

TOWARDS A HEALTHIER CANADA:

A Progress Report on the Relationship Between the Canadian Institutes of Health Research And National Health Charities

Background

Since the establishment of the Canadian Institutes of Health Research (CIHR) Task Force, the voluntary health sector, namely a cluster of health charities and other voluntary organizations – (non-charitable organizations and coalitions that have a specific vested interest in how the CIHR evolves) has been actively engaged in the development and implementation of the new health research enterprise in Canada. With the introduction of the legislation for the CIHR, the voluntary health sector worked hard through representation on the Interim Governing Council; meetings with the Standing Committee on Health, the Senate Committee on Science and Technology and through advocating with Members of Parliament, to show its support of the initiative. The sector pulled together and provided its views on a variety of issues ranging from governance to peer review to partnerships to the establishment of the institutes.

Health Charities Council of Canada

Formally established in June 2000, the Health Charities Council of Canada (HCCC) is the culmination of collective work that national health charities have initiated over several years, partly at the request of the federal Minister of Health. The HCCC is a national umbrella group with a mandate to provide a collective voice for national health charities on common interests and concerns. Member organizations of the HCCC comprise large, medium and small national health charities ranging from the Canadian Cancer Society, Heart and Stroke Foundation of Canada, and the Kidney Foundation of Canada to the Canadian Mental Health Association, the Canadian Public Health Association, the Canadian Celiac Association, and the Thalidomide Victims' Association of Canada. Collectively, this sector provides approximately \$300 Million annually for research in Canada. National health charities are accountable to their members, donors and funders. This accountability includes monitoring how funds raised for research are spent. National health charities come together to effect policy under broad areas of interest: health research; health information/surveillance; community/patient support with the ultimate goal of improving the health of the people of Canada.

Progress Report

This is the first Progress Report issued by the Health Charities Council of Canada on the state of the Canadian Institutes of Health Research (CIHR) and its relationship with national health charities. The objective of this Progress Report is to provide HCCC members with a summary of the status of the relationship and the HCCC commitment to ensure the shared principles of the CIHR continue into the future. Given that the principles of partnership are an integral component of the philosophy, legislation and operating principles of the CIHR, it seemed appropriate to discuss the relationship between the Canadian Institutes of Health Research and the Health Charities Council of Canada with specific reference to some key principles of partnership developed by the sector.

PRINCIPLE: SHARING CONTROL IS A SINE QUA NON OF ANY ENDURING PARTNERSHIP

Progress:

Since the formal announcement of the CIHR Governing Council in June 2000, the CIHR has been working very hard at establishing the right mechanisms to ensure accountability. As one of the sectors mentioned in the legislation, however, the HCCC believes that more work is needed to ensure that decision-making at all levels of the CIHR includes the voluntary health sector as well as other CIHR partners. The sharing of control through active partnership needs to be more effectively exercised on major initiatives such as discussing policy direction that has implications for the voluntary health sector.

Commitment:

The HCCC and its member organizations remain committed to working with the CIHR to establish mechanisms that ensure decision-making at all levels include representation from the voluntary health sector. The HCCC continues to believe that the Governing Council and Institute Advisory Boards have representation that reflects the partnership that occurs in research: 1/3 scientists; 1/3 funders; and 1/3 community/lay representation.

PRINCIPLE: SHARED INTERESTS MUST LIE AT THE HEART OF ANY ENDURING PARTNERSHIP

Progress:

The CIHR and the voluntary health sector have a strong interest that is shared, in working toward ensuring Canada has a robust health research enterprise with the ultimate goal of improving the health of the people of Canada. This shared interest must continue to be one of the pillars for the partnership between the CIHR and the voluntary health sector. A way for the sector, as it is defined in the legislation, to have direct input to the Governing Council is important. Regular meetings with CIHR officials and decision-makers must be established to provide the mechanism needed to discuss issues of concern.

Commitment:

The HCCC will continue to work with the CIHR on shared interests.

