# Assisted Human Reproduction Canada 2009–10 Departmental Performance Report

### **Table of Contents**

Minister's Message	3
President's Message	4
Health Portfolio Overview	5
Section 1: Departmental Overview	6
1.1 Summary Information	7
Raison d'être	7
Responsibilities	7
Strategic Outcome	8
Program Activity Architecture	8
1.2 Summary of Performance	8
Financial Resources	8
Human Resources	
Contribution of Priorities to Strategic Outcomes	
Risk Analysis	12
Expenditure Profile	
Section 2: Analysis of Program Activities by Strategic Outcome	15
2.1 Strategic Outcome: Protection and Promotion of the Health and Safety of Canadians	
against the Risks Associated with Assisted Human Reproduction Technologies	16
2.1.1 Program Activity: Licensing and Enforcement of a Regulatory Framework for	
Assisted Human Reproduction Technologies	
Program Activity Summary	
Performance Analysis	
Lessons Learned	
Benefits for Canadians	20
2.1.2 Program Activity: Health Information and Knowledge Management for Assisted	
Human Reproduction Technologies	
Program Activity Summary	
Performance Analysis	
Lessons Learned	
Benefits for Canadians	
2.1.3 Program Activity: Internal Services	
Section 3: Supplementary Information	
3.1 Financial Highlights	
3.2 List of Supplementary Information Tables	27

### Minister's Message



I am pleased to present the 2009 –10 Departmental Performance Report for Assisted Human Reproduction Canada (AHRC), which presents the Agency's progress in furthering its mandate of protecting and promoting the health and safety of Canadians in relation to reproductive technologies.

The issues and impacts in this area are of great importance to Canadians, and to people around the world. The Government of Canada decided, out of respect to the Court, not to pre-publish regulations while constitutional issues relating to the *Assisted Human Reproduction Act* are before the Supreme Court of Canada.

The Agency continues its enforcement activities of those provisions of the Act which are in force. It continues to monitor compliance with the Act and to respond to allegations of contraventions by taking appropriate action. While further regulations await release, AHRC has prepared the systems and processes required to establish a licensing framework and continues to promote the health and safety of Canadians who use reproductive technologies to build their families. AHRC continued to do extensive education and outreach as well as to build networks with stakeholders involved in assisted human reproduction, both across Canada and around the world. This outreach increases the inclusion of, and gives voice to, all Canadians with an interest in this issue.

I thank the Board of AHRC for their continued engagement in this important work.

The Honourable Leona Aglukkaq, P.C., M.P. Minister of Health

### President's Message

Continued developments in the field of assisted human reproduction (AHR) underline the importance of Assisted Human Reproduction Canada's (AHRC) role in protecting and promoting the health, safety, dignity and rights of Canadians who use, or are born of, assisted human reproduction technologies.

This Departmental Performance Report for 2009-10 demonstrates the Agency's continued diligence and commitment to these responsibilities.

Under its compliance and enforcement mandate, the Agency continued to promote compliance with the *Assisted Human Reproduction Act* (the "Act") and its regulations. In addition, the Agency focused on monitoring developments in the field and formalizing its process for responding to complaints brought to its attention about possible violations of the Act and regulations. Appropriate enforcement actions were taken as necessary to promote and achieve compliance. As we await the release of further regulations of the Act, the Agency continues to engage stakeholders proactively for education or information on the implications and requirements of the Act, to provide reliable information on assisted human reproduction to Canadians and to seek the perspectives of patient groups and health professionals in the field.

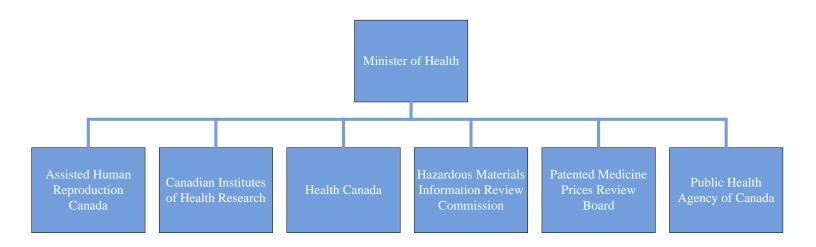
Under the direction of the Board of Directors, the Agency completed many key activities in support of its mandate including: the development of the 2009 Inventory of Health Surveillance Databases to assist policy makers and health practitioners to gauge the safety and effectiveness of various AHR options; the inclusion of questions related to the incidence of infertility among the Canadian population in the Statistics Canada 2009 Canadian Community Health Survey; and the sponsoring of a symposium on oncofertility in Canada to support the establishment of new networks among researchers, medical practitioners and patient advocates to encourage further research in this field. As well, the Agency gathered researchers, clinicians and infertility experts at the first Scientific Roundtable on the Prevention of Multiple Births Associated with Infertility Treatments to explore the challenges associated with multiple births related to AHR. These efforts culminated in the development of a Canadian framework. Much of this work was informed by the Agency's Science Advisory Panel as well as AHRC policy analysts and research experts.

