GFREI [Global Forum for Research Ethics & Integrity]

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Public Comment by Members of the Global Forum for Research Ethics and Integrity [GFREI]

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NIH Request for Information on DRAFT
Promoting Equity in Global Health Research

Notice Number: NOT-TW-22-001

This public consultation submission was developed by members of – an open, global, collaborative forum of individuals from 30+ countries focused on research ethics and research integrity. Secretariat support for GFREI is provided by the GE2P2 Global Foundation. Submission contact David R. Curry, MS, President, GE2P2 Global Foundation david.r.curry@ge2p2global.org

GFREI Working Group – NIH RFI :: Promoting Equity in Global Health Research

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Overview

The GFREI Working Group [WG] engaged a rapid response to this RFI given the relatively short timeline for submission.

Initially, WG member inputs were invited against the eight questions provided in the NIH RFI. In aggregating these responses, it became clear that the RFI questions were duplicative to some extent and we decided to explore a more ambitious approach.

Overall, the WG identified the following ten "elements of equity in global health research":

Elements of Equity in Global Health Research

- Global Health Research Agenda – Inclusive/Relevant/Transparent
- Global Benchmarking
- Ethical Resilience
- Access to/Realization of Opportunity - Research Funding/Resources
- Access to/Realization of Opportunity - Research Leadership
- Access to/Realization of Opportunity - Parity/Equality in Roles/Responsibilities/Rewards
  Access to/Realization of Opportunity - Capacity Building
- Research Life Cycle - Operational Transparency/Accountability/Integrity
- Risk/Benefits Sharing/IP
- Evidence Integrity/Data Quality/Data Sharing

Melding the eight RFI questions, we proceeded to populate a data structure as below:

Element X.0:

- *Summary*
- *Practice Realization [How would it look?]*
- *Current Ownership/Power Structures*
- *Barriers*
- *Positive Case Examples*
- *Current Guidance/Norms/Statements/Commitments*
- *Selected Supporting Literature/Analysis*

In the case of some elements, not all the information categories are equally "mature" and articulated, and we identify this in the text. GFREI WG plans to continue to explore all these elements to bring them into full resolution.

The Working Group would like to stress the importance of the existing journal literature and other selected analysis in grounding our response. NIH reviewers of this submission will note that a selected bibliography is included for each element. We will continue to monitor the literature and extend our review to journal titles in other languages where relevant articles may be found.

We advise that this work has now emerged as a central theme in the programme of work in GFREI. We anticipate building out a web resource which will evolve and be updated as our analysis, experience and the literature further informs thinking about this critical issue.

Quick Document Navigation – Links to Element Discussion

Elements of Equity in Global Health Research

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1.0 Global Health Research Agenda

Summary

We assess that "equitable global health research" might most expeditiously be realized through an evidence-driven, inclusive, and transparently-developed post-pandemic phase COVID global research agenda that integrates equity and integrity at its core.

Such an agenda would require global governance alignment and common political will across the ecology of research stakeholders, as suggested below. Each of the stakeholder communities represented are certainly multi-dimensional, with diverse expression at country and regional levels, and diverse views as to what that global health research agenda might look like, or what equity might mean and be measured against in any given context and globally.

[Used with permission, David R. Curry, GE2P2 Global Foundation, 2022]

We are not aware of analysis that has taken stock of the current "health" of this ecology. Indeed, we assess that there would be much work required to gain meaningful alignment across this stakeholder ecology, even if mechanism to identify and evolve global research priorities might be developed.

Further, the processes by which an evidence-driven, inclusive process for setting a post-COVID global research agenda are not well-defined. While there have been various attempts as such agenda setting in specific sectors, there is no precedent that would adequately serve as a template. Indeed, it is not even clear whether there is a convenor of these stakeholders which could credibly move the effort forward.

Practice Realization [How would it look?]

Realized in practice, equity in global health research would be so well integrated into the larger context of an evolving global health research agenda that the associated equity indicators and metrics would be a driver of the agenda, not a strategic issue impeding that agenda.

Current Ownership/Power Structures

Funders of global health research – country government agencies/ministries, multilateral agencies, academic research institutions, foundations and other private donors, and commercial entities – form the core power structure here. While various coalitions of funders have been formed to focus on a particular research issue – notably around COVID, for example – it is less clear whether viable models aligning parts of this power base have been entirely effective. Nominally, we would expect that WHO would exercise its remit to convene and galvanize a global health research agenda for the strategic period ahead, or perhaps that a group of UN agencies might have leveraged the SDGs and their underlying research requirement to forge such an agenda, bringing the funding community into alignment. We do not assess that this has been accomplished.

Barriers

We assess the principal barriers to framing and aligning around a comprehensive, coherent and adequately-resourced global health research agenda are weak global health governance structures and the lack of political will to address that weakness. Achieving equity in global health research is impeded in turn.

Positive Case Examples

Of course, the WHO R&D Blueprint *["..a global strategy and preparedness plan that allows the rapid activation of R&D activities during epidemics… aim is to fast-track the availability of effective tests, vaccines and medicines… on the basis of a list of identified priority diseases]* might be cited for the infectious disease space, but it does not seem sufficiently broad or effective enough.

The **SDGs/2030** – perhaps the broadest effort in a few generations to establish global goals and metrics across a very broad range of goals [most either directly or indirectly invoking global health] – has been largely compromised by COVID with progress reversed for many indicators, and open questions are now being engaged about the ways and means to get them "back on track" for 2030. The latest Sustainable Development Goals Report 2021 underscores the quality of the challenge.

Current Guidance/Norms/Statements/Commitments

We have not encountered guidance/norms which define the preferred mechanisms to establish, evolve, implement and stewardship such global agendas – for global health research or, indeed, for any other area of global challenge

Selected Supporting Literature/Analysis

The COVID-19 pandemic underscores the need for an equity-focused global health agenda
N. Jensen, A.H. Kelly M. Avendano
Commentary
Humanities and Social Sciences Communications, 8, Article number 15, 2021
Abstract
Over the past few months, COVID-19 has ravaged health systems and economies in countries across the world. While many would argue that a pandemic of respiratory disease was predictable, the systematic failures of the response came as a surprise. From the shortage of hospital beds and medical equipment to the gross insufficiencies in national surveillance systems, supply chains and laboratory capacity, COVID-19 has laid bare the health care limitations that 'global north' and 'global south' share. A stark set of differences, however, run across the parallels in our collective predicament: indeed, what has become ever-more apparent is the radically uneven distribution of the health, social and economic risks

associated with the pandemic—and the public health measures implemented in response—both within and between societies. As concerns grow over a prolonged period of COVID-19 waves, further insights are needed into who bears the largest share of COVID-19 burden and why. The pursuit of health equity is widely held to be global health's raison d'être; and yet, the deep inequities laid bare by the current pandemic underscore that the field must do more and we must do better. This article identifies five key domains for equity research and action going forward. These 'equity frontiers' are not meant to be exhaustive. Rather our emphasis here is on drawing lessons from the COVID-19 pandemic as a prompt for a revived—if not rethought—equity agenda for an evolving global health field.

A health systems resilience research agenda: moving from concept to practice

Saulnier DD, Blanchet K, Canila C, et al. A

BMJ Global Health, 2021

Abstract

Health system resilience, known as the ability for health systems to absorb, adapt or transform to maintain essential functions when stressed or shocked, has quickly gained popularity following shocks like COVID-19. The concept is relatively new in health policy and systems research and the existing research remains mostly theoretical. Research to date has viewed resilience as an outcome that can be measured through performance outcomes, as an ability of complex adaptive systems that is derived from dynamic behaviour and interactions, or as both. However, there is little congruence on the theory and the existing frameworks have not been widely used, which as diluted the research applications for health system resilience. A global group of health system researchers were convened in March 2021 to discuss and identify priorities for health system resilience research and implementation based on lessons from COVID-19 and other health emergencies. Five research priority areas were identified: (1) measuring and managing systems dynamic performance, (2) the linkages between societal resilience and health system resilience, (3) the effect of governance on the capacity for resilience, (4) creating legitimacy and (5) the influence of the private sector on health system resilience. A key to filling these research gaps will be longitudinal and comparative case studies that use cocreation and coproduction approaches that go beyond researchers to include policy-makers, practitioners and the public.

What is Global Health Equity? A Proposed Definition

Ella August, Lia Tadesse et al.

Annals of Global Health, 88(1), p.50, 2022

Abstract

The term "global health equity" has become more visible in recent years, yet we were unable to find a formal definition of the term. Our Viewpoint addresses this gap by offering a discussion of this need and proposing a definition. We define global health equity as mutually beneficial and power-balanced partnerships and processes leading to equitable human and environmental health outcomes (which we refer to as "products") on a global scale. Equitable partnerships actively work against racism and supremacy. Such partnerships foster processes with these same dynamics; for example, sharing lead authorship responsibilities with meaningful roles for host country researchers to frame relevant questions and to provide context and interpretation for the research findings. Equitable products, such as access to technology and tailored delivery of interventions effective in the specific context, are the fruits of these partnerships and processes.

When People Come First: Critical Studies in Global Health

João Biehl and Adriana Petryna

Princeton University Press, IBSN: 9781400846801

Abstract

When People Come First critically assesses the expanding field of global health. It brings together an international and interdisciplinary group of scholars to address the medical, social, political, and economic dimensions of the global health enterprise through vivid case studies and bold conceptual work. The book demonstrates the crucial role of ethnography as an empirical lantern in global health, arguing for a more comprehensive, people-centered approach.
Topics include the limits of technological quick fixes in disease control, the moral economy of global health science, the unexpected effects of massive treatment rollouts in resource-poor contexts, and how right-to-health activism coalesces with the increased influence of the pharmaceutical industry on health care. The contributors explore the altered landscapes left behind after programs scale up, break down, or move on. We learn that disease is really never just one thing, technology delivery does not equate with care, and biology and technology interact in ways we cannot always predict. The most effective solutions may well be found in people themselves, who consistently exceed the projections of experts and the medical-scientific, political, and humanitarian frameworks in which they are cast.
When People Come First sets a new research agenda in global health and social theory and challenges us to rethink the relationships between care, rights, health, and economic futures.

Interrogating the World Bank's role in global health knowledge production, governance, and finance
M Tichenor, et al
Review
Globalization and Health, Volume 17, Article number: 110 (2021)
Abstract
Background
In the nearly half century since it began lending for population projects, the World Bank has become one of the largest financiers of global health projects and programs, a powerful voice in shaping health agendas in global governance spaces, and a mass producer of evidentiary knowledge for its preferred global health interventions. How can social scientists interrogate the role of the World Bank in shaping 'global health' in the current era?
Main body
As a group of historians, social scientists, and public health officials with experience studying the effects of the institution's investment in health, we identify three challenges to this research. First, a future research agenda requires recognizing that the Bank is not a monolith, but rather has distinct inter-organizational groups that have shaped investment and discourse in complicated, and sometimes contradictory, ways. Second, we must consider how its influence on health policy and investment has changed significantly over time. Third, we must analyze its modes of engagement with other institutions within the global health landscape, and with the private sector. The unique relationships between Bank entities and countries that shape health policy, and the Bank's position as a center of research, permit it to have a formative influence on health economics as applied to international development. Addressing these challenges, we propose a future research agenda for the Bank's influence on global health through three overlapping objects of and domains for study: knowledge-based (shaping health policy knowledge), governance-based (shaping health governance), and finance-based (shaping health financing). We provide a review of case studies in each of these categories to inform this research agenda.
Conclusions
As the COVID-19 pandemic continues to rage, and as state and non-state actors work to build more inclusive and robust health systems around the world, it is more important than ever to consider how to best document and analyze the impacts of Bank's financial and technical investments in the Global South.

Reimagining Global Health Governance in the Age of COVID-19
Lawrence O. Gostin, Suerie Moon, et al.
Editorial
American Journal of Public Health, Vol. 110, no. 11 (November 1, 2020): pp. 1615-1619
Abstract

The COVID-19 pandemic reminds us that no country acting alone can respond effectively to health threats in a globalized world. Global governance is necessary to coordinate the global health response. Yet, the COVID-19 pandemic has revealed deep fissures in global health governance, with international organizations facing obstacles from nationalist governments in managing a common threat. The COVID-19 pandemic is reframing global health governance. Considering key structural limitations in meeting enormous challenges, how can we best realize global solidarity in an age of populist nationalism? With the sheer scale of human, social, and economic upheaval, we face an imperative to strengthen global health institutions and governance.

In this editorial, we reflect on the challenges that nationalism poses in the COVID-19 response, conceptualizing how we could reimagine global health governance. We begin by examining how international organizations have sought to bring nations together in responding to global health threats. However, international institutions are facing increasing pressures from nationalist governments, and we analyze these nationalist obstacles to global solidarity. The structural limitations of the pandemic response are reframing the global health governance landscape. Given this historic opportunity to reimagine global health governance in the age of COVID-19, we consider the rise of new institutional structures that reflect the realities of a divided world. We conclude that a new governance landscape will be crucial to strengthening global public health—rising out of crisis to secure a safer future.

'It's far too complicated': why fragmentation persists in global health
Neil Spiecer, Irene Agyeapong et al.
Open Research
Globalization and Health, Vol. 16, no. 16, 2020, https://doi.org/10.1186/s12992-020-00592-1
Abstract

Despite many efforts to achieve better coordination, fragmentation is an enduring feature of the global health landscape that undermines the effectiveness of health programmes and threatens the attainment of the health-related Sustainable Development Goals. In this paper we identify and describe the multiple causes of fragmentation in development assistant for health at the global level. The study is of particular relevance since the emergence of new global health problems such as COVID-19 heightens the need for global health actors to work in coordinated ways. Our study is part of the *Lancet Commission on Synergies between Universal Health Coverage, Health Security and Health Promotion.* We used a mixed methods approach. This consisted of a non-systematic literature review of published papers in scientific journals, reports, books and websites. We also carried out twenty semi-structured expert interviews with individuals from bilateral and multilateral organisations, governments and academic and research institutions between April 2019 and December 2019.We identified five distinct yet interconnected sets of factors causing fragmentation: proliferation of global health actors; problems of global leadership; divergent interests; problems of accountability; problems of power relations. We explain why global health actors struggle to harmonise their approaches and priorities, fail to align their work with low- and middle-income countries' needs and why they continue to embrace funding instruments that create fragmentation. Many global actors are genuinely committed to addressing the problems of fragmentation, despite their complexity and interconnected nature. This paper aims to raise awareness and understanding of the causes of fragmentation and to help guide actors' efforts in addressing the problems and moving to more synergistic approaches.

Global public health leadership: The vital element in managing global health crises

Goniewicz Krzystof, Burkle F. Manesh et al.

Scholarly Perspective

Journal of Global Health, Vol. 12, 2022, DOI:10.7189/jogh.12.03003

Abstract

The World Health Organization (WHO) and the International Health Regulations Treaty (IHRT) are responsible for modelling global public health crises, and management and mitigation of their consequences. However, both duties are delivered in all nations by their national public health systems. Therefore, the implementation of public health policies at the national level depends on the public trust of the national authorities. A trustful relationship is necessary for developing and maintaining the well-being of a community through various public health programs [1]. The principle aim of public health programs is to assess all risks, to identify underserved populations, and to initiate preventive measures, such as vaccines, non-pharmaceutical interventions (eg, social distancing, isolation) and vector control, through collaboration and coordination with other agencies and organizations, such as hospitals, schools [1]. These efforts require management authority, resources and financial support for public health and community research and sustainability of the changes they demand [1] (Figure 1). WHO declared early in the Covid-19 pandemic that "there's no going back to normal." This was a clear message that the existing public health infrastructure and response, seen as the "difference between life and death", was "inadequate for the impending crisis."

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2.0 Global Benchmarking: Frameworks/Tools

Summary

One indicator of the current state/relative maturity of the "equity in global health research" issue is whether we have salient indicators and metrics by which we can assess and measure it. Such indicators and metrics should be grounded by sufficient clarity and precision around "what it looks like in practice" and be informed by normative frameworks, etc., altogether providing useful and actionable benchmarks. We are not aware of an existing benchmarking tool for this area, or of any organized effort to establish such a tool. This NIH RFI could be a useful exercise triggering such action.

Practice Realization [How would it look?]

