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[1], Doreen Tuhebwe, Noel Namuhani, Frederick Makumbi,

Dinah Amongin, Simon Kibira and Rhoda Wanyenze, FHI, MOH and R4S
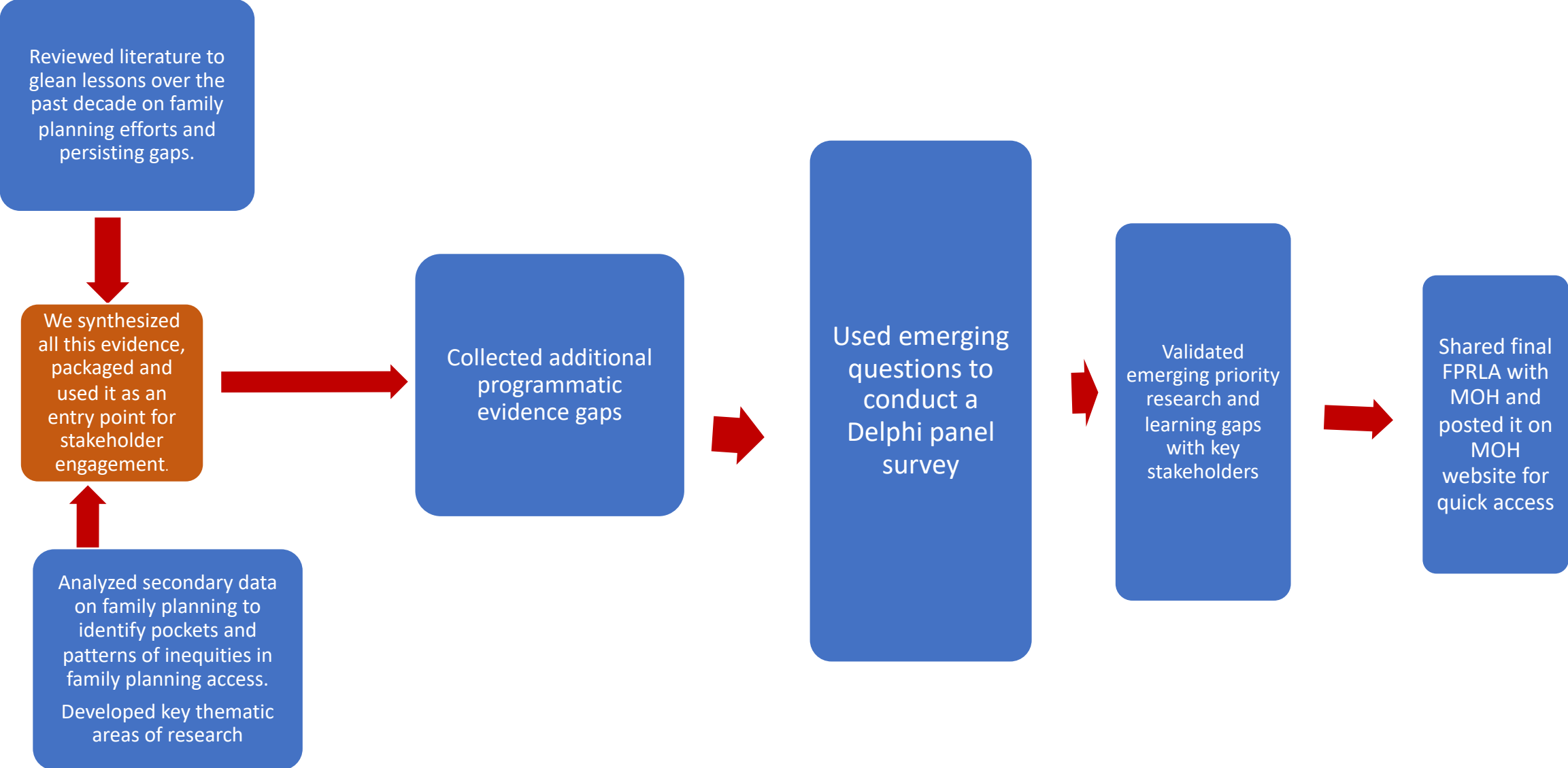
Makerere University School of Public Health

Background

- Research priority setting long driven by disease burden and focussed mainly on bio-medical drivers of disease (Pratt 2018).

- Led to the neglect of non-medical determinants of health.

- Research ethics should be underpinned by efforts to reduce inequities and to enhance justice in health (Benatar 2010).

- Research priority setting processes need to be participatory and inclusive to ensure alignment between them and wider societal needs.

Case study context

- Research for Scalable Solutions **(R4S)** project has supported the development of Family planning research and learning agendas (FPRLAs) across Côte d'Ivoire, Malawi, Mozambique, Nepal, Niger, and Uganda)—(Brittingham 2023).

