

# Ethics of health research priority setting

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## Exploring the ethics of research priority setting and enhancing the beneficence of research: a case study of the family planning research and learning agenda 2021/2022 in Uganda

Suzanne N Kiwanuka<sup>1</sup>(presenter), Doreen Tuhebwe<sup>1</sup>, Noel Namuhani<sup>1</sup>, Frederick Makumbi<sup>1</sup>, Dinah Amongin<sup>1</sup>, Simon Kibira<sup>1</sup> Charles Olaro<sup>2</sup>, Richard Mugahi<sup>2</sup> and Rhoda Wanyenze<sup>1</sup>, FHI, and R4S

1. Makerere University College of Health Sciences, School of Public Health
2. Ministry of Health Uganda

**Introduction:** Research priority setting has long been driven by disease burden and focussed mainly on bio-medical drivers of disease (Pratt 2018). This has led to the neglect of non-medical determinants of health. According to Benatar (2010), research ethics should be underpinned by efforts to reduce inequities and to enhance justice in health. It is also important that research priority setting processes are participatory and inclusive so that there is alignment between them and the wider societal needs.

**Case study context:** Family planning research and learning agendas (FPRLAs) enable countries to systematically identify priority evidence gaps and forge a path towards a robust knowledge base for more equitable family planning programming. They also aid in reducing duplication of evidence generation and enhancing the utility of existing evidence by aligning stakeholder resources around an expected outcome. The Research for Scalable Solutions (**R4S**) project has supported researcher teams and family planning stakeholders across 6 countries (Côte d'Ivoire, Malawi, Mozambique, Nepal, Niger, and Uganda) to develop FPRLAs— first of their kind in these countries (Brittingham 2023). The development of Uganda's FPRLA followed a two years multistage process of reviewing FP evidence from 115 documents, analyzing secondary DHS data and engaging stakeholders (n>150) in multiple engagements summarized below.

