INVOLVING STAKEHOLDERS IN RESEARCH PRIORITY SETTING: A SCOPING REVIEW

Christiane Grill*[a]

[a] Ludwig Boltzmann Gesellschaft, Open Innovation in Science Center, Vienna, Austria
* Corresponding Author: Christiane Grill, christiane.grill@lbg.ac.at

Abstract. This scoping review provides a thorough analysis of how stakeholders have so far been involved in research priority setting. The review describes, synthesizes, and evaluates research priority setting projects not only for the field of health – as previous reviews have done – but does so on a much broader scale for any research area. A comprehensive electronic literature search was conducted in the databases PubMed, Scopus, and Web of Science. Reflecting the importance of grey literature, Google Scholar and relevant websites were also screened for eligible publications. The scoping review encompasses 731 research priority setting projects published until the end of 2020. Overall, the projects were conducted within the realm of 50 subject areas ranging from agriculture and environment over health to social work and technology. Over time, 30 different stakeholder groups took part in research priority setting. The stakeholders most frequently asked to identify research priorities were doctors, patients, academics/researchers, nurses, allied healthcare professionals, family members, friends, and carers. Nearly two thirds of all projects have been conducted in Europe and North America. Overall, only 9% of the projects emphasized the importance of stakeholders in their goals and rationales and actively involved them. In around a quarter of the projects, stakeholders deliberated on their research priorities throughout the entire process. By mapping out the complex landscape of stakeholder involvement in research priority setting, this review guides future efforts to involve stakeholders effectively, inclusively, and transparently, which in turn may increase the overall value of research for society.

Keywords: priority setting, stakeholder involvement, patient and public involvement, research priorities, scoping review

1 INTRODUCTION

Traditionally, researchers, research institutions or funding organizations decide on the questions that research should answer. The corporate world, however, has demonstrated very early on that involving stakeholders in defining research and development (R&D) activities can be very beneficial [1]. Many of the best ideas for new products and services

(e.g., LEGO sets, Local Motors' cars, or telecommunication applications for Orange) have originated from stakeholders having a say in setting the R&D agenda [2], [3]. A gradual turn of tide can also be observed in science. Influential bodies, like the European Commission (EC) [4], the Organisation for Economic Co-Operation and Development (OECD) [5], and the World Health Organization (WHO) [6], or UK's National Institute for Health Research (NIHR) [7] are strongly advising researchers to actively involve non-research stakeholders in setting the scientific research agenda. And indeed, increasing efforts are made to identify stakeholders' research needs by involving them in "research priority setting".

Research priority setting encompasses any activities that involve stakeholders in identifying, prioritizing, and reaching consensus on those areas, topics, or questions that research needs to address [8], [9]. Particularly in the first stage of the research process, when deciding what to research, input by non-research stakeholders can be very beneficial. It has been shown to promote the uptake and implementation of research evidence, secure optimal return on investment, reduce "research waste", and foster the relevance and legitimacy of research overall [10].

This review sets out to describe, synthesize, and evaluate research priority setting projects not only for the field of health – as previous reviews have done – but does so on a much broader scale for any research field worldwide. The review questions touch three broad areas of interest: (1) the general characteristics of research priority setting projects with stakeholder involvement, (2) the importance of stakeholder involvement, and (3) the methods and approaches to involve stakeholders in research priority setting. The specific questions guiding the review are: (1) What are the general characteristics of those research priority setting projects that involved stakeholders to set the research agenda? More precisely: (1.1) For which subject areas are stakeholders involved in setting research priorities? (1.2) Which stakeholder groups are involved in research priority setting? (1.3) In which countries are stakeholders involved in research priority setting? (2) How much importance do the priority setting projects attribute to stakeholder involvement? (2.1) Is stakeholder involvement named as an explicit goal? (2.2) Is stakeholder involvement named as a reason for conducting research priority setting? (2.3) Are stakeholders included in governance structures (i.e., steering groups, advisory boards)? (2.4) On what level is the public involved in research priority setting? (3) How are stakeholders' research priorities elicited? More precisely: (3.1) What methods are applied to elicit stakeholders' research priorities? (3.2) What are the specific approaches to elicit stakeholders' research priorities?

