

RESEARCH PORTFOLIO

ANNUAL REPORT

APRIL 1, 2011- MARCH 31, 2012

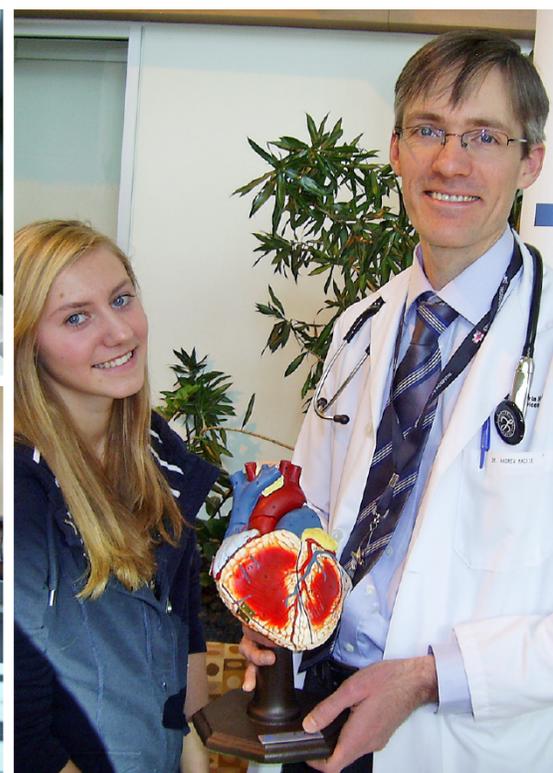


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1. EXECUTIVE SUMMARY

Research is a critical enabler within Alberta Health Services (AHS) that will support health system improvement and sustainability and make Alberta a leader in health research. A tremendous amount of health research occurs everyday in Alberta, across all care settings and involving all disciplines. The responsibilities of the AHS Research Portfolio are to support excellence in health research and innovation that improves the quality of health care, to provide meaningful data that inform improvements in performance, and to assess health technologies that give the best outcomes for the investment. This annual report describes key initiatives, successes, and progress for the 2011-2012 year.

Under the leadership of Dr. Robert Sheldon, Senior Vice-President, the Research Portfolio expanded its scope to include health system analytics and went through extensive reorganization to meet its broadened responsibilities. A key milestone achieved in 2011/12 was a draft of the AHS Research and Innovation Strategy, which will guide the efforts of AHS and its partners. The document identifies six strategies that will enhance AHS' capabilities to deliver better care to Albertans and position Alberta at the forefront of health research in Canada. Achievements for 2011-2012 are grouped according to the strategies that they support:

Strategy #1 – Aligning AHS within Alberta's Health Research Policy Framework (Section 2)

- Launched the first Strategic Clinical Networks to align with the Alberta Health Research and Innovation Strategy.

Strategy #2 – Building Strong Partnerships in Alberta (Section 3)

- Formed the Alberta Academic Health Network.
- Supported the Red Deer College Health Research Collaborative.
- Defined strategic priorities and working groups for the Alberta Clinical Research Consortium.
- Worked toward harmonization of provincial research ethics review processes.
- Explored emerging opportunities with the federal Strategy for Patient Oriented Research.

Strategy #3 – Being Efficient with AHS Resources

- Reorganized and expanded the Research Division (Section 4).
- Developed resources for researchers (Section 5).

Strategy #4 – Creating a Culture of Research and Innovation in AHS (Section 6)

- Supported the Research Community of Practice.
- Created a website for the Research Division.
- Began a newsletter: "Researchers Need to Know".

Strategy #5 – Incenting Research of Highest Value to AHS (Section 7)

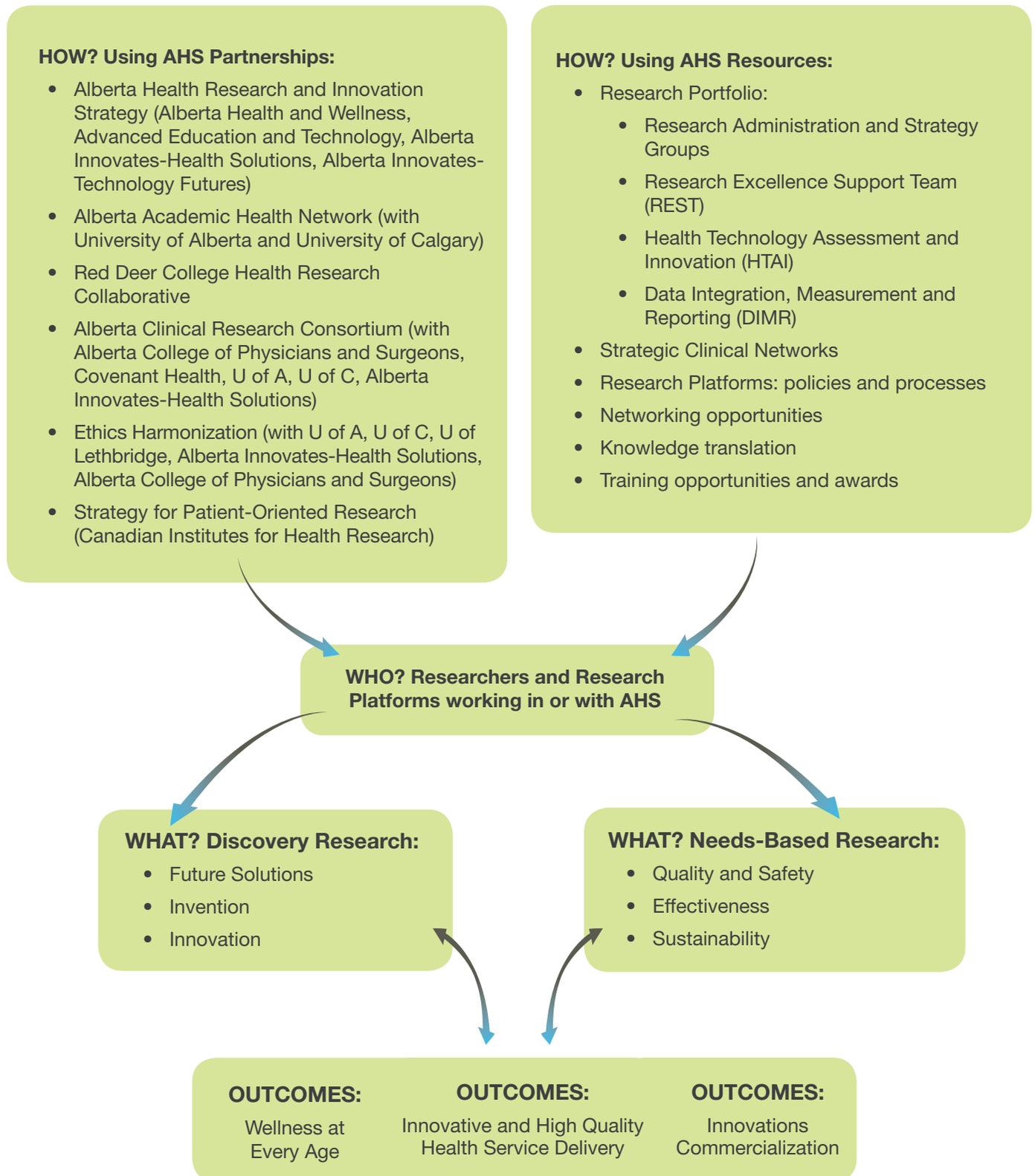
- Created training opportunities.
- Created the first President's Research Award of Excellence.

