Increasing Wellness in Canadians: The Role of Health Charities

Discussion Paper for the Health Charities Council of Canada (HCCC)
4th Canadian Health Charities Roundtable

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EXECUTIVE SUMMARY

This discussion paper presents findings from a research study that explored the use and meanings of the term “wellness” by members of the Health Charities Council of Canada (HCCC), as well as health charities’ current and future involvement in improving wellness in the Canadian population. The paper will be used to facilitate discussion at the HCCC’s upcoming 4th Roundtable to be held April 27-12, 2001. The theme of the Roundtable is “Increasing Wellness in Canadians: The Role of Health Charities”.

The research study utilized two qualitative methods – key informant interviews and an open-ended survey. Respondents were all familiar with the term “wellness”, although most health charities do not use the term. Many were concerned about the use of a new term in federal discourse about health, particularly in cases where it did not fit with the work of the health charity or with the nature of the disease or illness with which the charity was concerned. The adoption of the term “wellness” by health charities is not likely in the context of severe illness or disability. As well, attention to semantics may divert attention and resources that should be used for strategies and services.

“Quality of life” was a term preferred by many health charities (about 70%), as it applied to the health and well-being of their target populations. Health, health promotion, and prevention were other frequently used terms. For many health charities, “wellness” is implicit in their philosophies and their work. Many insights were provided on various dimensions of “wellness” – physical, emotional, intellectual, spiritual, social, and environmental – that could be used by the HCCC, Health Canada, or others interested in defining the parameters of the concept “wellness”.

Virtually all respondents saw health charities as playing a key role in decreasing health inequalities among Canadians. Addressing inequality was often articulated in terms of equal access to services across the country and participation in policy development. Some health charities paid special attention to “vulnerable groups” or provided financial support for constituents. Although the attitude that “everyone should have a role” in decreasing inequalities was prevalent, respondents also referred to specific mandates of organizations and a lack of resources as limitations on the extent to which health charities could, or should, address health inequalities. However, health charities have a “connection” to Canadians through local organizations and volunteers that provides them with a unique understanding of health and illness issues which could contribute significantly to a federal agenda for health.

Health charities are very much involved in reducing pressures on the health care system. They “fill the gaps” in the health care system by providing timely and credible information, programs and services, research funding and programs, education for the public and health professionals, and advocacy on behalf of their client groups. However, respondents were cautious about taking on roles which were seen as government “downloading”, and noted that health charities often seek to increase pressures on the health care system in order to provide for the needs of their client groups.

Respondents were aware of Health Canada’s work on developing a Wellness Agenda and offered many useful perspectives on it. They were vocal about the importance of governments, health charities and others working together to address the health of Canadians. Respondents agreed that the HCCC has an important role to play in developing a national agenda for health, including increasing public awareness of the HCCC, of the current roles of health charities, and of the importance of inclusive partnerships to formulate a national agenda for health.

INTRODUCTION

This discussion paper examines findings from a research study that explored the use and meanings of the term "wellness" by members of the Health Charities Council of Canada (HCCC), as well as health charities' current and future involvement in improving wellness in the Canadian population. The paper will be used to facilitate discussion at the HCCC's upcoming 4th Roundtable to be held April 27-12, 2001. The theme of the Roundtable is "Increasing Wellness in Canadians: The Role of Health Charities".

The theme of the 4th Roundtable has been chosen in the context of Health Canada's emerging "Wellness Agenda"[1]. For approximately the last two years, Health Canada has been working on the formulation of a Wellness Agenda for the nation. The use of the term "wellness" is a deliberate move away from the use of the term "health", as "health" is typically associated with illness and with the institutional health care system. Although "wellness" has not been defined by Health Canada (Paradis & Watson-Wright, 2001), three goals have been established for the Wellness Agenda: (1) to improve the health of Canadians; (2) to decrease health inequalities among Canadians; and, (3) to reduce pressures on the health care system[2]. The use of the term "wellness" is meant to shift the focus to personal health practices, prevention, and the determinants of health, and to engage other government departments in examining their roles in addressing current challenges to the health of Canadians (Paradis & Watson-Wright, 2001).

The Health Charities Council of Canada was established in 2000. At the 3rd annual HCCC Roundtable, held in June 2000, three main activities were identified as central to the work of all health charities in Canada: information/surveillance, research, and community/patient support. Historically, the health charities have worked individually in each of these areas. With the formation of the HCCC, the health charities have an opportunity to work together toward improving health for their various constituents and for the Canadian population as a whole. Health Canada's current development of the Wellness Agenda provides an opportunity for health charities to contribute to a national plan for health. This discussion paper explores the roles of health charities in improving "wellness" in Canada and provides insights on how health charities and the HCCC might contribute to the Wellness Agenda.

Contents of the Discussion Paper

Part I of the discussion paper presents an overview of the concept of "wellness" and its various dimensions. It then examines the relationship between "wellness" and "lifestyle", another emerging concept with the potential to provide conceptual guidance in the development

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[1] Health Canada now refers to the Wellness "Framework", rather than the Wellness "Agenda". However, "Wellness Agenda" is used throughout this paper, as this was the context in which the research was conducted.

[2] This third goal has been revised by Health Canada. It is now "to sustain the health care system", rather than "to reduce pressures on the health care system." However, this paper refers to the original goal, as this terminology was contained within the interview guide and email survey.

of a national health agenda. Part II outlines the methodology used to gather information from members of Canadian health charities related to the use of the term "wellness" and their roles in improving wellness in Canadians. Part III presents findings from indepth interviews with key informants who are members of Canadian health charities. Part IV presents findings from an email survey of the general membership of the HCCC. Finally, Part V presents a summary of the findings and posits a number of questions for discussion at the 4th Roundtable.

PART I: WHAT IS "WELLNESS"?

The term "wellness" gained currency in the 1960s, in conjunction with the "alternative health" movement (Reichler, 1999; Ardell, 1999; Price, 1998; Dunn, 1961). Although the roots of the concept can be traced back to various forms of medicine that have existed for many years (Fopeano, 2000), more common understandings are often in keeping with alternative interventions and approaches to health (Mannell, 1999) which are outside of the mainstream 'medical model'.

The notion of "wellness" generally focuses attention on optimal states of health and does not refer to illness contexts (Fopeano, 2000; Neilson, 1988; Myers, Sweeney & Witmer, 2000). However, emerging definitions of wellness are consistent with a 'population health' approach which recognizes the interplay between the individual and her/his environments (Health Canada, 1996; WHO, 1998).

The connection between "wellness" and "illness" is not explicitly articulated in current definitions of wellness, but there is an implicit recognition (with reference to the individual's environment), that wellness can be achieved despite illness. "*Whether we use the term health or wellness, we are talking about a person's overall responses to the challenges of living." (*Donatelle, Davis, Munroe & Munroe, 1998, p.123).

Dimensions of Wellness

The dimensions of wellness are very broad, encompassing various aspects of the person, as well as aspects of her/his environment. Taylor's definition, below, is typical of the broad understandings of wellness found in the literature.

"Wellness is a holistic approach to health that is multidimensional in nature. It has been described as an integrated life model that empowers and respects natural laws of the universe, and includes such dimensions as social, emotional, spiritual, occupational, intellectual, psychological and physical well-being" (Taylor, 1991, p.1).

Definitions of wellness typically contain a range of dimensions. For example, the NB Select Committee on Health Care (2000) describes five dimensions, while others describe six (Donatelle et al., 1998; Fopeano, 2000), or seven dimensions (Taylor, 1999; Insel & Roth, 1991). The table below outlines seven dimensions typically included in definitions of wellness.

DIMENSIONS OF WELLNESS (Insel & Roth, 1991)	
Dimension	**Description**
Physical	Eating well, being physically active, avoiding harmful habits, making responsible decisions about sex, regular medical and dental checkups, taking steps to prevent injury
Emotional	Optimism, trust, self-esteem, self-acceptance, self-confidence, satisfying relationships, ability to share feelings.
Intellectual	Openness to new ideas, capacity to question and think critically, motivation to master new skills, sense of humour, creativity, curiosity. An active mind is essential to overall wellness, for learning about, evaluating, and storing health-related information.
Spiritual	To possess a set of guiding beliefs, principles, or values that give meaning and purpose to life, especially during difficult times, involves the capacity for love, compassion, forgiveness, altruism, joy and fulfillment.
Interpersonal / Social	Satisfying relationships are basic to both physical and emotional health,involves good communication skills, developing the capacity for intimacy, cultivating a support network of caring friends and/or family.
Environmental / Planetary	From the safety of the food supply to the degree of violence in a society.
Occupational / Vocational	Ability to obtain personal satisfaction through work (Fopeano, 2000)

Most authors emphasize that the dimensions of wellness are interconnected (Fopeano, 2000; NB Select Committee on Health Care, 2000). The dimensions of wellness interact on a continuous basis. They influence and are influenced by one another (Insel & Roth, 1991).

Wellness and the Pursuit of Health

The terms wellness and health are often used interchangeably. In written materials on the Wellness Agenda, Health Canada uses the WHO definition of health: *"Health is the state of complete physical, mental and social well-being, not merely the absence of disease or infirmity"* (WHO & Health Canada, 1986). Although wellness and health are used interchangeably, the literature suggests that the concept of wellness goes beyond the concept of health in drawing attention to maximizing health.

*"Wellness… signifies something quite different from good health. Good health can exist as a relatively passive state of freedom from illness in which the individual is at peace with his/her environment – a condition of relative homeostasis. … High level wellness for the individual is an integrated method of functioning which is oriented toward maximizing potential of which the individual is capable, within the environment where she/he is functioning" (*Neilson, 1988, p.4*).*

In most definitions of wellness, the element of individual action and responsibility is evident. "*Wellness is health promotion in action*." (Fopeano, 2000, p.15). In other words, it is expected that wellness is something that people actively pursue (Neilson, 1998). While the advance of the information revolution of the 21st century has great potential to help people

improve their health (Insel & Roth, 1991), it also indicates an emphasis on individual responsibility for health.

While "health" is generally equated with health status and behaviour, "wellness" has greater connotations of "thinking about" or "aspiring to" a higher greater state of health (Dunn, 1961). "Health" is something that you have, "well" is something that you are or work toward. Many definitions of wellness contain the idea of working toward a 'future state'. For example, *"The wellness model focuses on excellence in health and progress toward a future state of health. A high level wellness involves direction in progress forward and upward toward a higher potential of functioning*" (Larson, 1991, p. 4).

Typically, definitions emphasize the pursuit of individual health. For example, *"[wellness] is the optimum state of health and well-being that each individual is capable of achieving*" (Myers, Sweeney & Witmer, 2000, p. 253). In this sense, wellness is about each person achieving the best health possible, while recognizing that the pursuit of wellness occurs in a "sometimes hostile environment" (Donatelle, David, Munoe & Munroe, 1998).

The Environmental Context of Wellness

The influence of physical and social environments on health is emphasized in public health, health promotion, and the current focus on population health and social inequalities (Glouberman, 1999). As stated above, many definitions of wellness emphasize the individual's pursuit of health, but some refer also to the environmental context in which health is achieved. The following definitions refer to both human and physical environments.

"We define wellness as a way of life oriented toward optimal health and well-being in which body, mind and spirit are integrated by the individual to live more fully within the human and natural community." (Myers, Sweeney & Witmer, 2000, p. 253).

