

# Ethics of health research priority setting

Montreux, 28&29 November 2023



## Pecha Kucha presentation

### Consideration of values when setting research priorities: a value-orientated guidance tool for priority-setting exercises

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#### Background papers

Hawwash D, Pinxten W, Bonn NA, Verstraeten R, Kolsteren P, Lachat C (2018) Perspective: Consideration of Values When Setting Priorities in Nutrition Research: Guidance for Transparency. *Adv Nutr.* Nov 1;9(6):671-687.

Hawwash D, Pinxten W, Raneri JE, Kolsteren P, Lachat C. (2020) Uptake and impact of priority setting exercises in nutrition research publications, *Eur J Clin Nutr*, Aug 27.

#### Brief description of case study context

Research priority setting is important but complicated. It requires the engagement of various stakeholders with diverse interests and insights, and a balanced approach to ensure that different voices and concerns resonate in the priorities that are set. In practice, however, such requirements may not always be fulfilled. Bringing together a variety of stakeholders does not guarantee an actual consideration of what matters most in research, be it from a scientific, social, or ethical perspective.

While nutrition research can guide interventions to tackle the immense global burden of diet-related diseases, priority-setting in nutrition research is often lacking systematic ways to explicitly define and consider relevant values. To avoid that priority setting would be inspired by personal interests, practical convenience, or mere coincidence, we developed a tool that enables a more comprehensive and systematic consideration of values.

As a starting point, we analyzed what values are reported in the 22 published priority exercises that were included in a scoping review. We found 8 clusters of values, which were translated into 3 main domains of reflection: impact, feasibility, and accountability. Within each of these domains, we formulated specific ethical considerations.

The tool does not assess the importance of specific values as such, nor does it serve as a quality stamp for research priority exercises. Rather, it aims to trigger explicit and open ended reflection on research, in which values can be adopted or forfeited, but not neglected.

The use of this tool increases transparency on what values have been considered, and what ethical trade-offs have been made when setting priorities. To calibrate the tool with the intentions of the authors of the papers included, we invited the first and last author of every paper to provide feedback on the tool.

## **Ethical issues**

1. Adequate and systematic consideration of relevant values in research priority setting

*Not all exercises refer to similar values, and a systematic approach to consider values is largely lacking. It can therefore not be taken for granted that priority setting exercises focus on what matters most for those affected.*

2. Transparency

*Trade-offs between values are usually not being described as part of the outcome of priority setting exercises. Transparency about which values have been considered and why they have (not) been translated in research priorities is usually absent.*

These two issues have far-reaching implications for every aspect of research priority setting, including or example fair representation of stakeholders.

## **Conclusions**

The findings of our review call for more consistency between the values used and the reporting of outcomes from the priority-setting exercises. For instance, although the majority of the papers valued impact, there was an apparent lack of transparency in the reporting of the follow-up plan, and outcome processes of the priority-setting exercises.

## **Recommendations**

1. Explicit consideration of relevant values, using a framework. The tool we developed can be an inspiration to do this, and probably has a wider relevance than nutrition research only
2. Transparent reporting on how values have been considered in the priority-setting process, and on the trade-offs that have been made

**This paper was prepared for GFBR 2023**  
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