Covenant Health RESEARCH
Issue 22, Winter/Spring 2013/2014

NEWS FLASH!
Covenant Health is now a CIHR-eligible institution!

The Covenant Health Palliative Institute
A model of community engaged scholarship

Can I use NetCare for research purposes?

Changes to Alberta’s health research ethics review system

Covenant Health Palliative Institute

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Cover: Photo of the Palliative Institute staff; Front row (Left to Right): Viki Muller, Danielle Baron, Karen Macmillan, Robin Fainsinger, Lara Fainsinger, Loretta Harbison
Back Row (Left to Right): Miriam Dobson, Alex Potapov, Marta Oleszczuk, Konrad Fassbender, Pat Selmser, Ann Syme, Kathy Robberstad

Covenant Health Research is published by the Covenant Health Research Centre (CHRC) several times a year. It features research or research-related articles, news and updates.

CHRC leads Covenant Health’s efforts to integrate research into practice, develop partnerships, facilitate inquiry and promote innovation in alignment with Covenant Health’s Mission, Vision, Values and strategic directions.

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Recap: Since the research grant was first offered in 2003, the CHRC has approved 90 grant applications totaling over $312,000 in funding. One such funded study by Dr. Stuart Cleary and Sonya Wheeler led to improved cough and pulmonary function for Amyotrophic Lateral Sclerosis (ALS) patients, see page 2.

Are our programs making a difference? An evaluation study of the Psychiatric Outpatient Program (PO) by Chris Jackowich demonstrated the impact and value of this important program to enrolled patients, see page 3.

Collaboration teams can make a difference! Engaging multiple disciplines to address a design problem is realizing benefits for patients at the Institute for Reconstructive Sciences in Medicine (iRSM), see page 4.

The Covenant Health Palliative Institute is profiled on page 5. The Institutes’ role in brokering knowledge in the realm of end-of-life care is already making great strides in the field, with several studies ranging from pain classification in cancer and improving access to specialists, to nutrition and weight loss in palliative patients.

Kristine Godziuk and the Pediatric Centre for Weight and Health (PCWH) discuss their research initiatives in the field of child obesity on page 8. And winner of the 2013 Community Connections award from the University of Alberta, Dr. Lola Baydala’s work is outlined in an article on page 10.

In the Librarian’s Corner, manager Sharna Polard introduces new subject guides available through Library Services on page 9.

Two feature articles centred on research ethics can be found on page 11. Kimberly Kordov discusses the use of NetCare for research purposes and Jon Hagan provides upcoming changes for research ethics reviews in Alberta.

Update: After 10 years as a research centre, the CHRC is undertaking a visioning initiative to develop a new mandate and framework; one that will provide optimal research services and support for Covenant Health researchers, programs and Institutes, and further enable collaborative work in alignment with our provincial partners and other provincial and national entities. Such work will continue throughout the year with the help of Covenant Health constituents and stakeholders. Keep an eye out for further opportunities to provide your input and for corresponding announcements of new initiatives!

Covenant Health is now a Canadian Institutes of Health Research (CIHR) eligible institution! This means that Covenant Health researchers can apply for CIHR grants directly, and have those grant funds managed in trust through Finance. This will expedite the processes for research projects that are Covenant Health-centric, or in research areas that may not be of high priority to the universities, and/or do not have collaborators from a university.

The 9th annual Covenant Health Research Day (RD2014) entitled “Fostering best practice, exemplary practitioners, and the impact on patient care – viewed through a research and knowledge translation lens” was held at the Grey Nuns Community Hospital on Feb. 6, 2014. This year’s event was exciting, with lectures and interactive discussion panels which informed and engaged. To learn more, go to our website at: http://www.caritas.ab.ca/Home/Research/default.htm

A copy of the new CHRC Annual Report is available on the website as a pdf, along with all Research Day presentations and abstracts.

The 2014 Faith, Spirituality and Health grant competition is active with submission of a letter of intent, due on Feb. 3. Information is available on the CHRC website. The CHRC grant is currently under review, so expect an announcement regarding the new grant offering in April 2014!

During the year 2013, the CHRC provided operational/administrative approval for 84 research projects. A listing of approved research is available on the back page of this publication for your reference. If you require assistance from the CHRC for your research project, please call 780.735.2274 or email research@covenanthealth.ca. If you would like to access services from the CHRC Grant Writer, please call 780.735.2431 or email researchprojects@covenanthealth.ca.

