles, concepts and arguments risks neglecting the development of the affective and imaginative dimensions of moral functioning and ethical deliberation. The aim of this paper is to examine this postulate. After presenting an overview of definitions of empathy (and its conflation with sympathy and compassion) as well evidence for the role of empathy in altruistic behaviour, we sketch evidence that empathy plays a significant role in practical wisdom. Empathy, we argue, is part of a specific class of morally-praiseworthy emotions and a personal trait that contributes to a sense of justice. We conclude by commenting on ways in which empathy could be fostered in the context of teaching biomedical ethics such as favouring affective engagement with moral problems in the form of other-directed perspective taking and using case studies that features individuals and social groups with whom students are unlikely to identify.

C80: Medical Students' First Clinical Experiences of Death

Author(s): *Emily Kelly, Jeff Nisker*

Objective: To examine medical students' first experience with patient death.

Methods: Final-year medical students at the Schulich School of Medicine & Dentistry were invited by email to share their experience of the death of a patient in their care, either in an interview or focus groups, or through email. These were recorded and transcribed verbatim, and then underwent qualitative analysis using grounded theory supported by N6™ software. Ethics approval was obtained from University of Western Ontario Research Ethics Board #10351E.

Results: Twenty-nine students had experienced the death of a patient and chose to participate (20 interviews, 5 in a focus group, 4 through email). A cyclical model of student experience was generated, proceeding in five stages; (i) "preparation"; (ii) "the event itself"; (iii) "the crisis"; (iv) "the resolution"; and (v) "the lessons learned". In "preparation" students begin with their personal experience and preclinical instruction. During "the event itself", students may encounter old, young or unexpected deaths, that may precipitate some degree of "crisis". In the "resolution" phase, coping mechanisms included rationalization, contemplation, or learning. The "lessons learned" not only shape medical students' understanding the death experience of future patients and their own experience of such deaths, but of their professional identity.

Interpretation: A tension between emotional concern and professional detachment is pervasive among medical students experiencing the death of a patient in their care. Based on the support and debriefing they receive from their communities, students negotiate this tension in complex manners that reflect the philosophically ambiguous place of death in the medical profession.

C81: Just Accommodation in Canadian Healthcare Education

Author(s): *Jason Millar*

Debates around the topic of student accommodation in Canadian healthcare education settings have emerged of late. Canadian universities and colleges are faced with designing policies for accommodation that recognize the diversity of both their student populations, and of the professional landscapes in which those students may eventually practice. In this paper the author examines two contested types of accommodation: 1) accommodation of healthcare students with 'non-standard bodies'; and 2) accommodation of healthcare students conscientiously objecting to offering particular services to which their (potential) patients have an uncontested legal right. With respect to the first type, the author uses evidence from nursing (and other health related fields) to argue that the traditional skill set portrayed as 'essential' to a profession often relies on an untenable implicit notion of a 'standard body'. By adopting a 'non-standard body' as a theoretical starting point, the author demonstrates a reasonable degree of flexibility in the resulting skill sets deemed necessary to a profession. The author argues that the flexibility demands, and justifies, a broader accommodation of students with 'non-standard bodies'. With respect to both types of accommodation, the author argues that the reality of the current population of students, and of their potential career paths, demand and justify a broader accommodation during their education. The author concludes by offering some specific policy recommendations intended for those individuals in healthcare education settings who are faced with designing accommodation policies.

C82: Moral distress and moral climate within the interdisciplinary ambulatory cancer care team environment

Author(s): *L.A. Martin, P. Rodney, and E. Serrano*

This pilot study used mixed quantitative and qualitative methods to examine and describe moral distress and moral climate within a stressed interdisciplinary ambulatory cancer care team environment. Perceived ability of clinical professionals to practice according to their ethical standards was explored in relation to measures of workplace quality and qualitative description of the team's moral climate.

The research setting was a large ambulatory cancer centre where the interdisciplinary staff voiced sufficient interdisciplinary practice discord to necessitate group meetings and outside facilitation. Eligible participants (107) included all cancer care professionals working within the centre's clinics from diverse disciplines including nursing, medical oncology, radiation oncology, pharmacy, patient and family counselling, nutrition, patient care aids, and health unit coordinators..

Quantitative measures of job satisfaction (Job in General) and job related quality of life (ProQOL) were administered by electronic distribution and anonymous response. Individual moral distress, and moral climate of the entire team were examined via representative individual interviews and interdisciplinary focus groups.

Outcomes include 1) discovery of themes and issues related to moral distress within disciplines, and moral climate within the care team in an oncology ambulatory care setting and 2) insights regarding the possible relationship of moral distress to the moral climate and quality of the healthcare workplace as reflected by standardized group measurement of job satisfaction and job related quality of life.

C83: Is Ambulatory Care Ethics Unique?

Author(s): Moji Adurogbangba, Laurie Hardingham

Increasingly, much of health care in Canada is provided to patients seen in the ambulatory care setting. If ethics is to guide healthcare practice, we need to complement the current emphasis on inpatient medical ethics with a fuller description of the kind of ethical issues that are occurring in the different outpatient settings, and develop a reliable process for decision making.

Issues in ambulatory care settings are related to the calculations of cost-effectiveness and the pressures which allow physicians and other health care providers less time with each of their patients. Where physicians are expected to see a certain number of patients an hour and each patient can only present maximum number complaints, can time be allowed for serious exploration of patient preferences, with respect to immediate treatment options, long term care plan and completing advance directives? These have ethical implications for patients' choices and considerations for the principle of justice.

As out-patient and in-patient situations are significantly different, this paper presents the uniqueness of outpatient ethics in order to support further research in this area. I will review existing literature on ambulatory care ethics, present taxonomy of ambulatory care ethics, and argue that early recognition of ethical issues in ambulatory care may prevent further inpatient dilemmas. I will argue that we need to bring attention to ethical issues in ambulatory care in order to assist health care professionals to provide more informed, rational, and consistent responses to patients, as well as to continue with critical thinking and compassionate care.

C84: Doing Taboo Work: Nurses' Experiences of Caring For Women Having Second Trimester Pregnancy Terminations For Fetal Anomalies Through Labour Induction

Author(s): *Susan E. Bishop*

Purpose: To explore and interpret the meaning of these nurses' experiences and to identify supportive recommendations.

Background: To date, there have been only two published research studies, from a sociologic perspective, focusing on the nurses' experiences.

Methods: A qualitative, Heideggerian phenomenological approach was used with the goal of interpreting and understanding the nurses' experiences. Eleven nurses, from three hospitals, who cared for the women and babies were interviewed.

Results: ***Doing Taboo Work*** emerged as the primary and overarching theme of the meaning of the nurses' experiences. Because the nurses perceived that caring for the women and babies was taboo they needed to ***make choices***. They also discussed ***being pulled in two directions***, voiced their concerns about ***being given token bones***, and discussed the ups and downs of ***riding an emotional roller coaster***. The nurses considered this taboo work to be "tough", "hard", "difficult", "sad", and "emotionally draining". Yet, these nurses showed great resiliency by continuing to work with the women and babies. While many of the nurses came to work each shift knowing that they can and do "make a difference" other nurses continued to struggle with doing taboo work and providing care to the women and babies.

Conclusions: My study is the first nursing study of its kind and is underpinned by moral motivation to offer voice to a collection of dedicated professionals who encounter moral distress on a daily basis because of doing taboo work. The recommendations stemming from my study have implications for not only nursing but, unit/hospital administrators, ethicists, genetic counsellors, physicians, social workers, clergy, counsellors, and psychologists.

C85: Just evidence in an unjust world: The case of pharmacogenomics research in the current global context

Author(s): *Catherine Olivier*

In 2005, Peter Singer's group wrote that pharmacogenomics (or pharmacogenetics) "will probably have an impact on global health, especially on neglected infectious diseases such as malaria, tuberculosis and HIV/AIDS"[1]. They suggested that pharmacogenomics, which aims to identify the genetic factors implicated in drug response, could contribute to improving global health by increasing access to better (more relevant) drug innovations worldwide. But, have these new genomics technologies actually helped address the global disparity in access to healthcare, by enabling drug development for diseases and populations of the developing world?

We approach this question, by assessing the potential of current global developments in pharmacogenomics research to contribute to better pharmacogenomics technologies that effectively address international health needs. To do this, quantitative measurements of scientific publications and developments referring to pharmacogenomics technologies are used as an evidence-based approach which enables a global analysis of the current context of pharmacogenomics research capacity. The resulting data, combined with a geographical mapping of international research teams and centers using pharmacogenomics technologies, provides crucial information for further ethical reflection on the societal impact of pharmacogenomics, namely regarding health distribution and policies. This analysis provides evidence of the potential for pharmacogenomics technologies to respond to needs of increased justice in international health. Moreover, it is the basis for developing effective evaluation models to help health policy-makers worldwide better judge the potential utility and efficacy of specific pharmacogenomics technologies in responding to the major health needs and social inequities facing populations in both the developed and developing world.

[1] Daar, A.S. and P.A. Singer. *Pharmacogenetics and geographical ancestry: implications for drug development and global health* Nature Reviews Genetics, 2005. 6(3): 241-246

C86: On Flying to Ethics Conferences : Climate Change, Justice, and Responsibility

Author(s): *James Dwyer*

Last year I flew to three bioethics conferences, one in Europe and two in North America. I also flew to Taiwan to teach in a weeklong bioethics course. These were good things to do, or so I thought. I learned more about bioethics, contributed to educational events, and visited with friends and colleagues. But I worry about my carbon footprint. I worry that flying and other activities in my life are contributing to climate changes that will harm other people. So in this presentation, I consider what it means to live a just and responsible life in the face of climate change. To begin, I review the evidence about climate change and its consequences. Because of climate change, heat waves will occur more often and last longer. Water-borne and vector-borne diseases will probably increase. Flooding from storms and rising sea levels will displace people, destroy habitations, and ruin cropland. Malnutrition may increase as changes in precipitation lead to lower crop yields in some regions. And whole ecosystems may be disrupted. Since the evidence suggests that people who contributed very little to the problem will be the most vulnerable to the consequences, I note how climate change raises issues about social, international, and intergenerational justice. Then I address the issue of moral responsibility. I explain why and how I view responsibility in terms of responsiveness – as consumers, as citizens, and as moral agents. And then I conclude with a suggestion about flying to ethics conferences.

C87: Uneven distribution of road traffic injuries and deaths across the Kenyan population: A social justice and political appraisal

Author(s): *Jacquineau Azetsop*

The link between level of education and the disproportionate distribution of road traffic injury and death (RTID) across population groups reflects the social inequities that structure life in Kenya. Road traffic injury (RTI) is becoming a growing public health problem. The road fatality rate per 100, 000 population during the period 1985 to 1998 ranged from 7.8 to 10.6. Furthermore, there are 68 deaths per 10,000 registered vehicles, which is 30-40 times greater than in highly motorized countries. Approximately 80% of the injured are young pedestrians or public transport users (15-44 years) from disenfranchised groups.

