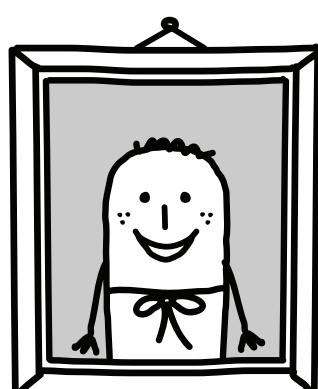
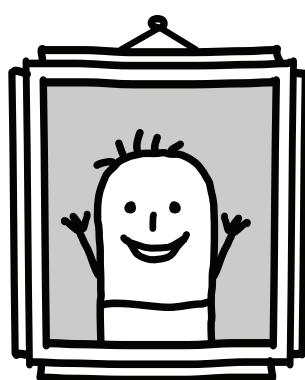
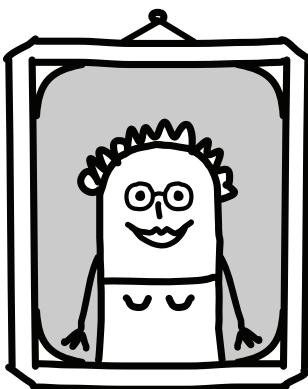




Health Research in Canada and You



Canadian Institutes
of Health Research

Instituts de recherche
en santé du Canada

Canada

Canadian Institutes of Health Research
160 Elgin Street, 9th Floor
Address Locator 4809A
Ottawa, Ontario K1A 0W9 Canada

www.cihr-irsc.gc.ca

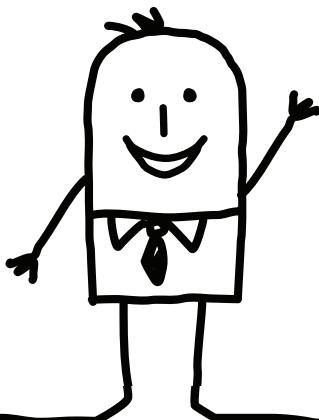
Also available on the Web in PDF and HTML formats
© Her Majesty the Queen in Right of Canada (2011)
Printed: Cat. No. MR4-8/2011E • ISBN 978-1-100-18268-1
Online: Cat. No. MR4-8/2011E-PDF • ISBN 978-1-100-18269-8

Également disponible en français sous le titre : La recherche en santé au Canada : comment y participer

Illustrations ©iStockphoto.com/NLshop

Created in 2000, The Canadian Institutes of Health Research (CIHR) is the Canadian government's funding agency for health research and knowledge translation. Its mandate is to "excel...in the **creation of new knowledge and its translation into improved health for Canadians, more effective health services and products, and a strengthened Canadian health care system**". In other words, CIHR's goals are nothing less than to make Canada a leader in health research and to apply that knowledge to make Canadians healthier.

In order to accomplish this, however, CIHR knows that we must have a strong, open relationship with Canadians. There is a great deal that citizens can teach us, and we want to learn from people who are interested in health research. Their opinions and views can help CIHR achieve its goals.



