



Ethics Representatives Meeting

Leduc Room, The Westin Edmonton

May 18, 2006, 7:00 pm – 9:30 pm

The goal of the Ethics Representative Meeting is to provide an opportunity for leaders of ethics services and programs in the province to discuss progress in the development of clinical ethics services and to share best practices

Attendees

Alberta Cancer Board

Cindy Winfield- Cross Cancer Institute Clinical Practice Ethics Advisory Committee

Alberta Health & Wellness

Dawn Friesen- Population Health Strategies Branch

Nora Johnston- Population Health Strategies Branch

Aspen Regional Health

Yolanda Lackie- Aspen Regional Health Ethics Committee

Calgary Health Region

Brian Farewell- Regional Clinical Ethics Service

Eric Wasylenko- Regional Clinical Ethics Service

Capital Health

Paul Byrne- John Dossetor Health Ethics Centre, University of Alberta

Neil Elford- Capital Region Health Ethics Coordinating Council

Gary Goldsand- Royal Alexandra Hospital Clinical Ethics Services

Angela Thachuk- Royal Alexandra Hospital Clinical Ethics Services

Chinook Health Region

Thaine Olsen- Chinook Health Region Ethics Committee

David Thompson Health Region

Donna Van Bruggen- David Thompson Health Region Ethics Committee

Fraser Health

Bashir Jiwani- Fraser Health Ethics Services

Northern Lights Health Region

Pat Furey- Northern Lights Health Region Ethics Committee

Palliser Health Region

Dan Stevens- Palliser Regional Bioethics Committee

Winnipeg Regional Health Authority

Sheila Toews- Winnipeg Regional Health Authority Ethics Services

Provincial Health Ethics Network Board

Joe MacGillivray

Nina Preto

Provincial Health Ethics Network Staff/Contract Personnel

Leanne Brown

Ashley Carlson

Amy Middleton

Al-Noor Nenshi Nathoo

Tara Tierney

Marika Warren

Regrets

Trish Clark- Tom Baker Cancer Centre Ethics Committee

Albert de Villiers- Peace Country Regional Health Ethics Committee

John Hnatuik- East Central Health Ethics Committee

Ian Mitchell- Office of Medical Bioethics, University of Calgary

Dick Sobsey- John Dossetor Health Ethics Centre, University of Alberta



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Agenda

- 7:00 Dinner Served (working dinner)
- 7:10 Welcome, Review of Agenda and Goals, Brief Introductions
- 7:20 Report and Update from PHEN
A brief synopsis of key Provincial Health Ethics Network initiatives and directions
- 7:35 Regional Updates & Questions
Representatives from each Region/ Board/ Centre will be offered an opportunity to provide a 2-3 minute update on their activities over the past year
- 8:15 Dessert Break
- 8:25 Looking Ahead
Discussion regarding key opportunities and challenges that the bioethics community in Alberta should be considering and responding to.
Questions for consideration:
- *What opportunities exist for non-urban RHAs to collaborate in delivering ethics services?*
 - *What opportunities exist for collaboration between Alberta and other provinces or national bodies?*
 - *Do you feel that ethics services in your Region/ organization receive adequate financial/ moral support?*
 - *What are the key ethics issues arising in your organization?*
 - *Do you feel that the clinical ethics committee(s) in your Region are effective? What would help them be more effective?*
 - *Is there a need for more interaction between clinical and research ethics streams?*
 - *What do you think will be the most significant challenges and opportunities facing the bioethics community in the year and years ahead?*
- 9:15 Open Discussion and Questions
- 9:25 Evaluation
- 9:30 Networking



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Summary

Update from PHEN

Al-Noor outlined a few recent PHEN activities and projects:

- *Web Seminars*
Delivered over the internet, these are intended for individuals who would not otherwise have access to ethics education. There have been two sessions so far, which have gone well. Both were over-subscribed.
- *Ethics in Health Care DVD Series*
PHEN will make available a package of readings and DVD modules for sale so that ethics committees and health organizations may deliver their own introduction to bioethics course
- *Pandemic Planning and Ethics*
In conjunction with Alberta Health & Wellness, PHEN will be coordinating a committee regarding ethical issues in pandemic planning. The proposal to establish the committee is in the final stages of review, with the budget likely to be approved in the next few weeks. The committee will develop guidelines to support clinicians making difficult ethical decisions in the event of a pandemic
- *Community Bulletin Board*
This will be a new web page on the PHEN website, with sections for sharing resources as well as a discussion board. The intent is to provide a space for networking for those interested in ethics.