If you are interested in submitting an article, photo or some news or would like to advertise your research event or just talk research, please email: researchprojects@covenanthealth.ca.
The effects of lung volume recruitment on coughing and pulmonary function in patients with Amyotrophic Lateral Sclerosis (ALS)

Authors: Stuart Cleary Ph.D, CCC-SLP, R-SLP and Sonya Wheeler. Contributor: Sonya Wheeler, RRT, B.Tech, CRE

- Amyotrophic Lateral Sclerosis (ALS) is a fatal, progressive neuromuscular disorder. The majority of persons with ALS will experience weakness of the breathing muscles. Weak breathing muscles cause a weak cough, shallow breathing and eventually, respiratory failure. Respiratory insufficiency is the main cause of decline and death in persons with ALS.

- Lung volume recruitment (LVR) is a simple, non-invasive means of breath stacking to support the respiratory muscles. A modified resuscitator bag is used to perform LVR. A one-way valve and a mouthpiece or mask is used on the resuscitator bag. The bag is squeezed and the patient inhales air from the mouthpiece or mask. Air is stacked in the lungs, breath by breath, and not expired until the lungs are completely full.

- A typical session is three to five breaths followed by a cough repeated five times. LVR is thought to increase lung volume and help cough effectiveness by improving movement of the lungs and chest wall and opening up areas of collapse in the lungs.

- 29 participants with ALS participated in a study on the effects of LVR on pulmonary function and coughing. Each participant completed one treatment session and one control session separated by a minimum of 24 hours and a maximum of seven days. Researchers measured both cough and lung function at various time intervals. The control session was the same but there was no LVR use.

- LVR had a significant effect on lung function and unassisted cough for up to 30 minutes after treatment. This fact is important for patients from a quality of life perspective. Using LVR within 30 minutes of eating may reduce the chance of aspiration for persons with ALS with swallowing issues. Keeping the lungs clear of secretions, food and liquids can reduce the likelihood of having lung infections. LVR can also help provide improved clearance of phlegm which can have a social benefit when the person with ALS is visiting with others.

- The results of this study suggest that LVR causes temporary changes in lung and chest wall compliance. Further research is needed on how LVR works to cause these changes. This study is important because there had not been a study of this type with a control group or that looked at how long the effects of the treatment lasted.

- The researchers appreciate the financial contribution of the Covenant Health Research Trust Fund for the pilot project which laid the groundwork for this larger study.
Grey Nuns Community Hospital’s Psychiatric Outpatient Program and its impact on psychological wellness

Chris Jackowich, RPN, BGS, Unit Supervisor, Outpatient Programs and Allied Health Professionals
Mental Health Program, Grey Nuns Community Hospital

The Psychiatric Outpatient Program (POP) is a 12-week intensive, psychodynamic day hospital group treatment designed for 24 to 30 patients. It is arranged in two streams (phase I and phase II) and is designed to deal with a range of psychiatric diagnoses, both acute (axis I) and chronic (axis II and/or axis III). The program involves both structured and unstructured group formats to work on patients’ problematic internal and relational patterns. Specifically, dysfunctional patterns of relating to others are seen as a significant driver of poorer health outcomes. The POP addresses these patterns from object relational and attachment theory perspectives through an eclectic combination of psychotherapeutic techniques ranging from psychodynamic to cognitive-behavioral to experiential.

This research assessed the impact of the POP treatment on the psychological wellness of its participants. Ryff’s Scales of Psychological Wellness were chosen as a measure of outcomes because of its applicability to the goals set for group members. These goals include: to grow in self acceptance and respect, to become tolerant of others’ differences, to learn how to make decisions and accept the consequences, to clarify personal values and to develop congruence between behaviour and values and to become sensitive to ways in which we affect other people and ways in which they affect us.

The results of three years of data collection and analysis exceeded expectations with significant statistical improvement on all scales of wellness. The greatest change was noted in the categories of Self Acceptance and Environmental Mastery. The results let staff know they are providing meaningful help to patients in the program. The results certainly echo what staff hear from patients; that the program has been a life altering experience.

Chris Jackowich, RPN, BGS, has been with Grey Nun’s Mental Health Program for 30 years! She is the unit supervisor of the Outpatient Programs and Allied Health Professionals. She has worked primarily in outpatients and is passionate about psychodynamic group therapy.

Email: Chris.Jackowich@covenanthealth.ca
Background
Swallowing impairments can lead to serious health problems, such as malnutrition and aspiration pneumonia, as well as psychosocial concerns and poor quality of life. Effective treatment can be enhanced with the use of adjuvant visual biofeedback from surface electromyography (sEMG) to monitor muscle movement during swallowing exercises. However, access to therapy is limited due to several barriers, ranging from low clinical capacity to expensive and impractical current technologies.

Methods
Our team, comprised of clinicians, Industrial Design students, and Biomedical Engineers met within the context of an interdisciplinary design course to draft an innovative solution to existing swallowing therapy challenges. The design was selected with input from biomedical engineers (weight, size, connections, signal quality), clinicians (target therapy, patient demographics, shoulder range of motion) and uses principles of universal design.