This element would likely adapt approaches and learnings from WHO Global Benchmarking Tools (GBT) already in use or in current development. It should also benefit from cross/trans-disciplinary contexts where health research is active, and equity in how it is conducted is challenged [see below]. We assess that development of a "Global Health Research Equity GBT" should be engaged to support broad assessment of equity in health research practice at global and country levels.

Current Ownership/Power Structures

WHO is the obvious anchoring multilateral agency for this area, with the GBT programs already well-established [1997 forward for regulatory assessment, and now with WHO GBT for ethics oversight of health-related research in draft. However, we assess that across the SDGs, health research is active and foundational to understanding progress against goals and the efficacy of interventions towards those goals. Much such research activity proceeds from within other disciplines and frames of reference. Equally, outside the SDGs proper, there are long traditions of sectors/disciplines which engage in health research in the larger context of their respective agendas, and funding new research with an emphasis on diverse, collaborative partnerships groups. We are not aware of a solid analysis of this larger context.

Barriers

We do not assess that there are specific, significant barriers to the evolution of existing benchmarking tools to potentially incorporate research equity indicators, although we suspect that such evolution would be slow at best. Barriers to framing a new, omnibus, global benchmarking tool around equity in global health research would include establishing clear ownership of the process, financial resources to launch and nurture it over time, and the political will to engage and implement it.

Positive Case Examples

One good example is the humanitarian sector where Research for Health in Humanitarian Crises [R2HC/ELRHA] has been instrumental in assessing the quality of existing evidence, setting norms for research practice, and funding new research with an emphasis on diverse, collaborative partnerships groups.

Current Guidance/Norms/Statements/Commitments

Guidance and normative frameworks around conducting health-related research are generally focused on issues of research integrity for the protection of the human subjects/populations that may be involved and should benefit, and rarely reference equity in the context of research funding, research team leadership/roles, publishing, capacity building and similar issues.

We note, for example, that the draft WHO Tool - benchmarking ethics oversight of health-related research [Dec 2021; full citation in bibliography below] does not employ the terms "equity" or "equitable" and does not, on our analysis, address how a national ethics committee might address these issues.

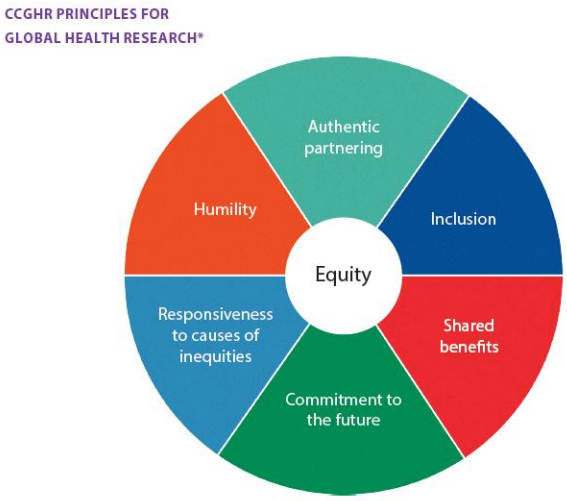
We note two examples of guidance/frameworks which do inform this element:

Framework for Action on Global Health Research – 2021-2026
Canadian Institutes of Health Research/Global Health 3.0
2021 :: 46 pages
PDF: https://cihr-irsc.gc.ca/e/documents/CIHR_framework_2021-en.pdf
Overview

In the spring of 2021, the Canadian Institutes for Health Research (CIHR) released its much-awaited Framework for Action on Global Health Research 2021-2026. This framework is the result of extensive consultation and engagement, including several in-person and virtual consultations hosted across Canada by the Coalition.

The framework recognizes that Canada's approach to global health research has evolved over the years, with the launch of the framework firmly positioning CIHR in a new era – what they are calling "Global Health 3.0". Among other things, this new chapter in Canadian global health research aims to empower Canadian researchers to strengthen coherence in research, promote evidence-informed decision making, & cultivate international collaborations to drive mutual benefits from global research and innovation.

Importantly, as part of this framework, CIHR has formally adopted the principles for global health research as a best practice in conducting global health research.
CIHR recognizes that the Principles provide an equity-centered framework and invite researchers to question their assumptions and roles in the global health research process. To foster a culture of excellence, CIHR formally adopts the Principles framework as a best practice in conducting global health research and will implement mechanisms to ensure that they are followed by researchers where relevant and appropriate.



KFPE Guide - 11 Principles & 7 Questions
KFPE's Guide for Transboundary Research Partnerships

Commission for Research Partnerships with Developing Countries (KFPE), Swiss Academy of Sciences

Based on an extensive consultation process, the KFPE has completely updated its "11 Principles for Research in Partnership" in 2012 and has integrated current trends and experience. In addition, we have also developed 7 fundamental questions that point to factors enabling or hindering research in partnership. The 7 questions are meant to help users to better understand and implement the 11 principles. They examine various aspects of research partnerships and also intend to stimulate reflection and debate.

Selected Supporting Literature/Analysis

Public consultation: WHO Tool - benchmarking ethics oversight of health-related research

2 December 2021

Call for consultation - Deadline for comments: 28 January 2022

Background

A core requirement of international guidelines on the ethics of health-related research with human participants is that an effective system of ethical oversight should exist at the institutional and national levels. WHO has been developing a Benchmarking Tool with the aim to support Member States in evaluating their existing capacity to provide appropriate ethical oversight of health-related research. Consisting of seven indicators and associated sub-indicators, the tool will help countries to identify strengths and limitations in their legal frameworks, organizational structures, policies, and practices of the bodies responsible for research ethics oversight. It is also intended to guide the development of recommendations to address the identified gaps and the assessment of countries' progress in implementing those recommendations.

Purpose of the public consultation

A WHO Expert Group has developed a draft version of the Benchmarking tool, for which WHO is now seeking feedback. The instructions for how to best provide your input can be found in these two documents:

- Draft document for consultation [pdf]
- Table to use for comments [word]

WHO Global Benchmarking Tool (GBT) for evaluation of national regulatory systems

The Global Benchmarking Tool (GBT) represents the primary means by which the World Health Organization (WHO) objectively evaluates regulatory systems, as mandated by WHA Resolution 67.20 on Regulatory System Strengthening for medical products. The tool and benchmarking methodology enables WHO and regulatory authorities to:

- identify strengths and areas for improvement;
- facilitate the formulation of an institutional development plan (IDP) to build upon strengths and address the identified gaps;
- prioritize IDP interventions; and
- monitor progress and achievements.

WHO began assessing regulatory systems in 1997 using a set of indicators designed to evaluate the regulatory programme for vaccines. Since that time, a number of tools and revisions were introduced. In 2014 work began on the development of a unified tool for evaluation of medicines and vaccines regulatory programmes following a mapping of existing tools in use within and external to WHO…

The GBT also incorporates the concept of 'maturity level' or ML (adapted from ISO 9004), allowing WHO and regulatory authorities to assess the overall 'maturity' of the regulatory system on a scale of 1

(existence of some elements of regulatory system) to 4 (operating at advanced level of performance and continuous improvement).

The GBT is designed to benchmark the regulatory programmes of a variety of product types, including medicines, vaccines, blood products (including whole blood, blood component and plasma derived products) and medical devices (including in vitro diagnostics). This is made possible by introducing supplemental criteria to a common set of criteria initially developed for medicines and vaccines in order to accommodate the specificities of blood products and medical devices e.g., hemovigilance for blood products; and risk-based classification/reclassification of medical devices.

A revised GBT user's manual has also been published to ensure consistency in the planning and conduct of benchmarking…The GBT is supported by a computerized platform to facilitate the benchmarking, including the calculation of maturity levels. The computerized GBT (cGBT) is available, upon request, to Member States and organizations working with WHO under the Coalition of Interested Partners (CIP).

The WHO Global Benchmarking Tool: a game changer for strengthening national regulatory capacity
Javier Guzman, Erin O'Connell, Kate Kikule, Tamara Hafner
Practice
BMJ Global Health, 2020; 5:e003181.
Summary box
- Effective regulation of medical products is critical for ensuring access to safe, effective and quality-assured medical products in a well-functioning health system.
- WHO's Global Benchmarking Tool (GBT) Revision VI is the first globally accepted tool for objectively assessing and strengthening regulatory capacity.
- The GBT provides countries with a systematic approach for strengthening their regulatory systems.
- The GBT fosters regulatory reliance and harmonisation, which increases timely access to quality-assured medical products and boosts pharmaceutical trade.

Abstract
Many low-income and middle-income countries lack the capacity to effectively and efficiently regulate medical products in their countries. To support countries in strengthening their capacity, WHO has developed the Global Benchmarking Tool (GBT) as the global standard for objectively assessing regulatory capacity for medicines and vaccines. The GBT is a game changer because it is the first globally accepted tool for assessing and strengthening national regulatory authorities. The inclusion of an institutional development plan in the GBT methodology provides context-specific actionable steps countries can take to advance their system's functionality and maturity. The GBT facilitates coordination and improves the effectiveness of regulatory strengthening efforts. The tool also facilitates regulatory reliance and harmonisation, which helps to improve timely access to quality-assured medicines, and creates incentives for trade, particularly in countries and regions with a strong pharmaceutical manufacturing base. The GBT is a necessary tool for creating strong and effective regulatory systems, which are critical for ensuring the efficacy, safety and quality assurance of medicines and populations' timely access to these medicines. In outlining the benefits of the GBT, this paper also offers some specific ideas for strengthening the GBT framework and process.

Global Health Security Index (GHS Index)
[Database]
The 2021 GHS Index measures the capacities of 195 countries to prepare for epidemics and pandemics. All countries remain dangerously unprepared for future epidemic and pandemic threats, including

threats potentially more devastating than COVID-19. Read the report's findings and recommendations, explore the data, view the country rankings, and learn more about the GHS Index.

The Equity Tool for Valuing Global Health Partnerships

Charles P. Larson, Katrina M. Plamondon, Leslie Dubent, Frank Bicaba, Abel Bicaba, Tran Hung Minh, An Nguyen, Jacques E. Girard, Jean Ramdé, Theresa W. Gyorkosb.

Original Article

Global Health: Science and Practice 2022; 10 (2).

https://www.ghspjournal.org/content/early/2022/04/18/GHSP-D-21-00316

Key Findings

- There is a need to more comprehensively advance equity in global health partnerships.
- The Equity Tool (EQT) offers a practical guide for considering equity in 4 domains of practice: governance and process, procedures and operations, progress and impacts, and power and inclusion.
- The EQT is equity focused, user friendly, and can support reflective dialogue at any stage of the partnership, by individuals at any level in the partnership.

Key Implications

- The EQT will spark questions that invite people to pause and think about their experiences within a partnership.
- By periodically engaging in relational, reflective dialogue about how equity is experienced in a global health partnership using the EQT, partners can embrace ways of recognizing, understanding, and advancing equity in all their processes.
- The EQT offers prompts for reflective dialogue about how equity or inequity is experienced in many different ways and moments throughout the process of partnering, which require attention to creating safe, learning-focused conversations with clear intentions and respect for the contributions and vulnerability of all involved.

Abstract

Global health partnerships (GHPs) involve complex relationships between individuals and organizations, often joining partners from high-income and low- or middle-income countries around work that is carried out in the latter. Therefore, GHPs are situated in the context of global inequities and their underlying sociopolitical and historical causes, such as colonization. Equity is a core principle that should guide GHPs from start to end. How equity is embedded and nurtured throughout a partnership has remained a constant challenge. We have developed a user-friendly tool for valuing a GHP throughout its lifespan using an equity lens. The development of the EQT was informed by 5 distinct elements: a scoping review of scientific published peer-reviewed literature; an online survey and follow-up telephone interviews; workshops in Canada, Burkina Faso, and Vietnam; a critical interpretive synthesis; and a content validation exercise. Findings suggest GHPs generate experiences of equity or inequity yet provide little guidance on how to identify and respond to these experiences. The EQT can guide people involved in partnering to consider the equity implications of all their actions, from inception, through implementation and completion of a partnership. When used to guide reflective dialogue with a clear intention to advance equity in and through partnering, this tool offers a new approach to valuing global health partnerships. Global health practitioners, among others, can apply the EQT in their partnerships to learning together about how to cultivate equity in their unique contexts within what is becoming an increasingly diverse, vibrant, and responsive global health community.

Towards equity in global health partnerships: adoption of the Research Fairness Initiative (RFI) by Portuguese-speaking countries

A Carvalho, C IJsselmuiden, K Kaiser, Z Hartz. et al.

Editorial
BMJ Global Health, 2018; 3:e000978.
Introduction/Excerpt
Research partnerships between high-income countries (HICs) and low- and medium-income countries (LMICs) often display a set of asymmetries that hinder the development of science, technology and health systems in the LMICs. In practice, this means that research partnerships, instead of addressing local priorities, often result in the appropriation of local data, the relegation of southern scientists to the category of 'field experts', the publication of research papers in high-impact journals without LMIC partners as coauthors and the tokenisation of LMIC partners and institutions to obtain competitive funding.1 2 There are numerous studies on power imbalances pertaining to research partnerships, often calling for general or specific interventions to improve them, but without apparent actual change in practice.3–5

Over the past 20 years, only two explicit guidelines have been developed to tackle these imbalances. The Canadian Coalition for Global Health Research (CCGHR) developed a set of recommendations, focused on six main principles, to promote ethical partnerships, including the use of innovative methodologies.6 The Commission for Research Partnerships with Developing Countries (KFPE)7 has also advocated the use of 11 principles which deal with a wide range of issues, from agenda setting to dissemination. The work of KFPE is 20 years old, but it is not well known outside Switzerland; moreover, it does not provide a practical framework to assess how these principles are implemented in research projects and actual collaborations.

Other agencies involved in the advocacy of ethical research partnerships include the United States Agency for International Development, the Dutch Ministry of Foreign Affairs, the International Development Research Centre (Canada) and the Norwegian Programme for Development, Research and Education (NUFU).8 The Sustainable Development Goal (SDG) 17 is focused on partnerships as means to achieve the other SDGs, recognising that joint research in health and other fields is essential.

Funders of research partnerships are struggling with equalising the balance between countries and institutions. The United Kingdom's Collective on Development Sciences (UKCDS) published a survey of research funder efforts to achieve more equitable research partnerships in 20179 while, in the same year, the UK's Independent Commission for Aid Impact (ICAI) published a report indicating substantial weaknesses in specifying, assessing and improving equity in research partnerships supported by the UK Grand Challenges Research Fund.10 …

Assessing how global health partnerships function: an equity-informed critical interpretive synthesis
KM Plamondon, et al.
Research
Globalization and Health, 17, Article number: 73 (2021)
Abstract
Background
Global health partnerships (GHPs) are situated in complex political and economic relationships and involve partners with different needs and interests (e.g., government agencies, non-governmental organizations, corporations, universities, professional associations, philanthropic organizations and communities). As part of a mixed methods study designed to develop an equity-sensitive tool to support more equity-centred North-South GHPs, this critical interpretive synthesis examined reported assessments of GHPs.
Results

We examined 30 peer-reviewed articles for power dynamics, equity and inequities, and contradictions or challenges encountered in North-South partnerships. Among articles reviewed, authors most often situated GHPs around a topical focus on research, capacity-building, clinical, or health services issues, with the 'work' of the partnership aiming to foster skills or respond to community needs.

The specific features of GHPs that were assessed varied widely, with consistently-reported elements including the early phases of partnering; governance issues; the day-to-day work of partnerships; the performance, impacts and benefits of GHPs; and issues of inclusion. Articles shared a general interest in partnering processes and often touched briefly on issues of equity; but they rarely accounted for the complexity of sociopolitical and historical contexts shaping issues of equity in GHPs. Further, assessments of GHPs were often reported without inclusion of voices from all partners or named beneficiaries.

GHPs were frequently portrayed as inherently beneficial for Southern partners, without attention to power dynamics and inequities (North-South, South-South). Though historical and political dynamics of the Global North and South were inconsistently examined as influential forces in GHPs, such dynamics were frequently portrayed as complex and characterized by asymmetries in power and resources. Generally, assessments of GHPs paid little attention to the macroeconomic forces in the power and resource dynamics of GHPs highlights the importance of considering the broader political. Our findings suggest that GHPs can serve to entrench both inequitable relationships and unfair distributions of power, resources, and wealth within and between countries (and partners) if inequitable power relationships are left unmitigated.

