Health research priorities in low resource settings – perspectives from rural North-east India

Starlin Vijay Mythri, Makunda Christian Leprosy and General Hospital, Assam, India

Brief description of case study context

Our not-for-profit hospital is situated in a remote rural part of North-east India, bordering Bangladesh. Over the past 30 years, we have established affordable secondary level healthcare with reasonable quality of service. We provide medical, surgical, pediatric and obstetric services to mostly poor and marginalized communities like Dalit and tribal or religious minorities. About 124,000 people accessed care at our hospital in the last year.

As our state in general and our district in particular have one of the highest maternal mortality rates in the country, we have prioritized obstetric care in our service provision and research. Our area has poor public healthcare and transport systems and about 46% of the population is multi-dimensionally poor[1]. As we provide affordable and quality care, we are a significant obstetric healthcare provider in this area. Although hospitals like ours in remote areas are chronically under-staffed, they have dedicated young professionals who are keen to address difficult local healthcare problems. We have sought research collaborations which would help us address some critical questions related to maternal and child health (hereafter, MCH). We are learning not to participate in research proposals which are not of relevance to the healthcare needs of our rural populations. Additionally, due to our organizational limitations, we do not want to participate in proposals which stretch our ability to provide the much needed clinical care.

We were approached by a global health research organization to participate in a multi-centric MCH research project with two goals: 1) to develop data-driven pregnancy risk stratification algorithms and commercial tools to address biological vulnerabilities which adversely affect MCH outcomes, and 2) to generate useful public health information regarding the readiness of local health facilities to provide MCH care. Commercial tools like these might take the form of a risk management solution in order to predict health risks during annual wellness visits for the insured and help healthcare organizations in revenue cycle management[2] or modestly, take the form of a mobile application which would run the patient data through an algorithm to come up with a pregnancy risk score in order to suggest an appropriate health facility for her[3].

We were interested in participating, to a large extent; due to the opportunities it provided us for better understanding and engaging with our surrounding communities. We were selected due to the availability of an appropriate sample in our hospital and in the surrounding communities and also due to our prior hospital based research experience. We were led by a national coordinating research institute which had experience in public health research. We had an initial opportunity to include certain locally-relevant data variables into the forms, but largely the job given to us was to collect data and ensure its quality. Data forms were created and were stored by an international data science group, whereas data management and analysis was done by the national coordinating institute.

The project consisted of demographic surveillance of about 150,000 individuals living in about 35,000 households and follow-up of a pregnancy cohort of about 2,000 women. We were unequipped to conduct such a herculean task, not only due to the lack of research and data management capacity in our organization but also due to the lack of an appropriately qualified data collection team. Because of the poor public education system, lack of local employment opportunities and general poverty, we faced difficulties in finding people with even basic science education or the particular skills required for the demographic surveillance. It was relatively easier to find qualified nursing staff for the pregnancy cohort follow-up which was conducted at the hospital. Our organization as well as our national coordinating institute struggled to employ and retain data management personnel due to the lack of employment policies geared to support research requirements. Although we were monitoring the data quality internally at our site, there was a lack of planned external evaluation by our national or international partners in order to provide course correction during the conduct of the project.

During the conduct of this project, the researcher in the national coordinating institute asked us to participate in a genomics research project, which was operationally aligned with it. This genomics project was to validate the findings of an earlier national study to predict the risk of preterm birth through the research on women who were enrolled into the above mentioned pregnancy cohort. Although we were unable to see the direct relevance of the genomics project for our community, we participated in it due to the relationship we had with the researcher and with the hopes that it might benefit our nation through knowledge generation. In this study, we struggled to justify to ourselves and to the participants the need to collect 15ml of blood for research every time they come to the hospital for their antenatal care visits, apart from other biological samples like the placenta. Another instance was the shipment of 85,000 USD worth of experimental health technology we received from our global funder with the implicit idea to validate the technology by using it on the pregnant research participants, even though nothing was mentioned about such an objective in the research proposal. However, our national coordinating institute intervened and helped us to ignore the implicit request.

After 2 years of demographic surveillance and pregnancy cohort follow-up, we could not meet the big-data standards of high-dimensionality and completeness which were expected by our global funder. In this scenario, we discussed with our national coordinating institute and successfully negotiated to branch out of the multi-centric platform into doing an interventional research study with the aim to address the prominent risk factor of anemia in pregnant women.

Ethical issues

1. Priorities and the ends of research

Health research is done to provide solutions to the challenges in healthcare practice. However, not all solutions generated by health research are holistic. It has been opined[4] that research priorities, when determined predominantly by the perspectives of the Global/ North partners, tend to generate technological solutions to healthcare challenges. These usually are not the holistic or deep solutions that improve health systems or the health care access as expected by the Local/ South partners. As these technological solutions come in the form of commercial products that are usually marketed to for-profit hospitals or people in the upper or middle socio-economic classes, suspicions are raised whether the solutions only tend to further existing inequities which are the result of the colonial agenda.

Although as a hospital in a remote region we prioritized MCH research, we did not think carefully enough about the direction this research was taking or the kinds of solutions it was providing. Even though the health systems assessment was a planned objective of the research, it was not given due importance and was in fact not conducted. We were learning that the efficient solutions in our context would be those that strengthen public health systems and community development which would address health inequities; however, the efficient solutions according to our global funder were more technological.

