Chapter 4
Population-Based Data and Community Empowerment

Janet Smylie, Aisha Lofters, Michelle Firestone, and Patricia O'Campo

Contents

Abstract This chapter focuses on the transformation of population-based data and data systems into social resources that actively contribute to social, economic and political solutions to reduce health inequities. Our first underlying premise is that current systems of population health data collection, management, analysis and use are too often disconnected from the communities being described and whose data are being collected. Our second and related premise is that, in order for data to become a tool for social empowerment and social change, the social structuring of data governance and management must change from systems that reinforce social exclusion by marginalizing communities from their data to systems in which

---

J. Smylie (✉) • A. Lofters • M. Firestone • P. O'Campo
Centre for Research on Inner City Health, St. Michael's Hospital, 30 Bond Street, Toronto, M5B 1W8 ON, Canada
e-mail: SmylieJ@smh.ca; LoftersA@smh.ca; FirestoneF@smh.ca; O'CampoP@smh.ca

P. O'Campo and J.R. Dunn (eds.), *Rethinking Social Epidemiology: Towards a Science of Change*, DOI 10.1007/978-94-007-2138-8_4,

communities are fully and centrally involved in data decision making. The first part of this chapter rationalizes these premises by providing examples of the ways in which existing data systems undermine the broader mission of social epidemiology to identify effective interventions that alleviate conditions of social marginalization and poverty. The remainder of the chapter focuses on strategies for transformation in health and social data and data systems.

Abbreviations

RCT	Randomized controlled trial
PHAC	Public Health Agency of Canada
OCAP	Ownership, Control, Access and Possession
RHS	Regional Longitudinal Health Survey
DSM	Diagnostic and Statistical Manual of Mental Disorder
CCHN	Community Child Health Research Network
WHO	World Health Organization

4.1 Introduction: Social Exclusion and Population Data Systems

A key achievement of social epidemiology, to date, has been the expansion of our awareness of the need to link social, economic and political resources with health. Descriptive work has documented poorer health outcomes for social groups who have restricted access to employment, housing, health care, education and training as compared to social groups with unrestricted access (Marmot 2005; Commission on Social Determinants of Health 2008). Although this work has been important, social epidemiologists now need to go further. There is a need to uncover the mechanisms by which social exclusion affects the well-being of society and to apply these findings to the identification of effective strategies for social change. With these goals in mind, we have chosen a working definition of social exclusion that covers a broad range of resource domains (including but not limited to material needs) and that is explicitly linked to the social hierarchies in which social exclusion is rooted: “Social exclusion is the inability of certain groups to fully participate in society due to inequalities in access to social, economic, political and cultural resources, where these inequalities arise out of oppression related to race, class, gender, disability, sexual orientation, immigrant status and/or religion” (Public Health Agency of Canada 2004).

Earlier chapters have already identified that one of the major challenges facing social epidemiology is the movement from descriptive, problem-focused research to action-oriented, solution-focused research (see Chap. 1). This chapter will focus on the transformation of population-based data and data systems into social resources that actively contribute to social, economic and political solutions to reduce health inequities. Our first underlying premise is that current systems of population health data collection, management, analysis and use are too often disconnected from the communities being described and whose data are being collected. Our second and related premise is that, in order for data to become a tool for social empowerment and social change, the social structuring of data governance and management must change from systems that reinforce social exclusion by marginalizing communities from their data to systems in which communities are fully and centrally involved in data decision making. The first part of this chapter will rationalize these premises by providing examples of the ways in which existing data systems undermine the broader mission of social epidemiology to identify effective interventions that alleviate conditions of social marginalization and poverty. The remainder of the chapter will focus on strategies for transformation in health and social data and data systems.

For the purposes of this chapter, we define communities as any group of individuals sharing a common interest. This definition includes cultural, social, political, health and economic issues that may link together individuals who may or may not share a particular geographic association (North American Primary Care Research Group 1998). Within the context of social epidemiology, these communities would typically be the communities whose data is being collected, and the unifying issues would be the cultural, social, political, health and economic factors upon which social hierarchies and subsequent social privileging and social marginalization are based. We note that, while this chapter (and much of social epidemiology) primarily attends to social marginalization in the effort to enhance social well-being, there is a pressing need to concomitantly expand the examination of social privileging and recognize its fundamental importance as a driver of social conditions.

4.2 Knowledge, Power and Data: A Post-colonial Approach

Social epidemiology provides a unique opportunity to reconcile and enrich the rationalist scientific assumptions of conventional epidemiology with social theory. One of the limitations of conventional epidemiology is that there is a purposeful effort to acquire knowledge that is distanced from and even devoid of social context. This distancing is based on an assumption that there are "objective" and generalizable truths, the discovery of which will be "biased" if contextual factors contaminate data collection and analysis.

Critical social theory positions rationalist scientific inquiry into a larger epistemological framework in which knowledge and knowledge systems are woven into the architecture of social hierarchy. Foundational critical theorists such as Foucault (1977) asserted a vision of the collection of social data, or surveillance, as a form of externally controlled and pervasive social control that perpetuated oppressive societal power hierarchies. Foucault's work provides important insights into the intrinsic connections between knowledge, power, social hierarchies and data collection. However, it is less helpful with respect to the transformation of health and social data systems into tools that will alleviate oppression, since in Foucault's worldview there is a strong hegemony of oppressive state "knowledge:power" that leaves the oppressed at the margins with few explicit tools of resistance and very little discussion of alternate knowledge and power systems beyond the local level.

For an in-depth discussion of how to move forward with respect to knowledge and data systems that empower communities rather than perpetuate marginalization, one must turn to modern post-colonial theory and literature. Indigenous scholars such as Tuhawi Smith, Littlebear and Youngblood Henderson are particularly helpful in mapping out Indigenous knowledge systems including Indigenous sciences as sophisticated, diverse and epistemologically distinct entities from the Western European knowledge systems that were actively imposed on Indigenous peoples worldwide as part of colonization (Smith 1999; Little Bear 2000; Youngblood-Henderson 2000). Preserving, recovering and revitalizing Indigenous knowledge is critical to the dismantling of colonial processes and the re-empowerment of Indigenous people worldwide. In the words of Indigenous scholar Marlene Brant Castellano (2004): "Fundamental to the exercise of self-determination is the right of peoples to construct knowledge in accordance with self-determined definitions of what is real and what is valuable." Notably, in this effort to strengthen Indigenous knowledge systems, Indigenous scholars rarely repeat the colonialist approach of rejecting and/or subjugating outside scholarship, philosophy and ideas but rather adapt a pluralistic and practical approach in which knowledge and knowledge systems are understood to be complex and dynamic, and the ability to interface both locally and globally is critical to the attainment of thriving societies. Examples later on in this chapter will highlight how Indigenous communities have focused on taking ownership and control of data collection rather than rejecting surveillance because it can be a tool for oppression.

Health and social data and data systems provide a unique opportunity for all sectors of democratic societies to contribute to the exercise of the right to self-determination for Indigenous peoples and the rights to health equity for socially excluded groups more generally. Social epidemiologists can contribute to these efforts through technical and methodological expertise and, perhaps more importantly, by critically understanding the connections among data, knowledge and power to ensure that data systems are reducing rather than contributing to social exclusion.

