**Government of Canada Submission:**

**Independent Expert on Cultural Rights’ Questionnaire: *The Right to Enjoy the Benefits of***

***Scientific Progress and its Applications***

The Government of Canada appreciates this opportunity to contribute to the research currently undertaken by the Independent Expert on Cultural Rights’ on the right to enjoy the benefits of scientific progress and its applications.

As a State Party to the International Covenant on Economic, Social and Cultural Rights, Canada is committed to the progressive realization of the right to the highest attainable standard of physical and mental health. The following response is an opportunity for the Government of Canada to highlight a few examples of how, through national programs in the health sector, Canada contributes toward supporting the enjoyment of the benefits of scientific progress and its applications.

**A) Accessing the Benefits of Science and its Applications:**

**1. What legal, administrative and policy measures exist or are planned in your country:**

*a) To ensure that marginalized groups benefit from scientific progress and its applications, including, women, persons with disabilities, minority groups, rural communities and indigenous peoples?*

In Canada, institutions and researchers receiving funds from the three federal research Agencies - Canadian Institutes of Health Research (CIHR), the Natural Sciences and Engineering Research Council (NSERC) and Social Sciences and Humanities Research Council (SSHRC) - must comply with the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS)* as a condition of funding. A second edition of the Policy, TCPS2, was released in December 2010 and can be found at the following site: <http://www.pre.ethics.gc.ca/eng/policy-politique/initiatives/tcps2-eptc2/Default/>.

One of the key chapters of TCPS2 (Chapter 4) focuses on fairness and equity in research participation. It promotes the appropriate inclusion of potential research participants regardless of culture, religion, race, mental or physical disability, sexual orientation, ethnicity, gender or age, unless there is a valid reason for exclusion. Chapter 9 of TCPS2 is dedicated to issues relevant to research involving First Nations, Inuit and Métis Peoples of Canada. It seeks to ensure culturally appropriate approaches to research with those Peoples through community engagement and other culturally respectful practices.

At its founding in 2000, CIHR first demonstrated a commitment to health research involving Aboriginal People by creating an Institute for Aboriginal People’s Health (IAPH) among its suite of 13 institutes. IAPH develops strategic regional, national, and international partnerships to advance Aboriginal health research. IAPH also enhances capacity and infrastructure for Aboriginal health research.

*b) To promote research and development in areas specifically relevant to marginalized groups by, for example, providing incentives for innovative research on neglected diseases?*

CIHR’s current strategic plan (2009-2014) includes as a strategic direction to “address health and health system research priorities”. Among the specific priorities cited is to “*reduce health inequities of Aboriginal peoples and other vulnerable populations*.” Within this research priority, CIHR has committed to launching strategic research funding initiatives that address the health disparities experienced by Aboriginal people and immigrant and refugee populations (Health Research Roadmap, p 21). Specifically, the CIHR signature funding initiative “*Pathways to Health Equity for Aboriginal People*” was announced earlier this year. CIHR also offers research funding through its Community-based HIV/AIDS research initiative, which works directly with and for HIV-affected populations who are often marginalized.

Additionally, since 2006, the Government of Canada, through CIHR, has invested over $85.1 million in research into rare diseases and blood disorders such as sickle cell disease and thalassemia, both known to affect unique ethnic groups. Additionally, Canada is also a founding member of the International Rare Diseases Research Consortium that was established earlier this year, and is now also a part of the Orphanet initiative – a rare disease and orphan drug information reference portal.

