Integrating the Social Sciences and Humanities in the Canadian Institutes for Health Research

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Karen R. Grant, PhD
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Abstract

This position paper examines the place of the social sciences and humanities (SSH) in the CIHR. We show that SSH perspectives and methods of investigation and analysis are particularly important in health research as one makes the move from pure science (the biomedical) to the application of that knowledge in clinical studies and in studies related to the delivery of services. It is through the ability of the SSH to understand human social dynamics that other types of biomedical, clinical and health services research can contribute to improvements in the health of Canadians. Further, we argue that if the CIHR aims to improve the health of Canadians, then all sources of data and explanatory models must be given due consideration. SSH research must be included as a necessary and cross-cutting theme in the CIHR because it has relevance to the other themes (whatever they are) and also to the major institutes (however they are formulated).

We use five case studies (social science research on HIV/AIDS, anthropological investigations of culture and illness, the narrative study of illness, human health in historical perspective, and participatory ergonomics) to demonstrate the ways in which SSH health research sheds new or different light on health and health care. Guided by an epistemology that recognizes that knowledge (including that related to health) is fundamentally a social construction, SSH health researchers add value to our knowledge of health and health care through an approach that is reflexive and critical, and through the innovative use of various methodologies, including partnerships with lay participants.

We conclude with a series of recommendations that centre on achieving the inclusive, transformative, and integrative aims of the CIHR. First, we argue that the CIHR needs to build and strengthen SSH health research capacity through the provision of adequate operational funds for SSH health research. As well, SSH health researchers must be fully integrated into all institutes (in governance, peer review, research priority setting, etc.). Second, we recommend that the CIHR must broaden its conception of partnership to include those in the policy and voluntary (community-based) sectors. Such affiliations contribute to mutual capacity building and greater accountability, while at the same time making research more relevant and useable in the uptake of findings. Third, we argue that the CIHR must ensure an inclusive and fair peer review process, which includes appropriate representation of SSH disciplines and perspectives. In keeping with our belief in the value of community-academic research alliances, we also recommend that the CIHR institutionalize the involvement of community representatives within the peer review system. And finally, we maintain that unless the CIHR institutionalizes mechanisms for true interdisciplinarity and knowledge exchange between the four CIHR sectors and between disciplines, the transformative vision of the CIHR will remain a mirage. Creative integration requires all health researchers to value and respect the distinctive contributions of diverse fields of research.

The vision of the CIHR, to transform how we do health research and to improve the health of Canadians, is a bold one. The SSH are integral to realizing this new future in health and health research.
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Integrating the Social Sciences and Humanities in the Canadian Institutes for Health Research

INTRODUCTION

The involvement of the social sciences and humanities (SSH) in health research is not new, and indeed the very origins of medicine and health care institutions are deeply steeped in the liberal arts. Hippocrates’ vision of medicine incorporated notions of morality and ethics, and his classical treatise *On Airs, Waters, and Places* recognized the importance of social and physical conditions as determinants of health and well-being (Cockerham 1989). The work of the philosopher Descartes in the 17th century profoundly shaped the practice of medicine by encouraging physicians to think about the body as a physical machine separate from the mind or soul (Mishler et al. 1981; Turner 1995). Rudolf Virchow is well known for his claim that medicine is a social science, and that the social conditions in which people live acutely affect their health (Waitzkin 1983). Each of these and numerous other thinkers from previous centuries remind us of how the social shapes the experience of health and illness, and the nature of health care.

In the present century, the influence of SSH perspectives on health and health care is also significant and well-documented. Whether it is through the explication of the social model of health, perspectives on health, disease etiology, and susceptibility to illness, the behavioural aspects of health and illness, the functioning of health care providers and the health care system, or studies on health policy, health promotion, and population health, the SSH provide perspectives that help us to understand how health and disease occur at the intersection of the biological and the social, and how health care is conditioned by social, cultural, economic, and political forces.

Whereas the various disciplines within the biomedical sciences give primacy to all things physical, the SSH turn their lens toward the social. There is a tendency for biomedical and social researchers to operate only within their own distinctive paradigms, and to disparage the work of those in the other “camp” (Fremont and Bird 1999). The Canadian Institutes for Health Research (CIHR) is presenting researchers with an opportunity to think differently about health research, and if we are wise, we will seize this moment to break down traditional parochialism in favour of true integration (Levine 1995).

This position paper examines the place of the SSH in CIHR-sponsored health research. We argue that the CIHR will realize its aims of being transformative and integrative only if it ensures that institutes draw upon the full range of knowledge and expertise (theoretical, methodological and substantive) in all disciplines engaged in studies of health and health care, including those in the SSH. We show that SSH perspectives and methods of investigation and analysis are particularly important in health research as one makes the move from pure science (the biomedical) to the application of that knowledge in clinical studies and in studies related to the delivery of services. Because it is through the ability of the SSH to understand human social dynamics that other types of biomedical, clinical and health services research can contribute to improvements in the health of Canadians. And if, as is also intended by the CIHR, the aim is to improve the health of Canadians, then we cannot afford to overlook any possible sources of data, or any explanatory models in accounting for what makes people healthy and sick, and what strategies are needed to promote and protect health, and prevent disease, disability, and premature death. In short, SSH research is integral to the CIHR in the same way as is research seeking the causes and cures of the leading causes of disease, disability and death. SSH research must be included as a necessary and cross-cutting theme in the CIHR because it has relevance to the other themes (whatever they are) and also to the major institutes (however they are formulated).

OBJECTIVES OF THE PAPER
The primary objective of this paper is to make the case for the inclusion of the SSH as integral to any comprehensive research program devoted to the study of health and health care. In addition, we will demonstrate:

1. how SSH perspectives and theories as well as methodological approaches contribute to a different understanding of health and health care or an enhanced understanding of clinical findings (Popay and Williams 1998; Pope and Mays 1995), both of which are necessary to understand health and health care in all their complexity;

2. that disciplinary diversity and integration are necessary and must be supported in the CIHR, and this can be accomplished without sacrificing rigour and without losing touch with stakeholders in the health care system, be they individuals deemed to be “at risk” or those with a disease, or workers providing care; and

3. that the CIHR’s transformative aims can only be realized through concerted efforts to facilitate cross-disciplinary dialogue, and institutionalize interdisciplinary research programs.

We use a series of case studies to show how SSH research contributes to our understanding of health and health care, and how such research has bearings on medical research and practice, health and social policy, and the health research enterprise, writ large. Through this discussion, we will show why it is necessary for all institutes in the CIHR to incorporate the SSH in their research programs, and why the transformative vision of the CIHR requires both a commitment to integration across the institutes and themes, as well as dedicated funding for SSH health research.

It is worth remembering that SSH perspectives and research on health and health care are vast, and it is not possible to do justice to all areas of research. Furthermore, the team of researchers commissioned to draft this position paper consists of individuals primarily drawn from social science disciplines (primarily, though not exclusively, sociology and anthropology). We do not discuss in detail the diverse and significant contributions to health research by those in the fields of economics, geography, and psychology. We are aware, however, that the (Interim) Governing Council will have access to position papers that speak in greater detail to these and other areas. This paper, we believe, provides an overarching view of the role of the SSH in health research, as well as a critical discussion of issues related to methodology and peer review. Readers are referred to the other commissioned position papers for more specific discussions of selected applications of SSH perspectives, approaches and substantive contributions.

BEING DIFFERENT AND MAKING A DIFFERENCE: SOCIAL SCIENCES AND HUMANITIES IN HEALTH RESEARCH

Interest in the study of health and health care has burgeoned in the last few decades as a result of a number of factors, including the increased role of the state in health care (Naylor 1986; Renaud 1978), the escalation of health care costs (Evans 1984), the greying of the population, and the increased demand on the health care system now that the baby boom generation is moving into senescence (Barer 1987; Foot 1996). As well, our society and our health care system have been faced with new health problems such as AIDS (Bolton 1989; Shilts 1987; Sontag 1988), as well as the various social, ethical, and legal challenges occasioned by the introduction and proliferation of organ transplantation (Fox and Swazey 1992) and technologies such as in vitro fertilization and genetic screening (Nelkin and Lindee 1995; Lippman 1992; 1998; Royal Commission on New Reproductive Technologies 1993; Stanworth 1987), and by debates about abortion, euthanasia, and the prolongation of life (Callahan 1990; Condit 1990; President’s Commission for the Study of Ethical Problems in
Significantly, there has also been a growing recognition of the influence of the social determinants of health (Evans, Barer and Marmor 1994; National Forum on Health 1997), and this has resulted in greater efforts to understand the non-random nature of both susceptibility and survival. The list of “health determinants” is now a lengthy one, including biology/genetic endowment, education, employment, gender, culture, race/race relations, income/socioeconomic status, personal health practices/lifestyle, physical environment, social environment, family, friends, and social support, nutrition/food, housing, the quality of working life/the quality of life, early childhood development, and health care. The determinants of health approach employs a broad set of categories, and not just those related to disease and ill health, as measures of the health of the population, so that we can begin to identify populations at risk, and to develop health promotion and disease prevention strategies. Significantly, too, this approach challenges us to focus on the ways in which disease and disability are socially produced, and therefore require interventions not at the level of individuals alone, but also in our social and cultural institutions. This approach to the study of the health of populations is one rooted in SSH perspectives and research findings, and has fundamentally altered our conceptions of health and health care.

For example, for decades, social science and public health researchers have shown that individuals’ socioeconomic and cultural background, as well as more generally, the contexts in which they live (physically, geographically, socially, and emotionally) dramatically shape their ability to live a good, healthy, and long life. A recent article in the *New York Times*, “For Good Health, It Helps to be Rich and Important” (Goode 1999), captured the essence of what social science health researchers have been saying for decades. Being poor can be hazardous to your health. *SocHealth*, an electronic newsletter distributed by La Trobe University, recently published a set of tips for staying healthy prepared by the Townsend Centre for International Poverty Research at the University of Bristol (UK). This tips include: “don't be poor – if you can, stop; if you can't, try not to be poor for long; don't have poor parents; own a car; don't work in a stressful, low paid manual job; don't live in damp, low quality housing.” Such a list reminds us that staying healthy is not simply a matter of genetic constitution, eating according to the *Canada Food Guide*, or getting enough exercise and proper rest.