The magnitude of RTID is often explained by risk or proximate factors while its social or distant causes are often neglected. An analysis of these social causes forces us to recognize the existence of a socioeconomic gradient (SEG) in RTID and provides us with compelling arguments to appreciate the inadequacy of an individual-behavioral approach. The relationship between education, which is often correlated to income, and car ownership is graded. Since mostly pedestrian and passengers rather than car owners are injured, it can be inferred that the link between injury and socioeconomic status is also graded.

Analyzing the SEG allows us to address RTID as an issue of justice from the perspective of human rights, the common good, and distributive justice. To confront the burden of RTID, a strong leadership as well as active participation of all constituencies to develop safety programs and reduce social inequities that fuel RTID should be done from an ecosocial perspective.

C92: Ethics Change in Healthcare: What is our Burning Platform?

Author(s): Jonathan Breslin, Jennifer L. Gibson

Ethics programs are mechanisms of change in health care organizations. Through ethics programs ethicists work to bring about improvements in “ethics quality” and create an ethical culture within their organizations (VA National Centre for Ethics in Health Care). It is well accepted principle in change management theory that one of the prerequisites for successful change is to convince others of the need for change, to create a “burning platform.” In this presentation we explore the concept of the burning platform with respect to ethics change, concluding with some recommendations for ethicists, ethics programs, and the field of health care ethics in general.

C93: An Advocacy Role for NSHEN : Ethics Evidence and the Accreditation Process
Author(s): *Marika Warren and Christy Simpson*
In 2008, several health care districts in Nova Scotia underwent the accreditation process. At their request, the Nova Scotia Health Ethics Network (NSHEN) is taking the lead in providing feedback to Accreditation Canada regarding the districts' experiences with the accreditation process. In this presentation, we will highlight some of the specific challenges experienced by the health districts with respect to Accreditation Canada's new ethics-related standards, the application of these standards, and communication between Accreditation Canada, surveyors, and accreditation coordinators.
We will also share our suggestions regarding how the standards and the process could be improved to increase fairness and consistency as well as help ensure that both are appropriate to the goals of accreditation. This will lead into an exploration of some of the broader questions around justice and evidence as they relate to the accreditation process. These questions include (1) What sort of evidence is appropriate to demonstrate that an organization or district is capable of addressing ethics issues and enhancing the ethical capacity of its members? (2) What constitutes fair evaluation of ethics evidence and ethics practices? (3) Is it possible to ensure that all institutions are held to a consistent standard while retaining appropriate flexibility that recognizes variation in organizational contexts? and (4) How could surveyors be trained to effectively evaluate the ethical aspects of an organization?
We will conclude with a brief discussion of why NSHEN, as a provincial-level network dedicated to building ethics capacity, is well-positioned to take on this project.

C94: Ethics and evidence: exploring the role of public engagement in health technology assessment Author(s):
Authors(s): *Yvonne Bombard, Les Levin and Tanya Khan*
Health technology assessment (HTA) involves the systematic evaluation of evidence for a particular health technology to inform health policy decision-making. Increasing health care costs coupled with limited resources have led to greater public scrutiny of health policy decisions. Involving the public in policy decisions is meant to ensure that decisions are informed, transparent and legitimate. Clearly the public is an important stakeholder of health policy decisions. The Medical Advisory Secretariat (MAS) in conjunction with the Ontario Health Technology Advisory Committee (OHTAC) have developed a public engagement (PE) strategy to incorporate social and ethical value judgments in its evidence-based process for HTA.
Objective: The objective of this presentation is to describe and evaluate a PE method adopted by MAS-OHTAC to systematically engage the public in their HTAs.
Methods: A focus group was conducted with relevant patients to ensure that the research questions for a particular HTA incorporated important patient-centered outcomes.
Results: Findings on the physical, psychological and social impacts associated with the current standard of care and the new technology will be presented. These perspectives may not have otherwise been incorporated into the HTA process. Evaluation of the strategy will be discussed.
Conclusions: PE within HTA agencies presents implementation challenges, particularly in ensuring that PE is timely and relevant to the HTA process. However, PE forms a critical part of developing research questions and gaining societal and ethical perspectives that are often left out of traditional HTA. Organizational resources, leadership commitment, and expertise are required for its successful implementation.

C95: Contributing to global health: An ethics framework for guiding international partnerships

Author(s): *L. d'Agincourt-Canning, T. McElroy, R. Armstrong*

BC Children's Hospital, through the Centre for International Child Health (CICH), has launched a number of international initiatives aimed at improving child health. By working with partners in developing countries (children's hospitals, associated universities, NGOs) the CICH aims to foster programs that are locally relevant, culturally sensitive and strengthen local capacity to deliver health care services. The first international programs of CICH were focused in China, but now have expanded to include Uganda and India as well. For example, for the past five years a cardiac team from BC Children's Hospital has travelled to the Children's Hospital of Fudan University, Shanghai, to: 1) assist with the diagnosis and management of children with complex forms of congenital heart disease; 2) build capacity by working alongside the local team to do complex cardiac surgeries and 3) provide comprehensive staff education and training in areas identified by the local team.

Yet, international partnerships present complexities. In this presentation, we will describe some of the ethical challenges experienced by health care clinicians working in China and other developing nations. We will then present an ethics framework developed to respond to these issues. The purpose of this ethics framework is to help guide the development of partnership agreements and inform practice in international settings. This framework is not meant to be a regulatory instrument; rather it offers an ethical basis to consider how collaborations and new programs might be structured in order to reduce injustice and improve child health. Partners' responses to the guidelines will also be discussed.

C96: An exploration of the moral experience of Canadian healthcare professionals in humanitarian work

Author(s): *Matthew Hunt*

Humanitarian emergencies and natural disasters can overwhelm the capacity of local and national agencies to respond to the needs of affected populations. In such cases, international relief agencies are frequently involved in the provision of emergency assistance. Health care professionals play a key role in these interventions. This practice environment is significantly different from the context of health care delivery in the home countries of expatriate health care professionals. Human rights, public health, medicine and ethics intersect in distinct ways as health care professionals provide care and services to communities affected by emergency or disaster. Clinicians who travel from a developed nation to a resource-poor setting that has experienced a humanitarian crisis experience a shift of professional, social, cultural and regulatory environments. I conducted a qualitative study to explore the moral experience of Canadian health care professionals in humanitarian work. Two groups of participants were interviewed: 15 health care professionals (9 doctors, 4 nurses, 1 nurse-practitioner and 1 midwife) with more than three months experience in humanitarian settings and three individuals who have experience as human resource or field coordination officers for humanitarian non-governmental organizations. I will present the study findings and discuss their implications for health care practice in humanitarian settings.

C97: "Playing God because you have to": Canadian health professionals' experiences of rationing care in humanitarian and development work

Author(s): *Christina Sinding, Lisa Schwartz, Matthew Hunt, Laurie Elit, Lynda Redwood-Campbell, Jennifer Ranford*

Non-governmental aid organizations are significant players in health care provision in low-income countries, yet scholarly attention to resource allocation and priority setting by such organizations is relatively rare. Codes of practice articulating standards for humanitarian organizations and their workers, while obviously important, offer limited direction for application on the ground, where all needs cannot be met and principles may conflict.

This presentation draws from interviews gathered through a CIHR-funded study, *Ethics in conditions of disaster and deprivation: Learning from health workers' narratives.* It explores the accounts of Canadian-trained health professionals working in humanitarian and development organizations who considered not treating a patient or group of patients because of resource limitations – constraints on the medication, equipment and staff they had available, either in that moment or over the time the resources were required. In the narratives, not treating the patient(s) was sometimes understood as the right thing to do, and sometimes as wrong. Assessments of right and wrong were also located at least in part in how the decision was reached and by whom.

In the analysis of participants' narratives we draw attention to key themes: how medications and equipment are conceptualized; how the role of health professionals is understood; who and what is seen to be at risk in treating or not treating; and the perspective taken. Participants' different responses to these themes help explain how they came to see not treating as either the right or the wrong thing to do.

C98: The Impact of Medical "Evidence" Regarding Prenatal Screening on Legal "Evidence" Regarding Wrongful Birth and Resulting Normative Implications

Author(s): *M. Pioro, R. Mykitiuk, J. Nisker*

Medical "evidence" indicating the majority of women who give birth to a child with Down Syndrome are under 35 years of age combined with new screening tests caused the Society of Obstetricians and Gynaecologists of Canada and Canadian Council of Medical Geneticists to produce a Clinical Practice Guideline (CPG) recommending all pregnant women (rather than those over 35 years) be offered prenatal screening. As this CPG delineates a new "standard of care", it will be used as "evidence" in court regarding negligence in wrongful birth litigation. A national policy of universal prenatal screening and its legal ramifications have normative implications. For example, through such a universal prenatal screening lens: persons living with preventable (through abortion) genetic-based conditions (indeed all disabled people) may be viewed as living lives of low quality, and the view that it is better to prevent existence rather than remove social barriers may be promoted. Although Canada's CPG on prenatal screening specifically expresses the need to be both respectful of women's reproductive choices and the needs and the quality of life of disabled people, a tension exists between these obligations that may be amplified with successful legal actions regarding a child being born with a condition that could have been predetermined. This paper will combine conceptual and legal research methodologies and examine the relationship between medical and social evidence and legal norms in this context.

C99: Consent for prenatal scanning and suggestions for best practice: a viewpoint from Sri Lanka

Author(s): *NTW Wijeratne, D Rodrigo, H Dodampahala*

Detailed prenatal ultrasound scanning is useful in detecting fetal anomalies. However, explicit consent needs to be obtained from the client prior to the procedure to ensure the best interest of both the patient and physician. Our objectives were to assess the current practice adopted in obtaining consent for fetal anomaly scan in a tertiary care Obstetrics hospital in Colombo, Sri Lanka and to develop a tool useful for obtaining consent.

In depth interviews with pregnant mothers and focus group discussions with physicians were conducted with data being analyzed based on the principle of grounded theory.

The current practice adopted in obtaining consent prior to routine antenatal fetal anomaly scan was inadequate, with little information being provided to the mother and consent not being specifically sought prior to the scan procedure. Information pamphlets and structured consent forms used in a two step process are viewed as useful commodities in obtaining consent for fetal anomaly scan which would help pregnant women make appropriate choices in consultation with their physician.

A consent checklist based on results was developed by the researchers and made available to all obstetric units of the hospital.