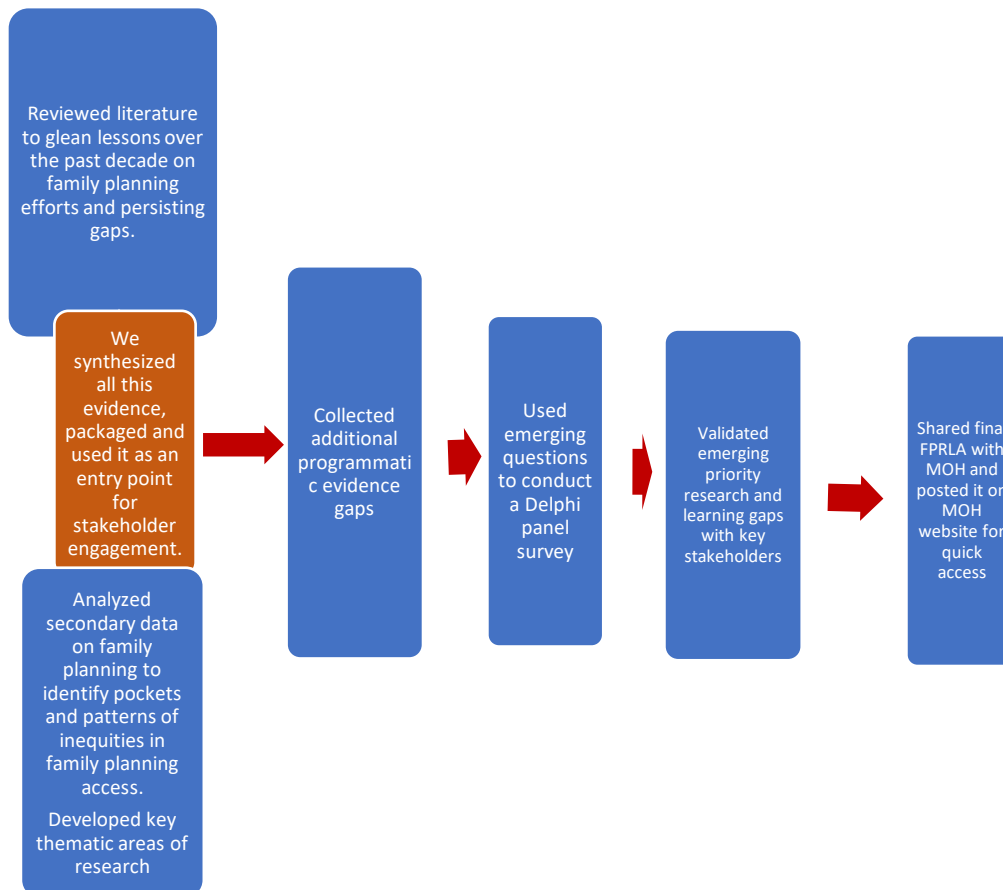


Figure 1: The research and learning agenda development process

The Uganda FPRLA was launched in 2022 and can be access via the [Ministry of Health Knowledge Platform](#). The following is a reflection of the extent to which ethical concerns such as beneficence, non-maleficence, and justice emerge from the research priority setting process in Uganda and a critique of the utility of existing research priority setting frameworks.

### Ethical issues emerging from the FPRLA exercise

**Beneficence through alignment of priorities:** In order to align global research priorities to local needs, the Ugandan FPRLA generated and documented research priorities by applying global priorities to local needs. For instance, global targets emphasize the need to focus on youth, (Kigali 2018) and encourage donors to allow countries to collect data on country specific indicators in addition to core FP indicators as well as map efforts to harness social norms towards improved family planning (FP2020). These global priorities were all contextualized for Uganda in this research priority setting exercise by using in country data to assess progress and identify evidence gaps. By drawing lessons from the country’s FP2020 commitments and assessing data on performance outcomes, this exercise was able to map persistent gaps in access to FP by youth and the impact of social norms as a barrier to access. The research priority setting exercise also identifies additional indicators which could help the country meet its 2030 FP targets.

This FPRLA exercise revealed that Uganda’s FP2020 priorities were in line with the national sexual and reproductive health and rights policy (2017-2022) and promote research to achieve national objectives for the SDGs. There were no conflicting priorities observed because this is the first FPRLA for the country. The Uganda FPRLA therefore complements other policies such as the reproductive health policy, the health sector development goals and the Reproductive, Maternal Newborn Child and Adolescent Health (RNMCAH) sharpened plan. The FPRLA was also referenced in the recently launched Family Planning Costed Implementation Plan II (2020/2021-2024/2025).

**Beneficence through guided and deliberative priority-setting:** The procedures followed by this research priority setting exercise maximized beneficence by fostering evidence used through extensive literature review, and secondary data analysis. This enabled the identification of published evidence as the entry point for deliberations on evidence gaps and research priorities with stakeholders. This exercise also facilitated the defining of four key thematic areas of research which included, self-care, high impact practices, young people and equity. However, our literature review might be limited by its inability to capture unpublished reports because most unpublished reports on family planning are archived in programmatic databases which are not readily available to the public. The secondary data analysis enabled the team to delve deeper into trends in the assess to FP performance nationwide and yielded valuable learning on persisting areas of inequity as well as descriptions of marginalized populations. This supported further discussions on available evidence for testing and scale up as well as evidence needed to address inequities in FP access and knowledge. Identifying pockets of inequity such as persisting low uptake of FP among youth, regional differences in demand of FP met and varying access to FP information enabled stakeholders to interrogate evidence gaps and the needed research and experiential evidence to address the inequities. This fostered a priority setting process for research with a lens towards beneficence.

**Beneficence through inclusion and ownership:** Our secondary data analysis exposed pockets of FP inequities whose implications were interrogated by providers, policy makers, funders and researchers with a goal towards finding joint solutions. The engagement of a broad spectrum of stakeholders to generate research priorities enhances ownership and ultimately the potential utility of the research agenda. There is also need to diversify stakeholders especially in the current SDG era where multi-sectoral involvement is critical. The diversity of stakeholders might be dictated by context, however the mandatory inclusion of research funders and advocacy/special interest groups is important to foster utility. Close collaboration with the policy makers throughout the exercise enhances ownership of the research priorities. There are additional issues relevant to research prioritization, generation and use globally which might not be captured by current research priority setting frameworks. Targeted stakeholder engagement ensures that the strategies to achieve national FP goals are evidence-based and effective.