I remain confident that the Agency will continue to build upon these achievements and strengthen its capacity as we move forward.

Dr. Elinor Wilson, President Assisted Human Reproduction Canada

### **Health Portfolio Overview**

The Minister of Health is responsible for maintaining and improving the health of Canadians. These efforts are supported by the Health Portfolio, which includes Health Canada, the Public Health Agency of Canada, the Canadian Institutes of Health Research, the Hazardous Materials Information Review Commission, the Patented Medicine Prices Review Board and Assisted Human Reproduction Canada. Each member of the Portfolio prepares its own Report on Plans and Priorities.





### 1.1 Summary Information

### Raison d'être

Assisted Human Reproduction Canada (AHRC) was established under the authority of the Assisted Human Reproduction Act (AHR Act). The Act seeks to protect and promote the health, safety, dignity and rights of those who use assisted human reproduction (AHR) technologies; prohibits unacceptable activities such as human cloning and commercialization of human reproductive capabilities, and places controls over AHR-related research. The Agency is responsible for issuing and reviewing licences, developing and managing a health reporting information registry, establishing a health surveillance system, and carrying out inspections and compliance and enforcement activities related to activities controlled under the Act. The Agency is also a centre of expertise and a focal point of AHR information for policy makers, health professionals and all Canadians.

### Responsibilities

### Responsibilities

Assisted Human Reproduction Canada (AHRC) is the federal regulatory agency responsible for protecting and promoting the health, safety, dignity and rights of Canadians who use or are born of assisted human reproduction technologies.

AHRC is also responsible for fostering an environment in which ethical principles are applied in all matters relating to assisted human reproduction, while allowing scientific advances that benefit Canadians.

AHRC's mandate and responsibilities are set out in the AHR Act. The Agency's key responsibilities include:

- implementing and administering the licensing framework for controlled activities, including AHR procedures and related research;
- developing an inspection strategy to ensure compliance with the AHR Act and its regulations;
- developing and maintaining a national Personal Health Information Registry (PHIR) on AHR that can become a key component of a more comprehensive AHR health surveillance strategy;
- becoming a centre of expertise on AHR by collecting and disseminating public information:
- communicating with and engaging stakeholders on AHR issues; and
- advising the Minister of Health on AHR issues.

### Strategic Outcome(s) and Program Activity Architecture (PAA)

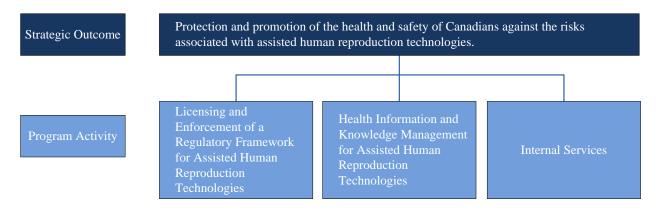
### **Strategic Outcome**

In order to effectively pursue its mandate, the Agency aims to achieve the following strategic outcome:

Protection and promotion of the health and safety of Canadians against the risks associated with assisted human reproduction technologies.

### **Program Activity Architecture**

The chart bellow illustrates Assisted Human Reproduction Canada's complete framework of program activities, which roll up and contribute to progress toward the Agency's strategic outcome.



### 1.2 Summary of Performance

### 2009–10 Financial Resources (\$ millions)

Planned Spending	Total Authorities	Actual Spending
10.5	10.5	5.2

The table above summarizes AHRC's total spending for the 2009-10 fiscal year. The Agency's actual spending was \$5.3 million less than planned spending. Note that the Agency received no funding under Canada's Economic Action Plan.

### 2009–10 Human Resources (FTEs)

Planned	Actual	Difference
44	13	31

Staffing was undertaken at a pace consistent with the incremental implementation of the Agency's mandate.

Strategic Outcome: Protection and promotion of the health and safety of Canadians against the risks associated with assisted human reproduction technologies.					
Performance Indicators	Targets	2009 – 10 Performance			
As the regulations come into force, develop operational guidelines to administer the Assisted Human Reproduction Act	In advance of the regulations coming into force:  • Develop the groundwork	Completed defining its draft Regulatory			
and its associated regulations.	to implement a licensing framework for controlled activities and Personal Health Information Registry	Implementation Framework and initiated drafting the guidance documentation in support of the licensing and inspection activities of the framework.			
	Develop an inspection strategy to ensure compliance with the AHR Act and regulations	Formally defined, documented and implemented the complaint management process for dealing with allegations of noncompliance with the AHR Act and its regulations. In support of its compliance and enforcement mandate the Agency also formalized its Compliance and Enforcement Policy.			
	Develop and progressively implement a stakeholder outreach strategy and information dissemination plan	Stakeholder Outreach Strategy and the Information Dissemination Plan continued to evolve in the past year with a focus on establishing new networks among researchers, medical practitioners, and patient advocates as well as identifying, producing and disseminating various products. Specifically AHRC:			
		<ul> <li>organized and held a Roundtable on the topic of Prevention of Multiple Births related to AHR;</li> </ul>			
		created a Healthy Singletons Birth Committee;			
		hosted a Symposium on Oncofertility in Canada;			
		<ul> <li>collaborated with Statistics Canada on the 2009 Canadian Community Health Survey and;</li> </ul>			