C100: Rescuing Prenatal Screening from the (Ethical) Quagmire

Author(s): *Victoria Seavilleklein*

The practice of offering prenatal screening to all pregnant women – recommended by the Society of Obstetricians and Gynaecologists of Canada – is an ethical quagmire. The screening is being offered to increasing numbers of pregnant women and searching for ever-expanding conditions. Ethically, the practice is being justified on the basis that it supports women's reproductive choice and promotes public health. However, evidence-based research shows that informed choice is not upheld in the vast majority of cases of prenatal screening. Similarly, prenatal screening is only moderately effective in terms of public health and reinforces a morally concerning public policy message that it is better not to be born than to be born with a disability. Thus, prenatal screening is not ethically justified as a public policy, and as a means for promoting autonomy it is failing.

Nevertheless, the practice is being bolstered by both health policy and Canadian courts. Since prenatal screening has been integrated into the prenatal care of some well-informed pregnant women, it cannot be eliminated without hindering autonomy. However, offering it routinely to all pregnant women reinforces the devaluation of people with disabilities. In this paper, I defend a plausible middle ground for the practice of prenatal screening, which recognizes the social, political, and cultural pressures on women's choices as well as the importance and consequences of this decision. I also suggest changes that could be made in both the clinic and the larger social-political context to reduce discriminatory attitudes and meaningfully enhance choice.

C101: Who is the research subject in cluster-randomzied clinical trials?

Author(s): *Andrew McRae*

Cluster-randomized clinical trials (CRTs) are commonly used in healthcare knowledge translation or quality improvement research. In a CRT, healthcare providers or organizations are randomly assigned to an educational or quality improvement intervention. Instead of measuring professional-level outcomes, the effect of the intervention is ascertained by measuring a change in the health outcomes of individual patients. For example, a trial comparing medical education initiatives will randomly assign physician practices to one of two rival medical educational programs. The effect of the intervention is determined by measuring changes in their patients' health status.
Current research ethics guidelines were developed to guide the review of studies that enroll individual participants. As such, they do not address the unique ethical challenges posed by the CRT study design.
The first key question that must be addressed in examining the ethics of CRTs is "Who is the subject in CRTs?" Is it the healthcare provider who receives an experimental quality improvement or educational intervention? Are the patients contributing outcome data subjects? When a healthcare provider participates in a trial, does any indirect impact on patient care make their patients research subjects? Only after the research subjects in a CRT are identified can an REB consider necessary consent requirements or weigh risks and potential benefits.
This paper critically examines arguments that address the proper identification of the research subject in CRTs, and the implications of these arguments for subject protections and the REB review of healthcare CRTs.

C102: Equipoise, Experimental Design, and Inferential Strength

Author(s): *Spencer Phillips Hey*

According to Freedman (1987), a clinical trial is ethical under two conditions: (1) At the start of the trial, there exists a genuine state of clinical equipoise; and (2), it is designed "in such a way … that, if it is successfully concluded, clinical equipoise will be disturbed." It follows from condition (2) that a trial be designed such that the inference about treatment effectiveness in the general population, which generalizes the evidence found in the trial's study sample, is as strong as possible. In so doing, the threat to equipoise is maximized.
But what must be done to maximize the strength of a generalization? Drawing on work from James Griesemer and Michael Wade in evolutionary biology, I argue that one of the heuristics they identify in their research on group selection models can be extended to analyze the inferential strength of generalizations from clinical trials.
Griesemer and Wade claim that the strength of inferences from the results of laboratory models to natural systems depends upon the extent to which the former is a plausible subset of the latter. Such a heuristic illuminates an important and general relationship between experimental design and the strength of inferences: The more simplifying assumptions are made in a design, the less the experimental system resembles a ``natural'' system, and the weaker the inference becomes.
I conclude that for clinical trials, Griesemer and Wade's heuristic suggests that generalizations from trial results are stronger when trial designs are pragmatic, rather than explanatory, and entry criteria are minimized.

C103: Extending Equipoise to Phase 1 Trials: A Bridge Too Far?

Author(s): *James A Anderson; Jonathan Kimmelman*

Notwithstanding requirements for scientific/social value and risk/benefit proportionality in numerous national and international guidelines for research involving human subjects, there are no widely accepted standards for judgments concerning risk, benefit, and value in phase 1 trials. In this paper we examine whether a principle applied elsewhere in research ethics – the principle of clinical equipoise (CE) – might be extended to phase 1 trials. This suggestion is attractive because, among other reasons, CE is already regarded by many as a keystone in the moral foundation of late phase trials. We conclude that the extension of CE to at least certain categories of phase 1 studies – in this case, first-in-human (FIH) trials – faces three major problems. Two of these relate to the epistemic aspects of CE: (1) FIH trials are generally initiated before a state of "imminent" conflict has arrived in the expert clinical community; and (2) FIH trials do not seem to disturb CE in any meaningful sense. The third problem relates to the ethical function of CE: (3) FIH study architecture is often inconsistent with therapeutic warrant as traditionally understood. These three challenges, however, also suggest the way forward. An alternative normative framework for FIH trials must satisfy four desiderata: (1) it must provide an evidentiary standard for initiating FIH studies; (2) it must spell out what counts as a decisive FIH trial result; (3) it must provide a standard for an acceptable risk-knowledge ratio; and (4) it must reconcile referral to, or conduct of FIH trials, with sound clinical care.

C104: Health-care Professionals' Perceptions of Nutritional Genomics

Author(s): *Mark Weir; Karine Mori; David Castle*

Nutritional genomics has advanced to the stage where commercial laboratories are providing genotyping services to provide personalized nutritional advice based upon an individual's genetic predispositions. Testing for nutritional genomics is primarily performed by American companies however, Canadians are free to pursue these services online. Direct-to-consumer genetic services have raised concern amongst health-care professionals and regulators in Canada as to how they might affect health service delivery in the future.

This study explores social, legal, and ethical issues involved with health-care professionals adapting to new genomic applications in clinical practice. As different health-care professions have different knowledge bases with regards to genomics, exploring which professions might be better suited to incorporate counseling on nutritional genomics into their practice may provide some direction on how health service delivery might adapt with these evolving applications.

The aim of the research was to explore a variety of health-care professional attitudes towards nutritional genomics (physicians, pharmacists, dieticians, nutritionists, and naturopaths), as well as gauge their capacity to be able to provide counseling advice to this new form of genomic application. Focus groups allowed participants to describe their perceptions of nutritional genomics. Data analysis involved identifying key themes which depicted participant attitudes, as well as identify which professions are more comfortable or suited to provide clients with knowledge, expertise, and clinical advice. Results will be presented.

C105: Conceiving the post-Prozac Self

Author(s): *Samantha Copeland*

This paper takes up the discussion about Prozac's impact on our conceptions of the self. Prozac makes some patients "better than well," and I argue in this paper that an analysis of this phenomenon provides insight into the relationship between the self and technology. As the particular effects of Prozac this paper examines tend to fall into the category of enhancement, the merits of the medical health paradigm being used in the research and distribution of Prozac is critically examined. This paper begins that analysis by drawing on three alternatives for conceiving the post-Prozac self, from the work of Peter Kramer and Jacqueline Zita.

C106: **Paediatric Advance Care Planning: Evidencing the Birth of a Paediatric Goals of Care Designation Policy in the Calgary Health Region**

Author(s): *Anna Zadunayski, Glenys Godlovitch, Sharron Spicer*

Recent Canadian cases have focused attention in ethics discourse on advance care planning. As a result, we recognise the need for an entrenched process of discussing treatment options and establishing long-term care goals. While frameworks for advance care planning have existed for adult populations, there is a paucity of information regarding how best to approach advance care planning in the paediatric context.

A novel advance care planning policy was recently developed within the Alberta Health Services (Calgary Health Region), including a paediatric policy in recognition of paediatric health professionals' clinical and ethical obligations to engage patients and families in conversations regarding goals of care. This new initiative provides a communication tool for paediatric health care professionals, to assist in rapid decision-making in times of crisis, and also to guide health care professionals, children and families regarding locations and intentions of care and interventions that will be provided. For children with life-threatening illnesses, standardised Goals of Care Designation orders will be documented on the health record to enable all paediatric medical staff to respect the carefully-considered wishes of children and families.

This paper discusses the nuances of paediatric advance care planning by exploring key differences between the paediatric and adult frameworks, including (1) location of care, (2) mature-minor decision-making, (3) potential conflicts, and (4) stakeholder buy-in including implications for schools and emergency medical services (EMS). The authors explore the impetus, development and implementation of the Calgary paediatrics policy, and discuss recent cases highlighting the importance of the initiative.

C107: Masking mental health information within the electronic health record : considerations raised in a regional ethics consultation

Author(s): *Connie Mahoney, Stacey Page, Susan Rich, Roxanne Rowan, Information Management*

Patients receive health care from multiple venues. Consequently their health information is typically held in numerous locations and the information held in each may vary. The move to electronic health records (EHR) is driven by the goals of improving quality and efficiency in health care as all information is held together and accessible electronically. Information, like that about STDs/HIV and mental health, is considered sensitive by some. If information is held in a single, electronic record, some argue that its contents should not be uniformly accessible: certain types of information within the record should be "masked" requiring special processes or permissions for access. The CHR mental health and addictions ethics committee recently facilitated a consultation on masking mental health information within the EHR. Stakeholders included clinicians, consumers and advocates, IT professionals, and ethicists. The discussion considered the capacity of current technology to mask portions of the health record and arguments for and against this practice. Arguments heard in favor of masking included respecting patient's autonomy in decisions regarding information disclosure, patients' rights to confidentiality, and patients' experiences of stigma from health care professionals outside the discipline of mental health. Arguments against the practice of masking focused on patient's well-being and health care providers need to readily access all health information in order to provide optimum care. Before a final decision can be made, further public consultation and clarification of professional record keeping standards is required. An urgent need to reduce stigma attached to mental health patient was also identified.

C108: Use of data from the electronic health record for health research – current governance challenges and potential approaches

Author(s): *Don Willison*

The common interoperable electronic health record (EHR) will create expanded opportunities for health research. However, important questions are not being addressed by planners, including:

- indistinct boundaries between research and other secondary uses exempt from consent;
- whether and how people should be informed of those uses;
- the limitations of current models of consent to address registries and biobanks;
- the absence of mechanisms for eliciting and documenting consent choices;
- whether information from the EHR can be used to screen patients for potential research participants; and overlapping responsibility for oversight of research uses and a vacuum in leadership in governance.

The paper frames research and privacy protection as two public goods. Areas of tension exist between them, and suggestions are made how they may successfully co-exist, including:
dissolution of artificial boundaries between research and quality improvement, system planning, and public health,

- with a proportionate approach to ethical review of all secondary uses;
- an expanded approach to consent, and mechanisms for eliciting and documenting consent choices for future uses;
- limitations on who may develop and operate registries and biobanks;
- an institutional approach to safeguards;
- specialized review bodies for individual research proposals;
- a mechanism for oversight of management of data and tissue research repositories; and greater public participation in the governance processes.