Conclusions

We argue that specific practices could enhance GHPs' contributions to equity, both in their processes and outcomes. Enhancing partnering practices to focus on inclusion, responsiveness to North-South and South-South inequities, and recognition of GHPs as situated in a broader (and inequitable) political economy. A relational and equity-centred approach to assessing GHPs would place social justice, humility and mutual benefits as central practices—that is, regular, routine things that partners involved in partnering do intentionally to make GHPs function well. Practicing equity in GHPs requires continuous efforts to explicitly acknowledge and examine the equity implications of all aspects of partnering.

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3.0 Access to/Realization of Opportunity - Research Funding/Resources

Summary

Meaningful opportunities to compete for and success in securing research funding is perhaps the single most relevant driver of progress in achieving equitable global health research. Winning such funding implies and requires critical competencies ranging from project conceptualization and grant writing, solid fiduciary capability/controls, research life cycle oversight, methodological/analytical competencies, reporting disciple and more. Equally there must be a commitment by and posture assumed by the singular or collaborative funding entity to engage the challenge of equity in all review, award, oversight, and M&E processes.

Practice Realization [How would it look?]

This element would involve establishing and sustaining funding resources adequate to implement a global research agenda as discussed above. Further, principal funders of global health research – including multilateral agencies, governments, academic institutions, foundations and private donors, and commercial entities – would need to align and assure that such financial resources are structured into effectively communicated and supported funding calls, RFPs and other solicitation mechanisms. Equally, proposal review, supporting grant applicant processes would demonstrate an inclusive, capacity building posture as funding awards are decided. At the grantee level, significant capacity building would be required across all the competencies above [e.g. fiduciary performance, methodological/analytical capability] to significantly improve the competitiveness of proposals and performance across the project life cycle.

Current Ownership/Power Structures

Obviously, the principal funders of global health research include multilateral agencies, governments, academic institutions, foundations and private donors, and commercial entities. While there are numerous examples of funding coalitions and various cooperative funding structure for specific research needs, it is not clear that we have meaningful analysis of "what works and why." Equally, regulatory guidance at country level is rare, likely deferential to major funding sources, and not harmonized. Recalibrating this power structure will not be easily accomplished.

Barriers

:: Lack of compelling incentives or regulatory requirements for funders to evolve their self-assessed best practices for funding and oversight, or to increase risk-tolerance and risk mitigation capability
:: Challenges to establishing/maintaining/auditing fiduciary capability to meet funder requirements/thresholds
:: Challenges to developing globally competitive research proposals in terms of strength of teams, focus of research effort

Positive Case Examples

:: Gates Foundation – evolution/commitments, et al.
:: COVID-19 Therapeutics Accelerator
:: Coalition for Epidemic Preparedness Innovations (CEPI)
:: COVID-19 Clinical Research Coalition

Current Guidance/Norms/Statements/Commitments

:: Unclear what examples may be available

Selected Supporting Literature/Analysis

Global Health Funders

Website: Inside Philanthropy

[Updated data base of approx 75 funders with brief descriptions of funding focus areas/priorities within the U.S.]

How to identify epistemic injustice in global health research funding practices: a decolonial guide

ESK Besson

BMJ Global Health, 2022

Abstract

Epistemic injustice is a growing area of study for researchers and practitioners working in the field of global health. Theoretical development and empirical research on epistemic injustice are crucial for providing more nuanced understandings of the mechanisms and structures leading to the exclusion of local and marginalised groups in research and other knowledge practices. Explicit analysis of the potential role of epistemic injustice in policies and practices is currently limited with the absence of methodological starting points. This paper aims to fill this gap in the literature by providing a guide for individuals involved in the design and review of funding schemes wishing to conduct epistemic injustice analysis of their processes using a decolonial lens. Placing contemporary concerns in a wider historical, political and social context and building from the intertwined issues of coloniality of power, coloniality of knowledge and coloniality of being that systematically exclude non-Western epistemic groups, this practice paper presents a three-step decolonial approach for understanding the role and impact of epistemic injustices in global health research funding. It starts with an understanding of how power operates in setting the aim of a call for research proposals. Then, the influence of pose and gaze in the review process is analysed to highlight the presence of epistemological colonisation before discussing methods to address the current funding asymmetries by supporting new ways of being and doing focused on knowledge plurality. Expanding research on how epistemic wrongs manifest in global health funding practices will generate key insights needed to address underlying drivers of inequities within global health project conception and delivery.

Accounting for mental health research funding: developing a quantitative baseline of global investments

E Woelbert, K Lundell-Smith, R White, D Kemmer

The Lancet Psychiatry, Volume 8, Issue 3, p. 250-258, March 2021

Abstract

High-quality data on funding for mental health research are essential to mapping funding levels, identifying gaps in the funding landscape, and tracking the impact of research funding. To date, quantitative analyses of research funding in mental health have been restricted in scope. In this Health Policy paper, we present a comprehensive analysis of grant funding for mental health research as a starting point for discussion among stakeholders globally. We drew on a major international research database and used existing definitions and automated classification tools for mental health research. Our analysis shows a flat and stable trend over the years 2015–19 and highly unequal geographical distribution of funding, and reveals patterns of funding across different conditions and across the research spectrum. Improvements in data availability and quality, in the definitions delineating mental health research from other areas, and in automated classification tools are needed to ensure funders

and policy makers can fully rely on the data and generate bespoke analyses as needed. We argue that collaborative reporting of funding for mental health research globally could help to inform and evaluate efforts to increase investments, to improve strategic dialogue, and to achieve the best possible allocation of finite resources.

Preparing for a pandemic: highlighting themes for research funding and practice—perspectives from the Global Research Collaboration for Infectious Disease Preparedness (GloPID-R)

A Norton, L. Sigfrid et al.

Commentary

BMC Medicine, 18, Article number 273, 2020

Abstract

Funders and researchers around the world are responding to the COVID-19 pandemic at urgent speed, with greater effectiveness and collaboration than ever before. In the past 8 months, the global health research community has collectively generated and shared a huge amount of knowledge in particular into the clinical characterisation, behavioural insights, genetics, epidemiology, viral pathogenesis, clinical management and diagnosis of COVID-19. This is built on substantial prior preparation, with researchers, public health professionals, funders and multilateral bodies in this field having anticipated and prepared for a pandemic for many years. Further knowledge is needed however to control this pandemic and for safe easing of public health measures.

The Global Research Collaboration for Infectious Disease Preparedness (GloPID-R) is an international network of global health funders and stakeholders formed in 2013 to ensure preparedness for a coordinated research response to epidemics and pandemics [1]. GloPID-R aims to address challenges to effective research in epidemics and pandemics, through both preparedness and response activities.

In December 2019, as part of its preparedness activities, GloPID-R convened a Frontiers meeting with their funded clinical trial networks and cohorts along with key stakeholders involved in emerging epidemic and pandemic preparedness and response globally. The aim was to identify how these groups might collaborate in delivering a coordinated research response in the event of an epidemic or pandemic. Now that we are in the midst of the COVID-19 pandemic, it is important to highlight and reflect on the recommendations identified by these participants, to inform the ongoing research funding and practice during the COVID-19 pandemic as well as preparedness for future outbreaks.

Funding global health product R&D: the Portfolio-To-Impact Model (P2I), a new tool for modelling the impact of different research portfolios

RF Terry, G Yamey, R Miyazaki-Krause…

Open Research, 2018 - ncbi.nlm.nih.gov

Abstract

The Portfolio-To-Impact (P2I) Model is a novel tool, developed to estimate minimum funding needs to accelerate health product development from late stage preclinical study to phase III clinical trials, and to visualize potential product launches over time.

Methods: A mixed methods approach was used. Assumptions on development costs at each phase were based on clinical trial costs from Parexel's R&D cost sourcebook. These were further refined and validated by interviews, with a wide variety of stakeholders from Product Development Partnerships, biopharmaceutical and diagnostic companies, and major funders of global health R&D. The tool was used to create scenarios describing the impact, in terms of products developed, of different product portfolios with funding ranging from $1 million per annum through to $500 million per annum. These scenarios for a new global financing mechanism have been previously presented in a report setting out the potential for a new fund for research and development which would assist in accelerating product development for the diseases of poverty. The P2I tool does enable a user to model different scenarios in

terms of cost and number of health products launched when applied to a portfolio of health products. The model is published as open access accompanied with a user guide. The design allows it to be adapted and used for other health R&D portfolio analysis as described in an accompanying publication focussing on the pipeline for neglected diseases in 2017. We aim to continually refine and improve the model and we ask users to provide us with their own inputs that can help us update key parameters and assumptions. We hope to catalyse users to adapt the model in ways that can increase its value, accuracy, and applications.

Strengthening health systems globally: a lingering challenge of funding
V Lin, A Ghaffar, et al.
Editorial
Public Health Research & Practice, Vol. 31(4):e3142115 2021
Abstract
In 1996, a World Health Organization (WHO) Ad Hoc Committee on Health Research recommended health policy and systems research (HPSR) as a global investment priority to strengthen health systems performance.1 The Alliance for Health Policy and Systems Research (Alliance) was subsequently established by WHO, development partners and national governments to advocate for greater financing and use of HPSR. Over the past 25 years, the HPSR community's advocacy efforts have led to an increase in HPSR funding, especially by global health funders and organisations. This has yielded a significant increase in the generation of policy-relevant knowledge for health system strengthening, particularly in low and middle-income countries (LMICs).2 However, most of this funding comes from a small number of international funders, making it vulnerable to changing donor priorities. We need stronger, sustained investment in HPSR – especially at a time when the coronavirus disease 2019 (COVID-19) pandemic has demonstrated the need for stronger health systems and context-relevant knowledge. As described by Stuckler et al. in this special issue of Public Health Research & Practice, the "political window of opportunity could not open any wider" than right now, to mobilise resources and partners to strengthen our health systems.

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4.0 Ethical Resilience

Summary

Norms around equity in global health research should presumably be evident/prominent in the range of ethics codes and frameworks which inform responsible research overall. Our observation is that such codes/frameworks have generally focused on the protection and rights of human subjects participating in research, including consent, access to research, benefits sharing, and the interface between research design and implementation and community engagement. Less focus has been applied to the issues specific to equity involving funding, researcher roles/rewards, capacity building and other research life cycle dimensions related to equity.

Of course, in thinking forward about "ethical resilience" and its connection to equity in global health research, we must be mindful of the foundations and background histories of the justice principle including the Belmont Report, "post-trial access" in the World Medical Association's Declaration of Helsinki, "community engagement" in the Guidelines by the Council for International Organizations of Medical Sciences, as well as benefit sharing clause of the Universal Declaration on Bioethics and Human Rights by the United Nations Educational, Scientific and Cultural Organization (UNESCO).

Practice Realization [How would it look?]

This element would involve accelerated creation, evolution, harmonization, and adoption of comprehensive and resilient ethics frameworks recognizing and effectively integrating equity imperatives such as those inventoried in this overall analysis.

Current Ownership/Power Structures

While WHO is the presumed multilateral agency responsible for continuing articulation of normative standards within which responsible global health research should proceed, there are a number of different actors with varying institutional structures which have generated, and which steward, the norms and frameworks mentioned above. As such, the ecology here is complex, and power seems to be unevenly distributed, especially involvement of LMIC-based entities.

Barriers

It is not clear whether there are specific barriers to progress in the articulation, implementation and evolution/harmonization of norms/frameworks that would move the issues forward [beyond the recurring matters of assumption of ownership, financial resources to drive and political will to implement and evolve].

Positive Case Examples

See discussion of *"Current Guidance…"* just below.

Current Guidance/Norms/Statements/Commitments

We include here an extended excerpt from the UKRI/UNICEF guidelines below reflecting their depth and nuance:

Ethical Research in Fragile and Conflict-Affected Contexts: Guidelines for Reviewers
UKRI and UNICEF Innocenti, 2021 :: 18 pages

PDF: https://www.ukri.org/wp-content/uploads/2021/11/UKRI-161121-Ethical-Research-in-Fragile-and-Conflict-Affected-Contexts-Guidelines-for-Reviewers.pdf

Rationale and Audience

These UKRI and UNICEF reviewer guidelines provide a unique tool for reviewers to assure themselves, as reviewers and/or funders that research projects funded will give systematic and on-going consideration to the ethics of research in fragile and conflict-affected contexts. The tool provides seven criteria for consideration and a checklist for reviewers to use systematically to support their review process.

The audience for these guidelines are all those involved in reviewing bids or proposals for research in fragile and conflict-affected contexts. The reviewing body itself must ensure that it is also conforming to ethical standards. This includes ensuring that review staff have the necessary competence, independence, diversity and that the process is transparent, accountable and of high quality. In addition, these guidelines or the accompanying guidelines for applicants4 should be shared as part of the call document package and used by those writing research applications/proposals.

Ethical Review Criteria

Once the research bids or proposals have been submitted, reviewers must work through seven criteria to assure themselves, and funders/ commissioners, that all efforts will be made to ensure that the research – both process and products – are ethical…

Criteria 1: Clear and robust commitment to creating and maintaining fair and equitable partnerships throughout the research process

Criteria 2: Research plan demonstrates systematic consideration of ethics at design phase

Criteria 3: Comprehensive protection protocol in place

Criteria 4: Research plan demonstrates systematic consideration of ethics during implementation phase

Criteria 5: Research plan demonstrates systematic consideration of ethics during dissemination phase

Criteria 6: Research plan demonstrates systematic consideration of ethics during monitoring and evaluation of the research

Criteria 7: Flexible, fair and transparent budget and timeline that meets the complex needs of ethical research in fragile and conflict-affected contexts.

Criteria 1: Clear and robust commitment to creating and maintaining fair and equitable partnerships throughout the research process

:: Does the application document demonstrate how the research will ensure local community partners will have an equitable role that values their local knowledge, competence and the potential risks that their involvement brings to them and their families?

:: Does the document demonstrate how power dynamics- often exacerbated in these contexts- between international and national, and national and local community researchers, and between researchers representing different positions in the locality have been mitigated?

:: In recognition of the fact that there has been a widespread erasure of local academics from published studies on conflict and fragility, are mechanisms in place to ensure that the intellectual property of local researchers is honoured in all outputs?

__ Has the local community, in all its diversity and with due attention to differing power relationships within the community, been consulted to determine their interest in engaging with this research?

Note: This in an ongoing question that needs to be systematically explored at different stages of the research process.

Criteria 2: Research plan demonstrates systematic consideration of ethics at design phase

Impact

:: Are the benefits of the research equitable?

Note: This involves balancing the benefits for the researchers and commissioners with those for the communities involved. For example, the new knowledge will be made accessible as a global public good in the languages of the countries studied or that there will be emotional, psychosocial, financial or other benefits for participants?

Note: If value is predominantly Northern, the design is not sufficiently ethical. If all products are in English and behind expensive firewalls, then the dissemination is not sufficiently equitable

Researchers' competence, background and conflicts of interests:

;; Do all researchers have the required qualifications, expertise and experience to ensure the research is conducted in a way that reflects the ethical specificities of conducting research in fragile and conflict affected contexts? For example, working with traumatized populations with different social identities and biological characteristics including age, sex, gender, race, class, sexual orientation and gender identity, religion, ability, country of origin and cultural, economic and physical background, among others.

Note: If researchers do not have the skill set and experience to work with traumatized populations with these different social identities and biological characteristics then they should not be engaging directly with these populations. For example, if the research involves children then a non- negotiable requirement is that researchers have experience of working with children from the type of context in question. There should be opportunities for researchers to be trained up and mentored in this area prior to engaging in the field. The project team should ensure regular supervision of less experienced members in order to build up relevant skills and experience.

:: Does the team include appropriate representation with regard to gender and a broad mix of backgrounds, skills and perspectives, including local, national and international expertise and expertise in working in fragile and conflict-affected contexts to ensure that different experiences are represented within the team and also to facilitate ethical research with specific groups?

Criteria 3: Comprehensive protection protocol in place

:: Have potential ethical risks in terms of the safety and security of local, national and international researchers been assessed in terms of both potential psychological and physical negative impacts in relation to the evolving specificities of the research context and for all stages of the research process?