"Wellness is a state of emotional, mental, physical, social and spiritual well-being, that enables people to reach and maintain their potential in their communities." (NB Select Committee on Health Care, 2000, p. 3). Therefore, environments are beginning to be recognized in relation to wellness, but little work has been done to concretize these connections.

Quality of Life and Wellness

Quality of life is a term that is often encountered in discussions of wellness. The following two definitions are typical of conceptualizations of quality of life found in the literature.

"*Quality if life is defined as an overall general well-being that is comprised of objective and subjective evaluations of physical, material, social and emotional well-being together with the extent of personal development and purposeful activity, all weighted by a personal set of values" (*Felce & Perry, 1996, p.52).

"… a person's perceived quality of life is related significantly to factors within three major domains that include home and community living, school or work, and health and wellness" (Schalock, 1996, p. 105).

These definitions underline key areas which can be applied when thinking about "wellness". Attention must be given to both objective and subjective perspectives on health, and

environmental contexts must be considered. Wellness and quality of life are overlapping concepts. Some of the objective and subjective indicators of quality of life are the same as those of wellness. For instance, the presence of major life stressors, access to preventive health services, and social support could be considered indicators of both wellness and quality of life. Wellness would likely be considered within the concept of quality of life.

Which is the most appropriate term to use when the two concepts are so closely related? On the one hand, quality of life indicators such as housing or employment contribute to wellness. On the other hand, wellness indicators such as feeling healthy and energetic contribute to quality of life. What is the appropriate term to use, quality of life or wellness, when addressing specific issues such as poverty or mental health, or when thinking about the best approach to examining and acting on the needs of specific populations such as individuals with chronic health problems?

Wellness and Lifestyle

The term "wellness" has connotations of individual choice and control, the idea being that people can choose to live in healthy ways through lifestyles choices (Fopeano, 2000, Mannell, 1999). Most definitions refer to modifiable determinants of health such as nutrition, physical fitness, stress reduction, and self-responsibility (California Wellness Foundation, 2001).

The ideas contained in a recent paper commissioned by Health Canada help to build awareness of environmental conditions affecting health, and draw attention to the need for collective and "determinants of health" approaches to health. *Healthy Lifestyle: Strengthening the Effectiveness of Lifestyle Approaches to Improve Health* (Lyons & Langille, 2000) points to the role of policy and decision makers in providing leadership to reduce the tensions inherent in a health system which places pressure on individuals (who are often living in unhealthy contexts) to live healthier lives. The paper suggests that individual responsibility (what I do) is by no means irrelevant, but society (what we do, what I do for those around me) and the state (healthy environments, healthy public policy, reduction in social inequities) must also be given due responsibility. The following sections briefly elaborate some ideas from the *Healthy Lifestyle* paper that might help in positioning "wellness" and "lifestyle" as key concepts in maintaining and improving the health of Canadians.

Emerging Concepts of Health

As our society evolves, so do the concepts we use to understand and act on the world around us. The concept "wellness", like the concept "lifestyle", has changed and is changing in the context of new thinking about health and responsibility for health. In the case of the concept "lifestyle", the ways that the concept has been articulated and understood may in fact be undermining its usefulness as a construct for understanding and acting on the determinants of health. Rather than emphasizing individual responsibility and choice, the authors of "*Healthy Lifestyle*" suggest an emphasis on the interdependence between individuals and their community or communities. Expanding "lifestyle" beyond an individualistic notion is key to fostering healthy people and healthy communities. The same is true of the concept "wellness". When people come to understand that health or "wellness" is achieved in the context of families, communities, and society, "what to do" about health can become clearer.

The concept of lifestyle assumed new importance for Canadian health policy with the 1974 publication *A New Perspective on the Health of Canadians* (Lalonde, 1974). This landmark document was among the first to identify lifestyle as a determinant of health and illness, and influenced thinking about health around the world. Lalonde defined lifestyle as:

> *"The aggregation of decisions by individuals which affect their health, and over which they more or less have control. ... Personal decisions and habits that are bad, from a health point of view, create self-imposed risks. When those risks result in illness or death, the victim's lifestyle can be said to have contributed to, or caused, his own illness or death."* (p. 32)

Early discussions of lifestyle centered primarily on nutrition, exercise, smoking, and alcohol use. Programs to improve lifestyle were founded on a belief that information and education would change lifestyles. While revolutionary in its day, our understanding of lifestyle and its relationship to health has evolved substantially since that time. Research and experience in health promotion has changed the way we think about lifestyle and how we work to improve health.

Over twenty years later, the WHO definition (WHO 1998) of lifestyle provided a broader understanding of the determinants of a healthy lifestyle. It stated that lifestyle is a way of living based on identifiable patterns of behaviour which are determined by the interplay between an individual's personal characteristics, social interactions, and socioeconomic and environmental living conditions.

The WHO definition suggested that patterns of behaviour are continually adjusted in response to changing social and environmental conditions. It also suggested that efforts to improve health by enabling people to change their lifestyles must be directed not only at the individual, but also at the social and living conditions which contribute to the behaviour or lifestyle. The WHO definition further stated that there is no one "optimal" lifestyle, and that many factors determine which way of living is appropriate for each individual. Individuals are connected to each other and to the society around them, and new ways of thinking about health or wellness must incorporate evidence on the impact of health promotion and lifestyles strategies on health behaviour and health status.

1. Interdependence Between Individuals and Society

Interdependence refers to the connection between individuals and their social environments. An individual's identity, choices, lifestyle, and degree of "wellness", are influenced to a large degree by the nature of one's independence. If conceived on the basis of interdependence, "healthy lifestyle" or "wellness" can be understood less as acquiring strictly personal health skills, and more as acquiring competencies and an orientation to creating a mutually supportive environment for optimal health.

The population health framework is based on strong evidence of the need for attention to the broader social level (Health Canada, 1996; Evans, Barer & Marmor, 1994). Somewhere on a continuum between the individual and society as a whole is the **community**. A community is a collective of people identified by common values and mutual concerns for the development and well-being of their group or geographical area (Green & Kreuter, 1999). The community is the locus of interaction between people as well as the locus of many health determinants external to individuals (e.g., environment and income). The impact of the community on health is not uni-directional (i.e., my community affects my health). The relationship is bi-directional (i.e., individuals strengthen or weaken a community and influence the well-being of others) and inter-connected (i.e., the community and its members are inseparable). Communities can

be defined on the basis of geography, ethnicity, religion, socio-economic status, or health or illness status.

2. Community Approaches to Health and Wellness

Community initiatives aimed at modifying the relationship between the individual and the environment hold great promise. These social ecological approaches have been shown to have a positive effect on health (Anderson, 1999; Glouberman, 1999; Stokols, 1996). Social ecological approaches view health as a product of the relationship between the individual and the environment, and focus on enhancing people's capacity to engage in and create their social environment. They are multi-disciplinary, with a strong citizen participation component. These approaches integrate individual and environment-focused interventions, and are embodied in initiatives such as the Healthy Communities movement (OHCC, 1999; Poland, 1996; Hancock, 1993), the Community Action Program for Children (CAP-C), and asset-based community development (McKnight, 1987; Lomas, 1998; Kretzmann & McKnight, 1993), participatory action research, and many other community health promotion programs (e.g., Raphael et al., 1999). Over the past decade, the Health Promotion and Programs Branch of Health Canada has supported hundreds of community based projects aimed at enhancing the capacity of individuals to engage in and shape their social environments.

Enhancing the scope for interdependence involves individuals interacting within their community as they address particular types of issues, and assist others in their community. As the scope of the problem being addressed becomes more complex, the level of action becomes more complex because people need more resources (chronic illness, for example). Therefore, knowing the level of collective action needed to effectively address an issue is an important coping skill. In fact, the "pursuit of health" might involve the acquisition of coping skills, the accumulation of coping resources, and the development of coping strategies from an interdependence perspective.

Which Strategies Are Most Effective in Fostering Healthy Lifestyles or Wellness?

General findings from research on health promotion and modifying health behaviours suggest that some strategies work better than others in improving lifestyles or health.

- Cultural norms often need a substantial injection of resources to stimulate prolonged change. In order for people to engage in healthy lifestyle and seek to achieve wellness, the norms and values of the society must support health.
- Target populations must be involved in initiatives in order to influence success and sustainability of efforts and activities.
- Information about health and wellness should be provided in conjunction with policy change (Anderson, 1999; Montonen, 1996; Reid, 1996). Information competes with a barrage of real life experiences that provide conflicting messages. Public policy can help to alter people's experiences.
- Some programs, by their very success, exacerbate the social gradient in relation to health status. In other words, those who are healthy and possess many resources, become healthier while by comparison, those who are less healthy and possess few resources, appear even more unhealthy. Decreasing inequalities in terms of health status and access to health

information and service must be a major consideration in national health or wellness strategies.

Population Health is Central to "Lifestyle" and "Wellness"

A population health, or "determinants of health", approach has been formulated by Health Canada in the past few years (Health Canada, 1996). These determinants include income and social status, social support networks, education, working conditions, social environments, physical environments, personal health practices and coping skills, healthy child development, biology and genetics, health services, gender and culture (Health Canada, 1996). Many of these determinants can be expanded to help build new frameworks for understanding health.

Understandings of the health determinant "education", for example, must recognize that learning goes beyond formal education. Lifelong learning is part of a healthy lifestyle and intellectual development is part of being "well". A sense of purpose and meaning in life is a key element of a healthy lifestyle (Ansbacher, 1959; Bhatti, 1999), and spirituality has also been identified as a key element of "wellness" (Insel & Roth, 1991; Fapeano, 2000). These ideas can help to expand our understandings of the determinants of health, and to bring broad social and environmental considerations to discussions of individual health status and behaviour.

Working Definition of "Wellness"

In order for the concept of "wellness" to be applicable to the work that health charities do, and to be a useful tool in moving toward improving the health of Canadians, "wellness" must be defined in keeping with a population health approach, and with due consideration to the interdependence between individuals and the social contexts in which they live. Health charities, by virtue of extensive experience in working with people who are ill, and in working toward health promotion and illness prevention, can offer a variety of perspectives that can be used in conceptualizing wellness in a way that fits with the health status of all citizens of Canada and incorporates understandings of the social contexts of health.

Assuming a range of knowledge and understandings of "wellness" on the part of members of the executive committees of national health charities, the researchers, with input from the Planning Committee for the HCCC 4th Roundtable, sought a "working definition" of wellness for the purpose of this study. The definition below incorporates the connection between individuals and society, and the idea that wellness can be achieved despite illness.

"Wellness is the state of optimum health and well-being achieved through the active pursuit of good health and the removal of barriers, both personal and societal, to healthy living. Wellness is more than the absence of disease; it is the ability of people and communities to reach their best potential in the broadest sense." (The California Wellness Foundation, 2001).

PART II: METHODOLOGY

In order to collect information related to understandings of the term "wellness" and health charities' roles in relation to wellness, a research project was undertaken. The research utilized two qualitative methods – key informant interviews and an open-ended survey. First, in-depth telephone interviews were conducted with selected members of the HCCC. Second, an

open-ended survey was sent to HCCC members and prospective members via electronic means (email).

