RESEARCH FOR HEALTH JUSTICE -

Ethical guidance for linking grants programs and research projects to health equity and social justice

Guidance for *funders* when designing grants programs for global health research*

*Global health research is defined as research focused on health problems typically (but not exclusively) experienced in low and middle-income countries. It encompasses research with groups considered marginalised or vulnerable in high-income countries as well as research in low and middle-income countries.

As a matter of health and social justice, global health research should generate new knowledge to improve the health and well-being of those considered disadvantaged or marginalised, foster their participation in decision-making about its conduct, and build research capacity in low and middle-income countries (LMICs). It should contribute to reducing health disparities between and within countries.

Yet simply undertaking global health research will not necessarily generate the knowledge needed to help improve health care and systems for those considered disadvantaged or marginalised. Global health research grants programs and projects must be structured in a particular way to generate that type of information. But how exactly should they be designed to do that?

The aim of this ethical framework is to guide funders in their design of grants programs so that they are better structured to incentivize global health research that promotes global health equity. The **Research for Health Justice framework** provides funders with guidance on what features of grant programs (selection criteria, requirements, budget support) to include in relation to:

- Research populations
- Research topics and questions
- Research capacity development
- Ancillary care
- Knowledge translation

It provides a structure for individual reflection, collaborative team discussions, and decision-making by those responsible for designing grants programs for global health research. The central questions to ask when reading through the framework's guidance individually or collectively are: how well does the grant program we're developing align with the framework's guidance and, if there are areas of weakness, is it possible to strengthen their alignment?

Framework Domain	Guidance	How to Uphold the Guidance: Corresponding Feature of grant Program Design	Examples from Existing Grants Programs
Research population	Target health research to badly-off countries and populations within them	 1a. Restrict host countries to those badly-off in health terms OR b. Restrict host countries to these badly-off in terms of multidimensional poverty 2. Require or prioritise research performed with or focused upon those considered disadvantaged, marginalised, and/or vulnerable within countries, e.g. populations or communities exhibiting worse health status or multidimensional poverty status relative to the national average 	 1a. Focal countries of grant program are countries where the under-five mortality rate is above 80 per 1000 live births and/or where the maternal mortality rate is above 300 per 100,000 births. 1b. Focal countries of grant program are largely low-income, including fragile and post-conflict states. 2. Grantmaking principle: Priority will be given to research that benefits the most vulnerable populations.
Research topics and questions (process)	Promote LMIC ownership of the research agenda	 1a. Restrict applicants to LMIC institutions/researchers OR 1b. Require and support LMIC researchers to lead priority-setting AND/OR 1c. Require and support demonstrated shared decisionmaking between LMIC researchers and high-income country (HIC) researchers in priority-setting 2. Require and support community members¹ to share priority-setting decision-making or, at a minimum, be consulted as part of priority-setting 3. Require and support those considered disadvantaged or marginalised within host countries to share priority-setting decision-making or, at a minimum, be consulted as part of priority-setting 	 1a. Require lead applicants be from LMIC institutions only 1b. Require that if the principal investigator is based in a HIC, there must be clear scientific leadership from LMIC co-investigators. Assess in the grant application by asking applicants to describe the leadership role of LMIC co-investigators. 1c. Require applicants to submit an expression of interest and, for a proportion of those expressions of interest, fund all partners to come together to develop the full proposal. Assess in the full grant application by asking applicants to describe how principal and LMIC co-investigators shared decision-making in research priority-setting and research design. 2. Support planning grants or phases for researchers to engage with LMIC community members in order to develop grant applications or to inform funded projects' design. 3. Grantmaking principle: Consulting and engaging others, particularly marginalised groups.

Research for Health Justice Guidance for Designing Grants

¹Community membership can be based on geography; on shared interests or goals; or on shared characteristics, situations or experiences, including experiences of marginalisation. Communities encompass (amongst others) community leaders and elders, non-aligned community members (the general public), and people who are part of the health system in the given community: namely, patients, health care providers, health care managers, insurers, policymakers, and others.

Framework Domain	Guidance	How to uphold the guidance: Corresponding feature of grant program design	Examples from existing grants programs
Research topics and questions (outputs)	Focus research on improving equitable health care and systems	Require research to generate new knowledge to improve access to high-quality health care, health services, and/or financial protection for those considered disadvantaged or marginalised within countries	Grantmaking principle that calls for research to address the root causes of unequal access to primary health services.
Research capacity development	Develop independent LMIC research capacity at individual, teams, institutional, and systems levels	Require and support applicants to help create a critical mass of LMIC researchers, teams, and research institutions, with networks connecting them, that that can obtain funding and perform research on their own	 Require applicants to have capacity building strategies and have selection criteria assessing their quality, including having realistic and achievable plans for building independent LMIC capacity at individual and institutional levels, e.g.: Postgraduate education Learning by doing Devolving responsibility Building grants management and technical capacity Building postgraduate education programs in health research
Ancillary care	Deliver ancillary care to study participants	 Require and support the identification of ethically essential ancillary care and support its provision by study investigators. Ethically essential ancillary care meets the following five criteria: Health conditions are a major contributor to the research population or host community's gap in health status from the optimal level of health achieved worldwide. There is an absence of others able to meet the health needs, including public or private health facilities run by the local government, local NGOs, or international NGOs. Researchers, or study staff, possess the expertise and technical capacity to meet the health needs safely. Available interventions for the health conditions are cost-effective and appropriate for use in the host community (e.g. don't violate any cultural or religious norms). Expenditure of funds, time, and expertise on the provision of ancillary care is not so great as to unduly burden the conduct of the study. 	Budget permits support for systems that enable researchers to identify ancillary care needs (e.g. epidemiological surveys, clinic data collection systems, or gathering information from local clinic staff) and for providing ethically essential ancillary care.

Framework Domain	Guidance	How to uphold the guidance: Corresponding feature of grant program design	Examples from existing grants programs
Knowledge translation	Have a lasting impact on health disparities	 Require applicants to have research translation objectives and strategies that promote changes in policy and practice to benefit those considered disadvantaged or marginalised within host countries. Offer budgetary support to implement those strategies. Require applicants to promote intervention sustainability as part of research translation (where applicable). Offer budgetary support to implement sustainability strategies. 	 Grantmaking principle: Informing and influencing policy, practice, and agendas to strengthen equitable health systems; Require 10% of project budget be designated for knowledge translation. Grantmaking principle: Making lasting change.

ACKNOWLEDGEMENTS

The author would like to thank all collaborators (Bebe Loff, Deborah Zion, Phaik Yeong Cheah, Khin Maung Lwin, Francois Nosten, Adnan Hyder, Prashanth N Srinivas, Tanya Seshadri, Cathy Vaughan, Jesusa Marco, Jantina de Vries, Joyce Brown, Kerstin Klipstein-Grobusch, and Rieke van der Graaf), research assistants (Natalia Evertsz, Nityasri S N, Jessica Snir, Michelle Walters, Mona Pindog, Katharine Allen), and participants in the interviews and case studies performed as part of developing The Research for Health Justice framework.

The development of the framework was supported by an Australian National Health and Medical Research Council (NHMRC) Early Career Sidney Sax Public Health Overseas Fellowship (Award No. 1052346) and an Australian Research Council (ARC) Discovery Early Career Researcher Award (Award No. DE170100414). It was also supported by Future Health Systems, which was funded by the U.K. Department for International Development, and by an Australian Postgraduate Award scholarship (2009–2012) from the Australian Federal Government and Monash University.