Results
Our team developed a prototype for a mobile health device that replaces the existing technology and translates sEMG information into a more engaging interface for the patient (Figure 1). Future development will involve pairing the small, portable device with iPads via a downloadable application. The application will provide meaningful visual feedback to the patient and upload home practice data to a central server for the clinician to monitor progress.

Conclusion
Engaging clinicians in the design process of medical devices can ensure patient-focused prototypes and increase the likelihood that new technologies will be adopted more rapidly.

Acknowledgments
The authors would like to thank Robert Lederer, Eleni Stroulia, PhD, for their guidance; Herman Lundgren, Dylan Scott and Mark Fedorak for their work on the mobile sEMG technology. Components of this project were completed as part of DES 500, The Practice of Industrial Design and CMPUT 605, Computing for Ubiquitous Health Applications, offered at the University of Alberta.
Research Teams

Covenant Health Palliative Institute
A model of community-engaged scholarship

Integrating clinical, educational, research, leadership and administrative best practices through extensive consultation with regional palliative care programs resulted in the establishment of a bricks and mortar palliative institute. Founded in Canada (1738) by Saint Marguerite d’Youville, the Grey Nuns represent a faith-based approach to the relief of suffering. Nearly three centuries later, faith, medicine and science intersect to create an institution strategically focused on the relief of suffering. Created on the basis of a solid business plan, the Institute is poised to augment and transform palliative care in Alberta. Principally, the Institute proposes to reinforce and enhance an internationally recognized model of regionally integrated, coordinated and comprehensive palliative care program. By forging strong relationships with universities, government and health authorities, the Institute is poised to transform the financing and delivery of palliative care. It will build on local strengths in advocacy, symptom assessment, the science of muscle wasting, health policy and models of care addressing non-cancer needs. Early initiatives include the deployment of end-of-life pathways, patient satisfaction surveys and Advanced Care Planning. The Institute is currently supporting our partners to establish provincial strategies, including a novel data warehouse and surveillance program.

The Covenant Health Palliative Institute champions a future where every Albertan can make informed choices about their end-of-life care and where their caregivers have the knowledge, expertise and resources to support them. The Institute’s distinctive role in achieving this future is to serve as a palliative and end-of-life care knowledge-broker for clinicians, policy makers, patients and families, and to lead informed public discourse on end-of-life issues.

Edmonton Classification System for Cancer Pain (ECS-CP)
For each of the following features, circle the response that is most appropriate, based on your clinical assessment of the patient.

1. Mechanism of Pain
   - No pain syndrome
   - Any nociceptive combination of visceral and/or bone or soft tissue pain
   - Neuropathic pain syndrome with or without any combination of nociceptive pain
   - Insufficient information to classify

2. Incident Pain
   - No incident pain
   - Incident pain present
   - Insufficient information to classify

3. Psychological Distress
   - No psychological distress
   - Psychological distress present
   - Insufficient information to classify

4. Addictive Behaviour
   - No addictive behaviour
   - Addictive behaviour present
   - Insufficient information to classify

5. Cognitive Function
   - No impairment. Patient able to provide accurate present and past pain history unimpaired
   - Partial impairment. Sufficient impairment to affect patient’s ability to provide accurate present and/or past pain history
   - Total impairment. Patient unresponsive, delirious or demented to the stage of being unable to provide any present and past pain history
   - Insufficient information to classify

ECS-CP profile (combination of the five: circled responses for each category):
Assessed by: ______________  Date: ______________

continued on next page...
Palliative Institute Timeline

**October 2005** - Carleen Brenneis, Robin Fainsinger, Karen Macmillan submit a briefing note to Capital Health discussing the concept of a “Palliative Care Centre/Institute.”

**December 2008** - Following extensive consultations within Capital health, a formal business case was written by Viki Muller and Konrad Fassbender.

**June 2012** - Covenant Health contracted KPMG to conduct further consultation and write a Business Plan.

**October 2012** - Building on its history and leadership in research and education, Covenant health officially launches the Palliative Institute.

Recently published research – Lay summaries


   A standardized approach for assessing and classifying cancer pain is necessary in order to improve treatment for patients with complex pain. The Edmonton Classification System for Cancer Pain (ECS-CP) offers a starting point for the evolution of a standardized international classification system for cancer pain. The primary purpose of this study was to describe the prevalence of the five ECS-CP pain classification features - pain mechanism, incident pain, psychological distress, addictive behavior, and cognition in a diverse international sample of patients with advanced cancer. A total of 1051 adult patients were evaluated from 17 international sites. A clinician completed the ECS-CP for each patient. 64% (n = 680) of the 1051 patients were assessed by a clinician as having cancer pain: nociceptive pain (n = 534; 79.7%); neuropathic pain (n = 113; 16.9%); incident pain (n = 408; 60.9%); psychological distress (n = 212; 31.6%); addictive behavior (n = 30; 4.5%); normal cognition (n = 616; 91.9%). The prevalence of ECS-CP features and pain intensity scores varied substantially across sites and locations of care.