Attention needs to be given now to these matters, lest the current process lead to further insufficient and inefficient *ad hoc* approaches rather than the establishment of a holistic solution.

C109: Ethical Use of RFID Technology in the Surveillance of People and the Tracking of Things in Healthcare Delivery

Author(s): Michael J.Wilson

The technological use of healthcare information using Radio Frequency Identification (RFID) systems comes replete with a plethora of privacy guidelines, rules, regulations, legislation and laws. There are burgeoning numbers of applications of RFID technology in healthcare, from resource location systems to patient location systems. The use of RFID technology in healthcare generally does not present any more privacy or security concerns than other forms of data collection technology, like Personal Digital Assistants (PDAs), Blackberries, notebooks, or other radio frequency medical devices running on wireless network systems. Since many of the RFID applications in healthcare have been modeled upon supply chain management practices like asset tracking, the social dimension, especially in clinical care, must be carefully considered. Healthcare professionals may not like the idea of being tracked like products in a supply chain if they are not allowed to consent to surveillance. They will lose their sense of personal autonomy. There may be mandatory monitoring or tracking of people in the middle of a pandemic, but on a normal shift, a healthcare professional might not feel comfortable being blanketed with "ubiquitous wireless technology" that tracks their every move. This paper will demonstrate that there are barriers to implementing RFID in healthcare in current research and evaluations, but on the whole it is very "human friendly" and ethical. Provided of course, one stays away from subcutaneous implants of RFID chips into patients and potential future patients.

C110: The Use of Meconium Testing : A Regional Health Authorities Response to a Growing Practice

Author(s): *Sarah Gebauer, Lynne Palmer, Bashir Jiwani*

Leaders from the Department of Obstetrics and Neonatology requested support from Ethics Services at our large RHA both to develop guidelines for a regional approach to requests for meconium testing.
This paper will discuss the background leading up to this request, the process used to work through the issue, and the overall outcome of the work engaged by the group. It will also discuss the challenges faced in implementing the guidelines as well overall impressions of the process and outcome, along with anecdotal feedback from those affected by the guidelines.

Meconium testing is a reliable test to determine drug use throughout pregnancy. The test is predominantly ordered by physicians and at the request of the Ministry of Children and Family Development (MCFD). It is often used as a means for testing new mothers for the past use of illicit street drugs. The use of the test is controversial because the findings may result in the removal of a child/children from a mother's custody.

There is a lack of consensus on the aims, purpose, and use of meconium testing; as a result, front-line staff required direction on how to approach this issue. Over a period of several months, a group with representatives from a variety of health professions and local leadership, met to review the issue using an ethics decision process aimed at developing an explicitly values based response.

C111: Authentic Research Relationships to Improve Aboriginal Health

Author(s): *Julie Bull*

Despite ongoing research and government programs aimed to improve the health of Canada's Indigenous Peoples, evidence shows that improvement is minimal. Community engagement and involvement in research has been shown to yield practical outcomes that can used by communities themselves to improve community health.

This paper includes a report on a study examining the use and uptake of the CIHR Guidelines for Research Involving Aboriginal Peoples (2007) and an environmental scan of current research ethics processes in Labrador. The results indicate that communities and researchers should strive to build "authentic relationships" throughout the research process. The researcher has established such a relationship with the Labrador Innu, Inuit, and Metis. This relationship was built on respect and reciprocity through ongoing consultation and negotiation. The best practices and methods from this study challenge the status quo and pave the way toward a different research paradigm. This shift to holistic methodologies informed by indigenous and non indigenous ways of knowing can be utilized in various contexts in Canada and Internationally.

C112: Ethical and social challenges in healthcare for adolescents and young adults with cerebral palsy

Author(s): *Danaë Larivière-Bastien, Eric Racine*

Cerebral palsy (CP) is the most frequent cause of physical disability in children. More than 50 000 Canadians are affected, but the ethical challenges faced by young people with CP are infrequently discussed. However, healthcare decisions may raise important ethical issues such as respect for autonomy and confidentiality. To identify and characterize the ethical and social issues faced by young people with CP, we conducted an extensive literature review by using many databases such as PubMed and PsycINFO.

Our critical analysis of the review has identified significant ethical challenges faced by young patients with disabilities, including:

1) transitional challenges from pediatric to adult healthcare services;
2) respect of confidentiality and privacy;
3) respect of autonomy and informed consent;
4) efficient communication and health information;
5) trustful provider-patient relationships;
6) equitable access to healthcare.

Our research has identified some ethical and social challenges faced by young patients with CP. To our knowledge, no such analysis has been reported in spite of the prevalence and implications of CP. Given the embryonic state of literature, it would now be important to further examine these issues using qualitative methods.

C113: Culturally Sensitive Obstetrical Care for Canada's Aboriginal Women Living in Urban Centres

Author(s): *Robyn MacQuarrie*

In recent years, there has been a much needed move towards culturally sensitive obstetrical care for Canada's Aboriginal women. This movement has been well supported by national organizations responsible for the obstetrical care of Canadian women, as evidenced by the 2007 Society of Obstetricians and Gynaecologists of Canada (SOGC) guidelines calling for a return of birthing to Aboriginal communities.

To date, efforts at improving obstetrical care in the pursuit of culturally sensitive care have focused primarily on Aboriginal women residing in remote rural locations. While this work is important, and the resulting changes in practice are encouraging, the needs of the majority of Aboriginal women remain unmet because of the trend among Aboriginal peoples in Canada towards regionalization. As reported in the 2006 census, 54% of Canada's Aboriginal people reside in or near urban centers; this represents an important shift as compared with earlier census data. This shift makes it imperative that the obstetrical care provided in these regions be more culturally sensitive.

While many large health care facilities in urban centers support mandates of non-discrimination, there are few well-developed culturally sensitive care models in place to meet the obstetrical care needs of Aboriginal women residing in or near larger cities. Appreciation of this issue requires an understanding of the barriers to culturally sensitive care delivery with particular attention to the "who" the "where" and the "how" appropriate care needs to be delivered followed by analyzing the components of successful models in which culturally sensitive care is a primary objective.

C114: The Dependent Adult Donor : A Challenge for Canadian Health Law and Health Policy

Author(s): *Brian R. Forzley, Anna C. Zadunayski, Rose Geransar, Isabelle Chouinard, Allen Dong, Glenys Godlovitch*

Transplant programs occasionally consider donation involving Dependent Adults (DA). Published literature and existing health policy offer little guidance on whether such donation should occur. The analogy of pediatric transplantation, while intuitive, has important limitations. Such donation may prevent harm to the DA, and save the life of another person, particularly if the recipient is a key care provider to the DA. This donation simultaneously raises concern for society abusing the rights of vulnerable persons: the historical and legal context of the *Sexual Sterilizations Act* lends credence to these concerns. In contrast, recent recognition that DAs should have a voice in such decisions cautions us against an overly paternalistic position of precluding donation.

We briefly consider the clinical and legal context of donation involving DAs. We outline the implications of this donation from a principle-based perspective, including paradoxical aspects of respect for persons and ambiguity surrounding beneficence. Using the example of Alberta's *Sexual Sterilization Act*, we highlight the importance of virtue and care while applying these principles.

We maintain organ donation should not preclude DA donors, and that each case must be carefully considered. We propose seven features of an ethically defensible donor involving a DA donor, intended to guide decision making that avoids abusing this vulnerable population. This proposal should aid development of ethically sound health policy.

C115: Does high-fidelity simulation facilitate staff preparation for the ethical and clinical care of patients and families in Donation after Cardiac Death (DCD)?

Author(s): *Barb Jennings, Maggie Zeman, Dianne Norman, Barb Flaherty*

Ethical issues associated with Donation after Cardiac Death (DCD) can be anticipated due to its infrequency in Canada, and the lack of knowledge of the process. It is necessary to recognize and apply core ethical values. These include respect for life and dignity of the donor, respect for family, and respect for professional integrity. Healthcare providers' knowledge and familiarity with DCD remains a barrier to successful implementation; this may be ameliorated by mock DCD scenarios.

A multidisciplinary committee investigated potential ethical issues, scenario complexities, medical fidelity, DCD literature and high-fidelity simulation. Objectives were established including a detailed timeline and patient scenario description. The full simulation involved a multidisciplinary team providing care to both the 'patient' and the standardized family from the Paediatric Critical Care Unit until the declaration of death in the operating room. Following the simulation, a recorded debriefing captured feedback from staff. Feedback combined with simulation multimedia was used to develop educational materials.

Debriefing revealed high-fidelity simulation to be effective in educating staff about the necessary inclusion of ethical values into the DCD process. Staff reported that it was the most realistic and effective simulation they had experienced. It was a positive introduction to the process.

Final revisions to the educational material, which is currently being piloted, will be completed based on the feedback. Once completed, the education materials will be presented to teams within the organization to help increase knowledge, familiarity and understanding of the roles in the DCD process.

C116: Can Ethics Really Be Taught? An Ethics Education Agenda for A Canadian Regional Health Authority

Author(s): *Bashir Jiwani, PhD, Sarah Gebauer, MA*

This paper provides a discussion of the ethics education approach taken at one of Canada's largest health authorities. The paper covers:

- The broad goals of the education agenda, ranging from general awareness raising about the role of ethics in clinical and organizational practice to developing skills for systematically guiding teams through specific issues using ethics decision tools;
- The rationale and justification for this approach, including a description of the history and context of the regional ethics service;
- The specific strategies used in the education agenda, ranging from co-hosting annual ethics conferences to an annual intensive bioethics skill and knowledge development course;
- The findings of the evaluation of the education initiatives;
- The overall strengths of the education program, including the proliferation of a shared language for discussing issues, increases in the numbers of people able to champion explicitly ethics-based analysis of issues and growth in capacity identify the salient ethics dimension of issues;
- The challenges of the program, including missed opportunities and resource constraints; and
- Future education directions for the ethics service intended to broaden the reach and systematically target the identified gaps.

The presenters seek to share their experience and learning and hope to benefit from the experiences of audience members who are involved in the delivery of ethics education services themselves.

Workshops

W01: Teaching Ethics to Medical Students: Achieving Effectiveness through Relevant Content and Respecting the Adult Learner

Author(s): *Dan Reilly*

The literature on medical students' ethical development through training indicates a gradual decline in ethical thinking. Ethics teaching has not been shown to impact this negative change. This may reflect the informal and null curriculum impacting medical students' behavior to a much greater degree than the formal ethics curriculum. The formal curriculum may be more effective if:

1. It directly addresses ethical challenges faced by students
2. It follows adult learning principles

Ethics teaching provided to McMaster University students during their obstetrics and gynecology clerkship fulfills these two principles and has been well received by the students. The design and implementation of these teaching sessions will be reviewed. Participants will share their successes and failures in teaching ethics so everyone can improve the effectiveness of ethics teaching for medical students.

