Linking GIHR and EMR: Environmental Scan & Tool Inventory

Motivation

Within Canada and abroad, two branches of health research are motivated by the challenge of enabling more equitable health outcomes worldwide: Global Indigenous Health Research and Equity Methods Research. While both fields are relatively new and both work to inform and promote the health of disadvantaged people worldwide, global indigenous health researchers and equity methodologists often labour independently, without referring to each other. To remedy this, the Canadian Coalition for Global Health Research and partners, with generous support from the Canadian Institutes of Health Research, are preparing for a project titled "Linking Equity Methods Research and Global Indigenous Health Research: towards the creation of a resource group" to explore potential syntheses between the two fields of research. In preparation for a meeting later this spring, a research methods inventory and environmental scan have been undertaken in advance to support the discussions.

"Equity in health reflects a concern to reduce unequal opportunities to be healthy associated with membership in less privileged social groups, such as poor people; disenfranchised racial, ethnic or religious groups; women; and rural residents." (Braveman & Gruskin, 2003, p. 540) Indigenous peoples worldwide make up thousands of these under-privileged social groups which are consistently over-burdened by negative health outcomes relative to their non-Indigenous compatriots[1].

Meanwhile, much of the GIHR research yields evidence of health disparities, and advocacy is an important element of GIHR as well as EMR. Many of the same indicators of health are widely cited, and show sharp disparities which are considered to be unfair, however the GIHR dialogue doesn't take advantage of the well-defined vocabulary and methodology of health equity to strengthen its argument.

Exploration Strategy

The following information was collected from communications with Colleen Davison and Erin Ueffing, and from there, browsing the works cited in the resources they recommended and scanning the work of additional researchers mentioned during these conversations. For GIHR resources, publications on the CCGHR website and the Global Indigenous Health Research Symposium were the main sources of information.

Findings

The findings of this scan can be arranged into the following categories:

- Definitions
- Conceptual frameworks
- Tools & Methods

[1] Stephens et al (2006); and the list goes on

Definitions

In equity methods research (EMR), the main definition is of *health inequity* – which involves some judgment of fairness - as opposed to *health inequality* – which implies a disparity in health outcomes. The standard definition of health inequity in EMR was introduced in Whitehead (1992) : "differences in health which are not only unnecessary and avoidable but, in addition, are considered unfair and unjust."

This definition of *health inequity* then requires definitions of "unfair" and "unjust", which are value-laden and may vary in different settings. In general, however, health disparities which are systematic across certain traits (characteristics which are protected from discrimination by law, for example) are strong indicator of inequity. Some important dimensions of health inequality which may lead to systematic health inequities can be summed by PROGRESS: **P**lace of residence, **R**ace, **O**ccupation, **G**ender, **R**eligion, **E**ducation, **S**ocioeconomic status, **S**ocial capital (Evans & Brown, 2003). This acronym has been adapted to PROGRESS Plus to include age, disability, and sexual orientation as parameters for health inequities (Kavanagh, Oliver, & Lorenc, 2008).

In global indigenous health research (GIHR) a key – and highly disputed – definition is that of 'indigenous[2]'. Both indigenous advocacy groups and governments reject a universally recognized formal definition of 'indigenous' peoples, though for different reasons. In the place of a formalized definition, Jose R. Martinez Cobo, Special Rapporteur of the Sub-Commission on Prevention of Discrimination against Indigenous Populations developed the following working definition:

> "Indigenous communities, peoples and nations are those which, having a historical continuity with pre-invasion and pre-colonial societies that developed on their territories, consider themselves distinct from other sectors of the societies now prevailing on those territories, or parts of them. They form at present non-dominant sectors of society and are determined to preserve, develop and transmit to future generations their ancestral territories, and their ethnic identity, as the basis of their continued existence as peoples, in accordance with their own cultural patterns, social institutions and legal system.
> "This historical continuity may consist of the continuation, for an extended period reaching into the present of one or more of the following factors:
>
> a) Occupation of ancestral lands, or at least of part of them;
> b) Common ancestry with the original occupants of these lands;
> c) Culture in general, or in specific manifestations (such as religion, living under a tribal system, membership of an indigenous community, dress, means of livelihood, lifestyle, etc.);
> d) Language (whether used as the only language, as mother-tongue, as the habitual means of communication at home or in the family, or as the main, preferred, habitual, general or normal language);
> e) Residence on certain parts of the country, or in certain regions of the world;
> f) Other relevant factors.