**Beneficence through monitoring utility:** The process of generating the FPRLA is costly and labour intensive therefore utility, which is missing in many research priority setting frameworks, should be a key ethical consideration. The Uganda FPRLA process culminated in an intentional dissemination of research priorities (through workshops and online via the ministry of health knowledge platform). A monitoring and evaluation plan embedded into the process revealed that stakeholders are using the FPRLA. The FPRLA has been cited in publications, informed program design and informed research over the past 12 months.

**Justice through multi-stakeholder participation:** Delphi panel surveys, and multiple stakeholder engagements enabled us to refine research priorities from the numerous questions and a validation engagement workshop clarified the questions, their relevance to Uganda and the potential scope of evidence needed from the perspective of policy makers, program implementers and academicians. This focus on relevance of the priority questions to country needs directed the process towards alignment and de-colonizing research priorities from external drivers. In terms for successfully collating perspectives from funders, researchers, program implementors and policy makers. The FPRLA process engaged more than 100 stakeholders but it was led and dominated by program implementers, policy makers and academia. There was minimal involvement from cultural leaders, advocacy groups and funders. The inclusion of stakeholder beyond the health sector (education, youth, sport and gender) is lauded due to the multi-faceted, multi-sectoral nature of reproductive health (Hardee et al 2018). Indeed, the current total market approach (TMA) to FP emphasizes collaboration between the public sector, nongovernmental organization (NGO) sector, and commercial sector in order to increase access to FP for all segments of the population. This is driven by the understanding that meeting the diverse needs of various population segments equitably requires strategic coordination of actors across sectors (Abt Associates 2015). We posit that although this process was led by academics, it was vital for academic researchers to lead the process because they are aware of the evidence needs. The process also brought on board a

diversity of voices and experiences to ensure representation of all stakeholders and therefore fostered inclusion.

**Best practices for stakeholder inclusion:** Apart from including a broad spectrum of stakeholders, we posit from this exercise that the predominance of academia, policy makers and program implementers was a positive thing because it brings on board the people who are aware of existing evidence and can generate evidence to bridge gaps as well as the evidence users. This exercise also did not limit evidence to only research generated evidence but allows the incorporation of program evidence which oftentimes is unpublished. This kind of exercise might wisely omit clients because they are mostly concerned with access to services and might not be fully conversant with evidence gaps. However, some poignant observations in our stakeholder groups is the need to include more funders. These should be funders of FP research rather than just funders of FP programs which could enhance the utility of the research agenda and mitigate the problem of wasteful research. However, caution ought to be exercised so that funders agendas do not overrun the priority setting process. In addition, culture and religion have a strong bearing on family planning in Uganda and elsewhere, therefore greater representation from these constituencies could be warranted even if only to raise awareness of existing evidence and their role in FP outcomes. There is representation from the Ministry of Gender however more representation from Gender advocacy groups should be encouraged.

**Missed-opportunity for FP User inclusion:** According to Pratt (2021) the engagement of people with lived experience and members of the public is an ethically and scientifically essential component of health research. She also posits that this should be emphasized during priority-setting for research projects. This exercise revealed several knowledge gaps around family planning utilization which could have been addressed by the intentional inclusion of FP users in this process. For instance, challenges with boosting FP uptake among young people and issue emerging around side effects of FP methods have long been highlighted as barriers to increasing FP uptake in Uganda. This priority setting exercise missed a great opportunity to capture the perspectives of these key populations and enabling their priorities to be captured.