Strategy #6 – Being Effective with AHS Resources (Section 8)

- Measured research outputs in AHS

Ultimately, evidence for the effectiveness of strengthening external partnerships (Strategies 1 and 2) and directing internal resources (Strategies 3-6) is high quality research that impacts the lives of Albertans (Fig. 1). During the 2011 calendar year, over 1,000 research studies were initiated within AHS. These studies were across the spectrum of AHS, from prevention to surgery, from children's to seniors' care. The projects involved a variety of internal and external partners (i.e. universities, funding agencies, industry) including over 60 different industry sponsors. Section 9 describes a few of these studies and their impact on the lives of Albertans.

FIG. 1. USING RESEARCH TO MAKE A DIFFERENCE IN THE LIVES OF ALBERTANS: 2011/2012



2. ALIGNING AHS WITHIN ALBERTA'S HEALTH RESEARCH POLICY FRAMEWORK

In August 2010, the Ministers of Alberta Health & Wellness and Advanced Education & Technology launched the **Alberta Health Research and Innovation Strategy (AHRIS)** to provide an overarching framework to guide health research and innovation investments in Alberta. The provincial strategy seeks to improve the quality of life of Albertans as a result of the knowledge created and applied by an integrated, world-class health research and innovation system. It calls for greater alignment between a multi-stakeholder research agenda and the needs of the health system, as well as greater focus on how research can contribute valuable new knowledge and enable more rapid knowledge translation in Alberta, including 'value-added' new technologies. Two high-level strategic priorities were identified, wellness at every age and innovative health service delivery, with these priorities supported by three pillars – highly skilled people, knowledge translation, and innovation platforms.

AHS shares responsibility for driving the strategy forward with Alberta Health and Wellness, Alberta Advanced Education and Technology, Alberta Innovates-Health Solutions, and Alberta Innovates-Technology Futures. Each partner works closely with the universities and other key stakeholders on each of the actions identified in the strategy. Among the 19 actions proposed within this strategic framework, AHS shares lead responsibility for three actions and leads another three. AHS also provides direct support to another eight actions led by our partners. Among the key AHS responsibilities are:

- To recruit and retain world-class health system, product design, management and research talent to Alberta.
- To focus research program investments in areas of strategic priority.
- To establish knowledge translation expertise in “research-intensive” hospitals and primary care service delivery organizations.
- To explore the development of an Alberta academic health sciences concept to increase informed health service delivery planning and to facilitate the intricate linking of education, research and clinical practice that takes place in both academic and the service delivery settings.
- To establish knowledge translation programs in support of innovation and implementation of best practices within service delivery organizations, including clinical practice.

The main mechanism that AHS will use to bring the AHRIS actions to life is the creation of novel platforms called “Strategic Clinical Networks” and “Operational Clinical Networks”.

2.1 Strategic Clinical Networks

Strategic Clinical Networks (SCNs) are engines of innovation set up to help AHS set priorities and find ways to achieve them.

The SCNs bring together the perspectives of all stakeholders; clinicians, policy makers, researchers, operations and strategy leaders, key community leaders, patients and families. They are provincially-focused and have the ability to identify pockets of innovation and excellence, and ensure that those best practices are shared in a way that benefits all Albertans.

Multiple leaders from across AHS were integral in preparing the foundations for launching the SCNs, including Dr. Cy Frank, Vice-President of Research Strategy. With an embedded research focus, the SCNs will develop and implement strategies, such as clinical pathways and care innovations, which improve patient outcomes and satisfaction, improve access to health care, and add to the sustainability of Alberta's health care system. Through Dr. Frank's leadership, each SCN is mandated to develop a provincial research program in collaboration with Alberta's university research community and will draw upon outcomes of current studies or commission new research. To help recommend research topics and projects, each SCN will hire a scientific director who will work with a voluntary provincial research network.

Once established, SCN research priorities will be reviewed regularly based on the demonstrated need of the population of interest. The SCNs are also encouraged to share their strategic resources, such as databases, registries, information technology systems, and health technology assessment capabilities, which can be used for multiple research projects.

SCNs will be encouraged to exploit opportunities to commercialize new products, methods, or services that arise from their research and innovation work. They will also work with universities to develop knowledge translation strategies and tools. Effective knowledge translation at the zone level of AHS will be crucial as the SCNs seek the collaboration of zone leaders to implement programs, alter practices, or adopt new technology.

An SCN/Academic Health Network Research Working Group has been set up that includes two AHS clinical-scientists and other members from AHS and Alberta Innovates-Health Solutions. This group hosted a provincial level meeting on January 23, 2012 with stakeholders from the universities, AHS, the Academic Health Network, and Alberta Innovates-Health Solutions. They discussed the preliminary concept for a Support for People and Patient-Oriented Research and Trials (SUPPORT) Unit in Alberta (see section 3.5) and the process to develop and submit one harmonized application from Alberta to the Canadian Institutes for Health Research to co-fund such a unit. Other efforts to support the emerging research mandates of the SCNs include the establishment of an AHS funding opportunity to support SCN research planning and networking events.

To access external resources for research support provincially, nationally and internationally, SCNs will go through normal competitive application processes. Funding organizations may include Alberta Innovates-Health Solutions, Canadian Institutes for Health Research, and the SUPPORT Unit. Phase 1 SCNs commenced in 2011-2012 included Seniors' Health, Bone & Joint Health, Cardiovascular Health & Stroke, Cancer Care, Addiction & Mental Health, and Obesity, Diabetes & Nutrition. The Research Portfolio supports the research goals of the SCNs specifically through its VP of Research Strategy, Dr. Cy Frank; its Director of Provincial Research Strategy and Priorities, Michelle Gagnon; and its service groups - Data Integration, Measurement and Reporting, Research Excellence Support Team, and Health Technology Assessment & Innovation.

2.2 Operational Clinical Networks

In the next reporting year, AHS will establish three operational clinical networks (OCNs) that build on the work of the existing networks in the areas of critical care, emergency and surgery. The OCNs are operational or service focused, which differs from the SCNs who focus on a particular area of health. Each OCN will work with each of the SCNs and focus on improving standards, processes and the patient's experience within their service area. As with the SCNs, research and innovation will be important components of the work of these networks. The Research Portfolio will also support the OCNs.

2.3 AHS Research and Innovation Strategy

Fundamental to the development of research within AHS and the operations of the Research Portfolio is the development of a comprehensive research strategy. Toward the end of this reporting year, the Portfolio's Research Strategy Group developed a draft strategic plan entitled "Research and Innovation Strategy: 2012-2017." It will be finalized in the next reporting year.

The goal is to develop a self-perpetuating cycle of identifying needs, targeting improvements, implementing those of value, and capitalizing on the value gained to start this cycle over again. Six research and innovation strategies were identified to achieve this goal:

1. Aligning AHS within the Health Research Policy Framework in Alberta
2. Building strong partnerships in Alberta
3. Being efficient with AHS resources
4. Being effective with AHS resources
5. Creating a culture of research and innovation in AHS
6. Incenting research of high value to AHS

3. STRATEGIC PARTNERSHIPS: BUILDING STRONG PARTNERSHIPS IN ALBERTA

Our most significant partners in health research in terms of breadth and depth are the major universities in Alberta: virtually all health research activity in Edmonton is conducted with the University of Alberta and likewise in Calgary with the University of Calgary. AHS' Research and Innovation Strategy emphasizes building on these strong partnerships in Alberta to leverage research capacity and resources. Within the 2011-2012 year, new partnerships were formed, ongoing partnerships were supported, and pan-provincial initiatives saw substantial progress.

3.1 Alberta Academic Health Network

In 2011, AHS, the University of Alberta, the University of Calgary and their Faculties of Medicine formed the Alberta Academic Health Network (AAHN) to define a coordinated provincial approach and strategy for academic medicine, including research, education and patient care, and to help achieve the goals of the Alberta Health Research and Innovation Strategy (AHRIS). There is an opportunity to align the goals of the AHRIS with the initiatives in the AAHN via the Strategic Clinical Networks. Dr. Sharla Sutherland was hired as the AAHN Operations Director in February 2012 and has begun discussing opportunities for collaboration with AAHN members. The AAHN is still in its early stages, and AHS looks forward to fruitful collaborations with this group.