Goode notes that inequality contributes to social disintegration and exclusion, which have negative consequences for the health of populations. Her recommendation, like that of others (Lomas 1997), is that we must increase social capital in order to realize improvements to the health of individuals living in their communities. Many in the social sciences would go much further to say that no significant improvements in the health of Canadians (particularly those in the lower social classes) will occur in the absence of fundamental social reforms, including those addressing the very high levels of poverty among Canadian children and adults (Chernomas 1999).

SSH research on why some people are healthy and others are not (Evans, Barer and Marmor 1994) has fundamentally transformed how we see health, disease, and disability. The shift away from seeing health status as primarily a product of health care began in the late 1960s when Thomas McKeown challenged conventional thinking about the role of medicine (McKeown 1976; McKeown and Lowe 1966). Drawing upon British data, he demonstrated that the contributions of biomedical measures to the improvements in the health of populations have been relatively modest, and that further improvements will only occur by considering health determinants in a much broader context. The determinants of health/population health approach, though only coined as such in the last decade or so, has been reflected in Canadian public health policy statements going back to Lalonde’s *A New Perspective on the Health of Canadians* (Lalonde 1974)

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1McKinlay and his colleagues have reported similar findings in the US (McKinlay 1979; McKinlay et al. 1983).
and Epp’s *Achieving Health for All* (Epp 1986), and this approach is also integrated in international policy statements such as the *Ottawa Charter on Health Promotion* (World Health Organization 1986). Most recently, the determinants of health/population health approach has been affirmed in the 1994 consensus statement of the Federal, Provincial, Territorial Advisory Committee on Population Health entitled *Investing in the Health of Canadians* (Federal, Provincial, Territorial Advisory Committee on Population Health 1994), and in the Report of the National Forum on Health (National Forum on Health 1997). The spotlight is on the social contexts of health and disease, and on addressing living and work conditions that have deleterious consequences for the health of Canadians.

This shift in our thinking about the factors that have an impact on health has been an important one, but much still remains unexplained. As Fremont and Bird note, “the biomedical community is making a conceptual shift toward a biopsychosocial model” (Fremont and Bird 1999, p. 126). Social scientific researchers, they add, have developed various models to explain variations in health status and help-seeking behaviours, but their research “rarely includes biological measures necessary to test physiologic mechanisms” (Fremont and Bird 1999, p. 126). From the standpoint of those working within social science disciplines, the trap of biological reductionism is reason enough to focus on the social and cultural determinants of health. Clearly the directions being taken in health research today are demanding that we explore both the social and biological pathways to human health and disease. We do have successful examples of how to meld different approaches. For instance, Cone (a biophysicist) and Martin (a cultural anthropologist) have collaborated on research that investigates how the global political economy of food production that includes the widespread use of pesticides and food additives, affects the prevalence of allergies and immune suppression (Cone and Martin 1998). Messing (an ergonomist) and her colleagues at the Centre d’étude des interactions biologiques entre la santé et l'environnement (CINBIOSE) have worked closely with social scientists and with workers in a variety of sectors of the Québec economy to understand the way in which work stress affects immune function and work processes put individuals at risk for injury (Messing 1998a; 1998b).

How social scientists and researchers in the biomedical sciences can do this work on the social and biological pathways to human health and disease hinges on a respectful recognition that our disciplines approach the study of health and health care in different ways. Our disciplinary approaches lead to different ways of framing a question, and this in turn affects what kind of research is conducted, and the sources of data and the methods of analysis that are used. In this paper on SSH health research, our focus is on what makes SSH disciplinary approaches different, and also how the SSH make a difference in our understanding of health and health care.

**The Disciplines**

The **social sciences** include the following disciplines: Anthropology, Economics, Geography, Political Science, Psychology, and Sociology. **Humanities** disciplines that contribute to research on health and health care include: Bioethics, Communication Studies, Cultural Studies, History, Linguistics, Literature, and Philosophy. Researchers in a number of **interdisciplinary fields** also draw upon the SSH including, for example, Environmental Studies, Participatory Ergonomics, Aboriginal Studies, International Studies, and Women’s Studies. Furthermore, SSH theories, methods, and approaches have been widely adopted by researchers in health disciplines such as nursing and rehabilitation science (e.g., physiotherapy and occupational therapy), and by those outside of academe, notably amongst those involved in non-governmental organizations, advocacy groups, and unions.

Within the various disciplines mentioned, there are naturally a variety of perspectives and methods that are used to study health and health care. But there is also a certain degree of unity amongst the SSH. That unity centres around four aspects:
Epistemology

As previously noted, how researchers view health, illness, disease and disability is firmly rooted in their disciplinary perspectives. While there are divergences amongst the various SSH disciplines, there is also significant convergence about what questions need to be problematized, and how one engages in enquiry. Fundamentally, we are talking here about epistemology, and the perspectives, approaches, and rules of evidence that are employed in the conduct of research.

From our perspective, the following are widely held presumptions about SSH health research:

1. Health is a multidimensional phenomenon that is far more than the absence of disease.
2. Individuals’ conceptions and experiences of health are situated within the contexts of their everyday lives.
3. It follows, therefore, that research on health must include the individuals’ standpoints about health if we are to capture that lived experience in meaningful ways.
4. There is no single approach that captures the nuanced experience of health and illness.
5. Wherever possible, complementary methods (quantitative and qualitative methods) should be employed to understand health.
6. Research is situated within the context of social values. Rather than treating values as if they did not exist or veiling them in the language of objectivity, SSH researchers use values to contextualize their research.
7. Another dimension to the value question focuses on the use of scientific knowledge, and for many in the SSH, our research is about effecting social and political change.

In short, the SSH have contributed to health research by broadening the definition of science and by helping us to understand how knowledge is a social construction. The SSH teach us that there are multiple ways of looking at health and health care, and there are many ways of doing research. Recognizing and valuing the diversity of approaches to health research creates the conditions for enhancing our understanding of health and health care, and ultimately, for fostering innovation.

Methods and Methodologies

SSH researchers have led the development of various methodological advances in health research. The history here is a long one, including the pioneering work done by survey and focus group researchers in the post-World War II era (Lazarsfeld, Berelson and Gaudet 1948; Merton, Fisk and Kendall 1956). As well, social scientists helped to shape how we measure the health of populations (McDowell and Newell 1987), as well as the determinants of health (e.g., socioeconomic status, personal health behaviours, etc.) (Brook et al.
Social scientists have also been at the forefront in developing methodologies to measure quality of life, and these measures have been integral to a variety of clinical studies (Croog and Levine 1989; Croog et al. 1986). In fact, survey research methodology and evaluation research are now mainstays within health research, alongside more traditional experimental methods such as randomized control trials, and epidemiological methods such as case-control and cohort studies. SSH health researchers play a pivotal role in evaluation research. In an environment that relies on evidence-based practice and policy, studies capable of assessing the efficacy and the psycho-social dimensions of programs and interventions are critical (see, for example, Blais et al. 1997).

In addition to various quantitative methods and measures in health research, social scientists (particularly in fields such as sociology and anthropology) have introduced qualitative methods in health research. Daly and McDonald observe that

Qualitative method is indispensable for the study of those aspects of health care which depend upon the social interactions between individuals or groups. Its contribution is made primarily in the study of two important aspects of health care: a) how patients and health care workers interpret their experience of health care and the significance which this has for the way in which the health care system functions and b) the cultural, historical and political circumstances which influence the nature of health care and its delivery. (Daly and McDonald 1992, p. 9)

Traditionalists remain sceptical about qualitative methods (Baum 1995). It would be a serious case of wishful thinking to assume that a paradigm shift has occurred; positivism is still the dominant framework within which most health research is conducted. Still, there has been a noticeable increase in the number of studies using qualitative methods, and these studies are published in both social science health journals (e.g., Social Science and Medicine, Sociology of Health and Illness, Journal of Health and Social Behavior, Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine) and in public health and medical journals (e.g., British Medical Journal, Family Physician, The Milbank Quarterly). Journals such as Qualitative Health Research have also been established in recent years to provide an outlet for the publication of qualitative research on health.²

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²In preparing for this position paper, a survey of health literature was conducted. Over 1200 articles and publications have been entered into a bibliographic database. A sizeable number of these articles focus on qualitative methods in health research.
It is undeniable that the techniques in the “qualitative toolkit” have made a significant impression on health research, and not just amongst those in social science disciplines (Black 1994; Brody 1991; Bungay and Keddy 1996; Carey 1993; Casebeer and Verhoef 1997; Chapple and Rogers 1998; Charmaz 1999; Charmaz and Olesen 1997; Corin 1990; de Vries et al. 1992; Green and Britten 1998; Gubrium 1995; Helman 1996). For example, in 1995, *The British Medical Journal* published a series of articles demonstrating the value and application of various qualitative techniques in health research (Britten 1995; Jones 1995; Kitzinger 1995; Mays and Pope 1995a; Mays and Pope 1995b; Pope and Mays 1995).\(^3\) In 1997, Greenhalgh published a series of papers (and then a book) on how to read published studies in health research, including those using qualitative methods (Greenhalgh 1997a; Greenhalgh 1997b; Greenhalgh and Taylor 1997). Even in discussions of evidence-based medicine which typically valorize the randomized clinical trial as the *sine qua non* of clinical research, qualitative research gets a nod as a useful and valid method to evaluate therapies and treatments (Green and Britten 1998).

Qualitative techniques commonly used in health research include interviews and focus groups, and ethnographic and observational techniques. A few examples of research using various qualitative methods will suffice to show their versatility and validity, as well as their capacity to tell us things about health and health care that we might not be able to access through quantitative techniques.