2. ***Benefits and risks for the participants***

   Global health research is done with vulnerable populations who usually are from the illiterate and marginalized groups like women, children, Dalit, and tribal or religious minorities. These specific populations are historically disempowered and carry sensitive private information related to child bearing, caste or religious practices, especially in the context of far-right politics. Risks compound when biological samples are taken for genomic studies which do not benefit them directly and which inevitably involve soft-coercion, therapeutic misconceptions, and exploitation of their trust.

   Although we participated in the genomics research project with a desire to generate universalizable knowledge, we realized after a few months that it was a mistake to conduct such research on vulnerable populations without first addressing their concrete healthcare needs, empowering them to understand and participate in such a technically nuanced research in an informed way, giving them ample opportunity to consider whether it is a priority for them or not. We could understand in retrospect how the justifiable priority to find decontextualized universalizable knowledge was actually far from the lived reality and priorities of our vulnerable populations. The ethical question here is what can we, the researchers, give in return to the participants who offer their bodies and private lives for study – better healthcare access, reduction of socio-economic and health inequities or concrete healthcare changes which will make them feel valued?

3. ***Interactions between the Global and the Local***

   Global/ North partners and Local/ South partners collaborate and conduct a lot of health research in the world today. These partnerships might help create and maintain useful health research ecosystems. Working in low resource settings with poor health indicators, inexperienced young local researchers are usually desperate and zealous to address huge public health problems[5]; while on the other hand, the global partners have money, knowledge and technology which lead to inherent inequality in the relationship. Local partners like us generally lack skilled human resources, governance, evaluation and monitoring systems. This will result in unsustainable research programs and loss of fruitful work if capacity building of the local partners doesn't happen. In our case, we were regarded only as an implementation or a data collection team. And it seems to us that the global funder unilaterally assumed that we could validate an experimental health technology even when it was not included in the research proposal.

Conclusions and recommendations

1. We believe that there is a ***need for a dialogic relationship between the Global/ North and the Local/ South stakeholders*** especially with regards to the priority setting exercise, so that the voice of Local/ South partners becomes more equal and research priority-setting more responsive to local health needs. Priority setting should not only involve finding a priority topic or a research question to be addressed, but also involve prioritizing holistic, locally-relevant and practical solutions to those priority problems.

2. We believe that ***planning the sustainability of a research program while initiating it, pays respect to the health research prioritization*** in low resource settings. Sustainability of a research program involves capacity building of local partners along with regular mentorship and helping the creation and maintenance of governance, evaluation and monitoring systems. Sustaining a prioritized research program through strengthening the local partners will have the effect of upholding the ethical intention of the initial priority setting exercise.

3. We believe that ***vulnerable populations should be the concrete[6] priority***. In the abstract construction of 'priorities' and their setting, we believe, the populations and individuals are objectified by the research gaze[7] even as the big-data is extracted from their de-identified bodies. The prioritization of the vulnerable populations in a real sense happens only by integrating the health-care priorities with the health-research priorities. So that, research might no longer wash its hands off the needed ethical reciprocation towards the people whose bodies generate data, which later becomes the (intellectually and commercially sought after) scientific knowledge.

4. We recommend that ***national and international agencies hold the global funders accountable due to the history of North-South research relationships[5]***. Such agencies must emphasize transparency and ongoing monitoring to ensure that global funders are upholding their said health research priorities and not misusing their power by softly making the local partners participate in parallel/ additional research which is not a research or a healthcare priority.

Acknowledgements
I thank the members of the Hospital Research Committee of Makunda Christian Leprosy and General Hospital and Dr. Vijay Anand Ismavel, for commenting on this draft and helping me improve it.

References

1. India national multidimensional poverty index 2021: baseline report | ophi [Internet]. [cited 2023 Sep 24]. Available from: https://ophi.org.uk/india-mpi-2021-report/
2. Prospective risk adjustment prioritization tool | hcc triage [Internet]. 2022 [cited 2023 Oct 29]. Available from: https://www.raapid.ai/clinical-decision-support/hcc-triage/
3. Evaluating the feasibility of using algorithms to stratify pregnancy risk [Internet]. Ki Global Health. [cited 2023 Oct 29]. Available from: https://www.kiglobalhealth.org/case-studies/evaluating-the-feasibility-of-using-algorithms-to-stratify-pregnancy-risk/
4. Brisbois B, Plamondon K. The possible worlds of global health research: An ethics-focused discourse analysis. Social Science & Medicine [Internet]. 2018 Jan 1 [cited 2023 Sep 24];196:142–9. Available from: https://www.sciencedirect.com/science/article/pii/S0277953617306998
5. Srinivasan S, Johari V, Jesani A. Cervical cancer screening in india. In: Schroeder D, Cook J, Hirsch F, Fenet S, Muthuswamy V, editors. Ethics Dumping: Case Studies from North-South Research Collaborations [Internet]. Cham: Springer International Publishing; 2018 [cited 2023 Sep 24]. p. 33–48. (Springer Briefs in Research and Innovation Governance). Available from: https://doi.org/10.1007/978-3-319-64731-9_5
6. Poder JC, editor. Kierkegaard and bioethics [Internet]. 1st edition. Routledge ; 2023 [cited 2023 Nov 21]. Available from: https://www.routledge.com/Kierkegaard-and-Bioethics/Poder/p/book/9781032207773
7. Libra M. Jean-Paul Sartre and John Paul II: Freedom, the Look, and Shame. 2015 [cited 2023 Nov 1]; Available from: http://bc.upjp2.edu.pl/dlibra/docmetadata?id=3042

This paper was prepared for GFBR 2023
For further details visit: www.gfbr.global