

## Publication

### Clinical trials in low-resource settings : the perspectives of caregivers of paediatric participants from Uganda, Tanzania and Kenya

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**Author(s)** van den Berg, Machteld; Ogutu, Bernhards; Sewankambo, Nelson K.; Merten, Sonja; Biller-Andorno, Nikola; Tanner, Marcel

**Author(s) at UniBasel** [Wyss-van den Berg, Machteld](#) ; [Merten, Sonja](#) ; [Tanner, Marcel](#) ;

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Vaccine clinical trials in low-resource settings have unique challenges due to structural and financial inequities. Specifically, protecting participant and caregiver autonomy to participate in the research study can be a major challenge, so understanding the setting and contextual factors which influence the decision process is necessary. This study investigates the experience of caregivers consenting on behalf of paediatric participants in a malaria vaccine clinical trial where participation enables access to free, high-quality medical care.; We interviewed a total of 78 caregivers of paediatric participants previously enrolled in a phase II or III malaria vaccine clinical trial in Uganda, Tanzania and Kenya. Interviews were qualitative and analysed using a thematic framework analysis focusing on the embodied caregiver in the political, economic and social reality.; Caregivers of participants in this study made the decision to enrol their child based on economic, social and political factors that extended beyond the trial into the community and the home. The provision of health care was the dominant reason for participation. Respondents reported how social networks, rumours, hierarchal structures, financial constraints and family dynamics affected their experience with research.; The provision of medical care was a powerful motivator for participation. Caregiver choice was limited by structural constraints and scarce financial resources. The decision to participate in research extended beyond individual consent and was embedded in community and domestic hierarchies. Future research should assess other contexts to determine how the choice to participate in research is affected when free medical care is offered.

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