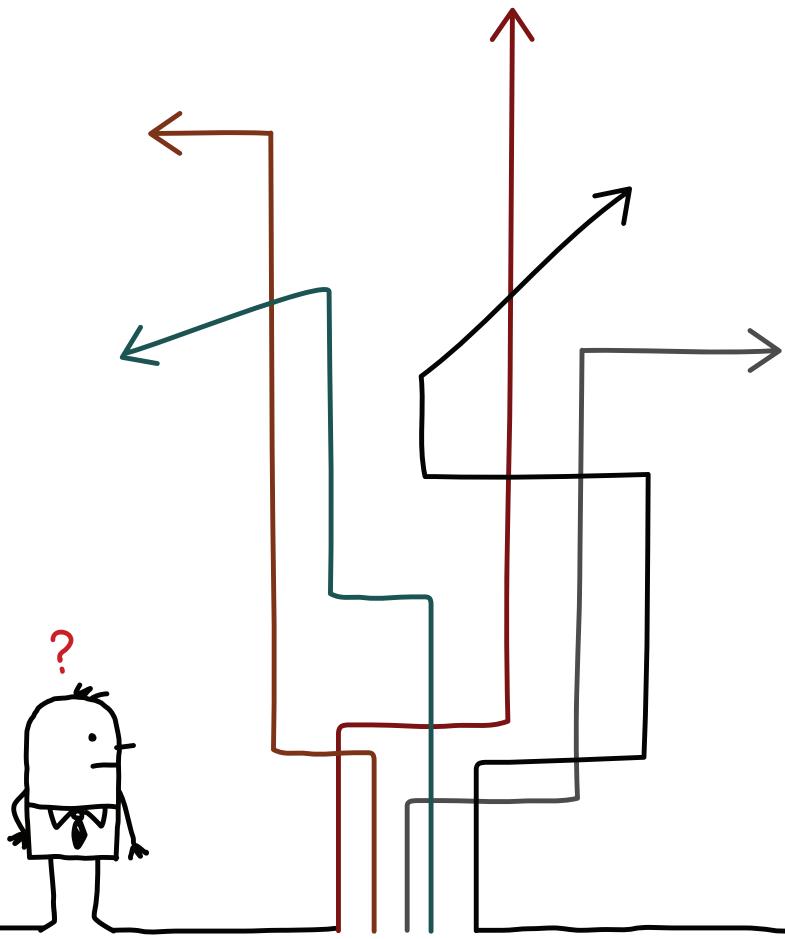
What is this booklet?

This booklet represents part of the important conversation between Canadians and CIHR. Inside, you will find an overview of CIHR and its activities, along with definitions and examples of health research. Just as importantly, however, this document also contains an overview of what we call "citizen engagement" and information about how Canadians who are interested in health research can engage with CIHR and participate in our ongoing work. Whether it is participating in community-based research or attending one of CIHR's Public Outreach activities, there are numerous ways for citizens to become engaged with health research in Canada. This booklet will examine those opportunities and explain why your participation is so important.

If you are:

- a consumer of health services, a patient, or caregiver who wants to get involved in improving health care in your community;
 - an advocate or representative from an affected community or voluntary health organization;
 - a journalist who needs to interpret health research for the public; or
 - anyone who wants to better understand health research and how you can get involved;
- then this booklet is for you.

Getting to know CIHR

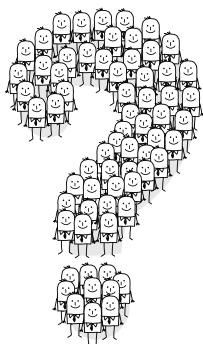


What we do

As CIHR's mandate indicates, our activities are based around two key activities: **the creation of health knowledge and its translation into improvements that can affect the health of Canadians.**

We pursue these goals in several ways. To create **the best new health knowledge**, CIHR works with organizations from the public, private, and voluntary sectors from across Canada to fund top research projects. We also provide awards to the finest students and trainees across all areas of health research, helping them to become the health research and knowledge translation leaders of tomorrow.

Knowledge translation is the term chosen by CIHR to describe the ways that research can be applied to real life situations. It refers to turning research discoveries into action for health and socioeconomic benefits. Knowledge translation ensures that the results of our funded research are shared with Canadians in order to improve their health and our health care system. This means that the individuals and organizations who will use the research (sometimes called “non-academic knowledge users”) can enjoy the benefits of research through a stronger health care system, better health services or products, and overall improved health.



Did you know that CIHR supports nearly 13,000 researchers and trainees in universities, training hospitals, and other health organizations and research centres in Canada?

How are we organized?

CIHR is comprised of 13 “virtual” Institutes, country-wide networks of researchers who share a similar focus. While these Institutes do not have a physical location at CIHR, they bring together like-minded researchers, health professionals, and policy-makers from across Canada. This network can include voluntary health organizations, provincial government agencies, international research organizations, industry, and patient groups.

Each Institute has a Scientific Director and an Institute Advisory Board (IAB), which is composed of representatives from the research community, health practitioners, and Canadians in the public, private, and non-profit sectors. The IAB advises the Scientific Director on decisions concerning the unique research focus of each institute, and both the Scientific Directors and the IABs of each Institute report to the CIHR Governing Council. Ultimately, this Council and CIHR itself, reports to Parliament through the Minister of Health.

