

# Ethics of health research priority setting

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## Prioritizing health research in KwaZulu-Natal, South Africa: who sets the priorities, and how are they translated into research conducted?

Gugulethu Eve Khumalo<sup>1</sup>, Rizwana Desai<sup>1</sup>, Xolani Xaba<sup>1</sup>, Elizabeth Lutge<sup>1,2</sup>

<sup>1</sup> KwaZulu-Natal Department of Health, South Africa

<sup>2</sup> School of Nursing and Public Health, University of KwaZulu-Natal, South Africa

### Brief description of the research project

The Department of Health in KwaZulu-Natal (KZN) sets health research priorities every five years. The first priority setting exercise was conducted in 2013 through a series of contact workshops. Due to budget and other constraints, the second was conducted in 2018 through an online survey. In each of the priority setting exercises, participants were requested to submit the research questions that would most impact on health and health care in their spheres of work, or in their communities using their discretion. Since there is no globally accepted gold standard for priority setting, we did not use one, but we did emphasize that the participants should develop priorities from their own perspectives and for their own interests. In 2013, the research questions were analysed qualitatively, that is, they were coded and grouped into themes, and the number of research questions in each theme was recorded. Priority questions were communicated to research organisations in KZN, for incorporation into their own research agendas. This case study describes: (1) How the 2013 and 2018 research priority setting exercises differed in terms of participation, representativity, and research questions generated and (2) To what extent the priority research questions generated in the 2013 priority setting exercise were translated into actual research conducted.

### Background

One of the key ethical values in setting research priorities is that of inclusiveness and stakeholder engagement<sup>1</sup>. This value poses two critical questions which are, **who sets the priorities or who are the stakeholders?** and **are their voices and concerns translated into prioritised research?** Ideally, research priority setting should be an inclusive process, with meaningful representation from a wide variety of stakeholders, including the vulnerable and voiceless<sup>2</sup>. However, identifying who the relevant stakeholders should be and ensuring that all relevant stakeholders are included in priority setting exercises may have their challenges. The Health Research Policy in South Africa (2001)<sup>3</sup> requires that community groups; NGO's, departments involved in health and development; providers of service; industry; researchers; international and local funders of research form part of the research prioritisation process<sup>4</sup>. Regarding the second question on whether the voices of the stakeholders translate into prioritised research, the Department of Health, in the province of KZN, South Africa (SA), has attempted to consider these questions, through the research prioritisation exercises that it has conducted since 2013.

KwaZulu-Natal is the second largest province in SA with a total population of 11.4 million; that is, 19.7% of the country's population resides in KZN<sup>5</sup>. The province is the epicentre of both the Human Immunodeficiency Virus (HIV) and Tuberculosis (TB) epidemics<sup>6-8</sup>. Non-communicable diseases such as diabetes and hypertension are placing an increasingly heavy burden on the poorly resourced health system. Additionally, the province is the third poorest province in SA, with communities in the rural areas having particularly high levels of poverty. KwaZulu-Natal is a research active province, and home to multiple well-known research and academic organisations. The National Health Act (Act 61 of 2003) and the KZN Health Act (Act of 2009) mandate the National and Provincial Health Research Committees to set research priorities for the country and province respectively. The KZN Department of Health, on behalf of the Provincial Health Research

and Ethics Committee, has undertaken to conduct priority setting exercises every five years. The first was conducted in 2013, and the second in 2018.

## Results

### 1. Comparing the 2013 and 2018 priority setting exercises in terms of participation, representativity, and research questions generated:

In 2013, the priority setting exercises were held in person, at workshops conducted across the province. One hundred and eighty-eight (188) people attended, including different cadres of health care workers, traditional healers, community leaders, academics, and representatives from non-governmental and faith-based organisations. In the 2018 exercise, seventy-three (73) people participated, and these were generally health care workers from within the Department of Health. In 2013, a total of 1018 priority research questions were generated. In 2018, a total of 213 priority research questions were generated. The representativity of the 2018 online survey was clearly far inferior to that of the contact workshops of 2013. The online survey by definition excluded all those who did not have access to computers and internet connectivity, thus effectively excluding traditionally poor and voiceless groups. Because the participants in 2018 were more homogenous than in 2013, the research questions generated were less rich, and failed to reflect the concerns of people from the variety of cultural, economic, and social settings within the province.

### 2. Determining the extent to which priority research questions generated were translated into research conducted:

A total of 1018 priority research questions were generated in 2013, and in the 5 years subsequent to this, 1235 subsequent research applications were submitted to the KZN Department of Health for approval. These research questions, and the titles of the research applications, were categorised into 32 primary themes. Overall, 23 of the 32 themes (71.8%) showed areas of unmet provincial research needs; that is, only 28.2% of research conducted after the 2013 prioritisation process overlapped with the priority research questions generated in that process. Clearly, the uptake of research priority questions for subsequent conduct of research was less than optimal.

## Ethical issues

South Africa has a history of excluding groups from participation in social and political life. Although this has changed in the political sphere, many people remain voiceless because of poverty, geographic isolation in rural areas, and lack of access to amenities. These groups bear the heaviest burden of diseases, and yet are voiceless in the process of setting priorities in health-related research. The inclusion of these marginalised communities was most effectively done in our 2013 priority setting exercise. However, this process was resource intensive, and could not be replicated 5 years afterwards. The question of **how to democratise research priority setting exercises sustainably, especially in countries characterised by extreme inequality**, remains.

- The deliberately inclusive process of our research priority setting exercises resulted in the development of 32 priority research themes in 2013 and 2018 respectively. Such a multiplicity of priorities begs the question – does including such a diverse range of voices render the process of priority setting ineffective, in that too many priorities are set? If so, how does one balance the two competing imperatives of inclusivity of process, and brevity of the list of priorities? In South Africa, the National Department of Health does not provide a specific standard for setting research priorities for the provincial governments as it believes that the process of priority setting is not static, but should be continuous and cyclical, responsive to the changing health environment and local need<sup>9</sup>.
- Even if participation in such exercises is optimised, the question of how to ensure that priorities are translated into research actually conducted is an ethical one and relates to academic freedom. Following our 2013 exercise, the research conducted clearly did not correspond to the priorities set. There are important ethical issues around how to ensure that priority research questions are taken up by researchers and academics. Should governments refuse to grant permission for research to be conducted if the research does not conform to an articulated

priority, or is this an infringement of academic freedom? Should funders refuse to fund research that does not respond to a priority, or does this undermine the potential value of “blue sky” research?

### **Conclusions and recommendations**

It is crucial that research prioritisation processes are widely and equitably inclusive of all groups in the population. However, this is difficult and resource-intensive to do. Further, ethical questions abound about how to ensure that research priorities are translated into research actually conducted, without infringing on academic freedom.

We have the two following recommendations to make:

1. That research prioritisation process is taken seriously by governments and funders, and that they make adequate resources available for these.
2. That government, funders, researchers, and academic organisations strengthen their relationships and communication to ensure that there is a balance between research that conforms to priorities identified, and the academic freedom of researchers.

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