collaborated with the Canadian Fertility and Andrology Society with respect to CARTR database evolution and associated activities in relationship to AHR Related Outcomes; Brochures published and disseminated: Counselling and Assisted Human

- Reproduction;
- Reproductive Genetic Testing and Screening Options; and
- Cancer and Preserving your Fertility: a Guide for Patients.

Revisions to the AHRC website are also currently being implemented in support of the evolving Stakeholder Outreach Strategy and the Information Dissemination Plan.

### (\$ millions)

	2008-09		2009	Alignment to		
Program Activity	Actual	Main Estimates	Planned Spending	Total Authorities	Actual Spending	Government of Canada Outcome
1) Licensing and Enforcement of a Regulatory Framework for Assisted Human Reproduction Technologies	2.8	4.2	4.2	4.2	0.8	Healthy Canadians
2) Health Information and Knowledge Management for Assisted Human Reproduction Technologies	2.5	2.6	2. 6	2. 6	0.8	Healthy Canadians
3) Internal Services <sup>2</sup>		3.7	3.7	3.7	3.6	
Total	5.3	10.5	10.5	10.5	5.2	

<sup>&</sup>lt;sup>1</sup> Commencing in the 2009-10 Estimates cycle, the resources for Program Activity: Internal Service is displayed separately from other program activities; they are no longer distributed among the remaining program activities, as was the case in previous Main Estimates. This has affected the comparability of spending and FTE information by Program Activity between fiscal years.

<sup>&</sup>lt;sup>2</sup> Internal Services includes expenditures related to the Deputy Head's Office, Chief Science Advisor's Office and the Corporate Secretariat. In addition, it includes a Memorandum of Understanding (MOU) with Health Canada (HC) for Human Resources, Finance and IT support, a MOU with HC Inspectorate for Inspection services and a MOU with the Department of Justice for legal services.

### $Contribution \ of \ Priorities \ to \ Strategic \ Outcome(s)$

Operational Priorities	Туре	Status	Linkages to Strategic Outcome(s)
1. To contribute to the development of AHR regulations by Health Canada	Ongoing	( Met All ) Health Canada is accountable for developing the policy and regulations under the AHR Act that AHRC will administer. The Agency actively contributes to Health Canada's regulatory development process.	SO 1
2. To increase the awareness of Canadians and health professionals about AHR and the Agency's role	Ongoing	( Met All) Through its outreach, education and communication activities, Assisted Human Reproduction Canada (AHRC) continues to build awareness of its mandate and of understanding of the AHR Act and regulations. Through its Web site and written materials, AHRC informs Canadians about AHR.	SO 1
3. To create the capacity in AHRC to implement the regulations (once developed)	Ongoing	( Somewhat met) The Agency continues to prepare, in synchronization with the policy and regulatory development timelines of Health Canada, the systems and processes required to implement the regulations. The preparation to date will ensure that the regulations are implemented as they come into force, particularly those related to licencing, inspections, and the Personal Health Information Registry.	SO 1

Management Priorities	Туре	Status	Linkages to Strategic Outcome(s)
1. Internal Management	Ongoing	(Mostly Met) The Agency develops and integrates its planning and reporting instruments, including Board of Directors strategic planning, integrated Agency-level business, and human resources planning and reporting. Planning and reporting is aligned with the Program Activity Architecture, with increased emphasis on performance measurement, evaluation and data collection.	SO 1
2. Human Resources	Ongoing	(Somewhat Met) AHRC continues to build its capacity in specific areas based on short-term needs, and will, as the Agency evolves and regulations come into force, need to attract additional qualified resources in specialized areas such as privacy, systems maintenance, inspection, licencing, communications, etc.	SO 1
3. Risk Management	Previously Committed to	(Met All) The Agency built a corporate risk management framework to manage its key risks. This included the development and implementation of an ongoing process for monitoring, reporting and updating the risk management framework. This framework will also be reviewed and updated once additional regulations come into force.	SO 1

### **Risk Analysis**

AHRC continues to monitor and manage its risks. Further to a systematic risk assessment, a risk management plan was developed, and risk monitoring and reporting processes were integrated into the Agency's planning cycle. The plan is reviewed on a semi-annual basis. This will serve as the Agency's corporate risk management framework, which will be updated and revised as the full regulatory framework is implemented.

