

The background features a complex geometric pattern of thin, dashed lines in a light olive green color. These lines intersect to form various triangular and polygonal shapes across the entire page. A single, small, solid olive green dot is positioned at the intersection of a horizontal line and one of the dashed lines, located just above the date text.

# CCGHR Principles for Global Health Research

CANADIAN COALITION FOR GLOBAL HEALTH RESEARCH

*Promoting better and more equitable health worldwide through the production and use of knowledge*

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November 2015

## Acknowledgements

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## Why principles for global health research?

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Alarming inequities in health exist within and between countries globally. Compelling evidence demonstrates they are caused by the unequal distribution of power, income, goods, and services, globally and nationally<sup>1</sup>. These inequities are unjust and avoidable consequences of human actions that disproportionately advantage some groups over others and negatively affect human rights, including the right to health<sup>2</sup>. Global health<sup>3</sup> research (GHR) is one response to inequities, but research activities have the potential to worsen, rather than address these injustices.

The Canadian Coalition for Global Health Research (CCGHR) is a network of people involved in global health research for equity. We are optimistic about the potential for GHR and aware of the need for conducting GHR in ethical and equitable ways. The CCGHR Principles for Global Health Research complement those of bioethics and research ethics (in the concern for individuals); public health ethics (in the concern for the health of collectives); and global health ethics (in the examination of transnational forces that affect health and health equity). Building upon the important core principles in the *Tri-Council Policy Statement – Ethical Conduct for Research Involving Humans* (TCPS2, 2014)<sup>4</sup>, the CCGHR Principles were developed through a multi-phase, dialogue-based research process. This study was launched in response to a call for action from researchers, funders, and administrators who indicated a need for greater governance to support GHR.

The principles contained in this document are intended to guide people involved in GHR toward more ethical and equitable GHR activities. Each principle is meant to complement the others, working collectively to inform any approach to GHR. Though not prescriptive, they offer a set of practical tools with examples to inform practice, spark dialogue, and inspire reflection. We see this work as both research and social action, aiming to influence GHR in a way that can also address current global health inequities.

## Who should use the CCGHR Principles?

These principles can be used by those involved in any aspect of GHR, including people designing, conducting, using, teaching, learning about, assessing, funding, or collaborating on GHR. They are relevant to any discipline or sector related to global health, including but not limited to: the social sciences, clinical research, health sciences, humanities, and health policy. The principles may guide the

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- 1 WHO Commission on Social Determinants of Health. (2008). *Closing the Gap in a Generation: Health Equity Through Action on the Social Determinants of Health: Commission on Social Determinants of Health Final Report*. Geneva: World Health Organization. p.1.
  - 2 Ottersen, O. P., Dasgupta, J., Blouin, C., Buss, P., Chongsuvivatwong, V., Frenk, J., ... & Scheel, I. B. (2014). The political origins of health inequity: Prospects for change. *The Lancet*, 383(9917), 630-667.
  - 3 Among the many different, sometimes contradictory, definitions of global health (and thereby global health research), there is a common assertion that the purpose of GHR is to contribute to greater health equity worldwide. We encourage rich debate about the substantive focus and nature of GHR, maintaining that it ought to be *for equity*.
  - 4 The three core principles in TCPS 2 (2014) are respect for persons, concern for welfare, and justice. The principle of justice incorporates the notion of equity and is an integral part of ethical research.