4.3 How Data Systems Can Undermine Communities and Perpetuate Health Inequities

Individuals and systems external to communities are typically the gatekeepers who control access to data and data systems across the spectrum of research, dissemination and policy application processes (Fig. 4.1). Data processes and systems that

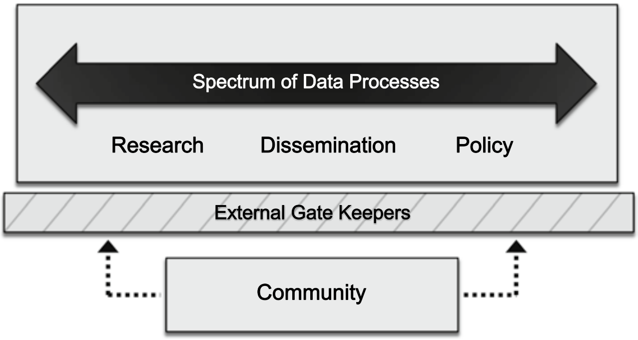

Fig. 4.1 Data and data systems that reinforce community marginalization

build on and perpetuate broader social exclusion by maintaining the barriers between communities and their data sets and/or contributing to the construction of inadequate data can be quite harmful to communities. For many communities, “data insults” resonate with historic human rights violations by health and social science researchers, such as the infamous Tuskegee experiments where syphilis treatment was purposely withheld from African American men without their knowledge to study the long-term effects of untreated syphilis; the immortalized HeLa human cell line, which was taken from a cancer-stricken African American woman, Henrietta Lacks, and used in decades of scientific research without her or her family’s consent; or Dr. Richard Ward’s unauthorized use of blood samples from members of the Nuu-chah-nulth First Nation in British Columbia, Canada for genetic studies that participants were never informed about (Randall 2006; Centers for Disease Control and Prevention 2008; Dalton 2002; Skloot 2010; Freimuth et al. 2001; Sateesh 2008). In recent decades, public privacy commissioners and health and social science research ethicists in democratic countries have challenged situations such as these where control lies outside the community as a violation of human rights, particularly in situations where the community of interest is already subject to one or more forms of social exclusion (Canadian Institutes of Health Research 2007; Battiste and Youngblood Henderson 2000; Battiste 2007; O’Neil et al. 1998; Israel et al. 2001; Minkler 2000). The underlying premise is that individuals and collectives should have access to information that is collected about them. However, with respect to health and social data, particularly for groups experiencing ongoing social exclusion, access itself is necessary but not sufficient. Ethicists and scientists agree that meaningful involvement throughout the data continuum is required, including involvement in data collection, data analysis, data management and governance and data dissemination and use (Royal Commission on Aboriginal Peoples 1993; Snarch 2004).

Unfortunately, there is a long list of ways in which health and social data and data systems can detrimentally impact communities whose data is being collected. For simplicity, we have identified two groupings of data system problems recognizing that there is, of course, overlap between groups and problems (Table 4.1).

Table 4.1 Ways in which health and social data and data systems can be detrimental to communities

Problem	References
Group A: exclusion or marginalization of community from data processes	
Absent, inadequate or late community engagement in data processes	Wenman et al. (2004) and Wallerstein (1999)
Indicators and/or measurement tools are in tension with community concepts of health and social well-being	Smylie and Anderson (2006), Smylie et al. (2006), and Altshuler and Schmautz (2006)
Euro-Western scientific analytical methods and assumptions are privileged over community epistemologies	Smith (1999) and Popay et al. (2008)
Data interpretation and dissemination perpetuate societal stereotypes and the marginalization of already marginalized groups	See Chap. 5
Community members are unable to access their community's data	Public Health Agency of Canada (2006)
Group B: technical and methodological issues that result in inadequate data	
Marginalized communities are excluded from, or are under-represented in, data collection	Statistics Canada (2000) and Canadian Hypertension Education Program (2010)
Data systems lack individual identifiers that enable for meaningful data disaggregation across strata of inequality	Health care utilization datasets in Canada (e.g., CIHI DAD) Anderson et al. (2006) and Rodney and Copeland (2009)
Uncoordinated health service performance measurement system and data sources	Anderson et al. (2006) and Anderson (1999)

Problems in Group A focus on the relationship between the data gatekeepers and the community. Problems in Group B highlight common technical and methodological issues that yield inadequate health and social data and data systems for marginalized groups. Cited references refer to either direct examples of detrimental data processes or additional information sources regarding the specific data problem. Problems and examples are further detailed in the text below.

4.3.1 Data Processes That Exclude or Marginalize Communities

4.3.1.1 Absent, Inadequate or Late Community Engagement in Data Processes

Data systems that exclude the communities whose data are being collected overwhelmingly predominate in current health and social sciences research and practice. Researchers and policy makers may not be aware of the importance of early and ongoing community engagement in health and social data work from either an ethical or a practical perspective. For example, when challenged on the absence of meaningful engagement of Aboriginal community stakeholders in a study of pregnancy risk factors and birth outcomes among Aboriginal women in Canada, Wenman et al. (2004) stated that this type of engagement was only required for studies using "participatory action research" methods and that, as a hospital based cohort, their study was excluded from the need to appropriately engage study subjects. Fortunately, there is a growing body of literature that clarifies the ethical requirements for and scientific merit of adequate community engagement in health and social research involving primary or secondary health and social data regardless of the subject or method (Canadian Institutes of Health Research 2007; Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council of Canada 2010; Israel et al. 2001; Wallerstein 1999).

A more insidious and increasingly common problem occurs when researchers, practitioners and policy makers are indeed aware of requirements to appropriately engage representatives of communities whose data are being collected and "learn the lingo" well enough to be successful in their acquisition of project funds, but upon project implementation do not have the commitment and/or skill set to adhere to existing standards. Wallerstein (1999) addresses this issue in her reflective examination of the New Mexico Partnership for Healthier Communities. The partnership was a community-based participatory research project with the goal of local communities creating collaborative planning and decision-making coalitions with the state to address community problems, such as domestic violence, and better meet community needs. Although the researchers and state agencies were committed to the study, several mistakes were made throughout the process. For example, state agencies did not provide communities with enough autonomy with regard to coalition development and organization, and the researchers did not seek out sufficient input from communities on the evaluation process, used language that distanced themselves from the community instead of using community definitions and did not openly acknowledge the power dynamics involved in the project. The non-community members of the study team did not have the skills to immediately recognize the inherent power imbalances in their project, which were expressed as communities being left out of the communication loop, not being consulted on key issues and having little or no decision-making authority (Wallerstein 1999). These power imbalances and lack of true collaboration led to tense relations between the researchers, state agencies and coalition members and to coalition members rejecting the negative aspects of the project evaluations as invalid and as "outsider" interpretations.

4.3.1.2 Indicators and/or Measurement Tools Are in Tension with Community Concepts of Health and Social Well-Being

When indicators and measurement tools are in tension with community concepts of health and social well-being, it is usually because they have been developed external to the community and are based on theories that are mismatched with community-based understandings and assumptions. For example, Indigenous communities internationally have articulated concerns that commonly used health indicators and health indicator systems marginalize Indigenous understandings of health and social well-being. In response, communities have responded by developing Indigenous-specific health indicator frameworks (Smylie et al. 2006).

A second example is found in the measurement of intelligence and academic ability through standardized tests. Although validated on mostly White, upper-middle class students and reflective of Euro-Western concepts of intelligence, these inherently biased tests continue to be used, which further perpetuate social marginalization and negatively affect self-perception as well as result in false assumptions about group cognitive ability (Altshuler and Schmautz 2006). The bestselling book *The Bell Curve* by Richard J. Herrnstein and Charles Murray (1994) argued that genes played a role in racial and class differences on IQ (intelligence quotient) tests and illustrated the significant and detrimental policy impacts such biased measurements can have (Muntaner et al. 1996). Subsequent reductions in welfare benefits in the United States have been linked to the policy recommendations of the authors of *The Bell Curve*, which included a call to end the subsidization of births among poor women in order to avoid an intellectually stratified society (O'Connor 2004).

