



Global Forum on
Bioethics in Research



MAKUNDA
CHRISTIAN LEPROSY &
GENERAL HOSPITAL

HEALTH RESEARCH PRIORITIES IN RURAL NORTHEAST INDIA

Starlin Vijay Mythri, GFBR 2023, Montreux

Introduction

- There is dearth of data on health research priority setting and research implementation in rural low resource institutions.
- We, at our secondary level hospital, prioritize maternal & child health in care provision and research.
- I present our experience with a Global health research collaboration.



Research project

- Demographic surveillance of 150,000 people and pregnancy cohort follow up of 2000 women.
- We, who are actually healthcare providers without much research capacity, implemented the project i.e. collecting data.
- National institute, who have public health research experience, guided us, provided data management help and planned to analyze the big-data.
- Global funder plans to create a pregnancy risk stratification algorithm which will be used to develop a commercial AI tool to help risk prediction and suggest best clinical way forward.



Linking *ad hoc* validation studies

1. We were asked us to participate in a genomic project to validate another national study to predict preterm births on the ‘participants’ in our pregnancy cohort. These two studies were operationally aligned.
2. Global funder shipped 85k USD worth experimental health technology to validate on our ‘participants’, without any prior intimation or proposal.

Such ‘piggybacking’ studies, though economical, disregard & complicate research prioritization.



Data quality and unsustainable research

- We could not meet data quality standards of our funder due to various reasons.
- We negotiated with the funder and branched out into an interventional study on anemia in pregnancy.
- However, future of the original research study is uncertain without a clear plan to continue the research program.



Ethical issues

- Priorities and ends of research
 - ▣ Technological solutions which further health inequities and colonial agenda
- Risks and benefits for the research participants
 - ▣ Social risks and minimal health benefits to the participants
- Global/ North – Local/ South interactions
 - ▣ Unequal relationship and unsustainable research



Recommendations

1. Need for a dialogic relationship between the Global/ North and Local/ South partners in order to strengthen Local voices which in turn lead to better research prioritization.
2. Need for planning the sustainability of research programs alongside the priority setting exercise in order to wholesomely respond to the ethical call of healthcare research.



Recommendations

3. Vulnerable communities and individuals should be our concrete priority: we need to emphasize the interaction between the health-care & the health-research prioritization.
4. Need to hold Global/ North funders accountable to their stated priorities in order to prevent usage of Local/ South partners for validating *ad hoc* research projects.



Thank you



MAKUNDA
CHRISTIAN LEPROSY &
GENERAL HOSPITAL