- Enable countries to systematically identify priority evidence gaps and generate robust knowledge for more equitable family planning programming.

- Reduce duplication of evidence generation and enhance the utility of existing evidence by aligning stakeholder resources around an expected outcome.

- In Uganda a two years multistage process of reviewing FP evidence from 115 documents, analyzing secondary DHS data and engaging stakeholders (n>150) in multiple engagements.

```
┌─────────────────────┐
│ Reviewed literature │
│ to glean lessons    │
│ over the past       │
│ decade on family    │
│ planning efforts    │
│ and persisting      │
│ gaps.               │
└─────────────────────┘
          │
          ▼
┌─────────────────────┐        ┌─────────────────────┐        ┌─────────────────────┐        ┌─────────────────────┐        ┌─────────────────────┐
│ We synthesized all  │        │ Collected           │        │ Used emerging       │        │ Validated emerging  │        │ Shared final FPRLA  │
│ this evidence,      │   ──▶  │ additional          │   ──▶  │ questions to        │   ──▶  │ priority research   │   ──▶  │ with MOH and        │
│ packaged and used   │        │ programmatic        │        │ conduct a Delphi    │        │ and learning gaps   │        │ posted it on MOH    │
│ it as an entry      │        │ evidence gaps       │        │ panel survey        │        │ with key            │        │ website for quick   │
│ point for           │        │                     │        │                     │        │ stakeholders        │        │ access              │
│ stakeholder         │        │                     │        │                     │        │                     │        │                     │
│ engagement.         │        │                     │        │                     │        │                     │        │                     │
└─────────────────────┘        └─────────────────────┘        └─────────────────────┘        └─────────────────────┘        └─────────────────────┘
          ▲
          │
┌─────────────────────┐
│ Analyzed secondary  │
│ data on family      │
│ planning to         │
│ identify pockets    │
│ and patterns of     │
│ inequities in       │
│ family planning     │
│ access.             │
│ Developed key       │
│ thematic areas of   │
│ research            │
└─────────────────────┘
```

Case study a reflection of the ethical concerns such as beneficence, justice, inclusion and utility encountered during the research priority setting process in Uganda.

Beneficence through Alignment of priorities

The Ugandan FPRLA aligned local priorities by applying global priorities to local needs. For instance global targets emphasize the need to focus on youth, (Kigali 2018)

Mapped persistent gaps in access to FP by youth and the impact of social norms as a barrier to access.

In line with global priorities, the FPRLA identified additional indicators which could help the country meet its 2030 FP targets.

FPRLA 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.

Complements other policies like the reproductive health policy, Maternal Newborn Child and Adolescent Health (RNMCAH) sharpened plan and was referenced in Family Planning Costed Implementation Plan II (2020/2021-2024/2025).

Beneficence by guided and deliberative priority-setting

- Extensive literature review, and secondary data analysis enabled the mapping of evidence gaps as the entry point for discussion research priorities with stakeholders.

- Secondary data analysis exposed trends in the access to FP performance nationwide and yielded valuable insights on FP inequity such as low uptake of FP among youth, regional differences in unmet needs 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.

- This exercise also facilitated the defining of four key research needs around thematic areas of self-care, high impact practices, young people and equity.

Beneficence through Use

- The engagement of a broad spectrum of stakeholders to generate research priorities enhanced ownership and ultimately the potential use of the research agenda.

- MOH launched and has disseminated the FPRLA while the Makerere and R4S team has monitored use.

- Online survey to monitor FPRLA reveals: *cited as a source document, used to inform program design, used to inform research questions and others.*

Ownership and Use

- Uganda FPRLA launched in 2022, accessed via [Ministry of Health Knowledge Platform](#).

