

Global Evidence Local Adaptation (GELA): Priority setting exercise to identify priorities for guidelines on newborn and child health in South Africa

Participant information sheet

You are being invited to participate in a research project to identify priorities for guidelines in the field of newborn and child health. This research is part of a larger project titled Global Evidence - Local Adaptations ([GELA](#))¹. You are invited to voluntarily participate in this project because you have been identified as a key stakeholder for guidelines in this field.

Why are we doing this research study?

The purpose of the GELA project is to maximise the impact of research on poverty-related diseases through enhancing decision-makers' capacity to use global research to develop locally relevant guidelines for poverty-related diseases (PRDs) in the field of newborn and child health. The project will support decision-makers in Malawi, Nigeria and South Africa, and build on and add value to the large-scale programme of child health clinical practice guideline (CPG) development lead by the World Health Organization (WHO), with adaptation and implementation lead by WHO Afro regional office and national ministries. The first step in this process is to identify priorities for guidance regarding PRDs in the field of newborn and child health, which is what this research aims to do.

Who can participate in this research study?

Individuals identified as key stakeholders, i.e., those who are involved, can affect, or are affected by national decisions or actions related to priority topics in the field of newborn or child health and PRDs in South Africa, Nigeria and Malawi. This includes individuals from relevant departments of the national department or ministry of health, professional associations, country-level WHO offices, policymakers, guideline developers, health professionals, civil society representatives, patients, and parents. A selected group of individuals will be invited to be part of the guideline steering group of the GELA project.

What will I be asked to do and how much time will it take?

You will be asked to complete an online survey to identify and rank priority topics in the field of newborn and child health and poverty-related diseases. The survey will be carried out on a secure online survey platform and will take between 15 and 20 minutes to complete.

The guideline steering group will also be asked to provide an initial list of potential topics and to participate in a consensus meeting to identify the final top three priority topics.

Will being in this research study help me in any way?

This study is not designed to benefit you personally as a participant; however, the results of this project may raise awareness on the high-priority issues linked to poverty related diseases in newborn and child health in your setting and improve care related to these conditions.

What are my risks of being in this research study?

There are no known risks in participating in this study.

¹ This project is part of the EDCTP2 programme supported by the European Union (grant number RIA2020S-3303-GELA)

How will my personal information be protected?

The online survey will be completely anonymous. To help protect your confidentiality, the information you provide will be private; no names will be used so there is no way that you can be identified as a participant in this study. In addition, all cookies and IP address collectors will be disabled to ensure confidentiality. Your name will not be reflected on the questionnaire or any document which might reflect the results of the evaluation. De-linked data will be stored electronically using password-controlled software only accessible to key project members and project analysts.

If you are part of the Steering Group and attend the consensus meeting, your name will not be anonymous as you will play an ongoing role in the GELA project; however, your inputs to prioritisation and refining the priority topics will be managed through anonymous online surveys within the meeting to enable fair contributions and confidentiality for specific decisions. De-linked data will be stored electronically using password-controlled software only accessible to key project members and project analysts.

The consensus meeting will be audio recorded and a researcher will be present taking notes. These will be used to for ongoing monitoring and evaluation of GELA project activities and processes. The recording on the digital recorders will be destroyed following safe storage and transcription, and any identifying information will be redacted from the transcript. Anonymised transcripts and notes will be stored electronically using password-controlled software only accessible to key project members and project analysts. Extracts from the meetings may be published in research reports but any direct information that could identify who you are will be removed.

What happens if I say yes, but I change my mind later?

Your participation in this research is completely voluntary. You may choose not to take part in the study. If you decide to participate in this research study, you may stop participating at any time. If you decide not to participate in this study or if you stop participating at any time, you will not be penalised or lose any benefits to which you otherwise qualify.

Who can I talk to if I have questions?

Should you have any questions regarding this study and your rights as a research participant or if you wish to report any problems you have experienced related to the study, please contact the Chairperson of the **South African Medical Research Council Human Research Ethics Committee (Adri Labuschagne, tel. (021) 938 0687; e-mail: adri.labuschagne@mrc.ac.za)**.