Workshop Outline

Target Audience: This workshop would be aimed at those providing ethics teaching to medical students.

Objectives: Review the literature regarding medical students' ethical development through undergraduate medical training.

Review the impact of ethics teaching on medical students.

Review the concepts of formal, informal, and null curriculum and apply this to teaching ethics.

Review the principles of adult education and apply these to the teaching of ethics to medical students.

Present the design of ethics teaching during the obstetrics and gynecology clerkship at McMaster University as an example of adult learning theory applied to ethics teaching.

Review the main ethical issues faced by medical students.

Brainstorm approaches to teaching ethics to medical students and share successes and failures of workshop participants.

Proposed Workshop Timeline:

Objectives 1 and 2: 10 minutes of didactic teaching

Objective 3: 5 minutes of didactic review. 10 min of participants brainstorming examples of the informal and null curriculum in their teaching environments

Objective 4 and 5: 10 minutes didactic teaching

Objective 6: 5 minutes presented by workshop leaders, 10 minutes of participant discussion

Objective 7: 40 minutes facilitated discussion by participants

W02: Bioethicists' Reflections on Proposed Changes to the TCPS (Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans

Speakers: Panelists: Françcoise Baylis (Dalhousie University), Jocelyn Downie (Dalhousie University), Jonathan Kimmelman (McGill University), Michael McDonald (University of British Columbia), with input from Susan Zimmerman (Executive Director, PRE) and Norman Frohlich (Chair, PRE). Moderator: Susan Sherwin

The Interagency Panel on Research Ethics (PRE) has undertaken a substantial revision of the TCPS and has circulated a Draft 2nd Edition of the TCPS and invited input on this draft until June 30, 2009. Panelists will share some of their thoughts on the document and offer their advice re its content and wording. The workshop format will also provide opportunities for participation from other members of the CBS who are interested in Canadian policy regarding the ethics of research involving humans.

W03: Shaping a Canadian Agenda for Research Ethics

Author(s): *Michael McDonald*

In research ethics, the predominant concern has been with formulating ethically correct norms for the conduct of health research involving humans. Recently, however, a number of bioethicists have called for much greater attention to evidence for those norms. This includes evidence that the norms are being followed and that the rules, regulations and governance arrangements actually achieve their stated ends. To further these objectives a number of Canadian bioethicists active in the study and practice of research ethics came together to form the Canadian Network for the Governance of Ethical Research Involving Humans. The Network focuses on issue involving "Evidence, Accountability and Practice". The Network is supported by a three-year CIHR grant.

This workshop will focus on articulating a shared practical and scholarly agenda for those involved in Canadian research ethics. There will be a short introduction by McDonald followed by brief presentations from Pullman, Upshur, and Weijer in which they put forward items for a shared agenda. These include ethical issues arising in Phase IV clinical trials, new modes of governance, REB review of longitudinal studies and biobanks and REB assessment of potential risks to research participants.

There will then be an open discussion of possible items for a shared Canadian agenda for research ethics. Based on notes taken during the workshop a summary will be presented at the end of the session.

W04: Case discussion of ethics in conditions of disaster and deprivation: learning from health workers' narratives

Author(s): *Lisa Schwartz, Matthew Hunt, Chris Sinding, Laurie Elit, Lori Luther, Lynda Redwood-Campbell, Naomi Adelson, Jennifer Ranford, Lucy Langston*

This workshop is drawn from the findings of a CIHR funded study of the ethical challenges reported by health care professionals providing humanitarian assistance in resource poor and disaster or conflict settings. The objective of the workshop is to use case discussion to introduce some of the ethical issues associated with health related humanitarian aid work, and describe the distinct (and familiar) ethical issues that arise in these contexts. We will begin by presenting a summary of the findings to date based on 26 qualitative interviews with health care professionals and students who have volunteered abroad as part of medical school electives. Three cases will be presented as examples of some of the more acute, and more frequently reported, issues described by respondents, with commentary from among the co-investigators, each of whom brings a unique scholarly background to the discussion. Disciplines represented are medicine, law, philosophy, physiotherapy, anthropology and sociology. Each case will be presented followed by commentary from the team and then open discussion with participants of the workshop.

Topics addressed will include:

Role and 'response ability': Canadian clinicians who participate in international work in a local medical system that has different hierarchical expectations.

Duty to warn: Local nurses attempt to protect a patient from the news of an HIV diagnosis by resisting the foreign doctor's decision to disclose.

Resource limitations and moral distress: An exploration of the ways in which humanitarian health care providers cope with the challenges of poverty and access to fair levels of care.

W05: Palliative Sedation Workshop: Stakeholder Engagement to Inform National Guideline Development

Author(s): *Victor Cellarius, Blair Henry, and Sally Bean*

Palliative sedation has been used in end-of-life care for over a hundred years, but has undergone close consideration over the last two decades. Though a growing consensus is appearing on appropriate indications, administration, and intent in utilizing this therapy, many clinical, legal, and ethical points of contention remain. In the spring of 2008, a working group, comprised of palliative care physicians and ethicists from across Canada, began developing guidelines for the practice of palliative sedation. The working group favors deliberative stakeholder engagement, and this workshop will become an informal part of this process.

The workshop will have four parts: 1) The session will commence with an overview of the nature and development of palliative sedation with a focus on areas that remain clinically, legally, and ethically contentious 2) participants will be asked to consider and discuss two cases that highlight areas of consensus and contention 3) small group discussion will aim at determining the key principles and practice guidelines that would define movement towards consensus on highly contentious issues 4) summary.

This workshop-based discussion will provide value-added experience for both organizers and attendees by educating participants, encouraging discussion, and informing the palliative sedation guideline development process.

W06: Qualitative Ethics Research: Evidentiary Needs and Directions

Author(s): *Leigh Hayden, Andrea Frolic, and Mona Gupta*

Purpose The purpose of this workshop is to encourage discussion and communication regarding: 1) the role of qualitative research in addressing ethical questions, 2) the challenges posed by qualitative methods, and 3) how to effectively transfer the knowledge developed in qualitative research.

Background Historically, bioethics has been divided into two sub-disciplines: theoretical ethics and applied ethics. Theoretical ethics is concerned with moral and philosophical arguments, while applied ethics is generally concerned with how to shape policy and practice. More recently, researchers have been using empirical approaches to inform arguments made in both theoretical and applied ethics. Empirical research has made significant contributions to the field, elucidating important information such as: the variability in how research ethics board policies (Willison and colleagues 2008), the role of trust in research ethics (MacDonald et al 2008) and measuring fairness of health policy (Light 2004). Scholars are encouraging bioethicists to support policy, practice, and theory with evidence (Sugarman 2004), and in particular social scientific evidence (Burgess 2007). Some researchers believe empirical research has the promise to bridge the two sub-disciplines of applied and theoretical ethics (Russell 2008).

Bioethics is a complex area, incorporating diverse topic areas such as: hermeneutics, subjective experience, relations of production, power/knowledge, and spirituality. Its diversity poses specific and significant challenges to traditional qualitative research approaches and methods. In addition, the socially important and temporal nature of bioethics research place increased demands on knowledge translation, an activity in which few qualitative researchers have expertise. These issues encourage the authors to ask what research questions are important to the field right now, how qualitative research might (and might not) significantly add to the field of empirical ethics, and how and to whom that knowledge can and ought to be relayed.

Learning Objectives Through a panel and group discussion, attendees will learn: (1) what areas of bioethics are important to funders and healthcare providers and what research questions these needs raise; (2) the challenges of employing qualitative research methods to ethical debates and dilemmas and fruitful qualitative methods to employ for ethics research questions; (3) knowledge transfer ideas for bioethics research.

Workshop Format Because the purpose of the workshop is to spark discussion and share ideas, there will be multiple opportunities for participants to present their ideas, ask questions, and engage with the panel and each other. Each section will start with small group discussions of the topic area, in which attendees will share their ideas and experiences and then relay those to the larger group. Then, panellists will present their own experience and reflections. Finally, all panellists and attendees will engage in an open discussion about the topic area. The authors will be the panellists for Topic 2, and invited guests will be panellists for Topic 1 and Topic 3.

Workshop Agenda Goals and learning objectives of the workshop. (2 min)
Introduction: panel members and workshop attendees introduce themselves. (5 min)
Topic 1: areas of bioethics ripe for qualitative research. (20 min)
Topic 2: methodological and instrumental challenges and opportunities for qualitative ethics research. (40 min)
Topic 3: knowledge transfer and ethics research (20 min)
Closing (3 min)

Outcomes Participants will increase their capacity to identify research topics in bioethics where qualitative methods can enhance the research program. They will also increase their understanding of how to best employ qualitative methods to meet the demands of bioethics research. Finally, participants will deepen their familiarity with successful knowledge transfer activities for qualitative ethics research.

At the end of the workshop, attendees will be more familiar with: (1) what areas of bioethics are important to funders and healthcare providers and what research questions these needs raise; (2) the challenges of employing qualitative research methods to ethical debates and dilemmas and fruitful qualitative methods to employ for ethics research questions; (3) knowledge transfer ideas for bioethics research.

Those who wish will be emailed a transcript and summary of the workshop to keep for their own work and distribute to colleagues.