- FPRLA embedded a monitoring tool to track use and a recent survey (n=104) shows
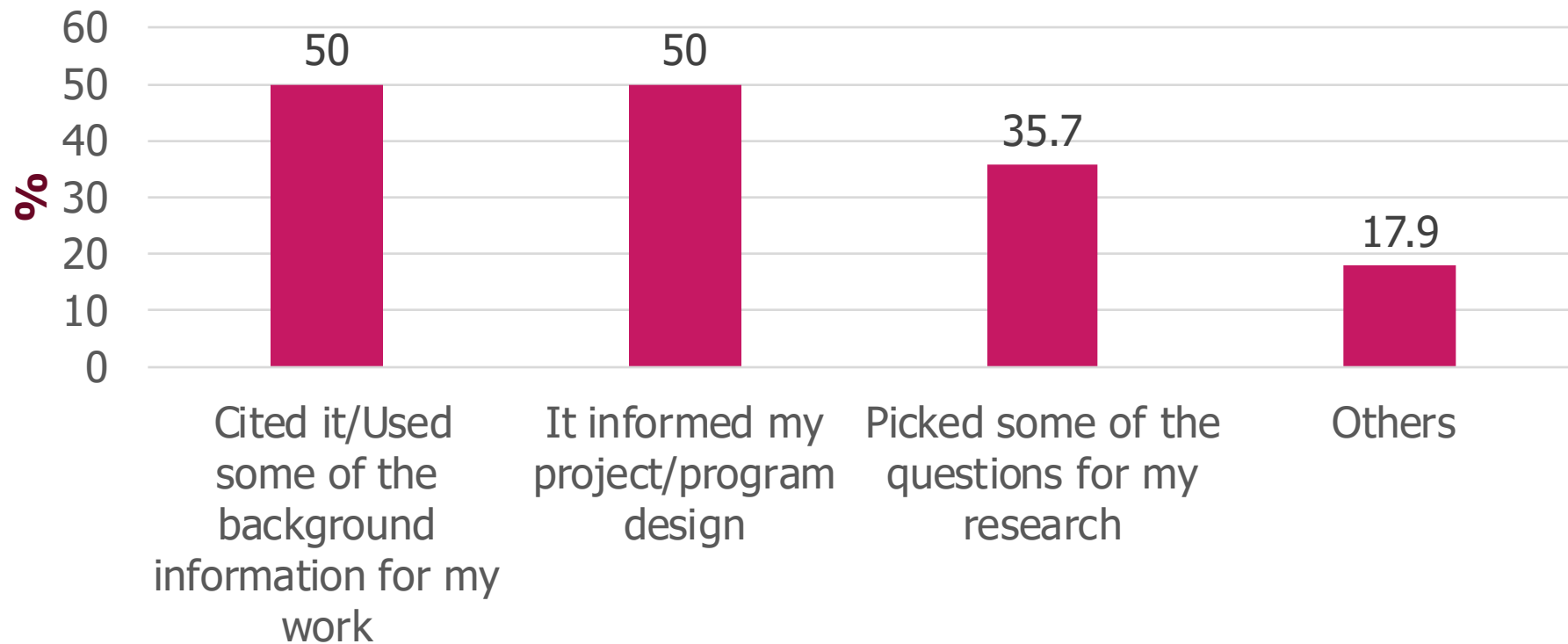
How FP-RLA was used

Inclusion and ownership

Close collaboration with the policy makers throughout the exercise enhanced ownership of the research priorities.

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.

There are additional issues relevant to research prioritization, generation and use globally which might not be captured by current research priority setting frameworks.

STAKEHOLDER REPRESENTATION DURING THE FPRLA PROCESS

- Academia
- Multisector representation
- Cultural leaders
- Providers
- Advocacy groups
- Policy makers
- Religious leaders
- District leaders
- Funders
- program implementers (NGOs)

Pie chart values: 20%, 19%, 24%, 4%, 6%, 1%, 5%, 13%, 3%, 5%
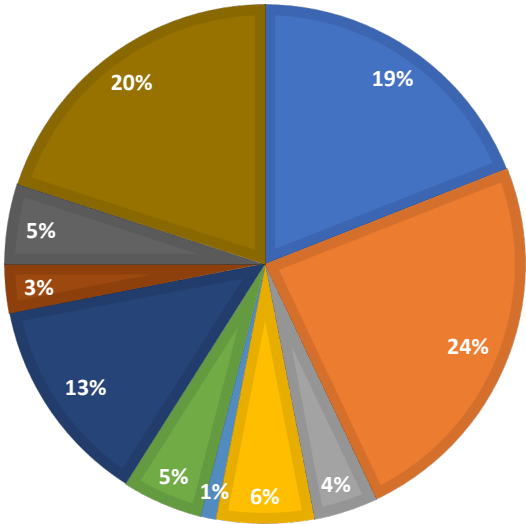
Multi-stakeholder participation and Justice

- Focus on relevant priority questions directed the process towards alignment and de-colonizing research priorities from external drivers.

- The FPRLA process was country led and dominated by program implementers, policy makers and academia (fostering inclusion and ownership).

- Inclusion of stakeholders from education, youth, sport and gender is lauded due to the multi-faceted, multi-sectoral nature of reproductive health (Hardee et al 2018).

- The current total market approach (TMA) to FP emphasizes collaboration multi-sectoral collaboration to increase access to FP for all segments of the population.