   The ECS-CP is a clinically relevant systematic framework, which is able to detect differences in salient pain classification features across diverse settings and countries.

   *This study was conducted in collaboration with the European Palliative Care Research Collaborative (EPCRC).


   Palliative care (PC) and palliative radiotherapy (RT) consultation are integral to the care of patients with advanced cancer. These services are not universally available in rural areas, and travel to urban centers to access them
can be burdensome for patients and families. The objectives of our study were to assess the feasibility of using videoconferencing to provide specialist multidisciplinary PC and palliative RT consultation to cancer patients in rural areas. The Virtual Pain and Symptom Control and Palliative Radiotherapy Clinic was piloted from January 2008 to March 2011. Cancer patients in rural northern Alberta attended local telehealth facilities, accompanied by nurses trained in symptom assessment. The multidisciplinary team at the Cross Cancer Institute in Edmonton was linked by videoconference. Forty-four initial consultation and 28 follow-up visits took place. Mean Edmonton Symptom Assessment System scores for anxiety and appetite were significantly improved at the first follow-up visit. Average per visit savings for patients seen by telehealth versus attending the CCI were 471.13 km, 7.96 hours, and $192.71. Patients and referring physicians indicated a high degree of satisfaction with the clinic. We conclude that delivery of specialist multidisciplinary PC consultation by videoconferencing is feasible, may improve symptoms, results in cost savings to patients and families and is satisfactory to users.


This study aimed to validate the Head and Neck Patient Symptom Checklist© (HNSC©), a tool designed to evaluate 17 symptoms affecting dietary intake. The study cohort was 52 treatment-naive head and neck cancer (HNC) patients. Patients were evaluated at baseline, at the end of six weeks radio-chemotherapy and two and a half months after treatment. Relationships among energy intake, weight loss, age, sex, treatment, tumor stage, and symptoms were evaluated. From baseline to end of treatment, 71% of patients had >5% body weight loss. Despite energy intakes returning to baseline levels at follow-up, 88% of patients continued to lose weight. At the end of treatment, 100% of patients reported two or more nutrition impact symptoms (NIS); these symptoms were still present at follow-up in 83% of the patients. Multivariate using Generalized Estimating Equations (GEE) analysis showed that depression, dysphagia, and sore mouth predicted energy intake, and dysphagia and sore mouth predicted weight loss. Cumulative Hazard analysis showed that NIS accelerated the time and probability of weight loss. The HNSC© is a valid tool for assessing NIS in HNC. Identification of NIS may aid in the management of symptoms associated with reduced energy intake and weight loss and thus decrease the malnutrition risk in HNC patients.

CONGRATULATIONS

Congratulations to Drs. Hagen, Fassbender and Simon on their recent award of an AIHS Collaborative Research and Innovation Opportunities (CRIO) grant. The project is a five year term (April 2013 to March 2018) and involves a team of researchers and knowledge end-users working together on Advance Care Planning and Goals of Care Alberta: a population based Knowledge Translation (KT) intervention study. The project will examine Alberta Health Services-led implementation of a provincial policy on Advance Care Planning (ACP) and Goals of Care Designations (GCD) in Alberta. For more information please visit http://www.acpcrio.org/

THANK YOU

Thank you to the Covenant Health Research Centre (CHRC) for providing funds for the following pilot study which assessed the study feasibility and generalizability of the Edmonton Classification System for Cancer Pain (ECS-CP) in a sample of Edmonton palliative care patients: Fainsinger, R. & Nekolaichuk, C. (co-principal investigators). Moving on – the next step in developing an international classification system for cancer pain.

KONRAD FASSBENDER

Konrad Fassbender is the Scientific Director for the Covenant Health Palliative Institute. He is a health economist and Assistant Professor in the Division of Palliative Care Medicine and holds a cross-appointment as Adjunct Assistant Professor in the School of Public Health. Konrad supervises medical trainees, graduate students and teaches health economics, health finance and econometrics. He works with clinicians, administrators and policy makers to measure cost and performance associated with the financing and delivery of health care and social services. Dr. Fassbender’s program of research examines the effects of health reform and technological change on health and economic outcomes of dying patients and their families.

Email: Konrad.Fassbender@ualberta.ca
The Pediatric Centre for Weight and Health (PCWH) at the Misericordia Community Hospital has been providing specialty care to overweight children and their families for more than seven years. Located in the Child Health Clinic, the PCWH is comprised of a multidisciplinary team that includes a pediatrician, psychiatrist, psychologist, registered nurse, registered dietitian and exercise specialist. The clinic’s focus has always been to provide evidence-based and family-centered care for children to improve their health and manage their weight. Recently the clinic has started working on research projects with the goal of contributing to the best practice research evidence on treating this complex chronic condition.