3.2 Red Deer College Health Research Collaborative

The Health Research Collaborative is an applied research initiative between Red Deer College and AHS-Central Zone that began in 2009 and is directed by Dr. Scott Oddie, Rural Health Research Chair at Red Deer College. The aim is to achieve excellence in collaborative applied research that effectively addresses health issues, improves health outcomes, and builds capacity for evidence-informed planning and decision making. Projects have ranged from developing Aboriginal HIV/AIDS prevention strategies to programs to enhance self-esteem and body image in children. Project teams generate knowledge and evidence that is immediately applied to improve health and wellness outcomes in communities.

In 2011, projects engaged 27 faculty, 61 community stakeholders, 21 health practitioners/decision makers and 26 students. Another 199 health practitioners and community stakeholders have received capacity-building programming (such as workshops, Knowledge Cafés or educational in-services) that provide them with skills to make evidence-informed decisions to enhance health and wellness in their communities. These teams submitted nine applications for research funding, seven of which were approved. The projects have engaged 34 rural communities.

AHS has a memorandum of understanding to provide financial support to the collaborative.

3.3 Alberta Clinical Research Consortium

Alberta needs to improve the efficiency, alignment, and integration of processes that support clinical research in all phases and disease areas. The Alberta Clinical Research Consortium (ACRC) is an inaugural collaboration between clinical researchers, community-based physicians, and administrators from AHS, the Alberta College of Physicians and Surgeons, Covenant Health, the University of Alberta, the University of Calgary, and Alberta Innovates-Health Solutions. ACRC's goals are to reduce barriers and streamline processes for conducting clinical research across this province. Its vision is high quality, integrated and efficient clinical research in Alberta. The Research Portfolio has identified this initiative as a priority and focused time and resources to helping it succeed.



An example of research within AHS: Biomedical engineer Ed Block (left) and researcher Dr. Cory Toth (right) study diabetic neuropathy and gait with patient Bryon Fischer.

In May 2011, three initial strategic priorities were identified and endorsed:

1. Improve the efficiency of clinical research administrative processes across the province,
2. Standardize legal review guidelines for contracts and agreements related to clinical research, and
3. Develop provincial standards and opportunities for clinical research training.

In the past year, three corresponding working groups developed work plans, which were endorsed by the ACRC Executive Committee. These working groups include several members of the Research Portfolio.

3.4 Ethics Harmonization Initiative

Alberta has six research ethics boards:

1. Alberta Cancer Research Ethics Committee (ACREC) for AHS,
2. Research Ethics Review Committee (RERC) for the College of Physicians and Surgeons Alberta,
3. Community Research Ethics Board of Alberta (CREBA) for Alberta Innovates-Health Solutions,
4. Health Research Ethics Board (HREB) for the University of Alberta,
5. Conjoint Health Research Ethics Board (CHREB) for the University of Calgary, and
6. Human Subject Research Committee (HSRC) for the University of Lethbridge.

In 2009, these six boards began to work towards a more aligned and coordinated provincial research ethics review system that would improve efficiencies, multi-site communications, and facilitate additional research investment.

A Research Ethics Reciprocity Agreement was signed on February 28, 2011. Alberta is the first province or territory in Canada to reach such an agreement. Once fully implemented, ethics review for multi-site health research studies will be streamlined. Thus, this Initiative sets the stage to encourage research across institutions and support additional health research activity and investment in Alberta. Central to the Initiative is to get all boards on common electronic platforms. This aspect will provide relevant, accessible system-level (provincial, aggregated) health research ethics information.

Over the past year, the Ethics Harmonization Implementation Steering Committee has identified four streams of activity:

- Reciprocity and Common Templates.
- Integrated Platforms.
- Governance.
- Strategic Needs Assessment.



Dr. Lorraine Shack, AHS epidemiologist and researcher specializing in cancer and cancer prevention.

In 2011, the partners in the initiative:

- Agreed on common informed consent form templates, including creation of a business case for the development of an electronic format.
- Completed second round stakeholder interviews on system level needs.
- Initiated a pilot study of ethics applications that require more than two approvals.
- Reviewed and ranked several electronic platforms.

The Research Portfolio's Senior Vice-President, Executive Director, and ethics coordinators are participating in this initiative.

3.5 Strategy for Patient-Oriented Research

The Canadian Institutes for Health Research's Strategy for Patient-Oriented Research (SPOR) provides an opportunity for Alberta stakeholders to work together to support research that focuses on the needs of Alberta's health system that the Strategic Clinical Networks and partners will identify and prioritize. The SPOR proposes to develop new Support for People and Patient-Oriented Research and Trials (SUPPORT) Units that will offer core services to a region's health system to support research excellence. SUPPORT units will provide a multidisciplinary team of health care professionals, methodologists, biostatisticians, social scientists, and data managers to help investigators design relevant research (including observational and interventional studies), conduct statistical analyses, manage data, and meet regulatory standards. Most importantly, all SUPPORT units will be integrated into clinical or care settings to be readily accessible to support a wide spectrum of research and knowledge translation activities.

Over the last year, AHS has been collaborating with the universities and Alberta Innovates-Health Solutions to develop a plan for a SUPPORT Unit in Alberta.

4. AHS RESEARCH RESOURCES: THE RESEARCH PORTFOLIO

During this reporting year, the Research Portfolio was expanded to include Data Integration, Measurement, & Reporting, and the reporting structure was amended with the Senior Vice-President reporting directly to the President and CEO. The Portfolio has focused on organizational realignment and process coordination to better meet the needs of AHS. Planning sessions took place to define the Portfolio's structure, vision, and mission. A draft Research and Innovation Strategy for AHS was developed.

4.1 Developing the Portfolio's Vision, Mission, Organizational Structure and Budget

Vision, Mission and Objectives

As part of the organizational realignment, a Vision, Mission, and Objectives were drafted for the expanded Portfolio.

The draft Vision is *Better health and sustainability through world-class knowledge creation and use in Alberta Health Services*. The draft Mission is to *Continuously create, systematically synthesize, and actively translate new knowledge to improve health and the sustainability of the health system for all Albertans*.

Draft objectives are to:

- Create new knowledge and translate knowledge into improved health and health care.
- Provide valid, reliable, timely, meaningful and actionable metrics to support AHS performance improvement and better health outcomes for our patients.
- Conduct health technology assessments and reassessments.
- Identify innovations and support their implementation and commercialization.
- Create and maintain valued internal and external partnerships and networks to achieve our mission.
- Create an embedded team of core internal partners essential for the success of the Portfolio, including Finance, Human Resources, Information Technology, Health Information Management, Contracting, Procurement & Supply Management, and Communications.

Organizational Structure

The **Research Administration and Support Group** is responsible for the overall direction and administration of the Portfolio, development of research services, and coordination of province-wide activities. Much of their work is in the background, making things easier for the researcher to navigate the system and be successful.

Calgary-based staff include Robert Sheldon (Senior Vice-President to June 2012), Rosemary Wilson (Assistant to SVP), Rachel Syme (Executive Director), and Sally Hafez (Operational Assistant to ED). Edmonton-based staff include Loretta Harbison (Executive Assistant to SVP), Sherry Thompson (Senior Transition Lead), Jim Raso (maternity leave replacement for Huey Chong, Director of Research Administration and Strategy), Ann Moore (Ethics Coordinator) and Weronika Sroczynski (Ethics Coordinator). Yvonne Jackson (Administrative Assistant, Research and Administration) and Audrey Hollingshead (Manager) are based in Wetaskiwin and Red Deer, respectively. The Research **Strategy Group** is responsible for AHS' research strategy and the development of mechanisms to support the SCNs' research and innovation mandates. Staff include Cy Frank (Vice-President of Research Strategy), Judy Crawford (Executive Assistant to VP), Michelle Gagnon (Director of Provincial Research Strategy and Priorities) and Paule Poulin (Research Scientist).