Few fields are changing faster than assisted human reproduction. Each technological innovation brings additional health, ethical, social and economic implications. AHRC has established the resources and mechanisms to enable it to keep abreast of a rapidly changing environment, in terms of both science and international developments. One such mechanism is the Science Advisory Panel which brings together recognized experts in the AHR field to advise the Board of Directors and identify priorities.

AHRC continued to build upon the infrastructure (i.e., policies, procedures and systems) to effectively and efficiently manage its operations, and the specialized systems that will be required to implement the regulatory process, once the remaining regulations come into force. Work to develop the important systems required to administer the regulations and Personal Health Information Registry continued on a modular basis, using a best practices approach to ensure alignment with the regulations being developed by Health Canada. Specialized resources were retained to ensure the appropriate analysis and safeguarding of the personal health information that the Agency will eventually be collecting.

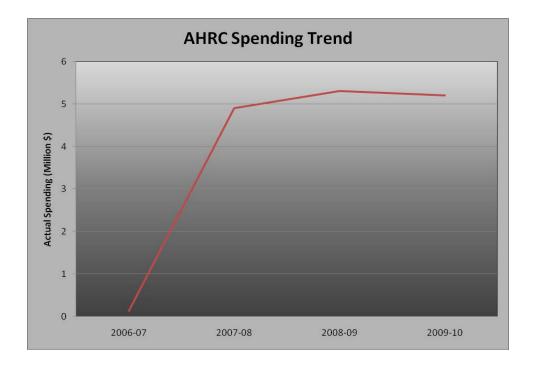
From the outset, AHRC has recognized the importance of collaborating with various stakeholder groups to deliver on its mandate. The Agency continued to conduct a comprehensive stakeholder outreach strategy that builds on its successful efforts to identify and ensure appropriate engagement of stakeholders. Fostering public and stakeholder awareness and understanding will be important for the Agency to meets its objectives.

Resource planning continues to pose a challenge for the Agency, as this planning must be aligned to the timing of the regulations coming into force and to plans to move remaining operations to the Vancouver headquarters. Key positions were staffed with indeterminate employees, and integrated business and human resource plans were reviewed and updated regularly.

### **Expenditure Profile**

### **Spending Trends**

AHRC spent \$5.2 million to meet the expected results of its program activities and contribute to its strategic outcome in 2009 -10. The figure below illustrates the Agency's spending trend from 2006-07 to 2009-10.



AHRC began operations in February 2007, and spending over its first few months of existence in 2006-07 totalled \$134,000. In 2007-08 and 2008-09. AHRC's spending increased to \$4.9 million and \$5.3 million respectively as the Agency began to create the infrastructure and hire staff to fulfill its mandate. Spending remained consistent in 2009-10 at \$5.2 million.

### **Voted and Statutory Items**

### (\$ millions)

Vote # or Statutory Item (S)	Truncated Vote or Statutory Wording	2007–08 Actual Spending	2008–09 Actual Spending	2009–10 Main Estimates	2009–10 Actual Spending
15	Program expenditures	4.6	4.9	9.9	4.8
(S)	Contributions to employee benefit plans	0.3	0.4	0.6	0.4
	Total	4.9	5.3	10.5	5.2

Parliament approved resources of \$10.5 million for the Agency, as per its Report on Plans and Priorities for 2009-10. The Agency's total actual spending for 2009-10 was \$5.2 million.

The only statutory item for AHRC pertains to contributions to employee benefit plans in the amount of \$390,600.

## SECTION 2: ANALYSIS OF PROGRAM ACTIVITIES BY STRATEGIC OUTCOME

### 2.1 Strategic Outcome

Protection and promotion of the health and safety of Canadians against the risks associated with assisted human reproduction technologies.

### **Program Activity by Strategic Outcome**

2.1.1 Program Activity: Licensing and Enforcement of a Regulatory Framework for Assisted Human Reproduction Technologies <sup>3</sup>						
2009–10 Fin	2009–10 Financial Resources (\$ millions) 2009–10 Human Resources (FTEs)					
Planned Total Actual Spending Authorities Spending			Planned	Actual	Difference	
4.3	4.3	.8	14	3	11	

The table above summarizes AHRC's total spending for the 2009-10 fiscal year and actual FTE's employed during that period under this program activity.