W07: FAB Panel
"Feminist Interrogations of Evidence-Based Medicine"
Bluhm: 'Incorporating patient values' and relational theories of autonomy
Borgerson: Feminist epistemology and the ethics of uncertainty in medicine
Goldenberg: An ethics of evidence: feminist considerations
Kukla: No evidence-based medicine without evidence: the paradox of pregnancy exceptionalism

W08: Public Health Ethics And Professional Development: A Collaborative Model of Engagement
Author(s): *Public Health Agency of Canada*
Bridging the government, academic, and professional public health divide this workshop will summarize ongoing collaborative work in the area of public health ethics and professional development. A summary of recent case-based engagement activities in Ontario will be provided from both academic and public health perspectives. Additionally, The Public Health Agency of Canada will highlight ongoing capacity building work in public health ethics and professional development. The workshop will conclude with a discussion on future opportunities for engagement, integrating public health ethics into professional development activities and building a strong foundation of post-secondary education in public health ethics across Canada.
Objectives:

- To summarize continuing work in Public Health Ethics and Professional Development
- To identify those with an interest and/or expertise in Public Health Ethics
- To foster future opportunities for collaboration and action in Public Health Ethics

Posters

P01 Title: Informed consent for functional neuroimaging research: Review of Canadian practices
Author(s): William Affleck[1], Constance Deslauriers[1,2], Nicole Palmour[1], Julien Doyon[2], Bruce Pike[3], Jonathan Kimmelman[3], and Eric Racine[1,2,3]
Background Functional neuroimaging research has expanded the horizon of neuroscience to new frontiers including the examination of brain activity in personality, social behavior, and decision-making. This research relying on techniques such as fMRI (functional Magnetic Resonance Imaging) and PET (Positron Emission Tomography) carries the capacity to contribute to basic knowledge, healthcare approaches, and social interventions. Due to the nature of the equipment involved, and its expanding use, neuroimaging research represents physical, psychological, and social risks. Accordingly, research ethics boards (REBs) need to tackle the unique attributes and applications of neuroimaging research. One vignette-based study has shown wide-ranging Canadian REB opinions. Based on the rapidly evolving context of neuroimaging and previous research suggesting REB variability, we examined approved informed consent forms of Canadian neuroimaging research protocols.
Methods We collected approved informed consent forms as part of an ongoing research project on research ethics in Canadian neuroimaging. Participating researchers were invited to submit their two most recently approved informed consent forms. We systematically analyzed informed consent forms for: (1) basic items of informed content as required *per* regulations (e.g., statement of the research purpose, identity of the researcher); (2) basic items of informed content not necessarily required by regulations (e.g., anticipated uses of data, responsibilities of the subject) and (3) qualitative analysis of language used to report salient issues (e.g., incidental findings, confidentiality).
Discussion We comment, based on our data, on the sharing of approaches and experiences between REBs, the trade-offs of standardizing multi-site review, and the complexity of managing incidental findings.

P02 Title: Elective Caesarean Section: How Clear Medical Evidence Fails to Produce Ethical Consensus
Author(s): *Dan Reilly*
Elective caesarean section (ECS) is an example of applying medical evidence to an ethical debate and failing to produce consensus. Studies show that, compared to labour, ECS is associated with greater risk of morbidity and mortality. Thus the International Federation of Gynecology and Obstetrics (FIGO) has declared ECS unethical. Yet obstetricians worldwide continue to perform ECS. FIGO's argument from beneficence and non-maleficence has failed to be persuasive because it makes two false assumptions.
The first is that all medical complications have equal significance for obstetricians and patients. For example, caesarean section increases risk of excessive maternal blood loss while labour increases risk of pelvic floor trauma. Studies assign these and other complications equal weight as "morbidity" and find labour is associated with the lesser risk of morbidity. But the patient or obstetrician who believes that pelvic floor trauma is a far greater harm than blood transfusion may disagree with FIGO based on the principles of beneficence and non-maleficence.
The second assumption is that obstetricians are willing to deny patient autonomy based on small risk of morbidity differences between elective caesarean section and labour. An obstetrician may believe that caesarean section carries a small increased risk but that respect for patient autonomy justifies taking that risk.
If FIGO wishes to persuade all obstetricians that ECS is unethical it must address differing opinions on the degree of harm caused by different types of morbidity and patient autonomy concerns.

P03 Title: An Ethical Framework
Author(s): *Judy King*
While most professionals involved in healthcare ethics commended CCHSA on its efforts to strengthen the role of ethics in healthcare, confusion has been expressed regarding the use of the phrase 'ethics framework'. The meaning of this term is uncertain and how it should be operationalized is less clear. Is an 'ethics framework' a policy or a decision-making tool?
An Ethics Framework for Southlake needed to meet the Accreditation standards/guidelines and address the needs identified through a Southlake hospital ethics scan.
The Framework is captured on a one page diagram (see attached). Southlake's guiding values and ethical principles, at the top of the diagram, are used at a very high level to guide decisions. Under these guiding principles rests the pillars of our Ethics Program, with defined roles: Clinical Ethics, Organizational Ethics and Research Ethics. Beneath each of the pillars are the documents, decision-making tools and resources, thought essential by Southlake and Accreditation Canada, to support all staff in ethical decisions. Below these tools, the Ethics Program sits as a

foundation for the structure above. Within the Ethics Program area, the roles and expectations of the HEC and Clinical Ethics team are detailed. The patient and HCT are situated within the framework, integral to all the processes. Arrows illustrate the flow of information/influence and the bidirectional flow between the Ethics Program and Framework above. The Framework meets the CCHSA ethics guidelines by including values, showing integration of all ethics programs, processes for handling ethical issues, legal requirements etc. It can be used within the organization and displayed publicly.

P04 Title: A Canadian Primary Care chronic disease Sentinel Surveillance Network (CPCSSN): Strategies developed to ensure patient privacy and ethical conduct of research.

Author(s): *Kotecha J., Manca D, Birtwhistle, R., Keshavjee K., Drummond N., Godwin M., Griever M., Lussier M-T., Stewart M., Rosser W., Moore M., Green M., Lambert-Lanning A., Grava-Gubins I.*

Context: Surveillance data enables policy makers and healthcare providers to understand disease prevalence, health maintenance, disease risk factors, and treatment outcomes. This project involves primary care research networks (PCRNs) in Alberta, Ontario, Quebec, and Newfoundland during phase I, which focuses on feasibility; expanding during phase II to include British Columbia and Manitoba in order to establish a data repository for research. The aim is to develop an electronic chronic disease surveillance network that follows cardiovascular disease, chronic respiratory disease, mental health disease, arthritis, and diabetes while respecting patient privacy. This project is funded by PHAC to the College of Family Physicians of Canada.

Objectives: 1) Establish policies for obtaining patient consent, REB approval, and ensuring patient privacy; 2) Establish a pan-Canadian primary care sentinel surveillance network; 3) Extract and validate chronic disease health information; and 4) Establish a central data repository for the conduct of primary care chronic disease surveillance and research.

Methods: Develop methods, standards, and policies to ensure patient and physician privacy, ethical recruitment, secure data collection and transfer, reliable validation, analysis, and reporting.

Conclusion: This team has developed pan-Canadian strategies that enabled the collection of anonymous health information from EMRs at participating family practice sites. In this poster presentation, we describe 1) Ethical and privacy issues encountered during the REB approval and practice recruitment phase; 2) The approach established for patient consent and adequate privacy compliance; and 3) Through diagrams, how data security was developed and is maintained during transfer and storage at the central repository.

P05 Title: Impact on parents of receiving individualized feedback on the results of language and developmental testing conducted as part of a research study.

Author(s): *Kelly Cox, Nancy Bandstra, Conrad Fernandez, Christine Chambers, Tessa Craig*

Background: Returning research results in summary form to participants has become more commonplace. Some believe that participants should also be offered their individual results, if valid and reliable. There has been little research examining the impact on parents of receiving individual results from their child's research participation. It has been hypothesized that parents will value receiving results; however, unexpected or negative results may cause distress.

Methods: Participants were parents of healthy children aged 18-36 month who participated in a study in which validated parent-report measures of their general (Child Development Inventory) and language development (MacArthur Communicative Development Inventory) were administered. Individualized results about their children's performance were mailed with a piloted and validated Impact Questionnaire assessing their emotional and behavioural reactions to this feedback. CDI scoring was 100% in the average range and for the MacArthur: 86% average; 10% below and 3% above.

Results: Return rate 55% (n=52). Receiving results was a positive experience for 75% of parent participants, with 25% feeling it was "neither positive nor negative" and none feeling negative. Participants found the results to be "helpful" (44%) or "neither helpful nor unhelpful" (50%) and only 6% of parents found it "unhelpful". All participants felt receiving the results by mail was appropriate and 92% would choose to receive research results again.

Conclusions: Receiving individualized results can be a positive experience for parents; however, even when the results indicate average scores, parents describe mixed emotional responses. A prospective plan to offer support when returning research results appears to be important.

P06 Title: Assessment of Children's Capacity to Consent for Research: A Descriptive Qualitative Pilot Study of Researchers' Practices and REBs' Expectations

Author(s): *Barbara E. Gibson, Shawna Gutfreund, Maria McDonald, Lauren Dade, Elaine Stasiulis*

Issue: To describe current practice of Toronto-based child health researchers, and the expectations of Ontario Research Ethics Board (REBs) regarding assessing children's capacity to consent to research.
Research Questions: 1. a) What procedures are used to *obtain consent* in research involving children? b) How is *children's capacity* determined? 2. What are the current requirements of Ontario REBs for capacity assessment?
Methods: The first research question was addressed through qualitative face-to-face interviews with 15 child health researchers and research assistants in the Greater Toronto Area. The second question was addressed through a telephone survey of Ontario children's health facility REBs (N= 8).
Results: Two of the eight REBs participating in the survey had basic guidelines (e.g. age criteria) in place for assessing capacity. None of the REBs recommended any specific tools/methods for assessing capacity. In the qualitative interviews, researchers identified several challenges in assessing capacity and seeking consent including: determining the appropriate role of parents in the capacity assessment and consent process, doubts regarding whether any research subject truly provides 'informed' consent, beliefs that researchers' methods of assessing capacity may not be sufficiently 'scientific', and potential discrepancies between the knowledge and training of clinician researchers versus non-clinician researchers and assistants.
Next Steps: The results of this pilot study will guide the development of a national study aimed at producing legally and ethically grounded capacity assessment guidelines for researchers and REBs in jurisdictions where children's ability to consent to research relies on capacity assessment (rather than age alone).

P07 Title: The Ethical Significance of Patient-Reported Outcome Measures

Author(s): *Leah McClimans*

Patient-reported outcomes are increasingly used as evidence regarding decisions about appropriate patient care, patient satisfaction, quality of support services, unmet needs and appraisal of health and health care options. The popularity of measures that report these outcomes is no doubt part of a larger initiative to provide patient-centred care. Yet Patient-Reported Outcomes Measures (PROMs) rarely figure in the bioethical literature. In this paper I will argue that ethicists and social scientists alike have overlooked the ethical significance of PROMs.
I suggest that this significance is two-fold. Firstly, PROMs are used to answer a multitude of questions supposedly supported by the patients' perspective. Yet little ethical work has been done to determine whether or not such claims are legitimate. I will argue that as things stand these claims are not legitimate and that medical ethicists ought to be involved in the critique and development of PROMs. Secondly, the introduction of PROMs into health care research implies that patients' experiences are fundamental to our understanding of health and illness. But this recognition means that health status cannot be determined independent of considerations of the good. For different understandings of what makes for a good life will affect how different individuals experience health and illness. This suggestion has consequences for bioethicists and social scientists. For the latter it means that valid PROMs must grapple with the normative character of these outcomes; for the former it means that bioethicists may be well placed to shed light in the analysis of the outcomes.