Sarah Cunningham-Burley and colleagues have used focus groups very effectively as a way to understand lay conceptions of the social and ethical issues associated with “the new genetics” (Cunningham-Burley, Kerr and Amos 1998; Cunningham-Burley, Kerr and Pavis 1999). In this research, which also focuses on medical and media discourses, Cunningham-Burley and colleagues found that professionals tend to distinguish between science and society, and knowledge and its application. Professionals understand that social factors obviously frame science, but “good science” (of which “the new genetics” is a part) is seen as “free from social contamination.” By contrast, lay participants in the study hold views that are much more ambivalent about what is acceptable and unacceptable research and practice in the new genetics, and how best to provide health and social care. Among other things, this study shows how the dominant discourse, in this case pertaining to genetics, risk and health, reflects views of the medical (and policy sector) elites, which drown out the voices of lay people. Studies such as this are important in showing why we need to engage with communities of interest in order to understand the implications of advances in science and technology (see the next section).

Ethnographic studies, a mainstay in anthropological and sociological health research, have provided clues into illness trajectories, the experience of chronic illness, and many other areas (Charmaz and Olesen 1997). Kathy Charmaz’s study Good Days, Bad Days shows us that individuals go through a variety of stages in their experience of chronic illness (Charmaz 1991; Charmaz 1999). While initially people hold onto their self-concept (because they do not wish to imagine anything other than a full recovery, nor do they wish others to impose a stigmatized identity on them), for many, the realization of the chronic nature of an illness or disability ultimately requires that one alter one’s definition of self, and this change has implications for how individuals manage the routines of everyday life. Another example of ethnographic research comes from a recently published book entitled The Making of the Unborn Patient (Casper 1998). In this study, Casper uses ethnography to understand the emergence and implications of fetal surgery as a new medical specialty. Among other things, her study shows that as this field emerged, physicians changed how they dealt with pregnancy (from a one-patient to a two-patient model of care). The effects of this shift were far-reaching, affecting the meanings of “fetuses” and “women” in medicine, and also in society and the law. These are just two of many highly influential qualitative studies that have shaped how we see various health issues.

It should be noted as well that ethnographic studies are sometimes used to particularly good effect in informing other types of research. For example, Tarasuk and Eakin studied the problem of legitimacy in the experience of individuals with work-related back injury (Tarasuk and Eakin 1995). Stigma, mistrust, and the suspicion of malingering from co-workers and supervisors damaged social relations at work, discouraged return-to-work and may have contributed to the development of chronic disability. This qualitative study was subsequently used to generate items for a large-scale epidemiological study of rehabilitation and return-to-work of back-injured workers. Perceptions of legitimacy and social evaluations, it turned out, proved to be key predictors of successful rehabilitation.

This example illustrates how important methodological innovations are in the social sciences. Not only do empirical studies in the social sciences contribute significantly to our understanding of various health issues, they also may inform how we study health and health care. As far as qualitative methods are concerned, this type of research can help in generating hypotheses to be investigated using experimental, quasi-experimental, and survey methods; or it can provide a means to interpret quantitative findings. Qualitative studies may also provide a perspective on different dimensions of a problem, and they may generate knowledge quite independently of quantitative research (Bauman and Adair 1992; Buchanan 1992; Carey

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4Chard, Lilford and Court conducted a study using citation analysis to select the world’s top 100 articles in qualitative medical sociology (Chard et al. 1997). Readers both inside and outside of the discipline of sociology will not be surprised that classics such as Erving Goffman’s Asylums (1961) and Stigma (1968), Becker et al.’s Boys in White (1961), Rosenhan’s “On Being Sane in Insane Places” (1973), Kleinman’s The Illness Narratives (1988) and “Culture, Illness and Care” (1978), and Glaser and Strauss’s Awareness of Dying (1965) are all listed in the top 25. Charmaz and Olesen review the focus and contributions of ethnographic research in their 1997 paper. The bibliography is quite extensive, listing hundreds of ethnographic studies which contend have

"(1) maintained a critical focus on the institution of medicine; (2) brought subjective experience into medical sociology; (3) provided empirical corrections to public, professional, and sociological assumptions about medical care and health and illness; (4) challenged accepted ideas in subfields of medical sociology; (5) deepened other social scientific analyses; and (6) extended the range of medical sociology" (p. 453).

Similar observations are made by Trouse and Summerfield (1996) and Agar (1996) regarding anthropology’s influence in epidemiological research.

This lengthy discussion about qualitative health research has another purpose, and that is that it serves as a reminder that there are many ways to conduct SSH health research. Daly and McDonald remind us that different approaches to research will ask different questions, collect different data and use different frames of analysis. Indeed, methods of analysis can be based on varying philosophies of knowledge, and the criteria for judging what counts as rigorous within one method cannot be transferred to another with fundamentally different epistemological assumptions. It follows that, unless funding bodies are familiar with the full range of study designs applicable to health care, prejudice against certain methods will lead to a systematic neglect of important issues. Funding bodies which lack the necessary criteria for judging research using non-experimental methods of research run the risk of ignoring much-needed analysis of social and community issues in health care, and the necessary eclectic and interdisciplinary approach to research will be inhibited. (Daly and McDonald 1992, p. 5-6)

The practical significance of these comments for the CIHR will be addressed at the end of this paper.

**Extending our Reach within Communities**

Social science research practice has been undergoing a dramatic shift in recent years. Traditionally, researchers, guided by theoretical questions of interest, or past research, would formulate a research hypothesis, identify the data requirements, and set about the task of conducting the research. This “top-down” approach to research is what most academic researchers know, and it is how research has been done. (It is also the kind of research that granting councils have been inclined to support.)

Growing dissatisfaction with this style of research on the part of academic researchers and on the part of the individuals who were seen as the “objects” of research, coupled with frustration on the part of community-based service providers and stakeholders has forced academic researchers to think about doing research in a very different way; i.e., that is, with and not simply on communities of interest.

It, of course, must be said that some academic researchers have typically rooted their work in the community, even before it became fashionable to encourage community-academic interaction and collaboration. The entire field of participatory research, which is firmly based in the liberation politics of the 1960s, makes clear that academic researchers alone are not the sole possessors of truth and knowledge (Cornwall and Jewkes 1995; Hagey 1997). In some fields, the need to employ more “bottom-up” approaches has been necessitated by the kinds of issues and populations being studied. For example, in reaching “hard-to-reach” populations (including persons on the fringes of society, as well as various elites), access may only be made possible by engaging with members of such populations. In some cases, research questions derive not from prior research or theoretical considerations, but from the “work-a-day” worlds of people who themselves are seeking creative solutions to the challenges they face. In some instances, communities may actually seek out the assistance of academic researchers to show the links between, for example, risk factors and health problems (Brown 1992), or to help them come to some understanding of the health needs of their communities (Knocknaheeny/Hollyhill Community Arts Development Project 1998).

For at least some members of the SSH health research community, this approach is not only desirable, but also necessary. This is because a mainstay of SSH health research is to examine health in context, and this works well when we engage with our communities. Furthermore, if research is intended to be action-oriented,
then extending our reach into communities becomes the way to make a direct link between knowledge and action. Whenever communities feel that they are able to participate in the construction of new knowledge and then can appropriate that knowledge, they are more likely to be empowered to effect changes to their conditions, either on their own or through political social action.

Various models have been established to provide for greater interaction between academic researchers and communities, based to some degree on the model of the Dutch “science shops.” The Conseil Québécois de la recherche sociale (CQRS) has funded partnerships between community organizations and universities since 1992. This program is unusual in that the community organizations administer the funds. The Social Science and Humanities Research Council, in 1999, launched the Community University Research Alliances (CURA) program, and will fund up to 24 CURAs in the inaugural competition. In the US, The Loka Institute in Amherst, Massachusetts, has created a network of those interested in community-based science (www.loka.org). Such initiatives greatly facilitate collaboration with community groups, non-governmental organizations, unions, and laypeople.

Community-university research partnerships involve a fundamental shift in how we think about the research enterprise – what questions we ask, what roles we take, etc. When done well, community-based and participatory research can shed light on the foci of research in ways that might not otherwise be possible. As well, this type of research recognizes that individuals are experts about their own lives. They create complementary, if not alternative, ways of knowing to that of accredited scientists (Popay and Williams 1996). For example, when individuals with a disease like breast cancer are engaged in, and not merely the subjects of, research, they contribute their embodied knowledge about breast cancer, and the net result is a fuller understanding of the disease. Their experiences provide insight into the disease beyond that attainable in laboratory studies, or through epidemiological surveys, or even in clinical studies of breast cancer, its diagnosis and treatment. What is more, the multiple and varied experiences of individuals living with a disease give them a kind of expertise that can lead to new and different research, as well as new and different interpretations of an observation. Including their perspectives, therefore, not only improves the validity and utility of research results (to individuals with a disease, as well as “scientists” studying the disease), but also produces better science.

**Reflexivity and Critique**

“In order to understand and explain social phenomena, we cannot avoid evaluating and criticizing societies’ (sic) own self-understanding.” Reflexivity leads us to recognize alternative ways of viewing “reality,” and prompts us to make explicit some of the world view which we and others bring to our research endeavour. (Eakin et al. 1996, p. 158)

Reflexivity and critique, while not qualities found only in SSH disciplines, are perhaps more common in these disciplines given the epistemological roots of the SSH. Researchers in the SSH are more practiced at the ability to critically examine the taken-for-granted world in which we live. Of course, the critical questions posed by the SSH are often simply seen as muck-raking and/or purely ideological. At the very least,

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5For example, see the research of Abby Lippman, Joy Laverdure and colleagues on communication among women living with a diagnosis of breast cancer. The study, entitled “I Heard it Through the Grapevine,” is funded by NCIC.
questions raised by SSH are viewed as awkward. Still, they demand our attention, if for no other reason than that they challenge us to imagine how things might be different – and better.

