

Reimagining research partnerships: Equity, power and resilience

Accra, Ghana 18 & 19 November 2025



Pecha Kucha presentation

No samples without justice: Lessons from a Malaysian TB research partnership

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Brief description of context

Global TB Burden:

Tuberculosis (TB) remains a pressing global health challenge. In 2023, an estimated 10.8 million people fell ill with TB and 1.25 million died from the disease (1). The burden is overwhelmingly concentrated in low- and middle-income countries (LMICs), which account for the vast majority of cases (2). Malaysia, while not among the highest TB burden nations, has witnessed a resurgence of TB – 26,781 cases were reported in 2023 (up from ~25,000 in 2022) (3).

Case Study in Malaysia:

Against this backdrop, we examine a 3-year collaborative TB research project between a Malaysian university hospital and a high-income country academic institution that illustrates ethical challenges in data and sample sharing. The foreign partner secured substantial international funding and drafted the research protocol with minimal input from the Malaysian team. The local institution's primary role was to collect sputum and blood samples from Malaysian patients and ship them abroad for genomic analysis and other components of the study. A research agreement and a material transfer agreement were executed to enable the transfer of biological specimens and anonymised data, but these documents did not clearly set out data ownership, authorship criteria, or fair benefit-sharing. Problems arose when Malaysian researchers were denied equitable access to the genomic data and were excluded from key decisions, particularly regarding secondary uses. Frustrations escalated as Malaysian contributors were underrepresented in publications, and possible intellectual property arising from a diagnostic finding was not addressed in a transparent manner. The local team reported feeling constrained, believing there was little they could do to challenge what they viewed as an intensely unfair partnership.

Discussion of ethical issues

Unfair Research Agreements in Research Partnership:

Formal research agreements such as Memoranda of Agreement (MoA) and Material Transfer Agreements (MTA) often reflect the power imbalance between high-income country (HIC) institutions and their LMIC partners. In many North-South collaborations, the legal documents are drafted by the HIC side (often using their templates) with little input from the LMIC researchers, resulting in terms that disproportionately favour the HIC partner (4). For example, crucial issues like ownership of data or specimens, intellectual property rights, and benefit-sharing are frequently skewed towards the HIC institution. One analysis noted that when research leads to valuable discoveries, "ownership and control of downstream discoveries can become contentious" if not clearly addressed (5). Yet, benefit-

sharing clauses in many agreements are vague or weak, offering LMIC institutions little guaranteed return. A review of South Africa's standard MTA found its benefit-sharing provision so "*vague*" as to have "*little practical effect,*" and that its dispute resolution and intellectual property terms failed to adequately protect the local institutions' interests (4). These kinds of unfair terms persist in the absence of robust pushback or negotiation from the LMIC side.

Why do such formal agreements fail to address inequities?

A major reason of this failure is the asymmetry in negotiating power and capacity. Typically, HIC funders or universities insist on their preferred preconditions, and LMIC partners often lack the leverage or resources to negotiate changes (6). It is "not unusual" for a HIC research manager with legal support to be negotiating against an LMIC researcher who has little or no access to legal counsel or research administration support. This imbalance leaves the LMIC side at a disadvantage in understanding and pushing back on complex contractual terms.

Moreover, local researchers are frequently hesitant to insist on fairer terms for fear of losing the collaboration opportunity. Indeed, collaboration in global health is sometimes seen as a benevolent offering by HIC partners, leading to a problematic expectation that the LMIC side should be "*grateful*" and compliant (7). Many LMIC investigators worry that objecting to one-sided terms or demanding concessions could jeopardize the funding or partnership. As one commentary highlighted, LMIC collaborators in the past often stayed silent and simply did the work, being told by some HIC partners that they were "*only hired to do the research and not to be involved in key decision making*" (7). This patronizing, neo-colonial attitude perpetuates a dynamic in which formal agreements go unchallenged by the LMIC party.

What did local researchers do (or not do) and why?

Frequently, LMIC researchers signed agreements "as is" with minimal alterations. The reasons range from lack of bargaining power to lack of familiarity with contractual intricacies. Many did not push back on unfair clauses regarding data ownership, specimen export, or intellectual property, often because they did not feel empowered to do so. As a LMIC researcher explained, without the collaboration they might not be able to conduct the research at all, so they accept being junior partners rather than risk the project (8).