Other units within the Research Portfolio are summarized below (sections 4.3-4.5).

Budget

In 2011-2012, AHS invested \$4.5 million in the administration of research and \$15.2 million for Data Integration, Measurement, and Reporting. As well, AHS held \$38.5 million in restricted research accounts. This total excludes health research funding held by other organizations such as the universities.

4.2 Alberta Cancer Research Ethics Committee

The Alberta Cancer Research Ethics Committee is the ethics board designated by the Health Information Act housed within AHS. Under the direction of chair Dr. Raul Urtasun the board and the ethics board staff support cancer researchers within AHS by approving in excess of 100 new projects each year, and providing oversight to an additional 600 ongoing projects. Additionally they have been actively involved in the Health Ethics Harmonization Initiative.

4.3 Research Excellence Support Team

Under its director, Shirley Leew, the Research Excellence Support Team (REST) provides comprehensive support to investigators in their efforts to secure scientific approvals and competitive funding to conduct research of the highest integrity. Assistance with research methodology, statistics, measures, databases, and finding research resources is provided through consultation, mentorship, presentations, teaching, and supervision of students. REST also creates valuable links among AHS researchers through the Research Community of Practice (see section 6.1).

A full description of the 2011-2012 achievements of REST is available online at <http://www.albertahealthservices.ca/6000.asp>.

4.4 Health Technology Assessment and Innovation

Under its Director, Don Juzwishin, Health Technology Assessment and Innovation (HTAI) supports the managed introduction and evaluation of innovative health technologies through an evidence-informed decision model. The decision model helps:

- Identify, prioritize, and assess health technologies (devices and processes, excluding drugs) expected to significantly impact patient safety, clinical or cost effectiveness, health outcomes, clinical practice, human resources, and/or policy.
- Investigate innovative alternatives for current health technology to improve safety, quality, and/or outcomes.
- Promote the effective and appropriate uptake of technologies.
- Validate the effectiveness of promising health technologies with access through evidence development initiatives.



Members of the HTAI team (from left to right): Dr. Thach Lang, Angela Camacho, Dr. Ulrich Wolfaardt, Rosmin Esmail, Tracy Ruptash, Dr. Mahmood Zarrabi and Dr. Don Juzwishin.

HTAI has two major streams of activity:

- Health technology assessment and reassessment—supporting the SCNs and leaders in AHS in a) evaluating new technologies for adoption or b) reassessing existing technologies for possible disinvestment or change in use. These evaluations occur at the front-line clinical level, and at the provincial level through the Ministry's Alberta Advisory Committee on Health Technologies.
- Health technology innovation—introducing standard processes, mechanisms, and tools to stimulate innovation at AHS.

Over the past fiscal year and its second year of operation, the HTAI team has operationalized its strategic plan (<http://www.albertahealthservices.ca/Researchers/if-res-htai-strategic-plan.pdf>) and further developed linkages and coordination with the Strategic Clinical Networks and the Alberta Health Technology Decision Process (<http://www.health.alberta.ca/initiatives/AHTDP.html>) of Alberta Health and Wellness.

Over the past year, major highlights were:

- Development of a Provincial Strategy on Health Technology Assessment and Reassessment within AHS to embed and support the requirements of the Strategic Clinical Networks, zones and clinical departments.
- Establishment of a screening sub-committee of the Alberta Health Technology Advisory Committee that will identify, prioritize and triage projects at the provincial level.
- Development of a proposed province-wide single point of entry for industry and innovation to improve access and efficiency.
- Development and implementation of a health technology submission form for innovation that is publicized on the external HTAI website and AHS corporate forms website.
- Development of a health innovation program proposal, business plan and resource allocation requirements.
- Development of AHS intellectual property procedures to facilitate health innovation for Alberta with stakeholders in the province.
- Launch of the HTAI website on April 1 at <http://www.albertahealthservices.ca/4122.asp>.

4.5 Data Integration, Measurement and Reporting

Under the direction of its Vice-President, Stafford Dean, Data Integration, Measurement and Reporting (DIMR) provides measures of performance for a wide range of decision-making purposes by pulling and integrating data from dozens of information systems across the province to create meaningful information. Highlights from the past year include:

Data Integration:

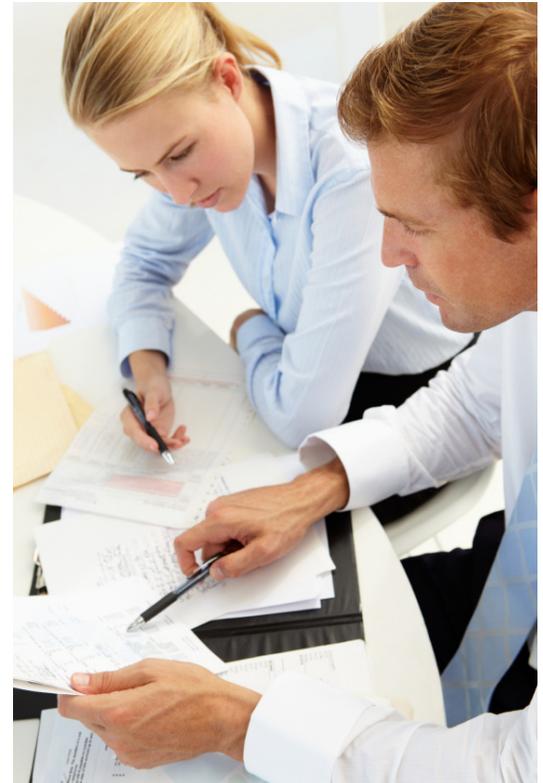
- Enhanced the comprehensiveness of information for provincial reporting purposes by adding 23 data sets to the AHS Data Repository for Reporting.
- Improved the quality, consistency, usability, security and availability of AHS' data assets by expanding the Repository's policy framework and privacy provisions.

Measurement:

- Re-aligned resources to better support Strategic Clinical Networks, Zones and Provincial functions.
- Established a Strategic Analytics function to respond to complex health system questions with long-term strategic impact.
- Conducted over 10,000 patient experience surveys (adult and child inpatients) to quantify provincial "patient experience with care" scores.

Reporting:

- Delivered eight new dashboards to monitor performance in targeted populations (e.g. cardiovascular & stroke, bone & joint health) and clinical operations areas (e.g. emergency department, surgery).
- Produced prevalence rates for several chronic diseases to identify disparities across the province and inform service planning in Primary Care and Chronic Disease Management.



A full description of the 2011-2012 achievements of the DIMR team is available at <http://insite.albertahealthservices.ca/dimr/tms-dimr-annual-report-2011-12.pdf>.

4.6 Northern Alberta Clinical Trials and Research Centre (NACTRC)

The Northern Alberta Clinical Trials and Research Centre (NACTRC) is a joint venture between Alberta Health Services and the University of Alberta to support their shared missions for collaborative clinical research. Established in 1999, NACTRC links pharmaceutical and research-focused companies with the medical researchers of AHS and U of A to facilitate clinical trial research in Alberta. NACTRC provides researchers and sponsors with administrative supports to guide both clinical and non-clinical trials from inception through to completion, including legal contract review and advice, budget templates, assistance in meeting Health Canada requirements, assistance in meeting AHS requirements, ensuring completion of operational approvals impacting AHS resources, setting up clinical trial research accounts, providing re-investment back into research, education and training for new research coordinators and operating and supporting a Phase 1 office and unit for clinical trials.