There is a long history of a reflexive posture in the SSH (Berger and Luckmann 1967). In studies of health and health care, there are several very compelling examples that can be cited. It must be said that such critiques are not especially well-received within biomedical circles, but at the same time, there is evidence that these (and other) critiques have resulted in important changes in health practices and public policies. One vivid and concrete demonstration is the feminist critique of childbirth practices and women’s health care more generally (Beauregard and De Koninck 1991; Bernhard 1995; Cohen 1998; Ehrenreich and English 1979; Keville 1993-1994; Kohler Riessman 1983; Krieger and Fee 1994; Rosser 1994). As a result of this critique (which is based both in academic research and in the advocacy work of those engaged in the women’s health movement), changes in practices and policies have occurred such as the resurgence of midwifery which has now been legalized in five Canadian provinces (see also Declercq 1998).

Another example comes from the critique of allopathic medicine, and the corresponding rise of complementary and alternative medicines. Sharma (1992) and Achilles et al. (1999) have provided much needed data about patient utilization, the appeal of complementary and alternative medicine and levels of satisfaction with complementary medicine, and profiles of complementary and alternative practitioners in Britain, United States and Canada, respectively. Other social scientists have examined the meaning of alternative medicines in both contemporary society (Cant and Sharma 1996; Coward 1989; Lyng 1990; McGuire 1988; O’Connor 1995), as well as historically (Cooter 1988). These studies demonstrate that, in part, the resurgence in interest in complementary and alternative health practices represents a rejection of the dichotomy between mind and body underlying the biomedical model, but at the same time questions the rigid distinction between ‘orthodox’ and ‘complementary and alternative’ made by both orthodox, and complementary and alternative practitioners alike.

SOME CASE STUDIES

To this point, a number of examples have served to illustrate the use and application of social science approaches in health research. More detailed case studies follow, and these are designed to demonstrate that this type of scholarship is absolutely essential in the CIHR’s reformulated health research infrastructure. The specific findings of social science research have bearings on medical research and practice, and the delivery of health services; it has bearings on health and social policy, and on the health research enterprise.

Health research in the humanities is equally important. Although their numbers are fewer, Canadian humanities health researchers (as well as those working in international circles) continue to play a vital role in helping us to understand how best to develop effective health and social policies. Of particular note is the work of bioethicists who grapple with issues such as the ethics of human experimentation, including, for example, the persistence of androcentrism in clinical studies (Baylis, Downie and Sherwin 1998), the

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allocation of scarce resources (Kizer Bell 1992), the social, ethical and legal implications of medical
technologies and procedures (Annas 1982; Annas and Elias 1999; Callahan 1990; Kass and Wilson 1998;
Overall 1993; Singer and Wells 1985; Stewart 1991; Veatch 1972; Wertz and Fletcher 1992), and issues
such as autonomy and social justice in health care (Sherwin 1998). Increasingly, bioethicists are being called
upon to address allocative issues at the bedside, and not just at the public policy level. Those in the bioethics
community play a vital role in “setting appropriate ethical boundaries for medical research which is important
in its own right, and is also important if medical research is to win the trust and support of the wider public.
Effective and morally defensible policy decisions about health research and national health policy are not
likely to emerge unless high quality scientific health research is carefully integrated with high quality
humanities and social science research.”

One further point merits comment at this stage, and that is that the case studies that follow are by no means
comprehensive. There are virtually thousands of other areas of research that might have been highlighted.
For example, consider the following:

1. feminist social science has contributed to our understanding the health consequences of violence
   against women, and to the development and refinement of effective research tools for the study of
   such sensitive health and social issues (Bell and Mosher 1998; Hanvey and Kinnon 1993); work in
   this area has provided the basis for revisions to training protocols for health care practitioners;

2. research on the social dimensions of alcohol and substance (ab)use is extensive (Bennett 1988;
   Brady 1995; Delaney and Ames 1993; Gilbert 1990-1991; Hurley 1991; Johnson 1993; O’Neill and
   Mitchell 1996; Single et al. 1995a; 1995b; Valverde 1997; Vinje and Hewitt 1992), and there is a
   substantial body of literature on lifestyle behaviours such as smoking (Aitken et al. 1985; Elkind 1985;
   Greaves 1995) and exercise (Bercovitz and Skinner 1996; Wardle and Steptoe 1991);

3. interesting and important work has been done in the area of mental health (Barham and Hayward
   1998; Barnes and Toews 1985; Barnes, Stein and Rosenberg 1999; DeVries 1997; Elliott, Taylor and
   Kearns 1990; Everett and Boydell 1994; Gallagher and Mechanic 1996; Good 1997; Harpham 1994;
   Kirmayer et al. 1999; Kleinman and Cohen 1991; McLean 1990; Morris 1997; Powell, Single and
   Lloyd 1996; Prior 1993; Riessman and Gerstel 1985; Vingerhoets and Marcelissen 1988; Walters
   1993; White and Mercier 1991);

4. social scientists figure prominently among those studying the health and social impacts of disasters
   (Blakie et al. 1994; Bolin, Jackson and Crist 1998; Enarson 1998; Enarson and Hearn Morrow 1997;
   Fothergill 1996; Joh 1997; Keene 1998; Krug et al. 1998; Ollenburger and Tobin 1998; Sundet and
   Meremstein 1996; Wiest, Mocellin and Motsisi 1994), while historians have documented societal
   responses to disasters throughout modern history (Bumsted 1997); and

5. there is an extensive body of research on health care providers and health services, as well as the interactions between users and providers of health care, and the impact of health system restructuring on the health of users and their carers (Armstrong 1999; Association feminine d'éducation et d'action sociale et al. 1998; Atkinson 1995; Barnes, Stein and Rosenberg 1999; Benson and Britten 1996; Birch, Eyles and Newbold 1993; Blais et al. 1997; Brannon 1996; Britten 1994; Campbell 1987; Campbell 1992; Campbell 1994; Charles et al. 1998; Chernomas and Sepehri

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8Arthur M. Scolar, Director, The Centre for Professional and Applied Ethics, University of
Manitoba, personal communication. August 26, 1999.
SSH health research spans the entire range from the micro-level through to the macro-level. It focuses on questions of a more basic nature (“of medicine”), as well as those of a more applied nature (“in medicine”). Appendix 1 provides a brief overview of the scope of SSH health research and its relevance to health and health care.

The following four case studies serve as exemplars of how SSH scholarship and research provide different or enhanced ways of understanding the experience of health and health care, the determinants of health, and the social, cultural and political contexts of health and disease.

**Social Science Research on HIV/AIDS**

AIDS is a new disease that first appeared in the early 1980s. At the time that the first cases were identified, relatively little was known about the exact mechanisms by which individuals became infected. Initially, gay men, Haitians, and intravenous drug users were identified as the populations at risk. But the higher incidence of the disease in homosexual males led to the tag “the gay plague.” This disease evoked fear and, some would say, moral panics fed by media sensationalism (Lupton 1995; Shilts 1987), and a certain amount of homophobia and xenophobia. In countries throughout the west, public health campaigns used scare tactics to tell people that sexual desire could mean death.

As medical researchers worked to identify the underlying mechanisms for the communication of the human immunodeficiency virus, it was social scientists (mostly in the fields of anthropology and sociology) who sought to understand how individuals internalize notions of risks, and how – on that basis – they engaged in
protective behaviours. As Lupton notes, “People do not conceptualize risk in terms of objective statistical probabilities but rather make subjective judgements based on ontological and cosmological assumptions... In the vain attempt to lessen the vagaries of fate, health promotional discourse urges modification of factors related to lifestyle... and in doing so, tends to obscure the factors that are not amenable to change... Risk discourse tends to assume universal experience and ignores social differentiations” (Lupton 1995, p. 85).

The work of social scientists, we now realize, was absolutely fundamental to getting the AIDS epidemic under control in the west. This was accomplished in several ways. First, social science research clearly indicated that it was not so much an identity that defined an individual’s risk status, but rather the individual’s behaviour. A large number of the men who were the early casualties in the AIDS epidemic were men who had sex with men, but they were men who did not identify as homosexual, nor did they consider themselves to be at risk. Studies in sexuality clarified the important distinction between identity and behaviour, and identified what is described by some as “the bisexual bridge” (Brendstrup and Schmidt 1990; Connell et al. 1990; Connell et al. 1994; Connell and Kippax 1990; Gagnon 1990; Hankins 1998; Lifson 1992; Ramos, Shain and Johnson 1995; Rosenthal, Gifford and Moore 1998; Sills 1994; Van de Ven et al. 1997a; Van de Ven et al. 1997b; Waldby, Kippax and Crawford 1993; Weatherburn et al. 1998). In short, these and many other studies demonstrated that identity does not cause this disease.

Furthermore, social scientific studies show that if individuals are going to change their behaviours, they will do so not on the basis of a rational assessment of epidemiological or scientific data, but rather on the basis of the meaning that they attach to behaviours. For example, those who get a “rush” out of risk-taking behaviour are not likely to change their behaviours, and thus may put themselves and others at risk. Connell and Kippax note that the emotional charge of anal sex places the most risky sex practice “close to the heart of the social process of constructing gayness” and this is difficult to change, particularly for young men who are marginalized within the gay community (Connell et al. 1989, p. 194).

Finally, sociological research has focussed attention on the male profile of AIDS and AIDS research. Studies such as Campbell’s Women, Families and HIV/AIDS points to the ways in which women have been overlooked and underemphasized (Campbell 1999). She notes that if we are to understand women’s risk of infection, we need to examine gender roles and gender stratification (i.e., the sexual politics of safe sex, etc.). She notes that few studies have examined the role of men in elevating women’s risk. (Traditionally, research focussed on women as vectors for the disease, and prostitutes were scapegoated as purveyors of the HIV virus.) As well, she observes that the male profile of the disease means that physicians have been slow to recognize the problem of HIV/AIDS in women (except insofar as woman-to-fetus transmission of the disease is concerned).

