

Preserving scientific data in developing countries: The Birth to Twenty data curation project

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Birth to Twenty is a birth cohort study of child and adolescent health and development in the Greater Johannesburg area in Gauteng, South Africa, and is one of the few large-scale longitudinal studies in the world. The study began in 1990 and has tracked the development of 3,273 subjects/participants. The study is a unique source of information on public health issues in an urban setting of a developing country. It has provided important information on social aspects of health amongst children growing up in a fast changing urban environment and is now able to provide data which allows comparison of early childhood nutrition and current development and bone health status.

This paper will present an overview of the conceptual framework that was used in the Birth to Twenty data curation project, and then will present some of the challenges in curating a complex longitudinal study that started over 20 years ago. It will also outline the broad challenges facing the curation of social science data more generally, with specific reference to developing countries.

The paper will then make suggestions with regards to the curation of social science data in resource poor countries. It will also outline the challenges which are faced in the dissemination of such datasets with specific reference to open access and copyright issues, and will propose basic **principles** of access which can inform policies on access to social science data.