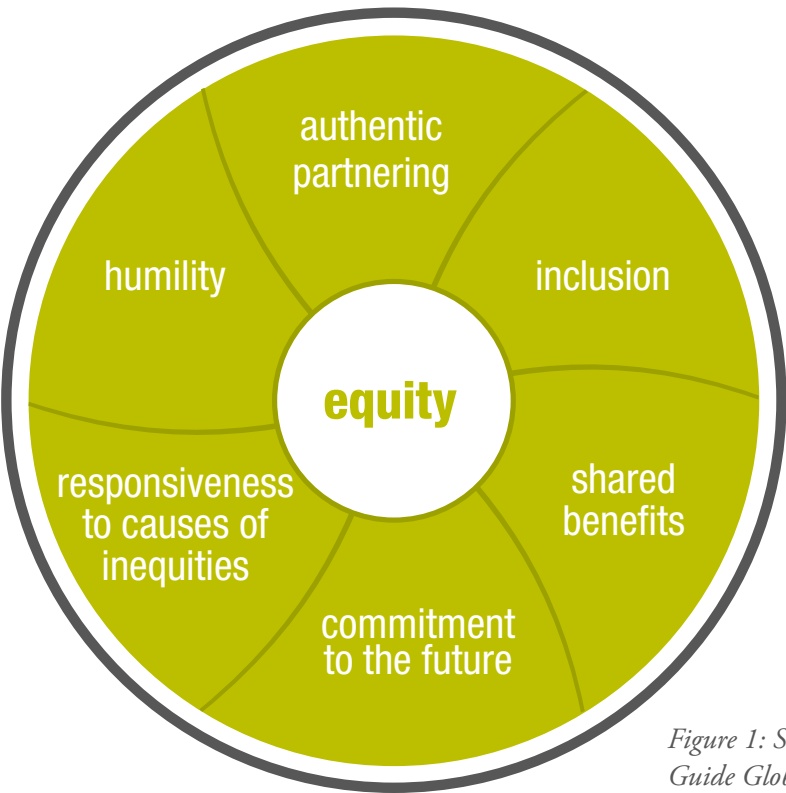
activities of individuals and groups across sectors, including universities, non-academic research organizations, funding bodies, government agencies, non-governmental organizations, private sector companies, professional associations, and community groups. The principles may be useful within and outside of Canadian contexts or research partnerships.

### **An Evidence-Informed and Ethical Frame for the CCGHR Principles**

Informed and inspired by the important work of others, including (but not limited to) the Nuffield Council on Bioethics report, the Canadian Institutes of Health Research Guidelines for health research involving Aboriginal peoples, and the Universal Declaration on bioethics and human rights, these principles were derived from data generated through the CCGHR Gathering Perspectives Studies (Phase I & II). These studies involved fifteen dialogues held in six provinces across Canada with more than 300 participants. Table 1 provides an overview of the types of dialogue, numbers of participants, and major results from this study.

The perspectives reflected in this data were diverse, including a range of disciplinary, substantive, and theoretical perspectives. Participants were evenly distributed from Western, Central, and Eastern Canada. Each dialogue included individuals from partner countries. About 40% of participants were faculty, 30% students, and the remaining 30% were evenly distributed amongst NGOs, government agencies, academic administration, and consultants.

Six principles to guide GHR are depicted in Figure 1 and described below. Each principle is accompanied by a brief description and an example of how it might be enacted. These principles speak not only to *how* GHR should be done, but also to the contexts or considerations that should be given in any kind of GHR. For further discussion about the process behind the development of these principles, and for an in-depth discussion on why participants believed these principles were needed, please visit our website ([www.ccghr.ca](http://www.ccghr.ca)) to access blog discussions and watch for announcements on future publications.



*Figure 1: Six CCGHR Principles to Guide Global Health Research*

Table 1: Overview of Dialogues & Major Results of the CCGHR Gathering Perspectives Study