Key Informant Interviews

The interview guide was developed in consultation with members of the Planning Committee for the 4th Canadian Health Charities Roundtable. Interview questions were directed toward understandings of "wellness", and current and future roles of Health charities in improving wellness in Canada. The fourteen questions explored HCCC member's conceptions of wellness, use of the term wellness, perspectives on Health Canada's three goals for the Wellness Agenda, use of a "determinants of health" perspective, current activities of health charities as they relate to wellness, and future directions of health charities in relation to wellness and the wellness agenda. The interview guide (Appendix A) was pilot tested with a local representative of a national health charity and reviewed by the Planning Committee. The guide was modified on the basis of consistency (order of questions) and length.

Non-random deliberate sampling, which is the purposeful selection of participants, was utilized for key informant interviews, in order to obtain a selection of informants who would reflect the general characteristics of member organizations. Participants were selected from the membership list of the HCCC. Key informants were chosen on the basis of size of organization (small, medium and large). In addition, several national organizations whose primary interest is health were added to the interview list. Key informants represented the HCCC 4th Roundtable Planning Committee, the HCCC Governing Council, and the general membership.

The researchers initially contacted potential interview participants by email. A cover letter explained the purpose of the project, assured confidentiality of responses, and outlined the topics to be covered during the interview. The email correspondence asked potential participants to contact the researchers by telephone or through email to arrange for a time to conduct the interview. Other interviews were arranged during telephone follow-up with those who did not respond to the email correspondence. Verbal consent to participate was obtained from each respondent before the interview commenced.

The Planning Committee identified seventeen individuals as potential participants in the key informant interviews. Two potential participants declined participation in the initial contact due to their perceived close relationship with the research project, and three more dropped out during the recruitment process. A total of 12 interviews were completed, representing a participation rate of 70.5%.

Email Survey

In order to reduce the length and content of the interview guide to gather information from all members of the HCCC, a teleconference took place with the researchers and the Planning Committee following the telephone interviews. The interview guide was reduced from fourteen to nine questions (Appendix B) for distribution to the HCCC general membership. All members and prospective members of the HCCC were invited to respond to the email survey. The initial email correspondence contained a cover letter that explained the purpose of the research, assured confidentiality of responses, and outlined the topics covered in the survey. Potential participants were asked to respond within one week. After one week, reminders were sent by both the researchers and the Executive Director of HCCC to those who had not yet responded to the initial invitation to participate.

Fifty-four individuals were identified as potential respondents to the email survey. Two messages were returned to the researchers as undeliverable. After one week, seventeen surveys

had been returned. In response to reminders, four more surveys were returned (total N= 23). Respondents to the survey included sixteen members of HCCC (69.5%), two non-members (8.6%), four respondents uncertain of their membership status (17.3%), and one person who did not indicate membership status (4.3%). The overall participation rate for the survey was 44.2%.

Data Analysis

The telephone interviews were tape-recorded and transcribed. Interviews were 30-60 minutes in duration. Code names (numbers) were applied to each interview in order to protect the confidentiality of respondents, and names of organizations were removed from quotations to be used in the text of the report.

Responses to the interview and survey questions were analyzed to extract themes related to the concept "wellness" and to the current and future roles of health charities in promoting wellness in Canada. For the purpose of presenting the findings, responses were quantified with reference to the strength of response. In the interview findings, none = 0, few = 1-3, some = 4-7, most = 8-11, and all = 12. In the survey findings, none = 0, few = 1-7, some = 8-14, most = 15-22, and all = 23.

PART III: FINDINGS FROM KEY INFORMANT INTERVIEWS

Findings from the key informant interviews are presented below. The key findings from each question in the interview guide are introduced in a "key findings" box, followed by quotations from respondents. Each quotation is identified by a "respondent code", assigned by the researchers.

A. PERSONAL FAMILIARITY WITH AND USE OF THE TERM "WELLNESS"

In the telephone interviews, key informants were asked whether or not they were familiar with the term "wellness". All were familiar with the concept, but understandings and use of the concept varied widely. It was described as a "difficult" concept, and several people made a distinction between their "personal" reaction to the term, which contrasted with their reactions in terms of the concept's usefulness for their organizations and current discussions about population health.

KEY FINDINGS
PERSONAL FAMILIARITY WITH AND USE OF THE TERM "WELLNESS"
1. Can "wellness" encompass "illness"? 2. Other terms were preferred – Health, health promotion, quality of life 3. "Wellness" can be pursued 4. "Wellness" has a social context

1. Can "wellness" encompass "illness"?

Informants speculated on whether the meaning of "wellness" could encompass illness, and the extent to which people who are ill could pursue "wellness". The term "wellness", for many respondents, is more congruent with illness that is preventable, than with illness or disease that is non-preventable.

"I find the first thing that comes to my mind is lack of disease." (02)

"It does not necessarily mean absence of illness." (07)

"… thinking of fitness, the jogger…, wellness is a good word for that." (06)

"Does it mean the absence of disease, or the absence of feeling lousy?" (02)

"A person with disease could achieve wellness if they received appropriate treatment and access to treatment and therapies." (12)

"I don't want to characterize it as bipolar. I think people will always have various degrees of abilities and disabilities, or of health and illness. There is a continuum there." (03)

2. Other Terms Were Preferred

Informants generally used terms other than "wellness" in their work. Health, health promotion, and quality of life were preferred terms.

Health

"I feel better about the word health, can understand that health is broader than just being well." (06)

"… the ability to be healthy; people having healthy mind, body, and spirit." (04)

"I am familiar with the WHO definition…" (07)

"Health and healthy have the same connotations." (08)

Health Promotion / Illness Prevention

"I use wellness in the sense of preventative." (05)

"Wellness can be defined as an outcome of health promotion, prevention." (10)

"What is needed is a health promotion and wellness agenda." (01)

Quality of Life

"Wellness is making sure that the quality of life is the highest quality possible." (03)

3. "Wellness" Can Be Pursued

"The pursuit of health" was evident in informants' responses to the interview questions. In addition, the elements of taking conscious action and personal control over health were described in definitions of wellness.

"You live well, you interact with your friends, you are an active participant it life." (02)

"It's a state of active commitment to doing things that promote health." (08)
"[Wellness] refers to mental outlook, surviving socially and in families." (05)

"I think of wellness as a state of positive well being, or consciousness, where people feel a sense of control and autonomy in their lives, and empowerment to successfully engage in society." (09)

4. "Wellness" has a Social Context

Informants recognized the social context of health. Some feared that using the term "wellness" placed too much emphasis on the individual.

"Use a holistic perspective, wellness in the home, workplace, in the community." (12)

"We are committed to wellness issues and to addressing determinants of health… how to maintain a state of good harmony for the individual in the context of society." (09)

"Wellness includes opportunities for a healthy life and therefore is affected by the social and economic determinants of health" (11)

"I worry about 'wellness' because it can sound very individualistic." (09)

"Health charities and the government focus a lot on individual risk factors and how we can intervene to get people to change their individual lifestyle, as opposed to pulling back and saying on a population basis, how can things like policy be used to change risk factors." (10)

B. Health Charities' Use of the Term "Wellness"

Key informants were asked whether or not their organizations used the term "wellness". Whether or not "wellness" was a part of the lexicon of the organization often depended on the health status of its constituents.

Key Findings
Use of the Term "Wellness"
1. Some health charities use the term, often in conjunction with other terms
2. Some health charities do not use the term at all, preferring other terms

1. Some health charities use the term "wellness"

However, it is often used in addition to other terms such as health promotion or prevention.

"Yes, it's an important part of the charity's mission and agenda." (01)

"Yes, it is a language that we use." (07)

"We use wellness…, also use prevention and health promotion." (09)

"It tends to creep in…. we tend to use health promotion" (08)

" The provincial division uses it, uses a holistic perspective." (12)

2. Some health charities do not use the term "wellness" at all

The concept "wellness" does not distinguish between the 'average' Canadian's definition of health, and a definition which might be used by someone who has a severe health problem or disability.

"For most Canadians, breathing artificially through a ventilator would not be seen as wellness." (03)

"No, we use ideas about the mind, body, and spirit…, quality of life" (04)

"Never." (06)

"No, it is just a restatement of something we have done for years and called health promotion." (10)

"No, we use health promotion, prevention, protection, although wellness is relevant." (11)

"We do [these kinds of activities]… but just do not use the terminology of wellness." (05)

"If you read our brochures, you won't see it anywhere." (03)

C. SHOULD HEALTH CHARITIES USE "WELLNESS"?

Key informants were asked if it would make sense to encourage the use of the term "wellness" within their organizations. Some informants did not think it was a good idea to encourage the use of the term "wellness", given the perceived lack of "fit" between the term wellness with their work and the ideas they are advancing. Many respondents commented on the need for a very broad definition of wellness, if the concept was to be useful for their organizations. For some, the discussion of wellness was a "semantic issue" which diverted attention away from addressing the health needs of Canadians.

KEY FINDINGS
SHOULD HEALTH CHARITIES USE "WELLNESS" ?
1. "Wellness" doesn't 'fit' with the work of some health charities 2. It's a question of semantics 3. If "wellness" is to be used, a broad definition is required 4. Some people are willing to work with the term "wellness"

1. "Wellness" Doesn't Fit With the Work of Some Health Charities

For some health charities, particularly those focused on non-preventable diseases, "wellness" does not fit well with their mandates and activities.

"No. We use the concept of independent living." (03)

"No. We use quality of life." (06)

"Use different terminology." (05)

"The reality is that the notion of wellness is a very foreign notion to many of the people we serve and we still have to serve them." (04)

2. It's a Question of Semantics

For many respondents, the issue of whether or not to use the term "wellness" was a question of semantics. For many, "wellness" is implicit in the work they do. The adoption of the term "wellness" was not likely in the context of severe illness or disability, and the introduction of a new concept distracted them from the treatment and prevention of illness. Attention to semantics may divert attention and resources that should be devoted to strategies and services.

"It's a semantic debate." (08)

"There is a semantic issue…. It is a difficult word for people with severe chronic illness or diagnosed terminal illness." (06)

"Who is going to define it? It is such a large subject, it has to be broken down for people to understand what it is they are trying to accomplish." (02)

"You would need a social marketing campaign to change people's understanding of the word. When you get into that, I would question whether it's the most useful word you could have. You are then convincing people that the word is right, as opposed to convincing them that there are things they can do, and that others can do in society, to help them live more fully with whatever they have." (06)

"We keep regrouping and renaming concepts that have been around for ages, we are just not implementing well enough." (10)

3. If "Wellness" is to be Used, a Broad Definition is Required

"Health Canada will have to define wellness in a broad sense. They may need a whole segment that is about living with illness and finding wellness." (06)

"You have to define it globally, but also in each section. I am sure that for diabetes, it means something totally different than it does for [our organization]. So it has to be a definition that encompasses them both." (02)

"[The term]… would have to stretch the domain to include people who are severely ill or disabled." (03)

"Wellness is an interdisciplinary, inter-issue focused process." (09)

4. Some People Are Willing to Work With the Term "Wellness"

"I am prepared to accept it." (08)

"… if there was a definition that would fit with what health charities are doing." (02)

D. What Would Help or Hinder Health Charities in Promoting The Use of the Term "Wellness"?

Key informants were asked what would help or hinder their organizations in promoting the use of the term wellness. Suggestions included integrating the concept into the formal health system and providing resources, particularly to smaller organizations. The integration of the term "wellness" into organizations is hindered by two constraints: (1) the need to respond to health concerns (e.g., treatment), rather than focusing on promotion and prevention; and, (2) a perceived national focus on short term, rather than long term, conceptual frameworks and commitments to improving health.