To initiate the research program at the clinic, the PCWH team compiled an overview of patient characteristics over a four year period and created a poster with the results. This poster titled, “Prevalence of medical and mental health co-morbidities in overweight and obese children referred to a hospital based pediatric weight management clinic during a 4 year period, 2008-2011,” was presented at the 2013 Canadian Obesity Summit in Vancouver.

This initial research poster highlighted many areas for future research and investigation, including looking more specifically at the frequency and severity of mental health and psychosocial concerns identified by children and their families. Research in this area is still emerging, and the PCWH is excited to help add to this body of knowledge. Many other practical research projects are also being developed that will help us to identify improvements and innovation in the care that we can provide children and their families.

There are currently three Pediatric Centres for Weight and Health clinics in Alberta: one Covenant Health clinic at the Misericordia Community Hospital, one Stollery clinic located at the Edmonton General Continuing Care Centre, and a new clinic at the Alberta Children’s Hospital in Calgary. Children ages two to 18 can be referred to the PCWH by their physician or nurse practitioner if their Body Mass Index is over the 85th percentile for their age and gender.

The PCWH Misericordia team:
Dr. Rena LaFrance, Psychiatrist and Medical Lead
Dr. Mohammad Ansarian, Pediatrician
Dr. Christine Orosz, Registered Psychologist
Jennifer Bothe, Registered Nurse and Clinic Coordinator
Kristine Godziuk, Exercise Specialist & Research Coordinator
Ashleigh Wanner, Registered Dietitian
Cheyan Kotch, Administrative Assistant

For any questions or comments on the research or clinical work at the PCWH Misericordia, please contact Kristine Godziuk at 780-735-2397 or Kristine.Godziuk@covenanthealth.ca

KRISTINE GODZIUK, MA, CSEP-CEP, KIN

Kristine Godziuk, MA, CSEP-CEP, KIN, is an exercise specialist at the Pediatric Centre for Weight and Health in the Misericordia Community Hospital. She has been with the clinic for over six years, and recently added the role of Research Coordinator to her responsibilities. The PCWH Misericordia team is currently working on research projects related to childhood obesity and mental health, hypertriglyceridemic waist and metabolic syndrome.
Today I would like to introduce you to a new set of subject guides on medical and health care related topics that specifically highlight resources available to Covenant Health and Alberta Health Services (AHS) staff. Produced collaboratively by staff at Covenant Health Library Services and AHS Knowledge Resource Service these guides are designed to provide you with a central location to discover the best information resources available in your discipline or speciality area. There are currently 18 guides completed on the following topics:

- Addictions and mental health
- Bone and joint health
- Cancer care
- Cardiovascular health and stroke
- Critical care
- Drug information
- Emergency
- Health administration
- Knowledge management
- Nurses
- Obesity, diabetes and nutrition
- Physicians
- Rehabilitation
- Respiratory therapy
- Senior’s health
- Speech language pathology and audiology
- Surgery
- Tobacco reduction
- Complementary and alternative medicine
- Complex medicine
- Health psychology
- Infection prevention and control
- Maternal health
- Neurological Disease, ENT, vision
- Newborn, youth, child health
- Palliative care
- Patient and family-centred care
- Surgery
- Patient safety
- Population, health and promotion
- Primary care and chronic disease management
- Quality improvement
- Spiritual care

We are working on another batch of subject guides and hope to have them posted on the website in February 2014:

You can find the subject guides at http://krs.libguides.com/subjectguides/  Each guide contains links to some of the latest research published on the topic along with listings of key databases, e-journals, e-books, patient resources, clinical guidelines and other grey literature resources in the area.

See the Library Services current awareness page (www.compassionnet.ca/Page506.aspx) on CompassionNet for instructions on how to set up e-TOCs or subject alerts, or contact library staff for assistance or if you have any questions:

Email: covenantlibrary@covenanthealth.ca

Grey Nuns Health Sciences Library: 780.735.7300

Misericordia Weinlos Library: 780.735.2708

Sharna Polard is the Manager, Library Services. Prior to joining the Covenant Health team in July 2012, she received her Masters of Library and Information Science (MLIS) degree at the University of Western Ontario (2002), and then worked for ten years at the Alberta Legislature Library. She believes that the role of health librarianship is a vital one in today’s world of information overload and is excited by the opportunities that new technologies offer for enabling library staff to better connect their clients to the information they need when they need it.

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Scholar’s heart is in Aboriginal communities
Pediatrician and professor Lola Baydala was honoured on May 23, at UAlberta’s first Community Connections Awards.

