



CIHR IRSC

Canadian Institutes of
Health Research

Instituts de recherche
en santé du Canada

C.E. Framework

**CIHR's Framework
for Citizen Engagement**

**Partnerships and Citizen Engagement
Branch**

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

CIHR'S Framework for Citizen Engagement

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Executive Summary

The purpose of the Citizen Engagement (CE) Framework is to help guide the Canadian Institutes of Health Research (CIHR) in developing a cohesive and consistent approach to engaging citizens in its research processes, including participating in decision-making and informing strategic priorities. This engagement is meant to ensure that funded research *reflects* the needs and values of Canadians. CIHR has adopted the term 'citizen engagement' because the essence of "engagement" is far more active than traditionally passive public consultation in its recognition of the capacity of citizens to discuss and generate options independently. As the Organisation for Economic Co-Operation and Development (OECD) points out, CE "requires governments to *share* in agenda-setting and to ensure that policy proposals *generated jointly* will be taken into account in reaching a final decision."¹

CIHR recognizes the value of moving forward with the establishment of a CE Framework as it will position CIHR to improve its access to valuable untapped public values, perspectives and experience. The objectives of the CE Framework are informed by the need to engage Canadians in CIHR's mandate in order to establish trust and legitimacy, and the desire to create a supportive internal environment to establish the common practice of CE within CIHR and its Institutes. For CIHR, CE is the *meaningful involvement* of citizens in its activities, from agenda-setting and planning to decision-making, implementation and review. The concept of CE is receiving greater attention both internationally and nationally as funding agencies such as Australia's National Health and Medical Research Council, the United Kingdom's Medical Research Council and the National Institutes of Health in the United States have developed programs for CE and are leading in the development of CE best practices for health funders. CIHR is currently lagging behind; however, it can now demonstrate leadership in this important area. In Canada, both the Public Health Agency of Canada and Health Canada have implemented frameworks and programs that support CE activities.

CIHR's Framework was developed based on a situational analysis of CE activities and programs in selected health organizations in Canada and abroad (research funders and regional health authorities), and on an internal survey of activities within CIHR, Health Canada and the Public Health Agency of Canada. It outlines the context within which CE operates by defining the concept and providing an overview of CE activities underway within CIHR and other agencies; it

¹ Quoted in "Primer on Public Involvement." Prepared by the Canadian Policy Research Networks for the Health Council of Canada (July 2006). Emphasis added.
http://www.healthcouncilcanada.ca/docs/papers/2006/PublicInvolvementPrimer_EN.pdf.

also highlights the general principles underlying the Framework, its objectives, implementation and how it will be evaluated.

The focus of CIHR's Framework is the effective engagement of citizens at the higher levels of Health Canada's public involvement continuum, which consist of collaborative decision-making and partnering activities. The internal survey of CIHR's Institutes and Branches revealed that, while CIHR has already engaged citizens in a variety of ways, engagement has been clustered around Levels 1-3 of Health Canada's spectrum, which range from informing and gathering information to education and time-limited consultation exercises. Levels 4 and 5 of Health Canada's continuum promote longer-term engagement and partnering, such as membership on standing committees and advisory boards. This Framework introduces an organizational strategy to build capacity within CIHR, within the public, and within the research community to increase the number of activities undertaken within the higher levels of engagement.

The CIHR Citizen Engagement Framework is underpinned by a value statement that articulates the importance of citizen engagement for the organization:

CIHR values the engagement of citizens in governance, research priority setting, developing its strategic plans and strategic directions and as an effective means of improving the relevance and translation of research into practice and policy. Ultimately, this will contribute to improving citizens' quality of life, more effective health services and products and a strengthened Canadian health-care system.

The Framework is also guided by five principles:

- Working with citizens will **add value** to the program or project.
- **Mutual learning/understanding** will build trust and credibility.
- **Openness** will enhance transparency and accountability.
- CIHR will be **inclusive** in its approach to citizen engagement.
- Citizens will be **supported** to ensure their full participation.

The Framework focuses on four key areas where citizens can inform CIHR's work, and provides recommendations for action in each area. The four areas are:

1. Membership roles on boards and committees;
2. Informing strategic plans, priorities, policies and guidelines;
3. Research priority setting/integrated knowledge translation; and
4. Knowledge dissemination and public outreach.

While implementation of the CE Framework is the responsibility of all Institutes and Branches of CIHR, the Partnerships and Citizen Engagement (PCE) Branch will exercise a coordination and oversight role, facilitating CE activities and providing guidance to all areas of CIHR. As part of this facilitation and guidance, the branch will develop a Citizen Engagement Handbook and Resource Centre. This tailored handbook will outline the methods, processes and checklists that can be used by CIHR staff members for specific levels of CE.

CIHR will be setting standards and demonstrating leadership in this area through performance indicators and evaluation. Evaluation methods for CE programs will be included in the Handbook, similar to Health Canada's public involvement planning guide, which features critical questions to consider in the development process of an overall CE plan so that objectives can be effectively measured.²

Through the implementation of this Framework and initiative, CIHR has the opportunity to be a leader in CE in Canada. By building on its existing strengths and taking realistic steps, CIHR will seize an opportunity to move forward with CE to fulfill its place in the global arena and to ensure that funded research connects with Canadians to improve their health and strengthen the Canadian health system. The vehicles already exist within CIHR, but a new way of thinking is needed to ensure inclusiveness and fair representation of citizens in CIHR's decision-making structures and in its research programs.

² "Public Involvement Plan Template." Developed by Health Canada (Healthy Environments and Consumer Safety Branch).

Section One: Introduction

The mandate of the Canadian Institutes of Health Research (CIHR) requires that it not only create new knowledge, but translate that knowledge into improved health, a strengthened health-care system and new health products and services.

The CIHR Knowledge Translation (KT) Portfolio has identified citizen engagement (CE) as playing a key role in achieving the KT imperative of CIHR's mandate and, on behalf of CIHR, is moving forward in realizing a more systematic, ongoing integration of citizens' input in research priority setting, governance and in funding programs and tools. The Act (Bill c-13) that created CIHR expressly directs the organization to achieve its mandate by encouraging interdisciplinary, integrative health research which includes engaging voluntary organizations, the private sector and others, in or outside Canada, with complementary research interests. It also requires CIHR to ensure transparency and accountability to Canadians for the investment of the Government of Canada in health research.³

CIHR has developed this CE Framework as a means to engage citizens effectively and systematically in its work. It has adopted the term **citizen engagement** because the essence of "engagement" is far more active than traditionally passive public "consultation", which may not always recognize the capacity of citizens to discuss issues effectively or generate options independently.

At the heart of the concept of CE lies a desire on the part of the organization to align its priorities with those of citizens and a recognition that CE requires more active involvement of citizens over a significant period of time, ideally through substantive, deliberative, in-depth consideration of values and principles. CE activities give us the opportunity to be open and transparent in our processes, and accountable for our decisions. CE processes, by definition, wield their accountability through the formation of strong relationships that are built upon trust, openness and responsiveness between citizens and government or public institutions. In other words, through the design of CE processes that "encompass dialogue and issue recommendations based on a real array of choices ...[through] open-ended yet structured public dialogue"⁴, the public contributes to decisions in a transparent, publicly accountable manner. Instead of holding the threat of sanction, CE mitigates the need for sanction and its associated

³ CIHR Act (Bill c-13), Objective 4D and 4I

⁴ Mendelsohn, M. and John McLean. "SUFA's double vision: Citizen engagement and intergovernmental collaboration." Policy Options (April 2000).

threats of public exposure and negative publicity. As such, a strong culture of CE renders the sanction tool less pivotal.⁵

CIHR's CE Framework will establish guidelines for implementing a more systematic approach to consulting and engaging citizens in the work of CIHR, such as in assessing the merit and relevance of research applications, developing strategic plans, setting research priorities and strengthening membership on CIHR governance structures.

The following conceptual model (Figure 1) represents the value of sustained CE for CIHR:

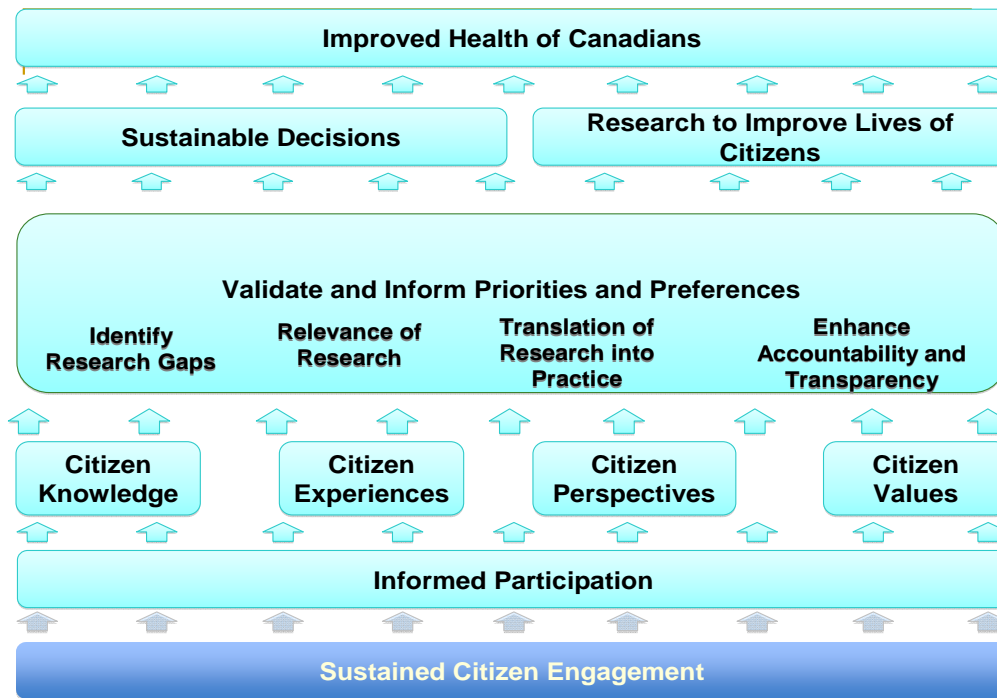


Fig. 1: The Benefits of Sustained Citizen Engagement

Figure 1 positions CE for CIHR and provokes thinking on the benefits and value of sustained engagement. The model is meant to be read from bottom to top: Informed participation leads to gathering citizen knowledge, experiences, perspectives and values. These inputs are used to validate and inform priorities and preferences, which will then contribute to improving the relevance of research, the translation of research into practice, the identification of research gaps, and CIHR's accountability and transparency. The long-term outcomes are more sustainable decisions and research to improve the lives of citizens.

⁵ Abelson, J and F.P. Gauvin. "Engaging Citizens: One Route to Health Care Accountability." Healthcare Accountability Papers, Canadian Policy Research Networks (April 2004).

1.1 Developing the Citizen Engagement Framework

CIHR's CE Framework was developed through two main activities: a situational analysis of CE activities and programs from select research agencies in Canada (and abroad) and from regional health authorities within Canada; and an internal survey of Institutes and relevant Branches within CIHR, as well as Health Canada (HC) and the Public Health Agency of Canada (PHAC). Activities were analyzed in the context of Health Canada's five levels of public involvement, which include: 1) inform and educate, 2) gather information, 3) discuss, 4) engage, and, at the highest level of involvement, 5) partner. (Please see the Figure 2 below; further information about this continuum can be found in Appendix 2.)

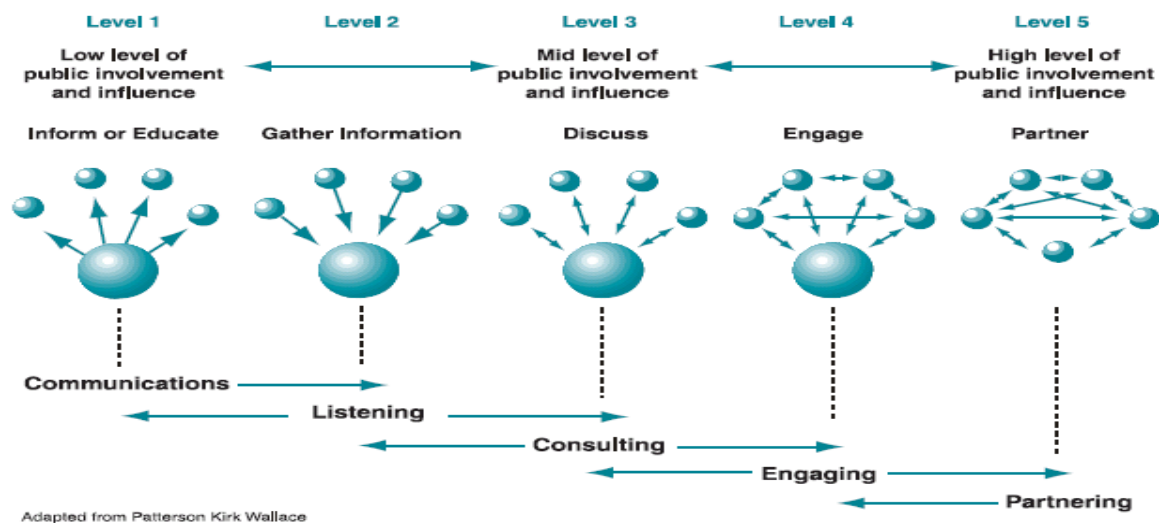


Fig. 2: The Five Levels of Public Involvement

To stimulate deeper discussion and gain more feedback about CE in the CIHR context, a consensus-building workshop with relevant staff from CIHR Institutes and Branches was held in May 2008. A CIHR Citizen Engagement Working Group, struck in 2007, with representation from staff across the organization (including Communications, Research, Ethics, Knowledge Translation and Institutes) has also provided guidance and advice on the development of the Framework and the overall organizational strategy. (Results from these activities can be found in section 2.2.2, below.)