	When & Type of Dialogue	Focus	Where	Major Results
PHASE I	May 2013 Full day, facilitated deliberative dialogue (n=24)	What would we love to see happen for GHR in a generation?	Vancouver, British Columbia	<ul style="list-style-type: none"> <li>Set a vision for a more cohesive, connected approach to GHR for equity</li> <li>Affirmed normative GHR values (equity, engagement, effectiveness, and ethics)</li> </ul>
	Jun – Sept 2013 Six half-day, facilitated dialogues (n≈25 per dialogue)  Facilitated workshops at CCGH conference and with CCGHR University Advisory Council (n=30 and 22 respectively)	How do equity, effectiveness, and engagement resonate as values in GHR? What do these look like in practice?	Alberta  Ontario  Maritimes	<ul style="list-style-type: none"> <li>Participants identified the need for a paradigm shift, challenging status quos in research that reinforce, rather than transform, inequities</li> <li>Equity is both a ‘why’ and ‘how’ we should do GHR</li> </ul>
	Jun – Sept 2013 Open, online dialogue using social media (Facebook, Twitter, blog posts) and an online response form	Issues emerging from facilitated dialogues	Global	<ul style="list-style-type: none"> <li>Issues raised include global sustainable futures, solidarity, the role of universities in society, the role of GHR in affecting change</li> </ul>
	Oct 2013 Full day, facilitated deliberative dialogue (n=17)  Facilitated workshop with CCGHR University Advisory Council (n=24)	What are the implications of study findings so far? What responses are needed immediately, within three years, and within five years?	Ottawa, Ontario	<ul style="list-style-type: none"> <li>Affirmation of GHR as research that aims to achieve greater health equity worldwide</li> <li>Calls for action focused on governance gaps in GHR, including the need for principles to guide practices and activities in GHR</li> </ul>
	Nov 2014 Full-day, facilitated deliberative dialogue, responding to environmental scan of existing codes/guides for equitable and ethical research (n=15)	Why is GHR needed? What principles should guide it? What further consultation is needed to elaborate principles to guide Canadian involvement in GHR?	Ottawa, Ontario	<ul style="list-style-type: none"> <li>Ten preliminary principles were identified as foundations for further consultation</li> <li>Participants called for deliberation on these principles, using the same approach used in Phase I (online + facilitated)</li> </ul>
PHASE 2	Mar – Aug 2015 Six half-day, facilitated deliberative dialogues in person and online (n≈15 per dialogue)  Structured, response conversations with self-selected stakeholder groups (two conversations)  Open, online responses through Fluid Survey (n=38; 35% from LMICs)	Why is GHR needed and what principles should guide it? How would you use such principles? How do the preliminary principles resonate (or not) with you? What changes are needed?	Alberta Saskatchewan Ontario (2) Online (2)  Ontario  Global	<ul style="list-style-type: none"> <li>Affirmed concepts and values outlined in preliminary document</li> <li>Focused and consolidated principles, emphasizing a focus of GHR on improving equity worldwide</li> <li>Asserted that the role of the principles should be to promote more equitable, ethical engagement in GHR</li> </ul>

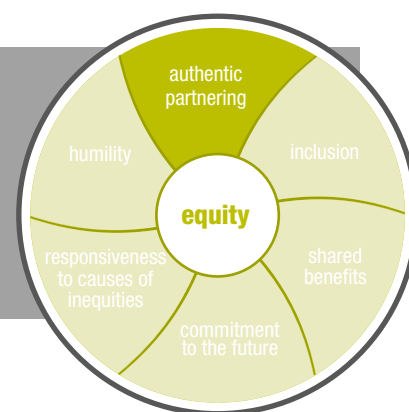
## How should the CCGHR Principles be used?

When we asked study participants how they thought these principles should be used, they identified a number of different ways the principles could support their involvement in GHR. These principles are a way of declaring normative values and intentions of GHR. Study participants suggested that the principles could guide practice, teaching, administration, and policy related to GHR at multiple levels. Participants stated that these principles could reduce fragmentation in GHR practice, encouraging greater cohesiveness across Canada, building upon the foundations of public health and informing the substantive focus of GHR. This set of GHR principles could be used as a supplement to other guides for the ethical conduct of research (i.e., TCPS2, Good Clinical Practice Guidelines<sup>5</sup>). We encourage CCGHR members, both individual and institutional, to use these principles to guide their involvement in GHR within their networks and partnerships.