4.3.1.3 Euro-Western Scientific Analytical Methods and Assumptions are Privileged over Community Epistemologies

In epidemiology (especially in clinical epidemiology) a hierarchy of evidence exists where randomized controlled trials (RCTs) are considered the strongest and most reliable form of evidence, and the opinions of respected authorities are considered the weakest. This hierarchy means that the knowledge of communities is automatically regulated to the weakest tier of evidence (assuming that community members are even viewed as respected authorities). Again, we see inherent power imbalances in the relationship between researcher and community. However, this community-based "lay" knowledge undoubtedly could provide critical information that is currently missing in epidemiologists' understanding of health inequalities (Popay et al. 2008; see also Burke et al. 2005 and O'Campo et al. 2009b for a discussion of concept mapping).

4.3.1.4 Data Interpretation and Dissemination Perpetuate Societal Stereotypes and the Marginalization of Already Marginalized Groups

Without awareness of its societal, political and economic context, research findings often lead to perpetuation of stereotypes and misguided interventions. For example, the higher prevalence of cigarette smoking among African Americans as compared to their White peers has been attributed to acculturation and to African Americans deeming themselves invulnerable to the harms of smoking due to "various culturally based, superstitious rituals" rather than to contextual factors such as targeted advertising, anti-smoking campaigns and coping mechanisms for chronic stress (Klonoff and Landrine 1996). Ethnicity or culture then becomes viewed as a risk factor when, in actuality, the problems that must be addressed are underlying inequities in the distribution of health and social resources. Chapters 1, 6, 8 and 10 in this book further discuss the importance of context in the interpretation of data.

4.3.1.5 Community Members Are Unable to Access Their Community's Data

When members of the community of interest, including practitioners and policy makers, are excluded from access to their own data, the obvious result is missed opportunities for individual- and community-level response, community empowerment and evidence-based advocacy. For example, Aboriginal groups in Canada have had extremely limited access to the Aboriginal data collected in the recent Maternity Experiences Survey, despite previous agreements with the Public Health Agency of Canada (PHAC) that they would be actively involved in the analysis and dissemination of this national dataset (Public Health Agency of Canada 2006). This exclusion has occurred despite longstanding expressed concerns by Aboriginal groups regarding their ability to access health and social survey data that has been collected in their communities by the federal government (Castellano 2004).

4.3.2 Technical and Methodological Issues that Result in Inadequate Data

4.3.2.1 Marginalized Communities Are Excluded from, or Are Under-Represented in, Data Collection

One sure way to mask health and social inequalities and, therefore, to further perpetuate them is to under-represent or even completely exclude marginalized populations from data systems. For example, First Nations people living on reserves are excluded from national health surveys in Canada and, therefore, are excluded from the statistics reported from these surveys and the benefits that are supposed to be gained (Smylie et al. 2006; First Nations Information Governance Committee 2007). Similarly, marginalized groups are frequently excluded from or are under-represented in clinical studies, and the results are often simply assumed to be applicable. For example, the Canadian hypertension guidelines make recommendations for the treatment of high blood pressure in Black Canadians based on the assumption that African American data are applicable, despite different histories, social circumstances and genetics between these two groups (Canadian Hypertension Education Program 2010; Campbell et al. 2010). Studies that do not recruit adequate subgroup samples may result in the combination of diverse populations into a single category for reasons of statistical power, which blurs important distinctions and limits the policy relevance of results. For example, the Canadian Community Health Survey (Statistics Canada 2000) and the Maternal Experiences Survey (Public Health Agency of Canada 2006) both had inadequate samples of First Nations, Inuit and Metis groups, therefore, requiring the collapsing of these three very distinct groups into one "Aboriginal" category in order to have statistically relevant results.

4.3.2.2 Data Systems Lack Individual Identifiers That Enable for Meaningful Data Disaggregation Across Strata of Inequality

Many vital registration data, health care utilization data and surveillance data sets in Canada lack consistent and meaningful ethnic identifiers. Even when racial or ethnic identifiers are present on vital records such as in the United States, it is not clear whether the identifiers used are sufficient to describe the populations of interest. Again, the result is the masking of health and social inequities, including the masking of inequitable access to health services. For those who may argue that there is no need to measure ethnicity in Canada or who argue that inequities do not exist, Rodney and Copeland (2009) have shown that whenever data are disaggregated in Canada, based on racial and ethnic categories, disparities are observed among Black Canadians. The systematic underestimation of disparities among marginalized populations is a direct result of this lack of consistent identifiers. For example, if one is trying to use rates to identify health status disparities for ethnic minority groups compared to White populations in North America, the tendency will be to miss events among individuals belonging to ethnic minority groups since they may be more likely to be misclassified as White than vice versa. This scenario is encouraged by the lack of systematic, effective methods for data collection and is exemplified by the underestimation of First Nations infant mortality rate in Canada (Smylie et al. 2006).

4.3.2.3 Uncoordinated Health Service Performance Measurement System and Data Sources

Perplexingly, current data sources are not yet well coordinated into integrated health performance measurement systems. In fact, the expression "water, water, everywhere, nor any drop to drink" from Samuel Taylor Coleridge's 1798 poem *Rime of the Ancient Mariner* (which describes the plight of sailors stranded at sea with no freshwater to drink) could aptly be applied to the availability of useful and relevant social and health equity data (Coleridge 1965). For example, Indigenous groups worldwide have complained that they are being "researched to death." Yet the large majority of Indigenous health and social research has been non-systematically driven by the interests of the academic researchers, and entire populations and subject areas have been overlooked (Young 2003). The resulting research data is a non-integrated "patchwork" of information characterized by large "holes," which are for the most part of little use to Indigenous health and social policy makers, particularly at the community level (Smylie and Anderson 2006; Smylie et al. 2006; Anderson and Smylie 2009; Anderson et al. 2008).

It is clear that solutions to the many harms that data and data systems have on marginalized communities need to be found. In the next section, we will outline four strategies for change that address the challenges that we have just detailed. Addressing the problems and power imbalances, which characterize the relationship between data gatherer and data owner, is of paramount importance. We will describe how addressing these challenges can lead naturally and directly to solutions for the technical and methodological problems described above.

4.4 Transforming Health Data and Data Systems: Strategies for Change

The focus of the remainder of this chapter will be to answer the following two questions: (1) What do data and measurement systems that are actively contributing to social, economic and political processes, which are in turn reducing health inequities, look like? and (2) What types of change strategies will help us get there?

4.4.1 Re-envisioning Health Data and Social Data and Data Systems as Beneficial Tools to Advance Health and Social Equity

Up to this point, we have emphasized the ethical, scientific and practical problems that result from the disconnection of data systems from the communities whose data is being collected. Figure 4.1 illustrates how this disconnection is often formalized with external gatekeepers controlling community access to their data. Our re-visioning of health and social data systems shown in Fig. 4.2 builds on clearly articulated aspirations from diverse communities across equity strata. Despite varied contexts, communities experiencing a wide range of social inequities have clearly indicated a desire to move from a marginal to a central role in the processing and management of their health and social data (Pivik and Goelman 2011; Kobeissi et al. 2011; Shalowitz et al. 2009).

Health and social data systems need to be re-conceptualized as a resource designed to serve communities that is located within communities and managed and governed in partnership with the appropriate community authorities. It is these authorities, rather than external stakeholders, who need to be the gatekeepers for managing the interface among researchers, policy makers and practitioners.