Joe MacGillivray, PHEN Chair, explained that PHEN is a society with a governing Board and membership. The board membership includes four members appointed by the health authorities, four appointed by the PHEN board and four elected by the PHEN membership. The last meeting PHEN had with Alberta Health & Wellness was positive.

Regional Updates

Alberta Health and Wellness: Dawn Friesen

- PHEN is an excellent organization that Dawn will miss being a part of, as she is transferring the role of liaison to her colleague Nora Johnston. She acknowledged the excellent work of the PHEN staff and Board, and indicated that they have done the job of developing a network, which is where the strength of the organization comes from.
- Al-Noor acknowledged on behalf of the PHEN board and staff that it has been wonderful working with Dawn and having her support on behalf of the Department.

Calgary Health Region (CHR) Clinical Ethics Service: Brian Farewell, Eric Wasylenko

- The Region commissioned an external review of bioethics, which recommended combining resources of the University of Calgary Research Ethics program and the CHR Clinical Ethics Service. They are recruiting a leader to launch the new joint initiative.
- There has been some expansion in the number of ethics committees in the Region. A Mental Health Ethics Committee is being formed. The Rural Ethics Resource Team is

developing capacity for ethics review and consultation via a distributed model throughout the rural parts of the Region.

- There are major educational efforts within the Region regarding pandemic ethics, including trying to engage staff on the issue of how one's ethical framework will need to change when and if a pandemic occurs.
- The ethics service is attempting to raise awareness within Regional administration regarding system issues and organizational ethics.
- They have established the "Ethics Corner" poster series sent monthly to all sites - health care providers can read about topics relating to ethics.
- The number of clinical & policy consults in the Region has been increasing

Capital Region Health Ethics Coordinating Council: Neil Elford

- Neil introduced himself as the Interim Chair of the Council
- The Council has recently been re-formulated to focus on: developing capacity in clinical ethics; providing and fostering ethics education using an informal approach; recognizing and discussing ethical issues that everyone deals with; and how situations impact entire health network.
- The Council meets several times each year.
- Representatives from the ethics committees in the Region will meet semi-annually. There is an upcoming gathering to take place on June 15, 2006
- Gary & the Royal Alexandra Hospital are hosting and providing support for education and networking.

John Dossetor Health Ethics Centre, University of Alberta: Paul Byrne

- The Dossetor Centre recently faced a significant loss with the departure of ethicist Barbara Russell, who has moved to Ontario.
- The diversity of the personnel at the Centre reflects the complexity of the health care system and the diversity of ethical stances.
- The faculty of the Centre is appointed through individual faculties.
- The Centre hopes to be a clinical ethics resource to other hospitals in the Region, and to provide research & academic teaching to keep pace with the evolution of demands within the University. For example, the Stollery Hospital will soon have its own transplant program.
- There will be an active search to fill Barbara Russell's position.
- Administration changes: Dick Sobsey of the University of Alberta will be taking over as Director of Centre, although it has not been officially finalized.
- The Dossetor Centre has a rich future and role to play in the unfolding of academic ethics in Alberta
- A significant area of opportunity is electronic education, whose potential has not been thoroughly tapped.
- The Centre hopes to become more prominent in the province with the new directorship and by securing funds to hire more faculty members.
- In response to Al-Noor's inquiry about whether there will be more opportunity for PHEN to work together with the Dossetor Centre in the future, Paul indicated that while both organizations have had the will to do this, time and resources have been limitations in bringing such partnerships to fruition. Hiring a full time Director will be a priority and will hopefully contribute to overcoming that limitation.

- The Health Ethics Summer Symposium, organized by the Dossetor Centre, is coming up on June 23. Arthur Frank from University of Calgary will present and Dossetor Centre faculty will assist as facilitators

Alberta Cancer Board- Cross Cancer Institute Clinical Practice Ethics Advisory Committee: Cindy Winfield

- Cindy attended the meeting on behalf of the Committee's chair Linda Tyre
- The Cross Cancer Institute will also miss Barbara Russell as she was a guide to their committee and an ethics education resource for the facility.