There is a vast body of anthropological research literature on the cultural dimensions of HIV/AIDS. The rich historical and cross-cultural analyses have added an invaluable dimension to the clinical studies of infectious immunosuppression. The social context of disease, for example, is highlighted in work by Emily Martin (1994), whose analysis of the body imagery associated with immunological discourse illustrates how perceptions of HIV/AIDS are not isolated within medical realms, but tied to economic and political discourses of flexibility and diversification. This has great relevance to both our general understanding of the scientific inquiries into human immune systems, and to our appreciation for how some health care strategies that utilize this imagery are more likely to be successful than those that do not. Similarly, Farmer’s detailed ethnographic research shows in alarming detail the way in which poverty exacerbates the risks of contracting HIV/AIDS (Farmer 1995). In addition, recent work by Downe illustrates the sophisticated understanding of HIV/AIDS by sero-positive women and offers ways in which health care providers can learn from their experiences (Downe 1997; see also Fee and Fox 1988; 1992; Feldman 1990). Downe's work with prostitutes in Costa Rica indicates that “contagion” was complexly linked to HIV/AIDS, diabetes, violence and the over-prescribing of pharmaceutical drugs and ultimately to the general conditions in which the women lived and worked (Downe...
1997). Downe’s current work with Métis prostitutes in Saskatchewan (forthcoming) continues to show that any HIV/AIDS prevention program targeted at sex workers will be successful only if it addresses the connections between disease (HIV/AIDS) and broader life circumstances.

Sills’s comments about AIDS not only underscore the social contexts of this disease, but also the limitations of viewing AIDS purely from a biomedical perspective.

AIDS is caused by a virus, but the disease is the result of human behavior that transmits the vector, HIV. The ‘enemy’ that activates the virus is human behavior – at truck stops and in the barracks of migrant workers, in the thatched huts of rural villages, in the slum shanties of the developing world, in the bedrooms of the inner-city poor, in the hotel rooms and large houses of the not-so-poor, in houses of prostitution, and in big-city bathhouses. This behavior is driven by culture, by ignorance, by despair, by desire, and by love – and of course by the age-old male domination of women. To change it is the challenge of our times. (Sills 1994, p. 260)

**Anthropological Investigations of Culture and Illness**

Medical anthropology has contributed in unique and significant ways to our understanding of the cultural, social, and political dimensions of disease, illness, and health. The cornerstone of anthropological studies is an ethnographic methodology which combines extensive participant-observation with a range of in-depth interviewing, survey distribution and/or cultural mapping techniques. The richly detailed analyses that emerge from ethnographic research provide a vital perspective in the analysis of both those who live with the burdens of disease and distress as well as their caregivers. Anthropological studies have outlined the cultural shaping of ideas about health and the body (Adelson 1998; Lock 1998; Wakewich in press), differing social constructions of disease and illness (Lock and Wakewich-Dunk 1990), and the social production of medical knowledge, and practice in biomedicine and alternative medical systems (Lindenbaum and Lock 1993).

Recent anthropological studies demonstrate the continued importance of culture in framing responses to disease, in classifying and treating mental health conditions, in shaping contemporary debates on the growth of technology in medical practice, as well as in framing both lay and medical responses to increasingly difficult ethical issues such as determining the beginning and ending of life. Margaret Lock’s study of the institutionalization and legitimation of "brain death" in Japan and North America, for example, highlights cultural distinctions in the definition of brain death and their impact on efforts to promote the value of organ transplants (Lock 1996a; Lock 1996b).

Anthropological studies in the field of mental health range from work on the symbolic and political aspects of somatic representations of distress (Dunk 1989; Lock and Wakewich-Dunk 1990), and the social dimensions of stress expressed as “social suffering” and its implications for the mental health of communities (Adelson in press; Kleinman 1992; Kleinman, Das and Lock 1997), to specific works on schizophrenia and psychosis (Corin 1998; Corin and Harnois 1991; Corin and Lauzon 1994; Corin 1990; Kirmayer 1989; Kirmayer and Corin 1998; Kirmayer, Fletcher and Boothroyd 1997; Kirmayer and Young 1998), suicide (Canetto and Lester 1998; Clark et al. 1990; Eggert et al. 1994; Kral 1998), substance abuse (Steinberg 1996), and psychiatric trauma (Rousseau, Corin and Renaud 1989). The Division of Social and Transcultural Psychiatry of McGill University houses various “culture and mental health” research units that exemplify the kind of multidisciplinary work that is done in this area. One project on the anthropology of psychiatry, for example, examines “Body, Memory, and Identity” through illness narratives as one of the variety of indicators of stress disorders and psychopathology (Young 1995).

One creative example of interdisciplinary research on health in which anthropologists are playing a central
role is the Native Mental Health Research Team housed at McGill University (and funded by the Fonds de la recherche en santé du Québec). This team is actively engaged in the study of emerging models of intervention for mental health and social problems in Native communities (including, but not limited to child abuse, suicide, and substance abuse) and is comprised of a range of urban and remote Inuit and First Nation community representatives, health boards, social scientific and medical researchers, practitioners, social workers, and Aboriginal and non-Aboriginal graduate students. The team employs clinical, epidemiological, ethnographic and qualitative field methods appropriate for research in small scale communities. The goals of the team include developing models of effective community and professional responses to a range of mental health problems, and materials for training indigenous community workers in adapting mental health approaches appropriate to their respective communities. The team is also developing methods to train Native community workers to systematically review the efficacy of new mental health programs (Kirmayer et al. 1999).  

The Narrative Study of Illness

One significant contribution of the SSH has been the examination of patients’ experiences of illness, aging and the dying process. Arthur Kleinman, a clinician and one of the anthropological pioneers in this area, draws our attention to the meanings of illness, disease and sickness and death (Kleinman 1988). “Illness narratives,” Kleinman writes, “edify us about how life problems are created, controlled and made meaningful” (p. xiii). Drawing on his studies in North America and China, Kleinman argues that body idioms highlight what is “both peculiar to distinctive cultural worlds and constrained by our shared human condition” (p. xiii). More recently, Arthur Frank’s autobiographical account of two life-threatening illnesses is a compelling story of his desire to maintain selfhood and identity while coping with the institutional features of medical and nursing practice (Frank 1991; Frank 1995). These themes are also taken up by Jo Spence who documents in her photographic essays her struggle with breast cancer and her decision to try alternative medicine (Spence 1988). In contrast, the poet, Audre Lorde, chronicles in her diaries her decision to pursue conventional medicine for the treatment of breast cancer and her decision to try alternative medicine (Spence 1988). In a very different context, Oliver Sacks, the renowned neurosurgeon, highlights the importance of the social and cultural environments which shape patients’ responses to chronic or profoundly altered neurological differences (Sacks 1983; Sacks 1985). These profoundly moving stories, told in a variety of different ways, are important reminders of the need for compassion in the treatment of individuals who are ill. All too often, the patient as a whole person disappears in the depersonalized world of medical practice.

In recent years, social scientists have begun to examine more closely the narrative structures of medical practice itself. Susan Sontag, writer and critic, examines the metaphors informing attitudes toward tuberculosis at the turn of the century and to cancer today (Sontag 1977). Because these “diseases of passion” are embedded in discourses of fear and dread, patients suffering from these diseases are demonized by family, friends and the medical system at a time when they are most vulnerable. Sontag later applied this same method to the analysis of AIDS (Sontag 1988). Taking an anthropological approach, Emily Martin demonstrates that women of different social classes have very different understandings of menstruation as a bodily process in which middle-class white women are more likely to conform to the biomedical model than working-class or racialized women (Martin 1987). In another groundbreaking book, Martin explores the traversing of immunology from the world of science to the broader culture where people from all walks of life actively use the immune system to organize and comprehend their lives (Martin 1994). Martin queries the rigid distinction between science and popular culture, and draws our attention to changing

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*A fuller discussion of aboriginal health issues is detailed in the HIDG paper by John O’Neil et al.*
conceptions of the body, health and disease, and shifts in identity and subjectivity resulting in “flexible bodies,” which Martin ultimately links to the reorganization of power relations in contemporary American society.

Much contemporary writing in the social sciences and humanities traverses traditional boundaries between and among the disciplines. For example, in his recent collection of essays, Georges Rousseau, the eminent literary critic, explores the intersections between literature, science and medicine in the Enlightenment period (Rousseau 1991). Also working in Enlightenment studies, Roy Porter, historian of medicine, explores the relationships between medicine and mathematics, taxonomy and the sciences of mankind (Porter 1995).

**Human Health in Historical Perspective**

Historical methods include a range of processes for collecting and interpreting both qualitative and quantitative information. Key to the historical method is a recognition of context – the importance of understanding experience as particular to specific times and places – and sensitivity to the limitations of evidence. Historians begin with the question, who collected this information and why, and why has it been preserved. They bring to their work a skepticism about the idea of progress, wariness about “presentism,” and a commitment to social constructionism. They also pursue comprehensiveness of source material, and a question-setting agenda that perceives both what is, and what is not, known about the past (however recent). These tools can be of considerable value in understanding contemporary issues in health care.

When applied to studies of health, illness and disease, history and its methods have served four distinct purposes. First, they have increased understanding of the case record (or case histories); second, they have improved the management of health and illness; third, they have enhanced the formation of health policy; and fourth, they have contributed to the development of effective strategies for the promotion of health and the management of disease.

For example, in their study of the recent history of AIDS, and the uses and misuses of historical narratives in framing health policy, Elizabeth Fee and Daniel Fox argue that historical methods and theoretical presumptions are fundamental to the social and policy sciences (Fee and Fox 1992; Fee and Krieger 1993). Similarly, Lerner shows how history can be used to study contemporary health issues such as genetic testing for breast cancer (Lerner 1999).