1.2 What the CIHR Citizen Engagement Framework will do

The focus of CIHR's framework is the effective engagement of citizens at the higher levels of Health Canada's public involvement continuum, as described in Appendix 2, which support

collaborative decision-making and partnering. Currently, according to the internal survey (described in more detail in Section 2), 80% of CIHR's CE activities are clustered around levels 1-3 of the continuum, with only 20% of the captured activities promoting longer-term engagement and partnering.

The Framework establishes guidelines and standards for evaluating gaps in our activities in which we would like to include the voices of citizens. A Handbook tailored to CIHR's programs and decision-making committees will also be created to accompany this Framework. It will outline the methods, processes and checklists that can be used by CIHR staff members for specific levels of CE. Staff professional development will be critical in order to ensure that CE processes are managed well, but also to avoid situations that have occurred in other organizations, where citizens take part in decision-making meetings and/or consultations but are not provided with the results of these exercises or how their input was used. This simple oversight contributes to public distrust of and cynicism about these exercises.

The Framework builds on the considerable, although variable, CE activities already underway at CIHR, including:

- Institute Advisory Boards;
- The Knowledge Exchange Task Force (KETF), an initiative of CIHR's Institute of Musculoskeletal Health and Arthritis. Created in 2004, the KETF is an innovative communication pathway linking researchers and key stakeholders, including clinicians and patients. Members become 'Research Ambassadors' in the dissemination of research findings to their respective organizations and communities.
- Regional Seniors Workshops conducted by CIHR's Institute of Aging in 2004, which involved extensive consultations with senior citizens for the purpose of informing future research priorities.
- The Community Reviewer program. Community Reviewers participate on peer review panels and are asked to comment on the extent to which lay abstracts are well explained and in language that is clear to members of the general public.
- The community-based research program, part of CIHR's HIV/AIDS Research Initiative. This program includes equal representation from experts and community representatives, including patients and community organizations, on its merit review committee.

Further examples of CIHR CE activities can be found in Appendix 1.

As CIHR implements its CE Framework, it will also incorporate other initiatives and promising practices, both within the Government of Canada's Health Portfolio and internationally. For instance, PHAC is undergoing a similar exercise as it implements its own framework, entitled *Public Involvement Framework: Involving the public in public health decision-making*. HC is currently updating its *Policy Toolkit for Public Involvement in Decision Making* and is undergoing some restructuring of its oversight and consultation services to its branches. Discussion and collaboration will continue as these initiatives within the Health Portfolio evolve.

A relevant and very timely activity being spearheaded by the Global Science Forum of the Organisation for Economic Co-Operation and Development (OECD) involves a study that will examine consultation practices in order to develop more effective dialogue between science and society. The related workshop brought together policy makers, science advisors and representatives of research institutions to exchange and evaluate the experiences of various countries. The reflection helped to bring science policy makers and the general public closer together, and to influence the practice of democracy. It is important to note, for our purposes, that the underlying principle for this activity is that true dialogue (that goes beyond traditional science education) is necessary as citizens refuse to be passive recipients of new products and technologies, however innovative they may be.⁶

This Framework is divided into specific sections. Section 2 sets out the context within which CE operates by defining the concept and providing an overview of CE in other research funding agencies, within CIHR, and within the Government of Canada's Health Portfolio. Section 3 outlines the Framework itself, including the general principles underlying it, its objectives, implementation and how it will be evaluated. Section 4 provides a brief conclusion, while Appendices 1-6 are included to provide the reader with relevant background material and survey results.

“Public involvement complements scientific research and evidence, and directs new research.”

- Dr. Frank Plummer, Scientific Director General, Public Health Agency of Canada, National Microbiology Laboratory⁷

⁶ “Improving the Dialogue with Society on Scientific Issues.” Workshop Draft Annotated Agenda, Organisation for Economic Co-Operation and Development Global Science Forum (July 21, 2008).

⁷ Interview to inform the Public Health Agency of Canada's “Public Involvement Framework: Involving the Public in Public Health Decision-Making.” *DRAFT* March 2008.

Section Two: Setting the Context

2.1 Defining Citizen Engagement

As defined by the OECD, CE “requires governments to *share* in agenda-setting and to ensure that policy proposals *generated jointly* will be taken into account in reaching a final decision.”⁸ CE involves proactive mechanisms for dialogue and shared agenda-setting in decisions that affect Canadians as health consumers and citizens. This engagement means sustained and active involvement over a long period of time through processes that promote mutual learning, shared decision-making and (possibly) ongoing partnership and collaboration.

For CIHR, citizen engagement is the meaningful involvement of individual citizens in policy or program development, from agenda-setting and planning to decision-making, implementation and review. It requires two-way communication that is interactive and iterative with an aim to share decision-making power and responsibility for those decisions. This requires bringing together a diverse group of citizens that includes the broader public, not just the usual stakeholders for ongoing dialogue, deliberation and collaboration in informing CIHR’s work.

While CE is a two-way exchange, it often begins with a one-way dissemination. CIHR, through its Institutes and its Marketing and Communications Branch, is now devoting more resources than ever before to improve the health science literacy of targeted populations. These activities are generating interest from members of the general public, who then want other opportunities to support CIHR’s work.

One of the means available to achieve this goal is to strengthen ‘integrated knowledge translation’ as a core element of the research process. Integrated KT (iKT) is a different way of doing research: it brings together researchers and research *users* to shape the research process (starting with collaboration to set the research questions, decide on the methodology, get involved in data collection and tools development, interpret the findings and help disseminate the research results). This approach, also known by such terms as collaborative research, action-oriented research, and co-production of knowledge, should produce research findings that are more likely be relevant to and used by the end users. For a complete glossary of terms and definitions related to CE, please refer to Appendix 6.

⁸ Quoted in “Primer on Public Involvement.” Prepared by the Canadian Policy Research Networks for the Health Council of Canada (July 2006). Emphasis added.
http://www.healthcouncilcanada.ca/docs/papers/2006/PublicInvolvementPrimer_EN.pdf.

The activities that are Institute-driven, such as strategic initiatives, bring stakeholders together as “knowledge users” in consensus conference forums that ultimately shape the research questions. This inclusion of knowledge users ensures that the initiative’s directions reflect the needs of these important constituencies.

Broadly speaking, CIHR stakeholders are made up of health charities and other not-for-profit organizations, federal, provincial and territorial governments and agencies, universities and academic health science centres, health professionals, health organizations, other research agencies, industry, the public, and international organizations. The internal scan of involvement activities demonstrated that some or all of these stakeholders take part in setting research priorities and plans, strategic directions, knowledge translation activities and in decision-making bodies of the Institutes and corporate governance committees at CIHR.

2.1.1 Citizens: A Typology for CIHR

The term “citizen” includes interested representatives of the general public, consumers of health services, patients, caregivers, advocates and representatives from affected community and voluntary health organizations. However, not all citizens have the same interests in participating in CIHR’s work and not all have the same contributions to make. CIHR has, therefore, adopted a typology of citizens (see Figure 3, below) to determine how and when to engage specific individuals or groups most appropriately, based on what their likely contributions will be.

This typology represents the range of interested citizens and will be used in the planning process to help identify who the relevant audiences are that need to be involved. The typology does not include individuals or groups who are considered special or technical experts or health professionals as CIHR is focusing on accessing the knowledge and experiences that reflect the public’s perspectives on values and priorities.

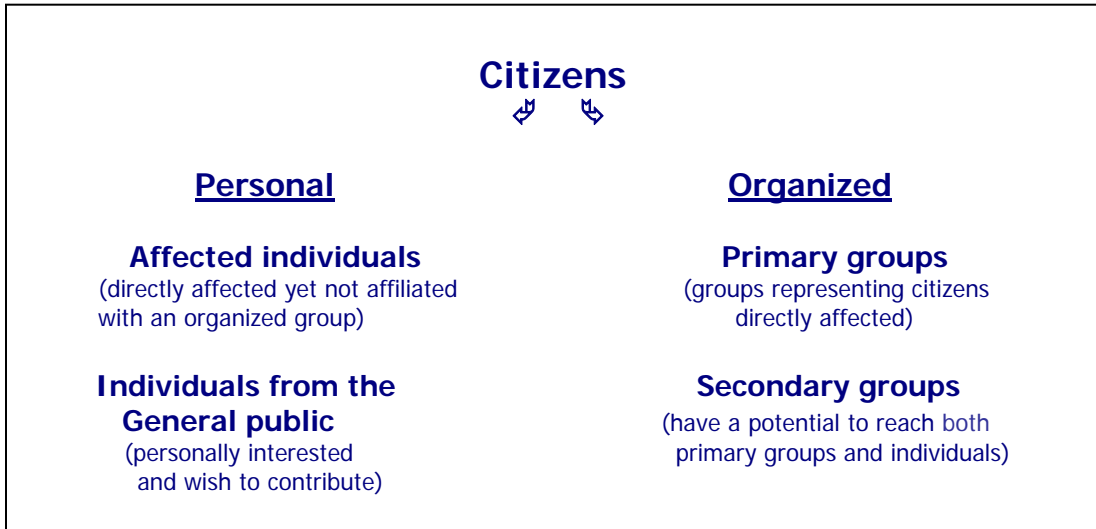


Figure 3: Citizens Typology⁹

Citizens: Citizens comprise both individuals and/or groups who may be affected by, able to affect, have a special interest in or are involved as either tax payers, consumers of health services, patients, professional caregivers, advocates, representatives of an affected community or as representatives of voluntary health organizations. It is clear that some overlap between groups and individuals can occur; they are not mutually exclusive.

Affected Individuals: These individuals are personally affected by CIHR-funded research and can speak to their own experiences, perspectives and ideas rather than represent the viewpoints of any organization with which they may or may not be affiliated. It is important to make this distinction as they are being asked to participate due to the fact that they are not affiliated with or directly represented by a group or organization. Their input will be sought to uncover their personal values, knowledge and experience.

Examples of affected individuals can be patients, consumers of health services, a member of an identifiable population (example: an aboriginal person, a youth, an elderly person) and/or individuals affected by specific diseases. Other affected individuals would also include those who have relationships with these individuals, such as family members or caregivers.

⁹ Adapted from the PHAC "Public Involvement Framework: Involving the Public in Public Health Decision-Making." *DRAFT* March 2008.

Individuals from the General Public: Individuals from the general public may become involved through their role as tax payers and, therefore, supporters of publicly funded health research. They may be genuinely interested in health research as a means of maintaining or improving their health, as well as in expanding their personal knowledge.

Working with both affected individuals and members of the general public offers an opportunity to hear directly from citizens and thus improve CIHR's ability to listen, understand and value the views, concerns and experiences of citizens.

Primary Groups: These groups consist of organizations or associations with the potential to contribute and affect decisions about current or future research priorities or with affiliated members who *are directly affected* and can contribute to shaping future health research directions. Tables 1 and 2 in Appendix 1 provide examples of how CIHR and its Institutes have engaged representatives of relevant voluntary health organizations in meetings or conferences for the development of strategic initiatives and for knowledge translation activities.

Secondary Groups: These groups are comprised of organizations or associations with the potential to reach other groups and *directly affected* citizens, or to contribute and affect future health research directions. Secondary groups in this example may include voluntary health organizations with mandates that involve education programs or public health services. Some examples include: local, federal or provincial Councils on Aging, community support organizations, Canadian Healthcare Association, Canadian Public Health Association.

Both primary groups and secondary groups are key stakeholder groups who represent the interests of patients, consumers, advocates, donors and volunteers. As such, they can help identify citizens who have a desire to contribute to CIHR's citizen engagement activities. (More discussion of this valuable role is explored in Section 3.)

2.2 A Review of Citizen Engagement Activities

2.2.1 A review of citizen engagement in research funding organizations in Canada and abroad

To gain a better understanding of how other research funding organizations have incorporated CE into their operations, CIHR commissioned a literature review¹⁰ of CE activities and programs used by research funding agencies in Canada and abroad. Figure 4, below, provides a summary of activities and programs offered by the international organizations examined in the review.