Researchers and policy makers external to a particular community may find it challenging to identify the appropriate community representatives with whom to

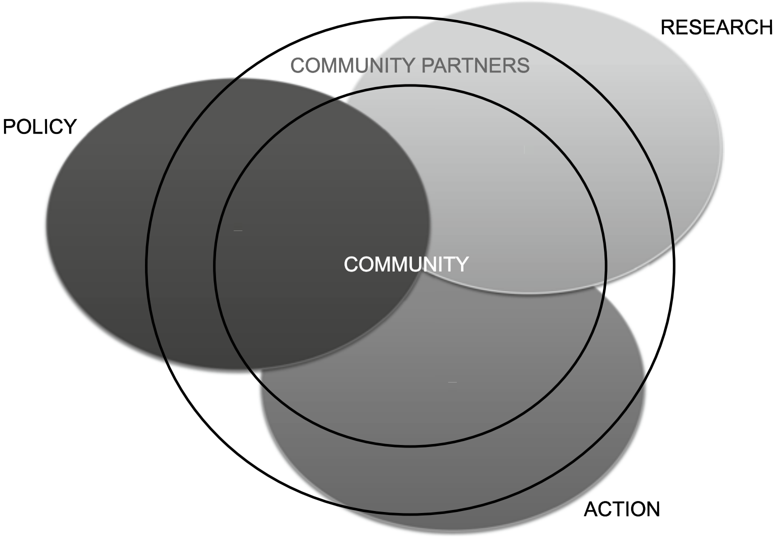

Fig. 4.2 Data and data systems that support community self determination

engage and/or partner. There is also the issue of understanding whether or not the identified community representatives have the relevant delegated authority and community-based legitimacy to hold this role. Familiarity with specific community contexts will greatly assist in addressing these challenges. In general, most communities of shared interest – no matter how small – have existing protocols and processes to identify leaders or representatives. While not always perfect, these existing protocols and processes can be a good place for the external researcher or policy maker to start. Another useful approach is to look for leaders or representatives who hold authority at a level of jurisdiction that matches the level of aggregation of data held in the data system of interest (e.g., a national-level data system link with national-level representatives).

It is not only the relationships upon which data systems are structured that need to change but also the content of what is being measured. The facilitation of social, economic and political processes that result in the reduction of health inequities requires data that enables social explanations of health problems. The processes that drive social exclusion clearly occur at the collective rather than the individual level. Therefore, it is at this collective, community level that they need to be studied, challenged and reversed. This approach will require a radical shift away from the overreliance on individual-level data and the ongoing development of analytic methods that will facilitate community-level understandings of the social phenomena that drive health inequity. In our experience, community partnerships can naturally inform this process, since community stakeholders are acutely aware of the day-to-day collective social, economic and political constraints that impact community health and well-being.

Table 4.2 Ways in which health data and social data and data systems can be beneficial to communities

Benefit	Examples
Informing community planning, including identification of gaps in services and barriers in access to care	First Nations Regional Longitudinal Health Survey (First Nations Information Governance Committee 2007); South Asian Health Equity Report (Council of Agencies Serving South Asians 2010)
Highlighting disparities and unmet needs to external community funders and policy makers	Street Health Report (Khandor and Mason 2007); First Nations Regional Longitudinal Health Survey (First Nations Information Governance Committee 2007); South Asian Health Equity Report (Council of Agencies Serving South Asians 2010)
Identification and/or affirmation of community strengths that contribute to positive community self-image and challenge negative stereotypes	Community Child Health Research Network (CCHN) (National Institute of Child Health and Human Development 2002)
Demonstrating effectiveness of community-based programs, services and policies	Partnered realist review on concurrent mental health and substance use disorders (O'Campo et al. 2009a); Baltimore City Healthy Start program (Boroff and O'Campo 1996); Kanawahke Schools Diabetes Project (Kahnawake Educations System 1998; Macaulay et al. 2006; Paradis et al. 2005)
Identification of programs and service areas in need of improvement	Realist review on concurrent disorders (O'Campo et al. 2009a)

Community partnerships facilitate the dissemination of data into readily useful formats, since community policy makers are well aware of their own data needs. In the community-centric model, the translation of data into policy and practice is intrinsically "built-in." With respect to external community dissemination, community policy makers are already interfaced with external policy makers, research and practitioners and are seasoned in their ability to appropriately package information for these diverse audiences. Table 4.2 provides a list of ways in which communities can benefit from social data and health data and data systems when they are active data partners, along with examples of research that exemplify these benefits. In most cases, the benefits to communities are multiple and overlapping.

Box 4.1 presents a vision of perinatal surveillance that was developed by a joint working group of national Indigenous health stakeholders in Canada. This group included four national Indigenous organizations representing the interests of different Indigenous groups as well as representatives from Health Canada and PHAC. This statement exemplifies the transformation of health and social data systems that we have described above. The leadership role of Aboriginal organizations in all data processes is clearly articulated. This data system is about serving community interests – so much so that a more general vision of family and community wellness precedes the description of the ideal perinatal surveillance system.

Box 4.1 A Vision of Aboriginal Family and Community Well-Being Supported by Perinatal Surveillance

The arrival of infants is celebrated by their families and communities. Infants, children and their families are 100% healthy, happy and safe. Mothers, fathers and their families are supported before, during and after childbearing. Primary health care, including access to traditional healing and traditional midwifery, is universally accessible to all individuals and communities regardless of geographic location. Meaningful, relevant and tailored prevention and education programs are in place for all Aboriginal peoples. Through this nurturance and protection of our infants and children our communities are strengthened and renewed.

Infant mortality rates in Canada are available for all Aboriginal peoples (First Nation and Status Indians living on reserve, Status Indians living off-reserve, Non-status Indians, Inuit and Métis). The method of data collection and calculation of infant mortality rates is standardized across provinces and territories. Aboriginal organizations are active and full partners in the governance and management of the data. The methods of data collection, analysis and reporting are appropriate for all Aboriginal people. Aboriginal organizations are recognized as the owners of the data, and with their approval, data is publicly available. Flexibility and adaptability are built into the data system. The accuracy and reliability of the data is internationally recognized.

Birth outcomes data are linked to a longitudinal, comprehensive and inclusive Aboriginal health information system that includes data regarding the social and environmental determinants of health such as income, housing, family size, family and community environment, including culture-based nurturance and parenting, geographic location and environmental issues. This system is also linked to health and social services and their data. This system allows us to track how each infant blossoms. It creates a picture of what each child is arriving into and flags adversity as required. This information is then communicated to local health and social service providers and policy makers and is used to empower infants, children and their families. Drawing on this information, providers and policy makers can then identify the best strategies for further assessment and community-based assistance in the form of a "hand up" versus a "hand out."

The disparities and gaps between the health of Aboriginal people and other Canadians no longer exist. Canada has surpassed the commitments of international conventions, declarations and agreements regarding the rights of children and Aboriginal people.

4.4.2 Four Strategies for Change

In this section, we outline four strategies to facilitate the transformation of health and social data and data systems into tools that support community empowerment. We will illustrate each strategy using specific examples, with the provision that the complexity and diversity of processes that contribute to inequity in different settings and in different communities preclude highly prescriptive approaches. Our intention is that community leaders and researchers interested in change may be able to draw both principles and practical ideas from the discussion that can then be adapted to the specific community contexts.

4.4.2.1 Strategy One: Community-Centric Approach

The first strategy for change involves the shift from a researcher- or policy maker-focused method to a community-centric approach, where the community is truly at the centre of the data system (Fig. 4.2). This shift in focus and approach requires the development of a meaningful and truly collaborative partnership with the community where the community is the initiator of data processes or engaged in the very first stages of data work. In a community-centric model, the community is the centrepiece of the governance, management, dissemination and application of their data sets, measurement tools and measurement systems. With such an approach, the Ownership, Control, Access and Possession (OCAP) of information lies within the community, necessitating meaningful community involvement throughout each of the data production, analysis, dissemination and use processes.