E. Health Charities' Attention to the Dimensions of Wellness

Key informants were asked "To what extent does your organization attend to the following dimensions of wellness: physical, emotional, intellectual, spiritual, social, environment?" All health charities attend to the physical and emotional dimensions of wellness. The least amount of activity was in the spiritual and environmental domains. As well, the degree of involvement in multiple dimensions of wellness varied from charity to charity. For example, in relation to the physical dimension of wellness, some charities were heavily involved in programming and activities in regions and communities, while others were solely involved at a policy level. It should be noted that the following table presents a simplified summary of whether activities occur in each of these dimensions. In some cases, informants simply responded 'Yes' and did not provide examples.

Attention to the Dimensions of Wellness						
Respondent Code	Physical	Emotional	Intellectual	Spiritual	Social	Environmental
01	✓	✓	✓	✓	✓	✓
02	✓	✓	✓		✓	
03	✓	✓	✓	✓	✓	✓
04	✓	✓	✓	✓	✓	✓
05	✓	✓	✓	✓	✓	✓
06	✓	✓		✓		
07	✓	✓	✓	✓	✓	✓
08	✓	✓	✓		✓	✓
09	✓	✓	✓	✓	✓	✓
10	✓	✓	✓		✓	✓
11	✓	✓	✓	✓	✓	✓
12	✓	✓	✓		✓	✓

Key informants, in the process of explaining their organizations' activities related to each of the dimensions of wellness, provided insights on how each of these dimensions might be

understood and addressed. As well, responses to this question revealed the various levels of functioning of health charities, from national offices to local associations.

"From an active point of view, it is mainly physical and mental, but all from a policy perspective." (01)

"[The organization] develops policies, programs, etc. that are implemented by others, and in turn, those organizations are influencing these dimensions." (11)

HEALTH CHARITIES' ATTENTION TO SIX DIMENSIONS OF WELLNESS

The table above indicates that most health charities attend to all dimensions of wellness to some degree. Examining the responses in depth provides insights into the nature of their work in these areas, and can help to broaden conceptualizations of "wellness".

Physical Wellness:

All key informants reported that their organizations were engaged in activities related to physical wellness/health.

"We educate people, give them tools." (02)

"You have to keep our boundaries in mind, we are dealing with people who are already ill." (04)

"It's very clear… diagnosis, diet." (05)

"To a great extent, we have programs and information delivery that are intended to improve physical well-being." (12)

Emotional Wellness:

Emotional wellness was also a significant concern for health charities.

"Informal peer support systems are encouraged very strongly. Have a peer support program which provide links between patients and professionals, which require training…. Also looking at telephone outreach program." (04)

"There are huge quality of life issues. Counseling, support groups…., family and social issues." (05)

"Support programs… , active programs across the country." (08)

"Focus on stress, psychosocial as a component… ." (10)

Intellectual Wellness:

Some key informants asked what was meant by "intellectual wellness". Responses were mainly of three types: (1) references to the amount of learning that people must often undertake to understand and treat an illness or disease; (2) reference to "research excellence"; and (3) reference to the materials produced by their organizations.

"I don't think so, unless you say learning about the disease, that's not the same thing as intellectual wellness." (06)

"There is a huge component of teaching the health aspects. I tell them you have to learn how to be a dietician and detective." (05)

"This is becoming increasingly important with the changing demands of our population. Baby boomers crave knowledge and information." (12)

"What do you mean by intellectual? We certainly do research developing knowledge in all of these areas." (08)

"We talk about research and program excellence, which continue the ongoing intellectual experience…. It is a very strong intellectual environment. We have patient symposiums, symposiums for health educators." (04)

"What does that mean?… We produce a range of materials..." (10)

"We have pretty impressive brochures, but we don't really go into intellectual… ." (02)

Spiritual Wellness:

Four key informants said "No", the organizations they represented did not engage in activities related to spiritual wellness. Another referred to a religious ritual (communion) in which people with a particular illness could not partake, and the related family and social issues. Others stated that they conducted activities related to this dimension if spirituality was "defined broadly", or tied to the emotional dimension of wellness.

"… it links with emotional, we certainly would try to make some bridges." (06)

"We don't have overt spiritual program interventions. We do have what I would call a culture of spirituality in the sense that you have to have suffered from this disease to know what it means to people and to know how valuable life becomes to people. It is implicit in everything we do, there is a spiritual dimension of the appreciation of life." (04)

Interpersonal / Social Wellness:

All but one of the key informants talked about the importance of social support in coping with an illness or disease. This dimension was talked about in conjunction with the emotional dimension of wellness.

"It's a big thing for us. People can become isolated very quickly. We have camps for children, socials for patients. It's an integral part of our programs." (04)

"Support groups are a big part. Dining out, travelling. Social environments, family environments… ." (05)

"We talk a fair bit about family and coping." (10)

Environmental Wellness:

A few key informants responded that their organizations were not involved in activities related to the environmental aspects of wellness. Perspectives on the environment included the immediate physical environment (e.g., the home), the context of coping, tailoring programs to fit with community environments, and exposure to risks in the environment.

"…in terms of physical changes to the home." (03)

"Moderately…. provide information on how to modify daily activities to minimize the physical effects of disease." (12)

"Individual's environment is a big thing. Environmental food issues." (05)

"We deal with issues related to what people deal with in disability... the environment the patient is dealing with, or thriving, or surviving…" (04)

"If you travel between communities, you may find that there are differences between the programs they offer." (07)

"Exposure to [risk factors in] the environment." (08)

"Through policy and advocacy... ." (10)

F. Health Charities' Roles in Improving the Health of Canadians

KEY FINDINGS
ROLES IN IMPROVING THE HEALTH OF CANADIANS
1. Levels of intervention/service
2. Action to improve health

1. Levels of Intervention / Service

With respect to Goal #1 of Health Canada's Wellness Agenda, improving the health of Canadians, five levels of intervention or service have been identified: individual, family, community, region, and nation. In order to explore the congruence between these levels of intervention or service and the work of health charities, key informants were asked to what extent their organizations conducted activities in these areas. The following table summarizes the results.

Various Levels of Intervention/Service					
Respondent Code	Individual	Family	Community	Region	Nation
01				✓	✓
02	✓	✓	✓	✓	✓
03	✓	✓	✓	✓	✓
04	✓	✓		✓	✓
05	✓	✓	✓	✓	✓
06	✓	✓		✓	✓
07	✓	✓	✓	✓	✓
08	✓	✓	✓	✓	✓
09	✓	✓	✓	✓	✓
10	✓	✓	✓	✓	✓
11				✓	✓
12	✓	✓	✓	✓	✓

Key informants reported that their organizations were involved to some extent at most of these levels of intervention or service. Most Charities were very involved with activities at the individual, family, regional and national levels. The greatest variability in responses was at the "community" level.

2. Health Charities' Engage in Various Types of Action to Improve Health

Health Canada has identified five types of actions for improving health in Canada. The third and final question addressing the goal of improving the health of Canadians was related to these actions. Key informants were asked "To what extent does your organization conduct activities in the following areas: health promotion, illness/disability prevention, health protection, health care services, and population health?". Responses are summarized in the table below.

TYPES OF ACTION TO IMPROVE HEALTH				
Respondent Code	**Promotion**	**Prevention**	**Protection**	**Health Care Services**
01	✓	✓	✓	✓
02	✓	✓	✓	✓
03	Not preventable	Not preventable		✓
04	✓	✓	✓	✓
05	✓	✓	✓	✓
06	Not preventable	Not preventable	✓	✓
07	✓	✓	✓	✓
08	✓	✓	✓	
09	✓	✓	✓	✓
10	✓	✓	✓	✓
11	✓	✓	✓	
12	✓	Not preventable	✓	

Most health charities conducted health promotion activities. The exception was in the cases where the disease or illness was not preventable. For those charities who represented illnesses or diseases strongly related to lifestyle, health promotion and prevention were key activities. Most charities delivered some form of health care services, while noting that they were "filling the gaps" in government-funded health services across population groups and across regions.

G. HEALTH CHARITIES' ROLES IN DECREASING HEALTH INEQUALITIES AMONG CANADIANS

Key informants were asked "What role, if any, does your organization currently play in decreasing health inequalities among Canadians?". Responses were related mainly to improving access to their own services or to the formal health care system, and improving individual health status. Just one respondent stated that his/her organization did not have a role in decreasing health inequalities, due to the nature of the organization and the nature of the disease associated with it.

KEY FINDINGS
ROLES IN DECREASING HEALTH INEQUALITIES AMONG CANADIANS
1. Addressing inequalities in access across Canada 2. Policy and advocacy efforts 3. Helping people navigate the health care system 4. Improving individual health status through programs and services

1. Addressing Inequalities in Access Across Canada

Many key informants noted the inequality of services available from one region of the nation to another.

"On the service side, … , that is our work. That is required because of the failure of the government to deliver it. That failure is huge and becoming bigger by the day and more asymmetric, particularly with the social union. So you have provinces that have nothing in terms of assistive devices and provinces that are fairly considerate… " (03)

"We are acting in the gap, that's the major focus of our regional units. We are not as active as we will be in reducing health inequalities, but we are certainly active in filling the current gap." (06)

"In bringing people together, they start to see the inequalities in the system, and we use that as a means of pushing and advocating and promoting what we call a transfer of knowledge." (04)

"There is huge inequality in what people can access across Canada." (05)

2. Policy and Advocacy Efforts

A few respondents indicated that they are reducing health inequalities through their policy and advocacy efforts with government to ensure that there are adequate services available, as well as targeting programs and services for "at risk" populations.

"We believe that our philosophy or approach to having access for Canadians comparable service wherever they live in this country does help to reduce inequalities" (01)

"At the policy level, we have worked in the past… to decrease health inequalities." (11)

3. Helping People Navigate the Health Care System

Another way to reduce inequality of access is to help people to learn how to 'navigate' the health care system.

"Part of our awareness strategy… is that people will know how to access the system and thus reduce the inequality that comes from not knowing how to get into the system." (06)

4. Improving Individual Health Status Through Programs and Services

Some respondents stated that they are reducing health inequalities in terms of health status through their programming and service delivery. Equality of access is also addressed by providing financial assistance for participation in programs.

"One in every five people using [our] services is there by virtue of financial assistance…" (07)

H. Should Health Charities Have a Role in Decreasing Health Inequalities in Canada?

Regardless of current activities, key informants were asked if health charities should have a role in decreasing health inequalities in Canada.

Key Findings
Should Health Charities Have a Role in Decreasing Health inequalities?
1. Health charities should have a role in decreasing health inequalities 2. Health charities are connected to Canadians 3. It depends on the mandate of the health charity 4. It is not the role of health charities to decrease health inequalities

1. Health Charities Should Have a Role in Decreasing Health Inequalities

Most informants felt that health charities should have a role in decreasing health inequalities.

"I believe that they have to because nobody else will do it." (12)

"We have a network to link with the patients themselves who are being treated." (05)

2. Health Charities are Connected to Canadians

Informants generally felt that health charities were in a unique situation because of their close relationship with their clients, which gave them a good understanding of the issues they were dealing with and allowed them to represent the views of their clientele. For some informants, everyone has a role in decreasing health inequalities, and a multi-organizational approach is needed.