Note: This should include assessing the team's experience level, autonomy, understanding of the context and dynamics

We include here excerpts from the CIOMS report below reflecting their focus on equity issues:

Clinical research in resource-limited settings

CIOMS, 2021 :: 136 pages isbn: 978-929036100-8

PDF: https://cioms.ch/publications/product/clinical-research-in-low-resource-settings/#

Overview

Evidence generated through responsible clinical research is one of the major pillars of the advancement of health care. In past decades there has been tremendous progress in the clinical

research and development (R & D) environment globally, with increasing attention being paid to the health needs of people in resource-limited settings, where most of the preventable morbidity and mortality occurs. However, financial, social, ethical and regulatory challenges persist in low- and middle-income countries (LMICs), and most clinical research today is still being conducted in and for high-income countries (HICs). The aim of this report is to provide balanced arguments to promote scientifically sound good quality clinical research in low-resource settings.

EXECUTIVE SUMMARY
Chapter 2: The research environment
Clinical research in resource-limited settings is challenging for many reasons. Corruption, legal uncertainties, regulatory weaknesses, excessive bureaucracy and limited public funding, as well as a lack of infrastructure such as safe road transportation and consistent power, significantly hinder research. Research funders' agendas do not always address the most pressing problems in LMICs. Access to health care is a major problem in LMICs but is an issue in all parts of the world, and there have been calls for alternative and more sustainable models, including delinking costs for R&D from product prices.[2]

Research infrastructure and capacity in resource-limited settings must be created and —even more importantly—sustained. This requires investments in training and career structures for researchers and reviewers, data and safety monitoring, laboratory infrastructure, quality assurance and capacity. Introduction of new technologies and an adapted digital regulatory and research framework is essential (see Appendix 2). Optimizing clinical research also means learning from each other's experiences. Researchers and sponsors should collaborate to create and maintain standing clinical research networks, with basic functions that could serve both academic and industry led clinical trials.

2.2.3 Corruption
Corruption in health care systems and the entire chain of agencies responsible for the supply of quality medicines and ancillary supplies is a major impediment to health care delivery and to development. Corruption (or the euphemism "weak governance") CLINICAL RESEARCH IN RESOURCE-LIMITED SETTINGS. CIOMS WORKING 20 GROUP REPORT is often not acknowledged openly, or it is actively concealed.[44] Corruption in various forms is ubiquitous and may feed on health inequity. It may prevent research, or it may affect the clinical trial process and threaten the quality of its outcomes.
Fighting corruption is urgent for the future of health globally. Corruption is embedded in health systems, and is sustained by both corrupted and corruptors. Therefore, everyone engaged in or supporting the health sector should recognize the threat of corruption, and encourage honesty and transparency and support law enforcement.[44]

2.3.1 Human resources
The role of skilled manpower is central in any efforts to maintain research infrastructure in resource-limited settings. These include for example scientists/ clinical investigators, research nurses and support staff, as well as trial pharmacists to manage the investigational products and study materials using the necessary IT resources for labelling and inventorizing. Career structures are needed to attract and

retain good investigators and thereby strengthen research capacity. Investigators need to see a future in clinical research in their own countries.

Funding for training is required to build up a sustainable pool of researchers in resource-limited settings. Specific training requirements include research ethics, grant proposal writing, clinical investigation, research methodology, statistical analysis, communication, and publication (see Chapters 4 and 5). Mentoring of researchers in these settings is essential to strengthen their research capability, enhance research quality and alleviate an unnecessary sense of inadequacy which may impede due recognition of the importance of their research.

RECOMMENDATIONS
To governments and regulatory authorities
Chapter 2
1) Invest in a sustainable research environment in terms of general infrastructure, security, health systems infrastructure, equipment and human resources; support the establishment and maintenance of standing centres and networks to conduct clinical research.
2) When planning to introduce electronic health records, consider lessons learned in other countries and aspire to bring clinical research and information technology experts together to build efficient and transparent systems that can be used for high quality clinical research (see Appendix 2).
3) Combat inefficiency and corruption in governmental institutions and ethics committees as a priority.
4) Create incentives and opportunities for engaging and training new researchers and for setting up and maintaining research sites; inform local researchers of options where funding for clinical research can be obtained.

Appendix 2. DIGITAL TECHNOLOGIES AND ELECTRONIC HEALTH RECORDS
…Challenges
In low-resource settings, researchers and innovators face tremendous challenges, including the lack of technical training, basic infrastructure, research tools, financial resources, and up-to-date access to scientific information through the internet. Of note, the unchecked availability of scientific data, as recently observed during the COVID-19 pandemic, can also lead to an increasing risk of misinformation of scientists and the public alike. All these obstacles impede developing and implementing innovative and low-cost technologies

Selected Supporting Literature/Analysis

Research ethics systems in Latin America and the Caribbean: a systemic assessment using indicators
Bernardo Aguilera, Sarah Carracedo, Carla Saenz
Health Policy
Lancet Global Health, Aug 2022 Volume 10 Number 8
Summary
To strengthen research ethics systemically, the Pan American Health Organization (PAHO) devised a strategy that includes objectives and indicators to address core components of research ethics systems. We assessed 22 countries in Latin America and the Caribbean using these indicators. Most countries have adopted legal instruments to govern research with human participants and have implemented national bodies tasked with the oversight of research ethics committees. However, performance with

regard to ethics training policies and clinical trial registration was less advanced, and efforts to adopt policies on responsible conduct of research and accelerated ethics review of emergency research did not meet the PAHO objectives in most countries. We discuss the pending challenges and provide recommendations aimed at helping countries from Latin America and the Caribbean to achieve the indicators, and, more generally, to strengthen research ethics with a systemic approach.

Community engagement and ethical global health research
Bipin Adhikari, Christopher Pell, et al.
Scholarly Perspective
Global Bioethics, Vol. 31, Issue 1, 2020
Abstract
Community engagement is increasingly recognized as a critical element of medical research, recommended by ethicists, required by research funders and advocated in ethics guidelines. The benefits of community engagement are often stressed in instrumental terms, particularly with regard to promoting recruitment and retention in studies. Less emphasis has been placed on the value of community engagement with regard to ethical good practice, with goals often implied rather than clearly articulated. This article outlines explicitly how community engagement can contribute to ethical global health research by complementing existing established requirements such as informed consent and independent ethics review. The overarching and interlinked areas are (1) respecting individuals, communities and stakeholders; (2) building trust and social relationships; (3) determining appropriate benefits; minimizing risks, burdens and exploitation; (4) supporting the consent process; (5) understanding vulnerabilities and researcher obligations; (6) gaining permissions, approvals and building legitimacy and (7) achieving recruitment and retention targets.

Sans Code of Research Ethics
[Booklet]
South African San Institute 2017

The Belmont Report
Department of Health Education and Welfare
Ethical Principles and Guidelines for the Protection of Human Subjects of Research

Universal Declaration on Bioethics and Human Rights

WMA Declaration of Helsinki - Ethical Principles for Medical Research Involving Human Subjects

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5.0 Access to/Realization of Opportunity - Capacity Building

Summary

We assess that capacity building is paramount to realizing equity in global health research. Our rapid literature/tools/analysis assessment below underscores a varied landscape including global initiatives, programs supported by research funders, and activity in international partnerships alike. We are not aware of an accepted metric around the volume of such activity or its quality/impact/outcomes, which limits assessment on a global level.

Practice Realization [How would it look?]

This element would involve structured and sustained investments by funders to build systems, lab and other supporting scientific infrastructure, graduate education and training programs, and ethical/regulatory capability – led by the countries which will benefit. Equally, capacity building initiatives would increasingly be originated in LMIC contexts, be led and strengthened by LMIC leaders, and be bi-directional, with researchers from Global North setting benefitting as much as those from Global South settings.

The current practice of conducting training for LMIC researchers in developed countries settings is useful, with some important precedents and templates having been established. However, it is less clear how well such training translates when LMIC researchers must return to the structural, social, cultural, and economic realities on the "local" research context.

In practice, effective capacity building would integrate:
:: capacity building elements in research projects that extend in time beyond short-term research objectives, and project timelines to help foster continuity and effective uptakes of learnings/skills/competencies,
:: funding for in-country research internships/mentorship programs for emerging LMIC researchers,
:: exploration with LMIC ministries to create mechanisms for career positions in global health research,
:: articulation of commitments to support diversity and inclusion of underrepresented groups in researcher cohorts, particularly women and indigenous persons

We take special note of a robust inventory of "obligations" for research capacity building in *Beran, et al.* [cited below] for organizations/sectors/groups including HIC funders, HIC universities and researchers, LMIC universities and researchers, and LMIC governments.

Current Ownership/Power Structures

While all stakeholders have joint ownership of this "equity element", we assess that research funders have a special place in the power structure that enables and fosters capacity building program that are either embedded in their sponsored research projects or are free-standing. It is not clear that there is a recognized and credible "convenor" of funders or the larger stakeholder ecology around this issue, so the dynamics of the power structures here are not evident. Also unclear is the landscape of organizations types – academic, NGO, commercial, governmental, international agency – which are currently *delivering* capacity building training/programs, or what mix or coalitions of such organizations might provide the best outcomes in this regard.

Barriers

Funding mechanisms and access to such opportunities continue to be major impediments to capacity-building initiatives specifically in LMICs (Dimitris 2021). Governments and political interests continue to present challenges to developing robust local research capacity. Knowledge flow is increasingly unidirectional from North to South which limits opportunities for LMICs to contribute meaningfully to the global health research community meanwhile LMICs carry over 20% of the global disease burden. This misalignment presents a unique opportunity for LMICs to lead global health research agendas that primarily affect LMICs.

We note the systematic review by *Naal, et al* [cited below] which observes the absence of standardized evaluation methods for capacity building programs. We also note the important "mapping" work by *Wenham et al.* [cited below] assessing current "capacity for health sciences research" across all 54 countries of Africa by collecting a range of available data including structural indicators (research institutions and research funding), process indicators (clinical trial infrastructures, intellectual property rights and regulatory capacities), and output indicators (publications and citations). Such mapping is helpful in understanding gaps, which are, in effect, barriers. We also note some of the specialty areas of capacity building such as the Pre-Publication Support Services (PREPSS) for authors in low-income and middle-income countries discussed by *Busse et al* [cited below].

Positive Case Examples

:: Kenya Medical Research Institute (Wellcome Trust)
:: Ethiopia. Implementation research with embedded capacity development
:: Central African Region. Neglected tropical diseases control with embedded capacity development
:: The consortium for Advanced Research Training in Africa (CARTA)
:: RegTrain-VaccTrain
:: PREPSS

Current Guidance/Norms/Statements/Commitments

While a host of capacity-building tools exist, we have not identified a unified guideline or responsible entity for ensuring capacity building access, depth or quality in global health research competencies.

Selected Supporting Literature/Analysis

Capacity Building Tools Collection
Website of capacity building publications, tools, and news. (2019)
Advancing Partners & Communities (APC) is a five-year project funded and managed by USAID's Office of Population and Reproductive Health and implemented by JSI Research & Training Institute, Inc., in partnership with FHI 360.

The Consortium for Advanced Research Training in Africa (CARTA)
Capacity Building Initiative in SADC 2008-Present
The Consortium for Advanced Research Training in Africa (CARTA) was formed, in 2008, to support the development of a vibrant African academy able to lead world-class multidisciplinary research that impacts positively on public and population health. The consortium enhances the capacity of African universities to create sustainable multidisciplinary research hubs by supporting junior faculty members to undertake their doctoral training locally and to become internationally recognized research leaders. Ultimately, CARTA strengthens university-wide systems to support research. CARTA offers a well thought out approach to rebuild and to strengthen the capacity of African universities to produce world-class researchers, research leaders, and scholars. CARTA is a collaboration jointly led by the African

Population and Health Research Center (APHRC), Kenya, and the University of the Witwatersrand (Wits), South Africa.

Evaluation of global health capacity building initiatives in low-and middle-income countries: A systematic review

Hady Naal, Maria El Koussa et al.

Systematic Review

Journal of Global Health, 2020, doi: 10.7189/jogh.10.020412

Abstract

Low- and middle-income countries (LMICs) are in dire need to improve their health outcomes. Although Global Health Capacity Building (GHCB) initiatives are recommended approaches, they risk being ineffective in the absence of standardized evaluation methods. This study systematically reviews evaluation approaches for GHCB initiatives in LMICs.

We searched the Medline (OVID), PubMed, Scopus, and Embase.com databases for studies reporting evaluation of a GHCB initiative in a LMIC from January 1, 2009 until August 15, 2019. To differentiate them from intervention, prevention, and awareness initiatives, included articles reported at least one approach to evaluate their learning modality. We excluded cross-sectional studies, reviews, and book chapters that only assessed the effect of interventions. Data identifying the learning modality, and evaluation method, level, time interval, and approach were extracted from articles as primary outcomes.

Of 8324 identified studies, 63 articles were eligible for analysis. Most studies stemmed from Africa and Asia (69.8%), were delivered and evaluated face-to-face (74.6% and 76.2%), mainly to professionals (57.1%) and community workers (20.6%). Although the use of online and blended modalities showed an increase over the past 4 years, only face-to-face initiatives were evaluated long-term beyond individual-level. GHCB evaluations in general lacked standardization especially regarding the tools.

This is an important resource for evaluating GHCB initiatives in LMICs. It synthesizes evaluation approaches, offers recommendations for improvement, and calls for the standardization of evaluations, especially for long-term and wider impact assessment of online and blended modalities.

Not enough traction: Barriers that aspiring researchers from low- and middle-income countries face in global health research

Constance S. Shumba, Adelaide M. Lusambili

Viewpoint

Journal of Global Health Economics and Policy, Vol. 1, 2021, https://doi.org/10.52872/001c.25802

Abstract

There is a growing concern of low representation of researchers from low-middle-income countries (LMICs) in the publication of global health research in high-impact peer-reviewed journals. Nobody denies that researchers from the developing world generally face several obstacles to publishing their research. In this viewpoint, we share some of the barriers we have observed from our experience working in both academia and global health practice in low and middle-income countries such as limited opportunities for research funding, gender disparities, and language barriers. Beyond presenting the barriers, we also provide some pragmatic solutions to addressing these barriers through increased research financing, capacity building, gender equity and inclusion, and editorial support. Most importantly, we call for setting a new level of ambition in redressing the imbalances and actualizing the leadership and emergence of a veritable critical mass of LMICs researchers.

Capacity building, local ownership and implementation of a multi-level HIV/AIDS positive health, dignity, and prevention initiative in Mozambique: approach, challenges and lessons learned

Carol Dawson-Rose, Sarah A. Gutin et al.
Study
Global Health Action, Vol. 13, Issue 1, DOI: 10.1080/16549716.2020.1769900
Abstract
Mozambique has for many years suffered from a high burden of HIV with an estimated prevalence of 11.1% among adults aged 15–49 years. In response, Positive Health, Dignity, and Prevention (or Positive Prevention as it is known in Mozambique), was developed as a method of integrating HIV care and prevention via capacity building. Through comprehensive holistic care, HIV transmission is prevented while simultaneously promoting the health of people living with HIV/AIDS. Our initiative used a three-tiered approach, and included activities at national, provincial, and community levels. In order to change patient behavior and successfully train health-care workers in Positive Prevention, it was therefore considered necessary to work at multiple levels of influence. This ensured that the individual-level behavior change of PLHIV and health-care providers was maximized through supportive environments and policies. Related national-level achievements included the establishment of a Positive Prevention technical working group; the development of a Positive Prevention policy document; training national policy-makers on Positive Prevention; the development and distribution of a nationally approved Positive Prevention training package; the integration of Positive Prevention into existing Ministry of Health curricula; the development and approval of national data collection forms; and the drafting of a related national strategy. The framework and key activities of the Mozambique Positive Prevention Program may help to inform and assist others involved in similar work, as well as advancing country or local ownership of HIV/AIDS treatment, care and prevention efforts. By using a three-tiered approach, a supportive system was created. This was critical to both optimizing Positive Prevention provision and building long-term capacity. In order for related efforts to be successful in other settings, we encourage implementing partners to also work at multiple levels, with local ownership principles in mind, in order that Positive Prevention programs may have the greatest possible effect.