Researchers should not assume that they have the skills or knowledge to implement this strategy if they have limited prior experience or training in community partnership work. The implementation of this strategy requires on the part of researchers the ability to collaborate with community partners, which to some might be a newer skill set. Specific elements of this collaborative skill set include but are not limited to: the ability to communicate effectively within the community context; the ability to appropriately demonstrate respect for the community; the ability to earn community trust and respect; and the ability to foster mutual understanding. Even the skilled and experienced collaborative researcher cannot expect these elements to occur without a considerable investment of time and energy. Another critical reflection for the researcher wanting to implement this strategy involves his or her internal comfort level and ability to adapt to a paradigm where the community, rather than the researcher, controls the data.

Despite these challenges, the benefits of acquiring this skill set and approach are clear. When properly and appropriately applied, data and data systems instantly become more relevant and useful, and community participation in the provision of data can markedly improve. Two examples illustrate this point. The first example is a community-based project focused on African Americans and the second is a national survey for First Nations populations. Through a true community-based participatory research framework, the African American Health Initiative Planning Project was able to actively engage a population considered "hard to reach" in planning of research and prevention activities (Woods 2009). In this project, the community was at the centre of deciding what information needed to be collected, how to collect it, what instruments to use and how to analyze and interpret data. Community participation was high, and after the release of the study report, the community selected a steering committee to ensure recommendations would be translated into practical solutions. The authors postulated that the traditional "hard to reach" moniker placed on African Americans was erroneous and was in fact rooted in the disconnection between the perceived versus real needs of this community. Of note is the fact that the community members in this initiative found it insulting that they could not be considered the lead agency for the associated grant, emphasizing the point that research ethics boards and funding agencies need to be vigilant on the true meaning of community involvement and engagement (Woods 2009).

The second example of a community-centric approach to using data as a tool of empowerment is the relatively new First Nations Regional Longitudinal Health Survey (RHS), the only First Nations-governed national health survey in Canada and the only national survey for the First Nations on-reserve populations (First Nations Information Governance Committee 2007). The purpose of the survey was to fill the void left by previous national surveys on the collection of relevant data for Aboriginal populations. In the past, other national surveys either completely excluded First Nations people living on reserve or were not able to reach enough on-reserve communities. The RHS serves to obtain data that is centred around First Nations conceptualizations of health, is controlled by First Nations, reflects the priorities of First Nations communities and uses both Western and First Nations traditional understandings of health and well-being. A community health governance policy framework called the OCAP (Ownership, Control, Access and Possession) of Data has been developed and successfully by the RHS governing committee. In RHS Phase I (2002–2003), the adult, youth and children surveys were collected from 22,602 individuals in 238 First Nations communities. RHS Phase II (2008–2009) covered a wide range of priorities, including health conditions and services, language, culture, education, housing, employment, sexuality, water quality, traditional medicine, mental health and disabilities.

These two examples demonstrate that, by putting the community at the centre of data processes and systems, we can ensure that they will feel a true sense of benefit from the collection of data and, therefore, will be willing participants in the process. The shift from externally- to community-controlled data and data systems can be challenging for researchers and policy makers who may fear that by giving up control of data sets means that their research findings will be tampered with or suppressed. It can also put pressure on community stakeholders who may not have the same infrastructure and/or human resources to govern and manage data. However, we would contend that there are far more examples of data suppression by researchers and policy makers than by community-governed data banks. Furthermore, the rebalancing of the distribution of data resources and building community-level data capacities not only will contribute to higher quality data that is more relevant and policy ready, it is also the only way to ensure that data work reduces rather than perpetuates social exclusions.

4.4.2.2 Strategy Two: Changing What We Measure

Secondly, we must change what we measure. We need to change both the focus of *what* we measure (i.e., data that can enable social solutions as opposed to just point out social gaps) and the tools that are developed for *how* to measure (i.e., match community perspectives, concepts and knowledge systems). As noted earlier, the processes that drive social exclusion and health inequities clearly occur at the collective rather than the individual level. Therefore, it is at this collective, community level that they need to be studied, challenged and reversed.

This change requires an emphasis on developing and assessing interventions designed to impact social and economic processes at a systems level in ways that decrease health inequities. Examples of these types of interventions include wage supplementation programs, accessible housing programs, affirmative hiring programs and health insurance programs. Clearly this kind of research is closely tied to policy and subsequently requires a high level of policy awareness and good working relationships with policy makers. One of the benefits of community-centric research approaches, as described above in Strategy One, is that this type of close interaction with policy and policy makers is typically built-in, since it will be community policy makers who are leading the research process.

Poverty research provides a good case study regarding the need to shift from descriptive research that documents social phenomena at the individual level to the evaluation of interventions that address social determinants of health at the systems level. Decades of poverty research in the United States have failed to create new knowledge on the modifiable societal-level causes of poverty because the focus of the research has been on individual characteristics of poverty such as dependency or employment history. The results of this individually-focused poverty research have thus informed interventions that address the causes of "dependency" in the United States versus interventions that focus on societal-level processes linked to poverty. This research has subsequently led to the dismantling of the "welfare" program and active maintenance (rather than reduction) of health inequities (O'Connor 2001). In contrast, the Mincome guaranteed income experiment that took place in the 1970's in three areas of Manitoba and the Self-Sufficiency Project in British Columbia and New Brunswick, which was designed to evaluate the impact of an income supplement for lone working parents, are both examples of intervention research aimed at addressing lack of money as an underlying and modifiable system-level cause of poverty. The Mincome experiment, although it was prematurely terminated due to changes in policy priorities, suggests that income assistance does not lead to significant decreases in labour force participation (Hum and Simpson 2001). The Self-Sufficiency Project demonstrated that income supplementation for full-time lone working parents led to wage progression over time (Zabel et al. 2006).

This example illustrates the need to strategically focus on the societal-level processes that maintain inequities, rather than the individual-level determinants of disparity, if the desire is to empower the communities experiencing the inequities. The data that we produce must provide the basis for convincing arguments to make social, economic and political changes – not for the perpetuation of marginalization and stereotypes. Furthermore, community representatives who have expertise in policy need to be active participants in the elucidation of meaningful causal models and mechanisms for change.

Community input is also essential in the development of relevant measurement tools or the identification and adaptation of existing ones. In order to avoid the imposition of indicators and measurement tools that are mismatched with community concepts of health and social well-being, there also needs to be a careful and thorough dialogue among community representatives and researchers who will be supporting measurement tool development. Concept mapping is one research tool that has been helpful in supporting communities in the process of articulating and documenting their understandings of health and social well-being and their measurement of priorities (Burke et al. 2005; O'Campo et al. 2009b). This type of baseline work is critical to ensuring that measures and measurement tools fit with community priorities and contexts. It is important to note that simple validity testing of an existing tool within the community setting does not ensure community relevance. For example, one could test the reliability and face validity of a psychometric scale designed to detect psychosis according to the Diagnostic and Statistical Manual of Mental Disorder (DSM) cross-culturally in an Indigenous population and arrive at the conclusion that the scale was reliable and valid. However, this approach would completely miss the profound issue of content validity that is created by differences in the ways in which the authors of the DSM and members of Indigenous communities might conceptualize mental health. The disciplines of psychiatry and psychology almost always consider visual and auditory hallucinations pathological, while in Indigenous contexts, it is relatively common for hallucinations to be sought out and those who have them may be considered gifted.