David Thompson Health Region Ethics Committee: Donna VanBruggen

- Membership of the Regional Ethics Committee is voluntary, not appointed. They have a diverse membership, representing a wide variety of geographical locations and disciplines.
- There are three physicians on the Committee: one is a community representative, one is the new Vice President of Medicine, and one completed the bioethics course last year and practices in a rural region.
- The Committee has an operational plan for two years, which gives them direction and keeps track of the Committee's progress and goals.
- One focus area is on education for committee members - half of the committee members have completed the PHEN Introduction to Bioethics course.
- They had number of education sessions in the last year and are planning to focus on areas of facilitation and cultural awareness
- The Committee developed evaluation and consultation forms
- In 2005, the committee had 24 formal requests for consultations, presentations, input into policy, or general questions on topics such as personal directives; there have been 8 formal requests so far in 2006.
- In addition to the formal reported requests, there are many one-on-one informal sessions and inquiries happening.
- The expanding goal of the Committee is education for staff and managers including promoting dialogue, reflection and a safe place to discuss ethical issues, and building capacity to teach front-line staff.
- During Bioethics Week, the Committee hosted a telehealth session on Respect in a Diverse Organization and launched a virtual water-cooler initiative that can be accessed by facility computers in order to promote networking within facilities. They also sent a brochure about the Ethics Service to each physician in region, which was a very large job!
- The Committee submits ethics-related articles in the staff newsletter 'Explorer'
- The Committee is currently involved in tobacco-free policy implementation discussions
- The challenges the Committee faces are consistency in membership, taking on presentation and consultation requests and keeping a broad representation of members.
- There is a waiting list for people to be on the Committee; they are struggling with creating a development process for new committee members.

Winnipeg Regional Health Authority Ethics Service: Sheila Toews (Special Guest)

- An overarching goal of the Ethics Service is to foster an ethical climate in all areas of the Winnipeg Regional Health Authority.

- The Ethics Service started an annual Regional Ethics Committee Representatives Forum last fall; it was well received and they will continue to have it each year.
- The Ethics Service is hiring a summer student to focus on aboriginal ethics.
- The Ethics Resource Strategy is working- they are promoting ethical decision- making using the (Michael) McDonald framework and staff who have completed the Level II: Ethics Resource Workshop are starting to network and support each other on ethics issues.

Provincial Health Ethics Network: Nina Preto

- With the support of a working group composed of representatives from health organizations across the province, Nina is coordinating the development of a booklet that provides information on dealing with ethical situations that arise at the end of life
- This is intended for the general public, not health care providers.
- There is also a need for more information for people who are appointed as guardians or agents. The group will be working on this in the future.

Palliser Health Region Bioethics Committee: Dan Stevens

- Dan just finished the PHEN Introduction to Bioethics distance education course today and found it to be very rigorous! He is the third member of his committee to take the course and will recommend that more colleagues take it.
- The committee has been running for a number of years (15-16 years.) It is presently struggling with issues of composition/membership.
- The committee has been focusing on research consultations, but would like more clinical consultations - they had two last year
- The Region is heavily involved in the process of pandemic planning. Dan is chairing a sub-committee on the ethics of pandemic planning within the region.
- During Bioethics Week, the presentations on pandemic planning were very well-attended.

Chinook Health Region Ethics Committee: Thaine Olsen

- Challenges for the Committee include educating new members and member turnover
- There has been a change in the role of the committee in that they are no longer involved in reviewing research projects.
- Newly developed display boards are being used to promote ethics within the Region.
- Also, bookmarks handed out by Ann Cook and Helena Hoas at last year's ethics representatives meeting were adapted for the Chinook Region. These are working well to make people think about ethical issues.
- There was a presentation in the region by a medical health officer regarding pandemic planning; the committee will be working with him in future. Thaine commented that the change in the ethical framework that will likely have to be adopted during a pandemic is fascinating.
- The Committee is working on capacity building and adding strength within the Ethics Committee.