By Bev Betkowski on May 20, 2013 (modified July 23, 2013) Reprinted, with permission

(Edmonton) As a pediatrician, Lola Baydala knows a lot. But when she started working side by side with Alberta’s Aboriginal people to improve child health in their communities, her knowledge also blossomed into understanding—and into something deeper.

“Once you engage with community elders, parents, teachers, students and administrators, you become part of that community, so even when funding ends, you are still a member of that community. You are still invited to celebrations, for coffee, and you still work with them.”

Baydala’s dedication to researching child health issues and seeking solutions at the community level has already earned her the gratitude and respect of her Aboriginal partners, including the honorary name of Wagcheshi Wiya (Brave Hearted Woman), bestowed in 2011 by the Alexis Nakota Sioux Nation.

Recently, Baydala was recognized for her ongoing work through the University of Alberta Community Scholar Award, one of three inaugural Community Connections Awards, given on May 23, as the University of Alberta celebrated the dedication of its campus citizens to the larger community.

Baydala, who holds science and medical degrees from the U of A and is an associate professor, was honoured in a
noon-hour ceremony at Edmonton City Hall as the university recognized the above-and-beyond contributions made to Edmonton by U of A people and partners. She joined two other recipients: Community Leader Award winner Sharon Morsink and UAlberta Advocacy Award winner Renée Vaugeois.

Baydala’s work—and that of her students and colleagues—reaches far beyond her medical practice in her work with members of the Alexis First Nation, Enoch Cree Nation and Maskwacis Cree Nation, as well as with Edmonton Public Schools to develop grassroots programs for child health education.

All of Baydala’s projects are first rooted in the cultural beliefs, protocols and input of community members and are based on mutual knowledge and respect.

“They have expanded my own capacity to understand and contribute to building healthy communities, and together, we are finding common ground where we can work together to address complex issues.”

Baydala began teaming with Aboriginal communities through her hospital-based teaching clinic at the Misericordia Community Hospital in Edmonton; many women from surrounding areas who had their babies in the hospital became her patients, and through them, she became aware of their needs.

“I got to know many of the families and I felt I had to learn more about their communities to provide better care.”

She asked the Alexis Nakota Sioux Nation, located west of Edmonton, whether she could provide a service. The band agreed, and asked Baydala to assess the learning needs of their school-age children to help secure funding for classroom support. That led to discussion and eventual funding of programs for preventing substance abuse for Alexis Nakota Sioux Nation, as well as for Maskwacis Cree Nation schools in Hobbema.

Along the way, grants and program results were co-presented by Baydala, her colleagues and her Aboriginal partners, sealing profound research relationships that reflect not only university knowledge, but also equally valuable community knowledge, Baydala noted.

That, in turn, helps assure the success of community programs, she believes.

“Often, the community has the answers to its challenges; if we as a university can build relationships with community, we will also build solutions together. The university can access the resources, but if we take the time to sit down and talk to the community and engage in deep listening, the answers are there, and we as a university can help actualize those solutions.”

Most rewarding for Baydala is the insight she’s gained as a person. Driven at first by curiosity to explore health issues, she established relationships with her community partners that extend beyond data maps and academic papers.

“I’ve learned to value heart knowledge as well as knowledge that comes from scientific evidence.”

Scholar’s heart is in aboriginal communities - news & events - university of alberta [Internet]; cited 7/24/2013. Available from: http://news.ualberta.ca/newsarticles/2013/may/scholars-heart-is-in-aboriginal-communities

Dr. Lola Baydala, MD, FRCP, is a pediatrician at the Misericordia Community Hospital Child Health Clinic and an associate professor in the Department of Pediatrics at the University of Alberta. Her work goes far beyond her medical practice, focusing on the promotion and development of health education. It is rooted in a community-based participatory research approach. By inviting community members to share their beliefs, protocols, and input, she has helped Aboriginal communities such as the Alexis Nakota Sioux Nation, Enoch Cree Nation, and Maskwacis Cree Nation, as well as Edmonton Public Schools create child-focused health programs. The programs she has helped to develop have been designed to meet the unique needs of each community in which she works.
Can I use NetCare for research purposes?

Kimberley Kordov, Research Ethics Officer, University of Alberta, Research Ethics Office

The Alberta Electronic Health Record (Alberta EHR) known as the Alberta Netcare Portal (ANP) is a health information repository provided by Alberta Health and Wellness that contains the health information of all Albertans. The ANP is available to all recognized health care providers to aid in providing a health care service to their patients. Health care providers are required to adhere to the ANP Information Exchange Protocol (“IEP”), the Health Information Act, and the policies of participating custodians.