Figure 4: Citizen Engagement Activities of Selected International Organizations

Purpose of engagement	Methods of engagement
<p>Dissemination of research findings and public outreach</p> <ul style="list-style-type: none"> - Medical Research Council (MRC) (UK) - National Institute for Health & Clinical Excellence (NICE) (UK) - National Health and Medical Research Council (NHMRC) (Australia) - National Institutes of Health (NIH) (US) 	<ol style="list-style-type: none"> 1) Annual Meeting open to the public: MRC 2) Public engagement opportunities on website: NICE; NIH; NHMRC; MRC 3) Resource guides to help public engage with the organization: NHMRC 4) Public presentations: NIH 5) E-mail distribution lists: NIH 6) Town hall meetings: NIH
<p>Governance accountability</p> <ul style="list-style-type: none"> - MRC - NICE - NHMRC - NIH 	<ol style="list-style-type: none"> 1) Lay members on committees: NHMRC;MRC; NICE 2) Governance level advisory body: Public Panel (MRC); Citizen's Council (NICE) Director's Council of Public Representatives (NIH);Advisory Committee on Consumer and Community Engagement (NHMRC) 3) Public participation on peer review: MRC
<p>Strategic planning</p> <ul style="list-style-type: none"> - MRC - NICE - NHMRC - NIH 	<ol style="list-style-type: none"> 1) Grant support provided to researchers to consult and engage with public: MRC; NHMRC 2) Public input sought for identification of research priorities: NICE 3) Consultation exercises for strategic plans and requests for submissions on policy guidelines: MRC; NICE; NHMRC; NICE
<p>Identification of Research priorities and participation in research studies</p> <ul style="list-style-type: none"> - MRC - NICE - NHMRC - NIH 	<ol style="list-style-type: none"> 1) Implemented Organizational Framework and Policy for Consumer, Community Participation: NHMRC; NICE 2) Grant support for researchers engaging and communicating with public: MRC, NHMRC 3) Consultations (both online and face to face): NHMRC; MRC; NICE; NIH

¹⁰ "A Review of the Public Engagement Activities of Select Research Agencies and Health Charities." Prepared by Roger Chafe, PhD., for CIHR (January 2008).

The international examples of CE provide a comprehensive range of opportunities for both involving citizens and disseminating research findings. The activities of the surveyed organizations engage citizens on a variety of levels. The websites of all the international agencies identify events and opportunities open to the public and include information for signing up for email distribution lists. They post reports of past consultation exercises, support documents, and contact information of dedicated engagement staff. In particular, the Australian National Health and Medical Research Council's model framework is comprehensive: it provides guidance on developing CE for a variety of users, including research funding bodies, research institutions, clinical and basic scientists, health consumers and researchers.

The scan of international organizations revealed methods and best practices that CIHR could use in expanding its own activities.¹¹ In the course of researching the above programs, interviews were conducted with key staff at the UK Medical Research Council and Australia's National Health and Medical Research Council (NHMRC). The Executive Director of the Health Evidence and Advice Unit from NHMRC, Mrs. Cathy Clutton, has shared information and guidance. Mrs. Clutton visited CIHR in summer 2008 to meet with the PCE Branch and to give a presentation to over 40 interested CIHR staff. Invitations were extended to other members of the Health Portfolio, resulting in the emergence of a collaborative relationship between NHMRC, CIHR, Health Canada and the Public Health Agency of Canada.

In the United States, newly elected President Barak Obama issued a memorandum on his second day of office: "Public engagement enhances the Government's effectiveness and improves the quality of its decisions. Knowledge is widely dispersed in society, and public officials benefit from having access to that dispersed knowledge. Executive departments and agencies should offer Americans increased opportunities to participate in policymaking and to provide their Government with the benefits of their collective expertise and information. Executive departments and agencies should also solicit public input on how we can increase and improve opportunities for public participation in Government."¹² CIHR will embrace opportunities to learn from and work with the National Institutes of Health (NIH) as their CE activities evolve under this direction.

Here at home, Canadian health organizations are also finding opportunities to engage citizens in their work. The Canadian research funding agencies examined in the CIHR-funded literature

¹¹ "Towards the Development of a CIHR Citizen Engagement Framework and Strategy." CIHR Partnerships & Citizen Engagement Branch (May 2008).

¹² "Memorandum for the Heads of Executive Departments and Agencies." Issued by President Barack Obama (January 21, 2009).

review (including the Social Sciences and Humanities Research Council, the Natural Sciences Engineering Research Council and the Canadian Health Services Research Foundation) are interested in expanding the scope, reach and impact of their public engagement activities. Canadian research funding agencies want to support more interactive engagement between the public and themselves, and between research teams and the communities they research. Furthermore, there is a desire by these organizations to communicate research findings to the public in a more effective manner and to develop tools that will assist their organizations to effectively engage the public. A recent review of articles on Canadian public participation in health-care governance found that most attempts in Canada to involve the public in health care have occurred at the regional and program levels. Although these are the levels at which most public engagement activities occur, few regional health authorities (RHAs) have sustained public engagement activities beyond having community members on their boards of trustees. Part of the reason for this lack of sustained activities may be due to confusion around to whom the RHAs are ultimately accountable, the public or the provincial Minister of Health.¹³ It may also relate to resource constraints. Still, many RHAs have tried at times to engage the public through various methods, including community advisory boards, public members on committees, surveys, focus groups, interviews and town hall meetings.¹⁴

The federal government's Science and Technology Strategy sets out recommendations for the three granting councils to enhance accountability and value for money. As part of these recommendations, CIHR (along with NSERC and SSHRC) is expected to seek out more business and community representation for its governing bodies to ensure that our investments reflect Canada's broad economic and national interests. Including this diverse representation on our governing bodies will improve our "responsiveness and accountability to the government, research community, and wider public."¹⁵

Despite the admirable examples of CE described in this section, there is a lack of high-quality evidence of the effectiveness of CE, due to a lack of formal evaluation, both in Canada and abroad. The evaluation gap for implemented programs has been documented in various studies, including one by the OECD (2005)¹⁶. Furthermore, Julia Abelson (2007)¹⁷ points to the need for

¹³ Chafe, R., Neville, D., Rathwell, T., Deber, R., Kenny, N., Nestman, L., et al. "Annotated Bibliography of Canadian Public Involvement in Health Care Governance (1980 - 2007)." Prepared as a component of a specialized study. http://schoolofhealthadministration.dal.ca/Files/basket_Annotated_Bibliography_October_10%2C_2007.pdf

¹⁴ "A Review of the Public Engagement Activities of Select Research Agencies and Health Charities." Prepared by Roger Chafe, PhD., for CIHR (January 2008).

¹⁵ [Mobilizing Science and Technology to Canada's Advantage](#). Federal Government of Canada (2007): p. 66.

¹⁶ [Evaluating Public Participation in Policy Making](#). Organisation for Economic Cooperation and Development (2005).

¹⁷ Abelson, Julia, et al. "Examining the role of context in the implementation of a deliberative public participation experiment: Results from a Canadian comparative study." *Social Science & Medicine* (2007).

rigorous public participation evaluation research. Efforts to use research evidence to inform public involvement decisions are not systematically integrated into public involvement strategies and implementation.

2.2.2 A review of CIHR's Institutes and Branches

In preparing this Framework, CIHR conducted an internal survey, asking its Institutes and Branches to categorize their CE activities according to Health Canada's five levels of public involvement (see Appendix 1). The survey revealed that almost two-thirds of those interviewed (11 of 17) thought that a CE Framework for CIHR is 'very important', while 6 rated it as 'somewhat' or 'possibly' important; no one indicated that this was 'not important'. Indeed, the survey revealed that CIHR's Institutes and Branches have already demonstrated admirable leadership and expertise in their initiatives and activities in the following categories (see also Table 1, Appendix 1):

1. **Governance:** i.e., involvement with decision-making bodies (e.g. members of standing committees, membership in peer review panels, task forces and working groups of the Institute Advisory Boards);
2. **Collaborations** with pre-existing or new partners, such as voluntary health organizations, non-governmental organizations (NGOs), and science/youth outreach non-profit organizations.
3. **Consultations for specific contexts:** e.g. the development of strategic plans and priority setting, the identification of research questions for specific initiatives and subsequent funding opportunities, involvement in the development of policies and guidelines and participation in activities relating to knowledge translation, including integrated KT funding programs (such as Partnerships for Health System Improvement, Knowledge to Action and Synthesis Grants) and community-based research programs.

Analysis of our internal survey and its resulting inventory reveals that most activities involve consultations with targeted audiences described in the Citizen typology (Section 2.1.1) representing citizens who are personally affected (such as patients/health consumers, general public) and groups (both primary and secondary), such as voluntary sector organizations whose stakeholders are volunteers, patients, advocates and members of the public. Some of these targeted audiences are also 'engaged' as members of permanent committees, task groups and/or community-based research peer and merit review committees, or with networks for clinical trials. Most of these consultations are undertaken for strategic planning or to inform research initiatives.

While it is not the primary focus of this Framework, the catalogue of activities found in Table 2 in Appendix 1 provides an overview of those designed principally to communicate information to targeted audiences within the scope of public outreach. Many of these communication/outreach activities involve the use of newsletters, reports, web posts and/or media interviews and public speaking engagements. These activities can also include organizing meetings for multiple stakeholders, including the public, and are often designed to promote science literacy within various target audiences or to educate the general public.

2.2.3 A review of the Government of Canada’s Health Portfolio

As noted in the Introduction, PHAC and HC are in the process of implementing or restructuring their centres of expertise for public involvement. The range of resources currently being offered includes training courses, which are also available to CIHR employees (see Appendix 3 for an example), and learning opportunities within a HC public involvement experts network. The resources, including policies and frameworks, offer CIHR some relevant examples that can be tailored to CIHR’s culture and aims. For example, the Health Products and Food Branch has developed a Policy on Public Input for the Review of Regulated Products (2007). The policy defines the various types of input that are considered, for instance, in the safety and effectiveness of a regulated product. It sets out parameters and methods for ensuring that public views are considered in dialogues pertaining to complex issues involving scientific or technical information while balancing societal values, habits and traditions that may influence the safe use and effectiveness of a product. This policy is of particular relevance to CIHR as it offers criteria and guidance for involving the public in decision making related to scientific topics. Health Canada has implemented a web portal to direct the public to opportunities for participation in consultations, primarily for regulatory policies. The website provides information about the type of activity, a listing of target audiences (including general public, health professionals, industry, patient groups and community groups), the timeframe, location and details for registration.¹⁸

Other departments and agencies within the Government of Canada are also developing opportunities for engagement. For example, the Consulting with Canadians website¹⁹ offers a range of opportunities to participate in consultations initiated by a number of federal

¹⁸ “Medeffect Canada – Consultations.” Part of Health Canada’s website. Additional information is available here: <http://hc-sc.gc.ca/dhp-mps/medeff/consultation/index-eng.php>

¹⁹ “Consulting with Canadians.” A website of the Government of Canada. Additional information is available here: <http://www.consultingcanadians.gc.ca/cpcPubHome.jsp?lang=en>

departments. The Canada School of the Public Service also offers a course entitled “Public Consultations and Citizen Engagement”, which features skill development and effective techniques. Another new course for managers, entitled “Engaging Citizens, Partners and Stakeholders”,²⁰ is being offered as well, designed to help managers employed in the public service re-think engagement in the context of public interest, identify and understand the players in complex systems, achieve results through engagement and offer new ideas on engagement in civil society.

A very relevant and compelling argument in favour of citizen engagement appeared recently (2008) in the Canadian Medical Association Journal that addresses the need for public engagement in health care priority-setting.²¹ The authors respond to some prevalent arguments against greater public engagement and address these in their Table 1, which has been copied here in its original form from their article:

Table 1: Perceived barriers to public engagement in setting health care priorities	
Barrier	Response
Members of the public are not objective — they have an inherent personal bias and cannot represent interests other than their own	<ul style="list-style-type: none"> • This concern is applicable to all participants in priority setting⁶ • Members of the public are not expected to be objective scientific experts, but rather to participate in value-based deliberations²
Members of the public are not well enough informed to contribute to priority setting in a meaningful way ⁷	<ul style="list-style-type: none"> • Members of the public are experts in the lived experience of using the health care system and offer insight into the values and beliefs of the public at large
Most members of the public do not identify themselves as appropriate people to be engaged in priority setting ⁸	<ul style="list-style-type: none"> • Some members of the public are interested in being involved under appropriate circumstances⁹
Members of the public involved in priority setting will not be representative of the public	<ul style="list-style-type: none"> • Fair-minded people from all relevant constituencies need to be at the table, participate in deliberations and articulate relevant values. They need not represent all sectors of their communities²
Involving members of the public will make decision-making too protracted ¹⁰	<ul style="list-style-type: none"> • Some methods of public involvement (e.g., appointing public members to decision-making committees) will have no impact on the time taken¹¹ • If the necessary time is not taken to obtain genuine input from stakeholders, more time may be spent later addressing objections to the process and outcome¹¹

These responses to the “perceived barriers to public engagement” are important points to keep in mind as CIHR moves forward with its own CE activities.

²⁰ “Engaging Citizens, Partners and Stakeholders.” Part of the Canada School of Public Service Catalogue. Additional information is available here: <http://www.cspc-efpc.gc.ca/cat/det-eng.asp?course=Z119>

²¹ Bruni RA, Laupacis A, Martin DK; Priority Setting in Health Care Research Group. “Public engagement in setting priorities in health care.” Canadian Medical Association Journal (2008).

Section Three: The CIHR Citizen Engagement Framework

3.1 Introduction

CIHR's CE Framework establishes guidelines for standard practices whereby citizens can be engaged at the higher levels of the involvement spectrum, as defined in Health Canada's public involvement continuum. These practices primarily revolve around Institute and corporate strategic plans, research priority setting and governance structures. A collaborative decision-making model involving citizens ensures that CIHR's research agenda is relevant to them.