PRINCIPLE: SHARED RISK MUST BE PROPORTIONATE TO SHARED BENEFITS

Progress:

The voluntary health sector plays a key role in health research in Canada: in funding, planning, advocating for government funding of research; in priority setting; and in serving as a bridge to putting findings into practice and healthy public policy. Current funding levels for CIHR are nowhere near what is required to support and sustain the kind of health research enterprise in this country that is envisioned. National health charities will therefore need to continue to ensure that they successfully engage Canadians in the funding of health research through their charitable contributions. Only active and direct involvement in all aspects of CIHR can ensure

that this and other aspects of the voluntary sector role are safeguarded.

Commitment:

The HCCC remains committed to ensuring that shared risk must be proportionate to shared benefits.

PRINCIPLE: SHARING INFORMATION IN A TIMELY FASHION IS ESSENTIAL TO BUILDING TRUST AND AN ENDURING PARTNERSHIP

Progress:

The HCCC recognizes that the CIHR is working under a great deal of pressure. Specific milestones must be met in the early days of the CIHR to show the success of the enterprise. Partners, such as the health charities, also need to demonstrate to their publics that it is valuable to partner and demonstrate early success. The CIHR is to be credited for the work that it has done in keeping the voluntary health sector informed about communications activities. The CIHR Director of Communications and his staff have met with representatives from the voluntary health sector to provide an update on activities and seek input on issues of concern. These meetings will need to continue to ensure the regular exchange of information and regular input from the voluntary health sector on CIHR communications. Officials from the Strategic Partnerships and Alliances Branch of the CIHR have met with some individuals within the voluntary health sector, however, more work is needed here. The decision of the CIHR to change some of its partnership programmes that involve national health charities without a more formal consultation with its present partners is of major concern to the HCCC. National health charities have a responsibility in communicating and information exchange with their stakeholders. This role must be strengthened in the months ahead to ensure that continuous and regular communication occurs between the CIHR and the HCCC.

Commitment:

The HCCC is committed to sharing information in a timely fashion and believes that both sides must make a conscious effort to ensure the exchange of information on a regular basis.

PRINCIPLE: SHARED COMMITMENT TO ADVANCING AND DEFENDING SHARED DECISIONS

Progress:

Overall, most of the decisions that have been made to-date have not had formal inclusion of the voluntary health sector as a collective. During the next year, it will be important for both the CIHR and the HCCC to determine how best to implement this principle.

Commitment:

The HCCC strongly supports advancing and defending shared decisions. The Health Charities Council of Canada is committed to participating in a strategic planning session with decision-makers within the CIHR to realize the vision of this health research enterprise.

PRINCIPLE: SHARED COMMITMENT TO INCREASING OVERALL RESOURCES, EFFICIENCIES AND PRODUCTIVITY

Progress:

A number of processes (e.g. peer review), were examined by the Interim Governing Council. Several recommendations were made, however, there seems to be little link between that work and the work that is presently being done by the CIHR. Resources for all involved in the health research enterprise in Canada are limited. It will be critical to ensure a commitment to increasing the resources, efficiencies and productivity. A number of workshops were held in 2000 on the CIHR. Some of these workshops were hosted by national health charities, others by the CIHR. It will be important to build on these workshops (e.g. peer review) in the months ahead.

Commitment:

The HCCC strongly supports the need for increased resources, efficiencies and productivity. The Health Charities Council of Canada believes that to maximize all resources, the CIHR needs to work with its partners to find the best mechanism and structure possible. The HCCC strongly supports the federal government's commitment to increase the funding base of the CIHR. It is committed to working with other partners to ensure that the funding base of the CIHR is dramatically increased during the next three to five years.

NEXT STEPS

Currently the Health Charities Council of Canada has had a more informal approach to research that has often been reactive. In the foreseeable future the issue of research, its funding, its dissemination, advocacy for increased resources and collaboration amongst health charities will become even more important. With this in mind, the Health Charities Council of Canada will be examining the following:

- Establishment of a more formal mechanism to monitor and respond to issues of research primarily with, but not limited to, the Canadian Institutes of Health Research; and
- Participation in the development of joint messaging and advocacy efforts with other national health research stakeholders for increased health research funding in Canada.