### **Program Activity Summary**

Expected Results	Performance Indicators	Targets	Performance Status	Performance Summary
An effective and efficient licencing and inspection framework.	As the regulations come into force, develop a documented licencing and inspection framework which is communicated to clinics and stakeholders and which sees inspections carried out consistent with the framework.	In advance of the regulations coming into force, and in collaboration with stakeholders, AHRC is concentrating on: - developing guidelines, processes and systems to support a licencing system - developing an inspection strategy that will ensure compliance with the AHR Act and regulations	Somewhat Met	<ul> <li>Note that publishing of draft regulations under the AHR Act is being deferred by Health Canada until after the Supreme Court of Canada releases its opinion on constitutional issues related to the AHR Act.</li> <li>The Agency completed defining its Regulatory Implementation Framework and initiated drafting all key guidance documentation in support of the licensing and inspection activities of the framework.</li> <li>AHRC formalized the process for receipt and assessment of allegations of noncompliance with the Act or regulations. All reported allegations of noncompliance were assessed, investigated as necessary and appropriate measures taken.</li> <li>Monitoring of websites for adherence to the legislation – particulary those related to payment for the purchase of gametes and the services of a surrogate mother – was initiated.</li> </ul>

<sup>&</sup>lt;sup>3</sup> Financial figures have not been adjusted to reflect the estimated expenditures under this Program Activity that are currently included in Program Activity 2.1.3, Internal Services

AHRC

A well-informed and engaged stakeholder community.	Prior to the regulations coming into force, communicating the framework to the stakeholders by various means including direct contact, presentations at professional forums, literature and electronic means such as a Web site.	In advance of the regulations coming into force, AHRC is concentrating on: attending professional forums and meetings to communicate the vision for the framework to key stakeholders communicating to stakeholders through the website, newsletter and other outreach initiatives, key aspects of the framework	Met All	<ul> <li>Continued to build productive relationships with stakeholders, through AHRC-sponsored working groups, formal and informal presentations.</li> <li>Responded to hundreds of questions from clinics, the public and other organizations via the toll free phone line and the AHRC central email regarding the AHR Act and its regulations.</li> <li>Continued to engage several partners to further the development of an integrated inspection and accreditation model to minimize administrative burden on regulated parties.</li> <li>Brought together approximately 75 researchers, clinicians and other national and international fertility experts for a scientific roundtable on the issues of multiple births related to AHR, resulting in a draft Canadian framework to prevent multiple births due to fertility treatments.</li> <li>Established the Healthy Singletons Committee, a continuation of the Multiple Births Roundtable steering committee.</li> <li>Worked with the Canadian Partnership Against Cancer (CPAC) as part of a symposium focused on Adolescent and Young Adult cancer issues.</li> <li>Increased overall understanding of the incidence of infertility among the Canadian population by requesting Statistics Canada to include questions relate to the issue in its 2009 Canadian Community Health Survey.</li> </ul>
--	--	--	---------	--

### **Performance Analysis**

The mandate of this Agency is to protect and promote the health, safety, dignity and rights of Canadians who use or are born of assisted human reproduction technologies. Its mandate and responsibilities are set out in the *Assisted Human Reproduction Act*. These activities are overseen by the Board of Directors of the Agency.

AHRC promotes an environment in which ethical principles are applied in all matters related to assisted human reproduction (AHR), while supporting scientific advances that benefit Canadians. The Agency is also a centre of AHR expertise for policy makers, health professionals and Canadians.

Activities under this mandate include:

- Conducting inspections and enforcement related to activities prohibited or controlled under the AHR Act and providing clarifications to clinics about the Act's requirements;
- Collecting and analyzing information relating to AHR;
- Transferring knowledge to health professionals and providing information to the public on AHR and associated matters, including risk factors associated with infertility;
- Consulting with individuals directly impacted by AHR matters and collaborating with organizations within Canada and internationally involved in AHR issues;
- Monitoring and evaluating AHR developments domestically and globally;
- Providing advice to the Minister of Health on all matters relating to assisted human reproduction; and
- Providing internal support services in accordance with governmental policies and regulations.

While Health Canada's development of regulations and policies continued, this work was affected by an opinion of the Quebec Court of Appeal on the constitutionality of certain provisions of the AHR Act. The Government of Canada appealed that opinion to the Supreme Court of Canada and decided, out of respect to the Court, not to pre-publish regulations while the constitutional issues were before the Court. In the interim, AHRC directed its efforts to meeting those targets within its control. The Agency continued to solicit, assess and compare advice and models from its counterparts and stakeholders in order to build an effective and appropriate framework for licensing and inspection of AHR clinics and facilities across the country. AHRC also continued to build productive relationships with stakeholders, through AHRC-sponsored working groups, formal and informal presentations.

As part of its efforts to build an effective and efficient licensing and inspection framework, the Agency completed defining its Regulatory Implementation Framework and initiated drafting key guidance documentation in support of the licensing and inspection activities of the framework. Guidance documentation is being drafted in a modular, "ever-greening" manner to synchronize with the phased regulatory development schedule of Health Canada.

AHRC completed work to formalize receipt and assessment of allegations of non-compliance with the Act or regulations. All reported allegations of non-compliance were assessed, investigated as necessary with appropriate measures taken.