Provincial Health Ethics Network & Rural Primary Health Care Network: Joe MacGillivray

- Joe is presently involved with a newly formed rural primary health care network based south of Calgary.
- One of the issues they are looking at is that of moral obligation and distress in medicine relating to primary care.
- Nuala Kenny of Dalhousie University will be working with them on this

Aspen Regional Health Ethics Committee: Yolanda Lackie

- This Committee, in its present form, is only a year old.
- When building the foundation for the committee, they chose to use Michael McDonald's ethical decision-making framework
- The two major activities of the committee are to promote ethical decision-making and to educate staff about health ethics.
- They have ten members participating in the PHEN Introduction to Bioethics course adapted for their region
- The Committee has a newspaper article entitled 'Ethics Corner' and is also using brochures in pay-stubs to advertise the committee.
- They are trying to move forward with PHEN's assistance in order to do more case consultations.

Fraser Health Ethics Service, British Columbia: Bashir Jiwani (Special Guest)

- Bashir commented that it is nice to see the volume and sophistication of ethics development in Alberta.
- Many in BC believe that an ethics network would be valuable for that province.
- Fraser Health is concentrating on enriching health ethics in seven areas: clinical consultation; linking with the existing administrative structure within the region; building ethics resource teams that can do consults in local communities where they work; broader ethics education; finding key ethics support leaders; policy support; ethical decision-making and its implications
- The Region will begin researching areas of ethics and building training facilities for surrounding areas to be educated.

Royal Alexandra Hospital Clinical Ethics Service: Gary Goldsand

- Clinical consultation is strong at the Royal Alex but given the endless demand, they must control the extent to which they spend time on it
- It is evident that many people within the facility are sharing moral dilemmas with each other, so the potential for ethical consultations is endless.
- Ethics consultation serves as a sounding board, giving space for moral reflection, and exploring possible routes of action.
- The number of consultations is approximately 4-5 per week.
- Participation in weekly rounds would help in opening up ethical discussions.
- Policy work includes a new DNR and 'comfort care' policy
- Continuing education- Gary is invited to team meetings to help with discussion
- There is an ethics residency program at the hospital. The current resident is Angela Thachuk. There have been six graduates of the programme so far. Gary is seeking more applicants, so he has extended the deadline.
- The Ethics Committee is doing very well. Membership terms are 3 years, though every year there is a turnover of three to four people. The new chair is Dr. Doug Matheson.

- University of Alberta Medical Humanities is appointing an Associate Dean to bring literature and philosophy to the medical humanities. Medical ethics is a very large part of medical humanities, so Gary is very excited about that.
- Gary commented that the policy of smoke-free facilities is interesting to an ethics committee that looks at all sides of problem. Capital Health has a total smoking ban, which is challenging particularly in psychiatric wards. This organizational ethics issue will be arising in many health regions.

Northern Lights Health Region Ethics Committee: Pat Furey

- The Fort McMurray region is 192,000 square km, has 7 facilities and 1300 employees.
- The Regional Ethics Committee was initially a self-education forum but moved on to being a resource to the communities.
- The Committee has broad representation and chose the McDonald framework as its decision-making model.
- In March and April there was extensive education with all staff regarding the Committee and ethics consultation.
- The Committee has had discussions with PHEN regarding support for ethics consultation.
- Currently, there is a new regional Board Chair and a new CEO
- They are looking at developing a code of ethics for the ethics committee itself as well as a corporate code of ethics.
- A major challenge is disseminating ownership for ethics in the region. The ethics committee is a passion of hers, but she is feeling guilty that she's not doing enough, yet hopes she doesn't run out of gas!
- Pat believes there should be an ethics representative on the regional policy committee.

Office of Medical Bioethics, University of Calgary: Ian Mitchell (Submitted via email)

- Major roles for the Office continue in the areas of education, scholarly enquiry, clinical ethics and review of research protocols
- Under education, they continue to be very involved with undergraduate medical students providing 40 hours of teaching in the first two years. The format is to provide an overview by one of the Bioethicists, small group interaction often using standardized patients in collaboration with colleagues in Communication. There is a lesser presence of ethics education in the medical school clerkship. Talks are given to all levels of medical, other health care professionals, administrators and members of the public on ethical issues.
- Scholarly enquiry includes issues of privacy, patient's attitudes to privacy, analysis of legal cases on Jehovah's Witnesses and adolescents, advice for health care practitioners arising from these cases, and implications for adult care from these cases. Newborn screening, when it should be done, what permission is required, issues of moral distress in health care providers, and governing structure in research ethics.
- Research Ethics includes continuing provision of ethical and administrative support to the Conjoint Health Research Ethics Board. There was a change of Chair late last year from Dr. Doig who had been Chair for five years to Dr. Glenys Godlovitch. The REB was also reviewed by Health Canada, and a result of that review detailed standard operating procedures being developed. A database and new web site are also under development.