[2] The Secretariat of the UN Permanent Forum on Indigenous Issues does not capitalize 'indigenous' in its document The Concept of Indigenous Peoples, and so I have not either.

> "On an individual basis, an indigenous person is one who belongs to these indigenous populations through self-identification as indigenous (group consciousness) and is recognized and accepted by these populations as one of its members (acceptance by the group).
> "This preserves for these communities the sovereign right and power to decide who belongs to them, without external interference".
>
> In PFII, 2004, p.2.

This definition is also paraphrased in Panel 1 of Stephens et al (2006), p. 2020. Bartlett et al (2007) further discuss the development of definition(s) for the word 'indigenous'. Of particular importance in these discussions is the right of indigenous peoples to define and identify themselves.

Durie, M. (2004) outlines the following attributes shared by Indigenous peoples worldwide:

1) A history of colonization
2) Always socio-economically disadvantaged relative to general population of their country.
3) Lower life expectancy than non-indigenous compatriots
4) Sense of unity with the environment

Ultimately, Durie (2004) conceptualizes 'indigeneity' as a state of fusion between the community and their accustomed environment.

Also important to GIHR is recognition and responsiveness to the fact that for many indigenous peoples, the word 'health' conjures up vastly different understanding from the narrow interpretation of 'absence of disease', or even from the [can I find the WHO def which includes well-being etc?]. Indigenous understandings of health are grounded in a particular worldview with unique interpretations of what knowledge is. Three distinguishing features of IK system:

1) It is the product of a dynamic system of relationships between generations of people and their environment;
2) [indigenous knowledge] is an integral part of the physical and social environment of their communities;
3) It is a collective good.

(Viergever M. (1999) in Durie (2004).)

These broader conceptualizations of health and knowledge present challenges and opportunities for researchers. In particular, they expand the horizons of possible research by opening new intellectual frontiers.

<u>Conceptual Frameworks</u>

FRAMEWORK	GENERAL DESCRIPTION
CNA – 10 attributes of social justice	Describing "Fairness" in theory, policy, or practice.
Caplan, Light & Daniels (1999)	
Ethics framework for public health	
Human rights approach to health	
Duhaime et al (2002)	Assessing community health.
Hancock, Labonté, & Edwards (1999)	

Marks, Cargo, & Daniel (2007)	
Global Equity Gauge Alliance	
Life course approach	
Social determinants of health	"Upstream" factors influencing health

Both EMR and GIHR are fields of research encompassing broad ranges of topics, bringing together researchers from a variety of academic disciplines and drawing on the strengths of many methods of analysis. For these reasons, researchers in both EMR and GIHR make use of numerous conceptual frameworks.

In the case of EMR, frameworks for deciding what constitutes 'fairness' are necessary for identifying and characterizing health inequities, as defined by Whitehead (1992). The Canadian Nurses Association (CNA) thinks of fairness in terms of 'social justice' which is encompasses ten attributes: equity, human rights, democracy and civil rights, capacity building, just institutions, enabling environments, poverty reduction, ethical practice, advocacy and partnerships (Davison, Edwards & Robinson, 2006).

Caplan, Light & Daniels (1999) elaborate on 10 benchmarks resulting collectively in a fair health care system, for a given definition of fair. The authors note that different groups and societies will have different understandings of fairness and that dialogue on what is "fair" is a key prerequisite before you can design a fair health care system. Different definitions of fair have different ramifications for the fair delivery of health care. The understanding of 'fair' that they use is based on "equalizing people's opportunities to participate in and enjoy life, given their circumstances and capacities" (p. 856). The benchmark they develop is for measuring the fairness of health reform proposals; they put forward a scoring system of -5 to 5 with 0 being the status quo, to evaluate the reforms in terms of how they affect the fairness of the health care system.

Kass (2001) presents a framework for analyzing whether public health programs themselves are ethical based on 6 considerations: the public health goals of the proposed program; effectiveness of the program at achieving its stated goals; known or potential burdens of the program; minimizing burdens and alternative approaches; is the program implemented in a spirit of distributive justice; and, are the benefits and burdens well-balanced? A similar framework is presented by Gostin & Lazzarini (1997) in the context of addressing HIV in public health initiatives.