P08 Title: The Experience of Working Age Adults in Residential Care

Author(s): *Sarah Chapple*

Long-term care residents between the age of 45 and 60 often face unique challenges while living in a residential care facility designed for a geriatric population. When a working age adult enters residential care, they often experience significant adjustment and relocation stress that can stem from issues not addressed by services designed for seniors. The existing literature shows a gap in knowledge about the experience of this particular demographic of people with a disability. This study looks at the perceptions of working age adults who reside in a long-term care facility, as well as the ethics around placing working age adults in a setting that is designed to meet the needs of a completely different population of clients. By exploring the perceptions of working age adults who live in residential care facilities, strengths and challenges can be highlighted and recommendations made to improve the experience of these residents. With the changing demographics of the population of Canada and the extensive health needs of clients of all ages, this is a timely research topic of special interest to those with a focus in health care ethics, social justice and disability rights.

P09 Title: Justice and Autism: Balancing public investments in research futures with the need for immediate and sustained services and supports

Author(s): *Timothy Krahn & Andrew Fenton*

A sharp increase in diagnosed cases of Autism Spectrum Disorders (ASDs) has forced questions concerning how to restructure current efforts to manage and meet the diversity of needs of all those affected by ASDs. In the wake of inadequate services and supports, more Canadian parents are using the courts to seek early intervention educational programming for their ASD children. Researchers are divided as to whether the sought after programming is suitable or effective. Arguably, there is a need for broader public engagement in policy design concerning the nature, distribution, and extent of services and supports for persons with ASDs, and also further upstream public consultation on questions of what ASD research to pursue and develop for the future.

Not uncommonly, pursuing new research is a risky investment. The public purse is responsible for funding almost all ASD research in Canada as well as providing for some of the existing services and supports (including educational programs) made available to persons with ASDs. This presentation seeks to explore the question of what kinds of ASD research are being publicly funded in Canada and where we should go in the future. In so doing, we will expose a current lack of national investment in ASD research beyond biomedical and clinical research. Using the case of Nova Scotia, we will also investigate reasons to consider realigning current provincial spending priorities to more judiciously balance the need for more research with the need for sustained services and supports for persons with ASDs of all ages.

P10 Title: Internet marketing of dietary supplements for Alzheimer's disease: Regulatory gaps and healthcare challenges

Author(s): *Brandy Vanderbyl[1,3], Nicole Palmour[1], Cynthia Forlini[1,2], Jennifer Fishman[3], Serge Gauthier[3], Eric Racine[1,2,3]*

Neuroethics Research Unit, Institut de recherches cliniques de Montréal

Université de Montréal

McGill University

Alzheimer's disease (AD) is the most common cause of loss of mental function in individuals over the age of 65. Five to ten percent of individuals over 65 have AD and this proportion increases to 10%-15% for individuals in their 70s and 30%-40% for individuals over 85. The consequences of AD are devastating (e.g., memory and language impairment) and ultimately, AD patients require assistance for all their basic needs. Unfortunately, only a handful of medications have been approved for AD and are modestly effective. The clinical and pharmacological context of AD creates an environment where patients and caregivers seek additional healthcare information, services, and treatments beyond mainstream medicine. In this regard, the offer of AD-related dietary supplements over the Internet merits close and specific attention given the vulnerability of AD patients and caregivers and the prevalent Internet use by those with stigmatizing illnesses (Berger, Wagner, Baker. 2005). The virtues of this Internet use have been debated and important general policy challenges have been identified in the Internet marketing of various neuroproducts (Racine, Van der Loos, Illes. 2007). This poster reports the result of a qualitative analysis of the 25 most frequently occurring Websites marketing dietary supplements for AD. We specifically examined: 1) website structure and format; 2) target audience; 3) health claims and supporting scientific evidence; 4) risk information; and 5) advertising strategies. We discuss our findings in the context of debates over the regulation of dietary supplements, direct-to-consumer advertising, and informed Internet use by AD patients and caregivers.

P11 Title: Rethinking the meaning and significance of consent in the context of tissue donation: Illustrative examples from a multiple case study

Author(s): *Rose Geransar, Glenys Godlovitch, Isabelle Chouinard, Brian Forzley, Allen Dong, Anna Zadunayski*

The Anglo-American concept of "fully informed consent" is the product of the historical evolution of practices in two distinct but related contexts: clinical practice and research with human subjects. In the legal context, informed consent emerged as a defense to the allegation of negligence or assault/ battery. In bioethics, informed consent is often thought to be anchored in the principle of respect for individual autonomy. Recently, bioethicists have been deconstructing the concept of informed consent to elucidate the features crucial to policy, clinical and research practices. Some of these critiques pertain to the import of the assumptions underpinning informed consent in the legal sense to the clinical and research context under the rubric of respect for patient autonomy. Other critiques challenge the idea that the ethical justification of informed consent is the principle of respect for autonomy.

This paper will draw upon a multiple case study of donors of cord blood for therapy and research to illustrate how the meaning and significance of consent can diverge from the classical ways in which consent is conceptualized and justified in bioethics and the legal context. Semi-structured, open-ended interviews will be used to draw insight from donors' perspectives. Consent will be explored as characterized by O'Neill and Manson: as a limited waiver based on intelligent placement of trust on part of donors. Preliminary analysis indicates themes in virtue ethics and relational ethics that enrich the current understanding of the concept of consent.

P12 Title: Controversies, updates and dilemmas in the ethics of care and research with comatose patients
Author(s): *Catherine Rodrigue and Eric Racine*
Medical advances and neurotechnology have increased chances of survival for patients with severe neurological injury. Although, coma rarely persists more than a few weeks, some patients remain in a vegetative state (VS) or a minimally conscious state (MCS). The nature of these conditions and the limited care that can be offered to these patients creates major bioethics dilemmas. This presentation will present an update on changes in the medical, social and ethical fields that upset some consensuses:
Evolution of diagnosis: The diagnosis MCS was added to that of VS in 2002 with significant medical and ethical controversy.
Understanding of diagnosis: Various studies have shown a high percentage of misdiagnosis of VS. Also, the public appears as confused as before while there are still challenges in end-of-life decisions and communication of poor prognosis.
Neuroimaging: New technologies cannot serve as diagnostic tools. However, recent research studies raise important scientific controversies about the integrity of the VS diagnosis.
Artificial nutrition and hydration: The consensus on the acceptability of the cessation of artificial nutrition and hydration is being challenged by political and religious groups.
Consent and participation in research: Proxy consent creates difficulties for comatose patients especially with the emergence of new technologies such as deep brain stimulation and neuroimaging. These raise controversies about the acceptability of risks for vulnerable patients who are unlikely to benefit directly from research.
Resource allocation: Despite the resources needed to support comatose patients, resource allocation and its impact on care is rarely discussed.

P13 Title: Evidence' of genetic discrimination: experiences among individuals at risk for Huntington disease
Author(s): *Yvonne Bombard, Joan Bottorff and Michael Hayden*
Context: Genetic discrimination (GD) is a potential risk associated with genetic testing (GT). Fear of GD has prevented individuals at-risk for various conditions from undergoing GT, hindering potentially beneficial engagement with genetic medicine. This widespread concern has heralded the U.S. Genetic Information Nondiscrimination Act (GINA), which prohibits the use of genetic information in health insurance and employment related assessments. GD is known to exist in Canada, however there is limited evidence to support similar protections.
Purpose and Method: The purpose of this presentation is to draw on findings from a self-report survey exploring experiences of GD among asymptomatic individuals at-risk for Huntington disease (HD) to point to practice and policy implications.
Results: Discrimination was reported by 40% of the respondents. Experiences occurred most often in insurance (29.2%), family (15.5%) and social (12.4%) settings. Surprisingly, there were few reports of GD in employment (6.9%), health care (8.6%) or public sector settings (3.9%). Although mutation carriers reported the highest levels of GD, participation in GT was not associated with increased levels of GD. Interestingly, family history, rather than the result of their test, was the predominant reason given for respondents' experiences. Psychological distress was associated with GD ($P < 0.001$).
Conclusion: GD is a frequently reported experience and source of distress for persons at-risk for HD. Our findings provide the first 'evidence' of GD in Canada. These results may inform policy and identify areas were more education and counseling may be needed to support individuals at risk for developing a genetic disease.

P14 Title: What do academic healthcare facilities tell their patients about research uses of health information in their custody?

Author(s): *Don Willison, Gillian Bartlett, Elaine Gibson, Michael Hadskis, Eleanor Pullenayegum, Jennifer Ranford, Lisa Schwartz, Karen Szala-Meneok*

Academic healthcare facilities (AHFs) may use personal health information (PHI) in their custody for a variety of research purposes involving: retrospective medical record review; development of registries and biobanks; and screening of records for potential research participants. To date, the focus of attention has been on what research use requires consent and what does not. Notification of information use policies may serve to either substitute or complement the consent process, but little is known about notification practices. Nor do we know the extent to which blanket consent forms, for which the legal foundations are dubious, are being introduced. We are currently conducting a cross-Canada survey of notification policies and practices in AHFs. Data collection is not yet complete so we cannot provide summary statistics. However, by the time of the CBS conference, data will be tabulated and we will have a very up-to-date picture of the range of notification practices

P15 Title: Marketing a 'better world': The many meanings of 'benefit' in the commercialization of medical innovations

Author(s): *Renata Axler, Fiona Alice Miller, Martin French*

Issue: What defines a 'better world' in the commercialization and technology transfer sector? We investigate how the technology transfer community markets medical innovations to the public, including what evidence is used to define benefit and success, how or whether success is correlated to health outcomes, and how these claims relate to formalized health technology assessment (HTA) reports.

Methods: The US-based Association of University Technology Managers (AUTM) has been compiling 'The Better World Report' yearly since 2006 to publicize 'success stories' for academic technology transfer and to identify the innovations that make up a better world. We analyze the content of stories of medical innovations in 3 annual reports (2006 – 2008), examine how 'success' is defined in their construction of global benefit and compare selected cases to the assessments of formal HTAs.

Results: What constitutes 'benefit' in Better World success stories is heterogeneous, and includes the life-saving potential of technologies, their capacity to generate institutional revenue, or the innovativeness of the researcher and research process. These types of benefits are sometimes internally inconsistent, and differ markedly from construals of benefit in formal HTAs.

Conclusions: Can we understand Better World 'success stories' as 'just evidence'? We conclude by considering the ethical choices embedded in the Better World narratives, focusing on how benefit is represented and marketed from within the academic commercialization and technology transfer sector itself, and what the implications of this are for health systems and public benefit.

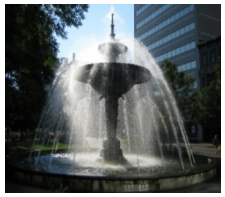
P16 Title: Cystic Fibrosis screening: do we help or cause harm?

