Ethics of health research priority setting

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Upholding autonomy and beneficence in research priority setting exercises in Ghana

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Brief description of case study context

There remains a huge disparity in research investment identified several decades ago referred to as the 10/90 gap: less than 10% of global funding for research is spent on diseases that affect more than 90% of the world's population[1, 2]. These disparities are more pronounced in the field of mental health[3], and will pose significant challenges in achieving the sustainable development goals[4]. There is an urgent need to develop national research agendas that align with knowledge gaps[5]. This can be achieved through well-designed research priority-setting studies. Research priority setting is an extremely useful strategy in identifying the most pressing mental health challenges in a given setting[6, 7]. However, the field is relatively new, and the processes may not be well established in LMICs[8, 9], and in the field of mental health research. This presents real vulnerabilities to the conduct of responsive (to the needs of a given population) and thus ethical research- weak science is bad ethics!

This case study does two things: demonstrate vulnerabilities of research priority setting related to issues of inclusivity and fairness, including goals; and illustrate how these were addressed- helping to move the debate towards ethically informed solutions. The paper examines these from the lens of a 'formal' research priority setting exercise.

Case evaluation

Panel 1: Research priority setting

Case study: Mental health and disability research priorities and capacity needs in Ghana: findings from a rapid review and research priority ranking survey.

Weobong and colleagues in 2020[10] embarked on setting an agenda for mental health and disability research for Ghana, with external funding from the Foreign Common Wealth and Development Office, through King's College London.

Approach: This was a mixed design study comprising a rapid review, research priority ranking survey, and research capacity needs assessment survey. Participants included five expert pools across research/academia, civil society/non-governmental organisations, policy makers, and funders/multilateral/unilateral organisations. The mixed design approach was deliberate to ensure **inclusivity, fairness, and goal-led:**
- The **rapid review** offered critical data on context. Priority-setting methodologies need to reflect the context[11] and country-specific needs[12]
- The **priority ranking survey** was deployed online to as many participants as possible, and followed a systematic process anchored on well-grounded assessment methodology
- The **research capacity needs survey** was also deployed online and ensured the authors related priorities with research capacity. This aligns with the norms of science[13] to the

extent that there is an ethical imperative to demonstrate whether and how the identified priorities can be tackled.

Ethical considerations and challenges in upholding autonomy and beneficence:

Autonomy (inclusion and fairness):
- In our study, we ensured a careful and inclusive selection of experts based on an existing local directory (e.g. mental health civil society organisations and NGOs).
- We employed the use of surveys but more importantly used the technique of open questions to elicit priorities. We did not provide any preconceived list of priority research areas but instead requested respondents to identify their top 3 priority areas. This ensured respondents were involved from the early stages of the process.
- We promoted engagement and community ownership of the exercise through validation workshops. In our study we validated the findings from the first step of the priority-setting survey and the rapid review with key stakeholders in a workshop before proceeding to the ranking stage.
- We established timeframes to ensure timeous conduct of research and sensible allocation of limited resources. We addressed the issue of time-framing as an important parameter in judging the urgency with which to tackle important research questions.

Beneficence (criteria and goals):
- We employed methodologies that reflect context and country/setting-specific needs. Rapid reviews are useful and less expensive approaches to provide important context information to guide initial decisions, and useful validation of the identified priority areas at the end of the exercise.
- Our study used the Child and Nutrition Research Initiative (CHNRI) methodology, an objective and widely used priority ranking tool. This also provides important guidance around value judgements on the social benefits of the identified priority. For example, one CHNRI criteria is an assessment of the likelihood of deliverability and affordability.

These notwithstanding, we faced important **ethical challenges** in arriving at the research priorities. First, even though individuals were offered the opportunity to participate, only 58% contributed to setting the research priorities for mental health in Ghana. Elements of **autonomy** such as **inclusivity** was thus challenging to achieve. Second, in our attempt to reduce the number of initial submissions of research questions and improve the response rate for the ranking survey, the research team pruned and grouped questions. Whilst we felt this was necessary, this weakens the **inclusivity and autonomy** criterion for setting research priorities- essentially, we may have dampened some important voices, **goals** and **social benefits,** and possibly violated the **beneficence** principle. Third, the direct beneficiaries of research in mental health should be persons with mental health conditions or lived experience, yet it was logistically challenging to include these persons, either through qualitative interviews or the structured survey.

Conclusions and recommendations
We discussed a scenario that poses ethical challenges to research priority setting in LMIC settings, and further demonstrated the central relevance of human research ethics in such atypical research activities. Based on the learnings from this study we have demonstrated that it is feasible to employ a systematic methodology for research priority setting that upholds key ethical principles of autonomy (inclusion and fairness) and beneficence (goals/criteria-value judgements about social benefits). Nonetheless, the field can be further challenged and refined and we make the following recommendations with a focus on key ethical principles of autonomy and beneficence:

Autonomy:
- We need to be deliberate and **inclusive** in our selection of participants. This could be achieved by employing innovative techniques to improve response rates, but even more importantly ensure diversity in selecting participants; we should aim to amplify the voices of persons who are direct beneficiaries of research. Further, we recommend the use of

validation workshops to promote engagement and community/stakeholder ownership of the priority setting exercise.

- Employ methodological approaches that preserve the integrity of the data from 'expert' participants. This is to avoid/lessen the risk of the research team assuming the expert role when deciding priority research areas or topics team.

Beneficence:
- Understand the context for setting research priorities. This ensures clear goals are identified from the outset and the usefulness of the priority-setting exercise established. We recommend rapid reviews as useful and less expensive approaches to provide quick important context information to guide initial decisions, and also as useful validation of the identified priority areas at the end of the exercise.
- Use an objective priority setting measure (e.g. CHNRI) that incorporates the importance of assessing relevant ethical considerations such as **feasibility** of pursuing the research idea so as to do no harm; and whether the product will be **affordable**. These value judgements on the social benefits of the identified priority area are critical.

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