The CE Framework promotes mutual learning and understanding in order to seek a better alignment between CIHR and the values and perspectives of Canadians. This engagement will lead to improving the relevance and translation of research into practice to improve citizens' quality of life. It will also help to validate the intent and importance of proposed research projects and ensure that they are well explained. Lastly, engaging citizens will enable CIHR to better communicate the merits of health research by helping citizens understand the value of CIHR's investments.

3.2 CIHR Citizen Engagement Value Statement

The following value statement is intended to promote an overall understanding of the role and importance of citizen engagement for CIHR:

CIHR values the engagement of citizens in governance, research priority-setting, developing its strategic plans and strategic directions and as an effective means of improving the relevance and translation of research into practice and policy. Ultimately, this will contribute to improving citizens' quality of life, more effective health services and products, and a strengthened Canadian health care system.

3.3 Guiding Principles

CIHR's CE Framework will be guided by the following principles:

Principle	Rationale
Working with citizens will add value to the program or project.	Soliciting citizen input should be done with <i>purpose</i> – not just for consultations' sake.
Mutual learning/understanding will build trust and credibility.	CIHR can learn from citizens in the same way that they can learn from us – and from each other. Understanding and valuing the views, concerns, and experiences of citizens will build trust and credibility on all sides.
Openness will enhance transparency and accountability.	Sharing information about CIHR's core business and decision-making processes will enable CIHR to demonstrate the value (and impact) of the tax-payer dollars that support health research.
CIHR will be inclusive in its approach to citizen engagement.	Barriers that prohibit or diminish engagement with a wide range of groups do exist; recognizing and addressing them will improve the diversity of CE representation and will enhance the quality of the feedback received.
Citizen will be supported to ensure their full participation.	Orientation tools and sufficient support are needed to help citizens contribute fully to the discussions and decisions being considered.

3.4 Areas of Focus

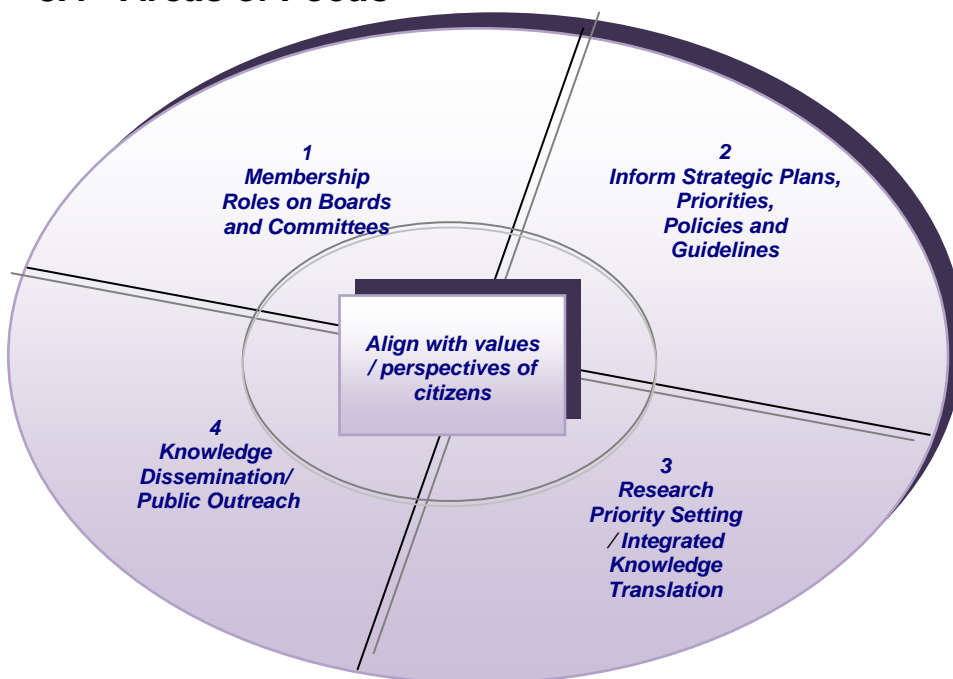


Fig. 5: The Four Areas of Focus

Figure 5 captures the four categories that the Framework outlines as major areas of focus for CIHR to invest more effort in gathering systematic input from citizens. These focus areas fall

within the scope of the activities that CIHR's Institutes and Corporate Branches have already used to engage and partner with citizens. These areas have been numbered on the diagram and are explored in more detail below with recommended actions for enhancing representation of citizens.

1: Enhance citizen representation on CIHR's Boards and Committees

Membership on CIHR's decision-making bodies, including Standing Committees of Governing Council, sub-committees of the Scientific Council and Institute Advisory Boards, provides a mechanism for mutual learning and understanding, for improved trust, transparency and collaborative decision-making. Participation of citizens on CIHR committees and boards can encompass both advisory and decision-making roles.

Recommended actions:

CIHR should increase the engagement of citizens in governance roles on its existing structures as well as in advisory roles in research priority-setting, peer-review and knowledge translation committees.

Governance:

- Provide guidance to Chairs of CIHR's Standing Committees and the Institute Advisory Boards on how to engage these representatives actively and meaningfully.
- Creation of a Citizen's Panel: The external scan of similar funding organizations, described earlier in Section 2, suggested models for developing ongoing relationships with citizens who are characterized by shared agenda-setting and collaborative decision-making. The Public Panel of the United Kingdom's Medical Research Council (MRC) recently underwent a formal evaluation and has now evolved to become a virtual panel coordinated by a staff member of the MRC's public involvement team. The staff match suitable lay people from the Panel to specific MRC activities in which a patient or public perspective would add value. The panel consists of individuals with an interest who can provide a lay perspective – perhaps by association with a health charity or through personal experience. These people are invited to provide advice and guidance to the MRC on a project-by-project basis. These are usually one-off projects that run for a limited period and usually address a particular health need, emerging public health concern or monitor the progress of research and knowledge translation

projects such as clinical trials or national initiatives such as the UK Stem Cell Bank:

<http://www.mrc.ac.uk/NewsViewsAndEvents/InvolvingThePublic/MRCPublicAdvisoryGroup/index.htm>

CIHR should adopt similar model for its own Citizen's Panel. Members of the Panel may be invited to give presentations to lay audiences on the research funding process and present at appropriate Café Scientifiques. The Terms of Reference, recruitment, screening, appointment and secretariat support would be developed by the PCE Branch using tools such as the CIHR Volunteer Application process that is already available on CIHR's website (for Community Reviewer and IAB recruitment, etc.). CIHR is already demonstrating some capacity of activities which are building a foundation of what has been coined the "already-engaged"²² citizens.

- The Community Reviewers program is managed by the Research Portfolio as it serves as a vehicle for receiving input from citizens during the peer review process. Continued support is required to meet the goal to expand the number of panels in which community reviewers participate from 25 (currently) to 50% of the open operating grants program panels.

2: Ensure that citizens' perspectives inform corporate and Institute strategic plans, strategic priorities, policies and guidelines

CIHR and its Institutes should include a plan to proactively seek citizen input into the development of any new direction or initiative as early as possible. Consultation with the public during the development of Institute strategic priorities will serve to gather information surrounding public values and ethics, to consult and explore/reconcile ideas or weigh priorities, and to establish trust and credibility. A statement of commitment should explain how the results of the exercise will be integrated in the final plan/direction/initiative and should make CIHR's commitment to the process clear (or the commitment of the Institute Scientific Director, IAB, etc.).

²² [1] 'Already-engaged' citizens (a term that was initially coined at the CIHR CE consensus-building workshop in May 2008) are people who have contributed or who currently serve as IAB members (patients, advocates, voluntary sector representatives), Standing Committee members (Stem Cell Oversight Committee), Community Reviewers within the Peer Review process, members of the Knowledge Exchange Task Force with IMHA, members of the Community-Based Research Committees for the IAPH and with the HIV AIDS Initiative. Other activities may also apply.

Recommended actions: CIHR's Institutes and Branches use a variety of methods to seek public input, including broad-based surveys; meetings with targeted audiences; forums that include all stakeholders; workshops; telephone surveys and focus groups; publicized consultations for input through online surveys; and small group dialogue sessions. These methods should be used to facilitate:

- proactive involvement of citizens in the development of all Institute strategic plans;
- proactive involvement of citizens in the early planning of CIHR's next strategic plan;
- involvement of our already-engaged citizens in preparing for the next International Review and in the review itself.

3: Develop tools to incorporate citizens as a category of targeted audiences in the development of research priority-setting approaches used in Integrated Knowledge Translation, including Community-Based Research

The integrated Knowledge Translation (iKT) research process, which includes community-based research, provides models for interested Institutes with strategic initiatives that involve stakeholder consultation in their program tools. Relevant Requests for Applications (RFAs) would stipulate the involvement of citizens as a criterion for CIHR funding, along with specific information for research applicants. For example, the RFA could include the following step in its application requirements: "Where appropriate, indicate how you are involving citizens actively in any of the stages of your research (e.g. in developing the research proposal and/or taking account of likely public reaction to your research). State what efforts you have for disseminating your results to citizens."

iKT requires a collaborative and participatory approach to research that is action-oriented and is focused on solutions and impact. Knowledge users and researchers are working together to shape the research process - starting with collaboration to set the research questions, decide the methodology, get involved in data collection and tools development, interpret the findings and help disseminate the research results. In iKT, which includes community-based research models, the affected community helps to define the research question(s) to ensure relevance to the community. The affected community can also be involved in conducting the research and promoting active participation in the development and implementation of a dissemination strategy for the results.

Recommended actions:

- Develop funding opportunities to increase researcher capacity for CE. (See the recent fellowship opportunity offered by CIHR's Institute of Health Services and Policy Research: <http://www.cihr-irsc.gc.ca/e/34548.html#II>.) There could also be opportunities to develop new research domains in this area and provide additional funding such as "Meetings, Planning and Dissemination" grants.
- Pilot a CE component within iKT research tools offered by the Knowledge Translation Portfolio, such as Partnerships for Health System Improvement (PHSI), the Knowledge Synthesis Initiative, the Knowledge to Action Initiative, Strategic KT initiatives funded through Institutes, the Proof of Principle (POP) and the Meetings, Planning and Dissemination grants. This component would help researchers to develop collaborative relationships and grant proposals. The PCE Branch can offer guidance and decision-making tools for careful consideration of the potential categories of citizens (as defined in the typology in Section 2) to be included as 'knowledge users' in the RFA descriptions.

4: Increase the effectiveness of Knowledge Dissemination and Public Outreach

This objective is one in which CIHR is concentrating much effort in order to communicate the benefits of health research to Canadians, to improve health services and ultimately improve the health of Canadians. As demonstrated in the survey results in Table 2 of Appendix 1, the efforts undertaken to achieve these objectives involve bringing together researchers with a variety of citizens, including voluntary health sector organizations, the media, parliamentarians, youth and the general public. The Communications and Marketing Branch is leading in the efforts to reach the media, parliamentarians, youth and the general public with such programs as the media workshops, Café Scientifiques and Synapse. The Institutes and branches are involved with more KT and outreach activities as part of their ongoing engagement efforts with voluntary health sector organizations. Both the media and the voluntary health organizations are important partners to reach the general public.

Recommended actions:

- Support enhancements to CIHR's website (CIHR's Web Strategy) with a new feature that offers opportunities for Public Involvement in its main navigation menu. This can eventually provide a comprehensive list of both current consultations opportunities and published reports of past consultations. The PCE Branch will also develop specific web

pages about CE at CIHR.

- Develop related resources, such as a guide (written in lay language) that outlines the nature of CIHR. It could offer information about ways that the general public can engage (become involved) with CIHR and its Institutes.
- In consultation with the Communications & Marketing Branch, develop opportunities to link stories about the impact of health research to opportunities to participate in Institute- or Branch-led consultation exercises (and vice-versa), ensuring that all material is written in comprehensible lay language. This cross-linking will increase visibility of both CE at CIHR *and* the value of investments in health research.

3.5 Coordination and Oversight

Implementation of CIHR's CE Framework is the responsibility of all Institutes and Branches of CIHR. However, the PCE Branch will exercise a coordination and oversight role, facilitating CE activities and providing guidance to all areas of CIHR.

As part of this facilitation and guidance role, the branch will be developing a Citizen Engagement Handbook and Resource Centre. This tailored toolkit will assist the Institutes and Branches in undertaking successful recruitment and involvement of citizens, and will include learning opportunities for staff and resource materials. Appendix 4 provides an example of many guidelines developed for assessment and matching methods.

Staff professional development will be critical in order to ensure that CE processes are managed well. There are, unfortunately, many examples of a distinct lack of feedback loops in which citizens take part in decision-making meetings and/or consultations but are not provided with results of these exercises or how their input was used. This simple oversight contributes to distrust of and cynicism about these kinds of exercises.

Evaluation methods for CE programs will be included in the toolkit, such as Health Canada's public involvement planning guide, which features critical questions to consider during the development phase of an overall CE plan so that objectives can be effectively measured.

The Handbook and Resource Centre will also include:

Tools to help the public engage with CIHR: Tools similar to the Resource Pack of Australia's NHMRC will inform citizens and researchers about effective methods for engaging their target audience(s). In addition, a background document, written in lay language, that explains CIHR and health research can be made available on our website and distributed to partner organizations and libraries. Such a document can incorporate information about the research process, how research is regulated, communicating the results of research, and research methods. The guide will explain what systematic reviews are and information about the Cochrane Collaboration and the Cochrane Library²³ to guide citizens to resources. This guide could also be made available at meetings that include the public. Furthermore, tools will include support for online involvement of Canadians from a CIHR web portal for the purpose of ongoing consultations and for feedback. Café Scientifique events designed for discussion on CE at CIHR will be developed as opportunities to let citizens know about how they can be involved in health research.