The Consortium of Universities for Global Health (CUGH)
Capacity building tools database

Addressing power imbalances in global health: Pre-Publication Support Services (PREPSS) for authors in low-income and middle-income countries
Clara Busse, Ella August
Practice
BMJ Global Health, Vol. 5, Issue 2 (2020)
Abstract
The contextual knowledge and local expertise that researchers from low-income and middle-income countries (LMICs) contribute to studies in these settings enrich the research process and subsequent publications. However, health researchers from LMICs are under-represented in the scientific literature. Distally, power imbalances between LMICs and high-income countries, which provide funding and set priorities for research in LMICs, create structural inequities that inhibit these authors from publishing. More proximally, researchers from LMICs often lack formal training in research project management and in publishing peer-reviewed research. Though academic journals may value research from LMICs conducted by local researchers, they have limited time and financial resources to support writing, causing them to reject manuscripts with promising results if they lack development. Pre-Publication Support Service (PREPSS) is a non-profit, non-governmental organisation that works to meet this need. PREPSS provides onsite training, peer-review and copy editing services to researchers in LMICs who wish to publish their health research in peer-reviewed journals. Authors are not charged for these services. After receiving PREPSS services, authors submit their manuscript to a peer-reviewed journal. The PREPSS

model is one of many interventions necessary to restructure global health research to better support health researchers in LMICs and reduce current power imbalances.

Research capacity building—obligations for global health partners
David Beran, Peter Byass et al.
Comment
The Lancet Global Health, 2017, Vol. 5, Issue 6, E567-E568
Summary
A prescription for change
HIC funders' obligations
::Ensure global health funding awarded to HIC institutes has a LMIC research capacity building element, especially training of LMIC researchers
::Ensure calls reflect local needs, rather than HIC funder interests
::Mandate that proposals are developed in equal partnership with LMIC researchers and institutes
::Increase funding for epidemiological, qualitative, and health system work to understand local burden of disease, health care beliefs, and other local contexts
::Ensure plans for hand-over of infrastructure in LMICs within a realistic, predetermined timeframe
::Mandate that funding panels attain balance in assessors from LMICs and HICs
HIC universities' and researchers' obligations
::Develop proposals in equal partnership with researchers in LMICs
::Ensure all LMIC researchers involved in studies have the opportunity to actively and substantively contribute to resultant manuscripts as authors
::Ensure time and funding within grants for HIC researchers to travel to LMICs to provide in-person training for LMIC partners
::Consider secondments for LMIC researchers in HICs (while recognising that in-country training might be more sustainable)
::Consider developing online programs for continued mentoring and training
::Consider institutionalising relationships with LMIC partners
LMIC universities' and researchers' obligations
::Tighten local governance; improve leadership and accountability at all levels of institutional hierarchy
::Ensure involvement in discussions about relevance of research proposals to local contexts
::Be firm in declining collaborations that do not fit with local priorities
::Create incentives for faculty to conduct research
::Ensure the provision of infrastructure necessary for conducting research
::Ensure adequate training, funding, and time for researchers to contribute to manuscripts
::Promote programmes, such as HINARI, for academic journal access
::Invest in and encourage use of online training tools and look to non-traditional income sources for funding, for example local businesses
LMIC government obligations
::Recognise the importance of local research and prioritise funding for this
::Consider raising funds for research by taxes on large-scale private industry in-country (eg, mining, mobile networks)
Journals' obligations
::Ensure fee waivers for open-access publication where research is not directly supported by HIC funders
::Mandate that publications from research done in LMICs include authors who are living and working in those countries
::Consider an extended development and mentoring role for authors in LMICs

Measuring health science research and development in Africa: mapping the available data

Clare Wenham, et al.

Research

Health Research Policy and Systems, Volume 19, Article number: 142 (2021)

Abstract

Background

In recent years there have been calls to strengthen health sciences research capacity in African countries. This capacity can contribute to improvements in health, social welfare and poverty reduction through domestic application of research findings; it is increasingly seen as critical to pandemic preparedness and response. Developing research infrastructure and performance may reduce national economies' reliance on primary commodity and agricultural production, as countries strive to develop knowledge-based economies to help drive macroeconomic growth. Yet efforts to date to understand health sciences research capacity are limited to output metrics of journal citations and publications, failing to reflect the complexity of the health sciences research landscape in many settings.

Methods

We map and assess current capacity for health sciences research across all 54 countries of Africa by collecting a range of available data. This included structural indicators (research institutions and research funding), process indicators (clinical trial infrastructures, intellectual property rights and regulatory capacities) and output indicators (publications and citations).

Results

While there are some countries which perform well across the range of indicators used, for most countries the results are varied—suggesting high relative performance in some indicators, but lower in others. Missing data for key measures of capacity or performance is also a key concern. Taken as a whole, existing data suggest a nuanced view of the current health sciences research landscape on the African continent.

Conclusion

Mapping existing data may enable governments and international organizations to identify where gaps in health sciences research capacity lie, particularly in comparison to other countries in the region. It also highlights gaps where more data are needed. These data can help to inform investment priorities and future system needs.

Quick Document Navigation – Links to Element Discussion

Elements of Equity in Global Health Research

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:::::::

6.0 Access to/Realization of Opportunity - Research Leadership

Summary

We have not identified helpful metrics on research leadership [PI/co-PI roles] for LMIC researchers across the spectrum of global health research. However, we assess that the Fogarty program, reporting in 2020 [see below] that since 1988, it has awarded grants to 408 LMIC PIs, or about 20% [of its grants] overall. We suspect that this 20% level would be at the high end of most research funder performance at least.

Practice Realization [How would it look?]

This equity element would involve establishing grant-making commitments, setting metrics, and measuring the pathways through which we enjoy a rich, globally-diverse cohorts of competent PIs and co-PIs to lead much of global health research. Indeed, such a cohort should be leading research projects as PIs/co-PIs across disciplines and in diverse geographic and cultural contexts – and be the norm for research conducted in LMIC contexts, with a declining number of exceptions over time.

Current Ownership/Power Structures

While all global health research stakeholders have joint ownership of this "equity element", we assess that research funders and academic institutions broadly have a special place in the power structure that would enable the practice realization above. That said, it is not clear that there is a recognized and credible "convenor" of funders or the larger stakeholder ecology around this issue, so the dynamics of the power structures here are not evident.

Barriers

At this writing, beyond the political will and risk tolerance that research funders would have to exercise to accelerate practice realization as above, we do not have a clear assessment of barriers.

Positive Case Examples

We encourage review of the selected journal articles below which describe some notable positive case examples. Two U.S.-anchored examples follow:

NIH - Launching Future Leaders in Global Health (LAUNCH) Research Training Program

(D43 Clinical Trial Optional) RFA-TW-21-004

The purpose of this program is to provide opportunities for up to six consortia to develop or expand global health research training programs that meet the following objectives: (1) provide one-year mentored research training for pre-doctoral students from the U.S. and recent post-doctoral and post-professional degree graduates (collectively referred to as trainees) from the U.S. and low- and middle-income countries (LMICs) in global health research at established biomedical and health research institutions and project sites in LMICs, particularly those supported by the NIH; (2) provide training opportunities within broad areas of research relevant to the health priorities of collaborating LMICs and aligned with the scientific priorities across the NIH Institutes, Centers, and Offices; (3) provide the solid scientific research foundation needed for trainees to rigorously develop and conduct research and effectively communicate research findings with increasing independence, with the goal of enhancing the global health research career potential of the trainees; and (4) provide more equitable access to and inclusive participation in this program to diverse populations in the U.S..

This Funding Opportunity Announcement (FOA) allows mentored training of trainees to serve as the lead investigator of an independent clinical trial or in a separate ancillary clinical trial, or to gain research experience in a clinical trial led by another investigator, as part of their research and career development.

Fogarty International Center

Decolonizing and democratizing global health are difficult, but vital goals
Opinion by Fogarty Director Dr Roger I Glass
Global Health Matters, July / August 2020 | Volume 19, Number 4
[Excerpt]

…In the 1980s, when Fogarty began its first research training program to build capacity in LMICs, in most cases trainees traveled to a HIC for their studies. Since then, the Center has supported significant training for more than 6,000 scientists worldwide. As a cadre of highly knowledgeable faculty developed in numerous LMICs, a transition began toward creation of local advanced degree programs in disciplines such as infectious diseases, epidemiology and public health. There are now 91 LMIC institutions that award degrees with Fogarty support, including more than 1,338 master's degrees and 452 Ph.Ds.

This is significant because, not only is it more economical so allows more students to be trained, LMIC curricula are far more relevant to the local disease priorities and available resources than in programs developed for HIC consumption. Our goal is to empower LMIC scientists so they can enter into equitable partnerships where they set the research agenda, based on national priorities, and direct studies that will produce data so that policymakers can make evidence-based decisions. We believe these equitable research partnerships should be reflected in the authorship of the resulting publications. We were encouraged to discover promising trends in a study done with the NIH Library of Fogarty-supported publications. In 2002, about 12% of Fogarty-supported publications had LMIC senior (last) authors and approximately 85% had U.S. senior authors. By 2019, LMIC senior authorship had increased to about 44%. In addition, LMIC first authorship surpassed U.S. authorship in 2014 and continues to climb.

This shift has also been reflected in our grantmaking. In 2015, 18% of our grants went to LMIC institutions. By 2019, that had risen to 31%. The NIH policy decision in 2006 to allow multiple Principal Investigators on grants has allowed more equitable recognition of research partnerships. Since 1988, Fogarty has awarded grants to 408 LMIC PIs, or about 20% overall…

Current Guidance/Norms/Statements/Commitments

While there are a range of aspiration statements from various institutions and organization types, and selected outstanding examples of action, we have not identified coherent guidance, agreed metrics, or a responsible convenor to address the underlying challenges here.

Selected Supporting Literature/Analysis

Strengthening research capacity through an intensive training program for biomedical investigators from low- and middle-income countries: the Vanderbilt Institute for Research Development and Ethics (VIRDE)
Holly M. Cassell, et al.
Research
BMC Medical Education, Volume 22, Article number: 97 (2022)
Abstract
Background

Capacity strengthening initiatives aimed at increasing research knowledge and skills of investigators in low- and middle-income countries (LMICs) have been implemented over the last several decades. With increased capacity, local investigators will have greater leadership in defining research priorities and impact policy change to help improve health outcomes. Evaluations of models of capacity strengthening programs are often limited to short-term impact. Noting the limitations of traditional output-based evaluations, we utilized a broader framework to evaluate the long-term impact of the Vanderbilt Institute in Research Development and Ethics (VIRDE), a decade-old intensive grant development practicum specifically tailored for investigators from LMICs.
Methods
To assess the impact of VIRDE on the research careers of alumni over the past 10 years, we surveyed alumni on research engagement, grant productivity, career trajectory, and knowledge gained in grant writing. Descriptive statistics, including means and total counts, and paired sample t-tests were used to analyze the data.
Results
Forty-six of 58 alumni completed the survey. All respondents returned to their home countries and are currently engaged in research. Post-VIRDE grant writing knowledge ratings were significantly greater than pre-VIRDE. The number of respondents submitting grants post-VIRDE was 2.6 times higher than before the program. Eighty-three percent of respondents submitted a total of 147 grants post-VIRDE, of which 45.6% were awarded. Respondents acknowledged VIRDE's positive impact on career growth and leadership, with 88% advancing in career stage.
Conclusions
Gains in grant writing knowledge and grant productivity suggest that VIRDE scholars built skills and confidence in grant writing during the program. A substantial proportion of respondents have advanced in their careers and continue to work in academia in their country of origin. Results show a sustained impact on the research careers of VIRDE alumni. The broader framework for research capacity strengthening resulted in an expansive assessment of the VIRDE program and alumni, illuminating successful program elements and implications that can inform similar capacity strengthening programs.

Training LEADers to Accelerate Global Mental Health Disparities Research (LEAD) Program: A Research Training Program Protocol

Ozge Sensoy Bahar, et al.
Frontiers in Public Health, 2021; 9: 749627. doi: 10.3389/fpubh.2021.749627
Abstract
Background: There is a critical need to address mental health needs across the globe, especially in low and middle-income countries where mental health disparities are pervasive, including among children. The global mental health disparities suggest an imperative for culturally and contextually-congruent mental health services models that expand upon the existing services and interventions for these groups. Rigorous research is a key tool in providing the scientific evidence to inform public policy and practice efforts to effectively address these needs. Yet, there is a limited number of researchers, especially those from diverse backgrounds, who study these issues. In this paper, we describe the "Training LEADers to Accelerate Global Mental Health Disparities Research" (LEAD) program, a research training program funded by the National Institute on Minority Health and Health Disparities and focused on global mental health disparities research for early career researchers from under-represented minority groups.
Methods: The LEAD program is designed as a two-phase training program for advanced pre-doctoral students, postdoctoral fellows, and junior faculty from diverse backgrounds in the U.S., including groups underrepresented in biomedical, behavioral, clinical and social sciences research, interested in global

mental health disparities research. Trainees are matched with mentors and participate in an intensive 12-week program.
Discussion: The LEAD program seeks to provide a robust platform for the development, implementation and expansion of evidence-based culturally and contextually-congruent interventions and services models addressing global mental health disparities across the life cycle, especially in low-resource communities in the global context. By producing a sustainable network of well-trained investigators from underrepresented backgrounds, LEAD will potentially contribute to the shared lessons and efforts relevant to addressing global mental health disparities and improving care for vulnerable populations in low-resource settings.

Practicalities of implementing burden of disease research in Africa: lessons from a population survey component of our multi-partner FOCAL research project

Binyam N. Desta, et al
Analytic perspective
Emerging Themes in Epidemiology, Volume 19, Article number: 4 (2022)
Abstract
Background
Collaborative research is being increasingly implemented in Africa to study health-related issues, for example, the lack of evidence on disease burden, in particular for the presumptive high load of foodborne diseases. The FOCAL (Foodborne disease epidemiology, surveillance, and control in African LMIC) Project is a multi-partner study that includes a population survey to estimate the foodborne disease burden in four African low- and middle-income countries (LMICs). Our multi-partner study team had members from seven countries, all of whom contributed to the project from the grant application stage, and who play(ed) specific roles in designing and implementing the population survey.
Main text
In this paper, we applied Larkan et al.'s framework for successful research partnerships in global health to self-evaluate our project's collaboration, management, and implementation process. Our partnership formation considered the interplay and balance between operations and relations. Using Larkan et al.'s seven core concepts (i.e., focus, values, equity, benefit, communication, leadership, and resolution), we reviewed the process stated above in an African context.
Conclusion
Through our current partnership and research implementing a population survey to study disease burden in four African LMICs, we observed that successful partnerships need to consider these core concepts explicitly, apply the essential leadership attributes, perform assessment of external contexts before designing the research, and expect differences in work culture. While some of these experiences are common to research projects in general, the other best practices and challenges we discussed can help inform future foodborne disease burden work in Africa.

Capacity & capability building for applied dementia research in low- & middle-income countries: Two exemplars from South Asia

Leroi et al. and on Behalf of the SENSE-Cog Asia
Indian Journal of Medical Research, 2020 Dec; 152(6): 614–625. doi: 10.4103/ijmr.IJMR_2095_19
Abstract
Background & objectives:
Cognitive and other neurodegenerative conditions related to ageing have become public health priorities in low- and middle-income countries. However, contextually based, applied research to support the development of awareness, diagnosis and care pathways for people with dementia in South Asia is still largely undeveloped. This study was aimed to use applied research studies for dementia in

South Asia as exemplars of how individual-level capacity and capability building for dementia research can be achieved.
Methods:
Using Theory of Change as a framework, we embedded capacity and capability building into the studies through six domains: people (human resources), research integrity and governance, study delivery skills, international collaborative working, patient and public involvement (PPI) (awareness raising, stigma and health literacy) and development of 'pathways'. For each aspect, development goals were defined and how they would be achieved.
Results:
New principal investigators, research assistants (including outcome raters), study coordinators and intervention practitioners were trained across eight study sites in India, Pakistan, and Bangladesh, for dementia research. Training was delivered at study start, and through booster sessions, using workshops, face-to-face sessions, online training and video-link sessions. International collaborations were fostered, leading to a proposal for international funding. Each study site co-created PPI events to raise awareness and to inform the research. The recruitment pathways and study logistics fostered the development dementia diagnosis and care pathways.
Interpretation & conclusions:
Embedding capacity and capability building in applied dementia research in South Asia fosters the sustainability of dementia research, which is essential in developing diagnostic and care pathways.