"I think that health charities which are well-functioning, represent the grass roots, the constituency."”(04)

"We all have a role in it, as individuals, as organizations… absolutely." (07)

"One of the things we have recognized is that there is lots to be done and we can't do all of it or most of it by ourselves." (08)

3. It Depends on the Mandate of the Health Charity

A few informants underlined that each charity has a specific mandate, and that issues considered important for one charity may not have the same emphasis for another.

"I think we also have to recognize that different health charities have different objectives." (01)

"One charity may focus on research for a cure for a specific disease and addressing health inequalities may not be much of a focus. Another may look only at access to care issues and not at some of the broader or more specific determinants of health." (11)

4. It is Not the Role of Health Charities to Decrease Health Inequalities

A few representatives of health charities suggested that it should not be the role of health charities to reduce health inequalities. It is the responsibility of government to assume this role. Addressing broad issues such as decreasing inequalities is difficult for some of the smaller health charities, who are resource poor and cannot address these issues in a comprehensive way. In addition, addressing health inequalities is a political issue, and health charities may not want to be "too controversial".

"Part of the challenge is... to think about what a health charity is. It is a not-for-profit organization that raises money from the public to do certain things. So presumably the public that donates to our organization is our client base.... Our mission tends to service that great clump of the middle class." (10)

"For the traditional charities, who have a disease focus, I think it is going to be tough... To be a charity means not being too controversial. But addressing health inequalities is, at its heart, controversial." (09)

I. Health Charities' Roles In Reducing Pressures On The Health Care System

In relation to the third goal of the Wellness Agenda, reducing pressures on the health care system, key informants were asked "What role does your organization currently play in reducing pressures on the health care system?"

KEY FINDINGS
ROLES IN REDUCING PRESSURES ON THE HEALTH CARE SYSTEM
1. There is a role for everyone 2. Health charities are reducing pressures on the health care system 3. Some health charities seek to increase pressures on the health care system

1. There is a Role for Everyone

Some informants felt that their organization should, and was, playing a role in reducing pressures on the health care system.

"There is a role for everyone in protecting the health of Canadians." (01)

2. Health Charities Are Reducing Pressures on the Health Care System

Ways in which health charities are reducing pressures on the health care system included health promotion, illness/disease prevention programs, and through the provision of timely information for their clients.

"Certainly they do, in that they can provide information, they can suggest ways that people can help themselves" (02).

"I think health charities have a role in helping their constituency understand evidence based care and to bringing forth their constituents interests and experiences" (09).

3. Some Health Charities Seek to Increase Pressure on the Health Care System

Some key informants stated that it was their task to put pressure on the health care system, not relieve it. If pressure was increased on the health care system, that meant that clients were receiving adequate care and support.

"Part of our job is to put pressure on the health care system … the health care system is accountable to deliver quality care. That's a fundamental right of Canadians." (04)

"We want to build pressures on the health care system. There would be fewer pressures if they responded quickly, with this disease." (06)

"We have in the past picked up where the health care system left off … we don't feel that that is our role to do things that really should be the role of the health care system." (08)

"We do have a role but it's an inappropriate role. We shouldn't be delivering assistive devices, that should be the responsibility of government. If health means having mobility aids to be able to live fully in the community, that should be the responsibility of the health care system. I don't want to reduce pressure on the health care system, quite the contrary. …" (03)

J. DO HEALTH CHARITIES HAVE A ROLE IN REDUCING PRESSURES ON THE HEALTH CARE SYSTEM?

Looking toward the future, key informants were asked "Do health charities have a role in reducing pressures on the health care system?". Most envisioned a role for health charities in relation to health services, but not necessarily in reducing pressures on the system. Many recognized the boundaries of what they could or should do in the area of health services.

KEY FINDINGS
DO HEALTH CHARITIES HAVE A ROLE IN REDUCING PRESSURES?
1. Health charities must recognize their limitations 2. Roles include the provision of information, advocacy, and policy

1. Health Charities Must Recognize Their Limitations

"Health charities have to recognize their limitations as well. They are important players in protecting the health of Canadians but they can not do what government is supposed to do." (01)

"Health charities have a psychotic role, a dual role. In ensuring quality care we have a definite role. That might be taking pressure off. It might be perceived as putting pressure on." (04)

2. Roles Include the Provision of Information, Advocacy, and Policy

Some key informants stated that they have a role in reducing pressures through providing credible and timely information to their clients, through advocating where health care is needed, and at a policy level focusing on health reform and restructuring.

"Definitely, their role should be to help government make good decisions." (12)

"Certainly they do, in that they can provide information, they can suggest ways that people can help themselves." (02)

"I think health charities have a role in helping their constituency understand evidence based care and to bringing forth their constituents' interests and experiences." (09)

K. Health Charities' Consideration of the Determinants of Health

Health Canada has identified twelve key determinants of health: income and social status, education, personal health practices and coping, environment, social support, child development, heredity, work/working conditions, health services, gender, and culture. Key informants were asked "Does your organization consider these determinants when developing or implementing policies, programs and activities? If so, in what way(s)?".

Key Findings
Consideration of the Determinants of Health
1. Health charities work with identifiable populations
2. Health charities address a range of health determinants
3. Not all determinants are relevant for some health charities
4. Some determinants are beyond the control of health charities
5. Challenges to addressing the determinants of health

All health charities consider the determinants of health to some degree when planning programs or activities to some degree. One of the key strategies of a "determinants of health" approach is to work toward improving the health of a particular population, or sub-population (FTP Advisory Committee, 1999).

1. Health Charities Work With Identifiable Populations

In every case, health charities are addressing the needs of an identifiable "population", whether the Canadian population or particular disease or illness populations. At the national level, the main activities are often policy and program development, and advocacy.

"We always talk about all [ ] patients in Canada, not just Toronto, or Calgary, or Vancouver." (04)

"A lot of things we have talked about are very strongly affected by the determinants of health." (05)

"Our organization hits every [age] segment of the population… children, seniors." (05)

2. Health Charities Address a Range of Health Determinants

Key informants are often very well aware of the effects of the health determinants. In particular, they referred to socio-economics, employment, education, and physical and social environments (communities).

"We have in our policy approach very clear notions on the importance of spending money on environmental issues, on the determinants of health other than the health care system, using income inequality and the important role of education in determining people's health." (01)

"When it comes to wellness issues, individual and society, we have a lot of data to say that most of what determines health has very little to do with the health service system." (09)

"We do consider these determinants in that we try to reach out to our own population… We encourage our chapters to go out into little communities… which has been successful." (02)

"Level of employment would affect how well they can care for themselves." (05)

"I am inclined to talk about employment counselling and training programs, to the extent that being employed and having job skills are related to health." (07)

3. Not All Determinants are Relevant for Some Health Charities

Whether or not a health charity was involved in addressing multiple determinants of health often depended on the type of population, or illness group, which their mandate served.

"Only a very few of those apply… genetics, health and social services." (06)

"To a small degree, but the determinants of health, as Health Canada has expounded them, do not have any link with [this illness], except for heredity." (03)

4. Some Determinants are Beyond the Control of Health Charities

While key informants recognized the importance of the determinants of health, many felt that altering the determinants was beyond their mandate, or their control.

"We don't see ourselves as being able to intervene in many of these areas." (08)

"… at the same time, we know the health of people is determined by all sorts of other things other than health promotion. So to what extent can we be held responsible for the health status within your region if you don't have control over the things that are economic and educational?" (01)

5. Challenges to Addressing the Determinants of Health

Respondents were also asked "What challenges does your organization face in addressing the determinants of health?" The three main challenges identified were: (1) lack of education regarding particular illness conditions, (2) the need for additional staff in order to address a greater number of determinants; and, (3) financial resources to offer programs to address specific determinants. It was suggested that health charities could undertake education related to linking personal issues to the determinants of health.

L. FOCUS ON THE FUTURE: RELATIONSHIPS BETWEEN HEALTH CHARITIES, HCCC, AND THE FEDERAL WELLNESS AGENDA

Participants were asked a series of three questions related to future roles of health charities and of the Health Charities Council of Canada. First, key informants were asked "How might health charities contribute to the national Wellness Agenda?" Second, informants were asked "How might the wellness agenda support the work of the health charities?" Finally, they were asked "What is the future role of the Health Charities Council of Canada in promoting wellness in the Canadian population?"

KEY FINDINGS
RELATIONSHIPS BETWEEN HEALTH CHARITIES, HCCC, AND THE FEDERAL WELLNESS AGENDA
1. Critical perspectives on the Wellness Agenda
2. Support from Wellness Agenda for the work of health charities
3. HCCC's role in promoting wellness in Canadians
4. Contributions of health charities to the Wellness Agenda

1. Critical Perspectives on the Wellness Agenda

Representatives of some health charities view the Wellness Agenda as exclusive of those with illnesses/diseases that are not preventable.

"We have to be very careful of applying the wellness concept to health charities whose role is not exclusively prevention…. A lot of us are dealing with people for whom the wellness efforts of the past have not worked." (04)

<u>There is "nothing new" in the Wellness Agenda</u>

"Is it the fact that we are proposing that we need a new agenda because the old one hasn't worked and I would say that the old one hasn't worked because we haven't invested in it. So what is the point of calling something the wellness agenda with exactly the same components, and not funding it any differently or changing any of the systems to make it a reality." (10).

"It is a repackaging of ideas and programs that people are already doing." (11)

"The wellness debate has been framed by Health Canada as a debate to reduce health costs." (03)

<u>"Wellness" Must be Defined</u>

"Who is going to define it? It is such a large subject, it has to be broken down for people to understand what it is they are trying to accomplish." (02)

<u>The Wellness Agenda Requires a Social Context</u>

"There is a social context that needs to be part of the agenda, right from the get-go, or you miss significant numbers of the groups or individuals." (09)

"If we are talking about a wellness agenda, who is going to be targeted by this agenda?... the same people we are already targeting.... " (10)

<u>Health Charities Can Make Significant Contributions to the Wellness Agenda</u>

"We are moving very quickly into the 21st century, and we don't want to be left behind." (02)

"I think the real discussion here is that health charities are doing valuable work in helping maintain the health of Canadians. That should be recognized and that they cannot do it alone... It is a catch 22 because the groups do make a difference but I don't think government is convinced that they do. On the other hand, if government believes in this wellness agenda, then as many partners as possible to help them achieve it would be important." (01)

"Perhaps the new terminology packages things in a way that promotes support for the health of the entire population in its broadest sense that goes beyond health care." (11)

"Health charities can shift the whole debate. Not to trivialize or exclude what is already understood and is important, but to go beyond that..." (03)

"The decision-making at the federal government has to be for the whole of the country and the largest number of people. That's the challenge of our particular disease, and we can learn a lot from the kinds of thinking the federal government officials are engaged in, but it will only happen with very serious discussion, early, middle, and late in the policy chain, and in the decision-making chain of the federal government. I see the requirement of dialogue, and an expansion of understanding of the word consultation. We want to be engaged. We are suitable partners for engagement." (06)

"To me, this is a systems issue, it is a policy issue." (10)

2. Contributions of Health Charities to the Wellness Agenda

Key informants emphasized that health charities are already contributing to the Wellness Agenda through a wide range of research, interventions and programs at many levels. Continuing with education and awareness were felt to be key contributions to the wellness of Canadians. Advocacy was also underlined as a key action in addressing the needs of constituents, and of policy development.