Tools to help the research community learn how to engage citizens: A resource guide will be developed and tailored for the research community to offer advice to researchers about the sort of information useful to citizens and the values that underpin their participation in health research. CIHR can collaborate with university institutions, such as Memorial University's Harris Centre, to offer outreach programs that promote science literacy and consult with citizens on specific policy questions. For example, the Harris Centre offers two different types of public policy forums that are open to the general public. There are no admission fees to the Harris Centre's public lectures, and parking for on-campus lectures is free of charge. A free reception is normally held after each lecture.²⁴ Similar opportunities through CIHR could include involving citizens who are already engaged with CIHR as presenters from the 'public perspective'.

Tools to strengthen the role of Voluntary Health Organization Partners: As demonstrated in Appendix 1, CIHR is currently partnering for research and KT purposes with many of Canada's Voluntary Health Organizations (VHOs). CIHR views them as key stakeholders representing the interests of Canadian patients, consumers, advocates and volunteers, and to provide a 'lay' perspective on most of the IABs. These organizations can help CIHR to communicate research in ways that are meaningful to the public.

²³ The Cochrane Library contains high-quality, independent evidence to inform healthcare decision-making. It includes reliable evidence from Cochrane and other systematic reviews, clinical trials, and more. Visit: <http://www.cochrane.org/>.

²⁴ "Public Policy Forums." Part of the Harris Centre's website. Additional information is available here: <http://www.mun.ca/harriscentre/Lectures.php>

As evidenced in the literature review, VHOs often act as gatekeeper organizations that nominate or recruit interested and informed individuals for consultations. CIHR's voluntary sector partners can impart valuable knowledge and skills in the management of volunteers and the engagement of their stakeholders. CE is similar to volunteer engagement in that it involves the same principles of the volunteer retention cycle: recruitment, selection, orientation and training, evaluation, retention and recognition. Some of CIHR's VHO partners have acted as key advisors in the development of this framework.

The PCE Branch will continue to provide support and to build capacity for the network of voluntary and NGO Sector IAB members who are meeting regularly with the renewed commitment from the KT Portfolio. In addition, the PCE Branch will continue to nurture the relationship with the health charities and other voluntary sector partners by organizing meetings such as the National KT & Partnerships Roundtable Meeting (originally organized in 2007). Future endeavours may include the development of a website directory of organizations, such as research networks, VHOs, and clinical research collaborations that are offering opportunities for citizens to get involved.

3.6 Evaluation

The PCE Branch will develop an evaluation framework as a component of the tailored toolkit with the implementation of activities in the four priority areas that have been identified. CIHR can distinguish itself from other organizations currently undertaking CE activities through evaluation of the effectiveness of its activities.

Table 6: Evaluation of Citizen Engagement Activities

Objectives	Outputs and Outcomes	Evaluation Issues
1. New or modified strategic priority setting, strategic plans, policies and guidelines	<u>Short term:</u> - Citizen Engagement Framework - Network of contacts - Synthesis documents - CE toolkit and resource library - Increased CE at Institute and corporate level	Representativeness Clear task definition & accountability Equal opportunity to participate
2. Integrated KT and Research Priority Setting	<u>Intermediate outcomes:</u> - Increased connection between researchers and citizens;	Timeliness Transparency
3. Membership on CIHR committees and boards	- Improved communication and engagement of citizens; - Increased capacity and opportunities for CE within the research cycle (RFA's encouraging CE) and governance structure;	Communication of results of CE activity Adequate resources Coordination
4. Knowledge Dissemination/ Public Outreach	<u>Long term outcomes:</u> - Consistent and cohesive CE engagement activities across CIHR; - Increased vehicles for knowledge dissemination; - Change in public attitude about CIHR; - Increased support for health research	Learning Capacity building Participant satisfaction Influence on decision making

Section Four: Conclusion

The successful implementation of the CIHR Citizen Engagement Framework will position CIHR to take a leadership role within Canada in engaging and partnering with a diverse group of citizens. By moving beyond traditional stakeholders in health research to include the broader public in opportunities to dialogue, deliberate and collaborate, CIHR will ensure that its strategic priorities and organizational policies are responsive to the needs of Canadians.

Tools to track, synthesize and report the results of all Institute- and Branch-led activities will contribute to the ongoing evaluation of the effectiveness of CIHR's efforts and will help to refine the Framework and accompanying resources. An evaluation framework will be an important resource to measure these efforts to engage citizens and to demonstrate the value to both CIHR and to citizens for participating in the activities.

Citizens want to be engaged in CIHR's work through processes that involve dialogue and collaborative decision-making practices. Citizens are responding to a "shift that has been occurring over the last 10 to 15 years from top-down models of government to horizontal governance, which is the process of governing by public policy networks including public, private and voluntary sectors. The rationale for the shift lies in the understanding from governments that better decisions are made when the affected stakeholder groups are involved."²⁵ Including these voices will be challenging, requiring the commitment and involvement of all areas of CIHR, including the endorsement of senior leadership, in developing the programs and initiatives that will transform this framework from a vision to reality. The rewards of success are great, however, as there is significant potential for citizens, experts and leaders to learn from each other through legitimate and accountable participation.

CIHR already has a solid foundation in CE that has developed naturally. This framework builds on the considerable and varied CE activities already underway at CIHR. By building on its existing strengths and taking realistic steps for the organization, CIHR will seize an opportunity to move forward with CE to fulfill its place in the global arena and to ensure that funded research connects with Canadians to improve their health and strengthen the Canadian health system. The vehicles already exist within CIHR, but a new way of thinking is needed to ensure inclusiveness and fair representation of citizens in CIHR's decision-making structures and in its research programs.

²⁵ Phillips, Susan D., Michael Orsini. "Mapping the Links: Citizen Involvement in Policy Processes." Canadian Policy Research Networks (2002).

Appendix 1: Spectrum of Citizen Engagement Activities

(Tables 1 and 2)

Table 1: Spectrum of Citizen Engagement Activities at CIHR LEVELS 3 – 5 (Consult / Collaborate / Engage / Partner)			
Objective	Activity	Level	Used by
Inform Strategic Priorities	Strategic Plans - broad-based consultations utilizing surveys and meetings with targeted audiences and communities that provided an environmental scan and perspectives for some of the Institute Strategic Plans	Consult/ Engage	IAPH, IA
	ICR's Research Alliance - comprised of representatives from the National Cancer Institute of Canada (NCIC), the Canadian Association of Provincial Cancer Agencies (CAPCA), Health Canada and ICR. In May of 2001, this group sponsored a large working group meeting at which cancer researchers from all pillars, lay persons, survivors and potential partners, were convened to begin the process of defining research priorities for cancer research. As a result of this meeting, a web-based Delphi process was initiated to further refine the priorities and seek input from a broader population. Resulted in identification of 7-8 priorities for the Institute	Involve/ Consult	ICR
	IMHA on the Move I January 31-February 1, 2003 - a forum where stakeholders from across Canada (over 150) contributed to the fine tuning of IMHA's strategic plan	Collaborate/ Engage	IMHA
	IMHA on the Move" II October 2006 -a forum where CRCs from across Canada and stakeholders from western Canada (over 80) contributed to the planning, development and implementation of a national IMHA strategy - 2007-2013	Collaborate/ Engage	IMHA
	Institute sponsored NGO Meetings - 2 NGO Roundtables have been held in 2001 and 2002 -there are 100+ NGOs/VHOs who relate to INMHA -workshop discussions and feedback was used to create the first strategic plan - also used to address communications and partnering issues/opportunities - Stakeholder Meeting planned for 2008 to discuss creative partnering	Involve/ Collaborate	INMHA
Provide mechanisms for assessing relevance/ merits of applications in the peer review proces	Peer Review Committees for Aboriginal Health Research - all have an informed lay person	Engage	IAPH
	CBR Merit Review committees - two categories: Aboriginal and general -equal representation between experts and community reps -4 people responsible for the review of an application (2 academics, 2 community) * (In the CBR program, the Nominated Principal Investigator doesn't need to be an academic – but needs to pair up with an academic in the Operating and, at times, the Seed grant program – and the community organization can be the host institution and holder of the funds)	Engage	HIV AIDs Initiative
	HIV Trials Network - 2007 - the Network gets a grant of \$4.5 million per year - the renewal application was very transparent - consultation was done regarding what the objectives/goals of the Network should be -3/30 participants were community representatives - all 3 reps were very strong; one could even be deemed the leading HIV research advocate in Canada -the community representatives have access to a wide range of stakeholders	Engage	HIV AIDs Initiative
Provide mechanisms for transparency, accountability on CIHR's peer review panels	Community Reviewers Program: enhancing public and stakeholder engagement on CIHR's Peer Review panels by: - reviewing lay abstracts to comment on the intent and importance of the research proposal & ensure the research is well explained; -communicating the merit of investment in health research; - individuals who are not currently academics or researchers, but who have a demonstrated interest in health and science. Spring (2008) the program will be increasing participation on panels from 15 to 25 community reviewers.	Engage	Research Portfolio

Inform Policy and Guidelines for Best Practices	CIHR Guidelines for Health Research involving Aboriginal People -involved Aboriginal Elders of First Nation, Inuit and Métis communities in a dialogue and consultation on traditional values and ethics with researchers and institutions built upon the ACADRE Network	Collaborate/ Engage	IAPH, Ethics, Tri-Council Secret.
	National Placebo Initiative (2002) - extensive consultations over 2 year span to inform Tri-Council policy decisions on the appropriate use of placebos in clinical trials. - Innovative strategy to engage citizens with series of workshops, telephone surveys, and focus groups held across Canada.	Involve/ Consult	Ethics Office
	CIHR's Privacy Best Practices for Health Research - open and targeted consultations were conducted in 2004 on a draft document. The consultations were advertised widely and included in an opportunity for the general public to provide comments <u>on an online survey</u> and in small group dialogue sessions.	Involve/ Consult	Ethics Office
	The international dialogue on trial registration - Participation in the work of the Scientific Advisory Group (SAG) of the trial registration platform (ICRTP) of the World Health Organization (WHO) -Consumers are included in these dialogues; one consumer is a member of the SAG, while several consumers attend the Ottawa group meetings and signed the Ottawa statements	Engage	KSE
	Advisory Group for Open Access Policy -informed the policy on access to the research outputs such as publications, questionnaires, surveys, "outputs" or outcomes of the research grants to promote accountability, promote dissemination of research from publicly funded organizations -Online survey targeted govt, research agencies, university decision-makers, librarians, charities, funders and general public. -Multiple phases which include posting of draft policy online for replies – was seen as forward thinking -Governing Council approved the policy March 2007 - Beginning Jan. 2008 researchers are to adhere to new responsibilities	Involve/ Consult	KSE
	Participation in NCEHR meeting to look at REBs for CBR (National Council on Ethics in Human Research) - will look at Research Ethics Boards for Community-Based Research (not specifically HIV-AIDS) -this meeting will involve a lot of community participants -effectively, they are doing an environmental scan of the capacity of CBR REBs -the results of this meeting and consultation will be reviewed to identify gaps	Consult/ Engage	HIV AIDs Initiative
Inform research priorities to ensure they are relevant to Canadians	Aboriginal Capacity and Development Research Environments -one of IAPH's first initiatives was to develop these centres of supportive research environments across Canada to facilitate and develop aboriginal capacity in health research. - each centre includes a volunteer advisory board with majority membership from the aboriginal community.	Engage/ Partner	IAPH
	Community Based Research Grants - designed to collaborate and empower the targeted communities to work with researchers as full partners in the research process and to use the results to improve their quality of life.	Collaborate/ Engage	IAPH, III (HIV/AIDS)
	HIV/AIDS Initiative Working Groups - CHARAC (CIHR HIV/AIDS Research Advisory Ctee) engage community reps to gain broader perspective - 8-12 people per working group; 1-2 community reps per group -these groups develop RFAs (the perspectives feed into the type and focus of the opportunity) - - 2006 – establishment of working groups model -recruitment is fairly informal; generally, nominations/ recommendations come from researchers there were 2 face-to-face meetings/consultations (Prevention and HS/PH working groups) conducted in 2006. There was another face-to-face meeting conducted in 2007 for the HS/PH working group.	Collaborate/ Engage	HIV AIDs Initiative
	IA's Regional Seniors' Workshops - involved five community consultations (Prairies, Yukon, BC, Ontario, Quebec and Maritimes) which involved over 250 senior citizens along with NGO representatives, practitioners, policy makers. Dialogue centred around current research in aging and how seniors could engage in identify their priorities	Involve/ Collaborate	IA
	Mobility in Aging Strategic Research Initiative - Developed in consultation with broad base of stakeholders including users: health practitioners, health institution administrators, public policy decision makers, front line educators, the media, health charities, persons living with diseases/conditions, consumers, family members and caregivers, the private sector and general public	Involve/ Consult	IA
	Boys and Men's Health Seed Grant - included consultations emanating from Canadian Conference on Men's Health at the University of Victoria. Multiple community members represented, both traditional and non-traditional advocacy groups	Involve/ Consult	IGH