Sofia Gruskin (2004) describes three frameworks for bringing human rights and public health activities together — the "law and policy framework," the "advocacy framework" and the "programmatic framework." Gruskin & Daniels (2008) argue that combining the human rights approach to health with distributive justice leads to a fair way of setting public health priorities as each emphasizes different elements of 'fairness' which may be valued to different degrees by different groups of people. Barnsley (2006) argues that a human rights approach to health affects indigenous health (in industrialized countries) in five ways: allows for other human rights violations to impact health status of indigenous people; possibility of stronger protection of indigenous health in law; encourages consideration of the substantive effects of government policies and programs; means of encouraging change; and, it informs the development and implementation of nongovernmental programs.

Duhaime et al (2002) present a model of social cohesion which is applicable to small-scale societies in industrialized countries, and describe how an existing framework was adjusted to better reflect another culture's social relations.

Hancock, Labonte, & Edwards (1999) present a framework for measuring population health at the community level. While not written specifically for indigenous peoples, this framework is compatible with indigenous health as it allows for a broad definition of 'health' and includes community-level indicators.

Marks, Cargo, & Daniel (2007) develop a framework for sorting and cataloguing existing indicators of indigenous community health and other social indicators based on the ''German System of Social Indicators'' (German Social Science Infrastructure Services Social Indicators Department, 2004). The GSSI was then supplemented, adapted, and expanded to accommodate indicators of indigenous community health. It is designed with the indigenous populations of Canada, Australia, and New Zealand in mind.

The Global Equity Gauge Alliance puts forward an action-oriented approach to measuring health disparities based on the following pillars:

- "Research and monitoring to measure and describe inequities
- Advocacy and public participation to promote the use of information to effect change involving a broad range of stakeholders from civil society working together in a movement for equity
- Community involvement to involve the poor and marginalized as active participants rather than passive recipients"

(from the GEGA website: http://www.gega.org.za/concepts.php.)

Over the last decade, a life course approach to understanding health status has received increased attention from Canada's Aboriginal health research field. Kuh et al (2003) "defined life course epidemiology as the study of long term effects on later health or disease risk of physical or social exposures during gestation, childhood, adolescence, young adulthood and later life" (p. 778). Reading (2009) explains that a exploring health and illness from a life course perspective both helps researchers integrate scientific, cultural, and social knowledge into a single theory explaining health status and allows for a holistic understanding of 'health' which is consistent with Aboriginal interpretations of the term.

Both global indigenous health research and equity methods research refer to the social determinants of health as 'upstream' factors which influence the health of communities and individuals. Petticrew et al (2008) used a 'rainbow model' of social determinants as described in Dahlgren & Whitehead (2007).

Tools & Methods

Both global indigenous health researchers and equity methods researchers are interested in demonstrating that certain disparities in health status are unjust and should be remedied through policy, programming, and social change. In order to do so, various measurements of health, well-being, or illness are compared according to various formulae. Brownell, Roos & Roos (2001) propose a report card system of evaluating the health equity effects of changes to the

provision of health services which includes measurements of standardized mortality rate (ages 0-74 to capture 'premature' mortality), disease prevalence, and self-perceived health status. They argue that this data should be disaggregated along various dimensions (ie: income) to reveal health equity effects of changes to health service provision. Brownell, Roos, & Roos (2001) also argue that impacts of health reforms on health access must be calculated in terms of the target population, not only the users of the health services, as the latter may disguise inequitable access to health services. This is a strong argument against utilization rates as proxies for access to health services in indigenous health research, which is frequently seen in Canadian and Australian studies. (However, this study still measures access to primary health care in terms of supply (pre- and post-reform), rather than by whether supply meets demand.)

Global indigenous health researchers use many different tools to assess the well-being of members of indigenous communities and the communities themselves. The following were identified by Kim Scott of Kishk Anaquot Health Research in her presentation at the Global Indigenous Health Research Symposium[3]:

- United Nations Human Development Index (HDI)
- Weighted Index of Social Progress
- Quality of Life Index
- Prescott-Allen's Indices of the Wellbeing of Nations
- Conference Board of Canada's Quality of Life Scorecard
- Genuine Progress Indicator
- Fordham Index of Social Health
- Fraser Institute Index of Living Standards
- Ontario Social Development Quality of Life Index
- Index of Relative Indigenous Socio-economic Disadvantage
- United Nations Permanent Forum on Indigenous Issues – Indicators of Wellbeing
- Assembly of First Nations Holistic Indicators

Many health indicators can be manipulated using the following approaches to measure the size of health disparities between different groups.

