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Key to successful global health collaborations: research, ethics and community engagement and involvement

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INTRODUCTION

Democracy is the government of the people, by the people and for the people, according to the ancient Greeks and Abraham Lincoln. Similarly, health research needs to be of low- and middle-income country (LMIC) people, by LMIC people and for people in LMICs, as well as people in high-income countries (HICs).

Vestigial views of 'global health research should be driven by our agenda and the outputs belong to us since we pay for it' can still be heard despite the calls for and drive towards more equitable partnerships in global health. Organisations such as the US NIH (Working Group on Promoting Equity in Global Health Research Collaborations)^{1,2} and the UKRI (UK Collaborative on Development Research 'Building Partnerships of Equals')¹ are working towards fairer research partnerships.

EQUITABLE PARTNERSHIPS IN GLOBAL HEALTH

There has been much written on equitable partnerships, recognising the importance in its own right,³ as well as in ensuring sustainability, efficiency and yielding better outcomes.³ One of the early writings on conducting ethical research in developing countries by Emanuel *et al* emphasised the need for minimising exploitation and collaborative partnerships.³ More recent writing by Kumar *et al* discussed the systemic inequalities reinforcing inequities and the need for individual and institutional empowerment in combating such inequity.³

Our experiences indicate three areas upon which equitable global health partnerships are built: equity in research, ethics as a mandatory requirement and community engagement and involvement (CEI).

The role of research in global health: bidirectional knowledge flows

We believe research is the way forward to address this inequity in global health. Research collaborations among HICs and LMICs can be the way forward to close the health, research and publication gap between Global North and Global South.⁴ In the current context of the 10/90 (LMIC/HIC) divide in resource allocation, research funding and publications, as well as the disproportionate burden of diseases in LMICs, it can be challenging for LMICs to swim against the tide, particularly given the less well-developed research culture.⁵

SUMMARY BOX

- ⇒ The need for more equitable partnerships in global health research is being increasingly recognised and valued, with powerful organisations such as the US NIH and UKRI investigating mechanisms to promote equity in global health research.
- ⇒ Despite these efforts, there is much to be achieved, with vestigial views of 'he who pays the piper calls the tune' still lingering and the practical difficulties of embedding the concept of equity in research partnerships.
- ⇒ As researchers from the Global South, we share our views on what research funders and intermediary organisations can do to achieve global health collaborations that are a 'win-win situation' for all partners, and summarise our experience: incorporating research, ethics and community engagement and involvement into partnerships is the key to successful global health collaborations.

There is some evidence that research carried out in the Global South had significant impact also on the Global North, though the quantum of research is limited (ie, 6% of total global research output).^{5,6} A clinical trial (1687 patients) conducted in South America, Africa and India⁶ that demonstrated magnesium sulfate as the treatment of choice for eclampsia is an early example of how collaborations can provide answers to global health problems. Another classic example is the research carried out by Patel *et al*.⁵ Before the findings of this study were disseminated, the WHO recommended syndromic management for vaginal discharge, where women were treated for some or all of five common reproductive tract infections, resulting in significant social cost through divorces due to mistrust among partners.⁷ A third example is the research carried out by Rahman *et al* on delivering psychosocial interventions by community health workers for maternal depression in Pakistan.^{8,9}

The inequities in health research are to be exacerbated by the modern trends in healthcare. For example, in the use of artificial intelligence (AI) in healthcare, AI draws conclusions and makes predictions based on the large healthcare databases it is trained on. The large, high-quality datasets required



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for training AI technologies are very limited in LMICs, so that the models and algorithms in AI usage will not function optimally for the under-represented people of LMICs.¹⁰

Despite the significant efforts from HICs to boost global health research in the recent past, the distance that is yet to be travelled was indicated by the investigation the senior author of this article carried out on under-representation of LMICs in the research literature in 2023: excluding USA, UK and other Euro-American countries, contribution from the Rest of the World in the research literature amounted to 6.5% in 2000 and increased to 11.9% after 17 years.¹¹

