



PRIORITIZING HEALTH RESEARCH IN KWAZULU-NATAL, SOUTH AFRICA: WHO SETS THE PRIORITIES, AND HOW ARE THEY TRANSLATED INTO RESEARCH CONDUCTED?

Global Forum on Bioethics in Research 29 November 2023 Dr G E Khumalo

GROWING KWAZULU-NATAL TOGETHER



BACKGROUND



Two of the key ethical values in setting research priorities is that of inclusiveness in stakeholder engagement and translation of prioritized research [1].



Ideally, research priority setting should be an inclusive process, with meaningful representation from a wide variety of stakeholders, including the vulnerable and voiceless [2]



The two ethical values pose two critical questions: who sets priorities? and if their voices (prioritized research areas) are then translated into research?



BACKGROUND CONT.

- ■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 [3].
- The province is the **epicentre** of both the Human Immunodeficiency Virus (HIV) and Tuberculosis (TB) epidemics placing an increasingly heavy burden on the **poorly resourced health system**.
- **Third poorest province** in SA, with communities in the rural areas having particularly high levels of poverty
- However, it is a research active province, and home to multiple well-known research and academic organisations.



RESEARCH PRIORITIZATION PROCESS IN KZN

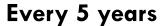
National Health Act 61 of 2003





National and Provincial Research Committees











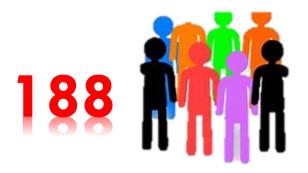
STAKEHOLDER ENGAGEMENT

methods

priority questions

Poor Average Poor





participants



On-line survey

ExcellentGood



Years





TRANSLATION OF PRIORITIES INTO RESEARCH



Research study conducted using 2013 data



A total of 1018 priority research questions were generated



1235 subsequent research applications were submitted to the KZN



Priority Questions and research titles coded into themes and quantified.



Overall, 28% (9/32 themes) of priority questions were translated into research



Uptake of research priority questions for subsequent conduct of research was less than optimal.



- Democratizing research priority setting exercises sustainably, especially in countries characterized by <u>extreme inequality</u> like SA is difficult
- With <u>South Africa's history</u>, many people remain voiceless because of poverty, geographic isolation in rural areas, and lack of access to amenities.
- ■These groups <u>bear the heaviest burden of diseases</u>, and yet are voiceless in the process of setting priorities in health-related research.
- The inclusion of these marginalized communities was most effectively done in our 2013 priority setting exercise

ETHICAL CONCERNS (1)



ETHICAL CONCERNS (2)



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?



RECOMMENDATIONS





Government and funders need to take the RPP seriously and they make adequate resources available for it so that it is as widely inclusive as possible. 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



THANK YOU

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