5. BEING EFFICIENT WITH AHS RESOURCES

Platforms of support are defined as resources or “essential things” used by large numbers of researchers who would otherwise have to spend considerable time and effort individually. Examples for applied health research include ethical review, clinical trials infrastructure, data handling, linkable databases, human material (e.g. banks for biological, clinical and health information), commercialization infrastructure, bioengineering infrastructure, knowledge translation support, and partnership development support.

Alberta Innovates-Health Solutions, in partnership with AHS, completed preliminary scan of all of these platforms in Alberta. The preliminary results show 193 health research platforms, of which 33 are “innovation platforms” (13 University of Alberta, nine University of Calgary, five both universities, five in AHS). Some of the key AHS innovation platforms include the Ward of the 21st Century (W21C), Glenrose Rehabilitation Hospital, the Institute for Reconstructive Sciences in Medicine (iRSM), and the AHS database developed by DIMR. As part of this platform and resource development, the Research Portfolio produced policies and processes to assist the researcher during this reporting year.

5.1 Research Policies

This year, the Research Portfolio sponsored or consulted on a number of policies relevant to researchers:

- Research Information Management Policy (#1146) to ensure that new or changed practices comply with the Health Information Act (Alberta) and the Freedom of Information and Protection of Privacy Act (Alberta).
- Privacy Impact Assessments Policy (#1145) to ensure that AHS completes risk assessments to measure the impact of a new project on privacy.
- Monitoring and Auditing Policy (#1144) to ensure that logging facilities and files are protected from unauthorized access, modification, or change.
- Collection, Access, Use and Disclosure of Information Policy (#1122) to ensure that only authorized persons collect, access, use, or disclose health information.
- Business Continuity Planning for IT Resources Policy (#1140) to ensure that AHS Information Technology can make available information and services in the event of damage, loss, or disruption to processes.
- Change Control for IT Resources Policy (#1141) to ensure that changes to AHS IT resources are applied correctly and securely.
- Social Media Policy (#CF-11) to provide direction on the management of social media by AHS.

As well, the Intellectual Property (IP) Policy (#IM-10) was finalized, approved, and announced in March 2011. The policy outlines the rights and obligations of AHS and IP creators in the disclosure, ownership, transfer, commercialization, and revenue sharing of IP. Subsequently, an IP policy implementation working group was struck to develop and implement a number of procedures to accompany the policy. Members of the Research Portfolio chair and sit on this working group. A detailed dissemination plan was developed and will be enacted once the procedures are approved.

As well, the Research Portfolio drafted guidelines for advertisements posted on the AHS website by researchers wanting to recruit study participants.

5.2 Research Costing

A project was initiated to develop a single cost list for the use of AHS resources for research. A single cost list means that investigators and their sponsors will no longer need to negotiate separate cost agreements with each site, as a single cost will apply for the major sites. This will assist investigators in project planning and budget negotiation, making Alberta a friendlier environment for health research.

In 2010, the Research Portfolio asked five service departments in AHS (Laboratory Services, Pharmacy, Diagnostic Imaging, Health Information Management, and Cardiology) to compile provincial standard price lists for providing research services. Templates were developed by each of these service areas, which addressed numerous comments from investigators. In 2011, provincial price lists were put into place in three of these areas, and the remaining two (Diagnostic Imaging and Health Information Management) are undergoing internal and external review. Using this information, a costing exercise is underway to look at the real costs of investigator-initiated research to AHS.

5.3 Research Access

The Research Portfolio has been collaborating with members of the AHS Privacy Policy Group and Alberta Health and Wellness to develop a process to enable access to Netcare (electronic records) by non-AHS researchers conducting clinical trials. The process was agreed upon and implemented during this reporting year.

6. CREATING A CULTURE OF RESEARCH AND INNOVATION IN AHS

The Strategic Clinical Networks (see section 2.1) will be instrumental in enhancing a culture of research and innovation in AHS, as they have a mandate to design provincial and zone-specific strategic improvement plans and drive research. In addition, the Research Portfolio aims to improve the research culture by fostering communities of practice and developing communication methods that bring practical, useful knowledge to researchers.

6.1 Research Community

The Research Community is a community of practice facilitated and supported by the Research Portfolio for anyone interested in health research within AHS. Through this group, connections are made, needs are brought up, and topics addressed by Community members at meetings that are held approximately every eight weeks via face-to-face and teleconferencing. The Community increases awareness of who within AHS is involved in specific areas of research and other facets of the knowledge cycle. Meetings also include speakers that offer informative resources including: Library Services, Health Information Act, and Privacy.

The Community currently has 127 members. A Community retreat, four meetings, and six speaking engagements were conducted in 2011. Researchers can join the Community by contacting either Mary Hodges at **Mary.Hodges@albertahealthservices.ca** or Shireen Kassam at **Shireen.Kassam@albertahealthservices.ca**.

6.2 Research Portfolio Website

The Research Portfolio has been working with a Senior Communications Advisor to develop a communications strategy to raise the profile of the Portfolio and its services and to profile the researchers working within AHS.

The website provides a wide range of resources and information for various research stakeholders, both internal and external to AHS (<http://www.albertahealthservices.ca/research.asp>).

6.3 “Researchers Need to Know” Newsletter

This reporting year saw the launch of the “Researchers Need to Know” newsletter. The newsletter brings researchers up to date on staff changes within the Research Portfolio, resources available to researchers, and updates on ongoing projects. It is available on the Research Portfolio’s website (<http://www.albertahealthservices.ca/research.asp>).

7. INCENTING RESEARCH OF HIGHEST VALUE TO AHS

AHS' Research and Innovation Strategy proposes the development of incentives for health professionals at all levels and care settings to make AHS the best performing health system in Canada. In the past year, training opportunities were developed and made available to AHS researchers, and the first President's Research Award of Excellence was created.

7.1 Training Opportunities

Helping researchers to be their best is critical to AHS' success. The Research Portfolio has made new training opportunities available to personnel working in or interested in research through the Collaborative Institutional Training Initiative (CITI).

CITI is a worldwide initiative aiming to advance and consolidate human research subject training and offers web-based training in human subject research. The organization N2 (Network of Networks), of which the Research Portfolio is a member, has developed and vetted the Canadian content of the training modules. N2 has been instrumental in the development of the CITI-Canada online education program with a volunteer committee adapting the international program to meet Canadian standards.

Currently, Canadian content CITI modules available to AHS-affiliated staff are: Good Clinical Practice, Responsible Conduct of Research, and Basic Biomedical Research Ethics. To date, 85 people have taken CITI training.

7.2 President's Research Award of Excellence

The President's Excellence Awards recognize those who demonstrate innovation, collaboration, and patient focus, and exemplify the AHS values of respect, accountability, transparency, engagement, safety, learning, and performance. The President's Excellence Award for Outstanding Achievements in Research recognizes a project or initiative that harnesses the collective efforts of AHS staff and physicians together with research and academic partners. The partnership should be innovative, use collaborative problem solving or practice in the delivery of effective clinical care, and show how research translation has contributed to improved outcomes for staff and/or patients.

In this reporting year, the Research Portfolio helped to define the criteria for the Research award. Finalists for the award were the Children's Intestinal Rehabilitation Program team, the Critical Care Research Team, the Bone and Joint Clinical Network – Hip & Knee Working Group, the Interdisciplinary Chronic Disease Collaboration, and the KidSIM ASPIRE Research Program team. Dr. Chris Eagle announced the winner in May 2012 (see section 9.8).

8. BEING EFFECTIVE WITH AHS RESOURCES

A component of the strategy "being effective with AHS resources" is measuring research outputs in AHS in order to direct future planning. The Research Portfolio used information from the ethic research boards, zone research committees, and clinicaltrials.gov to compile the following statistics on research within AHS.