A few participants expressed that the health charities contribution is through dialogue with government.

"Health charities need to be involved in the earliest beginnings of health policy development and direction and funding opportunities." (06)

Some suggested that the best support would be through partnering with government and through health promotion and illness prevention activities.

"Health charities have significant insights to offer – policy development, program planning, fund planning." (06)

3. Support from the Wellness Agenda for the Work of Health Charities

A few respondents stated that the best way for Health Canada's Wellness Agenda to support the work of the health charities was through program funding. Education of consumers regarding the nature and contributions of health charities was also suggested as a way for the Wellness Agenda to support the work of the health charities.

A few respondents stated that they were cautious when thinking about the relationship between a Wellness Agenda and the work of health charities.

"I think we have to be very careful of applying the wellness concept to health charities whose role is not exclusively prevention." (04)

4. HCCC's Role in Promoting Wellness in Canadians

Most key informants underlined the strength of the HCCC in providing a forum for the health charities to work together on identified issues. It was often stated that a future role for the HCCC is to facilitate collaboration between and among charities on issues that are shared. Identified issues included prevention, promotion, sharing new ideas and networking.

Some respondents suggested that partnerships are necessary in order for the HCCC and its members to attend to the many dimensions of wellness. The health of Canadians is seen as something that cannot be addressed just by health charities, or just by Health Canada. Other government partners (Industry Canada, Human Resources Development Canada) and the private sector can be involved in promoting health and wellness. While the HCCC could speak with government generally on behalf of all health charities, individual organizations must also be in contact with government on particular issues related to specific illness conditions or strategies to address client needs.

SUMMARY OF FINDINGS: KEY INFORMANT INTERVIEWS

Key informants were generally familiar with the term "wellness", although most preferred other terms such as health, health promotion, and quality of life. Informants noted limitations of the term "wellness" including the fact that it does not typically encompass illness. For that reason, it was not applicable in contexts where health charities are working with and for people who have a chronic or terminal illness. Whether or not "wellness" was part of the lexicon of a health charity often depended on the health status of its constituents, or whether other terms more accurately reflected the philosophy and work of the organization.

For many informants, the use of "wellness" was a question of semantics. It was noted that wellness was often implied in the work of health charities, as demonstrated by their attention to its various dimensions (physical, emotional, intellectual, spiritual, interpersonal/social, environmental). Although some informants indicated a willingness to "work with" the term "wellness", many felt that it did not "fit" well with the work of their organization. Furthermore, if "wellness" is to be used in the context of a national Wellness Agenda, it must be carefully articulated to reflect a broad range of understandings, and a variety of illness and disability contexts.

Health charities are involved to varying degrees in decreasing health inequalities among Canadians and reducing pressures on the health care system (two of Health Canada's goals for the Wellness Agenda). Increasing access to health information and health services, providing programs and services, participation in policy development, and advocacy were articulated as key roles of health charities in reducing health inequalities. Although these efforts do decrease pressures on the health care system, many health charities actively increase pressure on the health care system when it is seen to advance the needs of their constituents.

Key informants were quick to point out that their services and programs fill a "gap" where government-funded services fail to meet the needs of their constituents. As well, limited resources and specific mandates prevent many health charities from addressing broad inequalities in health arising from the determinants of health (socio-economics, physical environments, etc.). However, the anchoring of health charities at the "grass roots" through regional and local associations can benefit the federal health agenda by allowing the identification of real needs of people in communities.

Key informants offered critical insights on the term "wellness" and the federal Wellness Agenda. As stated, the use of the term "wellness" as it is generally understood does not "fit" with the work of many health charities. For many key informants, the Wellness Agenda does not offer anything "new" in the way of conceptual advances toward understanding or improving health. However, health charities make substantial contributions to improving the health of Canadians, and can make significant contributions to a federal health agenda. Partnerships and consultations with national health charities are seen as essential to the formulation of a federal health agenda.

A number of roles were suggested for the HCCC in promoting wellness in Canada. The HCCC can provide a forum for health charities to work together on identified issues, and can facilitate collaboration between health charities. At the federal level, the HCCC can advance the position of health charities in the formulation of a national health agenda, engage in partnerships with Health Canada and other federal departments to improve health or address the determinants of health, and engage in advocacy and policy development for the Canadian population and specific illness-related sub-populations.

PART IV: FINDINGS FROM THE EMAIL SURVEY

Of the 52 members and prospective members of the HCCC who received the email survey, 23 responded (44.2%). Sixteen were members of HCCC (69.5%), four were not certain of their membership status, two were not members, and one respondent did not indicate membership status. Respondents included Presidents, Executive Directors, National Executive Directors, and Health Consultants from various health charities**.** Findings from the email survey

are presented below. The key findings from each question in the survey are introduced in a "key findings" box, followed by quotations from respondents. Each quotation is identified by a "respondent code", assigned by the researchers.

A. Terms Used For "Maintaining And Improving Health"

Survey respondents were asked "What term do you use when you talk about maintaining and improving people's health?". They generally responded in three main categories: No (N=13 or 57%), Yes (N=5, 22%), and Seldom (N=3, 13%).

For many survey respondents, wellness was not a "dominant term" in their organization. Reasons for not using "wellness" included that the term is "too trendy and will go out of style", it is "not understood", and that "the reality is that our clients are not well". The term was occasionally used in reference to particular programs, such as "Journey to Wellness". Preferred terms included quality of life, quality of care, and health promotion.

TERMS FOR "MAINTAINING AND IMPROVING HEALTH" (N=23)		
Term	**Number**	**Percent**
Quality of life	16	69.5
Health promotion	4	17.3
Wellbeing	1	4.0
Wellness	2	8.0

"Quality of life" was used by nearly 70% of respondents. For one respondent, the term "quality of life" was seen to reflect the multidisciplinary aspects of illness. "Health promotion" was sometimes used in conjunction with "risk reduction". Other terms referred to by respondents included resiliency, coping, self help, empowerment, mental health, and mental well-being.

B. Health Charities' Attention to the Dimensions of Wellness

The email survey listed six dimensions of wellness and asked "Does your work incorporate these various dimensions of wellness?" The responses fell into three main categories: Attend to all (N=12, 52%), Attend to some (N=6, 26%) and "Out of reach" (N=3, 13%).

KEY FINDINGS
ATTENTION TO THE DIMENSIONS OF WELLNESS
1. Health charities address a range of dimensions of wellness 2. Some health charities use a "whole person" approach 3. The spiritual dimension may be the most difficult to address 4. All dimensions are beyond the mandate of most health charities 5. Health charities attempt to intervene at various levels

1. Health Charities Address a Range of Dimensions of Wellness

Most respondents recognized the importance of the range of dimensions of wellness, and commented on the similarities between the working definition of wellness and currently used concepts and definitions.

"The health work [of our organization] always includes addressing the physical, emotional and spiritual dimensions. Environmental issues are addressed in terms of families, and communities, and a full range of social issues are addressed." (104)

"This is the WHO definition of health, which we consider the basis of all our work." (105)

"Yes, we incorporate all these dimensions. They are all important." (112)

2. Some Health Charities Use a "Whole Person" Approach

Some survey respondents referred to a "whole person" approach to the services and programs offered by their organizations.

"Our clinics are encouraged as a first principle, to treat individuals as whole persons, and to ensure that services and supports are tailored to meet individuals needs." (102)

"The 'whole person' approach is essential, or you are destined to fail." (113)

3. The Spiritual Dimension May Be the Most Difficult to Address

Two survey respondents noted that the spiritual dimension is often the most difficult to address.

"We are in the process of developing a discussion paper on spirituality and children. It's the least understood determinant." (107)

"The spiritual aspect may be the most difficult dimension to reach… both the mind and the body must work together to heal." (117)

4. All Dimensions are Beyond the Mandate of Most Health Charities

A few respondents indicated that the dimensions of wellness were out of reach for health charities or that they simply did not address them.

"Attending to all dimensions of wellness is possibly beyond the capacity and mandate of all health charities." (111)

"It would depend on the type of organization and what their specific mandate was." (118)

5. Health Charities Attempt to Intervene at Various Levels

The survey responses remind us that the health charities are comprised of many different levels of organization and service. Ultimately, the ability to address all the dimensions of health depends on reaching individuals and families in their communities.

"We believe that if we can provide information and education as well as personal support through grass-roots contacts, then we can very often cover these dimensions. They may not happen all at the same time, but the overall results can be achieved. Because a health charity is usually made up of volunteers who have the illness, a better understanding of the patient's situation is achieved." (121)

"We focus mainly on the physical and social dimensions, although local chapters incorporate the other dimensions." (122)

"As a small to mid-sized national charity, we cannot attempt to offer comprehensive, hands-on care; however, the clinics which receive enhancement grants from us, do offer support services..." (102)

C. Activities to Maintain and Improve Health

Respondents were asked to list the key activities in which they were involved to help people maintain and improve their health. Eight major themes were identified in their responses: information, support, education, programs, research, funding, equipment, and advocacy.

Key Findings	
ACTIVITIES TO MAINTAIN AND IMPROVE HEALTH	
Activity	**Examples**
Information	Distribution of timely information not only to our patients, but to the medical and educational communities
Support	Individual and family counselling, support and self-help groups
Education	family and professional education, including in service presentation
Programs	Conducting programs that address the needs of clients
Research	Promotion and support of research
Fund Raising	Equipment purchasing, assisting clients, funding research
Equipment	Purchase, loans, assistive devices
Advocacy	Advocacy on behalf of people with [disease], advocating for comprehensive care.

D. Health Charities' Role in Decreasing Health Inequalities

Respondents were asked "Does your organization currently play a role in decreasing health inequalities among Canadians?". Virtually all respondents responded affirmatively to this question. The three who did not respond affirmatively explained that their role in decreasing health inequalities was limited by their organization's mandate or by a lack of resources to pursue this type of activity.

"To the extent that these affect members of our organization's constituency." (111)
"To the extent possible." (118)

"We don't have the funds to pursue this area." (112)

KEY FINDINGS
ROLES IN DECREASING HEALTH INEQUALITIES
1. Access to care 2. Provision of services 3. Attention to vulnerable groups 4. Collaboration 5. Advocacy

Survey respondents talked about five main roles in decreasing health inequalities. They provide access to care, provide services, take actions to address the needs of population groups who are "at risk" or "marginalized", work together with other organizations and governments, and provide advocacy for individuals and in national contexts.

1. Access to Care

"It goes without saying that charitable funds from some parts of Canada ensure the provision of service in other parts of Canada, where less charitable support may be available." (102)

"Our organization attempts to provide the same information and programs all across the country, without reference to size of the provincial organization or their financial situation." (121)

2. Provision of Services

"Partially through the services that we provide… ." (108)

"[Our organizations's] response is generally of a direct service nature… ." (104)

3. Attention to Vulnerable Groups

"We are focused on the high rate of [ ] in Aboriginal deaths." (103)

"We do reach out to high risk teens and adults." (105)

"We have lots of special targeted programs for families at high risk." (107)

"[Our organization] has the opportunity to reduce health inequalities through its focus on the vulnerable and marginalized in society." (104)

"We hope and believe we do, most particularly for persons with disabilities who are traditionally marginalized." (113)

4. Collaboration

"Yes, cooperative / collaboration." (110)

"We work with over 450 support groups, the National Voluntary Organizations in health, plus other organizations who complement what we do." (109)

5. Advocacy

"Our organization has been advocating…." (117)

"By arguing for a level playing field…." (120)

"… also in lobbying for governments to increase their services." (108)

E. SHOULD HEALTH CHARITIES HAVE A ROLE IN DECREASING HEALTH INEQUALITIES?

Survey respondents were asked "Should health charities have a role in decreasing health inequalities among Canadians? Why or why not?".