Ethics in research as a key pillar in successful and equitable global health partnerships

Incorporating ethical practice into research should be an essential prerequisite of global health research, given the inequity in resource distribution as well as the concentration of new knowledge production belonging to a minority of HICs despite contributions from LMICs in that knowledge creation. Research is carried out in LMICs with the beneficial intent of promoting access to more advanced technology, knowledge, treatment and care; at the same time, it is also considered an opportunity to conduct clinical research, for example, in a location where it can be carried out at a lower cost and where legal and regulatory requirements are simpler.¹²

Justice and fairness is a key ethical aspect that needs to be considered in research in LMICs. There is a move towards ensuring fairness in research by mandating reporting on research fairness: the Research Fairness Initiative reporting areas require that research projects report on the fairness of opportunity (relevance to communities, fair research contracting, fair recognition of management capacities), fair process (minimising negative impact, fair local hiring and training, fair data ownership, fair local hiring and full cost recovery) and, lastly, on the fair sharing of benefits, costs and outcomes.¹³

In a global health research context where the power differential is significant between HIC and LMIC partners, those from LMICs may become vulnerable. There should be respect for the autonomy and dignity of LMIC collaborating partners and their freedom of thought and action. LMIC partners should have an equal say in the collaboration. HIC partners need to respect the rights of LMIC partners and take necessary steps to provide support where the freedom of choice may be limited.

We identify five interconnected issues related to research that impact the level of equity in a global health partnership. These are matters that affect the research community in LMICs and need addressing independent of specific research projects.

Involving LMIC researchers throughout the research cycle

Priority and agenda setting based on funders or HIC partners' requirements is arguably inevitable.¹³ This, however, translates into issues of sustainability and effectiveness since these agendas do not always align with local needs and priorities where the research is carried out. What is certainly avoidable is the practice of limiting LMIC researchers to secondary roles (such as data gathering, gaining regulatory/ethical approvals, recruiting participants and operations management) while retaining the more scientific roles of research design, data analysis, research report generation and dissemination for HIC researchers. In our experience, what has invariably proven unsuccessful is the situation where HIC researchers arrive in LMICs with the research protocol written and instructing LMIC researchers to implement the research project. The most successful research was carried

out in LMICs where the research was codesigned by HIC and LMIC co-PIs, with bidirectional knowledge sharing.

Strengthening capacity in LMICs and HICs

Capacity building should in our view be a requirement of any LMIC-related grant funding. An excellent case in point for demonstrating the value of capacity building is the establishment of a genetics laboratory at the Institute for Research and Development in Healthcare in Sri Lanka. During the research project, to establish the Sri Lanka Twin Registry Biobank in collaboration with researchers from the Institute of Psychiatry, Kings College and the University of Sydney, there was some pressure to transfer the biological material to the UK/Australia for analysis due to the concern that it would take time to develop the necessary expertise in Sri Lanka. However, weighing the delay against the detrimental impact of LMIC researchers being relegated to mere data gatherers and losing the long-term benefits of developing capacity in Sri Lanka for genetic research, the HIC researchers supported the training and skill upgrading of the Sri Lankan team, leading to the highly successful genetic laboratory that today trains hundreds of Sri Lankans in genetic research (www.ird.lk).

Outputs: authorships, publications, presentations

Significant disparities in LMIC researchers receiving authorship, more notably as first or last authors, have been recorded. For example, a systematic review of authorship in collaborative health research in Africa revealed that there is low representation of authors from Africa in publications¹⁴; where there was collaboration with a top US university, only 41% of all authors and 23% of first authors were from the country where the research was carried out. Furthermore, 13.5% of all papers had no local coauthor. In the same vein, Smith *et al*¹⁵ pointed out that the power differential between HICs and LMICs in research collaborations is represented in unequitable distribution of authorships among collaborators. There is similar disparity in LMIC researchers having reduced opportunities for presentations and dissemination of findings.