- Clinical Ethics. Individual members are involved frequently in consultation on clinical ethics cases arising within the Calgary Health Region, and some members are part of Health Care Ethics Committees in the Calgary Health Region.
- The working relationship between the Calgary Health Region and the Office of Medical Bioethics has had an external review. At the time of the last representatives meeting there was conceptual agreement that there should be one ethics service in Calgary not two. As a follow-up there is a search underway for a Director, Centre for Health Care Ethics, who would have responsibility for ethics services in the Calgary Health Region.
- As an additional point, there has also been approval in principle for dedicated space in the new TRW (Teaching Research and Wellness) Building on the Foothills Campus. Space allocated will be between 361 to 460 sq. meters (4,000 to 4,500 square feet), including sufficient office and workspace for faculty members, administrative staff and a graduate program.

Looking Ahead (discussion)

What opportunities exist for non-urban RHAs to collaborate in delivering ethics services?

- *(Submitted via email)* There are considerable opportunities for collaboration between urban and non-urban regional health authorities in delivering ethics services. This can be done by collaboration on specific projects or by using resources such as bioethicists at the bioethics centres

What opportunities exist for collaboration between AB and other provinces or national bodies?

- *(Submitted via email)* There should be collaboration between Alberta and national bodies, but this is likely to be on an individual basis as networks are set up.

Do you feel that ethics services in your region/ organization receive adequate financial/ moral support?

- Some surprise was expressed at the relative dearth of ethicists employed within health care organizations. Is there a role for PHEN in discussions with RHAs about employing ethicists?
 - In Toronto, there are approximately 17 ethicists, which, if used as a gauge, would mean that Alberta was understaffed on a per capita basis.
 - There are opportunities to share ethicists between organizations and programs
- The question of whether ethicists be licensed was raised. One of the problems with doing so is that there are many ways to define ethicist, and it would be difficult to do. However, not licensing may be a mistake; young people may not see the profession as a possible career path.
- *(Submitted via email)* I know of no service in any hospital or region in which the provider/enthusiasts think that there is enough financial or moral support! In regards to ethics service, the Calgary Health Region has taken some tentative steps; time will tell how firm the commitment is, but at the present time the financial and moral commitment seems to be strong.

What are the key ethics issues arising in your organization?

- A number of regions and organizations are attempting to look at the issue of organizational ethics. It is a particular challenge for smaller regions with limited access to ethics resources. This may be a good place for PHEN to assist – by addressing organizational ethics issues in a centralized way. Alternatively, it may be that these issues have to be addressed on a local level, despite the challenges involved.
- *(Submitted via email)* There are a variety of ethics issues, as many as would occur to individuals, and despite the response to the previous question, provision of ethics resources to do a good job in delivery ethics services continues to be a struggle. In Calgary specifically integrating two separate services will be a task that will take some time, although I am confident that it will be successful given the existence of goodwill on both sides. Other ethics issues include issues of moral distress and staff, and the issues of resource allocation.

Do you feel that the clinical ethics committee(s) in your region are effective? What would help them be more effective?

- *(Submitted via email)* There will be a wide range of opinion on effectiveness of clinical ethics committees! I am not clear what and how effectiveness would be measured; this will be an important issue for discussion.

Is there a need for more interaction between clinical and research ethics streams?

- *(Submitted via email)* There should be interaction between all aspects of bioethics/health care ethics, clinical, scholarly enquiry, education and research.

What do you think will be the most significant challenges and opportunities facing the bioethics community in the year and years ahead?

- *(Submitted via email)* Resource allocation. Considerable public anxiety persists over issues of resource allocation and I believe these will continue.

It was agreed that PHEN would take responsibility for drafting possible strategies to address some of the issues raised during the discussion, for distribution to and in order to solicit feedback from meeting participants. While not all the questions and issues raised at this meeting will be addressed in the response, this will be one means of continuing this discussion.

The participants were thanked for their participation, and the meeting was adjourned at 9:30pm.