KEY FINDINGS
SHOULD HEALTH CHARITIES HAVE A ROLE IN DECREASING HEALTH INEQUALITIES?
1. Health Charities represent the interests of many Canadians 2. Everyone should play a role 3. Health charities help ensure access to the system 4. Decreasing inequalities is the government's role 5. If it fits with the organization's mandate 6. Health charities may have limited resources 7. Health charities have particular insights to offer

There was general agreement among survey respondents that health charities should play a role in decreasing health inequalities.

1. Health Charities Represent the Interests of Many Canadians

"We should be involved so that all Canadians will be included in the mission statement of Health Canada." (101)

"Of course, We need to constantly strive for equality for the disabled." (109)

"Yes, because it is just and fair." (114)

"In my opinion, health charities are the pillar that helps maintain and sustain this key element of our social safety net." (119)

"It is part of the service we should provide to our constituents." (12)

2. Everyone Should Play a Role

"Everyone involved in health would have a role to play in addressing inequalities in health among Canadians." It makes sense morally, and if certain diseases or issues are to be dealt with effectively, all aspects of their occurrence need to be addressed, including issues such as poverty, culture, education, environment, etc." (104)

3. Health Charities Help Ensure Access to the System

"Geographical locations are also a major determinant of health inequality." (105)

"Those most affected by services/issues of the health charities are often at risk groups." (107)

"There is a stigma associated with many diseases and disorders, and therefore it is important that all Canadians have equal access to health care." (122)

4. Decreasing Inequalities is Government's Role

"Health charities are not governments - they pursue the mandates for which they are constituted... Members of our charity consider that it is the government's role to ensure reasonable health care for all Canadians... ." (102)

"Yes, but this is a tricky area, since if charitable organizations pick up more of the services and programs for which governments should be responsible, there is a danger that governments will do less." (108)

5. If it Fits With the Organization's Mandate

"To the extent that this is in accordance with the organization's mandate." (111)

"Not necessarily, certainly not always on their own if it does not pertain to their mission. However, effective involvement through coalitions, e.g. HCCC, is always appropriate." (113)

6. Health Charities May Have Limited Resources

"Yes, to the best of the charity's ability within existing resources." (118)

"Where they are not able to provide this service comes from a decrease in funding to accomplish their goals."

7. Health Charities Have Particular Insights to Offer

It was expressed that health charities are in a unique situation in that they are close to clients, families, and communities, and can represent their needs and concerns.

"Health charities are the 'front line' for Canadians dealing with illnesses which have organizations established to provide help. They are very often closest to the individual and family in the community." (121)

F. Health Charities' Roles in Reducing Pressures on the Health Care System

Survey respondents were asked "Does your organization currently play a role in reducing pressures on the health care system?".

KEY FINDINGS
ROLES IN REDUCING PRESSURES ON THE HEALTH CARE SYSTEM
1. Provide programs and services 2. Health promotion 3. Provide specialized expertise 4. Reduce physician and hospital visits 5. Fund research 6. Educate health professionals 7. Add pressure to the system

1. Provide Programs and Services

"All organizations play an extremely important role in reducing pressures on the health care system by providing support, education, information, and research to a aystem that would be capable of providing such services… ." (101)

"We pay for materials for public education, fund a toll-free line used in government brochures., and provide peer support." (103)

"It is possible that by taking responsibility for some programs and approaches or by adding monies to government funds that [our organization] is reducing pressures on the health care system." (104)

"Through self-help and support groups." (120)

"When families and individuals access our services, they are 'not alone'". (112)

2. Health Promotion

'Every dollar spent on prevention or health promotion… saves the health system $10.00 in one year." (105)

"Only through promotion and prevention strategies." (107)

3. Provide Specialized Expertise

"Our organization provides specialized expertise which lies outside / beyond provision of basic health care services by the government." (111)

4. Reduce Physician and Hospital Visits

"By giving them the proper information, it stops people from running from doctor to doctor and from hospital to hospital." (109)

"Our home infusion program relieves the health care system by reducing the number of visits our clients make to hospitals and clinics." (117)

"Through education, information and support we attempt to help the individual be as well as they can through education about managing the disease, so they don't need hospitalization as often." (121)

5. Fund Research

"We also finance research. Every cent we put in has an impact." (122)

"We fund medical research." (103)

"We help raise funds for research, to help find a cure and to improve treatment. We believe this helps reduce the health care pressures." (121)

6. Educate Health Professionals

"We also place great emphasis on training support for medical and clinical personnel." (102)

7. Add Pressure to the System

"We both reduce and add to the pressure. We reduce by offering certain services and programs, but we add to the pressure by demanding that government treat all Canadians equally in terms of access to drug treatment, other therapies, home care, long term care, etc." (108)

G. Should Health Charities Have a Role in Reducing Pressures on the Health Care System?

Survey respondents were asked "Should health charities have a role in reducing pressures on the health care system?".

Key Findings
Should Health Charities Have a Role in Reducing Pressures ?
1. Fear of government "downloading" 2. Health charities provide necessary services 3. Health charities provide better service and help avoid duplication 4. The resources of health charities are limited 5. Where appropriate, health charities increase the pressure on the system

1. Fear of Government "Downloading"

There was a fair degree of caution expressed in relation to the extent to which health charities should relieve pressures on the health care system.

"I think we do play a role but I am gravely concerned at the amount of offloading to the health charities, because they know they must fill the gaps because of their membership needs." (103)

"In Canada we have a universal system and health charities would need to be very clear that their work did not allow the government to abdicate their responsibility to the Canadian public." (104)

"This is not any easy question. While charitable organizations can pick up some of the slack this could be a 'slippery slope' to less government responsibility." (109)

"It may be inadvisable for charities to accept responsibility for providing basic health care services which should be the responsibility of government." (111)

"To a certain point, yes, but there is a danger that government will expect us to replace them. We should be a complement to the system, not a substitute." (122)

2. Health Charities Provide Necessary Services

"I think it could not be done if it were not for the health charities that exist to provide for their members." (101)

"Through self-help and mutual aid strategies." (107)

"If one receives support in the areas of wellness mentioned above, one is less likely to need to see their physician... ." (112)

"Promoting wellness contributes to reduced demands on the system." (119)

"More patient education and awareness on managing diseases will help to relieve some of the burden that presently haunts the system." (117)

"Should they? No. They should not have to, as health care should have more priority with government and there should not be any gaps. Must they? Yes, as there are too many gaps and inequities." (113)

3. Health Charities Provide Better Service and Help Avoid Duplication

"It is the provision of better service." (114)

"Health charities can play a significant role not only in softening the burden on the government and the medical community but also by working closely enough so that nothing is duplicated. Since the health charities usually refer to specific illnesses, they are close to where the action is and are in a better position to advise where the problems are and can help in solving the problems." (109)

4. The Resources of Health Charities are Limited

"Yes, to the best of the charity's ability within existing resources."

"To some degree they are able, however their budget limitations are such that they are not able to reach the numbers they would like to in order to make this measurable in a lot of cases." (118)

"If they can be funded adequately, charities can provide valuable help in reducing pressures on the system." (121)

5. Where Appropriate, Health Charities Increase Pressure on the System

"When it is appropriate. It may be that the best treatment for a person is one that is expensive. In this case, the health charity should advocate for what is best for the patient." (120)

H. Future Roles of Health Charities in Promoting Wellness Among Canadians

Survey respondents were asked "What do you see as the future role of your organization in promoting wellness among Canadians?". Most stated that they would continue to engage in education, information, support, research, health promotion and prevention.

Key Findings
Future Roles of Health Charities in Promoting Wellness
1. To educate the public and the medical community 2. To fund research and seek cures 3. Continue with present services and programs 4. Use of electronic technology for information sharing and retrieval 5. Address the determinants of health

1. To educate the Public and the Medical Community

"I see the future role of our organization as an educator and provider not only to patients, but to the medical and educational communities, and the government of Canada." (101)

"Our charity is focused on support to a small, well-defined population. However, we have built up a store of specialized expertise... ." (102)

"More public awareness and to encourage physicians to listen more... ." (110)

"With increasing revenue and in increased focus on education and awareness at our national office, we are moving in this direction [promoting wellness]... ." (116)

2. To Fund Research and Seek Cures

"Our central aim is to cure a major disease, and wipe it off the map!" (102)

"To encourage physical and environmental wellness through research, access to medications, and cures for rare disorders." (112)

"We are dealing with a condition for which there is no prevention. Our contribution to wellness is in making sure that people who are diagnosed have access to the best possible support, medicine, and treatment. We also fund research that will hopefully make prevention a possibility in the future." (120)

"Support for research to provide new methods of treatment, new medicines, and ultimately, a cure!" (121)

"To eliminate the stigma surrounding [ ] and to eventually find a cure." (122)

3. Continue With Present Services and Programs

"I believe the role of the [organization] will remain constant… ." (104)

"Our programs are proving effective so we will continue to do what we do as long as we can survive the cost cutting that prevails in spite of government rhetoric about the value of NGOs and volunteer work." (105)

"Continue representing the priorities of our health interest group. Continue our current role in services and programs. Continue to pressure governments to provide services and programs on an equitable basis to all Canadians." (108)

"Continue to provide specialized services, education and research for members of our constituency." (111)

"Our future remains in health protection and prevention… ." (113)

4. Use of Electronic Technology for Information Sharing and Retrieval

"A major change is that we are reaching more people via the internet and websites, so our work has changed tools but not message or purpose." (105)

"Move from traditional print to electronic methods… ." (107)

"Building on our present structure, an increase in methods of sharing information (website technology, etc.)… ." (121)

5. Address the Determinants of Health

"Promoting wellness, networking and self-managed care approaches, and any other health enhancing mechanisms that affect the determinants of health." (119)

I. Future Roles of The Health Charities Council of Canada in Promoting Wellness Among Canadians

Survey respondents were asked "What is the future role of the Health Charities Council of Canada in promoting wellness in the Canadian population?".