A final consideration with respect to changing what we measure is the importance of working in partnership with community and organizational representatives to ensure that appropriate identifiers are in place in all data systems and that sampling of each group is adequate to ensure that data can be disaggregated across equity strata. Carefully articulated agreements that mandate the active involvement of community representatives in the governance and management of these disaggregated data sets and appropriate and respectful protocols for the collection of equity information (e.g., ethnicity, race, income) are necessary prerequisites for this type of work. Studies must be designed so that samples across ethnicity strata are adequate in size to ensure "equal explanatory power" for each subgroup.

Box 4.2 illustrates how this partnership has been achieved with respect to the measurement of ethnicity in New Zealand (Curtis et al. 2005; Te Rōpū Rangahau Hauora a Eru Pōmare 2002). We note that when making efforts to include marginalized groups in research studies, researchers need to be mindful of the skills required for effective community engagement, which we have detailed in the preceding section on community-centric approach (Hasnain-Wynia 2005; Baker et al. 2006, 2007; Kandula et al. 2009).

Box 4.2 Equal Explanatory Power in New Zealand

There has been recent debate around the sampling frame for the New Zealand Health Survey and its inability to generate productive health information for Mäori development. Furthermore, there is a growing body of literature that describes disparities in Mäori and non-Mäori health, yet very few efforts have been made to provide explanations for these inequalities, thereby allowing the gap to widen further. With a legislative imperative, the New Zealand Ministry of Health currently has a mandate to reduce health disparities by improving the health outcomes of Mäori and other population groups.

The principle of equal explanatory power "recognizes Mäori statistical needs as having equal status with those of the total New Zealand population… Including equal numbers of Mäori and non-Mäori in survey samples allows data to be analyzed to equal depth and breadth for each population" (Te Rōpū Rangahau Hauora a Eru Pōmare 2002). It is this principle that will support the government's goals to reduce inequities in New Zealand.

In order to understand the implications of this principle, we can look at the age-mortality structure of the New Zealand population as an example. The Mäori population has a an age-mortality pattern with most deaths occurring around 10 years earlier than the non-Mäori population, resulting in higher rates of co-morbidity, disability and more severe health needs at earlier ages. The funding of health services, however, are structured around mortality patterns of the total New Zealand (or non-Mäori) population, which has obvious negative impacts on the health care needs of the Mäori. Sample sizes will, therefore, need to be large enough to produce adequate age-specific data for the Mäori, which is a critical component of ethnic data analysis, policy and intervention development.

Using data obtained from the New Zealand Health Information Service for 1996–2000, Curtis et al. (2005) applied the principle of equal explanatory power in the first New Zealand study to conduct an analysis of age-specific breast cancer incidence and mortality, adjusting for ethnicity misclassification. Specifically, the analysis found that, despite similar age-specific breast cancer incidence rates, Mäori women had higher age-specific mortality rates from breast cancer than non-Mäori women, particularly below the age of 60 years. These results have important implications for the delivery of accessible and culturally appropriate breast cancer screening services to Mäori women.

4.4.2.3 Strategy Three: Cross-Community, Cross-Sector Partnerships and Alliances

Cross-community, cross-sector partnerships and alliances are an additional strategy for optimizing the effectiveness of health and social data systems as tools to address inequities. Partnerships and alliances across communities and across equity strata can optimize political leverage and prevent a “divide and conquer” resistance to change both within and across groups experiencing social exclusion. Practically, these partnerships and alliances require an investment of time, energy and open dialogue among community representatives to ensure that every communities’ interests are fully represented by the collective. This investment is beneficial because leaders working together across jurisdictions are usually better able to advocate for change and can maximize the perceived credibility of data sets. Box 4.3 illustrates a multisite project concerned with documenting the social determinants of infants’, young children’s and families’ well-being. It is one of the first community and university partnerships funded by the United States’ National Institute of Child Health and Human Development (2002).

Box 4.3 Community Child Health Research Network: Five Communities Across the United States

The Community Child Health Research Network (CCHN) was established in 2003 in response to a call for community-academic partnerships across the United States. Five sites were selected and represented urban, suburban and rural environments and communities that were predominately African American or Latina. The network has been collaborating for 8 years, and for several of those early years the division between community priorities and academic or funder priorities was apparent. Examples of challenges included timelines for deliverables (e.g., research questions, study design details, research proposal), balance at the initiation of the project between community desires and academic foci and the development of a common “culture” of collaboration. From the start, the community sought to implement an intervention or provide services to the communities being researched, but funders made it clear that the original call for proposals was for a longitudinal study. Hard work, common vision and growth in trust on all sides (including funder, community and university partners) led to strong working relationships after several years.

All stages of the research project from conceptualization of the research foci to the design of surveys and to the prioritization of papers and analyses of the data have been enriched by the community-university partnerships. University partners have deepened their understanding of the issues facing residents of high risk communities and been challenged to operationalize such understandings in the research being undertaken. Communities learned a great deal about how research is conducted and how it can be used to improve the community even if it is not an intervention. The processes developed to enhance multisite collaboration have, over time, evolved to be respectful of differences in priorities of the partners.

(continued)

Box 4.3 (continued)

The existence of multiple sites has meant multiple challenges as well as multiple benefits. Systematic differences between the partner priorities were more easily understood to be due to the nature of the collaboration when observed to be true across sites (e.g., when communities needed more time to sign off on deliverables) and were less likely to be interpreted as personality or personal flaws. Given the power differentials due to academic institutions holding the purse strings and university partners having more research experience, communities could draw from the strength of multiple sites to bring forth their issues and be heard more easily than they would have had only one site been involved. Finally, the funder has grown from being concerned with internal deadlines early on in the project to understanding the unique needs of a community-partnered project.

4.4.2.4 Strategy Four: Integration of Data Systems with Social, Economic and Political Levers for Change

Our final strategy for change involves working toward the integration of health system performance measures – with each other, with mainstream data and with services, policies and programs. We need integrated health and social data systems that can monitor and compare resource utilization. Such systems could highlight both over- and under-access to resources for various communities and confront the underlying causes for social gaps and gradients. They would also directly and effectively track the impacts of health assessments on the reduction of health inequities. As described in Box 4.1, these systems would be governed by communities and operate for communities.

This final tactic is perhaps the most complex, and we do not have any examples of an operational integrated health and social data system that is directly and effectively monitoring the impacts of policies, programs and services on the distribution of social resources and linking these impacts to a reduction in health inequities. In fact, it appears that this type of work is just beginning. For example, some researchers have now begun to investigate the contribution of Cochrane-type reviews to the reductions of health inequities (Welch et al. 2009; Ogilvie and Petticrew 2004; Tsikata et al. 2003). We believe that the effective implementation of this strategy is closely linked to the earlier three strategies such that if there is a community-centric approach to data (i.e., where communities have control over linked data and thus are supportive of integrated data systems; where the data collected are meaningful to the community with opportunities to incite social change; and where partnerships are in place across communities, jurisdictions and domains) then an integrated data system could be a crucial step toward meaningful and lasting change for many communities.

4.5 Anticipating and Addressing Challenges

We would be remiss to not explicitly state that the adoption of the aforementioned or similar strategies will not be without its challenges. Tensions between community groups and researchers are longstanding and rooted in differences that need to be understood and negotiated. These differences include but are not limited to: differences in needs; differing capacities; differences in the desired outcomes from the use of data; differences in expectations about data ownership and control; and differing ways of valuing expertise.