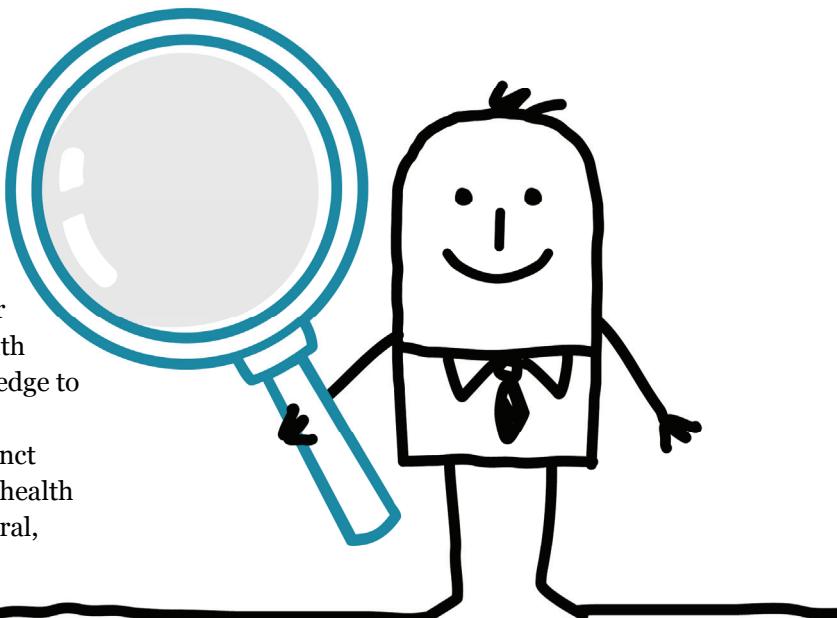
You will notice that some of CIHR’s Institutes focus on populations, while others focus on disease and health conditions, stages of life, and one on health services and policy. CIHR’s 13 Institutes are:

- Aboriginal People’s Health
- Aging
- Cancer Research
- Circulatory and Respiratory Health
- Gender and Health
- Genetics
- Health Services and Policy Research
- Human Development, Child and Youth Health
- Infection and Immunity
- Musculoskeletal Health and Arthritis
- Neurosciences, Mental Health, and Addiction
- Nutrition, Metabolism, and Diabetes
- Population and Public Health

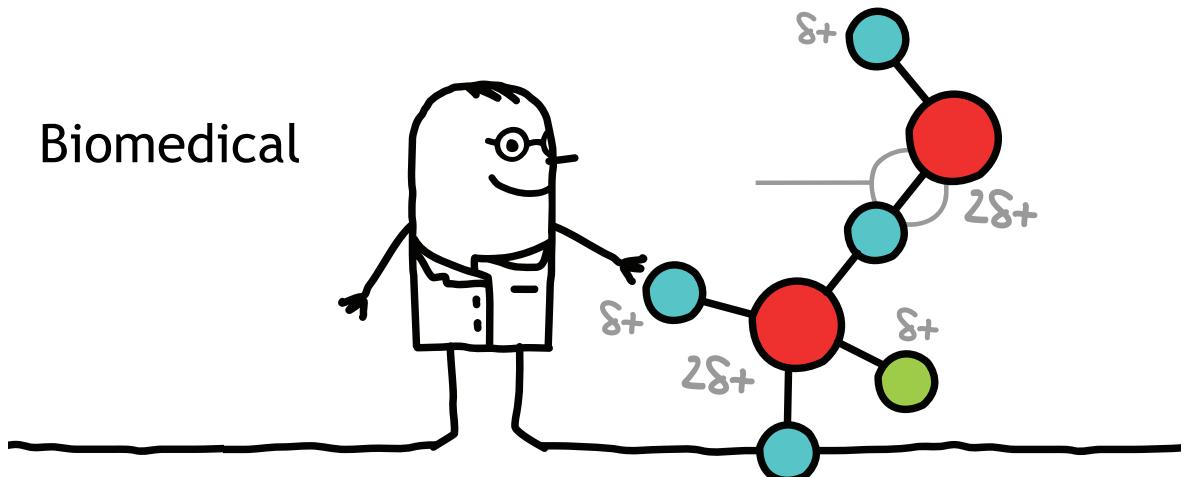
Health Research and CIHR

What kind of research does CIHR fund?

Health researchers aim to increase our knowledge of health, disease, and health services, and to then apply that knowledge to help people lead healthier lives. CIHR separates their research into four distinct research themes: biomedical, clinical, health systems and services, and social, cultural, environmental and population health.



