

# Provincial Health Ethics Network Programmes and Services

June 2011

The primary programmes and services of the Network are described below in relation to each of the organization's goals: Education, Connection and Coordination. Additional information is provided on projects in development.

## Education

### **Adult Guardianship and Trusteeship Act Education**

PHEN is working with the Office of the Public Guardian to provide education to healthcare professionals, administrators and potential guardians and co-decision-makers in Alberta on the new Adult Guardianship and Trusteeship Act. The focus will be on providing information regarding the important changes from the Dependent Adults Act as well as a case-study approach to dealing with ethical issues that arise in dealing with individuals who lack decision-making capacity, within the framework of the new legislation.

### **Book Reviews**

In an effort to provide PHEN members and other interested individuals with summaries and reviews of health ethics books recently added to the PHEN library, PHEN coordinates the Book Review programme. The initiative also exposes ethics contacts in Alberta to new and useful literature in the field. When available, book reviews – written by PHEN members - are posted on the PHEN website.

### **Clinical Ethics Committees**

PHEN has traditionally played a strong role in providing various avenues of support for ethics committees, at both institutional and regional levels, across the province. The nature of this support ranges from taking an advisory role in the formation and development of a new committee, to fulfilling workshop requests in order to further strengthen the efficiency and effectiveness of more established committees.

Clinical ethics committees play an important role in the delivery of health care by providing a neutral forum for thinking about and exploring various ethics issues that arise, which clinicians may not otherwise have the opportunity to systematically explore during the course of their practice. The role of ethics committees is not to make decisions or pass judgment on the actions of care providers, but rather to act in a supportive and advisory capacity through the ethics resolution process. The Executive Director provides support to a number of ethics committees as well as for select policy and particularly difficult case consultations

### **Comfort, Hopes & Wishes: Making Difficult Health Care Decisions**

PHEN continues to coordinate the development and dissemination to Albertans of printed and online booklet and brochures regarding health care decision-making at the end of life. The intent is to have the materials available in hospitals, continuing care centres, hospices and other health centres where they might be most needed as well as in community settings to promote advance care planning. The project has two main goals: 1) to provide Albertans - particularly those making difficult health care and treatment decisions - with accessible, accurate information on some of the ethical, psychosocial and legal issues that arise when making such decisions; 2) to provide materials that are at once a source of information and an access point to related resources.

A number of Alberta organizations and departments have been involved in the project, including the University of Alberta John Dossetor Centre and Health Law Institute; Office of the Public Guardian; Alberta Association of

Registered Nurses; Alberta Cancer Board; Calgary Health Region Ethics Service and Palliative & Hospice Care Services; Medicine Hat Regional Hospital; Red Deer College Faculty of Nursing; David Thompson Health Region Quality Improvement Department; University of Alberta and Stollery Hospitals; the Southern Alberta Huntington Disease Resource Centre; Hospice Calgary; Royal Alexandra Hospital; Southern and Northern Alberta Human Organ Procurement and Exchange Programs; Alberta Children's Hospital; Capital Health's Northern Alberta Renal Program; and University of British Columbia's W. Maurice Centre for Applied Ethics.

In 2009 - 2010, the Network completed two draft publications that were distributed among health professionals, patients and members of the public for feedback. This feedback is being incorporated into a final draft that will be printed and distributed throughout the province in Fall 2011.

### **Distance Education Course: Introduction to Bioethics**

In 2001, the Network launched a unique distance education course in introductory bioethics, in response to a need communicated by its membership for programs that would support the health ethics education of those in rural areas and those with limited access to formal education resources. Due to the overwhelmingly positive feedback received from the past course participants, the Network has been offering the course annually, educating approximately 335 individuals in its 11 offerings. Given an extraordinary amount of interest in the course this year, the course was expanded to accommodate over twice as many participants as usual; 60 individuals participated from January - May 2011.