Mentorship and Ethics in Global Health: Fostering Scientific Integrity and Responsible Conduct of Research

Elizabeth A. Bukusi, Yukari C. Manabe et al.
Am J Trop Med Hyg, Vol. 100(1 Suppl):p. 42–47, 2019
Abstract
Addressing ethical issues through mentorship is key to encouraging scientific integrity and increasing research capacity. Across the global health arena, mentorship requires helping mentees understand and negotiate the regulatory aspects of research—which can substantially differ even between countries with similar resources. Mentorship support spans across the research framework from obtaining ethical approval and ensuring scientific integrity, to determining authorship and disseminating study results—providing multiple opportunities to model ethical behavior for mentees. The power imbalances between the global north and south in accessing funding resources produce further challenges in setting the research agenda and for ensuring equity in the dissemination of research findings. Gender further complicates the aspiration for equity; the proportion of women in high administrative or research positions remains low. This study explores four specific mentoring case scenarios commonly encountered in the global health research field in low- and middle-income institutions.

Research Capacity and Training Needs for Cancer in Conflict-Affected MENA Countries

Zahi Abdul-Sater, et al.
Annals of Global Health, 2020; 86(1): 142. Published online 2020 Nov 6. doi: 10.5334/aogh.2809
Abstract
Background:
The global cancer burden is disproportionately greater in low- and middle-income countries, including those affected by conflict in the Middle East and North Africa (MENA) region. Contributing factors include inadequate control of risk factors plus limited surveillance and treatment options. Weak healthcare infrastructure may be further compounded by the conflict prevalent in multiple MENA countries. Improved cancer surveillance, research, and capacity strengthening are essential for

implementing cancer control plans in the MENA region, requisite for reducing the disproportionate cancer burden.
Aims:
This article aims to understand the barriers to cancer research and training in conflict-affected MENA countries, and to identify opportunities for developing capacities for reliable cancer research strategies.
Methods:
This study employs a mixed-method approach utilizing an online questionnaire with open and close ended questions targeting oncologists and cancer researchers in conflict-affected MENA countries. For open-ended questions, we performed a qualitative content analysis to identify thematic barriers.
Results:
Forty-eight respondents, mostly Medical and Radiation Oncologists, completed the questionnaire. The most significant training needs were conducting clinical, basic, and qualitative cancer research. The most prominent barriers identified were insufficient training in data analysis and research design (77% and 75% of respondents, respectively) and insufficient institutional and government funding (94% and 85%, respectively). For the qualitative data, we organized the barriers into six themes, the most common was the lack of research infrastructure (28%).
Conclusions:
Despite an escalating cancer burden, conflict-affected MENA countries are lagging in knowledge production and implementation of evidence-based cancer research. Novel modes of knowledge transmission and collaboration across geographical and political boundaries are sorely needed. Based on our study, we recommend developing innovative and accessible training opportunities focusing on developing basic, clinical, and qualitative research skills. Research capacity-strengthening initiatives should encourage the investigation of context-specific research questions with the potential to make a meaningful impact on cancer control in the region.

Stuck in the middle: a systematic review of authorship in collaborative health research in Africa, 2014–2016

Bethany L Hedt-Gauthier, Herve Momo Jeufack et al.
BMJ Global Health, Vol. 4, Issue 5, 2019
Abstract
Collaborations are often a cornerstone of global health research. Power dynamics can shape if and how local researchers are included in manuscripts. This article investigates how international collaborations affect the representation of local authors, overall and in first and last author positions, in African health research. We extracted papers on 'health' in sub-Saharan Africa indexed in PubMed and published between 2014 and 2016. The author's affiliation was used to classify the individual as from the country of the paper's focus, from another African country, from Europe, from the USA/Canada or from another locale. Authors classified as from the USA/Canada were further subclassified if the author was from a top US university. In primary analyses, individuals with multiple affiliations were presumed to be from a high-income country if they contained any affiliation from a high-income country. In sensitivity analyses, these individuals were presumed to be from an African country if they contained any affiliation an African country. Differences in paper characteristics and representation of local coauthors are compared by collaborative type using χ^2 tests. Of the 7100 articles identified, 68.3% included collaborators from the USA, Canada, Europe and/or another African country. 54.0% of all 43 429 authors and 52.9% of 7100 first authors were from the country of the paper's focus. Representation dropped if any collaborators were from USA, Canada or Europe with the lowest representation for collaborators from top US universities—for these papers, 41.3% of all authors and 23.0% of first authors were from country of paper's focus. Local representation was highest with collaborators from another African country. 13.5% of all papers had no local coauthors. Individuals, institutions and funders from high-income countries

should challenge persistent power differentials in global health research. South-South collaborations can help African researchers expand technical expertise while maintaining presence on the resulting research.

North–south collaboration and capacity development in global health research in low- and middle-income countries – the ARCADE projects

Salla Atkins, et al.& for the ARCADE consortium

Article

Global Health Action, published online: 06 Oct 2016

Special Issue: Capacity building in global health research: is blended learning the answer?

Abstract

Background

Research capacity enhancement is needed in low- and middle-income countries (LMICs) for improved health, wellbeing, and health systems' development. In this article, we discuss two capacity-building projects, the African/Asian Regional Capacity Development (ARCADE) in Health Systems and Services Research (HSSR) and Research on Social Determinants of Health (RSDH), implemented from 2011 to 2015. The two projects focused on providing courses in HSSR and social determinants of health research, and on developing collaborations between universities, along with capacity in LMIC universities to manage research grant submissions, financing, and reporting. Both face-to-face and sustainable online teaching and learning resources were used in training at higher postgraduate levels (Masters and Doctoral level).

Design

We collated project meeting and discussion minutes along with project periodic reports and deliverables. We extracted key outcomes from these, reflected on these in discussions, and summarised them for this paper.

Results

Nearly 55 courses and modules were developed that were delivered to over 920 postgraduate students in Africa, Asia, and Europe. Junior researchers were mentored in presenting, developing, and delivering courses, and in preparing research proposals. In total, 60 collaborative funding proposals were prepared. The consortia also developed institutional capacity in research dissemination and grants management through webinars and workshops.

Discussion

ARCADE HSSR and ARCADE RSDH were comprehensive programmes, focussing on developing the research skills, knowledge, and capabilities of junior researchers. One of the main strengths of these programmes was the focus on network building amongst the partner institutions, where each partner brought skills, expertise, and diverse work cultures into the consortium. Through these efforts, the projects improved both the capacity of junior researchers and the research environment in Africa, Asia, and Europe.

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7.0 Access to/Realization of Opportunity - Parity/Equality in Roles/Responsibilities/Rewards

Summary

Beyond the research leadership roles [PIs, co-PIs] discussed above, there is a rich ecology of project-critical and more general supporting roles involved in global health research, varying broadly depending on the discipline areas, sites, and other factors involved. We assess that issues around and realization of parity and equality for those holding such roles [some who may have trained or otherwise come from HIC versus LMIC settings] are complex, challenging and not well documented.

Beyond research project roles held by "employees" and "contractors", there are also important questions around the larger stakeholder ecology surrounding a given project. We note here the various discussion of "co-production" of health research in selected articles from the literature section below. The formal integration of such diverse stakeholders – even if not contractual or compensated – into a research project's operational and power structures is a nuanced challenge, at least. We have not encountered helpful metrics and substantive analysis on this to date.

Practice Realization [How would it look?]

We are less confident as a working group about articulating a coherent, grounded statement on practice realization here. We note and suggest review of the analyses of Tembo, et al., Beran, et al, Agyepong, et al. [cited below] for perspectives.

Current Ownership/Power Structures

We have not encountered substantive, credible analysis of the ownership and power structures and dynamics at this writing. Turk, et al. below is a helpful source listing some of the complex ecology of stakeholders and contextual issues.

Barriers

We have not encountered substantive, credible analysis of the barriers to practice realization at this writing.

Positive Case Examples

None identified as establishing a solid precedent or template.

Current Guidance/Norms/Statements/Commitments

We did not identify coherent or grounded guidance or helpful metrics at this writing.

Selected Supporting Literature/Analysis

Research partnerships across international contexts: a practice of unity or plurality?
Mia Perry, Jo Sharp, Kevin Aanyu, Jude Robinson, Vanessa Duclos & Raihana Ferdous
Article
Development in Practice, Volume 32, Issue 5, 2022
ABSTRACT
Partnership is not a benign practice; it is culturally and ethically loaded. The way in which partnerships are construed in international research determines its design, ethics and impacts. Despite this, and the growing assumption of partnership practice in our field, the concept has become increasingly abstract

and the practice under-analysed. This article provides critical perspectives of current understandings of partnership in international development research from three angles: the motivations behind partnership working; an epistemological perspective in relation to epistemic justice and the agency of language; and finally, the systems that mediate partnerships, and the range of resources that guide them.

Effective engagement and involvement with community stakeholders in the co-production of global health research

Doreen Tembo et al.

Analysis

BMJ, 2021;372:n178

Abstract

:: Co-production of research is key to achieving more equal relationships in global health research and to delivering positive benefits to a wide range of stakeholders

:: Co-production requires investment in time and resources and a commitment to building trust between researchers and communities

:: To deal with the power imbalance between researchers and communities, and within research collabo-rations, it is important to include experiential knowledge and participatory methodologies

:: Global health research funders and institutions based in the global north can better support co-production by embedding best practices in their funding criteria and systems for career progression and rewards.

Rethinking research processes to strengthen co-production in low and middle income countries

David Beran, Maria Amalia Pesantes et al.

BMJ, 2021;372:m4785

Abstract

Co-production needs to become an integral part of the training and funding of researchers to ensure research meets everyone's needs, argue David Beran and colleagues

Global health research needs to include a greater diversity of stakeholders within the research process. Involving people who are not academics in the co-production of research has many potential benefits: generation of a wider range of ideas; including the needs of people directly affected by the research; inclusion of broader sets of skills and views, values, and epistemologies in designing projects; allowing dialogue, participative decision making processes throughout the development and delivery of research; ensuring uptake of research results; increasing legitimacy and acceptance; and assuring sustainability.12345

However, co-production has its own challenges.167 For example, finding practical ways to collaborate with stakeholders outside academia to prepare grant applications and proposals is a substantial challenge. The "negative" costs of co-production are described as the costs of actually doing co-production; personal and professional costs to the researcher; costs to participants; and costs to projects in general of this appraoch.7 Successful co-production requires the corresponding skills and appropriate tools and resources to include a wide variety of stakeholders. This in turn challenges current training, career progression pathways, and funding processes for researchers. Research funders are key to many of these and include government research councils or foundations, independent foundations, and government development agencies, particularly in low and middle income countries (LMICs). Stakeholders include people with a given health problem, community members, healthcare providers, civil society organisations, and policy makers.

Changes are required in global health research to ensure that co-production is strengthened and help overcome the challenges that researchers face in implementing it.

The first obstacle is the pressing challenges in many LMIC settings, ranging from high disease burden to fragmented health systems, poverty, and inequities. These are complex and interconnected problems.8

Secondly, this complexity necessitates interdisciplinary, multidisciplinary, and transdisciplinary approaches.9 This requires the recognition by researchers and funders that contributions from a broad spectrum of relevant experts and stakeholders is crucial for co-production910 and that they need to be included in the research process from the beginning.

Finally, researchers need to work with existing partners, or identify possible partners, in countries and start adapting or developing new ideas and translating these into a comprehensive research proposal. This process also raises the issue of unequal power relations between different parties involved, in terms of the value placed on their ideas and knowledge. Overcoming these three challenges takes time and requires building trust with academic and non-academic partners in the funding application as well as multiple stakeholders beyond the research proposal.11 In addition, training, career progression, institutional decisions and investment, and funding processes need to be rethought.

International experiences with co-production and people centredness offer lessons for covid-19 responses

Eva Turk, Anna Durrance-Bagale et al.

Analysis

BMJ, 2021;372:m4752

Abstract

Eva Turk and colleagues believe that there is much to learn from the experiences of low and middle income countries in co-producing knowledge and working with communities to find feasible and acceptable solutions to healthcare concerns.

The development and implementation of health policies and interventions must be done with, and not simply done to, the people affected. Collaborative healthcare requires engaging with individuals and communities using models of care that are patient centred. These models are informed, rather than dictated, by scientific knowledge that might or might not apply to an individual patient and their circumstances.1

Collaboration allows patients, user groups, and communities to assert some control over delivery of their care and hold health providers to account. Given the uncertainty and mistrust about how best to deal with the covid-19 pandemic, collaboration is more important than ever.

Co-production of healthcare can take place throughout the health system, ranging from governments working with patient organisations, to health facilities involving patient representatives, to the clinical meeting between a health professional and a patient.2 Put simply, it involves “getting everybody around the table so you are valuing everyone’s knowledge.”3 It demands building a shared understanding between researchers, policy makers, practitioners, and managers, as well as patients and their families, and working together to improve quality and care.

While there should be little disagreement that co-production is a good idea, it does need a supportive culture and regulatory framework, with organisational structures and procedures in place.45 It also requires acceptance of the need to share power, take account of each other’s perspectives and skills, respect and value different types of knowledge, and commit to building and maintaining the relationships within the collaboration process. Co-production is therefore a dynamic and often complex process in which information, resources, timescales, and people are continually changing.67

Co-production is increasingly used within health research, building on methods such as participatory research, engaged scholarship, collaborative research, and integrated knowledge translation.89 We see it as occurring where researchers work in partnership with knowledge users, comprising patients and care givers, clinicians, policy makers, health system leaders, the public, and others, to identify a problem

and produce a solution, sharing power and responsibility throughout the research.10 Consequently, co-production in health research overlaps with its application in healthcare provision. Both focus on improving quality, whether of health research, policies, or interventions, in order to increase acceptance and uptake of healthcare by end users.

Collective sensemaking for action: researchers and decision makers working collaboratively to strengthen health systems

Lucy Gilson, Edwine Barasa et al.

BMJ, 2021;372:m4650

Abstract

Lucy Gilson and colleagues draw on experiences from Kenya and South Africa to consider the practice, benefits, and challenges of research co-production for strengthening health systems

Health policy and systems research has gained traction in low and middle income countries over the past few decades. It seeks to understand and improve "how societies organise themselves in achieving collective health goals, and how different actors interact in the policy and implementation processes to contribute to policy outcomes."12 "Getting health research into policy and practice," also promoted by global funding agencies, is a central concern.3 However, the mechanisms proposed for doing so can assume a linear pathway from research to policy change, overlooking the power and politics entailed in knowledge generation and use.4 Limited attention may also be given to the important role that knowledge gained through experience can have in health system decision making, as distinct from research evidence.5

By contrast, research co-production is based on the understanding that knowledge mobilisation is the "activation of available knowledge within a given context" by those who will use it.6 It supports intentional and systematic learning from action, valuing both formal and experiential knowledge. While research processes, particularly participatory approaches,5 are one way of stimulating such learning, other stimuli of knowledge mobilisation include co-design approaches6and workplace based training activities.7

Co-production of knowledge supports collective sensemaking—the generation of shared understanding about problems or new initiatives, for example—that supports learning and health system strengthening.8 This aligns well with recent calls to institutionalise knowledge use within health systems9 and to develop learning health systems that innovate and adapt over time.10 It also links to embedded research approaches where researchers work inside or alongside a host organisation to support collaborative research and learning processes.1112 All these approaches recognise that the distinctions between knowing and doing and between research and practice are false binaries. Health system decision makers are curious and reflective, as are researchers. Researchers seek to bring about change, as do decision makers. Each group brings valuable and necessary knowledge resources to enrich decision making and action.

Decision making within health systems entails collaboration between many groups.5 These can include patients and families; frontline, mid-level, and senior decision makers within public health sector hierarchies; as well as non-state actors such as managers of community based health structures and organisations. In this paper, we consider our experiences with five co-production initiatives focused on engaging researchers and public health decision makers in Kenya and South Africa (box 1). All aimed to strengthen decision making practice within the health system, but only two entailed formal research activities.

Strengthening capacities and resource allocation for co-production of health research in low and middle income countries

Irene Agyepong, Sue Godt, et al.