Biomedical



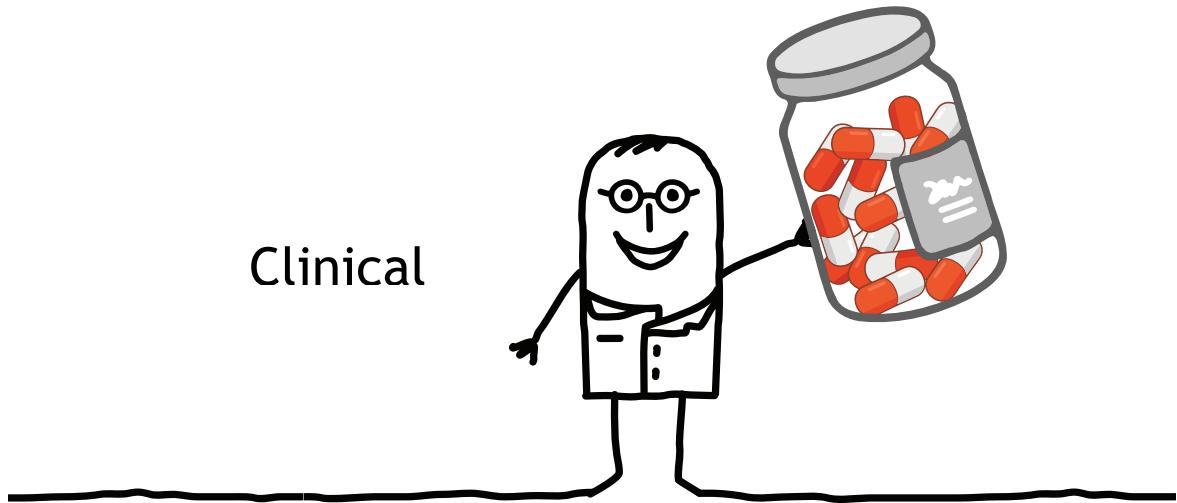
This type of research studies normal and abnormal human function from the level of cells and molecules all the way up to the whole body. Basic biomedical researchers do their work in a laboratory using test tubes, cell samples, microscopes, chemical analysis, and other applicable tools or methods.

Examples of disciplines that conduct this kind of research

Microbiology, Genetics, Pharmacology, Medicine (including specialities such as Oncology and Cardiology)

Research in action

The study, “Molecular Mechanisms of Lung Cancer Development in Former Smokers,” will look at the difference between airway cells of ex-smokers with and without lung cancer. It will also examine the DNA sequence of these regions in lung tumors of ex-smokers to find out why they develop lung cancer.



A clinical trial is a research study involving patients (and sometimes healthy people too). It may involve researchers asking questions, taking blood and tissue samples, or checking the progress of patients as they take a treatment according to a trial's protocol.

Clinical research involving participants often has inclusion criteria, conditions that dictate who can be recruited or enrolled in a particular study. The best study design to evaluate effectiveness of drugs, medical devices, and practices is known as the randomized controlled trial (RCT). An RCT is an experiment in which investigators randomly assign eligible participants into groups to receive (or to not receive) one or more treatments that are being compared.

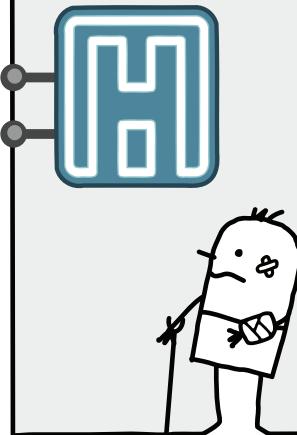
Examples of disciplines that conduct this kind of research

Kinesiology, Medicine, Psychology, Social Work, Nursing, Biostatistics, Clinical, Epidemiology

Research in action

The 4-year study, “Health Outcomes of Low Vitamin D in Toddlers,” will follow a selected group of children during their doctor’s visits. The aim is to find the links between low Vitamin D levels and their risk for getting asthma, respiratory infections, obesity or high blood pressure later on in life.