The course has been designed to create a bridge between academic bioethics and those working on the front lines of health care. The curriculum provides participants with the groundwork of formal bioethics theory before moving into specific bioethics issues such as end-of-life care and resource allocation. The goal is that participants will take from the course a set of comprehensive tools and analytical skills that will assist them in addressing ethical dilemmas they face in their daily practice. Participants in the course come from a range of professional backgrounds including nursing, medicine, allied health and health care administration, and many are members of their institutional or regional ethics committee.

Participants are primarily Albertans with a number of individuals participating from outside of the province. Those enrolled in the course engage in distance learning through the use of DVD presentations, readings, web-based and teleconference discussions. Course instructors include some of world's most distinguished bioethicists, including Robert Veatch, Jim Childress, and Edmund Pellegrino of the Kennedy Institute of Ethics at Georgetown University.

### **Distance Education Course II: Health Ethics in Complex Times**

In Winter 2011, PHEN completed the shooting of two educational videos as part of the development of a second distance education course in health ethics. The videos will feature Susan Sherwin (Relational Autonomy) and Francoise Baylis (Public Health Ethics). Editing is currently underway with the videos scheduled for completion in Summer 2011. External funding is currently being sought in order to complete the course videos and corresponding curriculum.

### **DVD Resources**

PHEN has developed several DVD resources that are made available for purchase. These publications are used by health organizations in all regions of the country and throughout the USA and countries worldwide. Revenue generated from sales of the DVDs is used to develop additional resources.

**Ethics in Health Care DVDs** - This 12-DVD set provides an intense introduction to important issues in the field from some of its most renowned experts. This tool is recommended for clinicians, health

administrators, members of ethics committees and anyone interested in furthering their understanding of compelling moral questions in health care. It can be used for individuals for self-study; by organizations and ethics committees to serve as a curriculum to provide training to staff in introductory bioethics; or by libraries seeking public performance rights. Proceeds from the sale of these materials will be used to continue to update and upgrade PHEN's educational resources to the benefit of those within Alberta.

**Global Health Ethics: Duty, Justice and Responsibility** - What are we to make of a world with such unequal health prospects? What does justice demand in terms of global health? Do those working in health care in the developed world have a duty to do anything about it? In this 22-minute DVD presentation, Dr. James Dwyer, Associate Professor of Bioethics and Humanities at the State University of New York, explores these and other questions. The video helps us to examine our personal, professional and social responsibilities, and how we can focus more attention on issues of justice that arise at the local, national and global levels.

**Spirituality in Dialogue, Decisions and Duties** - This 45 minute DVD presentation features Daniel Health Care: Sulmasy, Franciscan Friar and Associate Director of MacLean Center for Clinical Medical Ethics at the University of Chicago. Addressing the importance of caring for the whole person, Dr. Sulmasy describes how spiritual needs encompass questions of meaning, value and relationships that are often insufficiently addressed in health care. He suggests that simply understanding and acknowledging that a patient has spiritual needs can go a long way in nurturing respect and providing opportunities for improved care.

### **Ethics and Pandemic Planning**

PHEN continues to maintain its website containing an extensive collection of resources on ethical issues in pandemic planning. Developed as a resource for the aforementioned committee and in response to a growing interest in ethical considerations surrounding pandemic planning, the site includes existing ethics guidelines, current scholarly articles, tools and presentations and related news articles. This webpage is referred and linked to from the World Health Organization's website *Addressing Ethical Issues in Pandemic Influenza Planning*.

### **Featured Article**

PHEN continues to select recent and relevant articles from the health ethics literature to send to its members on a regular basis, with an accompanying executive summary. In 2010-11 PHEN distributed to its members, *If I Could Say Five Things* by George Webster (Summer 2010), *Evolution of hospital clinical ethics committees in Canada* by Gaudine, Thorne, LeFort & Lamb, Marianne (Fall, 2010) and *Can Ethics be Derived from Facts?* by Alister Browne (Winter 2011). The feedback received from PHEN members indicates that this is a valuable service the Network provides to its members who are highly invested in health ethics issues, but often too busy to read current literature in the field.