## The Principles

### Authentic Partnering

How has attention to these principles informed this partnership?  
How am I (are we) assessing equity in this partnership?  
What am I (are we) doing to foster equity in this partnership?



Research partnerships often involve navigating the norms and requirements of differing country contexts and differentials in power among a variety of actors in the process. Authentic partnering is about ensuring our intentions and actions as global health researchers are aligned around equitable research relationships, processes, and outcomes. It involves creating and maintaining a strong foundation of trust.

Authenticity in research partnering extends to the reciprocity and equity considerations that are built into any research activity. Recognizing limited resources and capacity for ethical review of research in many lower-middle income countries<sup>6</sup>, we recommend that those involved in conducting GHR in such settings adopt an open dialogue with local partners (e.g., communities and community stakeholders, researchers, university administrators, or health systems decision makers) about the ethical considerations and implications of research. Such a dialogue should be transparently documented and included as part of a submission for ethical review to a Canadian research ethics board.

Given the complexity inherent in inequities, global health research problems are inherently complex. Authentic partnering invites research teams to find ways to address these complex research problems through multi-pronged, inter-sectoral, and transdisciplinary (rather than individually framed) programs of research.

5 International Conference on Harmonization of Technical Requirements for the Registration of Pharmaceuticals for Human Use. Good Clinical Practice Guidelines. More information available at: <http://www.hc-sc.gc.ca/dhp-mps/prodpharma/applic-demande/guide-ld/ich/efficac/e6-eng.php>

6 Yassi, A., Breilh, J., Dharamsi, S., Lockhart, K., & Spiegel, J. M. (2013). The ethics of ethics reviews in global health research: Case studies applying a new paradigm. *Journal of Academic Ethics*, 11(2), 83-101.

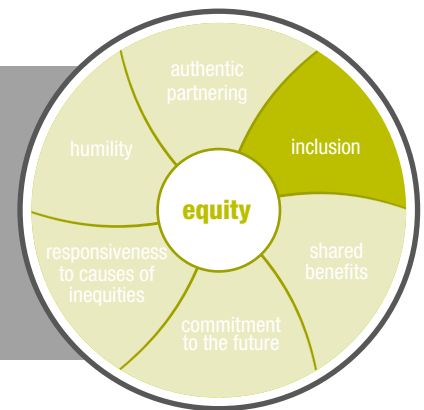
Further, we advocate for shared responsibility among all partners involved in GHR for the creation and use of knowledge. As such, authentic partnering involves shared responsibility by all GHR partners in the creation and use of knowledge.

### Putting the principle of authentic partnering into action might involve:

- Researchers, teachers, administrators, or funders using the CCGHR Partnership Assessment Tool<sup>7</sup> as a backbone for establishing new or assessing existing research partnerships
- Examining the applicability of the TCPS2 Chapter 9 principles to a GHR partnership and looking for ways to incorporate similar governance models
- Creating ongoing global health partnerships for clinical education, service and research, aiming to extend beyond a single healthcare mission, and to use research as a tool to foster capacity building and partnership

### Inclusion

How do our research practices proactively promote the involvement and participation of people who are historically marginalized (e.g., because of their race, class, sex, ability, religion, sexual identity, Indigeneity, etc.)?



Informed by our understandings of solidarity, commitment to inclusion invites those involved in GHR to promote equity by proactively and intentionally providing opportunities for diverse people to be engaged in research processes.

The principle of inclusion also challenges those involved in GHR to seek diverse perspectives in the definition of research questions, formation of research teams, or creation of research initiatives. When GHR focuses on global health issues primarily situated in low and middle income countries, Canadian researchers should make every effort to challenge academic or funding structures that could restrict genuine participation. Honouring this principle involves actively exploring ways to create opportunities for other voices, particularly for stakeholders who might not be immediately identified.