*c) To ensure and facilitate broad access to information and communication technologies (e.g., computers, Internet and mobile phones)?*

Nil

*d) To identify and develop the scientific applications necessary for sustainable solutions to ensure the right of everyone to have access to safe and nutritious food, access to potable water and sanitation, and to address climate change?*

One of the strategic priorities of CIHR’s Institute of Nutrition, Metabolism, and Diabetes is food and health. This institute is developing a stronger evidence base to inform future nutritional practice and food policy, including for northern and remote regions of Canada. Through the institute, CIHR fosters research on the total diet and specific nutrients to enhance health and reduce the risk of chronic disease. This includes, for example, the evaluation of biomarkers of nutritional adequacy, emerging innovations in food engineering, and the ethical issues posed by these changes particularly with respect to people with vulnerabilities. In addition, CIHR is a funding partner on the International Research Initiative on Adaptation to Climate Change. Further information on this program is available here: <http://www.idrc.ca/EN/Programs/Science_and_Innovation/IDRC_Challenge_Fund/Pages/IRIACC.aspx>

**2. What are the key challenges faced in your country in undertaking research at the domestic level and ensuring access to scientific developments and its applications, particularly for marginalized groups?**

Although there are demonstrated pockets of excellence in Aboriginal health research in Canada, this field requires the systemic development of both human resources and supportive research environments in order to ensure continued growth in research and the appropriate application of results. In response, the CIHR Institute for Aboriginal People’s Health established the Aboriginal Capacity and Developmental Research Environments centres to foster a national network that facilitates the development of Aboriginal capacity in health research and its translation and uptake. This program was succeeded by the “Network Environments for Aboriginal Health Research” program, which continued to build capacity in research and its application.

Another challenge that is actively being addressed is to systematically take into account sex and gender based differences across all CIHR activity, including in the outputs of research. CIHR is subject to the Canadian Ministry of Health’s Sex and Gender Based Analysis (SGBA) policy, which it is actively implementing through funding activities: <http://www.cihr-irsc.gc.ca/e/42874.html>

Finally, it should be recognized that the nature of the Canadian population – both geographically dispersed and increasingly multicultural – poses inherent challenges for involvement in research, as well as for the application of research results, particularly for marginalized groups which have a diminished ability to safeguard their interests in the context of a specific research project.

**B) Scientific Responsibility, Safeguards and Remedies**

**3. What legal, administrative and policy mechanisms exist or are planned in your country:**

*a) To regulate and monitor scientific research and its applications in the private and public sector so as to provide safeguards against any infringement upon the full enjoyment of human rights? In particular, to safeguard the human rights of participants in research activities and applications by public and private scientific institutions (e.g., rights to information, free and informed consent)?*

The Tri-Council Policy Statement (TCPS2) – which applies to the three federal research institutes – is founded on respect for human dignity and expressed through three core principles: (i) respect for persons, (ii) concern for welfare, and (iii) justice. (i) Respect for persons incorporates the dual moral obligations to respect autonomy and to protect those with developmental, impaired or diminished autonomy. It is expressed through respecting participants’ autonomy in research by seeking their free, informed and ongoing consent. For those who lack capacity to exercise autonomy because of youth, cognitive impairment, other mental health issues or illnesses, this is reflected through the incorporation of additional measures to protect their interest and to ensure that their wishes are respected. (ii) Concern for welfare of an individual is reflected in the quality of the individual’s experience of life in all its aspects. Contributing factors to welfare include privacy and the control of information about the person. Welfare consists of the impact on individuals of factors such as their physical, mental and spiritual health, as well as their physical, economic and social circumstances. (iii) Justice refers to the obligation to treat people fairly and equitably with equal respect and concern.

*b) To protect the rights of indigenous peoples and local communities whose traditional knowledge is utilized, in the development, dissemination and commercialization of scientific information and knowledge?*

The Tri-Council Policy Statement (TCPS2) – which applies to the three federal research institutes – acknowledges the unique status of First Nations, Inuit and Métis Peoples and provides guidance on the approach and special ethical considerations in engaging these communities in research, as well as how to interpret the underlying value of respect for human dignity in diverse Aboriginal contexts. It addresses issues relevant to respect for community customs and codes of practice; privacy and confidentiality for First Nations, Inuit and Métis communities, issues relevant to interpretation and dissemination of research results involving these communities; intellectual property issues; and the secondary use of information or human biological materials identifiable as originating from First Nations, Inuit and Métis communities.