### **Health Ethics Week 2011**

Health Ethics Week was held across Alberta during the period March 7- 13, 2011. This event was designed to: 1) highlight the importance of examining values underpinning the health system; 2) facilitate the health ethics education of various stakeholders in the system, from members of the community to institution staff; and 3) provide greater visibility for clinical ethics committees and health ethics issues across the province. This year's theme *Doing the Thing Right – Doing the Right Thing* attempts to highlight a tension between a compliance-based and a virtue-based approach to ethical decision-making by exploring the relationship between doing the right thing (acting ethically) and doing the thing right (following rules, codes, laws). The event was held in conjunction with Alberta Health Services, Covenant Health, the University of Alberta's John Dossetor Health Ethics Centre and Health Law Institute and the University of Calgary's Office of Medical Bioethics.

Across the province, health zones, health institutions/ organizations, ethics committees, community-based health groups, health professionals and members of the public were invited to participate in Health Ethics Week by hosting or attending local events such as workshops, presentations and video screenings, with the goal of raising awareness of ethics issues in health. PHEN served as the provincial coordinating and resource body for the initiative, distributing publicity and support materials, publicizing planned events, and assisting organizations and committees who were interested in hosting an activity.

### **Legislation Resources**

PHEN provide a continually updated online collection of resources related to new Alberta legislation, including the Alberta Health Act, Adult Guardianship and Trusteeship Act, Mental Health Amendment Act and Personal Directives Act.

### **Libraries**

The Network maintains libraries in both its Edmonton and Calgary offices. Books, videos and DVDs on a wide variety of health ethics topics are listed for viewing on the PHEN website and available on loan to any Albertan or PHEN member. As a resource to library users, the Network recently updated its library webpage to include summaries of the videos available for lending. It continually expands the library collection with recent titles in health ethics literature, regularly updates the list of holdings on the PHEN website and fills weekly requests to borrow materials.

### **Print Resources**

The Network has several print resources that are made available for purchase. These publications are used by health organizations in all regions of the country and throughout the USA and countries worldwide. Revenue generated from sales of the materials is used to develop additional resources.

**Article Packages** - Through an agreement with Access Copyright, PHEN has developed packages of relevant and timely articles on 18 different areas of health ethics. Each package contains 5-6 articles that are meant to provide a general overview and introduction to a selected topic. Examples of topics: Ethics & Disability, Ethics of Pandemic Planning, Ethical Issues in Health Promotion & Population Health, Ethical Issues in Home Care.

**Clinical Ethics Committee Member Manual** - A comprehensive introduction to the structure and activities of ethics committees in general and, through modification and tailoring by local committees, a convenient introduction and resource to protocols, procedures and guidelines for each particular ethics committee. Over 500 copies have been sold and distributed within Alberta. There has also been a strong interest from outside the province for the material, as it is the only known resource of its kind. Given the recent relevant legislative changes, PHEN is working with the University of Alberta Health Law Institute to update the Member Manual section on legislation.

**Ethics and Health Resource Allocation: A Primer for Policy Makers** - Developed by PHEN as part of its Resource Allocation Ethics Project and developed for use at the *Tough Choices: The Ethics of Allocating Health Resources* conference held in 2003. Since then, there has been considerable demand for this resource. Several hundred copies have been sold, including as part of the curriculum for Hamilton Health Sciences' Ontario Health Care Leadership course, and it is now in its third printing.

**Health Ethics Tent Cards** - Developed as educational tools for ethics committees, health organizations, and anyone wanting to stimulate thought and discussion about health ethics issues. Each package contains 12 cards that outline: a) information about health ethics and ethics services or b) an ethics case

with a possible response for each. They may be displayed in common areas at health facilities or used as a starting point for a facilitated discussion with colleagues or committee members.

**An Introduction to Health Ethics Committees** - A resource for those interested in becoming more informed members or chairs of health ethics committees. Subjects covered include an introduction to health ethics, the function of ethics committees, procedures and policies, decision-making frameworks, and regional ethics committees, amongst others. The book is currently in its sixth print run.