Analysis
BMJ, 2021;372:n166
Abstract

Ghana's universal health insurance scheme provides a good example of co-production of research. In 1991, Ghana's director of medical services asked researchers to determine whether health insurance could be an equitable and feasible health financing option in a low income country, such as Ghana, with a large informal sector. The research team, which had expertise in public health, health policy and systems, and medical anthropology, worked with frontline health workers and managers, local government, community members, and leaders to explore the acceptability, design, and feasibility of a district-wide health insurance scheme. The resulting design embedded principles of equity and social solidarity and ensured financial sustainability in a resource constrained context, and evidence from this research informed the Ghana national health insurance scheme (NHIS), which was launched in 2001.1234

This example shows the important role that co-production of health research can have in generating relevant evidence and innovative, context specific solutions for public health and clinical care challenges. Despite this potential and the growing literature, co-production remains relatively limited in low and middle income countries (LMICs).56789 Globally, researchers in high income countries lead most current work. For example, a rapid PubMed search on 19 October 2020 yielded 2009 articles for the terms "co-production" and "research." Adding the terms "developing country/countries" or "low- and middle-income country/countries" reduced the results to fewer than 30. This neglect in LMICs is partly because of capacity and funding challenges. In this article we share experiences and ideas for capacity strengthening and resource allocation for health research co-production in LMICs.

How global is global health research? A large-scale analysis of trends in authorship
Michelle C Dimitris ,1 Matthew Gittings,2 Nicholas B King
Original Research
BMJ Global Health, 2021;6:e003758. doi:10.1136/bmjgh-2020-003758
ABSTRACT

Many have called for greater inclusion of researchers from low- and middle-income countries (LMICs) in the conduct of global health research, yet the extent to which this occurs is unclear. Prior studies are journal-, subject-, or region-specific, largely rely on manual review, and yield varying estimates not amenable to broad evaluation of the literature. We conducted a large-scale investigation of the contribution of LMIC-affiliated researchers to published global health research and examined whether this contribution differed over time. We searched titles, abstracts, and keywords for the names of countries ever classified as low-, lower middle-, or upper middle-income by the World Bank, and limited our search to items published from 2000 to 2017 in health science-related journals. Publication metadata were obtained from Elsevier/Scopus and analysed in statistical software. We calculated proportions of publications with any, first, and last authors affiliated with any LMIC as well as the same LMIC(s) identified in the title/abstract/keywords, and stratified analyses by year, country, and countries' most common income status. We analysed 786 779 publications and found that 86.0% included at least one LMIC-affiliated author, while 77.2% and 71.2% had an LMIC-affiliated first or last author, respectively; however, analagous proportions were only 58.7%, 36.8%, and 29.1% among 100 687 publications about low-income countries. Proportions of publications with LMIC-affiliated authors increased over time, yet this observation was driven by high research activity and representation among upper middle-income countries. Between-country variation in representation was observed, even within income status categories. We invite comment regarding these findings, particularly from voices underrepresented in this field.

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8.0 Research Life Cycle - Operational Transparency/Accountability/Integrity

Summary

Science broadly, and global health research specifically, are not immune from the effects of operational weaknesses, the exercise of political influence, corruption in procurement and other financial matters, incompetence, skirting of regulatory guardrails and the like – any and all of the factors can compromise the integrity of the research endeavor and more. Despite this harsh reality, mechanisms by which research stakeholders can mitigate such challenges are not well documented. We have not encountered the kind of forensic analysis that would helpfully calibrate the efficacy and risks [some reputational] of the tools and techniques in use.

Practice Realization [How would it look?]

This element would involve accelerated creation, harmonization and adoption of measurable norms addressing research practice: maximizing public transparency, enforceable accountability, and effective prevention and mitigation of challenges to integrity including from political or ideological influence, corruption, or similar threats.

We found the analysis of Storeng et al. helpful in making practical recommendations to protect the independence and integrity of global health research and the roles of commissioning bodies, research funders, researchers and research institutions, ethics and research governance committees, and academic journal and editors. These stakeholders track nicely with our stakeholder ecology concept map from the introduction to this submission, but omits regulatory agencies and civil society organizations, which each have a role here even if not typically realized.

Current Ownership/Power Structures

We have not encountered substantive, credible analysis of the ownership, power structures and related dynamics here at this writing.

Barriers

We have not encountered substantive, credible analysis of the barriers to practice realization at this writing.

Positive Case Examples

None identified as establishing a solid precedent or template.

Current Guidance/Norms/Statements/Commitments

We did not identify coherent or grounded guidance or helpful metrics at this writing, except that ESG codes, broadly, are attempting to address the underlying issues from the corporate/commercial sector.

Selected Supporting Literature/Analysis

INTEGRIDAD CIENTÍFICA, INTEGRIDAD DECISIONAL, INTEGRIDAD SOCIAL
Fernando Lolas Stepke
Editorial
Acta Bioethica, 2022; 28 (1): 7-8. DOI: http://dx.doi.org/10.4067/S1726-569X2022000100007
[Extracto]

…La sindemia ha sido solamente una ocasión para reflexionar. Es probable que algo semejante ocurra siempre y que la integridad en la pesquisa, en las decisiones y en la implementación esté siempre amenazada por espurios componentes que no suelen discutirse. Entre ellos, la llamada "interferencia política" merece un lugar especial. No se quiere solamente significar que intereses doctrinarios o uso y abuso del poder falseen conclusiones y maticen decisiones. Quiere decir también que, a las transgresiones individuales, que pueden explicarse por ambición, deseo de prestigio o psicopatología individual, hay que agregar el tono ético de las comunidades y su potencial para el engaño y el autoengaño. En las fake news puede esconderse una ecología de la corrupción que precisa ser tenida en cuenta. No digamos desenmascarada y eliminada, porque los conflictos de interés y el dolo necesariamente deben ser custodiados por alguien. Y el problema no es de quienes controlan, sino que quienes controlan a los que controlan…

Bridging research integrity and global health epidemiology (BRIDGE) guidelines: explanation and elaboration

Sandra Alba, Annick Lenglet et al.

Analysis

BMJ Global Health, 2020, Vol 5**:**e003237

Abstract

Over the past decade, two movements have profoundly changed the environment in which global health epidemiologists work: research integrity and research fairness. Both ought to be equally nurtured by global health epidemiologists who aim to produce high quality impactful research. Yet bridging between these two aspirations can lead to practical and ethical dilemmas. In the light of these reflections we have proposed the BRIDGE guidelines for the conduct of fair global health epidemiology, targeted at stakeholders involved in the commissioning, conduct, appraisal and publication of global health research. The guidelines follow the conduct of a study chronologically from the early stages of study preparation until the dissemination and communication of findings. They can be used as a checklist by research teams, funders and other stakeholders to ensure that a study is conducted in line with both research integrity and research fairness principles. In this paper we offer a detailed explanation for each item of the BRIDGE guidelines. We have focused on practical implementation issues, making this document most of interest to those who are actually conducting the epidemiological work.

Action to protect the independence and integrity of global health research

Katerini T. Storeng, Seye Abimbola et al.

Editorial

BMJ Global Health, 2019, Vol 4**:**e001746.

Abstract

In a recent *Viewpoint* in *the Lancet*, some of us shared our experience of censorship in donor-funded evaluation research and warned about a potential trend in which donors and their implementing partners use ethical and methodological arguments to undermine research.[1]

Reactions to the *Viewpoint*—and lively debate at the 2018 Global Symposium on Health Systems Research—suggest that similar experiences are common in implementation and policy research commissioned by international donors to study and evaluate large-scale, donor-funded health interventions and programmes, which are primarily implemented in low resource settings. 'We all have the same stories', was one of the first comments on the Viewpoint, followed by many private messages divulging instances of personal and institutional pressure, intimidation and censorship following attempts to disseminate unwanted findings.

Such pressure comes from major donors and from international non-governmental organisations (NGOs) obliged to have an external assessment but who then maintain a high degree of confidentiality and control. That such experiences are widespread reflects the deeply political nature of the field of 'global health' and the interconnections between priority setting, policy making and project implementation, which sit within a broader set of deeply entrenched power structures.[2,3] Researchers in this field routinely find themselves working within—and studying—complex power relations and so experience challenges in negotiating their own position between interests of commissioning agencies and funders, implementers and country governments, as well as those of their own research institutions and their partnerships with other researchers spanning high-income, middle-income and low-income countries.[4–7] They often receive research funding from major donor agencies like the UK Department of International Development (DFID), the US Agency for International Development (USAID), the Agence Française de Développement (AFD), UNITAID and the Bill and Melinda Gates Foundation,[8] who commission evaluations for their own funded projects, even though they have a stake in results that demonstrate the success of a multibillion-dollar investment.

Effects of interference in the research and evaluation process are compounded by more subtle acts of self-censorship and data embellishment that can arise as researchers become embroiled in what was recently called the global health 'success cartel'.[9] Their involvement in a collective drive to demonstrate success can unintentionally 'instill a fear of failure, stifle risk-taking and innovation, and lead to the fabrication of achievement'.[9] For example, research that threatens the position of powerful elites—such as research into high-level corruption—is lacking.[10] Meanwhile, selective reporting of 'unwelcome' findings can be a way to avoid contractual terminations even though it undermines learning.[1,11,12] Moreover, perverse incentives exist across the global health and development sectors to use simplistic indicators of success and bad or fudged data.[13–15] Donor agencies exacerbate the problem by distorting research findings to exaggerate their own successes.[16–19]

Researchers are responsible for conducting research ethically and with integrity. Yet, without strong and reliable institutional support, they are often in a vulnerable position when faced with vested interests. What action is needed to avoid undermining independent and critical research findings? What kind of institutional structures and practices might support researchers in dealing with the ethical and political dilemmas associated with the dissemination of (potentially) contested research findings and evaluation results? To start a discussion on ways forward, we invited input from an international network of global health, health systems and policy researchers from diverse disciplines. Below, we discuss suggestions, endorsed by more than 200 researchers based in 40 different countries (see the full list of signatories below), on how the organisations that commission, undertake and publish research and evaluations can safeguard independence and integrity.

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9.0 Risk-Benefit Sharing/IP

Summary

We assess that these three, interrelated issues in global health research require fresh articulation and calibration in the context of the World Trade Organization's TRIPS waiver action in June 2022, the Convention on Biological Diversity's work on the Nagoya Protocol on Access and Benefits Sharing, and other spheres of activity provide a complex backdrop for the issues here.

More immediately, the ramifications of the TRIPS waiver – triggered in important part by inequities in access to and issues around "local" production of COVID vaccines and therapeutics – are just emerging but they will color the landscape for the next decade plus. We do assess that shared risk and shared benefit is a powerful concept when integrated.

Equally, the notion that health – and the research that produces the evidence and interventions which support health – are global public goods adds another layer of complexity.

Practice Realization [How would it look?]

This element would involve advancing intellectual property [IP] regimes at global and country level to create the systems and processes which will enable measurable and meaningful benefits sharing proceeding from all/any research activity – whatever the focus, wherever conducted, however funded, however led. However, how risk-benefits sharing might ideally operate in global health research at practice level is much less clear.

Current Ownership/Power Structures

We have not encountered substantive, credible analysis of the ownership, power structures and related dynamics here at this writing. We assess that global governance overall – under which IP is stewarded and global benefits sharing is defined at the convention/treaty level – means that WTO and the CBD entities must be involved in any analysis. The larger context of the SDGs is another layer in this ecology.

Barriers

We have not encountered substantive, credible analysis of the barriers to practice realization at this writing.

Positive Case Examples

None identified as establishing a solid precedent or template.

Current Guidance/Norms/Statements/Commitments

We did not identify coherent or grounded guidance or helpful metrics at this writing, except that ESG codes, broadly, are attempting to address the underlying issues from the corporate/commercial sector.

Selected Supporting Literature/Analysis

A framework for the promotion of ethical benefit sharing in health research
Anja Bedeker, Michelle Nichols et al.
Practice
BMJ Global Health, Vol.7:e008096, 2022
Abstract

There is an increasing recognition of the importance of including benefit sharing in research programmes in order to ensure equitable and just distribution of the benefits arising from research. Whilst there are global efforts to promote benefit sharing when using non-human biological resources, benefit sharing plans and implementation do not yet feature prominently in research programmes, funding applications or requirements by ethics review boards. Whilst many research stakeholders may agree with the concept of benefit sharing, it can be difficult to operationalise benefit sharing within research programmes. We present a framework designed to assist with identifying benefit sharing opportunities in research programmes. The framework has two dimensions: the first represents microlevel, mesolevel and macrolevel stakeholders as defined using a socioecological model; and the second identifies nine different types of benefit sharing that might be achieved during a research programme. We provide an example matrix identifying different types of benefit sharing that might be undertaken during genomics research, and present a case study evaluating benefit sharing in Africa during the SARS-CoV-2 pandemic. This framework, with examples, is intended as a practical tool to assist research stakeholders with identifying opportunities for benefit sharing, and inculcating intentional benefit sharing in their research programmes from inception.

Forms of benefit sharing in global health research undertaken in resource poor settings: a qualitative study of stakeholders' views in Kenya

Geoffrey M Lairumbi, Micheal Parker et al.
Open Research - ncbi.nlm.nih.gov
doi: 10.1186/1747-5341-7-7. PMID: 22251457; PMCID: PMC3274462, 2012
Abstract
Increase in global health research undertaken in resource poor settings in the last decade though a positive development has raised ethical concerns relating to potential for exploitation. Some of the suggested strategies to address these concerns include calls for providing universal standards of care, reasonable availability of proven interventions and more recently, promoting the overall social value of research especially in clinical research. Promoting the social value of research has been closely associated with providing fair benefits to various stakeholders involved in research. The debate over what constitutes fair benefits; whether those that addresses micro level issues of justice or those focusing on the key determinants of health at the macro level has continued. This debate has however not benefited from empirical work on what stakeholders consider fair benefits. This study explores practical experiences of stakeholders involved in global health research in Kenya, over what benefits are fair within a developing world context.

African genomic data sharing and the struggle for equitable benefit

Michèle Ramsay
Open Research - ncbi.nlm.nih.gov
Patterns (N Y), Vol. 3(1):100412. doi: 10.1016/j.patter.2021.100412
Abstract
Genomic and related health data from Africa remain scarce and are extremely valuable, due to an abundance of variants often rare or absent in the rest of the world. Insights from such data will benefit global populations, but will Africa be neglected by limited access to affordable benefits resulting from research that uses their data?

A scoping review of considerations and practices for benefit sharing in biobanking

Allan Sudoi, Jantina D. Vries et al.
Scoping Review
BMC Medical Ethics, Vol. 22, Issue 102, 2021

Abstract
Despite the rapid global growth of biobanking over the last few decades, and their potential for the advancement of health research, considerations specific to the sharing of benefits that accrue from biobanks have received little attention. Questions such as the types and range of benefits that can arise in biobanking, who should be entitled to those benefits, when they should be provided, by whom and in what form remain mostly unanswered. We conducted a scoping review to describe benefit sharing considerations and practices in biobanking in order to inform current and future policy and practice.

Benefit Sharing: From Compensation to Collaboration
Kadri Simm et al.
Cambridge University Press, p. 148-157, 2021 doi:10.1017/9781108620024.019
Abstract
Benefit sharing pertains to the distribution of benefits and burdens arising from research. More specifically, it concerns what, if anything, is owed to individuals, communities or even populations that participate in research (benefits to investors, to other populations or the social value of research more generally understood are not the focus of benefit sharing). In what follows, I will give a brief overview of the ethical arguments and historical dynamics behind benefit sharing practices, then outline major governance frameworks and discuss the potential problems around applying this concept in health research. The overall aim of this chapter is to highlight the complexity of benefit sharing and argue that success hinges on the careful balancing of universal research ethics duties with the particularities of concrete research projects taking place in distinct locations. Benefit sharing is no panacea for solving the inequalities of access and opportunities associated with global health research. Yet it can be a profoundly empowering tool, especially as the framework is shifting from compensation to collaboration.