*c) To provide effective remedies and safeguards for any human rights violation related to scientific research or the applications of science or technology? (e.g., judicial review, national human rights institutions or ombudspersons, and other administrative arrangements)*

Institutions and researchers receiving Canadian federal research funds from the Canada’s three federal agencies – CIHR, NSERC and SSHRC – are also required to follow the *TCPS2* as a condition of funding. They are also subject to the Agencies’ *Tri-Council Policy Statement: Integrity in Research and Scholarship*, including its Framework for Tri-Council Review of University Policies Dealing with Integrity in Research. In December 2011, the Agencies will launch a new “Tri-Agency Framework: Responsible Conduct of Research” which will replace the previously-mentioned policy and framework. This new Framework addresses all aspects of the responsible conduct of research, including research integrity principles, financial accountability, process, breaches, and remedies. While researchers are subject to sanctions from the institutions that employ them, the Agencies have the authority to take additional recourse of their own for breaches of Agency policies. For example, where a researcher has been found to be in breach of an Agency policy, the Agency may revoke that researcher’s funding or may bar that researcher from applying for further funding.

**C) The Rights of Scientists and Collaborative Work**

**4. What measures have been put in place to recognize, respect and protect the rights of scientists?**

1. *To freedom of expression, information and association?*

A fundamental premise of the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS2)*, adhered to by Canada’s federal research agencies, is that in order to maximize the benefits of research for human society, researchers must have academic freedom. TCPS 2 states that academic freedom comes with researchers’ responsibility to ensure that research involving humans meets high scientific and ethical standards that respect and protect participants. TCPS 2 makes reference to institutions’ responsibility to defend researchers in their efforts to uphold academic freedom and high ethical, scientific and professional standards.

*b) To collaborate with colleagues nationally and internationally, including through sharing data, samples, research findings, and other information, by travelling freely within and outside of the country, and conducting joint research projects?*

CIHR offers a number of standard funding tools that support the development and strengthening of research networks, both through strategic and open funding competitions. Additionally, the recently announced Strategy on Patient-Oriented Research (SPOR) specifically seeks to support research networks in key priority areas. CIHR also supports international health research collaborations through multi- and bilateral partnerships.

CIHR is also a partner in the government of Canada’s Research Data Strategy initiative (<http://rds-sdr.cisti-icist.nrc-cnrc.gc.ca/eng/index.html>). This is a collaborative effort to address the challenges and issues surrounding the access and preservation of data arising from Canadian research. Partners include Canadian universities, institutes, libraries, granting agencies, and individual researchers who all recognize the need to deal with Canadian data management issues.

**5. What legal, administrative, policy or other measures have been adopted/are under consideration to eliminate barriers to scientific communication and collaboration, such as censorship, restrictions on access to the Internet or on free availability of scientific literature and journals?**

CIHR supports open access to research to facilitate scientific progress, collaboration and the application of knowledge. CIHR promotes open access through a number of initiatives:

* An Access to Research Outputs Policy that requires CIHR grant recipients to make research articles publicly accessible within six months publication.
* PubMed Central Canada, a free web-based repository of health sciences literature established in partnership with the National Research Council's Canada Institute for Scientific and Technical Information and the US National Library of Medicine. CIHR-funded researchers may deposit articles in the repository.
* A suite of programs that support knowledge synthesis and exchange between researchers and knowledge users (e.g., health care providers, health system managers). These programs include Best Brains Exchanges and Partnerships for Health System Improvement.
* A Cafe Scientifique program that brings researchers and the public together for informal discussion in relaxed settings on health topics

CIHR also uses a variety of formats and social media to provide timely and reliable information and to engage Canadians on health research. CIHR has a presence on the following social media platforms: Facebook, YouTube, Twitter and Flickr. CIHR also runs a blog to support the Cafe Scientifique program, and contributes to a "Eureka! Canada" page, which was created by federal research funding agencies.

**D) Participatory decision-making and transparency**

**6. What measures are put in place to ensure dissemination of information about ongoing scientific research and its applications, including potentially adverse effects of emerging areas of research and its applications to the public at large?**

CIHR has an open access policy (<http://www.cihr.ca/e/32005.html>) that requires all CIHR funded researchers to ensure that all research papers generated from CIHR funded projects are freely accessible through the Publisher's website or an online repository within six months of publication.