	<p>Gender, Mental Health and Addictions Initiative - Current funding opportunity : Research user engagement early in the research cycle is critical to help identify policy/practice relevant research foci and potential interventions that will ultimately translate into mental health benefits. Evidence of input from, and commitment to, the proposed program of research by the relevant potential users such as policy makers, private (e.g. workplace), public and voluntary sector program administrators, clinical and public health practitioners, and/or community-based organizations.</p>	Involve/ Consult	IGH, INMHA Health Canada; CIDA and IDRC
	<p>OA Consensus Conference 2002 - a conference to set strategic research priorities in osteoarthritis for Canada. All stakeholder groups from across Canada (over 200) were involved in this activity including the Canadian public, decision/policy makers, healthcare providers, patients/patient groups, private sector, researchers.</p>	Engage/ Collaborate	IMHA
	<p>Inflammatory Joint (IJD) Diseases Consensus conference 2003 -a conference to set strategic research priorities in IJD for Canada. All stakeholder groups from across Canada (over 200) were involved in this activity including the Canadian public, decision/policy makers, healthcare providers, patients/patient groups, private sector, researchers.</p>	Engage/ Collaborate	IMHA
	<p>Consensus Conference on skin research 2004 - a conference to set strategic research priorities in skin research for Canada. All stakeholder groups from across Canada (over 60) were involved in this activity including the Canadian public, decision/policy makers, healthcare providers, patients/patient groups, private sector, researchers.</p>	Engage/ Collaborate	IMHA
	<p>Bone and Joint Decade (BJD) International Consensus Conference 2005 - a conference to set strategic research priorities in Bone & Joint research for Canada and internationally. All stakeholder groups were involved in this activity including the Canadian and foreign public, decision/policy makers, healthcare providers, patients/patient groups, private sector, researchers. Over 40 countries were represented along with WHO representatives (over 250)</p>	Engage/ Collaborate	IMHA
	<p>Summit for the Canadian Arthritis Standards of Care 2005 - a conference to set strategic research priorities in IJD for Canada. All stakeholder groups from across Canada (over 250) were involved in this activity including the Canadian public, decision/policy makers, healthcare providers, patients/patient groups, private sector, researchers.</p>	Engage/ Collaborate	IMHA
	<p>Muscle: From Molecule to Mobility Consensus Conference 2006 - a conference to set strategic research priorities in muscle and rehabilitation research for Canada. All stakeholder groups from across Canada (over 90) were involved in this activity including the Canadian public, decision/policy makers, healthcare providers, patients/patient groups, private sector, researchers.</p>	Engage/ Collaborate	IMHA
	<p>III Pandemic Preparedness Strategic Research Priorities - Canadian Foundation for Infectious Disease had input in direction-setting workshop in 2005 - Task Group often work with lay representatives and researchers working with task group to develop Funding Opportunities</p>	Involve/ Consult	III
	<p>IG Symposium- Aboriginal cross-border collaborations Planning meeting for May 2008 to develop a modified model of committees with Aboriginal Researchers, with Community- Based Research standards. Including representatives from different aboriginal groups (to involve input from the communities). -modified model of other Planning & Priorities committee</p>	Involve/ Consult	IG
	<p>Funding to support Citizen Engagement (including patient involvement) IHSPR - Spans 24 grants and awards including July 2007 – Fellowship in CE, Dec 2007 – CE – Access to Drug Care Policy</p>	Involve/ Consult	IHSPR
	<p>III Strategic Priority Setting - meetings with invited NGO's to involved the wider community in 'Research Symposium' on "Auto-Immune" diseases</p>	Involve/ Consult	III
	<p>Lay Summaries (IMHA) - work with researchers to develop lay summaries of research (Cochrane-matched)</p>	Engage	IMHA
Support a culture of science literacy in Canada	<p>Synapse – Youth Connection - originated in Blueprint to collaborate with partners in the educational and science youth outreach non-profit organizations to create mentors for the next generation of health researchers by engaging children/youth in science discovery. Extensive environmental scan of best practices in Canada and abroad, focus group consultations informed the tools which were developed.</p>	Involve/ Engage	Comm. Branch
	<p>IBRO Science Schools This initiative involves research and education in developing countries. INMHA sponsors 2 schools per year (one in Africa, one in South America). The sponsorship is for 2-week intensive courses for PhD students or Post-Docs. Last year, the students were brought to Canada for a meeting; they gave presentations at the meeting and had a 1-week course afterwards</p>	Involve	INMHA

Mechanisms for improved trust, transparency and accountability at governance level	CIHR Institute Advisory Boards 1 – 2 members per board represent voluntary sector, consumers, advocates	Engage/ Partner	Nominating and Governance Committee T of R
	Stem Cell Oversight Committee - public representative is full member of this committee	Engage/ Partner	Nominating and Governance Committee T of R
	HIV/AIDS Research Advisory Committee - subcommittee of CIHR-III's IAB, but essentially functions as an IAB itself - 2/12 members are community representatives, who are appointed by a nomination process - strong push from the HIV/AIDS research community to create this initiative, so community interest (academic and otherwise) is very keen -their terms last 2 years (with the possibility of renewal for another 2 years)	Engage/ Partner	HIV AIDs Initiative
	HIV/AIDS CBR Steering Committee (Standing committee) - community reps needed for depth of experience (CBR truly engages the community throughout the research process (from deciding what the focus of the research will be to the dissemination of the research results; has several CBR RFAs) -8-12 people; equal representation from experts/academics and community reps - 2 funding streams: 1. General, and 2. Aboriginal (also equal representation between Aboriginal and non-Aboriginal people for that committee) -modeled after other countries recruitment, based on recommendations from the community (HIV Networks, etc.)	Engage/ Partner	HIV AIDs Initiative
	IMHA IAB sub-committees - 1-2 voluntary sector/lay representative on the IAB -each sub-committee of the IAB is represented by at least one patient representative	Engage/ Partner	IMHA
	PROCTOR - Public reporting of Clinical Trials Outcomes and Results; the purpose PROCTOR is to identify issues and concerns regarding the public reporting of results; consumers are one of invited constituencies and a special analysis is done	Consult	KSE
Knowledge Translation	IMHA Knowledge Exchange Task Force (KETF) - Was spearheaded by former IAB member Flora Dell - innovative approach to creating a communication pathway linking researchers and key stakeholders, including clinicians and patients. - - Members become Research Ambassadors for the program and expedite dissemination of findings to their respective organizations and communities.	Engage	IMHA
	Strategic Training Initiatives in Health Research (STIHR) - 3 of our annual meeting of STIHRs included KT on the agenda – first agenda item was on what is KT? Second was a ½ day/breakout pilot conducted by Cochrane Collaborations and the 3 rd meeting was a full-day pilot on 'train the trainer' in KT. KETF research ambassadors (patients) participated in this pilot. STIHR Directors and trainees from across Canada are main participants in these meeting (70-80 participants)	Consult	IMHA
	Stakeholder Database IMHA - (IMHA) believes that establishing consistent, open, two-way communication with stakeholders is critical to its success. Stakeholder database enables the Institute to send pertinent information about current programs and activities, but will also enable two way communication.	Involve	IMHA
	Canada on the Move - Kellogg's began putting pedometers in their Special K cereal, which led SD Diane Finegood to the idea that the Institute should try to link Kellogg's with research ("Donate your steps to research!"); - People could log onto the website and register as a participant -the website informed/educated people re: the importance of walking; -discussion was done using electronic mechanisms; -researchers used the website as a starting point (data) to generate further research – integrated KT; -national perspective, high profile, innovation, crossing health promotion + research; -resources: outside source for website (about \$100K per year) -other companies copied the idea ("America on the Move", etc.)	Involve	INMD
	Ministerial Advisory Council of HIV/AIDS - really increased the credibility , accountability and validity http://www.phac-aspc.gc.ca/aids-sida/fi-if/minister_e.html (includes several Canadians living with HIV/AIDS. - - - The main focus of its work is on evaluating and monitoring the Federal Initiative, championing current and emerging issues, and offering a vision for the long-term)	Engage	HIV AIDs Initiative

Partnering for research and KT with Canada's Voluntary Health Organizations	KT National Roundtable with VHOs 2007 - The focus for the day was to develop a common understanding between researchers who have received CIHR KT Funding and Voluntary Health Sector partners; this understanding allowed all the participants to discuss knowledge translation best practices and to explore common goals for potential collaborations.	Engage/ Collaborate	KSE jointly with PCE
	Canadian Genetic Alliance Organization - modelled after the US based organization. Currently being developed as an information provider to multiple stakeholder groups including families/patients with genetic diseases. It will build capacity in advocacy organizations and educate policymakers by leveraging the voices of these groups. Web site is tailored to lay people. Creates a more powerful voice for advocacy to govt.	Collaborate /Partner	Originally lead by IG
	Priority-setting workshops co-organized with researchers and partner organizations. These include: - 2002 Tobacco Summit - 2003 Workshop on Alcohol and Illicit Drugs - 2003 Workshop on Problem Gambling - 2004 Workshop on Early Life events - 2007 Consultation on Research Priorities for Substance Abuse and Concurrent Disorders - 2007 National Autism Research Symposium: an effort was made to include grassroots representation from the autism community (parents, advocates, treatment professionals) and to provide an opportunity to hear some of those whose voices may not yet have been heard publicly. Autism workshop communications materials created with Health Canada, PHAC, and CIHR Communications Branch	Consult/ Engage	INMHA
	Institute sponsored NGO Meetings - 2 NGO Roundtables have been held in 2001 and 2002 - there are 100+ NGOs/VHOs who relate to INMHA - workshop discussions and feedback was used to create the first strategic plan - also used to address communications and partnering issues/opportunities - Stakeholder Meeting planned for 2008 to discuss creative partnering	Involve/ Collaborate	INMHA
	Representation at Voluntary Sector and NGO Workshops/ AGMs/Forums - INMHA staff and IAB members participate in numerous in priority-setting meetings/exercises - INMHA gets involved to help set and implement the organization's priorities (not just vice-versa)	Collaborate	INMHA
	INMHA Annual Meeting - NGOs are invited to annual meetings (INMHA originally paid for an attendee from each NGO who wanted to attend). The meetings included sessions specifically for the NGOs to network, discuss partnerships and mutual issues, etc., as well as to attend sessions that involved researchers, consumers, and policy makers.	Involve/ Collaborate	INMHA
	IPPH Joint public forums with various organizations - such as CPHA conference- implement "Public Forum" style events with presentations (intended to attract public to learn about an issue re: public health) - David Suzuki PUBLIC FORUM: 'Our Environment is Our Health' with the Ontario Public Health Association (involved an open question panel)	Involve/ Consult	IPPH
	Institute of Genetics Voluntary Health Organizations (VHOs) Working Group - mandate is to cultivate a partnership between VHO's from genetic diseases community and IG. The working group will influence the development of the IG as an integrative health research Institute and promote public engagement among stakeholders.	Engage/ Partner	IG
	Listening for Direction II (2004) Listening for Direction III (2007) - Responding to public expectations for consultation in research priority setting by involving VHO's and decision makers. - consultation workshops were held across Canada: one national workshop, five regional workshops in the south, and three northern regional workshops in each of the territories. Overall, 1,230 individuals were invited and 202 people attended the workshops. Of these, 107 participants were decision makers (including senior hospital and health region managers, clinical leaders, and national and provincial government policy analysts and advisors); 40 were researchers (mid-career and senior academics and researchers in decision-maker settings); and 55 came from a variety of other settings (such as consultants, knowledge brokers, research administrators, healthcare associations, and professional associations).	Involve / Consult	IHSPR
	Reducing Health Disparities and promoting equity for Vulnerable Populations Strategic Initiative - Extensive consultation with voluntary health charities and NGO's (ie: HSFC, Alzheimer's Society, CBCRA, Lung Association, Tobacco Control) to develop RFA's - included conference presentations and networking events to reach out to smaller groups	Consult/ Involve	IGH

	<p>Participation as CIHR representative on stakeholder working groups - participating as a rep allows the staff to build a network and relationships with the HIV-AIDS community -staff also learns about the priorities of the community and other organizations (find out priorities of each side) -some groups are NGO-led; others are gov't-led -education + consultation: two way exchange</p>	Involve / Collaborate	HIVAIDS Initiative
	<p>III & JDRF Search for a Cure for Type 1 Diabetes -partnerships supporting the New Emerging Teams; III also partnered with JDRF in support of a Stem Cells and Diabetes Workshop in March 2002, convened to bring together diabetes and stem cell researchers for discussions on applying stem cell technologies to the treatment and management of diabetes</p>	Collaborate/ Partner	III