### Inclusion, in practice, could be demonstrated by:

- Working collaboratively with community partners to identify diverse stakeholder groups and then opening possibilities for their involvement in research processes (i.e., forming the research questions, developing funding proposals, determining data collection fields, writing the scientific manuscript)
- In the spirit of integrated knowledge translation, researchers collaborating with a community-based organization to jointly develop research questions
- Research teams promoting equity and inclusion in hiring practices, seeking to include those who are historically marginalized as members of the research team

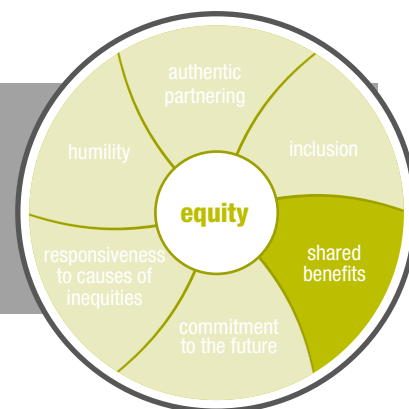
7 Murphy, J., Hatfield, J., Afsana, K., & Neufeld, V. (2014). Making a commitment to ethics in global health research partnerships: A practical tool to support ethical practice. *Bioethical Inquiry* (10 p.) doi:10.1007/s11673-014-9604-6



- Using activities to support the use of an anti-oppression lens in the exploration of research problems (e.g., popular education techniques inspired by the work of Paulo Freire<sup>8</sup>)

## Shared Benefits

How is each partner benefiting from this research?  
How are benefits distributed amongst those involved?



The principle of shared benefits is about collectively striving to share emerging benefits, knowledge, evidence, and innovations in equitable, openly accessible ways. It invites us to find ways to prioritize equity amongst all those involved in research in the distribution of benefits. This extends to all players in research, including trainees and research participants.

Ensuring shared benefits is not exclusive to GHR, but critical in particular to research that involves partnerships across sectors or countries where there are differences in power or culture. It demands a deep attentiveness to process across all research paradigms, spanning from clinical trials to community-based participatory action research. Further, it requires explicit efforts to identify and honour the needs of all partners involved in GHR with an intention to ensure those with the greatest need benefit the most from research activities and outcomes.

This principle speaks also to the ways in which we manage and use data. The creation of data repositories that can expand our collective capacity to understand global health issues or interventions is a strategy for equity that Canadian institutions are already in positions to support<sup>9</sup>. Academic forums can systematically exclude the participation of many through prohibitive language or cost requirements. This principle guides those involved in GHR to foster scholarly exchange that challenges the privileging of ‘high-income country’-situated researchers in favour of more equitable, accessible vehicles for knowledge exchange.

## Encouraging the principle of shared benefits in practice could include:

- Adopting integrated approaches to planning and doing knowledge translation
- Using the CCGHR Partnership Assessment Tool<sup>10</sup> as a discussion and planning guide for data management and knowledge translation
- Looking to the OCAP (ownership, control, access, possession) Principles<sup>11</sup> as a promising practice for research relationships, data, and outcomes

8 For resources and discussion on Freire’s philosophies and approaches, visit <http://www.freire.org/paulo-freire/concepts-used-by-paulo-freire>

9 See, for example the Open and Collaborative Science in Development Network background paper, Catalysing Open and Collaborative Science to Address Development Challenges, available at: [http://www.nasaonline.org/attachments/article/218/Open\\_Access\\_JFC.pdf](http://www.nasaonline.org/attachments/article/218/Open_Access_JFC.pdf)

10 Available online: <http://www.ccgrr.ca/resources/partnerships-and-networking/partnership-assessment-tool/>

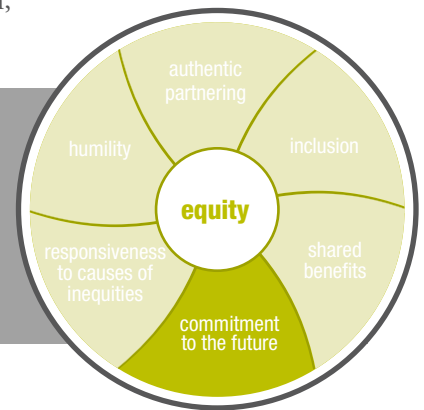
11 See the First Nations Information Governance Centre for more: <http://fnigc.ca/ocap.html>