As per CIHR’s *Grants and Awards Guide*, all applicants are encouraged to include an [end-of-grant knowledge translation plan](http://www.cihr-irsc.gc.ca/e/41594.html) in their research proposals, describing how they intend to disseminate their findings to the appropriate knowledge user audience(s), including the public.

Chapter 11 of the TCPS-2 (on Clinical trials) requires that all funded researchers promptly report new information that may affect the welfare or consent of participants to appropriate regulatory or advisory bodies.

CIHR further requires that its grant recipients conducting trials:

* update trial registries with any changes in the trial protocol, adverse events that occur during a trial, and decisions taken to end a trial early;
* disclose serious adverse events at the end of the trial in subsequent publications and to the registry; and
* deposit aggregate data in an unbiased, publicly accessible database (e.g., the trial registry).

1. **What opportunities exist for meaningful public participation in decision-making about existing and new developments in science and technology?**

CIHR has a developed a citizen engagement framework, which is available here: <http://www.cihr-irsc.gc.ca/e/41753.html>. The goal of the Framework is to provide direction for the organization to gain a better understanding of the values and needs of Canadians to inform its priorities and policies, to increase the relevance of health research to Canadians and to improve how such research is put into practice.

For CIHR, citizens are defined as interested representatives of the general public, consumers of health services, patients, caregivers, advocates and representatives from affected community and voluntary health organizations.

CIHR encourages researchers to involve citizens where appropriate, and to provide in their research proposal a brief description of how they intend to involve them, when applicable.

1. **What steps have/are being taken to promote quality science education at all levels for all, in particular for girls, rural populations and the poor?**

In 2006, Synapse was established as a meeting place between CIHR-funded health researchers and Canadian youth (<http://www.cihr-irsc.gc.ca/e/39429.html>). This program is specifically designed to motivate students to consider the value of science for the overall well-being of people, and to stimulate their interest in health research as a career. To achieve this, Synapse encourages CIHR-funded researchers, graduate students and postdoctoral fellows to become mentors by passing on their passion for health research to young Canadians. Since its inception, over 7,000 Synapse mentors have signed up.

Additionally, through this Synapse request for funding application, CIHR wishes to work with well-established national science awareness organizations in an effort to a) create more youth outreach opportunities for CIHR Synapse mentors, and b) offer a large number of health research-related hands-on activities to young students across Canada. These include summer science camps, virtual mentorship connections, science fairs, lab-mentorship programs and in-school, hands-on science workshops for youth.

CIHR Café scientifiques are informal discussion about scientific subjects that provide insight into health-related issues of popular interest to the general public, and in turn provoke questions and provide answers (<http://www.cihr-irsc.gc.ca/e/34951.html>)

**E) International cooperation, achievements and challenges**

The CIHR *Act* is the legislation that establishes CIHR as a Departmental Corporation and it stipulates a perspective and scope of action that transcends national boundaries. Stated objectives in the Act include: “providing support for the participation of Canadian scientists and partnerships” and “exercising leadership within the Canadian research community and fostering collaboration…with individuals and organizations in or outside Canada that have an interest in health or health research”.

Furthermore, the CIHR Strategic Plan (2009-2014) explicitly calls for the promotion of interdisciplinary and international innovation, within Strategic Direction #1: Invest in world class research excellence. To achieve this, CIHR is committed to: connecting scientists internationally; leading the development of international health research consortia; facilitating health research; and building capacity in low and middle income countries (CIHR Health Research Roadmap, p 16).

Thus, CIHR encourages applications in the field of global health that demonstrate the proposed research project has the potential to improve the health of the global community. As an example, CIHR has entered into a cooperative arrangement with the Canadian International Development Agency (CIDA), Health Canada (HC), the Public Health Agency of Canada (PHAC) and the International Development Research Centre (IDRC). Referred to as the Global Health Research Initiative (GHRI), it aims to strengthen capacity to do research and use research findings that address global challenges by linking researchers and knowledge users in Canada and low- and middle-income countries.