Monitoring of websites for adherence to the legislation – particularly those related to payment for the purchase of gametes and the services of a surrogate mother – was initiated in support of the Agency's compliance and inspection mandate.

Exploring and incorporating best practices in the areas of IT security, privacy and personal health information management continued to inform the Agency's regulatory database architecture and design.

Efforts to extend a well-informed and engaged stakeholder community continued as well. The Agency initiated new relationships with stakeholder groups, while continuing to support and

collaborate with medical associations and patient groups to encourage the incorporation of as much expertise and as many perspectives as possible in the development of national guidelines for assisted human reproduction.

The Agency compliance staff received hundreds of questions from clinics, the public and other organizations via the toll free phone line and the AHRC central email seeking clarification on the AHR Act and its regulations. All inquiries were responded to as completely as possible within the current regulatory environment.

AHRC continued to engage several partners, including Accreditation Canada, to further the development of an integrated inspection and accreditation model to minimize administrative burden on regulated parties.

In an effort to address the issue of multiple births the Agency brought together approximately 75 researchers, clinicians and other national and international fertility experts for a scientific roundtable on the issues of multiple births related to AHR. The roundtable culminated in a draft Canadian framework addressing the prevention of multiple births due to infertility treatment.

The Healthy Singletons Committee, a continuation of the Multiple Births Roundtable steering committee, was also established to identify tangible and achievable targets and actions in support of the Multiple Births Framework.

Also, AHRC worked with the Canadian Partnership Against Cancer (CPAC), as part of a symposium focused on Adolescent and Young Adult cancer issues. AHRC organized a symposium "Oncofertility in Canada: Building Connections for the Improvement of Fertility Preservation Options", to facilitate knowledge transfer among reproductive scientists, oncology staff, fertility preservation specialists and patient advocates. This event was successful in increasing understanding and encouraged research partnerships for the future – a further step in generating increased opportunities for cancer survivors to build families.

AHRC increased overall understanding of the incidence of infertility among the Canadian population by requesting that Statistics Canada include questions related to the issue in its 2009 Canadian Community Health Survey – the largest survey sample of its kind in roughly two decades since the Royal Commission on New Reproductive Technologies.

AHRC worked with the Canadian Institutes from the Health Research's (CCHIR) Institute of Gender and Health and Institute of Human Development, Child and Youth Health to facilitate a workshop that identified research priorities related to AHR. As a next step, the collaborators supported a funding initiative through CIHR focused on psychosocial impacts of AHR.

### **Lessons Learned**

While awaiting the coming into force of further regulations of the *Assisted Human Reproduction Act* the Agency continued to consult with key stakeholder groups and associations to incorporate best practices from other jurisdictions (compliance and enforcement agencies, and accreditation

bodies) into the licensing and inspection policies and procedures related to assisted human reproduction.

### **Benefits for Canadians**

Through this program activity, AHRC contributes to fostering the health of Canadians. Specifically, the Agency protects the health and safety, dignity and rights of Canadians using AHR technologies by monitoring compliance with the AHR Act and its regulations.

2.1.2 Program Activity: Health Information and Knowledge Management for Assisted Human Reproduction Technologies <sup>4</sup>						
2009–10 Financial Resources (\$ millions) 2009–10 Human Resources (FTEs)						
Planned Total Actual Spending Authorities Spending			Planned	Actual	Difference	
2.6	2.6	.8	11	2	9	

The table above summarizes AHRC's total spending for the 2009-10 fiscal year and actual FTE's employed during that period under this program activity.

### **Program Activity Summary**

Expected Results	Performance Indicators	Targets	Performance Status	Performance Summary
A Personal Health Information Registry that complements an eventual AHR surveillance network.	The successful development of a Personal Health Information Registry that is integrated into an overall surveillance network, once the regulations come into force.	In advance of the regulations coming into force, AHRC is concentrating on: - initiating a pilot project using voluntary information to build the foundation for a Personal Health Information Registry	Somewhat Met	AHRC continued to concentrate on building the foundation for the Personal Health Information Registry. The business requirements for meta-data collection were documented and defined for the initial Health Canada regulatory package.  In response to a priority for improved and additional information related to reproductive technology, identified by patients, fertility centres and researchers, AHRC began exploring, with the Canadian Fertility and Andrology Society and other experts, potential models around the measurement of outcomes.  AHRC supported development of the 2009 Inventory of Health Surveillance Databases which collects information related to the health outcomes of AHR.

<sup>&</sup>lt;sup>4</sup> Financial figures have not been adjusted to reflect the estimated expenditures under this Program Activity that are currently included in Program Activity 2.1.3 Internal Services.