- Considering how to adapt and apply principles from participatory research into GHR processes<sup>12</sup>
- Making all raw data, data analysis, and data interpretation available to each research partner. This includes potentially supplying the software necessary to open and operate research files.
- Sharing the final research outputs equitably among research partners including authorship on published manuscripts and reports, funding to attend and present at scientific conferences, and invitations to disseminate research results with key stakeholders (i.e., working groups, meetings, invited presentations)
- Exploring equity issues in post-study access to products of research, including drugs and services

### Commitment to the Future

How are contexts of global connectivity considered in this research?

How does this research contribute to a more equitable future?



The rapid increase in global connectedness over the last century has vastly changed the nature of our world. Global health research is future-oriented because it aims to contribute to improving equity in the short and long term and across generations. Our commitment to the future is about honouring our global citizenship and investing in a better, more equitable world where human rights, including the right to health, are protected and promoted.

This principle also relates to the concept of sustainability. This concept has become fundamental to the ways in which we talk about addressing inequities and improving the lives of people around the globe, especially the poorest, and has been integral in formulating the sustainable development goals<sup>13</sup> which will guide the future development agenda. Understanding our role in shaping possible futures, and acknowledging the fragility of the global ecosystems that we are all part of, we encourage collaboration across sectors and disciplines for GHR that prioritizes issues of sustainability and the needs of future generations.

Further, we recognize that the greatest potential to contribute to equity will come from commitments to long-term visions for GHR. Those involved in GHR for equity need to think about how to leverage short-term or immediate opportunities within a long-term vision. This principle calls upon those involved in GHR to challenge the tendency to cycle through project-driven agendas to foster linkages as part of long-term, authentic partnerships that are aimed at improving health equity.

### Putting our commitment to the future into action might be done through:

- Looking to environmental sustainability movements as possible research partners

12 See, for example Cochran, P. A. L., Marshall, C. A., Garcia-Downing, C., Kendall, E., Cook, D., McCubbin, L., & Gover, R. M. S. (2008). Indigenous ways of knowing: Implications for participatory research and community. *American Journal of Public Health*, 98(1), 22–27. doi:10.2105/AJPH.2006.093641

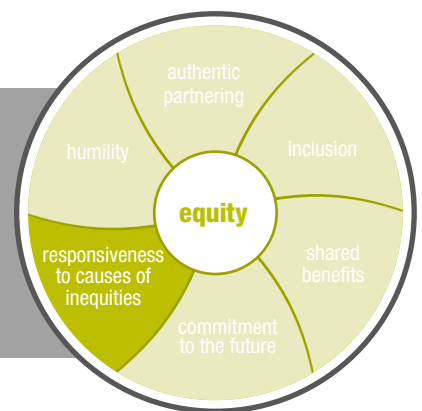
13 United Nations (2015). *Transforming our World: The 2030 Development Agenda*. Available at: [http://www.un.org/ga/search/view\\_doc.asp?symbol=A/70/L.1&Lang=E](http://www.un.org/ga/search/view_doc.asp?symbol=A/70/L.1&Lang=E)

- Framing research questions around inherently global health issues<sup>14</sup>
- Considering human rights in GHR questions or contextual analyses
- Thinking about our contributions in GHR as part of a greater whole, aiming to collaborate and mentor in every research endeavour
- Mentoring new global health researchers through involvement in existing research partnerships and projects
- Exploring post-trial access issues as part of research proposals and ethical reviews of clinical research
- Learning from the ‘seven generations principle’, which informs approaches to environmental management among many Canadian First Nations, is usually sourced to the Great Law of the Iroquois Confederacy (Haudenosaunee)<sup>15</sup>. This Law holds decisions made today should be evaluated with respect to their implications as far as seven generations (~240 years) into the future.