Researchers and community representatives do not necessarily have the required skills to effectively interface these differences. Furthermore, the systems that they are working within are usually structured in ways that amplify rather than bridge differences. For example, research funding structures (with few exceptions) are set up to be accessible only to "eligible institutions" such as universities, colleges and hospitals, and it can be very difficult for other, community-based agencies to access these funds directly. This undermines attempts at a "community-centric" partnership, as it is usually the academic researcher who has initial access to and control of the research funds. The existing protocols of research administration at universities, colleges and hospitals have been set up for researcher-controlled and -initiated projects, usually from the basic science and clinical or pharmaceutical domains. Research agreement templates, for example, are usually focused on ensuring that the commercial and liability interests of the institution and the researcher are protected, and they are not set up to deal with issues of community ownership, control and access to data.

Finally, with respect to challenges it is important to remember that research institutions and community agencies do not operate in a vacuum. Rather, their day-to-day reality is heavily influenced by the larger political, economic and social policy context. It is this context that controls the large majority of funding for both groups in Western democracies. It is also this context that can impose policy decisions that can negate decades of work with a single policy decision. For example, in Canada the federal cabinet recently imposed a decision on the national statistics agency (Statistics Canada) to cancel its mandatory long-form census and replace it with a voluntary household survey. Since Canada does not ask questions about race or ethnicity on the short-form census questionnaire or in the large majority of its health care utilization and vital surveillance databases, this decision, if implemented, will severely undermine the already compromised ability of researchers and communities to document and address health and social inequities across ethnic groups.

All of these challenges will not easily be overcome. However, as illustrated in Sects. 4.1 and 4.2 of this chapter, community sentiments are not born out of irrational paranoia but are instead the creation of many years of policies that produce ongoing social exclusion, whether deliberate or unintended. Therefore, it is crucial that external stakeholders see community involvement in the research, provider and policy arenas as enhancing rather than undermining the credibility and capabilities of the data system.

The current global context provides a rich opportunity for change. The World Health Organization (WHO) released its report on social determinants of health in 2008, and subsequently in May 2009 the World Health Assembly passed Resolution 62.14. This resolution calls upon the international community to consider health equity when working toward the achievement of the core global development goals, including developing indicators to monitor progress and strengthening international collaboration (Commission on Social Determinants of Health 2008; World Health Organization 2009). New measurement tools and processes will be critical to ensuring that measurement systems that result from this policy empower communities to address the social, economic and political processes that drive social exclusion rather than reiterate the harms described in Sect. 4.2.

In closing, it is our belief and experience that population-based data can be a tool for community empowerment. In this chapter, we have provided evidence regarding the need for a transformation of social epidemiology into a discipline that is focused on the development of community-owned and -driven health and social data systems. This work needs to be done in partnership with community representatives. A key role for social epidemiologists will be the bridging of differences between researchers and the community at the individual, collective and systems levels.

References

Altshuler SJ, Schmautz T (2006) No Hispanic student left behind: the consequences of “high stakes” testing. Child Sch 28:5–14

Anderson I (1999) Performance indicators in Aboriginal health services. In: Handock L (ed) Health policy in the market state. Allen and Unwin, Sydney

Anderson M, Smylie J (2009) Health systems performance measurement systems in Canada: how well do they perform in First Nations, Inuit, and Métis Contexts. Pimatisiwin 7:99–115

Anderson M, Smylie J, Anderson I et al (2006) First Nations, Métis, and Inuit health indicators in Canada. A background paper for the project: action oriented indicators of health and health systems development for Indigenous peoples in Canada, Australia, and New Zealand, Indigenous Peoples’ Health Research Centre, Saskatoon

Anderson I, Anderson M, Smylie J (2008) The national Indigenous health performance measurement system. Aust Health Rev 32:626–638

Baker DW, Cameron K, Feinglass J et al (2006) Development and testing of a system to rapidly and accurately collect patients’ race and ethnicity. Am J Public Health 96:532–537

Baker DW, Hasnain-Wynia R, Kandula NR (2007) Attitudes toward health care providers collecting information about patients’ race, ethnicity and language. Med Care 45:1034–1042

Battiste M (2007) Research ethics for protecting Indigenous knowledge and heritage: institutional and researcher responsibilities. In: Denzin N, Giardina M (eds) Ethical futures of qualitative research: decolonizing the politics of knowledge. Left Coast Press, Walnut Creek

Battiste M, Youngblood Henderson J (2000) Protecting Indigenous knowledge and heritage. Purich Publishing, Saskatoon

Boroff M, O’Campo P (1996) Baltimore City Healthy Start Medical Reform for reducing infant mortality. Patient Educ Couns 27:41–52

Burke JG, O’Campo P, Peak GL et al (2005) An introduction to concept mapping as a participatory public health research method. Qual Health Res 15:1392–1410

Campbell N, Kaczorowski J, Lewanczuk RZ et al (2010) Canadian Hypertension Education Program recommendations: scientific summary. University of Calgary, Calgary

Canadian Hypertension Education Program (2010) CHEP recommendations for the management of hypertension. http://hypertension.ca/chep/wp-content/uploads/2010/04/FullRecommendations2010.pdf. Accessed 4 Aug 2010

Canadian Institutes of Health Research (2007) CIHR guidelines for health research involving Aboriginal peoples. http://www.cihr-srsc.gc.ca/e/documents/ethics_aboriginal_guidelines_e.pdf. Accessed 26 Apr 2010

Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, Social Sciences and Humanities Research Council of Canada (2010) Tri-council policy statement: ethical conduct for research involving humans, The Agencies, Ottawa

Castellano MB (2004) Ethics of aboriginal research. J Aborig Health 1:98–114

Centers for Disease Control and Prevention (2008) Tuskegee study timeline. http://www.cdc.gov/tuskegee/timeline.htm. Accessed 2 Aug 2010

Coleridge ST (1965) The rime of the ancient mariner. In: Gardner M (ed) The annotated ancient mariner. Clarkson Potter, New York

Commission on Social Determinants of Health (2008) Closing the gap in a generation: health equity through action on the social determinants of health. Final report of the Commission on Social Determinants of Health, World Health Organization, Geneva

Council of Agencies Serving South Asians (CASSA) (2010) A diagnosis for equity: an initial analysis of South Asian health inequities in Ontario. http://www.cassaonline.com/index3/downloads/Front/DiagnosisforEquity_May14_report.pdf. Accessed 12 Apr 2011

Curtis E, Wright C, Wall M (2005) The epidemiology of breast cancer in Maori women in Aotearoa New Zealand: implications for ethnicity data analysis. J N Z Med Assoc 118:U1298

Dalton R (2002) Tribe blasts “exploitation” of blood samples. Nature 420:111

First Nations Information Governance Committee (2007) First Nations Regional Longitudinal Health Survey (RHS) 2002/03: results for adults, youth and children living in First Nations communities, 2nd edn. Assembly of First Nations, Ottawa. http://www.rhs-ers.ca/english/pdf/rhs2002-03reports/rhs2002-03-technicalreport-afn.pdf. Accessed 28 Feb 2009

Foucault M (1977) Discipline and punishment. Tavistock, London

Freimuth VS, Quinn SC, Thomas SB et al (2001) African Americans’ views on research and the Tuskegee Syphilis Study. Soc Sci Med 52:797–808

Hasnain-Wynia R (2005) Patients’ attitudes toward health care providers collecting information about their race and ethnicity. J Gen Intern Med 20:895–900

Herrnstein RJ, Murray C (1994) The Bell curve: intelligence and class structure in American life. Free Press Paperbacks, New York

Hum D, Simpson W (2001) A guaranteed annual income? From Mincome to the millennium. Policy Options Jan/Feb:78–82

Israel BA, Schulz AJ, Parker E et al (2001) Community-based participatory research: policy recommendations for promoting a partnership approach in health research. Educ Health (Abingdon) 14:182–197