Policy	Number of printed	The Agency		3 Information brochures produced and
makers,	information products	will establish	Somewhat	disseminated:
health	distributed for	baseline	Met	Counselling and Assisted Human
professionals,	external use	measures		Reproduction;
patients,		related to its		Reproductive Genetic Testing and
children born	Number of	information		Screening Options; and
of AHR	persons/organizations	products in the		Cancer and Preserving your Fertility: a
procedures,	accessing the	first year, as		Guide for Patients.
researchers	Web site (statistics)	the basis for		
and the	Results of periodic	setting targets		Other information products created and
Canadian	surveys to gauge	in future		disseminated included:
public have	utility of products	years.		2009 Inventory of Health Surveillance
access to				Databases;
information				2009 Winter Newsletter; and
regarding				Annual Report – 2008-2009.
AHR.				
				Revisions to the AHRC website
				initiated in support of the evolving
				Stakeholder Outreach Strategy and the
				Information Dissemination Plan.
				Additional baseline data collection will
				be refined as the website redesign is
				completed

### **Performance Analysis**

AHRC continued to concentrate on building the foundation for the Personal Health Information Registry. The business requirements for meta-data collection were documented and defined for the initial Health Canada regulatory package.

In response to a priority for improved and additional information related to reproductive technology, identified by patients, fertility centres and researchers, AHRC began exploring, with the Canadian Fertility and Andrology Society and other experts, potential models around the measurement of outcomes.

Adequate information is essential for both health policymakers and practitioners to plan and provide appropriate resources to health programs and allow confirmation that the programs are producing the intended results.

One of the means to accomplish this is through relevant and effective monitoring of health outcomes, an area that AHRC is actively advancing. Health researchers across the country collected and collated information related to assisted human reproduction, as well as reproductive, perinatal, infant and children's health in the 2009 *Inventory of Health Surveillance Databases*, which will help confirm the outcomes of AHR procedures.

As part of the work under the Agency's mandate to provide policy makers, health professionals, patients, children born of AHR procedures, researchers and the Canadian public with access to information regarding AHR, information brochures were produced and disseminated which shared news about the latest technological developments with Canadians. It is important to note

that the development of all communications products benefits from the input of AHRC Editorial Committee members. The Committee is composed of representatives from stakeholder groups with knowledge of AHR issues, including a counsellor, a patient representative, a donor-conceived person, as well as an embryologist, a gynaecologist, a nurse and a physician.

AHRC developed a new brochure for prospective parents, which provides them with an overview of genetic testing and screening options that they may want to consider during the early stages of pregnancy. This brochure, *Reproductive Genetic Testing and Screening Options*, briefly explains what genetic testing involves, how it is performed, and outlines advantages and limitations of this technology.

Knowing what to anticipate and how to deal with the uncertainty surrounding AHR is another subject explored in a recently-released brochure, *Counselling and Assisted Human Reproduction*. The leaflet explains what AHR counselling entails for men, women and families. It outlines the medical aspects of various procedures as well as the kinds of social, emotional, and ethical issues that are linked to reproductive technologies. The leaflet reinforces that counselling can help individuals and couples cope with the many challenges associated with being unable to conceive without medical intervention, and with the complex decisions they may need to consider during different stages of AHR.

A third brochure was produced to raise awareness of advances in reproductive technologies that can increase the chances of conception among cancer survivors. *Cancer and Preserving your Fertility: A Guide for Patients* was distributed by mail and on the AHRC's website. The Agency also disseminated other products in addition to the brochures mentioned, including the 2009 Winter Newsletter, and the Agency's Annual Report for 2008-09.

Revisions of the Agency's website were initiated in support of the evolving Stakeholder Outreach Strategy and the Information Dissemination Plan due to the site's role as an important tool for all stakeholders. These revisions, both technical and content-centric, will facilitate and enhance AHRC's dissemination capacity as well as introduce utilities for monitoring access to the various products AHRC makes available via the website. The redesign, scheduled for completion by summer 2010, will also incorporate refinements to the collection of relevant baseline data.

### **Lessons Learned**

The Agency continues to actively consult and consider practices, procedures and standards from national and international experts and organizations working in the rapidly changing field of assisted human reproduction in order to learn from the experience of its international counterparts, and to inform its planning and development of policies and procedures related to AHR in Canada. The quality and reliability of information collected is attributable to the rigor and inclusiveness of the consultation with all stakeholders, including researchers, policy-makers, patients, industry, professional associations, and Canadians.

### **Benefits for Canadians**

The establishment of a Personal Health Information Registry (PHIR) will be useful in monitoring and improving the safety and effectiveness of AHR procedures. The registry will also provide a valuable resource to children born of reproductive technologies to enable them to access their medical and genetic information. The PHIR will eventually become a key component of a larger AHR health surveillance system capable of providing information needed to determine health outcomes relating to persons undergoing certain AHR procedures and children born as a result of those procedures. This will allow Canadians to make more informed decisions related to the use of these technologies.