Historical studies of disease temper the universality of biomedical research so that scientific findings have a more human and personal face, and hence are seen as more applicable in clinical and social settings. For example, Feldberg’s and Lerner’s research on the history of tuberculosis demonstrates that although tuberculosis is universally a disease caused by the tubercle bacillus, the experience of having tuberculosis varies greatly over time, and different cultures in different periods identified various social determinants that also contributed to the illness (Feldberg 1995; Lerner 1998). Such investigations – while historical in nature – do remind us that these additional social variables (e.g., socioeconomic status) help to frame the experience of the disease, and accordingly should guide us in the development of more effective clinical and policy responses to this (and other) disease(s) (Labisch 1998).

Historians of medicine and literary critics have also provided rich accounts of medical practice in the past which reveal the radical shifts in medical thinking which took place in the latter part of the 19th century. For example, the literary critic, Jonathan Sawday examines “the culture of dissection” in Renaissance culture in partition (Sawday 1995). “Partition stretched into all forms of social and intellectual life: logic, rhetoric, painting, architecture, philosophy and medicine, as well as poetry, politics, the family and the state... The pattern of all these different forms of division was derived from the human body” (p.3). In his groundbreaking book, Thomas Laqueur persuasively argues that the two-sexed model of biological difference between males
and females is a modern idea (Laqueur 1990). Before the modern period, from Plato to Versalius, a one-sexed model prevailed in which male and female bodies were conceptualized as correspondences rather than in terms of difference. Laqueur draws our attention to the authority of seeing, and the power of dissection in the art and rhetoric of Renaissance anatomies. Similarly, the art historian, Barbara Stafford examines the visualization of knowledge in art and medicine in the Enlightenment (Stafford 1991). Stafford argues that during the Enlightenment a radical shift took place from a text-based to a visually-dependent culture. The desire to know the human body and to make visible the unknown through novel scientific instruments and optical devices was central to the Enlightenment project, and was reflected not only in anatomical atlases, but also through art and literature.

While these historical studies of the intersections between medicine and the larger culture can be interpreted as examples of the “unscientific” nature of medical practice, studies of contemporary medical practice have also emphasized the interconnectedness between culture and medicine. They invite us to examine the ways in which “cultural ideas saturate medical language, how biomedical conceptions of the body put pressure on social ideologies, and how much we take for granted the idea that we can establish an objectively defined delineation of the “normal” with respect to the human body” (Epstein 1995, p. 6). The study of medical storytelling tells us much about cultural expectations for the understanding of mind and body, self and identity, and their intersection with race, ethnicity, class, gender, religion, sexual orientation, age and ability. For example, Julia Epstein examines the construction of the “normal” in the definitions of disease, the production of diagnoses, and the history of medical-keeping. She then applies this methodology to three case studies (hermaphroditism, birth malformations, and AIDS), and illustrates the ways in which culture drives medical explanations and, in turn, are driven by them. Katherine Young, an ethnographer, explores the phenomenology of the body in medicine in a variety of medical disciplines and procedures (internal medicine, gynaecology, surgery and pathology), and demonstrates the tensions between body-as-self and body-as-object (Young 1997). Although much of this literature represents a fundamental critique of the epistemology of medicine, and implies a dissolution of medicine as an institution, a recent collection of essays (Berg and Mol 1998) argues that the differences within medicine may translate into conflict (e.g., the contested domain of fetal surgery), but more often than not, the tensions within medicine can lead to coordination (e.g., the management of pain or asthma).

Issues of self, body and identity, and their intersections with cultural expectations are explored also in studies of medical technologies. SSH researchers have examined the paradoxes of new imaging technologies which have made visible the workings of the brain and the body as never before, but the knowledge and insights gained through these technologies are constrained by institutional, cultural, and economic forces (Treichler et al. 1998; Cartwright 1995). For example, Cartwright examines the reception of the Visible Human Project through the analysis of images, texts and digital techniques (Cartwright 1998). Although touted as a major innovation by medical scientists, Cartwright argues that the Visible Human Project replicates older anatomical paradigms and reinforces prevailing views of gender difference. The development of the new reproductive technologies has raised concerns by feminist writers about the impact of the new reproductive technologies on women’s health, and more broadly the implications for the status of women in contemporary society. The almost uniformly dystopic vision produced by feminist writers working in a number of fields has had some impact on public policy, leading to the establishment of the Royal Commission on New Reproductive Technologies in 1989 (see the Royal Commission’s Final Report published in 1993).

**Participatory Ergonomics**

Participatory approaches have been an integral part of many occupational health research programs (Mergler 1987; Messing 1998a; 1998b). Ergonomics was developed in France (Laville 1976; Teiger 1977; Wisner 1972) and involves the analysis of work activity. It has always integrated observation of work activity in the workplace with the perceptions of workers, in order to create a more accurate portrait of working conditions.
Participatory approaches to ergonomics have been developed in several countries (including Canada), and involve a decision-making role for workers in the conception and conduct of work analyses. As pointed out by Garrigou and colleagues, this analysis must have both technical and social components (Garrigou et al. 1995). Methodological choices and results are validated with the workers. At the end of the process the results of the research are reported to workplace participants, whose comments are integrated into a final report.

Several groups have developed methods of participatory ergonomics (Garrigou et al. 1995; Guérin et al. 1991; Lamonde and Montreuil 1995). In a Canadian example, researchers at CINBIOSE (Université du Québec à Montréal) planned and carried out a study in collaboration with the union of tellers employed by a major Canadian bank (Seifert, Messing and Dumais 1997). Health problems were identified in initial joint interviews with a group of six tellers from different branches, chosen by the union executive. Criteria for choice of the six were worked out in collaboration with the union executive so as to give a view of the most important differences in working conditions. The choices of the most important health problems were verified with representative structures of the unions, and potential causes of these problems (lower limb pain and prolonged static standing; anxiety, and bank robbery, etc.) were explored during 87 hours of observations in the workplace, together with interviews involving tellers and managers. Associations between health problems and potential causes were verified using a questionnaire. After discussion with tellers, recommendations were made to change aspects of the work environment such as the arrangement of the working surface and the way de-briefing was done. Beyond the specifics of the recommendations, the research team was able to increase its understanding of the standing work posture, a heretofore little-explored health-related parameter. This work eventually led to the addition of two questions to the Enquête Santé-Québec (Quebec Health Survey). (The responses are now being analysed.)

For some time, UQAM has had a partnership program with three major trade unions (Confédération des syndicats nationaux, Fédération des travailleurs et travailleuses du Québec, and Centrale de l’enseignement du Québec) to study women’s occupational health. The aim of the research is to provide empirical evidence that will lead to changes in union, government, and workplace prevention programs. The partnership is funded by the Québec Ministry of Health and Social Services, and thus far, collaborative studies have shown that women are inadequately served by government prevention programs in occupational health (CINBIOSE 1996), that women are discriminated against when making claims for compensation (Lippel 1995; Lippel et al. 1996; Lippel and Bienvenue 1995), and that working conditions place certain workers at risk of disease, injury or disability (Messing et al. 1993; Messing et al. 1997; Messing 1998a; 1998b; Seifert et al. 1997). Coordinating committees are established involving academic researchers (in biology, law, and social work), and union representatives with expertise in women’s issues and in occupational health and safety. The partnership is coordinated by an employee of UQAM’s Service aux collectivités.
Thus the collaboration of ergonomists, sociologists and epidemiologists is leading to a greater understanding and possible prevention of musculoskeletal pain from one of the most common working postures.

DISCIPLINARY AND METHODOLOGICAL DIVERSITY AND INTEGRATION IN THE CIHR

The foregoing discussion is a prelude to our central assertion that the CIHR must support disciplinary and methodological diversity if it is to realize its aims of improving the health of Canadians, and transforming the health research culture in this country. This will not be a simple task. More than rhetoric will be needed to convince the SSH health research community that the CIHR will indeed be inclusive, transformative, and integrative.
The SSH and the Four Cross-Cutting Themes

“Culture, society and the health of populations” provides a logical home for much of the health research conducted in the SSH. But the SSH belong in each of the four quadrants envisioned in the CIHR. As noted earlier, research in the SSH has relevance to the other themes (whatever they are) and also to the major institutes (however they are formulated).

Take the example of cancer research. Cancer is the second leading cause of death in Canada, and an estimated 129,300 new cases will be diagnosed in 1999. An estimated 63,400 Canadians will die from cancer in 1999. While heart disease kills more Canadians, cancer results in more potential years of life lost for women and men, and for adults and children. At present, there is a veritable army of researchers studying cancer. Many involved in cancer research are focussed on identifying the underlying causes of this disease in order to prevent it, and to find more effective treatments and cures. Biomedical disciplines such as oncology, immunology, physiology, toxicology, and genetics carry out laboratory and applied studies in order to answer questions related to the etiology of various cancers, their pathogenesis, expression, and the conditions that cause cancer to spread. Those working in clinical fields are preoccupied with issues related to diagnosis, prevention, and treatment.

It would be inappropriate to suggest that biomedical and clinical research is devoid of questions about the social. In each of these spheres of research, there are social questions and perspectives that demand inclusion. Appendix 2 provides a sample listing of the myriad questions that might be posed in cancer studies, questions drawn from the theories, methods, and perspectives of the SSH. All of these, whether focussed on biological, environmental or treatment-related questions, can include social questions that are relevant to understanding cancer, to reducing its toll on Canadians, and to improving the quality of care of those affected directly and indirectly by this disease.

In addition, the SSH can contribute through studies of the institution of medicine and of science, as well as studies of the various ways in which culture, politics and society influence cancer. Without SSH perspectives, the influence of social factors in cancer, and more generally, the significance of the social context of health and disease, will continue to be underestimated. What is more, without this type of integration in the various quadrants of the CIHR (biomedical science, clinical applications, health services and systems, and culture, society and the health of populations), the transformative vision of CIHR will remain a mirage.

