

Reflexivity statement

1. How does this study address local research and policy priorities?

Almost all the children affected by Congenital Zika Syndrome were born in Brazil. Consequently, the care of these children became an important concern of the Brazilian government. However, there was a lack of information on the needs of these children, given that the condition was new. This project sought to understand the social and economic impacts of Congenital Zika Syndrome, to help inform the response of the government and to maximise support to families. This study is therefore clearly focussed on addressing local research and policy priorities.

2. How were local researchers involved in study design?

Three research teams from three settings were involved in the study: Fiocruz in Rio de Janeiro, Fiocruz and affiliated organizations in Recife, The London School of Hygiene & Tropical Medicine. The current study built upon two existing studies, which had been designed and implemented by the two Brazilian research teams. Moreover, the local researchers determined the current study design, by contributing to decisions on the research questions, developing the data collection tools, and defining the approach for achieving the study sample. A one-week planning workshop was held in Recife with all research partners to facilitate agreement on the study design. Most notably, MP is an economist and guided the development and pilot-tested the collection of costing data for the current paper.

3. How has funding been used to support the local research team(s)?

Approximately £300,000 in funding was given by Wellcome for the project. This amount was divided into three equal parts, for the three research settings (Rio de Janeiro, Recife, London) with a principal investigator (EM, TL, HK) from each setting responsible for the funding decisions and reporting for her setting. The Brazilian funding was mostly spent on supporting research staff and for the collection of data.

4. How are research staff who conducted data collection acknowledged?

All research staff who contributed towards data collection and interpretation are included as authors. They all contributed during the writing process and reviewed and agreed the final draft.

5. How have members of the research partnership been provided with access to study data?

All members of the research partnership have access to the study data.

6. How were data used to develop analytical skills within the partnership?

Presentations on economic analysis and our plans for modelling were presented during a group workshop, to improve the knowledge and awareness of researchers within the partnership. The economists from Rio de Janeiro (MP) and London (SF) worked closely with a professor of economics (MJB) to guide the analysis of the project, including through a one week visit by MP to London.

7. How have research partners collaborated in interpreting study data?

A workshop was held in Rio de Janeiro with all the research partners to present preliminary findings and agree the interpretation of the study data.

8. How were research partners supported to develop writing skills?

The overall study led to the publication of 9 papers (given below), with two further in submission. Seven of these papers have a local researcher as first author and all of which included local researchers as authors. For each paper, British academics support local researchers in identifying appropriate journals, structuring the paper, revising the English language and improving the presentation to be more appropriate for international journals. The writing skills of the research partners were supported through these steps.

9. How will research products be shared to address local needs?

A dissemination meeting was held in Recife to share the main findings of the research, with the audience including other researchers, policy makers and mothers of children with Congenital Zika Syndrome. Information presented at that meeting was tailored to help inform practice and policy and therefore address local needs.

10. How is the leadership, contribution and ownership of this work by LMIC researchers recognised within the authorship?

Two previous publications on the economic data have been submitted (Cad SAude Publica, and Wellcome Open), led by a local researcher (MP). The authorship of the current paper includes 9 authors, 6 of whom are from Brazil. We acknowledge that in this publication the first and last author are from a high income setting. However, of the 9 published papers, 7 have a Brazilian first author and 5 have a Brazilian senior author (see list below). On all the publications, the majority of the authors are Brazilian.

11. How have early career researchers across the partnership been included within the authorship team?

We have included early career researchers (SF, LB) in the research team including as first author.

12. How has gender balance been addressed within the authorship?

All authors are female.

13. How has the project contributed to training of LMIC researchers?

Two workshops were held with all the researchers to agree research methods and to validate the main findings. These workshops were instructive to all researchers. The LMIC researchers were generally highly experienced and required little training in the conduct of research. However, they received support to publish papers in international journals.

14. How has the project contributed to improvements in local infrastructure?

This project has not directly contributed to improvements in local infrastructure.

15. What safeguarding procedures were used to protect local study participants and researchers?

Ethical approval was received for this study from the relevant agencies in Brazil and in the UK. Informed consent was achieved from all participants. We were committed to keeping information confidential and anonymised. We have not made data openly available as we are concerned that individual participants could be identified. The subject matter was distressing and the researchers formed a support group and met regularly to discuss the research and issues that arose.