Kahnawake Education System (1998) Kahnawake schools diabetes prevention project code of research ethics. Kahnawake Education System, Kahnawake

Kandula NR, Hasnain-Wynia R, Thompson JA et al (2009) Association between prior experiences of discrimination and patients’ attitudes towards health care providers collecting information about race and ethnicity. J Gen Intern Med 24:789–794

Khandor E, Mason K (2007) The street health report. Street Health/The Wellesley Institute, Toronto

Klonoff EA, Landrine H (1996) Acculturation and cigarette smoking among African American adults. J Behav Med 19:501–514

Kobeissi L, Nakkash R, Ghantous Z et al (2011) Evaluating a community based participatory approach to research with disadvantaged women in the Southern suburbs of Beirut. J Community Health. 11 Feb 2011 [Epub ahead of print]

Little Bear L (2000) Jagged worldviews colliding. In: Battiste M (ed) Reclaiming indigenous voice and vision. University of British Columbia Press, Vancouver

Macaulay AC, Cargo M, Bisset S et al (2006) Community empowerment for the primary prevention of type 2 diabetes: Kanien'keha:ka (Mohawk) ways for the Kahnawake Schools Diabetes Prevention Project. In: Ferreira ML, Lang GC (eds) Indigenous peoples and diabetes: community empowerment and wellness. Carolina Academic Press, Durham

Marmot M (2005) Social determinants of health inequalities. Lancet 365:99–104

Minkler M (2000) Using participatory action research to build healthy communities. Public Health Rep 115:191–198

Muntaner C, Nieto FJ, O'Campo P (1996) The bell curve: on race, social class, and epidemiologic research. Am J Epidemiol 144:531–536

National Institute of Child Health and Human Development (NICHD) (2002) Development of community child health research. RFA: HD-02-008, National Institutes of Health, Rockville

North American Primary Care Research Group (1998) Responsible research with communities: participatory research in primary care. A policy statement. http://www.napcrg.org/resources-responsible.cfm. Accessed 10 Apr 2011

O'Campo P, Kirst M, Schaefer-McDaniel N et al (2009a) Community-based services for homeless adults experiencing concurrent mental health and substance use disorders: a realist approach to synthesizing evidence. J Urban Health 86:965–989

O'Campo P, Salmon C, Burke J (2009b) Neighbourhoods and mental well-being: what are the pathways? Health Place 15:56–68

O'Connor A (2001) Poverty knowledge: social science, social policy, and the poor in twentieth-century U.S. History. Princeton University Press, Princeton

O'Connor B (2004) A political history of the American welfare system: when ideas have consequences. Roman and Littlefield, New York

O'Neil JD, Reading JR, Leader A (1998) Changing the relations of surveillance: the development of a discourse of resistance in aboriginal epidemiology. Hum Organ 57:230–237

Ogilvie D, Petticrew M (2004) Reducing social inequalities in smoking: can evidence inform policy? A pilot study. Tob Control 13:129–131

Paradis G, Levesque L, Macaulay AC et al (2005) Impact of a diabetes prevention program on body size, physical activity, and diet among Kanien'keha:ka (Mohawk) children 6 to 11 years old: 8-year results from the Kahnawake Schools Diabetes Prevention Project. Pediatrics 115:333–339

Pivik JR, Goelman H (2011) Evaluation of a community-based participatory research consortium from the perspective of academics and community service providers focused on child health and well-being. Health Educ Behav 38(3):271–281

Popay J, Williams G, Thomas C et al (2008) Theorising inequalities in health: the place of lay knowledge. In: Bartley M, Blane D, Smith GD (eds) The sociology of health inequalities. Blackwell Publishers, Oxford

Public Health Agency of Canada (2004) Social inclusion as a determinant of health. http://www.phac-aspc.gc.ca/ph-sp/oiar/03_inclusion-eng.php. Accessed 10 Apr 2011

Public Health Agency of Canada (2006) The Canadian maternity experiences survey. Public Health Agency of Canada, Ottawa

Randall V (2006) Dying while Black: an indepth look at a crisis the American healthcare system. Seven Principles Press, Dayton

Rodney P, Copeland E (2009) The health status of Black Canadians: do aggregated racial and ethnic variables hide health disparities? J Health Care Poor Underserved 20:817–823

Royal Commission on Aboriginal Peoples (1993) Royal commission on Aboriginal peoples. Appendix B: ethical guidelines for research, Royal Commission on Aboriginal Peoples, Ottawa

Sateesh MK (2008) Bioethics and biosafety. IK International Publishing House, New Delhi

Shalowitz MU, Isacco A, Barquin N et al (2009) Community-based participatory research: a review of the literature with strategies for community engagement. J Dev Behav Pediatr 30: 350–361

Skloot R (2010) The immortal life of Henrietta Lacks. Crown Publishers, New York

Smith LT (1999) Decolonizing methodologies: research and Indigenous peoples. Zed Books Ltd., London/New York

Smylie J, Anderson M (2006) Understanding the health of Indigenous peoples in Canada: key methodological and conceptual challenges. CMAJ 175:602–605

Smylie J, Anderson I, Ratima M et al (2006) Indigenous health performance measurement systems in Canada, Australia, and New Zealand. Lancet 367:2029–2031

Snarch B (2004) Ownership, control, access, and possession (OCAP) or self-determination applied to research: a critical analysis of contemporary First Nations research and some options for First Nations communities. J Aborig Health 1:80–95

Statistics Canada (2000) Canadian Community Health Survey (CCHS), cycle 1.1. http://www.statcan.gc.ca/imdb-bmdi/instrument/3226_Q1_V1-eng.pdf. Accessed 21 July 2010

Te Rōpū Rangahau Hauora a Eru Pōmare (2002) Mana Whakamarama – Equal explanatory power: Maori and non-Maori sample size in national surveys, Ministry of Health, Wellington

Tsikata S, Robinson V, Petticrew M et al (2003) Is health equity considered in systematic reviews of the Cochrane Collaboration? Cochrane Systematic Reviews, 11th Cochrane Colloquium, Barcelona

Wallerstein N (1999) Power between evaluator and community: research relationships within New Mexico's healthier communities. Soc Sci Med 49:39–53

Welch V, Tugwell P, Wells GA et al (2009) How effects on health equity are assessed in systematic reviews of interventions (Protocol). Cochrane Database Syst Rev (3):MR000028

Wenman WM, Joffres MJ, Tataryn IV (2004) The Edmonton perinatal infections group: a prospective cohort study of pregnancy risk factors and birth outcomes in Aboriginal women. CMAJ 171:585–589

Woods V (2009) African American health initiative planning project: a social ecological approach utilizing community-based participatory research methods. J Black Psychol 35:247–270

World Health Organization (2009) Sixty-second World Health Assembly. Geneva, 18–22 May 2009, resolutions and decision, annexes, World Health Organisation, Geneva. WHA62/2009/REC/1. http://apps.who.int/gb/ebwha/pdf_files/WHA62-REC1/WHA62_REC1-en.pdf. Accessed 31 Aug 2010

Young TK (2003) Review of research on aboriginal populations in Canada: relevance to their health needs. BMJ 327:419–422

Youngblood-Henderson J (2000) Ayupackhi: empowering Aboriginal thought. In: Battiste M (ed) Reclaiming Indigenous voice and vision. University of British Columbia Press, Vancouver

Zabel J, Schwartz S, Donald S (2006) Analysis of the impact of SSP on wages, Human Resources and Skills Development Canada, Ottawa. http://www.srdc.org/uploads/zabel_et_al-wages.pdf. Accessed 7 Mar 2011