Key Findings
Future Roles of The HCCC in Promoting Wellness
1. Provide a voice to promote quality of life and influence policy
2. Increase general awareness of health charities
3. Provide a forum for linking health charities
4. Promoting "wellness" and the role of health charities

1. Provide a Voice to Promote Quality of Life and Influence Policy

"I see the role of the HCCC as a voice for the Associations of Canada to promote quality of life and wellness for all Canadians, and to help educate the Government of Canada to the needs of Canadians in order to achieve quality of life and wellness." (101)

"To promote and influence the determination of policy." (117)

"I think it will play a very important role as an advocate for health charities, and in the role of policy which directly affects consumers (our members)." (103)

"Represent the views of its members to the federal government, and especially Health Canada." (108)

2. Increase General Awareness of Health Charities

"Creating awareness among Government and general public that small national charities encompass the largest population of disabled people in Canada." (112)

3. Provide a Forum for Linking Health Charities

"HCCC should continue to provide a forum in which charities can come together, identify common cause, and help each others." (102)

"By providing support, mentoring and information sharing. HCCC can provide the means for organizations to work together regardless of size. This, in turn, help the organization work better in their communities across Canada." (121)

"The HCCC can identify areas of common ground among health charities to enable collaboration. In can also increase the flow of information among various health charities." (120)

4. Promoting "Wellness" and the Role of Health Charities

"I see the Council working collaboratively in promoting the overall theme of wellness and possibly launching and ad campaign that would promote the value of the sector and the need to support it." (118)

"Council public relations, multi-media campaign on broad issues affecting wellness." (107)

"It [wellness] should be a key function of the HCCC." (116)

SUMMARY OF FINDINGS: EMAIL SURVEY

Survey respondents echoed many of the insights provided by key informants. Nearly 70% of respondents used the term "quality of life", rather than "wellness", when referring to the maintenance or improvement of health. The health charities represented by survey respondents addressed a variety of dimensions of "wellness", although it was also noted that addressing all dimensions may be beyond most health charities, and that the spiritual dimension is perhaps the most difficult to address.

Survey respondents are engaged in a variety of activities to maintain and improve the health of Canadians, including the provision of information, support through programs, education, research, fund raising, advocacy, and policy development.

Health inequalities are addressed through provision of or access to services, attention to vulnerable groups, collaboration with other organizations, and advocacy. Some respondents questioned whether or not health charities should have a role in decreasing health inequalities. Others stated that everyone has a role, but that health charities often have specific mandates that must be a priority. As in the key informant interviews, health charities are characterized as having significant insights as a result of working closely with individuals, families and communities.

According to survey respondents, health charities reduce pressures on the health care system by providing necessary programs and services, by providing specialized expertise, by reducing hospital and physician visits, through funding research, and through health promotion activities. Some respondents feared the "downloading" of government responsibilities on health charities. As well, it was noted that health charities increase pressures on the health care system when "gaps" in the system are evident, or when the system does not respond to the needs of their constituents.

Educating the public and the medical community, funding research and seeking cures, and continuing with present programs and services, were seen as future roles of Canadian health charities. Suggested future roles of the HCCC included providing a voice to promote quality of life and influence policy, increasing public awareness about health charities, providing a forum

to link health charities, and promoting the role of health charities in improving "wellness" among Canadians.

PART V: SUMMARY & DISCUSSION QUESTIONS

Indepth telephone interviews (N=12) and an email survey (N=23) gathered information from members and potential members of the HCCC related to the meaning and use of the term "wellness", as well as to national health charities' current and future involvement in improving wellness in the Canadian population. Although more detail was provided in the telephone interviews, the findings from the key informant interviews and email surveys were highly consistent. Therefore, participants are collectively referred to as "respondents" in the summary and discussion below.

Respondents were all familiar with the term "wellness", although most health charities do not use the term. Many were concerned about the use of a new term in federal discourse about health, particularly in cases where it did not fit with the work of the health charity or with the nature of the disease or illness with which the charity was concerned. The adoption of the term "wellness" is not likely in the context of severe illness or disability. Attention to semantics may divert attention and resources that should be used for strategies and services.

"Quality of life" was a term preferred by many health charities (about 70%). Health, health promotion, and prevention were other frequently used terms. For those who did use the term "wellness", it was often used in conjunction with other terms and/or equated with a "holistic" or "whole person" approach to health. For many health charities, "wellness" is implicit in their philosophies and their work. Many insights were provided on various dimensions of "wellness" – physical, emotional, intellectual, spiritual, interpersonal/social, and environmental – that could be used by the HCCC, Health Canada, or others interested in defining the parameters of the concept "wellness".

Virtually all respondents saw health charities as playing a key role in decreasing health inequalities among Canadians (a Health Canada goal for the Wellness Agenda). Addressing inequalities was often articulated in terms of equal access to services across the country, and through participation in policy development. Some health charities paid special attention to "vulnerable groups" or provided financial support for constituents. Although the attitude that "everyone should have a role" in decreasing inequalities was prevalent, respondents also referred to specific mandates of organizations and a lack of resources as limitations on the extent to which health charities could, or should, address health inequalities. For some, it is the government's responsibility to address health inequalities. However, health charities have a "connection" to Canadians through local organizations and volunteers that gives them a unique understanding of health and illness issues which could contribute significantly to a federal agenda for health. Respondents were aware of the Wellness Agenda and were vocal about the importance of governments, health charities and others working together to address the health of all Canadians, as well as specific subgroups of the population.

Health charities are very much involved in reducing pressures on the health care system (a Health Canada goal for the Wellness Agenda). They "fill the gaps" in the health care system by providing timely and credible information, programs and services, research funding and programs, education for the public and health professionals, and advocacy on behalf of their client groups. However, respondents were cautious about taking on roles which were seen as

government "downloading", and noted that health charities often seek to increase pressures on the health care system in order to provide for the needs of their client groups.

When representatives of health charities were asked about their potential contributions to the Wellness Agenda, they indicated five critical perspectives on the Wellness Agenda: (1) the Wellness Agenda is exclusive of people with non-preventable illnesses/diseases; (2) the Wellness Agenda is a "repackaging" of old ideas, framed to reduce the cost of health services; (3) the Wellness Agenda requires greater attention to the social contexts of health and illness; (4) health charities already make a significant contribution to the Wellness Agenda through education, research, support services, advocacy and policy development; and, (5) consultation and partnerships are essential to the development and implementation of a federal agenda for health or "wellness". Furthermore, the Wellness Agenda should link with current health promotion and quality of life initiatives, with attention to the development of long term strategies for the health of Canadians.

Respondents generally agreed that HCCC has an important role to play in the development of a national agenda for health or "wellness." The Council can provide a collective voice for health charities in policy development. Some respondents underlined the importance of providing a greater public awareness of the HCCC, of the roles that health charities already play in improving health in Canada, and of the potential for inclusive partnerships to formulate a national agenda for health.

Discussion Questions

1. Does the term "wellness" work for health charities?

2. If health charities use the term "wellness", how should it be defined?

3. Are there terms other than "wellness" that are more appropriate for health charities?

4. Who should be included in a Wellness Agenda?

5. What might an inclusive structure for establishing and implementing a Wellness Agenda look like?

6. How should the HCCC proceed in relation to the Wellness Agenda?

7. What goals (short, medium, long term) should the HCCC establish?

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APPENDIX A
INTERVIEW GUIDE

Objectives of the Project:

1. To determine the current role of health charities in increasing "wellness" in Canadians
2. To determine the future roles of health charities in increasing 'wellness' in Canadians

Working Definition of "Wellness":

"Wellness is the state of optimum health and well-being achieved through the active pursuit of good health and the removal of barriers, both personal and societal, to healthy living. Wellness is more than the absence of disease; it is the ability of people and communities to reach their best potential in the broadest sense." (The California Wellness Foundation, 2001) Note: There is a growing recognition that wellness can be achieved despite illness.

A. Role of "wellness" in organizations' philosophy and activities:

1. Are you familiar with the term "wellness"? How do you understand/define the term?

2. Does your organization use the term "wellness"?
   a) If so, how is "wellness" defined or understood within your organization?

3. Would it make sense to encourage the use of the concept of 'wellness' within your organization?
   a) What help might your organization need in order to promote "wellness"? (e.g., clarity of definition, links with other organizations, time, money, etc.)
   b) What might hinder your organization in promoting "wellness"? (e.g., lack of understanding, focussing on illness, time, money, opportunities)

B. Three goals of 'Wellness Agenda': Health Canada has determined three goals for the 'wellness agenda'. One goal is to improve the health of Canadians, another goal is to decrease health inequalities among Canadians and the 3rd goal is to reduce pressures on the health care system.

1st Goal – Improve the health of Canadians

Health Canada has identified five levels of intervention or service which may be addressed in improving the health of Canadians.

4. To what extent does your organization conduct activities in the following areas:
   a. Individual
   b. Family
   c. Community
   d. Region
   e. Nation

5. To what extent does your organization attend to the following dimensions of wellness:
   a. physical health/wellness
   b. emotional health/wellness
   c. intellectual health/wellness
   d. spiritual health/wellness
   e. interpersonal and social health/wellness
   f. environmental health/wellness.

Health Canada has identified five types of actions for improving health in Canada.

6. To what extent does your organization conduct activities in the following areas:
    a. Health promotion (e.g., skills development, education, awareness)
    b. Illness/disability prevention (e.g., early childhood education, public education)
    c. Health protection (e.g., legislation, surveillance, standards for housing)
    d. Health care services (screening, access to services, crisis intervention)
    e. Population health

2nd Goal: Decreasing Health Inequalities:

7. What role, if any, does your organization currently play in decreasing health inequalities among Canadians?
    a) Can you envision a future role for your organization in decreasing health inequalities among Canadians?
    b) Should health charities have a role in decreasing health inequalities in Canada?

3rd Goal: Reducing Pressures on the Health Care System
Another goal of Health Canada's 'Wellness Agenda' is to reduce pressures on the health care system.

8. What role does your organization currently play in reducing the pressures on the health care system?
    a) Can you envision a future role for your organization in reducing pressures on the health care system?
    b) Do health charities have a role in reducing pressures on the health care system in Canada?

C. Population Health
Health Canada has identified 12 key determinant of health: income and social status, education, personal health practices and coping, environment, social support, child development, heredity, work/working conditions, health services, gender and culture. Understanding these determinants and the relationships between them is often referred to as "population health".

9. Does your organization consider these determinants when developing or implementing policies, programs and activities? In what way(s)?
    a) **If not**, how do the activities of your organization fit into the larger picture of population health? Population health focuses on the determinants of health and the interactions among them that determine the health and well-being of Canadians.

10. What challenges does your organization face in addressing the determinants of health?
11. What could your organization do (or what does your organization need) to better address the determinants of health?

D. Future Directions

12. How might health charities contribute to the national “Wellness Agenda’?
13. How might the ‘Wellness Agenda’ support the work of health charities?
14. What is the future role of the Health Charities Council of Canada in promoting wellness in the Canadian population?

APPENDIX B
EMAIL SURVEY

1. What term do you use when you talk about maintaining and improving people's health (e.g., wellness, quality of life, health promotion)?

2. What are the key activities you engage in to help people to maintain and improve their health?

3. Do you use the term wellness in the work of your organization?

4. Most definitions of wellness include physical, spiritual, emotional, interpersonal or social, intellectual and environmental dimensions. Does your work incorporate these various dimensions of wellness? Do you think it is important for health charities to attend to all of these dimensions?

5. a. Does your organization currently play a role in decreasing health inequalities among Canadians?
   b. Should health charities have a role in decreasing health inequalities among Canadians? Why or why not?

6. a. Does your organization currently play a role in reducing pressures on the health care system?
   b. Should health charities have a role in reducing pressures on the health care system? Why or why not?

7. What do you see as the future role of your organization in promoting wellness among Canadians?

8. What is the future role of the Health Charities Council of Canada in promoting wellness in the Canadian population?

9. Is your organization currently a member of the Health Charities Council of Canada?

Thank you for participating in this survey and contributing to the discussions!!!