In the 2011 calendar year, there were over 1,000 new research studies launched in AHS (Table 1). About three quarters (724/1013) were observational and about one quarter (289/1013) involved an intervention. This figure excludes ongoing health research studies started in previous years.

Table 1: Number of Research Projects Opened in 2011 by Zone in AHS^a

AREA	# OF STUDIES
Edmonton Zone ^b	553
Calgary Zone ^c	450
North Zone ^d	6
Central Zone ^d	10
South Zone ^d	8
Province-wide Studies ^e	17
TOTAL	1,044

^a Table does not reflect ongoing studies opened in prior years.

^b Sum of Edmonton research projects receiving AHS administrative approval by the Northern Alberta Clinical Trials and Research Centre (NACTRC) and the projects receiving ethics approval from the Alberta Cancer Research Ethics Committee (ACREC) for Edmonton sites.

^c Sum of research projects receiving ethics approval from the Conjoint Health Research Ethics Board (CHREB) and the research projects receiving ethics approval from ACREC for Calgary sites.

^d Data from Zone Research Committee.

^e Cancer research studies with multiple sites that received ethics approval through ACREC.

Most of these studies (74%) were led by Individual Investigators, 22% were industry sponsored, and 4% were sponsored by a cooperative group or had other sponsors (Table 2).

Table 2: AHS Research Studies Opened in 2011 by Sponsor Type*

AREA/ZONE	ACREC	CENTRAL ZONE	NACTRC	NORTH ZONE	SOUTH ZONE	TOTAL
Cooperative groups	7	0	1	0	0	8 (2%)
Investigator initiated	50	3	396	3	8	460 (74%)
Industry	40	4	92	0	0	136 (22%)
Other	8	3	0	3	0	14 (2%)
TOTAL	105	10	489	6	8	618

*Breakdown by sponsor type was not available for CHREB data (426 studies)

There were over 200 registered Clinical Trials launched in Alberta in 2011. The largest proportion of Clinical Trials was in the area of cancer care, with 43 research studies, second was cardiovascular health and stroke with 25 studies, gastrointestinal with 23 studies, infections with 21 studies, and bone and joint with 16 studies (Table 3). There was research across the spectrum from prevention to surgery, from children's to seniors' care.

Table 3: New Registered Clinical Trials Opened in 2011 by Discipline

DISCIPLINE	TOTAL
Cancer care	43
Cardiovascular health & stroke	25
Gastrointestinal	23
Infection	21
Bone & joint health	16
Obesity, diabetes & nutrition	13
Primary care & chronic disease management	11
Neurological disease; ear, nose & throat; & vision	11
Maternal health	10
Complex medicine	10
Addiction & mental health	10
Hematology	3
Surgery	2
Seniors' health	2
Newborn, child and youth health	2
Critical care	1
Other	5
TOTAL	208

Data were collected from <http://clinicaltrials.gov/ct2/home>. Ongoing clinical trials started in prior years are not reflected in this table.

9. RESEARCH MAKES A DIFFERENCE IN THE LIVES OF ALBERTANS

Albertans expect their health and their health care system to be among the best in the world, with system and care decisions informed by evidence. They also expect the system to be continually improving by producing new evidence, including providing proof of value for their money invested in it. They want a seamless system that proactively keeps them healthy, has strong primary care, and provides access to specialty care when and where needed. They expect care across the lifespan in a system that is easy to navigate, provides choices for continuing care, and that “works for them.” Research and innovation are key enablers towards Alberta achieving the highest performing health system over time.

The following examples show how research studies are making a difference in the lives of Albertans. These studies were chosen to reflect a variety of disciplines and geographic areas as well as both discovery and needs-based research. As well, the AHS Communications Department regularly publicizes research news via its website (<http://www.albertahealthservices.ca/6038.asp>).



Dr. Francois Bernier and Hannah Richardson

9.1 AHS physician helps pinpoint cause of genetic disorder

Ever since their daughter Hannah was born eight years ago, Ronalynn and Kevin Richardson have never known for sure whether she has a rare genetic disorder called Nager Syndrome, or some other unexplained condition. “We’ve been living without answers Hannah’s whole life,” says Ronalynn. Although clinicians believed Hannah has Nager Syndrome, a condition that causes deformation in a child’s face and limbs, as well as deafness, they have never been able to make the diagnosis with 100 per cent certainty. Today, however, they can.

Dr. Francois Bernier, Hannah’s physician at Alberta Children’s Hospital who led a team of North American researchers, has identified the gene that causes Nager Syndrome. The discovery has enabled scientists to develop the first test for the condition.

“You can’t imagine the relief that comes with knowing your child is going to be all right,” Ronalynn says. “I want that for all the other families who are faced with the same situation of not knowing what life will hold for their child living with a mysterious syndrome.” People with Nager Syndrome go on to lead successful lives, meaning the Richardsons can now have the same hopes for Hannah.

“Genetic disorders of children are individually rare but collectively common, affecting the lives of hundreds of thousands of children in Canada,” Dr. Bernier says. “And most of the genes that cause these conditions have yet to be found. While Nager Syndrome may be rare, it doesn’t feel like it when it’s your child whose future health is unknown.” The discovery will allow experts from around the world to:

- Provide earlier and more accurate diagnosis for children
- Provide more accurate reproductive counselling to families
- Work toward reducing or preventing patient complications
- Develop tailored treatments
- Work toward the development of drugs that will one day improve the lives of affected children.

This discovery was the result of an international collaboration between FORGE Canada and the University of Washington. FORGE Canada is a national consortium of clinicians and scientists, which includes Bernier's team. The researchers use next-generation sequencing technology to identify genes responsible for a wide spectrum of rare pediatric disorders present in the Canadian population

9.2 The Tomorrow Project: tracking the health of Albertans

Cancer affects everyone in some way. Here in Alberta, one in two Albertans will be diagnosed with cancer in their lifetime, and one in four will die from it. As Alberta's population grows and ages, cancer diagnoses and deaths are projected to increase.

The *Tomorrow Project* is the largest research study ever undertaken in Alberta. Its primary goal is to discover more about what causes cancer, so that it may be prevented in the future. Researchers hope to track 50,000 Albertans between the ages of 35-69, who have never had cancer to join this long-term study by mid 2013. So far, more than 22,000 Albertans have joined the fight against cancer.

"Much of the important knowledge to be gained from this project about what causes cancer will benefit our children and grandchildren," says Dr. Paula Robson, principal investigator for the *Tomorrow Project*. "We are getting better at early detection of cancer and better at treatment, such that people are living longer after receiving a cancer diagnosis. However, one area we need to get better at is learning how to prevent cancer in the first place."

In 2008, Alberta's *Tomorrow Project* joined forces with other provinces to form the *Canadian Partnership for Tomorrow Project*, the largest long-term health study of its kind in Canada. With five regional study teams and tens of thousands of Canadians participating, the project may help researchers better understand why some people develop cancer and other chronic diseases.

The *Tomorrow Project* in Alberta has study centres in Calgary and Edmonton, with the combined capacity to process over 350 participants per week. The *Tomorrow Project* also has a provincial team that travels across Alberta, setting up mobile study centres in different communities. To date, the *Tomorrow Project* has visited 36 towns and cities across the province. Participants also have the option to fill out the questionnaire at home and be sent a saliva kit, to be returned to the *Tomorrow Project* by mail, eliminating the need for a study centre visit.

The *Tomorrow Project* is supported by Alberta Health Services, the Alberta Cancer Foundation, Alberta Innovates-Health Solutions and the Canadian Partnership Against Cancer.