In some cases, local scientists were essentially relegated to data/sample collectors: "*just being used for collecting materials*" that would later be analysed and capitalized on by foreign labs, yielding publications or patents with little local benefit. This scenario arises especially when the LMIC team lacks the lab infrastructure or analytical capacity. Similar with case study above, they collect samples and send them abroad, where the HIC partner conducts advanced analyses and reaps the rewards in terms of intellectual property or high-impact publications (7). Local researchers historically acquiesced to such arrangements due to a combination of *necessity, lack of support, and fear*: necessity because the research addresses local health problems that would otherwise remain unstudied; lack of support because their institutions had limited legal/administrative frameworks to negotiate better terms; and fear because saying "no" might mean the HIC collaborator takes their project and potential resources elsewhere.

Notably, formal agreements rarely contained provisions to counteract these issues unless LMIC stakeholders actively fought for them, which was rare. For instance, issues of fair data access or equitable authorship are seldom codified in MoAs, leaving such matters to informal understandings that often default in favour of the HIC investigators. Likewise, material transfer agreements have often focused on protecting the material provider (if the HIC is providing reagents) or the recipient (if the HIC is receiving valuable samples) without ensuring *mutual* benefit. In summary, the combination of HIC-dominated contract templates, LMIC lack of negotiating capacity, and willingness to concede for the sake of collaboration explains why standard agreements did not redress partnership inequities. Instead, they often embodied and reinforced those inequities (6).

Shift towards more negotiation power among LMIC partners?

Over the years, some LMIC researchers and institutions have grown more aware and assertive about fair partnership terms. Encouragingly, there are reports of African researchers directly asking foreign partners upfront: “*Do you want me to work with you or to work for you?*”, signalling that they will no longer passively accept subordinate status (9). This kind of pushback, though still not the norm, indicates a shift toward negotiating more equitable roles and agreements.

Towards fair and equitable partnerships: Addressing the challenges

To rectify these inequities, the global research community, including funders, HIC institutions, and LMIC stakeholders, is gradually recognising the need for change. Addressing the unfairness in agreements requires building negotiation capacity on the LMIC side and commitment to fairness on the HIC side.

Initiatives have highlighted that LMIC institutions must have access to legal and managerial support to negotiate contracts, otherwise they will remain at a disadvantage. Providing training and resources for research management in LMIC universities (e.g. dedicated grants offices or legal advisors for international projects) is one practical step. This would help local researchers understand their rights and options before signing a MoA/MTA, enabling them to, for instance, insist on clauses for shared data ownership, benefit-sharing (such as technology transfer or a portion of future royalties), and equitable publication credit.

There are now tools like the COHRED Fair Research Contracting toolkit and guidelines on best practices which aim to empower LMIC institutions as equal partners in contracting (10). Similarly, some funders and consortia promote the use of model agreements that incorporate equity principles (for example, the Global Code of Conduct for Research in Resource-Poor Settings, developed in 2018, provides ethical guidance to prevent “ethics dumping” and encourage fair partner treatment) (10). These frameworks encourage transparency and mutual accountability e.g., requiring that any human samples exported be used only for agreed purposes and that results be shared promptly with the origin country. While guidelines alone are not enough, they set expectations that can be reinforced by institutional policies.

Ultimately, HIC partners should be willing to modify their boilerplate agreements: rather than a “*take it or leave it*” approach, contracts should be co-developed, acknowledging the LMIC contributions (intellectual and material) and including provisions to ensure the LMIC side tangibly benefits from the research (6, 10).

Conclusions and recommendations

The central problem in many HIC and LMIC collaborations lies in how research agreements are drafted and enforced. When MTAs and MoAs are written unilaterally, vague on data ownership, authorship, benefit sharing, IP, and secondary use, they concentrate control with the fund holder and sideline local partners. The Malaysian TB setting illustrates these risks, where those closest to the burden sign instruments that do not adequately protect their interests or the interests of participating communities. The remedy is straightforward. Build clarity and reciprocity into the documents from the start through explicit provisions on rights and responsibilities, shared decision making for data and samples, transparent authorship criteria, and practical dispute resolution. This is a legal and ethical task before it is a leadership one. Once agreements are fair and enforceable, partnerships become more trustworthy and productive, and importantly, the likelihood of LMIC led studies rises naturally in diseases that primarily affect LMIC populations.

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