- Gap approach: relative or absolute
- Gradient approach: regression or Gini
- Gradient concentration index: World Bank method, graphically-oriented
- Gradient or gap-benefit incidence: distribution of public expenditure on health care across PROGRESS groups by utilization of health services

Note: Each of the above, in addition to the targeted approach measuring the size of an intervention's effect on the disadvantaged group, can be used to measure the effect of an intervention on health equity.

Different measurement techniques will illustrate health disparities differently, and selecting one technique over another involves a value judgment. Harper et al (2010) present an interesting discussion of the implicit value judgments made in the application of several measurement techniques. Of particular interest are case studies 1 & 2 where the implications of using the relative or absolute gap approach (1) and the decision of 'who should count' (2) are addressed.

[3] See links page for access to more information.

In a 2004 study by Whitehead, Petticrew, Graham, Macintyre, Bambra & Egan, the following five types of evidence of health inequalities were reported to have the greatest impact on policy change: observational evidence that the disparity exists; narrative accounts of how policies affect households; controlled evaluations; natural experiments; and, historical evidence. Natural experiments are further touted as untapped opportunities in Petticrew (2005).

Other methods include:

METHOD	GENERAL DESCRIPTION
Rapid Appraisal Method	'health for all' policy analysis
Report card for monitoring health reform	Method for evaluating health equity impacts of changes to health services provision.
CIET cycle	Aid for making evidence-based policy decisions
Ottawa Equity Gauge	Applying the GEGA principles in an industrialized country setting
Equity Effectiveness Loop	Assessment tool allowing calculation of EER
Equity Effectiveness Ratio	Explains differences in intervention effectiveness across different dimensions of inequality

The Rapid Appraisal Method developed by Peiro et al (2002) maps the development of health strategies, compares policies in different areas, and forecasts their usefulness. Brownell, Roos & Roos' (2001) report card for monitoring health reform presents a methodology for studying the health equity impacts of changes to health services provision using indicators described at the beginning of this section. The CIET cycle is described in both Tugwell, O'Connor, Anderson, Mhatre, Kristjansson et al. (2006) and the WHO Collaborating Centre for Health Technology Assessment's Equity-Oriented Toolkit as a decision-making aid to facilitate evidence-based planning at local and regional levels. The Ottawa Equity Gauge project – also discussed in Tugwell, O'Connor et al (2006) – assesses and responds to health inequities in Ottawa based on the GEGA framework for action-oriented monitoring of health inequities.

Tugwell, de Savigny, Hawker & Robinson (2006) describe an equity effectiveness loop which aids the development and assessment of policies and programs for reducing health disparities. It models community effectiveness of an intervention as the product of access, diagnostic accuracy, service provider compliance, and consumer compliance for the most and least wealthy strata of the study population. Interventions are not always equally effective across income levels (or other PROGRESS dimensions), and the ratio of the two products is the equity effectiveness ratio which illustrates the relative equity-effectiveness gap.

The extent of research being conducted on various health interventions is such that systematic reviews are an important means by which researchers can compress the information and makes sense of it all. However, not all systematic reviews collect and interpret health research in a way that is mindful of the health inequities that exist in all countries. To this end, the Cochrane Collaboration developed a protocol for assessing the effects of interventions on health equity in systematic reviews (Welch, Tugwell, Wells, Kristjansson, Petticrew et al 2009). The Cochrane

Health Equity Field has also produced a checklist for review authors who wish to incorporate health equity considerations into their systematic reviews.

The WHO Collaborating Center for Health Technology Assessment developed an Equity-Oriented Toolkit – a useful index of tools in areas of community effectiveness; knowledge translation; burden of illness; and, economic evaluation – to facilitate evidence-based decision-making. Below is a listing of some resources which take into consideration either (or both) the Equity Gauge or PROGRESS concepts/dimensions of inequity.

Knowledge Translation and Implementation

- Evidence-based planning, CIET
- Government committee on choices in healthcare, the Dunning Commission in the Netherlands
- Primary Healthcare Management Advancement Program (PMC MAP) – Needs Assessment Module
- Equity Checklist for Systematic Review Authors
- Formal protocol for incorporating health equity assessment into systematic reviews of health intervention literature (Welch et al, 2009)

Burden of Illness Toolkit

- PMC MAP – Needs Assessment Module (repeated)
- Sentinel Community Surveillance
- World Health Organization Quality of Life

Community Effectiveness Information

- Cochrane Library (www.cochrane.org)
- Evidence-Based Medicine (www.evidence-basedmedicine.com)

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