### **Resources for Teachers**

PHEN continues to maintain its *Bioethics in the Classroom* initiative designed to provide tools to Alberta teachers at the Kindergarten to Grade 12 levels to assist them in incorporating health ethics discussions and activities into the classroom. An introductory booklet is available along with exhaustive targeted information posted on the PHEN website that offers an explanation of how health ethics relates to students and Albertans, suggestions for fun and innovative classroom activities on health ethics, and a complete guide to the areas of the Alberta Learning Curriculum that have direct relevance to issues of health ethics.

### **Website**

PHEN's website, located at [www.phen.ab.ca](http://www.phen.ab.ca), continues to be the most heavily utilized of the organization's resources. Although it is targeted at Albertans, anecdotal evidence indicates that the website has also become an important source of health ethics resources for individuals from across Canada and worldwide, further bolstering PHEN's position as an international leader in providing access to relevant health ethics resources for care providers and the general public. In 2007 - 2008, PHEN secured \$30,000 funding from the Wild Rose Foundation to develop an expanded, revised website that will be a world-class resource on health ethics for the province. The new website was launched in Spring 2011 and extensive updates were made in Winter 2011 to the site's E-commerce system; the website continues to be maintained and enhanced on an ongoing basis.

### **Workshop Modules**

PHEN's comprehensive set of multimedia teaching modules can be tailored to the particular size and learning needs of each interested group and provide a unique opportunity for individuals to explore, discuss and analyze ethical issues. The teaching modules are specifically designed with the intention of providing a range of health professionals with practical information and tools that will assist them in the explicitly ethics related components of their daily decision making and practices. To date, the Network has delivered or facilitated over 400 modules and presentations for a variety of Alberta groups from health region boards and staff, to continuing care centre personnel, health professional associations/ colleges and members of the general public. Information regarding the content of the sixteen available modules and the process of booking a workshop is disseminated to the membership and the general public in brochure format as well as via the organization's website. In the 2010 – 2011 period, PHEN continued to provide workshops and presentations to health zones, departments and organizations around the province. Recent presentations include the Nephrology Society, AHS Home Care, AHS Mental Health, Foyer Richelieu Long Term Care Centre, and Yukon Continuing Care.

## **Connection**

### **Alberta Health Services Consultation Team**

A PHEN representative attends bi-weekly meetings with Alberta Health Services and Covenant Health clinical ethics staff to discuss provincial trends, best practices and services being provided in ethics consultation throughout the province.

### **Clinical Ethics Committee Directory**

The Alberta Clinical Ethics Committee directory is posted on the PHEN website and updated regularly. It contains the contact information for over 50 clinical ethics committees throughout Alberta. The directory serves as one way to connect the committees with each other and to connect the health care professionals, patients and patient families with the ethics committee in their institution or region.

### **Communiqué - Monthly Email Update**

PHEN distributes an email *Communiqué*, sent to PHEN members on a monthly basis, providing announcements on new health ethics activities and resources and information on upcoming health ethics events. Resources and programmes developed by PHEN as well as those from external organizations are included. PHEN Members are encouraged to share this email with others for whom it would be of interest.

### **Membership**

Membership in PHEN, a registered society under the Societies Act, provides numerous benefits including a means of connection with others interested and involved in health ethics in the province, notification of upcoming PHEN initiatives and events, and access to various PHEN services such as module delivery and other educational materials. Membership in the Network in the 2010 – 2011 fiscal year totalled approximately 300.

### **Organizational Ethics Study**

PHEN has agreed to be party to a Project Advisory Committee for a collaborative study involving a national survey of health executives, managers, and ethicists on the subject of organizational ethics. The Committee would provide strategic and expert advice/input on refinement of the survey instrument, interpretation of survey findings, identification of knowledge transfer opportunities, definition of emerging research questions, and assist with distributing information on the study and its findings. Other partner organizations include Accreditation Canada, Canadian Council of Health Service Executives and Patient Safety Institute. A grant proposal for this study has been submitted to CIHR.

### **Partnerships with Other Networks**

PHEN continues to stay in contact with and facilitate discussion and collaboration among groups from outside Alberta interested in establishing of similar networks in other provinces or at the National level. The move to establish similar networks elsewhere stands as an affirmation of the success of PHEN in Alberta. In 2008, Nova Scotia established the Nova Scotia Health Ethics Network (NSHEN) and in 2009 the Manitoba Provincial Health Ethics Network (MB-PHEN) was established. PHEN continues to foster positive relationships with these organizations in order to share learning and make efficient use of resources.