Why a Population Health Research Institute is Not Enough

There have been some discussions during the consultative phase in the CIHR’s development that suggest the possible establishment of a research institute on population health. Some believe that the establishment of such an institute would more than adequately address concerns voiced in the SSH health research community. We strongly urge the Interim Governing Council not to mistake population health research for SSH health research. As already demonstrated, there is significant variation in the research conducted and approaches used within the SSH, and not all SSH researchers are guided by the theoretical and/or methodological tendencies among those working within the population health framework. SSH health research is much broader than population health research, just as health research is a broader concept than biomedical or clinical research.

Our message is a straightforward one: the SSH have made important and unique contributions to the study of health and health care, and they possess a particular skill set that equips them to carry out their scientific investigations. SSH health research is more than asking a few questions (not everyone can
do an interview), or creating a survey to assess patient satisfaction. SSH health research goes beyond the analysis of administrative claims data or other health databases. It is about penetrating the taken-for-granted worlds of individuals in society, in order to understand their experiences of health and health care. It is about asking hard questions about the social production of disease, and about the private consequences of public policy. It is about turning a spotlight on medicine, health care, and social institutions that bear on health.

SSH researchers are well positioned to lend their expertise to the new research environment envisioned by the CIHR. They will do so in a population health research institute (should there be one named), and they will do so in other institutes as well. What SSH health researchers need is the means to ensure their contributions are supported financially and seen as meaningful by their colleagues in other health disciplines.

RECOMMENDATIONS

In light of the foregoing discussion, we offer the following recommendations to the (Interim) Governing Council of the CIHR. Some of our recommendations are directly relevant to the SSH; others speak more specifically to the integrative and transformative aims of the CIHR.

Building and Strengthening Research Capacity

The SSH health research community in Canada is both vibrant and productive, and its contributions to our understanding of health and health care are significant and well-documented. It is estimated that the number of Canadian health researchers in the SSH is in the range of 2,000-2,500. In addition, there are thousands of community-based researchers in unions, non-governmental organizations, and community and voluntary organizations who conduct health research using SSH perspectives and methods, who work alone and in partnership with academic researchers on health issues. In short, there is already a significant research capacity in the SSH, and this must be nurtured further so that the benefits of SSH expertise can be fully realized in the vision put forward by the CIHR.

We applaud the proposed CIHR/SSHRC initiative to provide various career awards for post-doctoral fellowships, junior faculty, and senior career scientists in the SSH. This program will provide an important boost to the SSH health research community, and will ensure that there is a strong, productive, and innovative complement of health researchers in Canadian universities.

Building and strengthening the research capacity of the SSH health research community requires as well that there be adequate operational funds for the conduct of SSH health research. We believe that this must occur at two different levels – in all aspects of governance (including research priority setting), and ensuring dedicated funding for SSH health research.

Each institute must be required to include at least two SSH researchers in its governance structures (on advisory boards and peer review committees) to ensure that SSH perspectives are reflected in the research and activities of institutes. It follows, therefore, that each institute must also ensure that relevant SSH research is included in the research program or agenda of the institute, and that each institute commit the necessary resources for such research.

In order to facilitate the process of including SSH researchers in the various institutes, the CIHR should
request that SSHRC, CHSRF, and the Humanities and Social Sciences Federation of Canada (along with its member organizations) maintain a “bank of researchers” so that appropriate SSH health researchers can be identified to participate in all of the institutes of the CIHR.

A specific funding envelope must be established that is earmarked for SSH health research, and administered through SSHRC’s Strategic Grants Program.

In this connection, we recommend that the CIHR establish a separate advisory committee on SSH health research. One of the tasks of this committee would be to assess how well the institutes are integrating SSH research into their programs. SSHRC would then be able to set special competitions in its Strategic Grants Program so that gaps in the research programs of the institutes can be filled by SSH researchers not already connected to institutes.

Fostering Partnerships

Throughout the documentation of the CIHR, and more generally in government programs and policies, there is explicit encouragement of partnerships, primarily with the private sector. SSH health researchers commonly also partner with individuals and organizations in the policy and voluntary (i.e., community-based) sectors. Such partnerships accomplish several goals simultaneously:

1. alliances contribute to **mutual capacity building** (academics benefit from the knowledge and expertise that individuals from community groups bring to a project, and community organizations have the benefit of university expertise);
2. alliances help to make research more **relevant** to stakeholders through policy uptake; and
3. alliances ensure **greater accountability** to the public that funds most (health) research in this country.

Support for academic-community research partnerships is now deeply entrenched in Québec through programs funded by the Conseil Québécois de la recherche sociale (CQRS), and SSHRC has recently launched the Community-University Research Alliances (CURA) program. As well, the Centres of Excellence in Women’s Health Program (funded by Health Canada for the period of 1996-2002) has as a central defining feature that academic and community-based researchers shall collaborate in research conducted under the auspices of the centres.

In short, we have models of success that involve academic researchers and various partners.

The CIHR should institutionalize funding for research involving a variety of partnerships, including those with community-based organizations and individuals from the policy sector, and not just with private sector partners.
Ensuring an Inclusive Peer Review Process

Earlier in this paper, we argued that the SSH are distinctive in a number of ways. Epistemologically, the SSH are concerned with questions that are sometimes quite different than those put forward by researchers in biomedical and clinical fields. Even amongst the SSH, there is considerable variation in the approaches taken, questions asked, and perspectives used. Similarly, there is diversity in the methodological orientations of researchers in the SSH. Methods used run the gamut of quantitative and qualitative, including, for example, data analysis of large administrative claims data and other health databases, surveys on health practices, qualitative interview and focus group studies, participatory action research, feminist methods, historical and archival research, studies on discourse and narrative, cultural and literary studies, etc.

We recognize the value of multidisciplinary assessment committees and know that the CIHR can look to the Tri-Council (SSHRC, NSERC, and MRC) and various other joint initiatives for models of peer assessment that are effective. We want the CIHR to ensure that the peer assessment process is also fair and appropriate.

The CIHR must ensure appropriate representation of SSH disciplines and perspectives in all multidisciplinary assessment communities.

In our view, it is essential that the scientific review of SSH research proposals be undertaken by peers with SSH expertise and experience. Would it be appropriate for research on cell biology to be evaluated by individuals without any expertise in that field? No more than it would be appropriate to have SSH evaluated by those without any expertise in these fields! As we have noted earlier, there is a particular expertise that the SSH possess, there are rules of evidence specific to our disciplines, there are standards for the evaluation of SSH research. SSH researchers know what these rules and standards are, and therefore, should be the ones (primarily) involved in the assessment process. Given that there is a sizeable SSH health research community in this country, there is simply no reason not to utilize that expertise in the creation of appropriate peer assessment panels.

Furthermore, given that SSH and other health researchers are increasingly engaged in community-based research and research partnerships, the peer review system should allow for the inclusion of community input.

We recommend representation from communities of interest in all aspects of CIHR governance and research, including the peer review system.

Realizing the Interdisciplinary Vision of the CIHR

Gandhi once commented that democracy is a good thing – if only anyone ever did it.12 The same is true of interdisciplinarity. Fremont and Bird (1999) point out that interdisciplinarity is not easy, but there are biomedical researchers interested in the determinants of health, and there are some social scientists who are prepared to consider the physiological pathways to disease. The challenge is to create the conditions for a

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12Dorothy Broom, Senior Fellow, National Centre for Epidemiology and Population Health, Australian National University, Canberra, Australia, personal communication, September, 1999.
transformed, truly interdisciplinary health research agenda, through a commitment to “creative integration” (Levine, 1995).

Researchers in the CIHR must recognize the fundamental difference between multidisciplinary and interdisciplinary research. Most of what happens now is disciplinary or multidisciplinary research. Few of us know how to do interdisciplinary research. Perhaps that is because interdisciplinarity is hard to do. Some topics that we study demand a certain amount of interdisciplinarity, but for researchers, this is easier to do by oneself. The same is not necessarily the case when we constitute teams of researchers who are wedded to their own ways of seeing the world. True interdisciplinarity and collaboration is not about adding a new element (in this context, the SSH) and stirring.

In order to realize a truly interdisciplinary vision for health research, we have to respect the contributions that our various disciplines make to understanding a problem, and we have to commit to opening our minds to the possibilities created by looking at the world through different, albeit complementary, prisms. Doing so does not mean that we have to sacrifice rigour. It does mean that we can approach the topics of our research in a more comprehensive and holistic manner.

The CIHR must establish and institutionalize mechanisms for knowledge exchange between the four CIHR sectors and health research disciplines.

Without a clear plan for fostering interdisciplinarity, that part of the CIHR vision will not be realized. Most researchers, trained in their own disciplines, will continue to do what they know. Therefore, in the first year of the CIHR and on a regular basis thereafter, a series of workshops bringing together researchers across various disciplines should be held so that dialogue and education can be facilitated. Such workshops would create the conditions for the CIHR to be truly interdisciplinary, and not just multidisciplinary. Workshops could focus on methods of investigation, theoretical issues, the identification of new areas of research, etc.

CONCLUSION

The CIHR represents a unique opportunity and a bold vision about the future of health research in this country. The SSH health research community is primed to be a part of this new health research infrastructure, and its previous and on-going contributions to knowledge about health and health care have already positioned Canada as an international leader. The inclusion in the CIHR of the cross-cutting theme “Culture, Society and the Health of Populations,” is a clear indication of the value of SSH perspectives on health and health care. But the involvement of the SSH must not be marginalized in that quadrant alone. The SSH can and should be involved in all aspects of the CIHR, in the research programs and governance structures of all of the institutes. As already noted, without SSH perspectives, the influence of social factors in health and health care will continue to be underestimated.

We close with one final example that should serve as a cautionary tale. In 1997, floodwaters ravaged Manitoba’s Red River Valley. In its wake, the principal investigator on this paper organized a research symposium on the flood. In attendance was a member of the International Red River Basin Task Force. When he introduced himself, he commented that he had learned that floods were about people, not water, a heartening observation. But nearly two years later, the initiatives being undertaken by the International Red River Basin Task Force and its parent organization, the International Joint Commission, almost all focus on hydrology.