Study participant Gerard (Mike) Coady (left) and *Tomorrow Project* Assistant James Whitworth

9.3 Right-ventricle research aims to reduce heart transplants

Over the years the left ventricle has hogged the limelight in the scientific community — but that’s all changing with the realization that the right ventricle really calls the shots when it comes to preserving lifelong heart health. Research into the right ventricle — which can thrust a patient into a life-or-death heart transplant scenario if it fails — is underway at the Mazankowski Alberta Heart Institute, thanks to a \$300,000 grant from the University Hospital Foundation.

To date, almost all of the global research on heart disease has focused on the heart’s left ventricle, or chamber, which pumps blood throughout the body, and almost none on the right ventricle, which pumps blood to the lungs. This is expected to change as researchers learn more about how common diseases and conditions — such as pulmonary hypertension, or high blood pressure in the lungs — can cause the right ventricle to fail. When this happens, a heart transplant becomes necessary for survival.

A new AHS multidisciplinary research team — comprised of cardiologists, scientists, clinicians, a biomedical engineer and medical imaging experts — will spend two years studying right ventricular diseases in animals and humans.



Dr. Jayan Nagendran

“As we start to appreciate the disease process and how it can potentially be used to predict patient survival, we’re gaining a better appreciation for right ventricular disease and how to protect against it,” says cardiothoracic surgeon Dr. Jayan Nagendran. “Our study will be the first to use cutting-edge magnetic resonance imaging (MRI) technology in combination with blood tests to determine if there are substances in the bloodstream that can be used to predict patients at risk of developing weak right ventricles, so we can intervene early and prevent the deterioration.”

Gaining greater knowledge about the right ventricle is expected to lead to new therapies that could extend lives, improve quality of life and ultimately reduce the number of patients who require a heart or lung transplant to survive, he adds.

Funding for the Innovative Team Research Grant Competition comes from donors to the University Hospital Foundation. This year, the University Hospital Foundation, in partnership with the Allard Foundation, is providing a total of \$1.2 million to fund four interdisciplinary teams through the Innovative Team Research program.

9.4 Edmonton autism researchers join North American network

Autism researchers and clinicians at the Glenrose Rehabilitation Hospital are now linked to hundreds of their counterparts across the U.S. and Canada since joining the Autism Treatment Network (ATN), a prestigious U.S.-based research initiative.

The Glenrose, together with the Stollery Children’s Hospital, was awarded a grant of \$417,000 over three years by the ATN to work on improving standards of medical care for children with autism spectrum disorders (ASD), a complex, neurobiological condition that inhibits a person’s ability to communicate and develop social relationships, and is often accompanied by behavioral challenges.

“We are really proud to be associated with the Autism Treatment Network,” says Dr. Lonnie Zwaigenbaum, Co-director of the Autism Research Centre at the Glenrose. “The funding of an Edmonton site reflects on the excellence of our clinical and research programs supporting children with autism spectrum disorders. Being part of the Autism Treatment Network gives us the opportunity to better address the medical needs of children with ASD in a more coordinated and comprehensive way.”

ASD is the fastest-growing serious developmental disability in North America, currently diagnosed in one in 110 children, affecting four times as many boys as girls. Its causes are unknown; however, research indicates lifelong interventions can result in significant improvements. The ATN pools the expertise of more than 200 practising physicians, nurses, specialized therapists, behavioral specialists and clinical researchers at 17 leading children’s hospitals and academic medical centres. The Glenrose is only the second Canadian ATN site.

The network is a project of Autism Speaks, a not-for-profit group whose mission is to change the future for people who struggle with ASD. The group funds research into the causes, prevention, treatments and finding a cure for autism, as well as raising awareness, and supporting family services and advocacy programs.

Edmonton resident Tami Alger believes the sharing of knowledge within the network will positively affect the treatment her six-year-old daughter receives at the Glenrose. “The Autism Treatment Network will help create a coordinated and holistic link between our daughter’s autism and all of her other medically complex needs,” says Alger. “It will help in putting together all the pieces of her puzzle.”

9.5 AHS neurosurgeon named to Order of Canada

When Paige Nickason went to have her brain tumour removed in March 2008, she knew she was making surgical history. In a medical first, doctors at Foothills Medical Centre removed Nickason’s tumour navigating a two-armed robot, called neuroArm, from a remote workstation in an adjacent room.



Dr. Garnette Sutherland

“With my condition, I had gone through surgery after surgery. But I was actually looking forward to the procedure,” recalls the 25-year-old, who has Neurofibrominosis Type II, a disease that causes recurring tumours in her head and spinal canal. “It gave me a lot of piece of mind, knowing it was less invasive and they could make more precise cuts.”

Dr. Garnette Sutherland, the Alberta Health Services neurosurgeon who helped develop and design neuroArm, has been named a member of the Order of Canada for his contributions to neurosurgery. He was honoured earlier this year in a ceremony with Governor General David Lloyd Johnston in Ottawa.

“It’s an acknowledgement that we’ve done some great work – not just me, but all the people who have worked on these projects to improve patient care and outcomes,” Sutherland says. “I’m glad the technologies we have developed are now being used around the world.”

Sutherland developed neuroArm in 2004 along with MacDonald, Dettwiler and Associates Ltd., the group responsible for Canadarm and Canadarm2. NeuroArm is the world’s first surgical robot that can perform microsurgery and image-guided biopsies. During surgery, Sutherland and his medical team control neuroArm from a workstation, guiding its movements via images on a screen. Because it can move in smaller increments than the human hand, neuroArm enhances surgeon control, which is crucial when performing delicate surgery inside the brain. Since 2008, his team has used neuroArm in 30 surgical cases.

NeuroArm is made possible by intraoperative MRI, a technology also developed by Sutherland and collaborators at the National Research Council Canada. Intraoperative MRI allows surgeons to bring an MRI scanner into the operating room on demand and take pictures of a patient's brain during surgery.

Sutherland's intraoperative MRI technology is now being used by neurosurgeons, endovascular surgeons and oncologists in 40 sites around the world, including University of Alberta Hospital.

9.6 World-first cancer technology being developed in Alberta

A new cancer radiation therapy machine promising precise and life-saving treatment methods will be developed in Alberta following a substantial funding boost. The federal government announced in 2011 a \$2.5-million investment to support AHS, the University of Alberta and industry take the next crucial steps towards developing, testing and commercializing cancer radiation therapy technology called Magnetic Resonance Real-time Guided Radiation Therapy (MRrtgRT). The technology is a world-first and has the potential to significantly improve the quality of radiation therapy for cancer patients in Alberta and internationally.



Medical physicist Brad Murray (left) and Dr. Gino Fallone

Cross Cancer Institute Medical Physics Director, Dr. Gino Fallone, and the research team beat the rest of the world to do what was previously considered impossible: they built a working prototype in 2008 that combined existing medical devices – a magnetic resonance imaging (MRI) scanner and a linear accelerator (LINAC) – a pairing previously thought to be incompatible.

The technology has the ability to produce high-quality, real-time 3D images showing exactly where a tumour is and guide radiation to it in real time. This allows radiation beams to focus on a moving target – such as the lungs, liver, stomach and pancreas – and reduce the amount of radiation delivered to surrounding, healthy cells. It also has the potential to broaden the range of tumours that can be treated using radiation therapy.

“We believe this technology will provide our patients with one of the best integrated cancer treatment options available in the world,” Fallone says. “It could revolutionize the way cancer patients are treated around the world.”

The funding will allow the project research team to move to the next stage: a human scale machine, which will be constructed and tested onsite at Edmonton's Cross Cancer Institute. Once this has been successfully completed, the project will move onto its third stage, a pre-production prototype for clinical trials, and then eventually commercial distribution. If the project continues as planned, it will be ready for commercial distribution in about six years.