In our experience, collaborative partnerships with HIC researchers can ensure equity in research outputs by fair sharing of authorship; the twin registry project previously mentioned resulted in a number of papers with Sri Lankan researchers as first author. More recently, a research on participation in genomic research was published with the Sri Lankan researcher as the first author and the HIC researcher as the last author.¹⁶

Funding structures and grant reviews

Grant reviews are usually carried out by HIC institutions, and LMIC researchers have limited input into the process. The systemic constraints of lack of administrative and financial capacity to meet the requirements of the grant application process for LMIC researchers are exacerbated by the limits placed on indirect costs for LMIC institutions. The practice of reimbursement too imposes difficulties on LMIC research institutions which lack the financial strength to fund a project up-front and wait for reimbursement. Again, we have encountered HIC institutions which have been understanding of these constraints, going the extra mile to change grant conditions to accommodate the realities of doing research in LMICs.

Data ownership, analysis and access

This is also an area of significant contention since some HIC institutions have a requirement that all data generated by the

research vest in the HIC institution. This is sometimes in spite of the funders' specific rule that data and the intellectual property generated belong to the place that generates it, evidently with the requirement to share access with all partners. For example, the MRC UK Grant award conditions specify that the 'ownership of all intellectual assets rests with the organisation that generates them'¹⁷; however, some UK intermediary institutions that administer grant collaborations have the condition that 'all intellectual property... developed by any member of the staff of any of the Parties shall vest in the UK institution'.¹⁸ This undermines equity in the partnership.

Community engagement and involvement

CEI, a key requirement for ethical research, simply means 'research being carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them'.¹⁹ CEI can occur throughout the research cycle; community members can, for example, participate in identifying research priorities, serve as members of advisory or steering groups, provide input on research design, contribute to the development of patient information materials, advise on patient recruitment strategies and help conduct interviews with research participants. Community members can also work with primary researchers as joint grant holders or coapplicants in research projects. This comprehensive involvement ensures that research aligns with community needs and fosters collaborative and impactful outcomes. In the global health context, CEI can also be framed as collaborative partnerships between the researcher and the local communities to involve them in addressing health needs.²⁰

Public accountability is essential since research relies on people, public resources and existing knowledge in the public domain. CEI ensures that public good results from research, though not necessarily immediately. CEI contributes to generating bidirectional mutual benefits for researchers and communities, and it is important in health and social care research since it drives social change by influencing stakeholders with government, political or funding power to implement public health projects and policies that primarily benefit communities. CEI is therefore an ethical obligation in the global health context, where ethics is a critical but supportive friend in research.

CONCLUSION

Achieving equity in health for all people worldwide is challenging in the current world. Collaborative research between the Global North and Global South can help navigate the challenges and barriers to equity in health. Such research collaborations should operate ethically as a 'win-win situation' for all stakeholders. Global health research should promote the public good and address the health priorities of both HICs and LMICs, with researchers accountable to the public. CEI is the way forward to ensure that research is sensitive to the needs of the populations (including vulnerable groups) and beneficial to communities in all parts of the world.

We therefore propose that these three essential pillars, (1) research, (2) ethics and (3) CEI, should be brought together as mandatory interconnected components of all global health research collaborations. We believe research excellence can only be achieved through a holistic approach, involving deep understanding, practice and capacity development in each of these three pillars.

As researchers originating from the Global South, our experience in collaborative work with institutions from

the Global North over the past two decades has been that most researchers and organisations are very willing to go extra mile to ensure ethical, equitable and mutually beneficial partnerships between the Global North and the Global South. A case in point is the willingness many UK universities showed to amend research contracts to share ownership in data generated by research in the South, whereas archaic regulations required the Northern institutions to have sole ownership of data generated. In another situation, when the lack of ethical considerations in grant applications was pointed out to a major funding institution in the UK, they took measures to incorporate ethical review as a mandatory requirement in future funding calls. This is why we believe it is important to draw the attention of the research community towards ethics, research and CEI as the three fundamental pillars of successful global health collaborations.

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