2.1.3 Program Activity: Internal Services							
2009–10 Fin	ancial Resources	s (\$ millions)	2009–10 Human Resources (FTEs)				
Planned Total Actual Spending Authorities Spending		Planned	Actual	Difference			
3.7	3.7	3.6	19	8	11		

The table above summarizes AHRC's total spending for the 2009-10 fiscal year and actual FTE's employed during that period under this program activity.

### **Performance Analysis**

Internal Services are groups of related activities and resources that are administered to support the needs of programs and other corporate obligations of an organization. These groups are: Management and Oversight Services; Communications Services; Legal Services; Human Resources Management Services; Financial Management Services; Information Management Services; Information Technology Services; Real Property Services; Material Services; Acquisition Services; and Travel and Other Administrative Services. Internal Services include only those activities and resources that apply across an organization and not to those provided specifically to a program.

Internal Services includes expenditures related to the Office of the President, activities of the Chief Science Advisor's Office (includes support to the Science Advisory Panel) and the Corporate Secretariat (which includes support to the Board of Directors). In addition, it includes a Memorandum of Understanding (MOU) with Health Canada (HC) for Human Resources, Finance and IT support, a MOU with HC Inspectorate for Inspection services and a MOU with the Department of Justice for legal services.

AHRC continued to build sustainable Internal Services by developing policies, processes and service delivery in the areas of finance, procurement, human resources, information management (including Access to Information and Privacy), and information technology. Wherever practical, the Agency reviewed best practice models and worked towards an integrated management system that considers human resources, risk management, performance management, and financial management.

The Agency also reviewed its Internal Services performance to ensure delivery of service in a transparent, cost effective, and timely manner, and worked to create an Internal Financial Control Framework to encompass financial management, risk management, financial delegation and contracting.

In the area of human resources, AHRC worked to integrate its business planning and human resource planning and its resourcing strategy in accordance with Public Service Commission and other relevant Central Agency policies. As regulations come into force, resourcing plans will be implemented to ensure that AHRC has the personnel and expertise required to fulfil its mandate that are appropriate to the anticipated broadening of activities as the regulations come into force.

# **SECTION 3: SUPPLEMENTARY INFORMATION**

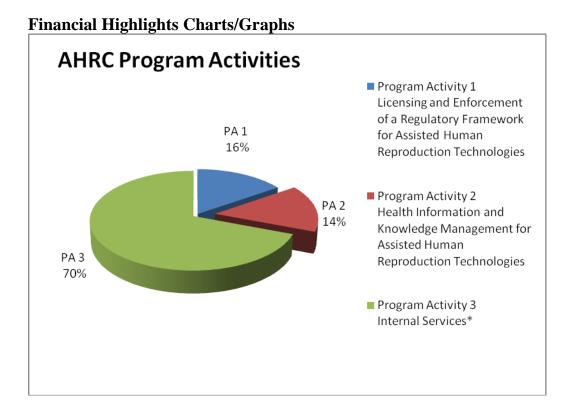
### 3.1 Financial Highlights

### (\$ thousands)

Condensed Statement of Financial Position	0/ Changa	2008–09	2009–10
At end of Fiscal Year (March 31, 2010)	% Change	2000-09	2009-10
ASSETS			
Total Assets	21%	286	346
TOTAL		286	346
LIABILITIES			
Total Liabilities	(3%)	546	528
EQUITY			
Total Equity	(30%)	(259)	(182)
TOTAL		287	346

### (\$ millions)

Condensed Statement of Financial Operation At end of Fiscal Year (March 31, 2010)	% Change	2008–09	2009–10
EXPENSES			
Total Expenses	1%	5.7	5.7
REVENUES			
Total Revenues	0%	0	0
NET COST OF OPERATIONS		5.7	5.7



\*Internal Services includes expenditures related to the Deputy Head's Office, Chief Science Advisor's Office and the Corporate Secretariat. In addition, it includes a Memorandum of Understanding (MOU) with Health Canada (HC) for Human Resources, Finance and IT support, a MOU with HC Inspectorate for Inspection services and a MOU with the Department of Justice for legal services.

### **Financial Statements**

The financial highlights presented within this Departmental Performance Report are intended to serve as a general overview of AHRC's financial position. The Agency's financial statements can be found on AHRC's website at:

http://www.ahrc-pac.gc.ca/doc.php?sid=32&lang=eng

### 3.2 List of Supplementary Information Tables

Table 9: Green Procurement

Table 10: Response to Parliamentary Committees and External Audits

Table 11: Internal Audits and Evaluations, 2009-10

All electronic supplementary information tables found in the 2009–10 Departmental Performance Report can be found on the Treasury Board of Canada Secretariat's website at: <a href="http://www.tbs-sct.gc.ca/dpr-rmr/2009-2010/index-eng.asp">http://www.tbs-sct.gc.ca/dpr-rmr/2009-2010/index-eng.asp</a>.