Health systems and services



This type of research seeks to improve the efficiency and effectiveness of health professionals (such as doctors, nurses, and physiotherapists) and the health care system itself through changes to practice and policy. Health services researchers often use surveys, focus groups, randomized controlled trials, and comparisons of data from health records and other sources in their studies.

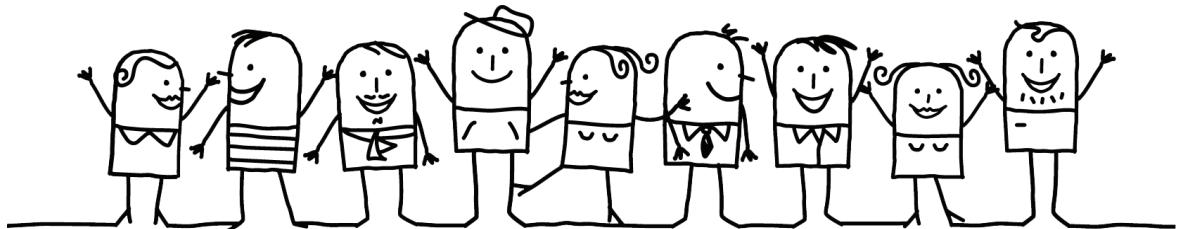
Examples of disciplines that conduct this kind of research

Health Economics, Public and Health Administration, Political Sciences, Sociology, Geography, Anthropology

Research in action

"The Impact of a Resident Work Schedule Change on Patient Safety" is a study of health systems and services. Its goal is to assess the effect that reducing long work shifts for residents (new doctors working under the supervision of more experienced practitioners) has on patient safety.

Social, cultural, environmental and population health



This research works to enhance the health of the Canadian population (or of sub-populations, such as those from a particular region or ethnic group) by understanding how social, cultural, environmental, work-related, and economic factors affect people's health. It also involves the evaluation of certain health interventions such as the effect of tobacco control programs on populations.

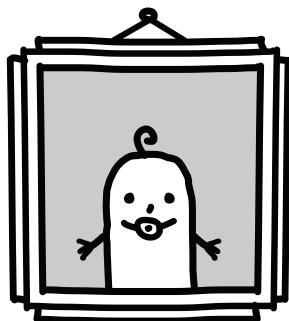
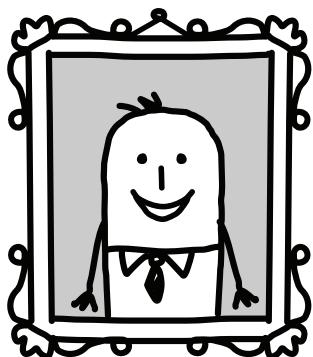
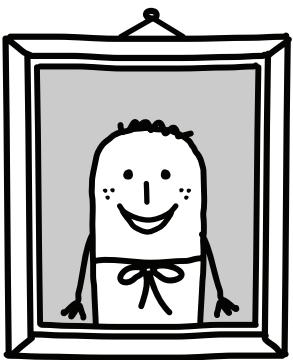
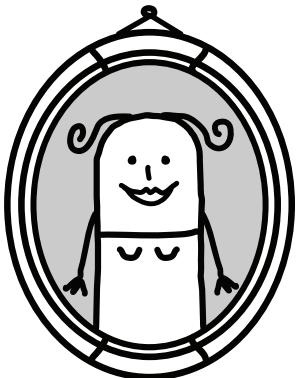
Population health researchers often use case studies, cohort studies (studying similar groups of people), or observation methods to do their research.

Examples of disciplines that conduct this kind of research

Performing Arts, Visual Arts, Sociology, Psychology, Law, Philosophy, Nutrition, Public and Population Health, Epidemiology

Research in action

The study, "Food insecurity among Inuit women in Igloolik, Nunavut: The role of climate change and multiple socio-economic stresses" looks at why women in Igloolik and other northern communities report higher levels of food insecurity (lack of food during certain times). Using a community participatory approach, this research will identify and describe why this is the case, while looking at socio-economic and environmental changes in the area.



Ethics in health research involving humans

CIHR-funded research that involves people must follow the ethical standards for research that are laid out in its *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans*. This policy states that research of this kind should be based on a fundamental moral commitment to protecting and advancing human welfare, knowledge, and understanding, while also examining cultural dynamics. The Policy contains Guiding Ethical Principles indicating that research should respect:

- free and informed consent;
- vulnerable persons;
- privacy and confidentiality; and
- justice and inclusiveness.