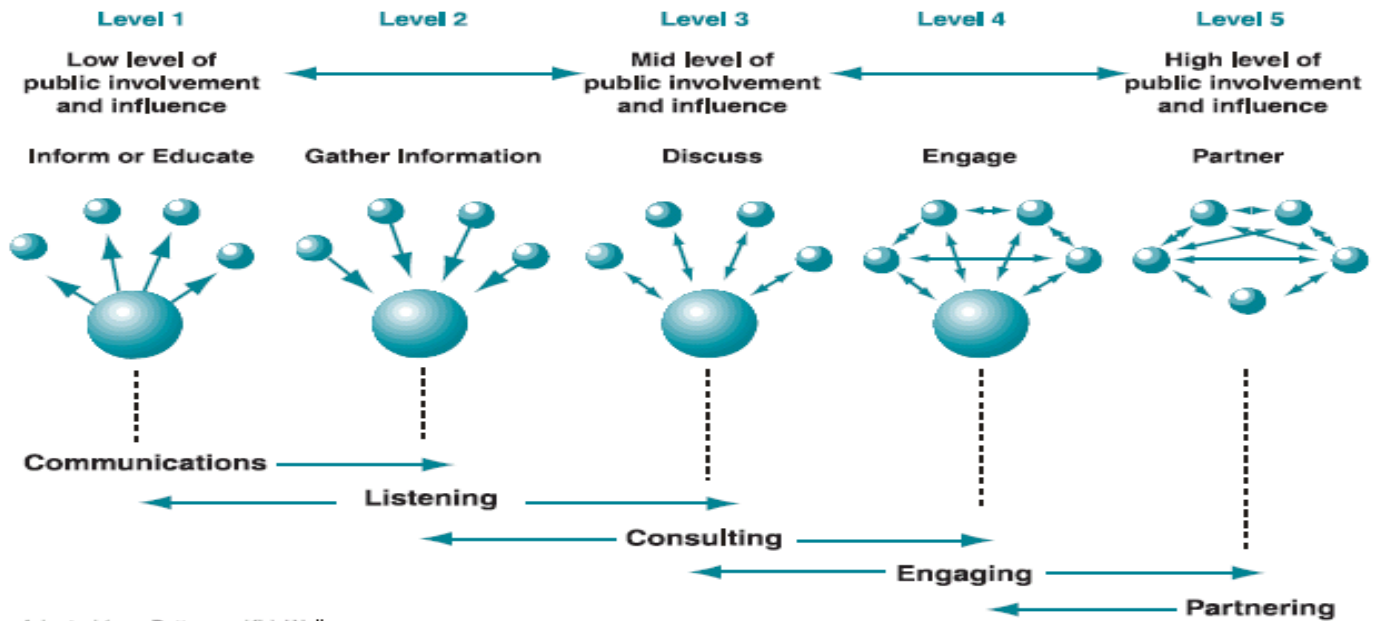
TABLE 2: Spectrum of Activities at CIHR: Inform/Educate/Outreach/Listen
(Levels 1 – 2)

Objectives (Overall)	Activity	Level	Used by
<p>To provide the public with balanced and objective information to assist them in understanding the problems, alternatives, and/or solutions.</p> <p>To give knowledge of something, to tell, and/or to acquaint the public with a fact.</p>	<p>Public Forums / Workshops (sponsorship) Sponsor “Public Forum” style events with presentations intended to attract public to learn about an issue re: public health. Re-Genesis (TV Program): Program is partnering with Jay Ingram of Let's Talk Science, which is committed to understanding the impact and outcomes of our work. IG is one of the sponsors of an upcoming public forum Dec. 2007, to engage with geneticists and increase understanding of what is really happening in gene science.</p>	1	IPPH, IG
	<p>Informative Websites “Canada on the Move” initiative: This initiative involved multiple levels of engagement. At Level 1, INMD used a website to inform/educate people about the importance of walking. While the website also included elements of interactivity (to be discussed below), it was a useful tool for health promotion and the dissemination of information. “The Brain” website: http://thebrain.mcgill.ca/. INMHA has sponsored this website for 6 years. It provides the public with descriptions of the brain (from top to bottom) and is accessible for all ages. Outcomes of KSE funded events are posted in lay language on our website for general public.</p>		INMD, INMHA, KSE
	<p>Public Speaking The SD gives talks on obesity, physical activity, and nutrition in layman’s terms to inform/educate the public in varied settings. She discusses positive change/results/research.</p>		INMD
	<p>Media Interviews / Media Outreach Both Paul and Diane do lots of community-based radio and print interviews. They give practical tips on how Canadians can use the results of research in their everyday lives. Most interviews occur around holidays associated with sweets (Hallowe’en, Valentine’s Day, Easter, etc.) and throughout the summer. These interviews become excellent tools for health promotion.</p>		INMD
	<p>Public Outreach / Communication Initiatives Once per year, 3 grants of \$10K (based on a competition) are given to NGOs to reach the public. This activity is more of a Knowledge Translation exercise; the funds are used to create brochures, websites, etc. to translate validated research to the public (i.e. integrated KT). NGOs apply for an annual award: Communications Award: The NGO gets \$10K to develop communications</p>		INMHA
	<p>Town-Hall (“learning-style” format) (Toronto and Quebec City): Stakeholders from the community were invited to come and learn about ICRH and its activities as well as to pose questions to the Scientific Director and advisory board members.</p>		ICRH

<p>To provide the public with balanced and objective information, but in a more engaging, dynamic, and/or interactive style than in Level 1.</p> <p>More input / feedback from the public is incorporated than in Level 1 activities, but involves less input / feedback than Level 2 activities.</p>	<p>Educational Outreach Lectureships: Via IAB meetings, the IG broadcasts events to various faculties to attend lectures. Anyone interested can attend; the invitations can include more than universities. Food for Health: developed with the Canada Agriculture Museum, III and ICR, this initiative involves an online interactive site geared towards schools and children (includes games). It addresses a need for public education, taking the results of the research on food and water-borne illness and translating this research into action by applying it to public practice. Mental Health in the Workplace workshop: INMHA brought in Insurance companies and other workplace organizations to help address the gap between the business world and the research world. An employer perspective has also been incorporated. The Task Force on mental health in the workplace involves lots of other organizations "Brain Bee": This competition for high school students has been across Canada and the US in the past, but in May 2008, INMHA will host the first international Brain Bee competition. INMHA is also organizing the Canadian national competition. Lots of volunteers will be used to organize the events and to act as "patient actors" (the contestants will need to make a diagnosis). The competition involves knowledge of the brain, diseases of the brain, and mental health. Electronic Health Records: This initiative involves engaging the public to brainstorm about ways in which consent can be obtained to make data available for secondary analysis. While the brainstorming involves consultation, education is involved, as well; the public needs to be informed about anonymization to deal with privacy issues/ concerns. (Sept. 2008 = a summit planned for all stakeholders.)</p> <p>Café Scientifiques Café scientifiques started in the late-20th Century as an informal discussion about scientific subjects. They were never intended to be lectures. The same holds true for CIHR Café scientifiques. They provide insight into health-related issues of popular interest to the general public, and in turn provoke questions and provide answers. For that reason, the CIHR Café scientifiques are all about accessibility. They involve interaction between the public and experts in a given field at a café, a pub or a restaurant. If you want to take part in a CIHR Café scientifique, there is no need for you to have a science degree. You just need to have a deep-rooted desire to talk about a particular health subject; you could learn how health research may provide answers to your questions.</p> <p>Community / Town Hall Events / Open Forum Wherever an INMHA-IAB meeting takes place, Rémi works with a local university to set up poster displays for an open forum for the university community. For IMHA, every IAB meeting will host events intended to keep stakeholders informed of activities. Evaluation forms are used to receive feedback.</p> <p>SYNAPSE – Youth Connection (1 & 2) Collaborative partnerships with non-profit organizations help mentors create the next generation of Canadian health researchers through use of accessible scientific info and hands-on experience. 4,000 CIHR-funded researchers have now officially registered to be Synapse mentors. To date they have reached over 20,670 students directly and another 26,600 indirectly.</p> <p>Public Affairs (1 & 2) The objectives for these activities include communicating the benefits of Health Research to Canadians, and letting them know about CIHR and what we do. The intention here is to position CIHR to the media as a useful and reliable source of story ideas and commentary. To do this, Communications advertises our services to the media, offers workshops on various topics of interest to the media, etc. The media is also used to reach the general public. Tools include: Journalist workshops (educate public through more informed media), MP kits, Web profiles, regular expert alerts to media using health or other issue calendar days as well as issues in the news, Communications plan for each institute, Monthly e-mail to media, monthly e-mail to researchers (by Research Portfolio w/help from Marketing and Communications), well developed media room that includes a database of experts for media use, Awards night advertising and media relations plan, Media promotion for cafés, joint events w/Research Canada and other tri-council agencies such as Health Researchers on the Hill and Media Science Forum, twice a year national funding announcements in concert w/the Universities, regular distribution of matte articles via media distribution networks and News Canada, support of the Canadian Science Writers Association and Association des communicateurs scientifiques du Quebec, recognition guidelines for CIHR-funded researchers and outreach to universities to promote them, and a pamphlet for media.</p> <p>Media Workshops Used to give health reporters broad overviews of important areas of research.</p>	<p>1-2</p>	<p>IG, ICR, III, INMHA, IHSPR</p> <p>Comm., All Institutes</p> <p>INMHA, IMHA</p> <p>Comm.</p> <p>Comm.</p> <p>All Institutes (Comm.)</p>
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To obtain public feedback on analysis, alternatives, and/or decisions.	<p>Integrated KT in research design Resource Allocation Decisions NET Grant 2004: The thematic focus of this RFA reflected the increasingly urgent need for new research and knowledge translation initiatives in the areas of financing, funding and resource allocation in health care - options, impacts and public expectations. New and emerging teams were funded in order to support the formation of sustained research and knowledge translation capacity in these important areas.</p>	2	IHSPR
	<p>Workshops KT Workshop: Timely Access to Quality Health Care: Knowledge exchange with Voluntary Health Organizations.</p>		IHSPR
To seek an opinion from, ask the advice of, or turn to the public for information.	<p>KT Handbook Based on the IHSPR/IPPH call, this handbook was developed to be a resource/outreach for general public on different types of KT across all sectors of health research. It was purposely written in lay-language and included a public call for submissions.</p>		KSE
	<p>Health Research Communications Award Purpose: to build capacity in health journalism and communications across all sectors of health research. By increasing the number of Canadians engaged in communicating the results of health research, in a variety of formats, CIHR hopes to raise the level of understanding of health related issues and research among a variety of audiences, including the general public, health professionals and policy makers. The KSE branch refined tool in consultation with Journalists and Chair of review committee.</p>		KSE
To present the public with a solution, a draft, or an alternative and specifically ask for their reaction and/or comment.	<p>Audience-Based / Interactive Website As part of the Web Strategy, CIHR's "monster" website will be changed into an audience-based website. 80% of the audience is made up of researchers, but the media, decision makers, and universities are also making use of the website. The website will be changed so that the user can click on "For Media", "For Researchers", or "For Canadians", and the information relevant to each audience type will be grouped accordingly. The information will be regrouped so that themes, etc. are easily accessible. Feedback about the website was requested from users in order to inform the redesign. "Canada on the Move" Initiative: As mentioned above, this website had some Level 1 components. In addition, people could log onto the website and register as a participant (and could "donate" their steps to research). Discussions were held electronically. Researchers used the website as a starting point for further research.</p>		Comm., INMD
	<p>Parliamentary Outreach This outreach is part of the mandate for Communications. Working with Policy & Planning, outreach is done via the Hill. "Health Researcher's Day on the Hill" is a researcher reception that gives health researchers the chance to tell MPs about their work. Awards Night is also aimed at MPs. Three times per year, Communications writes an MP newsletter</p>		Comm.

Appendix 2: Health Canada’s “Policy Toolkit for Public Involvement in Decision Making”
 Prepared by the Corporate Consultation Secretariat, Health Policy and Communications Branch, 2000.



Adapted from Patterson Kirk Wallace

Level	Description	When to Use	Examples
1	Inform or educate: Distribution of information to help the public understand the issues, the process, the options and the solutions.	A decision has already been made; there is no opportunity to influence the final outcome; the issue is relatively simple.	Conducting public awareness campaigns, web postings of public advisories or other information, etc.
2	Gather information: Collecting the public’s concerns and perspectives.	Primarily to listen and gather information; policy decisions are still being shaped; no firm commitment to do anything with the views collected.	Surveys, focus groups, discussion documents for feedback (mail-out or web posting), etc.
3	Discuss: Two-way information exchange where the public discusses the policy or issue. Discussion among and with different stakeholders is encouraged.	Individuals or groups will likely be affected by the outcome; the final outcome can be influenced; input may shape policy/program decisions.	Public or town hall meetings, bilateral meetings, etc.
4	Engage: Thorough and in-depth deliberation about the policy or issues. Different perspectives are shared and parties can influence each other. Underlying values and principles are highlighted.	There is a need for citizen dialogue regarding complex, value-laden issues; there is a capacity for citizens to shape decisions that affect them.	Citizens’ juries or panels, deliberative discourse, study circles, advisory committees, etc.
5	Partner: Parties share responsibility for implementing aspects of policy or program decisions. Often involves joint decision-making.	Citizens and groups agree to develop their own solutions; governing organizations assume the role of enabler; it is agreed that solutions generated by citizens will be adopted and implemented.	Public or patient representation on decision-making committees

Appendix 3: Selecting & Implementing Effective Public Involvement Techniques

Do you have the right tools for the job? Effectively involving your stakeholders (the public), knowing what public involvement techniques exist, how to select the appropriate techniques for the situation and how to use those tools effectively may seem challenging. As a follow-up to its introductory public involvement training, Health Canada presents a new, one-day advanced course to equip you with the knowledge and skills to select and implement effective public involvement techniques.

Utilizing a different approach to traditional PowerPoint, the training will explore 10 public involvement techniques, spanning all levels of the public involvement continuum – from informing to partnering. Participants will gain answers to such questions as – Which technique is appropriate for which situation? What factors should I consider when choosing a technique? What are the strengths and weaknesses of various techniques? How do I implement the technique successfully?

