

OPPORTUNITIES AND CHALLENGES FOR THE MANAGEMENT OF LONGITUDINAL PAEDIATRIC DATA IN LOW- AND MIDDLE-INCOME SETTINGS

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Introduction and Aims

Longitudinal paediatric research requires sustainable and ethical data management practices. Pregnant mothers and children constitute a vulnerable research population. This vulnerability is further compounded for participants living in poorly resourced communities and exposed to multiple risk factors, including intimate partner and community violence.

This poster discusses the opportunities and challenges of managing longitudinal data for the Khula Study, a longitudinal birth cohort study aimed at characterizing the development of emerging executive functions over the first 1000 days of life in a sample of 600 mother-infant dyads in Cape Town, South Africa and Blantyre, Malawi.

Opportunities and Challenges

The collection of multi-modal longitudinal data from two sub-Saharan African birth cohorts that differ in terms of culture presents an opportunity to understand common and context-specific influences of executive functions in the early years. Additionally, the collection of scalable low-field brain measures (in addition to traditional high-field measures) in this study has global relevance.

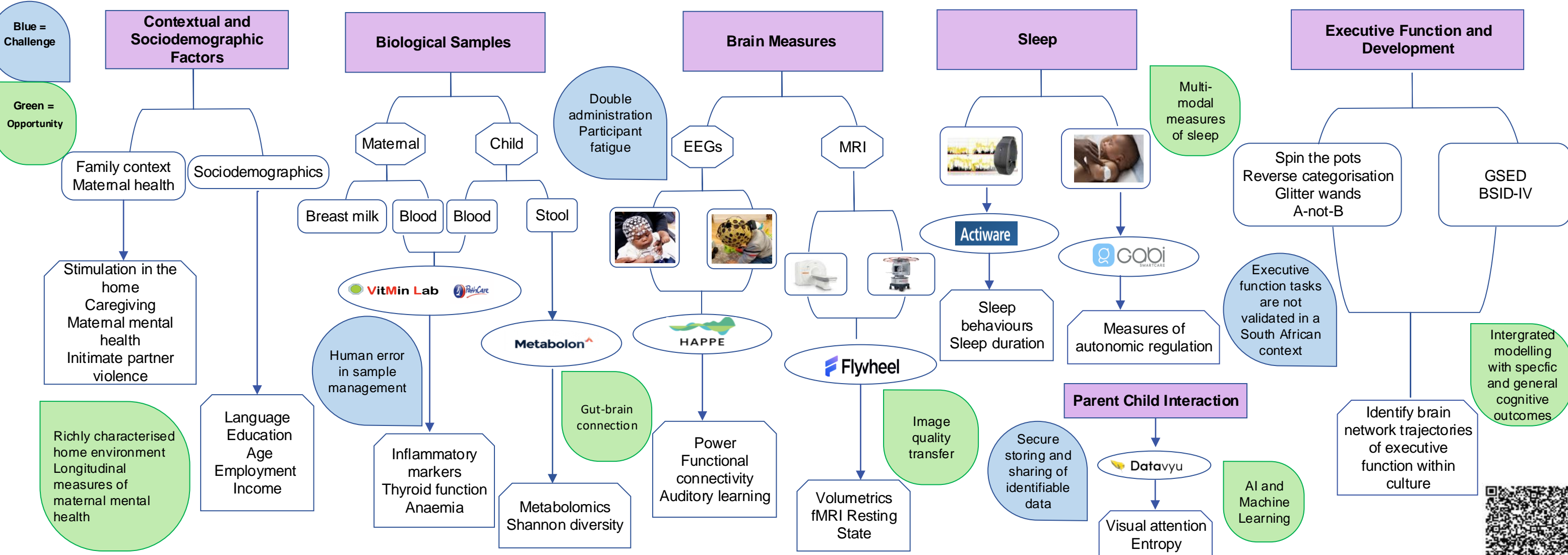
Key challenges include (i) technical issues, such as internet access and digitization of paper-based records, (ii) harmonization and adaptation of variables across sites, (iii) integrating multiple data modalities processed in different places, (iv) maintaining quality control over these many different data types, and (v) tracking participants to promote data completeness.

Conclusion and Acknowledgments

The management of longitudinal paediatric data is multidimensional, and calls for data management practices that are ethical, streamlined, and collaborative to ensure the success of the research. Examining the challenges, opportunities and strategies implemented in the Khula Study may provide a framework for future paediatric research in low- and middle-income regions.

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Key:



Study Timeline