Use of the ANP for research

There are also specific rules outlined in the IEP that govern the use of the ANP for research purposes. These requirements are:

1. The research must be approved by one of the recognized health research ethics boards (REB) in Alberta.
2. Information from the ANP may be eligible for use in research only where such research requires EXPLICIT CONSENT TO PARTICIPATE from the individual who is the subject of the information. As outlined in HIA, explicit consent must be written or electronic, where electronic provides a sufficient level of individual authentication. Types of research where a waiver of consent is granted by the REB to conduct the research, cannot use the ANP as a source of this data (i.e. retrospective chart review type research).
3. Research participant written consent must be obtained prior to access. Consent must meet all of the requirements as defined in the Health Information Act (this will have been addressed by the REB when approving the research).
4. The researcher must adhere to the Health Information Act – including the requirement for a research agreement.
5. The collected information is restricted to the information described in the research proposal and approved by the research ethics board.

Who can access the ANP for research

1. Health care providers that have access to the ANP may use their access for research.
2. Researchers that do not have ANP access for patient care purposes cannot obtain access solely for research. Researchers may approach a participating custodian and request the custodian to provide them with the information contained in the ANP.

While the rules governing the use of the ANP are not an ethical issue, the REB will not approve studies which propose to use NetCare without consent. Should you require more information related to this, please feel free to contact your REB Administrator or Kimberley Kordov, Research Ethics Officer, University of Alberta, Research Ethics Office at 780.492.2615.
Changes to Alberta’s health research ethics review system

Jon Hagan, Communications Officer, Ethics and Innovation Platforms, Alberta Innovates – Health Solutions

The partners of Alberta’s Health Research Ethics Harmonization (HREH) initiative (www.aihealthsolutions.ca/eip/hreh/) are close to achieving their mutual objectives to further streamline how ethics reviews are accomplished in the province.

Reduction in number of designated health research ethics boards:

- The Honorable Fred Horne, Minister of Health, has signed a Designation Regulation that reduces the number of Health Information Act (HIA) designated boards in the province from six to the following three:
  - The Health Research Ethics Board of Alberta (HREBA)
  - The University of Alberta – HREB
  - The University of Calgary – Conjoint HREB
- The newly created HREBA includes three former research ethics boards reconstituted as committees with the following names found in the chart below.
- HREBA will be housed at Alberta Innovates – Health Solutions and brings all of Alberta’s provincially-focused research ethics committees under one roof, making it easier to manage and align the day-to-day operations.
- The University of Lethbridge REB will continue to service that university community, but will no longer be HIA-designated. Arrangements are being made to ensure access to an HIA REB for applications involving health information.

Full reciprocity and electronic platforms for ethics submission and review:

- Further to the above designations, the parties have achieved an “agreement in principle” on full reciprocity across all three HIA designated REBs. Full reciprocity will mean that an ethics application in Alberta will require only one review to be accepted at all health research locations in the province. Watch for formal announcements early in 2014 once final details have been settled.
- Work is also well underway to transition Alberta’s three REBs, including the new HREBA committees, onto a secure online platform for ethics submissions and reviews. There will be an adjustment period as the REBs, researchers and their study teams learn how to use the new system, but its many benefits including ease of access for submissions, amendments and renewals as well as transparency of the process should make the transition worthwhile.

Streamlined ethics reviews will contribute to enhanced access for Albertans to new prevention, treatment and care approaches, while continuing to protect them as participants in health research. Improvements to ethics review will also support researcher development of innovations and the attraction of investment to the province to boost its and Canada’s competitiveness.

For more information please contact Norma Brown, Project Manager for the Health Research Ethics Harmonization initiative: Norma.Brown@albertainnovates.ca

<table>
<thead>
<tr>
<th>Former Research Ethics Board Name</th>
<th>New HREBA Committee Name</th>
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<tbody>
<tr>
<td>Alberta Cancer Research Ethics Committee (ACREC)</td>
<td>HREBA - Cancer Committee</td>
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<tr>
<td>Community Research Ethics Board of Alberta (CREBA)</td>
<td>HREBA - Community Health Committee</td>
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<tr>
<td>Research Ethics Review Committee (RERC)</td>
<td>HREBA - Clinical Trials Committee</td>
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**Listing of research approved** from Sept. 2013 to Dec. 2013