Ethical health research should always work to maximize benefits while minimizing harm.

How are health research applications evaluated and approved?

Applications for CIHR funding must be evaluated through a competitive process in order to receive a grant. CIHR uses three kinds of review in order to determine the quality and potential of a research application:

Peer review

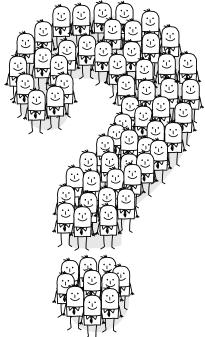
Peer review is an internationally-accepted benchmark for ensuring quality and excellence in scientific research. CIHR's peer reviewers, who are researchers from all over Canada and around the world, discuss and rate applications for research funding. Their final recommendations help CIHR make its funding decisions.

Merit review

Merit review is another type of peer review used by CIHR. This evaluation is done by a committee of researchers and knowledge-users that assesses both the scientific value and potential impact of a project that engages knowledge-users.

Community review

CIHR's Community Reviewer program permits members of the Canadian public interested in health and science to sit on a peer review panel. A Community Reviewer is assigned to a specific peer review panel. While community reviewers don't vote on the research proposals, they are asked to comment on both the plain-language summary of the research applications and on the peer review process itself.

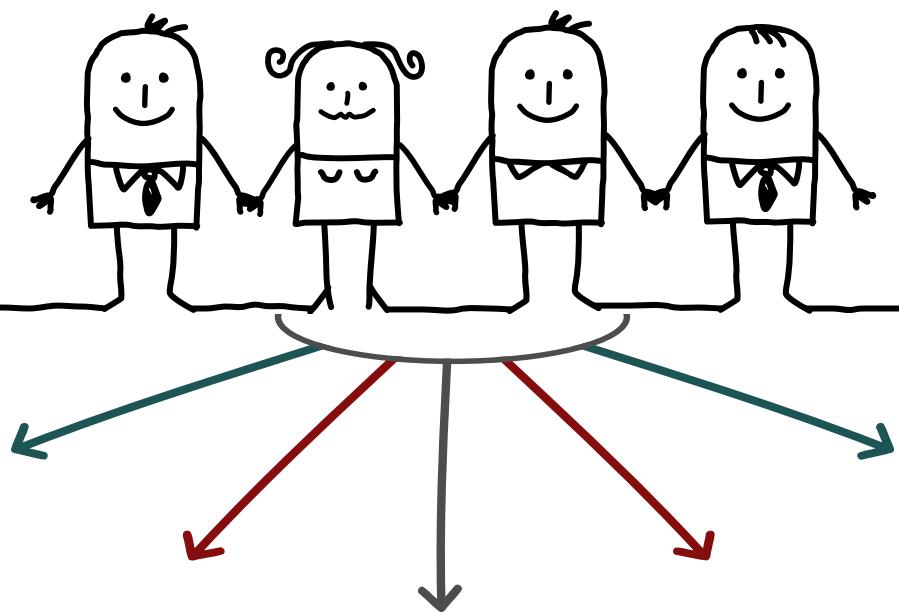


Did you know that non-researchers can be included in the research process?

Integrated knowledge translation (iKT), also known as collaborative and participatory (including community-based) research, includes patients, community organizations, and users of health services in the research process. Researchers and knowledge-users work as a team to make decisions throughout the research process. This conversation allows the researchers to learn important information

about the public's views, values, and experiences, ensuring that the research results are relevant and accessible to those people who will eventually use the knowledge that is gained. CIHR has developed several iKT funding programs that promote collaborative approaches which help to bring knowledge users and researchers together.

How we can work together

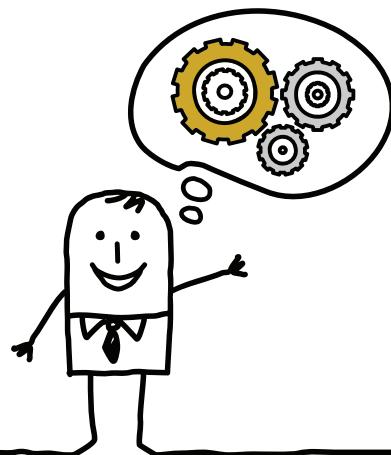


What is Citizen Engagement?