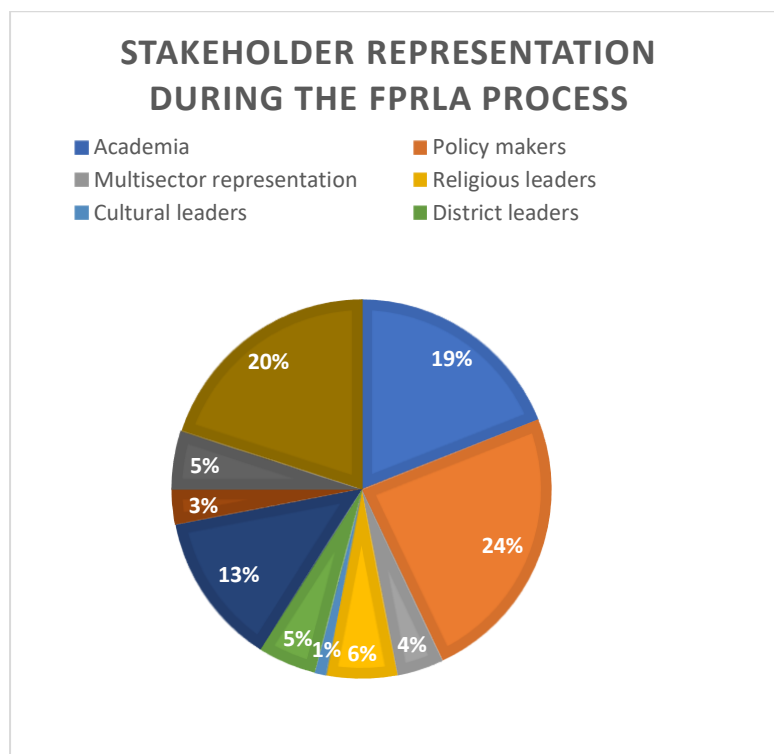


Figure 2 Stakeholder representation during the FPRLA process in Uganda

**Fostering equity by decolonizing research priority setting:** For decades the process of research priority setting has been mostly driven by northern partners, who consequently fund most research efforts. This has been reported to lead to inequities in global health research. The process of generating the Ugandan FPRLA was country led and driven by critical FP stakeholders. The FPRLA has been owned by the Ministry of Health which is lobbying government and international partners to focus their research on the basis of this plan. This is a great step towards fostering equity in funding for research. Still, the utility of the FPRLA will depend on the availability of research funds within the country and the willingness of funders to align themselves to the FPRLA.

**Aligning priorities, reducing the 10/90 gap, boosting justice in research priority setting:** More than two decades ago, the concept of the “10-90 gap” emerged to highlight disparities in research and development support for neglected diseases affecting the world’s poorest countries. According to this 10/90 gap, only 10 percent of all health research funded globally targeted diseases such as HIV/AIDS, tuberculosis, and malaria, diseases that affect 90 percent of the world’s population. Since then, concerted efforts have been made to reduce this gap. Our experience co-developing the research and learning agenda in Uganda revealed that the exercise of initially mapping existing evidence gap as a stakeholder entry point to research priority setting is critical for guiding future research priority setting. It ultimately reduces duplication and wastage of research resources and enhancing adoption and scale up of existing evidence. This process further helped the country to guide research funders of country priorities since the bulk of research funding still comes from external sources.

### **Conclusions and recommendations**

The Ugandan FPFLA was a research priority setting process which fostered beneficence through ensuring diversity in stakeholder participation (inclusion) and ownership. However, a gap was noted with the failure to capture the perspectives of the users of family planning methods as a key population. By laying the foundation of the FPRLA on a map of existing evidence, this process fostered evidence uptake and reduced duplication which ultimately enhances justice in that resources can be channeled where there is most need. Although not emphasized in most research priority setting frameworks, this exercise concluded that the utility of a research agenda should be a key ethical consideration for ethical priority setting and indeed the research agenda should be monitored to assess utility. Research agendas should not be merely a means to an end and resources should be allocated to implement these agenda in order to further reduce the 10/90 gap and to foster utility of research. A monitoring and evaluation plan should be part of the research priority setting process to ensure utility of the product. Although the inclusion of research funders into the priority setting process has been reported to bias the process towards special interests, we posit that the need for research funders in the priority setting process is critical because they need to be aware of how research priorities have been generated and tailored for contexts. Finally, we recommend that country teams should lead research priority setting processes in order to build capacity and generate ownership with stakeholders, however the participation of external partners is encouraged.

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