What worked

Prior evidence mapping to elicit gaps- entry point and guided

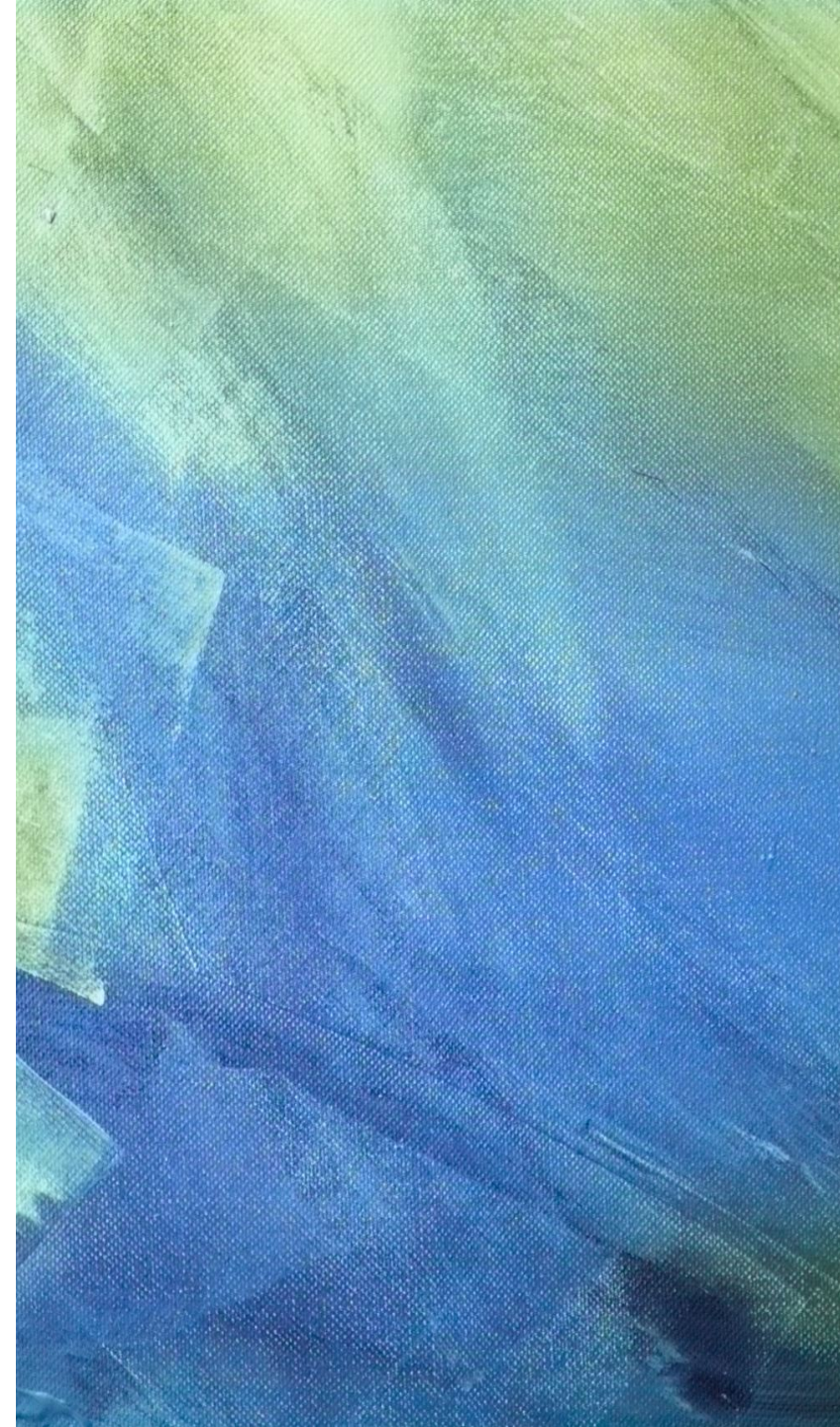Inclusion of programmatic evidence-

Multi-stakeholder participation- legitimacy and ownership

Alignment to country policies and targets – equity considerations

Monitoring use

What did not work

Overlooked engagement of people with lived experience and members of the public. Pratt (2021) posits that this should be emphasized during priority-setting for research projects.

Great inclusion of research funders especially FP to enhance use

Caution that funders agendas do not overrun the priority setting process.

Greater representation of cultural and religious leaders warranted even if only to raise awareness of existing evidence and their role in FP outcomes.

Underlying tension between global priorities and local needs.

Conclusion

Multi-stakeholder involvement is critical, fosters beneficence through ensuring stakeholder participation (inclusion) and ownership

Mapping existing evidence reduces duplication, enhances justice through efficient use of resources

Monitoring the use of RLA should be a key ethical concern for research priority setting efforts

Inclusion of research funders in the priority setting process is critical to enhance generation of evidence tailored to contexts.

Research priority setting processes should be country led to build capacity and generate ownership with stakeholders.