Since 2007, CIHR has worked hard to establish clear ways for interested Canadians to participate in our work and in health research. We have launched a “Citizen Engagement Initiative” to create opportunities for people to get involved in a variety of ways. These participants (or “citizens”) can range from interested representatives of the general public, consumers of health services, patients and caregivers, to advocates, voluntary health organizations, and even community representatives. When they come together during policy or program development, these interested parties can “engage” in the definition of issues, consideration of solutions, identification of priorities for action, and other activities.

In particular, CIHR’s Citizen Engagement Framework, which guides our organization in moving forward with approaches that will meaningfully involve citizens, highlights four focus areas for the participation of Canadians interested in health research. These are:

1. membership on CIHR’s boards and committees;
2. input on Corporate and Institute strategic plans, policies and guidelines;
3. research priority setting and integrated knowledge translation; and
4. knowledge dissemination and public outreach.



Why is it important?

CIHR believes that the public can have a role to play in shaping health research. Citizens are “**knowledge users**,” individuals or organizations who use, benefit from, or are otherwise affected by the results of research, even though they are not necessarily involved in its production. This means that they have an important role to play in the research cycle that goes beyond promoting health or participating in research. Citizens can comment on the usefulness of proposed research, help to identify missing elements, inform research priorities, and apply research findings.

Input from Canadians on decisions about research funding priorities is particularly important because:

- the production of high quality research requires more involvement from knowledge users, including the citizen community, to ensure that the research being funded is relevant to the needs and values of Canadians;

- those most affected and most familiar with the issues of health services should be involved in the research’s ongoing development; and
- feedback and involvement by the community and taxpayers is important for the accountability and the transparency of CIHR.

Health researchers and communities are recognizing the value of working together to study health issues that affect certain communities, such as homelessness, HIV/AIDS, and poverty. They are creating joint partnerships that lead to superior research, a better understanding of the affected community, and, ultimately, improved research results. Working together produces lasting solutions that benefit everyone, and citizens can play a critical role in this success.

How can I participate?

CIHR welcomes and encourages the involvement of everyone who has an interest in health research. In fact, we are working to provide more opportunities for citizens to participate in these four focus areas:

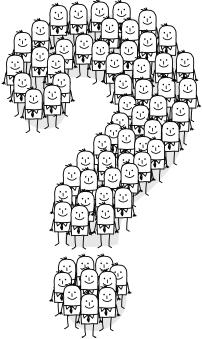
Membership on CIHR's Boards and Committees

This includes membership on CIHR advisory boards, standing committees, and ad-hoc committees related to new initiatives and programs. The citizen's perspective is important as it represents the views and values of Canadians potentially affected by health research and its application.

Input on Corporate and Institute Strategic Plans, Policies, and Guidelines

These opportunities include participating in the planning processes for the development of plans, priorities, policies, and guidelines for CIHR's Institutes. The inclusion of citizens in these processes allows CIHR to learn from their different knowledge, experience, and perspectives.





Did you know that CIHR is expected to hold 96 Café Scientifiques in 2010/2011 with topics as diverse as aging, arthritis, nutrition, mental health at the workplace, air pollution, the health consequences of urban cities, personalized medicine, wait times, infectious diseases, and the public's ability to participate in health research?

Research Priority Setting and Integrated Knowledge Translation

This focus area highlights the importance of creating and maintaining relationships between the public and CIHR's funded researchers. These relationships are beneficial to both groups because the feedback they generate can be used to decide if the proposed research is relevant, to see if anything is missing in the research, and to help decide on topics for future research. Being a part of the research process can empower communities and increase the scientific literacy of Canadians.

Knowledge Dissemination and Public Outreach

This area emphasizes communicating information about research results in a way that people can understand. CIHR has established several programs to do this, such as the **Café Scientifique**, a forum that promotes interaction between the public and experts in a given field at a café, restaurant, or pub. These venues provide more informal settings for researchers and the public to exchange ideas, information or questions.

Another example of knowledge dissemination and public outreach is the **Synapse Youth Connection Program**, a mentorship program that brings together researchers and Canadian youth so that they can exchange ideas and information about science and the life of a scientist.