With this in mind, we should not forget that health is, after all, also about people.
## I. CONTRIBUTIONS OF THE SOCIAL SCIENCES AND HUMANITIES (SSH) TO VARIOUS SUBSTANTIVE FIELDS IN HEALTH RESEARCH

| DISEASE ETIOLOGY/SUSCEPTIBILITY TO GOOD/ILL HEALTH | There is mounting evidence of the significance of the social determinants of health, in particular, inequality, cultural environment, sex/gender, social cohesion/social capital, area of residence, etc. |
| BEHAVIOURAL ASPECTS OF HEALTH AND ILLNESS | SSH research shows how illness is produced (i.e., the conditions that put individuals at risk), and how illness is constructed (i.e., how disease categories are understood, how clinical decision-making involves the application of technical knowledge, but is also fundamentally a social activity). |
| FUNCTIONING OF HEALTH CARE PROVIDERS AND THE HEALTH CARE SYSTEM | SSH research focusses on: |
|  | · conceptions of health and illness, including how biomedical and lay conceptions may vary (which influences health care practice, and explains behaviours that are associated with various health outcomes); |
|  | · health-related behaviours (behaviours that influence health); e.g., risk-taking, health-promoting, help-seeking, self-care practices, as well as how the resiliency of cultural beliefs and practices shapes ideas about the body, health and health-seeking behaviours etc.); |
|  | · the practitioner-patient relationship (including the nature of communication, the effects of the relationship on the healing process and patient compliance, etc.); |
|  | · responses to illness and treatment (e.g., the social and psychological dimensions of pain; the influence of social support on well-being, recovery, and longevity); and |
|  | · the entire illness trajectory, including rehabilitation and disability, in particular the social and psychological dimensions. |
|  | SSH research on the behavioural aspects of health and illness has had an explicitly applied focus (in response to problems identified by health care providers). It also contributes significantly to basic enquiry in the SSH (e.g., studies of social roles and institutions; patterns of social action, etc.). |

Social scientists pioneered research on medicine as a social institution, examining it at three different levels:

· the individual/behavioural level (e.g., the experiences of practitioners vis-à-
vis patients, and vis-à-vis the larger medical and social system); 

- the organizational/administrative level (e.g., how health care services are organized, the health care division of labour, and the role of various health professions in the provision of services, how health care “teams” function and what “comprehensive care” means to providers and recipients, the effectiveness and appropriateness of services, etc.); and

- the macro-social level (e.g., how social, economic, and political forces influence health and health care at the local, national, and global levels; how inter-professional relations shape health care systems and practices; how social movements such as self-help and alternative/complementary health care influence health care providers and recipients, as well as the policy sector in health).

SSH research has examined the training and socialization of health care providers, exploring how factors internal and external to health care and the professions shape the practice of health care workers. (SSH involvement extends into the health sciences curricula which includes instruction in the SSH, particularly around bioethics.)

SSH research also is key to understanding the organization and delivery of health services (e.g., traditional as well as new, challenging health modalities). For example, research on community-based alternatives to institutional care and complementary (alternative) care services and products have become increasingly important in the present health care environment. SSH research examines the efficacy of treatments and the allocation of health care resources, considering the social, economic, psychological and ethical dimensions, particularly as they relate to human experimentation.

SSH theory and methods are core to all of these areas of practice and theory inasmuch as they are oriented to dealing with the determinants of health, and with large-scale change in society and its institutions. Social sciences (in particular, anthropology, psychology and sociology) provide the primary disciplinary basis for current conceptualizations in the field of health promotion.

SSH provide the keys to understanding health and social policy as it affects individuals and institutions. For example, recent studies focus on applying a “gender lens” to discern how women and men are affected by policies such as home care. As well, population health research focuses on access to, and utilization of, health services, thereby having an influence on public policies and resource allocations.

II. CONTRIBUTIONS OF THE SOCIAL SCIENCES AND HUMANITIES (SSH) TO EPISTEMOLOGY AND METHODOLOGY

SSH research clearly reveals the social nature of health/health care.
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<th><strong>SOCIAL IN HEALTH/HEALTH CARE</strong></th>
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<td>Theorizing by social and behavioural scientists has fundamentally transformed understandings of health/health care, such that a strictly biomedical approach is now seen as indefensible. The <strong>social model of health</strong> is preeminent in all facets of health research today, and requires that we consider the whole person, and how the contexts of their lives influence their susceptibility to disease, their conceptualization of health, their health-related behaviours, etc.</td>
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<th><strong>METHODOLOGICAL INNOVATIONS</strong></th>
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<td>Applied researchers in the social sciences have developed methodological techniques that are now widely used in health research, including <em>surveys, case studies, participatory methods, narrative analysis, and a variety of qualitative techniques</em>. Opportunities abound for the continued refinement of these various SSH methodologies as they apply to health/health care research.</td>
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In addition, SSH researchers provide important methodological expertise in *clinical studies and health systems/services research* (e.g., clinical trials, quality-of-life measurements, practice variations, etc.).

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<th><strong>SSH AS CRITIQUE</strong></th>
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<td>SSH have, through an emphasis on <em>reflexivity and critique</em>, focussed attention on the taken-for-granted elements of health/health care. In short, SSH analyses provide a way of understanding how things are, imagining how they might be conceptualized differently, thereby creating the possibility for social change. This type of critique is a critical capacity for an institution seeking ways to produce imaginative and creative solutions to pervasive health problems in society.</td>
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Appendix 2
A CASE STUDY: INTEGRATING SSH IN CANCER RESEARCH

Many disciplines currently study the disease of cancer, and each brings its own unique perspective to research. What would the SSH contribute to cancer research? How might we broaden our understanding of cancer as a disease (a physical state), as an illness (a subjective state), and as a sickness (a social experience rooted in individuals’ daily lives and social networks)? How can we integrate different theories, perspectives, and research methods to enhance our understanding of, and approaches to, the causes, diagnosis, and treatment of Canada’s second leading cause of death? This handout provides a partial listing of examples of how SSH research questions complement – and in some cases, challenge – existing research in biomedical, clinical and health services cancer research. The breadth and scope of SSH in cancer research (and other areas of health research) reveals how integral these disciplines are in the new environment envisioned by the CIHR.

THE BIOLOGICAL CAUSES OF CANCER:
- psychosocial studies on the meaning and effects of being informed that one is a carrier of a particular gene (e.g., BRCA1/2)
- research on the consequences of early intervention (e.g., preventive surgery, tamoxifen)
- geographic studies into disease clusters
- studies into the relationships among family members, some of whom have been identified as possessing a gene for cancer susceptibility
- consideration of the ethical basis of consent and recruitment of individuals into clinical studies in cancer research
- ethical and legal questions involving the identification of susceptible individuals (e.g., the connections between genetic testing and employment/insurance discrimination)

THE ENVIRONMENTAL CAUSES OF CANCER:
- studies on the factors that motivate girls and young women who smoke
- research on the key elements of effective information and educational campaigns for cancer prevention
- studies on the ways in which exposure to carcinogens and cancer vary by social class, race, and gender
- observational studies of the work of those with potential occupational exposure in order to identify methods of radioprotection
- studies of the influence of psychosocial stressors on cancer initiation and promotion
- analyses (historical and contemporary) of public policies related to environmental protection and carcinogens
- participatory research with lay persons to identify the social patterning of cancer (e.g., Woburn)

RESEARCH ON THE DIAGNOSIS OF CANCER:
- studies on how diagnosis varies by social class, race, and gender
- research on the ways in which culture shapes conceptions and experiences of cancer
- changing cultural representations of cancer in literature, film, and art
- research on the communication of a cancer diagnosis
- studies of the variations in diagnostic practices across regions and by country
- geographic studies on access to, delivery and planning of cancer services
- research on the experiences of health care providers, and the relationships between providers and health care managers
- studies of work organization in diagnostic laboratories
- research on technicians’ exposures to blood and blood products
TREATMENT OF CANCER:
- the history of cancer care
- studies of illness trajectories (from diagnosis through treatment, and onto palliation)
- studies of the relationship between contemporary medical discourse and narrative texts in art, literature, poetry and film (e.g., NYU Medical Humanities Database at http://endeavor.med.nyu.edu/lit-med)
- studies of illness narratives
- research on patients’ preferences for treatments and involvement in decision-making around their care
- psychological studies on the factors (i.e., personality, attitudes, behaviours) that influence disease prognosis
- the influence of age, race, ethnicity, class, and gender on the experience of cancer treatment
- psychological studies on pain management
- research on “special” populations (e.g., children with cancer)
- studies on the impact of cancer on families
- research on informal care provided by family and friends
- studies on the role of support groups in cancer care, and the role of support groups for family members of cancer patients
- economic studies on cancer treatment options
- studies on the efficacy of alternative/complementary treatments
- research on why individuals choose alternative/complementary therapies
- geographic mapping of cancer services
- analysis of drug marketing practices
- ethical issues involved in treating cancer patients and in clinical studies of cancer treatments
- research on the quality of working life in and the organization in oncology services
- safe waste management in oncology services
- studies on the impact of palliative care on professional caregivers
- research on the ethics of the administration of analgesic drugs to terminal cancer patients

RESEARCH ON THE TRAINING OF ONCOLOGISTS:
- the development and evaluation of innovative methods of physician education
- studies on the choice of oncology as a specialty
- optimizing work schedules among residents
- research on the private and work worlds of oncologists (e.g., delayed childbearing, quality of life studies, burnout, etc.)

RESEARCH ON THE SOCIOLOGY, ECONOMICS and POLITICS OF CANCER
- studies on the inseparability of the biological and social bases of cancer
- studies on the politics of cancer research within funding bodies
- research on cancer statistics (i.e., what they reveal about society’s and medicine’s response to the disease)
- research on the implications of viewing cancer as a genetic, lifestyle, and/or environmental disease
- research on “bandwagons” in cancer research; e.g., Fujimura’s Crafting Science (1996)
- economic analyses of the burden of cancer
- studies on involving individuals diagnosed with cancer in research on cancer
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