### Responsiveness to Causes of Inequity

What are the causes (and the roots of these causes) of inequities related to the research issue?

What are the implications for responding to these causes?



Global health inequities are vast, persistent, and recognized for their causal links to social determinants of health<sup>16</sup>. These links are complex, intersecting, and often avoidable. People involved in GHR should be aware of the historical, social, cultural, political, economic, and environmental reasons for health inequities. They should strive to understand health inequities as inseparable from issues of power.

Acknowledging the *avoidable* nature of social and health inequities globally means acknowledging that humans have created (and continue to perpetuate) structures, processes and policies that lead to inequities, but that we also have the ability to reverse or change these inequities. Being aware and sensitive to the causes of inequity informs the ways in which we conceptualize and justify a research problem, how we frame research questions, what methods we adopt, and what kinds of partnerships we seek to build. To assist with this process, those involved in GHR can benefit from exploring (e.g., through reading,

14 See, for example: Labonte, R., & Spiegel, J. (2003). Setting global health research priorities. Burden of disease and inherently global health issues should both be considered. *BMJ: British Medical Journal*, 326(7392), 722.

15 See the Haudenosaunee Confederacy website for more information (<http://www.haudenosauneeconfederacy.com/values.html>)

16 See, for example: WHO Commission on Social Determinants of Health. (2008). Closing the Gap in a Generation: Health Equity Through Action on the Social Determinants of Health: Commission on Social Determinants of Health Final Report. World Health Organization (Ed.). World Health Organization. Labonte, R. & Shrecker, T. (2011). The state of global health in a radically unequal world: Patterns and prospects. In S. Benatar & G. Brock (Eds.). *Global Health & Global Health Ethics*, (pp. 24-36). New York: Cambridge University Press.

seminars, or course work) the ideas that underpin a broad body of critical philosophy and scholarship that examines the conceptual and theoretical bases of knowledge, challenging status quos<sup>17</sup>.

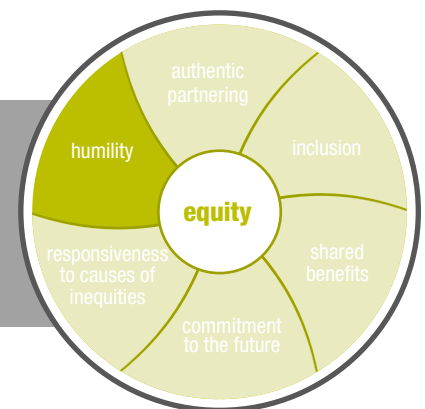
Informed by the global health ethics principle of solidarity, responding to the causes of inequities invites those involved in GHR to explore their role as allies collaborating toward greater global health equity worldwide. Solidarity guides the consideration of our mutual entanglement in the structures and processes that contribute to avoidable inequities<sup>18</sup>.

**In practice, the principle of responsiveness to causes of inequity could include:**

- Using GHR, or elements of GHR, to highlight and seek ways to mitigate inequities
- Making a regular effort to explore and describe the influence of existing inequities in our actions, policies, processes, and knowledge dissemination activities (e.g., privilege afforded to English-language publications; accessibility of scholarly events)
- Using tools to help assess inequities in research relationships and contexts (e.g., Global Health Equity Gauge [www.gega.org.za](http://www.gega.org.za))
- Staying informed about emerging equity-focused reports (e.g., Global Health Watch) and movements, such as the People's Health Movement
- Incorporating critical teaching strategies into coursework for undergraduate and graduate students<sup>19</sup>

## Humility

Who am I (are we) in this research context?  
How am I positioning myself (ourselves) in this research?