Further information. The full list of papers published through this study, to provide context:

1: Pinto M, Moreira MEL, Barros LBP, Costa ACCD, Fernandes S, Kuper H. Gasto catastrófico na síndrome congênita do vírus Zika: resultados de um estudo transversal com cuidadores de crianças no Rio de Janeiro, Brasil [Catastrophic expenditure on congenital Zika syndrome: results of a cross-sectional study of caregivers of children in Rio de Janeiro, Brazil]. *Cad Saude Publica*. 2021 Nov 22;37(11):e00007021. Portuguese. doi: 10.1590/0102-311X00007021. PMID: 34816948.

2: de Melo APL, Lyra T, de Araújo TVB, de Albuquerque MDSV, Valongueiro S, Kuper H, Penn-Kekana L. "Life Is Taking Me Where I Need to Go": Biographical Disruption and New Arrangements in the Lives of Female Family Carers of Children with Congenital Zika Syndrome in Pernambuco, Brazil. *Viruses*. 2020 Dec 8;12(12):1410. doi: 10.3390/v12121410. PMID: 33302536; PMCID: PMC7763975.

3: Simas C, Penn-Kekana L, Kuper H, Lyra TM, Moreira MEL, de Albuquerque MDSV, de Araújo TVB, de Melo APL, Figueira Mendes CH, Nunes Moreira MC, Ferreira do Nascimento MA, Pimentel C, Pinto M, Valongueiro S, Larson H. Hope and trust in times of Zika: the views of caregivers and healthcare workers at the forefront of the epidemic in Brazil. *Health Policy Plan*. 2020 Oct 1;35(8):953-961. doi: 10.1093/heapol/czaa042. PMID: 32681164; PMCID: PMC7553755.

4: Passos MJ, Matta G, Lyra TM, Moreira MEL, Kuper H, Penn-Kekana L, Mendonça M. The promise and pitfalls of social science research in an emergency: lessons from studying the Zika epidemic in Brazil, 2015-2016. *BMJ Glob Health*. 2020 Apr;5(4):e002307. doi: 10.1136/bmjgh-2020-002307. PMID: 32345582; PMCID: PMC7213811.

5: Sá MRC, Vieira ACD, Castro BSM, Agostini O, Smythe T, Kuper H, Moreira MEL, Moreira MCN. De toda maneira tem que andar junto: ações intersetoriais entre saúde e educação para crianças vivendo com a síndrome congênita do vírus Zika [The need to act together in every way possible: inter-sector action in health and education for children living with the congenital Zika syndrome]. *Cad Saude Publica*. 2019 Nov 28;35(12):e00233718. Portuguese. doi: 10.1590/0102-311X00233718. PMID: 31800795; PMCID: PMC7612576.

6: Kuper H, Lyra TM, Moreira MEL, de Albuquerque MDSV, de Araújo TVB, Fernandes S, Jofre-Bonet M, Larson H, Lopes de Melo AP, Mendes CHF, Moreira MCN, do Nascimento

MAF, Penn-Kekana L, Pimentel C, Pinto M, Simas C, Valongueiro S. Social and economic impacts of congenital Zika syndrome in Brazil: Study protocol and rationale for a mixed-methods study. *Wellcome Open Res.* 2019 Sep 11;3:127. doi: 10.12688/wellcomeopenres.14838.2. PMID: 31667356; PMCID: PMC6807146.

7: Kuper H, Lopes Moreira ME, Barreto de Araújo TV, Valongueiro S, Fernandes S, Pinto M, Lyra TM. The association of depression, anxiety, and stress with caring for a child with Congenital Zika Syndrome in Brazil; Results of a cross-sectional study. *PLoS Negl Trop Dis.* 2019 Sep 30;13(9):e0007768. doi: 10.1371/journal.pntd.0007768. PMID: 31568478; PMCID: PMC6786834.

8: Albuquerque MSV, Lyra TM, Melo APL, Valongueiro SA, Araújo TVB, Pimentel C, Moreira MCN, Mendes CHF, Nascimento M, Kuper H, Penn-Kekana L. Access to healthcare for children with Congenital Zika Syndrome in Brazil: perspectives of mothers and health professionals. *Health Policy Plan.* 2019 Sep 1;34(7):499-507. doi: 10.1093/heapol/czz059. PMID: 31369667; PMCID: PMC6788207.

9: Moreira MCN, Nascimento M, Mendes CHF, Pinto M, Valongueiro S, Moreira MEL, Lyra TM, Kuper H; SEIZ Research Group. Emergency and permanence of the Zika virus epidemic: an agenda connecting research and policy. *Cad Saude Publica.* 2018 Aug 20;34(8):e00075718. doi: 10.1590/0102-311X00075718. PMID: 30133655.