Author(s): *Ian Mitchell, Ms. Lisa Semple, and. Mark Montgomery*

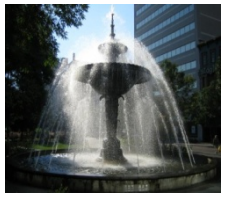
Background: modern medicine commonly attempts to identify illness before clinical manifestations appear. Specific conditions with a poor prognosis may now be identified by neonatal screening and treatment initiated early. Changing the natural history of such disorders in vulnerable neonates seems self evidently to be a good. For cystic fibrosis (CF) neonatal screening is possible and improves prognosis. Since April 2007 all infants in Calgary have had two stage screening for CF and possible cases notified to us for definitive testing to confirm the diagnosis (true positive) or exclude it. However in 15% we cannot clarify the diagnosis or give prognostic information.

Concerns: even when we confirm the absence of CF there often remain problems, including parental assumption of vulnerability of a child who is a carrier. It is unclear whether this leads to parents being overprotective in the long-term. There are more potential problems in families whose child has continued equivocal results. They may have homozygous genetic findings but no likelihood of clinical manifestations any time before mid adult life, if then. However parents of these children have been enthusiastically cooperative with medical care and reorganize family life around medical monitoring. Again the long term implications of this on family functioning and on the child is unclear

Conclusions: the rapid introduction of neonatal screening may bring unexpected negative results to families. There is a requirement for public debate and for education on this topic, and for funding for long-term study and support of the families involved.



20Th Annual Canadian Bioethics Society Conference Evaluation



Please indicate your agreement/disagreement with the statements below.

Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
1	2	3	4	5

General Comments:

1	The program fulfilled its announced educational objectives	1	2	3	4	5
2	The program met my learning needs	1	2	3	4	5
3	The program was well organized	1	2	3	4	5
4	The knowledge and skill gained during the program will be applied to my work	1	2	3	4	5
5	The conference syllabus was adequate	1	2	3	4	5
6	The meeting facilities were adequate	1	2	3	4	5

Comments:_____

Plenaries

1	Plenary Speakers were engaging and informative	1	2	3	4	5
2	Choice of plenary topics was appropriate to the them	1	2	3	4	5
3	Choice of plenary topics was appropriately divers (reflected peoples' areas and needs)	1	2	3	4	5
4	Choice of plenary topics encouraged (reflection, critical thinking on theme, made us think)	1	2	3	4	5
5	There was adequate time for audience participation	1	2	3	4	5

Comments: _____

Concurrent Sessions:

1	The time limit for presenters was managed well	1	2	3	4	5
2	Door-way noise during presentations was kept to a minimum	1	2	3	4	5
3	The theme "Just Evidence" provided useful guidance to presenters and audience	1	2	3	4	5
4	There was adequate time for audience participation	1	2	3	4	5
5	I was able to attend the presentation of my choice with little difficulty	1	2	3	4	5

Comments:_____

Posters:

1	There was sufficient time to view the posters	1	2	3	4	5
2	Presenters were on hand to answer my questions	1	2	3	4	5
3	The number of posters was adequate	1	2	3	4	5

Comments:_____

Social/Logistics:

1	Meals provided were of good quality	1	2	3	4	5
2	Refreshments provide during breaks were sufficient	1	2	3	4	5
3	The Latin Evening in the Garden was an appropriate and enjoyable event	1	2	3	4	5
4	There was adequate time for networking	1	2	3	4	5

Comments: Suggestions for themes, topics or speakers for future meetings

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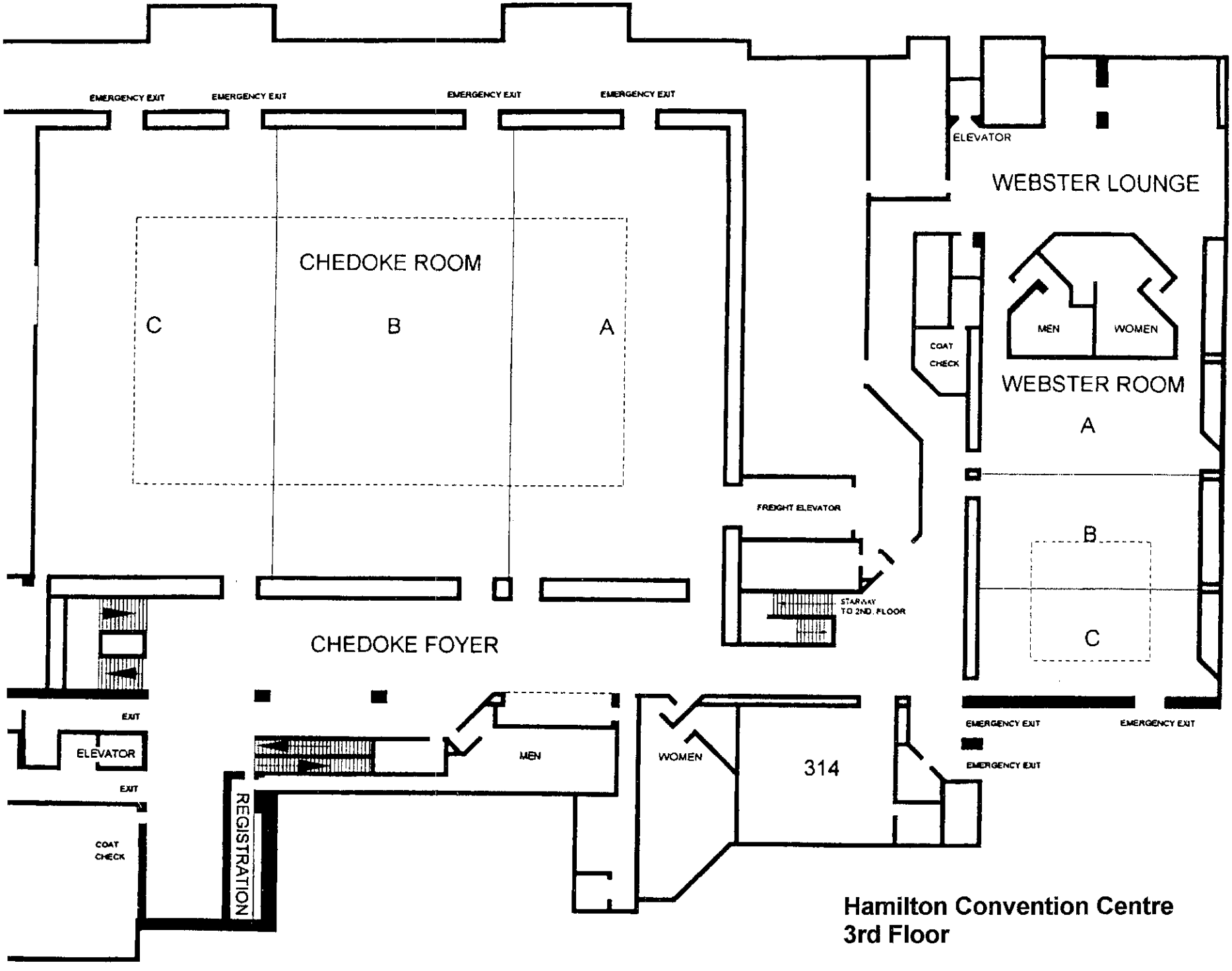

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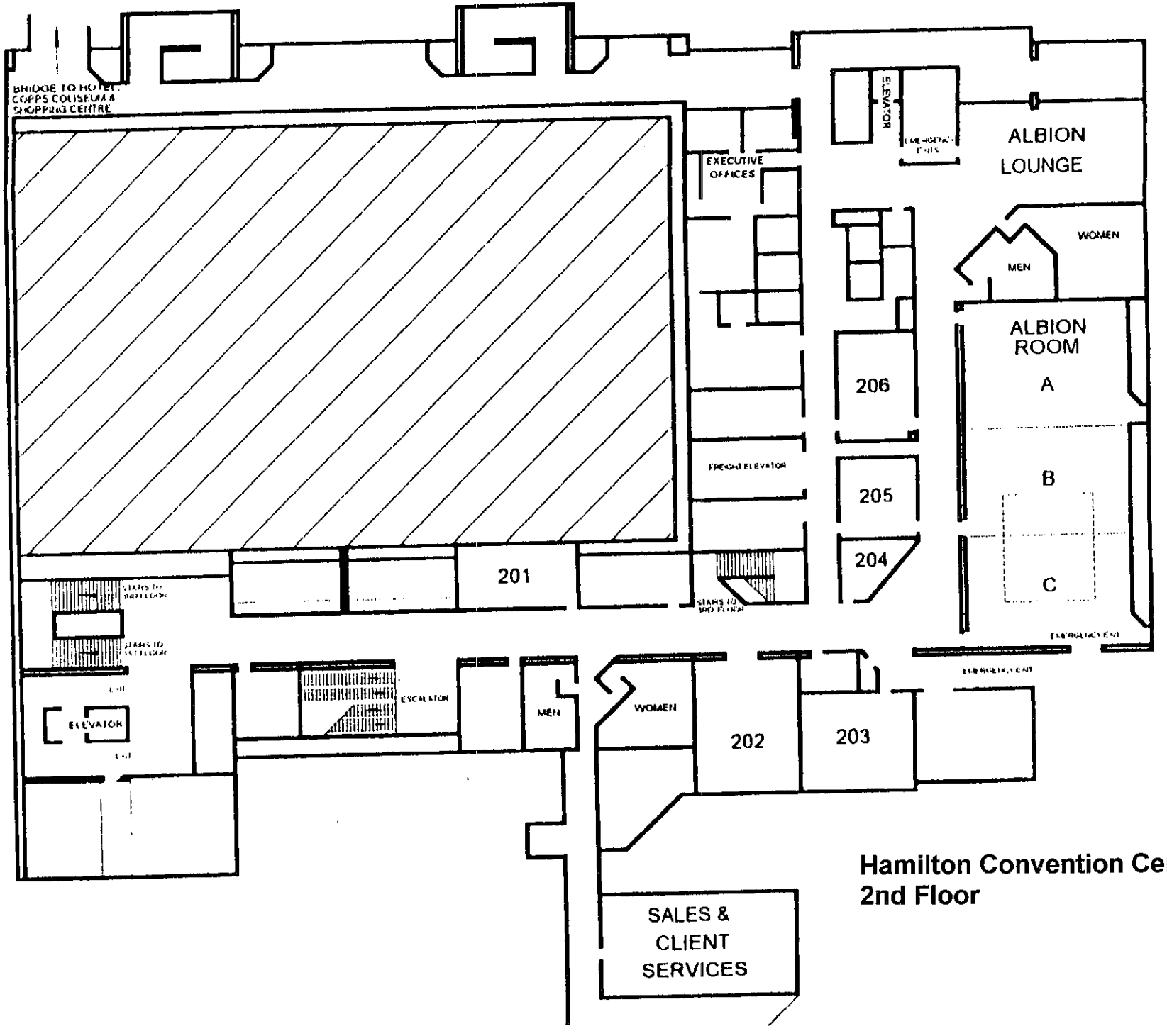

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