<table>
<thead>
<tr>
<th>Study Title</th>
<th>PI</th>
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<tr>
<td>The CBCF Tumor Bank (CBCF TB) - A branch of the Alberta Cancer Research Biorepository (ACRB)</td>
<td>Weinfeld, Michael</td>
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<td>Asymptomatic stroke in atrial fibrillation patients (ASAFP)</td>
<td>Butcher, Kenneth</td>
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<td>Professional development of dental hygiene students based on experiences in long-term care settings</td>
<td>Compton, Sharon</td>
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<td>Three-dimensional assessment of tongue volume after free flap reconstruction: Validation of technique and correlation with function</td>
<td>Jeffery (Xu), Caroline</td>
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<td>MiTy Kids (Metformin in Women with Type 2 Diabetes in Pregnancy Kids Trial) 2 Research</td>
<td>Haqq, Andrea</td>
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<td>Relational ethics of the parental experience of congenital anomaly in the NICU</td>
<td>van Manen, Michael</td>
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<tr>
<td>Evaluation of insulin pumps in paediatric and adult patients with type 1 diabetes</td>
<td>Menon, Devidas</td>
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<tr>
<td>The role of vitamin D in anti-TNF induced remission in patients with Inflammatory Bowel Disease</td>
<td>Kroeker, Karen</td>
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<td>The acute effects of protein intake on the regulation of ghrelin and insulin in children with Prader-Willi Syndrome compared to controls.</td>
<td>Haqq, Andrea</td>
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<tr>
<td>Autonomic nervous system activity and metabolic profiling in children with Prader-Willi Syndrome compared to controls</td>
<td>Haqq, Andrea</td>
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<tr>
<td>Relationship between brain-derived Neurotrophic Factor (BDNF) Level, BDNF haplotypes and neurocognitive performance in children with Prader-Willi Syndrome</td>
<td>Haqq, Andrea</td>
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<td>Stigma in Alzheimer’s Disease - Experiences of the person with Alzheimer’s Disease and their caregivers</td>
<td>Harper, Lori</td>
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<tr>
<td>Impact of cardioversion on quality of life for treatment of atrial fibrillation</td>
<td>Sandhu, Roopinder</td>
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<td>Moving research to practice: Development of quality indicators for hip and knee arthroplasty rehabilitation</td>
<td>Jones, Catherine Allyson</td>
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<tr>
<td>A randomized, double-blind, placebo-controlled, phase 3 study to assess the efficacy and safety of AMG 416 in the treatment of secondary hyperparathyroidism in subjects with chronic kidney disease on hemodialysis (KAI 20120230: SHPT Study)</td>
<td>McMahon, Alan</td>
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<thead>
<tr>
<th>Title</th>
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<tr>
<td>Improving heart failure outcomes in rural communities: Moving from understanding to practice change</td>
<td>Clark, Alex</td>
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<tr>
<td>POINT: Platelet-Oriented Inhibition in New TIA and minor ischemic stroke (POINT) Trial, a randomized, double-blind, multicenter clinical trial</td>
<td>Buck, Brian</td>
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<td>Retrospective review of Edmonton emergency department algorithm for diagnosis and treatment of deep vein thrombosis</td>
<td>Wu, Cynthia</td>
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<td>An appraisal of professional attitudes in recent MLS graduates</td>
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<td>The role of fetal hypoxia in fetal myocardial changes and long-term cardiovascular programming</td>
<td>Jain, Venu</td>
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<td>Trellis DVT registry</td>
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<td>Regional diagnosis, management, and outcomes of patients with heparin-induced thrombocytopenia</td>
<td>Sandhu, Irwindeep</td>
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<td>Brachial Plexus block chart review</td>
<td>Tsui, Ban</td>
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<td>Portable Swallowing Therapy Unit: End user feedback on alpha model</td>
<td>Rieger, Jana</td>
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<td>Constructing critical thinking: A qualitative analysis of health science educators’ interpretations</td>
<td>Kahlke, Renate M.</td>
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<td>Defining “technicity” for Edmonton: a retrospective study of method of hysterectomy at the Grey Nuns Community Hospital/ Royal Alexandra Hospital, comparing 2001 &amp; 2011</td>
<td>Schulz, Jane</td>
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<td>Neurophysiological mechanisms of read in aphasia</td>
<td>Kim, Esther</td>
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<td>Manufacturing of scaffold and bone Plates using 3D Bioplotter technology</td>
<td>Rieger, Jana</td>
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<td>Neural behaviour correlates of the role of motor experience and augmentative manipulation in infant cognition</td>
<td>Cook, Albert</td>
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<td>Advance care planning: the patient and family experience</td>
<td>Syme, Charlotte (Ann)</td>
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<td>High androgen/low progesterone exposures and ovarian cancer</td>
<td>Koebel, Martin</td>
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<td>Immunization of women with diptheria &amp; tetanus toxoid combined with acellular pertussis (Tdap) during mid-third trimester of pregnancy: An evaluation of potential for immunological protection for the neonate</td>
<td>Vaudry, Wendy</td>
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<td>Use of the FICA Tool: Integrating spirituality as a key component of care by inter-professional palliative and geriatric hospital-based teams</td>
<td>Bremault-Phillips, Suzette</td>
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<tr>
<td>Evaluate the diagnostic accuracy of JM-103 TcB device as compared to total serum bilirubin (TSB) in preterm infants in pre-phototherapy, during and post phototherapy phases</td>
<td>Kumar, Manoj</td>
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