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NO SAMPLES WITHOUT JUSTICE: LESSONS FROM A MALAYSIAN TB RESEARCH PARTNERSHIP

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CONTEXT & GLOBAL TB BURDEN

TB remains a pressing global health challenge.

2023: ~10.8 million people fell ill; ~1.25 million deaths.

Burden is overwhelmingly concentrated in LMICs.

MALAYSIA — RECENT TREND

Not among the highest-burden nations, but cases are resurging.

2023: 26,781 reported cases (up from ~25,000 in 2022).

CASE STUDY OVERVIEW

- Collaboration: Malaysian university hospital + HIC academic institution.
- Foreign partner secured major funding and drafted protocol with minimal local input.
- Local role: collect sputum/blood; ship samples abroad for genomic analysis.
- Agreements existed (research agreement & MTA) but lacked clarity on key protections.

WHERE IT WENT WRONG

- Local team denied equitable access to genomic data and key decisions (esp. secondary uses).
- Under-representation of Malaysian contributors in publication (3 papers but only one paper with local team)
- Potential IP from a diagnostic discovery – no involvement local team.
- LMIC partners felt constrained and unable to challenge unfair terms.

THE CONTRACT PROBLEM (MOA/MTA)

- Templates usually drafted by HICs; LMIC input limited.
- Key issues (data/specimen ownership, IP, benefit-sharing) skewed to HICs.
- Benefit-sharing clauses often vague; dispute resolution may not protect LMIC interests.



WHY AGREEMENTS FAIL TO ADDRESS INEQUITIES

- Asymmetric negotiating power & capacity (legal/admin support vs. none).
- Fear of losing collaboration or funding if LMICs push back.
- Patronizing expectations: LMICs should be grateful and compliant.

WHAT LOCAL RESEARCHERS DID (AND DIDN'T)

- Often signed agreements 'as is' with minimal changes.
- Limited pushback on data access/ownership, authorship, and IP clauses.
- Rationale: necessity (local health needs), lack of support, fear of losing out.

SIGNS OF CHANGE



Some LMIC researchers (South African) now query roles explicitly: “work with us or for you?”



Gradual shift toward negotiating equitable roles and recognition.



Still not the norm, but momentum is building.

TOWARDS FAIR PARTNERSHIPS: PRACTICAL STEPS

1. Build LMIC
negotiation capacity:
grants/legal support,
research admin units.



2. Co-develop
agreements; avoid
'take it or leave it'.

TOWARDS FAIR PARTNERSHIPS: PRACTICAL STEPS

3. Embed clear, enforceable provisions on data/specimen rights, authorship, IP, and benefit-sharing.



4. Adopt equity frameworks (e.g., Global Code of Conduct) and toolkits (e.g., COHRED FRC).

CLAUSES TO INCLUDE (EXAMPLES)

- Shared data ownership and timely reciprocal access; governed secondary use approvals.
- Transparent authorship and contributorship criteria agreed at project start.

CLAUSES TO INCLUDE (EXAMPLES)

- Defined benefit-sharing: technology transfer, training, co-ownership of IP/royalties where appropriate.
- Practical dispute resolution mechanisms accessible to LMIC partners.

IMPLICATIONS FOR SCIENCE & EQUITY

Fair

Fair agreements build trust and reduce friction.

Better

Better alignment with local disease burden
→ more LMIC-led studies over time.

Sound

Ethically sound partnerships often produce more impactful, context-relevant science.

CONCLUSION

- Unilateral, vague agreements concentrate control and sideline local partners.
- Remedy: clarity + reciprocity in MoA/MTA from the outset.
- When agreements are fair and enforceable, partnerships become trustworthy, productive, and more LMIC-led.