Finally, CIHR is in the process of developing and implementing a social media policy. Platforms such as Facebook, Twitter and Youtube will now be used to engage with the public and share research results.



How can I learn more?

If you are interested in learning more about participating in CIHR's citizen engagement activities, the following list will give you some idea of how you can connect with us and help us make Canadians healthier.

Join an advisory board!

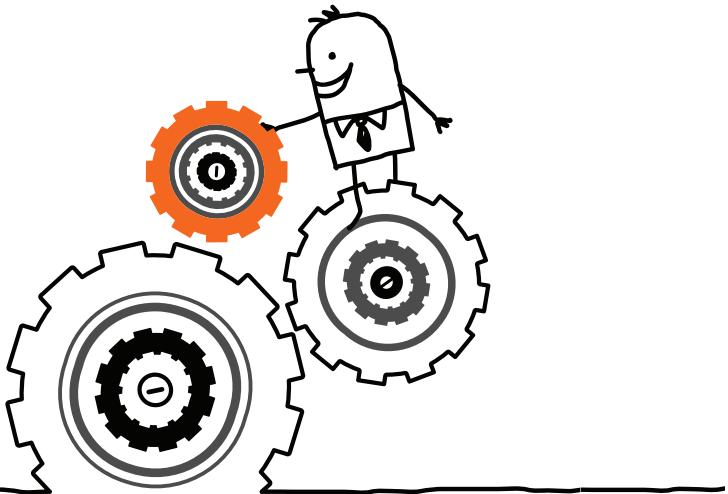
Be a part of setting the agenda for one of the 13 Institute's activities on an **Institute Advisory Board**. You can self-nominate and fill out an online application:
www.cihr-irsc.gc.ca/e/26486.html

Get involved!

Serve on **ad-hoc committees or advisory groups** for specific initiatives or guidance. From time to time, CIHR needs people to participate in these activities, and you may contact pce.pec@cihr-irsc.gc.ca to express your interest in learning more about such opportunities, when they arise.

Stay in touch!

CIHR's **newsletters** and **listservs** will often highlight opportunities to participate in our activities. The Partnerships newsletter (www.cihr-irsc.gc.ca/e/27335.html) is available online and contains information about upcoming events that may be of interest. Also, the individual Institutes have their own newsletters, which can be accessed through their respective Institute links (see the list of CIHR Institutes: www.cihr-irsc.gc.ca/e/9466.html). Some Institutes even allow you to sign up to be part of their regular distribution lists.



Follow us through social networking!

CIHR's Communications and Public Outreach Branch has created a "Health Research in Canada" Facebook page, a Facebook page dedicated to the Café Scientifique program, and a CIHR Twitter feed. Join up and receive the latest information about our activities and research.

Attend a Café!

Visit our website for information about upcoming Café Scientifiques:

www.cihr-irsc.gc.ca/e/34951.html

You can also visit the new Café Scientifique blog at www.cihrcafescientifique.com.

Become a Community Reviewer!

For more information on how to apply, please visit the following webpage:
www.cihr-irsc.gc.ca/e/31928.html

Learn more!

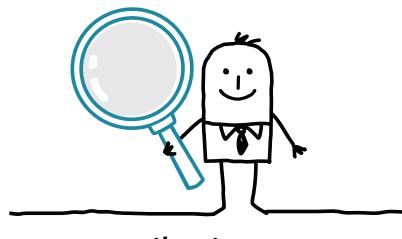
Finally, if you would like specific information about eligibility requirements for CIHR funding or on opportunities to participate at CIHR, contact the **Partnerships and Citizen Engagement Branch** at pce.pec@cihr-irsc.gc.ca.

Please contact us for more information on the various activities and find out how you can participate at CIHR. Even with a small commitment, Canadian citizens can affect research directions and ensure that funded studies are relevant to the needs of Canadians.

Acknowledgements

The Canadian Institutes of Health Research greatly acknowledges the contributions of several of our own engaged citizens in the development of this booklet. Thank you to Norma Drosdowech, Pam Sherwin, Cheryl Robertson, and Jim Bennett for generously reviewing drafts of the booklet and providing advice.

We would also like to thank Chris Lendrum (PhD) of Scriblerus Communications for editing, Claire Belanger for drafting and coordinating, and Erin Dunn for designing the booklet.



www.cihr-irsc.gc.ca