Intellectual property waiver for covid-19 vaccines will advance global health equity
Parsa Erfani, Agnes Binagwaho et al.
Analysis
BMJ,374:n1837, 2021
Abstract
Parsa Erfani and colleagues argue that a temporary intellectual property waiver for covid-19 vaccines is vital to increase supply, achieve global herd immunity, and advance global health equity
By late June 2021, 46% of people in high income countries had received at least one dose of the covid-19 vaccine compared with 20% in middle income countries and only 0.9% in low income countries.1 This inequity has been driven by a global political economy that has permitted some countries to purchase more vaccine than they require while others have very limited supplies. Canada, for example, with a gross domestic product (GDP) of $46 000 (£32 000; €39 000) per head has vaccines for 434% of its population, whereas Jordan, which has twice the incidence of covid-19 and a GDP of $4400 per head, has secured doses for only 6% of its people.2 As covid-19 variants are already showing some ability to evade the current vaccines, it is evident that without global vaccine equity and immunity, our efforts against covid-19 are in jeopardy.
Equitable vaccine distribution to the world's highest risk populations requires a multipronged approach that includes vaccine development and approval; scaling manufacturing; streamlining shipment, storage, and distribution; and building vaccine confidence. International collaborations have helped tackle several of these fundamentals. However, the global community remains deeply divided on how to overcome the scarcity of supply. Pharmaceutical trade associations claim that supply is not a problem as manufacturers can supposedly provide 10 billion doses by the end of 2021.3 But as suppliers

consistently fall short in achieving manufacturing targets, production is clearly a bottleneck to global vaccination.3

Decolonising human rights: how intellectual property laws result in unequal access to the COVID-19 vaccine
Sharifah Sekalala, Lisa Forman et al.
Analysis
BMJ Global Health, Vol. 6:e006169, Issue 7, 2021
Abstract
The recent rapid development of COVID-19 vaccines offers hope in addressing the worst pandemic in a hundred years. However, many countries in the Global South face great difficulties in accessing vaccines, partly because of restrictive intellectual property law. These laws exacerbate both global and domestic inequalities and prevent countries from fully realising the right to health for all their people. Commodification of essential medicines, such as vaccines, pushes poorer countries into extreme debt and reproduces national inequalities that discriminate against marginalised groups. This article explains how a decolonial framing of human rights and public health could contribute to addressing this systemic injustice. We envisage a human rights and global health law framework based on solidarity and international cooperation that focuses funding on long-term goals and frees access to medicines from the restrictions of intellectual property law. This would increase domestic vaccine production, acquisition and distribution capabilities in the Global South.

The Intellectual Property Turn in Global Health: From a Property to a Human Rights View of Health
Laura G. Pedraza-Fariña
Article
Therapeutic Properties: Global Medical Cultures, Knowledge, and Law, Vol. 36, 2021
The University of Chicago Press journals doi.org/10.1086/713703
Abstract
International intellectual property (IP) law for pharmaceuticals has fundamentally shifted in the twenty-first century from a property-centric to a human rights view. Scholars tend to explain this transformation in the context of both the power struggle between developing and developed countries, and the influence of a social movement that criticized IP rights as hindering access to essential medicines. Yet, these explanations leave out the central role of two international organizations, the World Trade Organization (WTO) and the World Health Organization (WHO), and particularly their permanent staffs, whose boundary disputes have shaped international IP law at the intersection of trade and global health. Bringing into conversation historical and legal literatures on global health and IP, this article traces how a human rights perspective on IP emerged as a strategy to reconcile the WHO staff's sociomedical views of health with an increasingly dominant set of global IP rules. It shows how the WHO staff used the language of economics—an analytical frame favored by the WTO—to advance a then unorthodox economic understanding of IP as a type of governmental regulation. This allowed the WHO to argue that states should enjoy regulatory autonomy to curtail IP rights in order to meet broader state objectives, such as human rights protection. Paradoxically, despite their divergent views on the nature of IP, both WTO and WHO engagement with it heralded the emergence of a new technocratic view of global health that focuses on patentable medicines and technologies, and that has ultimately turned away from the WHO's sociomedical roots.

COVID-19 Vaccine, TRIPS, and Global Health Diplomacy: India's Role at the WTO Platform
Vijay Kumar Chattu, Bawa Singh et al.
Special Issue Article

Biomed Research International, Vol. 2021, 6658070, doi.org/10.1155/2021/6658070

Abstract

In light of the devastation caused by COVID-19, the Agreement on Trade-Related Aspects of Intellectual Property Rights (TRIPS) and vaccine research and development (R&D) have been occupying a prominent position in the field of global health diplomacy (GHD). Most countries, international organizations, and charitable organizations have been engaged in the R&D of COVID-19 vaccines to ensure timely affordability and accessibility to all countries. Concomitantly, the World Trade Organization (WTO) provides some provisions and enforcements regarding copyrights, patents, trademarks, geographical indications, and industrial designs. Given these safeguards, it is considered that intellectual property rights (IPRs) have become major barriers to the affordability and accessibility of vaccines/medicines/technology, particularly to the developing/least developed countries. Realizing the gravity of the pandemic impact, as well as its huge population and size, India has elevated this issue in its global health diplomacy by submitting a joint proposal with South Africa to the World Trade Organization (WTO) for a temporary waiver of IPRs to ensure timely affordability and accessibility of COVID-19 medical products to all countries. However, the issue of the temporary waive off had become a geopolitical issue. Countries that used to claim per se as strong advocates of human rights, egalitarianism, and healthy democracy have opposed this proposal. In this contrasting milieu, this paper is aimed at examining how the TRIPS has become a barrier for developing countries' development and distribution of vaccines/technology; secondly, how India strategizes its role in the WTO in pursuant of its global health diplomacy? We conclude that the IPRs regime should not become a barrier to the accessibility/affordability of essential drugs and vaccines. To ensure access, India needs to get more engaged in GHD with all the involved global stakeholders to get strong support for their joint proposal. The developed countries that rejected/resisted the proposal can rethink their full support.

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10.0 Evidence Integrity/Data Quality/Data Sharing

Summary

Science and research activity across disciplines, and the evidence base this activity generates, should be presumed to enjoy full integrity regardless of where it is conducted. That presumption is subject to the scientific process, including examination and challenge by peers, reproducibility, transparency, ethical resilience including robust protection of human subjects, freedom from conflict of interest and corrupting influences, and adherence to global norms. Science and research activity should not be evaluated or utilized/not utilized on the basis of immutable characteristics of persons, including country of origin or country of residence, family history, economic circumstance or gender.

Data Quality

Recognizing the presumption and principles above, the realities and pressures faced by researchers, research institutions and the full ecology around science are considerable and probably growing. This makes rigorous confirmation of the source, quality and continuing integrity of datasets a contuing imperative.

Data Sharing

It is also imperative for equity in global health research that research institutions/sponsors/funders including NIH embrace data sharing according to the FAIR principles; respecting the data ethics around collection, storage, anonymization and confidentiality, and aligning with Open Science principles. To successfully involve more LMIC researchers/institutions/countries in global-scale research, guidelines are needed on preparing the necessary human, technological, and scientific resources to deliver transparent, top-quality, and standardized data to relevant researchers and national/international research coalitions. This posture presumes alignment to the view that global health research should be treated as a global public good.

Practice Realization [How would it look?]

We are developing a grounded statement on practice realization but it was not ready in time for this submission.

Current Ownership/Power Structures

We have not encountered substantive, credible analysis of the ownership, power structures and related dynamics here at this writing.

Barriers

We have not encountered substantive, credible analysis of the specific barriers to practice realization at this writing.

Positive Case Examples

None identified as establishing a solid precedent or template.

Current Guidance/Norms/Statements/Commitments

We are aggregating various guidances/statements around data quality/data sharing/open science but this was not completed in time for this submission.

Selected Supporting Literature/Analysis

Establishing a blockchain-enabled Indigenous data sovereignty framework for genomic data
Tim K. Mackey, Alec J. Calac, B S Chenna Keshava, Joseph Yracheta, Krystal S. Tsosie, Keolu Fox
Commentaries
Cell, Jul 21, 2022 Volume 185 Issue 15
Technological advances have enabled the rapid generation of health and genomic data, though rarely do these technologies account for the values and priorities of marginalized communities. In this commentary, we conceptualize a blockchain genomics data framework built out of the concept of Indigenous Data Sovereignty.

Equitable Research Partnerships; A Global Code of Conduct to counter Ethics Dumping
Doris Schroeder, Kate Chatfield et al.
Book
Springer, 2019 ISBN 978-3-030-15745-6 (eBook) https://doi.org/10.1007/978-3-030-15745-6

Adjusting the focus: A public health ethics approach to data research
Angela Ballantyne
Special Issue: Research and Ethics
Developing World Bioethics, Vol. 36, Issue 6, 2019
Abstract
This paper contends that a research ethics approach to the regulation of health data research is unhelpful in the era of population-level research and big data because it results in a primary focus on consent (meta-, broad, dynamic and/or specific consent). Two recent guidelines – the 2016 WMA *Declaration of Taipei on ethical considerations regarding health databases and biobanks* and the revised CIOMS *International ethical guidelines for health-related research involving humans* – both focus on the growing reliance on health data for research. But as research ethics documents, they remain (to varying degrees) focused on consent and individual control of data use. Many current and future uses of health data make individual consent impractical, if not impossible. Many of the risks of secondary data use apply to communities and stakeholders rather than individual data subjects. Shifting from a research ethics perspective to a public health lens brings a different set of issues into view: how are the benefits and burdens of data use distributed, how can data research empower communities, who has legitimate decision-making capacity? I propose that a public health ethics framework – based on public benefit, proportionality, equity, trust and accountability – provides more appropriate tools for assessing the ethical uses of health data. The main advantage of a public health approach for data research is that it is more likely to foster debate about power, justice and equity and to highlight the complexity of deciding when data use is in the public interest.

Data quality assessments stimulate improvements to health management information systems: evidence from five African countries
Jennifer Yourkavich, Debra Prosnitz et al.
Journal of Global Health, Vol. 9, Issue 1, 2019
Abstract
Health service data are used to inform decisions about planning and implementation, as well as to evaluate performance and outcomes, and the quality of those data are important. Data quality assessments (DQA) afford the opportunity to collect information about health service data. Through its Rapid Access Expansion Programme (RAcE), the World Health Organization (WHO) funded non-governmental organizations (NGO) to support Ministries of Health (MOH) in implementing integrated community case management (iCCM) programs in the Democratic Republic of Congo, Malawi,

Mozambique, Niger and Nigeria. WHO contracted ICF to support grantee monitoring and evaluation efforts, part of which was to conduct DQAs to enhance program monitoring and decision making. The contribution of DQAs to data-driven decision making has been documented and the purpose of this paper is to describe how DQAs contributed to health management information system (HMIS) strengthening and the findings of subsequent DQAs in those areas.

Data Quality of Chinese Surveillance of COVID-19: Objective Analysis Based on WHO's Situation Reports

Alvaro J. Idrovo, Edgar F. Manrique-Hernândez

Analysis

Asia Pacific Journal of Public Health, Vol 32, Issue 4, 2020

Abstract

Was there quality in the Chinese epidemiological surveillance system during the COVID-19 pandemic? Using data of World Health Organization's situation reports (until situation report 55), an objective analysis was realized to answer this important question. Fulfillment of Benford's law (first digit law) is a rapid tool to suggest good data quality. Results suggest that China had an acceptable quality in its epidemiological surveillance system. Furthermore, more detailed and complete analyses could complement the evaluation of the Chinese surveillance system.

Use of standardised patients for healthcare quality research in low- and middle-income countries

Ada Kwan, Benjamin Daniels et al.

Analysis

BMJ Global Health, Vol 4, Issue 5e001669, 2019

Abstract

The use of standardised patients (SPs)—people recruited from the local community to present the same case to multiple providers in a blinded fashion—is increasingly used to measure the quality of care in low-income and middle-income countries. Encouraged by the growing interest in the SP method, and based on our experience of conducting SP studies, we present a conceptual framework for research designs and surveys that use this methodology. We accompany the conceptual framework with specific examples, drawn from our experience with SP studies in low-income and middle-income contexts, including China, India, Kenya and South Africa, to highlight the versatility of the method and illustrate the ongoing challenges. A toolkit and manual for implementing SP studies is included as a companion piece in the online supplement.

The IHME in the Shifting Landscape of Global Health Metrics

Manjari Mahajan

Special Issues

Global Policy, Vol 10: 110-120, 2019

Abstract

The rise of the Institute for Health Metrics and Evaluation (IHME) has augured profound changes in the landscape of global health metrics. Primarily funded by the Bill and Melinda Gates Foundation, the IHME has offered donors a platform for assessing many health-related Sustainable Development Goal (SDG) indicators and a toolkit to measure the progress of different countries. The IHME's increasing influence reveals the relative sidelining of international agencies and especially the World Health Organization

which has long been central to global health metrics production. This shift reflects a growing conflict between the expertise and norms of national and intergovernmental statistical production on the one hand, and the distinct epistemologies and logics of new non-state data actors. These transitions – from an international world of statistics to a more plural, global realm of data – have acute implications for the politics and accountability of knowledge production related to the SDGs and development writ large. Even as the SDGs embrace the rubric of 'no one left behind', the emerging data politics might be eroding the ability of poorer states to know and act upon their development problems on their own terms.

Health data poverty: an assailable barrier to equitable digital health care
Hussein Ibrahim, XiaoxuanLiu
Viewpoint
The Lancet Digital Health, Vol. 3, Issue 4, p. E260-e265, 2021
Abstract
Data-driven digital health technologies have the power to transform health care. If these tools could be sustainably delivered at scale, they might have the potential to provide everyone, everywhere, with equitable access to expert-level care, narrowing the global health and wellbeing gap. Conversely, it is highly possible that these transformative technologies could exacerbate existing health-care inequalities instead. In this Viewpoint, we describe the problem of health data poverty: the inability for individuals, groups, or populations to benefit from a discovery or innovation due to a scarcity of data that are adequately representative. We assert that health data poverty is a threat to global health that could prevent the benefits of data-driven digital health technologies from being more widely realised and might even lead to them causing harm. We argue that the time to act is now to avoid creating a digital health divide that exacerbates existing health-care inequalities and to ensure that no one is left behind in the digital era.

The ethics of data sharing and biobanking in health research
Susan Bull, Niresh Bhagwandin
Open Research - ncbi.nlm.nih.gov
Wellcome Open Research, Vol. 5:270. doi: 10.12688/wellcomeopenres.16351.1, 2020
Abstract
The importance of data sharing and biobanking are increasingly being recognised in global health research. Such practices are perceived to have the potential to promote science by maximising the utility of data and samples. However, they also raise ethical challenges which can be exacerbated by existing disparities in power, infrastructure and capacity. The Global Forum on Bioethics in Research (GFBR) convened in Stellenbosch, South Africa in November 2018, to explore the ethics of data sharing and biobanking in health research. Ninety-five participants from 35 countries drew on case studies and their experiences with sharing in their discussion of issues relating to respecting research participants and communities, promoting equitable sharing, and international and national approaches to governing data sharing and biobanking. In this editorial we will briefly review insights relating to each of these three themes.

It is not enough that we require data to be shared; we have to make sharing easy, feasible and accessible too!
Gabriela Karolina Hajduk, Nina E Jamieson et al.
Commentary
BMJ Global Health, Vol. 4:e001550, 2019
Abstract

:: The sharing of health data, including clinical trial data, is required more and more often by research publishers, regulatory agencies, ethics committees and funding bodies.
:: Despite these requirements, there are currently no clear standards and guidelines of how, where and when researchers should share their data.
:: The confusion among researchers regarding issues related to data sharing has led funders such as The European and Developing Countries Clinical Trials Partnership (EDCTP) to devise initiatives that will provide their grantees, and the wider scientific community within the field of global health research, with clear guidance and a range of tools to facilitate the data sharing process.
:: In an effort to support and facilitate data sharing, the EDCTP is working in collaboration with The Global Health Network to assess whether a cross-cutting knowledge hub around data sharing would help researchers find the optimum repository and to gather their data in a form that is ready for sharing.

Ethical principles for promoting health research data sharing with sub-Saharan Africa
Evelyn Anane-Sarpong, Tenzin Wangmo, et al.
Original Article
Developing World Bioethics, Vol. 20: 86– 95. https://doi.org/10.1111/dewb.12233
Abstract
A powerful feature of global health research is data-sharing with regions which bear the heaviest burden of disease. It offers novel opportunities for aggregating data to address critical global health challenges in ways higher than relying on individual studies. Yet there exist important stratifiers of the capacity to share data, particularly across the Global North-South divide. Systemic challenges that characterize sub-Saharan Africa and disadvantage the region's scientific productivity threaten the burgeoning data-sharing culture too. Like all endeavors requiring equal commitments under unequal circumstances, a strong ethical impetus is needed to help reduce inequities and imbalances to encourage adherence. This article discusses mandatory data-sharing in relation to peculiar challenges faced by sub-Saharan African scientists to suggest ethical principles for rethinking and reframing solutions. We propose six principles which mirror guidelines from the Institute of Medicine and encapsulate principles from the Emanuel Framework, Nairobi Data Sharing Principles, and the COHRED guidelines.

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