Course Objectives

The training will help employees choose the most effective public involvement techniques/activities to enhance the success of their public involvement plans. Following completion of the training, participants will have the skills and tools to:

- identify key considerations for selecting techniques/activities for meaningful public involvement;
- determine the best techniques/activities for different public involvement circumstances; and,
- describe and understand a range of techniques for public involvement.

Target Audience

This training session will be of interest to site managers from all custodial departments, communications officers and other interested parties, where space is available. **Please note:** ideally you have taken the Improving Stakeholder Relationships course or some introductory Public Involvement Planning training. The training will run from 8:30 a.m. – 4:30 p.m. There is no cost for this training. Participants are responsible for their own travel, accommodations and incidentals. Registration is limited, so please register early.

Appendix 4: The Toolbox for Citizen Engagement

(Source: Canada School of Public Service course

"Managing the public consultation and citizen engagement process")

Method	Positives/Strengths	Negatives/Weaknesses
<p>Advisory Committees and Boards</p> <ul style="list-style-type: none"> - Selected members participate in ongoing discussions and/or decisions for a defined purpose 	<ul style="list-style-type: none"> - Good when information or technical expertise are essential to decision making processes 	<ul style="list-style-type: none"> - Can be taken over by vocal minority; - Advisors may want to become decision makers
<p>Citizen Juries</p> <ul style="list-style-type: none"> - Citizens' juries use a representative sample of voters from different constituencies. The participants are briefed in detail on a particular issue and asked to discuss possible solutions 	<ul style="list-style-type: none"> - allows participants to take a wider and more objective perspective, seeing issues from others' points of view 	<ul style="list-style-type: none"> - Resource intensive
<p>Conferences/Colloquiums</p> <ul style="list-style-type: none"> - A large-scale meeting taking place over one or more days with a key issue or theme to be discussed through sub-topics 	<ul style="list-style-type: none"> - provide a useful forum to showcase programs, challenges and issues of the day (similar to workshops); - allows public to interact in a neutral setting with experts and opinion leaders 	<ul style="list-style-type: none"> - Some people are reluctant to speak in an open forum
<p>Electronic democracy</p> <ul style="list-style-type: none"> - Includes a variety of different Internet-based tools, including Web sites, E-mail lists, on-line chat rooms, web forums, etc. 	<ul style="list-style-type: none"> - A comparatively fast, inexpensive and logistically simple method to request and obtain information 	<ul style="list-style-type: none"> - Computers are still not accessible by all participants; - Concerns over the confidentiality, security; - Individuals may express themselves less courteously on-line than in person
<p>Open House</p> <ul style="list-style-type: none"> - A planned event that allows stakeholders to meet with staff to review and discuss specific issues 	<ul style="list-style-type: none"> - involves the entire staff of the organization; - informal discussions are normally more positive 	<ul style="list-style-type: none"> - some people will want to turn it into a public meeting; - off-track issues are brought up
<p>Open space technology</p> <ul style="list-style-type: none"> - participants offer topics and others participate according to interest 	<ul style="list-style-type: none"> - provides structure for giving people opportunity and responsibility to create valuable product or experience; - includes immediate summary of discussion 	<ul style="list-style-type: none"> - most important issues could get lost in the shuffle; - can be difficult to get accurate reporting of results

Appendix 4: continued

<p>Polling</p> <ul style="list-style-type: none"> - a process where trained interviewers ask a specific segment of the population a list of pre-tested questions 	<ul style="list-style-type: none"> - good for discovering perceptions; - can be cost-effective for reaching populations in wide-spread areas; - all respondents get equal weight 	<ul style="list-style-type: none"> - results can be skewed unless tracking mechanisms are firmly in place; -obtaining results can be time consumer; - participation rate can be highly dependent on interest in the subject
<p>Public Dialogue</p> <ul style="list-style-type: none"> - a structured process that allows citizens to discuss policy issues and to struggle with the inherent tensions and trade-offs 	<ul style="list-style-type: none"> -allows for interaction between government and citizens; - provides in-depth thinking from citizens; - helps to understand the range and intensity of views expressed on issues; - may provide more validity than traditional focus group. 	<ul style="list-style-type: none"> - Very expensive; - requires a facilitator trained in the public dialogue method; preparation of background discussion papers can be resource intensive
<p>Public meeting</p> <ul style="list-style-type: none"> - formal meetings with scheduled presentations offered 	<ul style="list-style-type: none"> - provides opportunity for public to speak without rebuttal; - meets legal requirements; - puts comments on record 	<ul style="list-style-type: none"> - does not foster dialogue; - creates us vs. them feeling; - may dislike public speaking
<p>Task force</p> <ul style="list-style-type: none"> - a group of experts or stakeholders formed to develop a specific product or policy recommendation 	<ul style="list-style-type: none"> - findings of a task force of independent or diverse interests will have greater credibility; - provides constructive opportunity for compromise 	<ul style="list-style-type: none"> - task force may not come to consensus or results may be too general to be meaningful; - time- and labour-intensive
<p>Workshops</p> <ul style="list-style-type: none"> - a combination of a meeting and an advisory group. Workshops attempt to achieve specific results/steps in a plan 	<ul style="list-style-type: none"> - effective when there is a tightly constrained time frame and a need for expert knowledge of a group of experts; - group work identifies areas of agreement and areas that require further work 	<ul style="list-style-type: none"> - problem needs to be carefully defined and participants well selected for their knowledge, credibility and representation; - can result in statement that stiffens other's opposition

Appendix 5:

1) Key informant meetings occurring between May 2007 and August 2008:

Mary Pat MacKinnon, former Director of Civic Engagement for the Canadian Policy Research Networks, Senior Fellow with the University of Ottawa's Graduate School of Public and International Affairs and now a Director with Ascentum Professional Services

Beth Allan, Facilitation Expert and Facilitator for May 2008 Consensus-Building Workshop with CIHR Staff

Amanda Sheedy, University of Toronto and Canadian Policy Research Networks

Sylvie Cantin, Former Director of Public Involvement at the Office of Consumer and Public Involvement, Health Products of Food Branch, Health Canada.

Natasha Manji, Senior Communications Advisor, Public Health Agency of Canada

Joseph Peters, President, Ascentum Professional Services

Wendy Atkin, Senior Risk Communications & Public Involvement Officer, Safe Environments Programme, Healthy Environments and Consumer Safety Branch, Health Canada

Kim Hannah, Consultation Policy Advisor, Health Canada, POLICY COORDINATION

Connie Berry, Senior Policy Research Analyst, Office of the Voluntary Sector, PHAC

Stephanie Mehta, Senior Policy Analyst, Public Health Agency of Canada, HIV/AIDS POLICY, COORDINATION AND PROGRAMS DIVISION

Cathy Clutton, Executive Director of the Health Evidence and Advice Branch, Australia's National Health and Medical Research Council

Hala Patel, Public Involvement & Consultation Officer, UK Medical Research Council

Francois-Pierre Gauvin, PhD, McMaster University in the Health Research Methodology

Roger Chafe, CHSRF-CIHR post-doctoral fellow in the Department of Health Policy, Management and Evaluation at the University of Toronto and the Cancer Services and Policy Research Unit at Cancer Care Ontario.

2) Consultations on the draft CE Framework:

- Members of the CE Working Group: Andrea Wilson, Research Portfolio, Susan Crawford, Assistant Director of the Institute of Aging, Michelle Gagnon, Acting Director of KSE Branch, Christian Riel and Andrew McColgan, Communications and Marketing Branch,
- Ian Graham, VP, Knowledge Translation Portfolio
- Partnerships and Citizen Engagement team
- 5 of CIHR`s community reviewers serving on Peer Review Panels
- Meeting of the Knowledge Exchange Task Force (IMHA) – Sept 25, 2008
- Meeting of the IAB members who represent the voluntary and NGO sectors - October 28, 2008

3) Survey participants for CIHR`s internal scan – December 2007 - April 2008:

IA	Susan Crawford
IAPH	Cynthia Stirbys, Earl Nowesgic
ICR & III	Benoit Lussier, Judith Bray
ICRH	Ilana Gombos
IG	Ursula Danilczyk , Stephanie Robertson,
IGH	Louise Robert
IHDCYH	Anne-Cecile Desfaits
IHSPR	Ellen Melis
HIV/AIDS Initiative	Jennifer Gunning, Andrew Matejcic
IMHA	Elizabeth Robson , Louise Desjardins
INMD	Paul Bélanger
INMHA	Barb Beckett, Astrid Eberhart, Richard Briere
IPPH	Fiona Webster, Erica DiRuggiero
Marketing and Communications	Angela Prokopiak, Christian Riel, Andrew McColgan, Karen Spierkel
Ethics Office	Genevieve Dubois-Flynn
KSE	Michelle Gagnon
Research Portfolio	Andrea Wilson, Danika Goosney

Appendix 6: Glossary of terms

Advisory Committee (or board, or group, etc.): Committee composed of representatives of stakeholder groups. May be charged with different responsibilities, ranging from overall governance of the project to feedback on critical issues referred to it.

Citizen: An individual Canadian who is neither a delegate nor a representative of any government, organization, association or interest group.

Citizen engagement: For CIHR, citizen engagement is the meaningful involvement of individual citizens in policy or program development, from agenda-setting and planning to decision-making, implementation and review. It requires two-way communication that is interactive and iterative with an aim to share decision-making power and responsibility for those decisions. This requires bringing together a diverse group of citizens that includes the broader public, not just the usual stakeholders for ongoing dialogue, deliberation and collaboration in informing CIHR's work.

Community: The term community delineates a wide variety of human associations, with no single set of defining criteria appropriate to all types. Characteristics of particular importance or relevance to communities in biomedical research can be identified and used to delineate types of communities (see Table A). Communities may be arrayed along a spectrum of cohesiveness, from those that have all the characteristics to those that have only a few. In this tutorial, we broadly use the term community in this sense to encompass any identifiable or self-identifying group interested in or impacted by a particular research study.

Community Based Research: A particular flavour of Participatory Research (see below) where the principal study focus is within a given defined community.

Communications: The techniques that inform the public about policies, programs and services.

Consultations: The techniques involving a two-way flow of information that offers options for consideration and encourages feedback, such as additional ideas or options, from the public.

Continuum of public involvement: The full range of public involvement in issues of public concern. This document refers to five levels of public involvement and pinpoints an array of public involvement techniques along a continuum. Communications techniques are at the "low end", consultation is in the "mid range" and citizen engagement is at the "high end" of the public involvement continuum.

Dialogue: Dialogue is a process that allows people, usually in small groups, to share their perspectives and experiences with one another about difficult issues we tend to just debate about or avoid entirely. Dialogue is not about winning an argument or coming to an agreement, but about understanding and learning. Dialogue dispels stereotypes, builds trust and enables people to be open to perspectives that are very different from their own. Dialogue can, and often does, lead to both personal and collaborative action.

Deliberation: Deliberation is a closely related process with a different emphasis. Deliberation emphasizes the use of logic and reasoning to make better decisions. Decisions about important public issues like health care and immigration are too often made through the use of power or coercion rather than a sound decision-making process that involves all parties and explores all options.

Dialogue and deliberation processes tend to use skilled facilitators and carefully constructed ground rules or agreements to ensure that all participants are heard and are treated as equals.

Dialogue often lays the groundwork for deliberation. The trust, mutual understanding and relationships that are built during dialogue enable participants to deliberate more effectively, and to make better decisions. For groups that want to move from talk to a decision or action.

Dialogue and deliberation are used for a variety of reasons: to resolve conflicts and bridge divides; to build understanding about complex issues; to foster innovative solutions to problems and launch action; and to reach agreement on or recommendations about policy decisions.

Governance: The set of processes and traditions that determine how a society or organization steers itself, how citizens are accorded a voice on issues of public concern and how decisions are made on these issues.

Integrated knowledge translation: An approach to research that weaves knowledge translation activities throughout the research process and that involves knowledge users and others affected by the envisioned results at key stages of the project. Partnerships of researchers and integrated knowledge users actively engage in designing, conducting and disseminating research and assuring its translation to action.

Involvement: The level of participation by the public, or the extent to which the public is actively involved, in understanding, assessing or resolving issues of public concern.

Participatory Research: An approach to research using a partnership between researchers and those impacted by envisioned results, for the purpose of educating, taking action or building capacity to address current and future issues. PR is used as an umbrella term which includes action research, participatory action research, collaborative action research, community-based PR, community-partnered PR, cooperative action research, emancipatory research, participatory rural appraisal, and participatory evaluation.

Partner: An individual, group or organization who participates in, or is responsible for, sharing responsibility for the implementation of various aspects of policy or program decisions.

Partnerships: For CIHR, partnerships are formalized working relationships between two (or more) organizations with separate identities and independent accountabilities. They are based on mutual benefit and a clear understanding or agreement that sets out the shared goals, objectives, and terms of the arrangement.

Public: Individuals, consumers, citizens, special interest groups and/or stakeholders.

Public involvement techniques: A broad range of strategies and methods used to inform citizens and/or accord them a voice on issues of public concern and/or include citizens in decision-making processes related to these issues.

Stakeholder: An individual, group or organization having a "stake" in an issue and its outcome.