In addition to federal funding from Western Economic Diversification, the Government of Alberta is investing \$250,000 towards the initiative, while the Alberta Cancer Foundation is contributing \$2.15 million. AHS and its industry partners, ASG Superconductors and Paramed, are contributing \$1.1 million.

9.7 Alberta breast cancer study extended

A groundbreaking Alberta study to help reduce the risk of breast cancer has been bolstered by additional funding to extend the trial. Since its inception, 370 Alberta women ages 50-74 have been recruited to take part in the Breast Cancer and Exercise Trial in Alberta (BETA) – the first study in the world that aims to pinpoint exactly how much exercise is required by post-menopausal women to reduce their risk of breast cancer. The study is an extension to the Alberta-run ALPHA (Alberta Physical Activity and Breast Cancer Prevention) trial, which found previously inactive post-menopausal women can experience biological changes to their bodies that lower their risk of breast cancer by following a moderate- to vigorous-intensity exercise program.

In the BETA trial, participants were randomized into two specific groups – one doing 150 minutes of exercise per week, the other 300 minutes per week – and had biological changes as a result of exercise measured. A range of breast cancer biomarkers such as fat levels, sex hormone levels, insulin resistance and inflammation were measured at the start of the year-long exercise trial and again at the end.

Thanks to extra funding of \$400,000 from the Canadian Cancer Society, a third set of tests will now occur a year after the completion of prescribed exercise – instead of only getting participants to fill in a simple questionnaire.

Principal investigator Dr. Christine Friedenreich, an AHS cancer epidemiologist, Alberta Innovates-Health Solutions senior health scholar and adjunct professor at the University of Calgary's Faculty of Medicine, says the extra funding means researchers can more accurately measure the lingering benefits of such an intensive exercise intervention, and see if that amount of physical activity can be sustained.

“We’ll know whether women continue to experience lower risks for breast cancer a year after an aerobic exercise intervention, and how risk reductions are sustained or eroded over time, based on how much exercise they do,” says Friedenreich. “That is important when making public health decisions. Ultimately, this will help improve data for physical activity guidelines from a cancer prevention perspective, and arm women with the knowledge that could help them reduce their cancer risk.”

The BETA trial is funded by the Alberta Cancer Foundation. The first results from the study are expected to be published by the end of 2013.

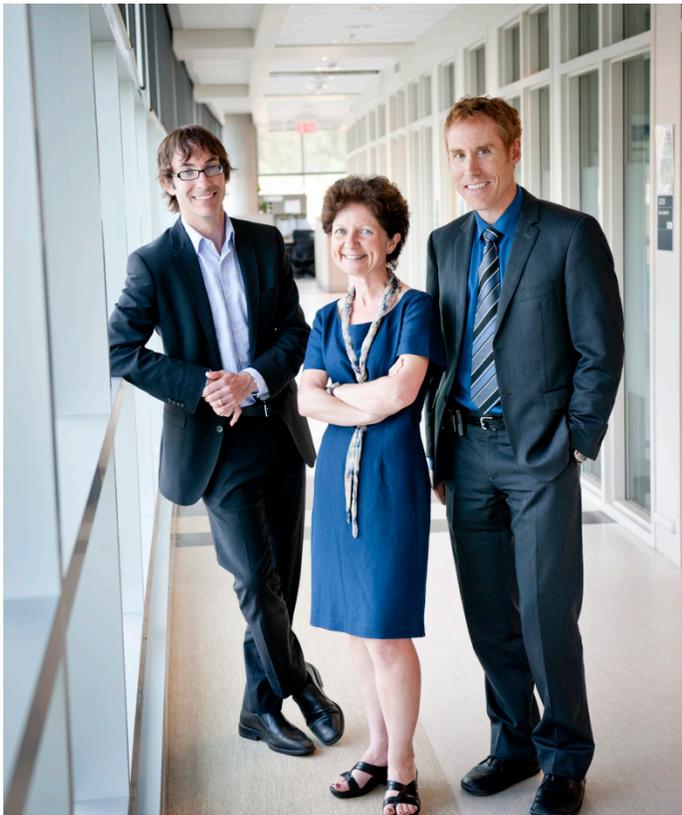


Study participant Marlene Nelson (left) and Dr. Christine Friedenreich

9.8 Chronic disease research earns President's Award

Three Alberta medical researchers focused on improving the quality of care for people with chronic diseases have been named the recipients of the first-ever President's Excellence Award for Outstanding Achievements in Research (see also section 8.2). Although the award was announced in May 2012, outside the coverage dates of this annual report, the research was ongoing during the reporting year.

Dr. Brenda Hemmelgarn, Dr. Braden Manns and Dr. Marcello Tonelli led the Interdisciplinary Chronic Disease Collaboration, which aims to support higher quality, more equitable, efficient care for Albertans with or at risk of common chronic diseases such as kidney disease, diabetes and heart disease.



Drs Brenda Hemmelgarn, Braden Manns (right) and Marcello Tonelli (left)

The team meets regularly with senior policy makers at AHS and Alberta Health and Wellness to discuss the issues and challenges facing Albertans in relation to health and wellness. “We assess what the biggest challenges and issues for these policy makers are, and determine whether our research could help to inform their decisions,” explained Tonelli, an AHS medical staff member and U of A associate professor, as well as being chair of the Canadian Task Force for Preventive Health Care and president of the Canadian Society of Nephrology. “In areas where we can help, we then turn their priorities into researchable study questions, which can be addressed using our data and research skills.”

Their work has helped secure ongoing funding for First Nations medical outreach kidney disease clinics, multi-disciplinary care programs for severe chronic kidney disease patients, including group-based education classes, and night-time hemodialysis for people with kidney failure. In addition their work has influenced international clinical practice guidelines to improve clinical care, including the use of a simple urine test to identify people who are at risk of developing kidney failure and heart disease, as well as geographic mapping techniques to identify optimal clinic locations to improve care delivery for remote dwelling Albertans with kidney disease.

9.9 New congenital heart research holds key to lifelong care

Research on how to best transition young adults with congenital heart problems to adult care is underway at the Mazankowski Alberta Heart Institute in Edmonton, thanks to a \$300,000 grant from the University Hospital Foundation.

“To date, no research has been done on how to best organize and deliver programs that transition teens with heart problems from child-centred to adult-oriented health care,” says principal investigator Dr. Andrew Mackie, an Alberta Health Services (AHS) pediatric cardiologist and University of Alberta Assistant Professor, Division of Pediatric Cardiology, Department of Pediatrics. “Our team will address this gap through three research projects.”

The first project is a nurse-led intervention, one-on-one, with 16- and 17-year-olds to make them aware of their heart anatomy, to review operations and procedures they’ve had, and to make them aware of how to obtain adult cardiology care. The second project will see a trained nurse-interviewer speak by telephone with young adults (18 to 25 years) and their parents to find out what worked and what didn’t in their transition to adult care. The third project will explore transitional barriers faced by physicians, nurses, administrative assistants, psychologists, physical therapists and others involved in an adolescent’s care.

As a result of medical advances, more than 90 per cent of children born with heart defects now reach adulthood, yet many remain at risk for further cardiac problems.

One congenital heart patient, Edmonton teen Annabelle Wardeck, underwent surgery to repair transposed heart arteries when she was 10 days old. Although she’s now active in sports such as track and field, soccer, volleyball and gymnastics, she applauds transitional research.

“I may be fine now but there are some people who still have problems after they grow up,” says the 16-year-old, “and they have to be careful what they do. I’m really glad they’re doing this kind of research to help people like me get better care throughout our lives.”



Annabelle Wardeck, 16, who underwent heart surgery when she was 10 days old, helps Dr. Andrew Mackie get the word out about congenital heart research at the Mazankowski Alberta Heart Institute in Edmonton.