### **PHEN Membership Directory**

The PHEN Membership directory is available on the PHEN website. PHEN Members may choose to have their names and primary areas of interest and/or expertise in ethics listed. The Directory serves as one means of connecting these individuals with each other and others interested in health ethics.

## **Coordination**

### **Ethics Consultation Secondary Review Service**

PHEN coordinates the special formation of a full ethics consultation team, with expertise from across the country, as requested, to provide secondary review of particularly difficult ethics consults. In 2010-11 PHEN was asked to provide a special external ethics consultation to a health region in British Columbia regarding a difficult organizational ethics issue. PHEN developed an ethics consult team and provided an ethics analysis and

consultation report. This work was done on a fee-for-service basis

### **Health Ethics Resource Information Lines**

PHEN operates 1-800 phone lines from both its Northern and Southern Alberta offices and responds to hundreds of inquiries and requests each year for ethics-related information. While the Network is not designed to provide direct consultation services regarding ethical dilemmas, it continues to provide referrals to the most appropriate resources (e.g. professional colleges/ associations, ethics committees or specific individuals) as well as sharing written or other background information for those who seek, or could be assisted by, additional material.

### **Policy and Legislation Consultations**

PHEN continues to provide input into the development or review of new or existing public or organizational policy. During the 2010-11 fiscal year, the Network was asked to review and submit a written report on the proposed Alberta Health Act. PHEN convened a small group of ethicists in Alberta to provide feedback on the Act, compiled it into a summary document and submitted it to the AHA Advisory Committee. PHEN was also invited to a panel session with the AHA Advisory Committee to answer some questions and provide input on ethical considerations in the Act

## **Projects in Development**

In order to expand the services of the Network, be responsive to the needs of its members, and continue providing new and innovative resources to those utilizing its services, PHEN has several projects that are currently in various stages of development and implementation, as described below.

### **Continuing Ethics Education Program & Certificate in Health Ethics**

This initiative would provide an overarching framework for health professionals earning continuing education credits in ethics. PHEN recognizes that expertise or experience in ethics may come in a variety of forms, thus is proposing this programme as a means for existing health professionals seeking further training in ethics to be recognized for their achievements. The purpose is to provide incentive and structure for advancement in ethics and to work towards consistency in continuing education in ethics. Credits would be earned by participating in PHEN education programs or equivalencies. This would be the first program of its kind in Canada, situating Alberta on the leading edge of continuing ethics education & advancement

### **Ethics Consultation Boot Camp**

The Network is developing a three-day program to provide intense training to clinical ethics committee members in clinical ethics consultations. The Boot Camp will be held November 2011 in Banff, Alberta and involve teaching and mentorship from experts in the field from across North America.

### **Organizational History**

PHEN is developing a paper reflecting on the 'experiment' of PHEN in Alberta, with a view to allowing others to benefit from its successes and challenges.

### **Partnerships for Potential Projects**

PHEN has engaged a fund development specialist to seek external partnerships and support for a number of initiatives, including: the further development of *Distance Education Course II - Ethics in Complex Times*; printing and distribution of *Comfort, Hopes and Wishes: Making Difficult Health Care Decisions*; *Ethics Consultation Bootcamp*; and *Provincial Ethics Policy Think Tank*.

**Provincial Ethics Policy Think Tank**

This project would be an initiative coordinated by PHEN bringing together representatives from a number of health organizations & bioethics/health law bodies across the province, including Alberta Health Services, Covenant Health, Health Law Institute, Universities of Alberta John Dossetor Centre and University of Calgary Office of Medical Bioethics. The mandate of the collaborative would be to identify commonly occurring ethical issues that arise at the clinical level in health care in Alberta, to conduct literature reviews and collect best practices from other regions on how these are addressed elsewhere, to develop brief papers which elucidate the underlying ethical tensions, and where possible develop recommendations to address these issues in a systematic, proactive rather than individual, reactive way.