The principle of humility is about positioning ourselves in a place of learning rather than knowing<sup>20</sup>. It is about opening ourselves to exploring how our personal values, beliefs, motivations, and assumptions influence what we see or don't see in any given context. Humility also involves recognizing our own limitations. Individuals involved in GHR can challenge both themselves and others to do so through an active practice of reflection.

Striving for continual expansion in self-awareness, active reflection should focus on how our individual and collective values, beliefs, motivations, and assumptions manifest in what we do, how we do it, and with whom (and how) we partner. It should be open, honest, and frank. It should illuminate status quos so that assumptions can be questioned—from the ways in which a research problem is identified and framed to the ways in which research is used to respond to that problem. This invites taking risks to

17 See, for example, the Centre for Critical Qualitative Research at the University of Toronto ([www.ccgqr.utoronto.ca](http://www.ccgqr.utoronto.ca)) Kincheloe, J. L., McLaren, P., & Steinberg, S. R. (2011). Critical pedagogy and qualitative research: Moving to the bricolage. In N. Denzin & Y. Lincoln (Eds.) *The SAGE Handbook of Qualitative Methods in Health Research* (4<sup>th</sup> ed.), (pp. 163-178). [Insert place of publication and publisher].

18 See, for example: Benatar & Singer; Benatar & Brock (as cited above).

19 See, for example: Hanson, L., Harms, S., & Plamondon, K. (2011). Undergraduate international medical electives: Some ethical and pedagogical considerations. *Journal of Studies in International Education*, 15(2), 171-185. doi:10.1177/1028315310365542

20 Pinto, A. D., & Upshur, R. E. G. (2009). Global health ethics for students. *Developing World Bioethics*, 9(1), 1-10.

explore difficult questions about power and privilege, particularly in our response to global health issues and the layers of context that inform why, what, and how we do GHR.

By understanding the relationship of our values, beliefs, assumptions and motivations with our actions, we can more honestly and strategically examine how equity is being framed in both qualitative and quantitative research.

**Practicing the principle of humility might look like:**

- Holding graduate student seminars to ‘unpack’ the values, beliefs, motivations, and assumptions underlying each student’s proposed research
- Encouraging research ethics boards, university administrators, and funding agencies to ask researchers to describe how their values, beliefs, motivations, and assumptions influence their proposed research and address how this will be managed in the research process
- Creating time for reflection and dialogue through student-supervisor, student-teacher, peer-peer interactions<sup>21</sup>

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21 See, for example: Cole, D. C., Hanson, L., Rouleau, K. D., Pottie, K., & Arya, N. (2013). Teaching global health ethics. In A. Pinto & R. Upshur (Eds.). *An Introduction to Global Health Ethics*, (p. 148-158). New York: Routledge.

## Next Steps: CCGHR Commitment to Continued Dialogue

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The CCGHR is committed to fostering dialogue about GHR and the principles described here. We will revisit these principles periodically (e.g., every five years) to open pathways for adjusting the principles in response to evolving contexts. We will continue to engage Canadians involved in GHR in open, constructive conversations about why we do GHR, what to focus on and how we do GHR.

### By promoting these guiding principles, the CCGHR strives to:

1. **Encourage dialogue** about the benefits, challenges, and possibilities of responding to health inequities through GHR.
2. **Challenge those involved in GHR** to build capacity to address imbalances in power and equity in the contexts they work in.
3. **Support people involved in GHR** in a way that promotes ethical and equitable actions and decisions.

For more information or to contact the CCGHR, visit us online at [www.ccgghr.ca](http://www.ccgghr.ca). We will post regular content and invite discussion through this site.

### Additional Resources

To access materials and reports for the CCGHR Gathering Perspectives Studies, visit our main website ([www.ccgghr.ca](http://www.ccgghr.ca)).

To learn more about the CCGHR, visit our 'About Us' page ([www.ccgghr.ca/about/](http://www.ccgghr.ca/about/)).

You can also follow us on Twitter (@CCGHR) or Facebook.

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