2   METHODS

Studies that reported how non-research stakeholders were involved in setting priorities for research and published by the end of 2020 in English were included. Studies in which only

researchers were involved in setting priorities for research were excluded. Furthermore, studies assessing priorities for practice and policy, non-research articles (e.g., policy documents, clinical guidelines, editorials, commentaries), and articles that did not include information about stakeholders and methods were excluded. A comprehensive electronic literature search was conducted. To minimize any possible biases, several sources were searched. Additionally, the searches were updated in January 2021 to include all research priority setting projects published by the end of 2020. A data extraction form was then developed specifically for this review and piloted on a small sample of randomly selected studies (n=25). For all included studies, the following information was extracted into a csv file. As to the general characteristics of research priority setting projects with stakeholder involvement, the project's subject area, involved countries, and the study's publication year were extracted. To measure the importance that the projects attribute to stakeholder involvement, the project's goal, the reasons for conducting research priority setting, details on the governance structure (i.e., steering groups, advisory boards), and information on the level of public involvement in these projects were extracted. As to the procedure to elicit stakeholders' research priorities, the specific methods, and approaches to do so were extracted. In a subsequent step, the extracted information was manually coded (i.e., classified along broader categories), and in a last step due to the large amount of data quantitatively analyzed.

3   RESULTS

The scoping review encompasses 731 research priority setting projects that involved stakeholders and were published until the end of 2020. The first research priority setting that involved stakeholders was published in 1975 and is titled "Delphi Survey of Priorities in Clinical Nursing Research" by Carol A. Lindeman [11]. Until the mid 90's, research priority setting projects were isolated occurrences. Since the beginning of the 2000s, the number of published projects has grown steadily with a particular large increase since 2007. The largest number of published research priority setting projects can be found for the years 2019 (n=100) and 2020 (n=89).

Overall, the research priority setting projects in which stakeholders were involved were conducted within the realm of 12 subject areas ranging from agriculture and environment over health to social work and technology. As to the stakeholder groups that have so far been involved in research priority setting, the findings reveal that experts by profession (i.e., individuals who have expertise due to their formally learned knowledge in higher education or professional experience) have always been involved in research priority setting. Over time, experts by experience (i.e., individuals with direct lived experience) brought their knowledge and perspectives also into priority setting and in the last years, their involvement – especially those of patients and family members/friends/carers – has particularly increased. Figure 1

presents a heatmap of the stakeholder groups involved in research priority setting projects over time.

Figure 1: Heatmap of Involved Stakeholder Groups over Time

Regarding the importance of stakeholder involvement in research priority setting, the findings of this review are mixed. Only half of all projects explicitly mentioned to aim to involve stakeholders and justified the research study with a lack of knowledge about stakeholders' research priorities. But if involving stakeholders is not explicitly highlighted within the objectives and rationales for research priority setting, stakeholder involvement can quickly become mere lip service. Furthermore, in half of all projects the public neither participated nor was actively involved in research priority setting. In only 17% of the identified projects, the public were indeed actively involved by being members of advisory boards or steering groups, co-developing materials and so forth.

4   CONCLUSION

Involving stakeholders at the beginning of the research process, when deciding what to research, can undoubtedly be a very beneficial endeavor. Such involvement not only leads to more direct applicability of research results to stakeholders and better practical uptake, but it also fosters the democratization of research and improves the relevance and legitimacy of research overall. By mapping out the complex landscape of stakeholder involvement in research priority setting projects, this review guides future efforts to involve stakeholders effectively, inclusively, and transparently, which in turn may increase the overall value of research for society. However, considering researchers' still existent skepticism towards the benefits of involving stakeholders in research priority setting [12], future research on this matter is greatly needed. Thus far, there exists anecdotal evidence. Isolated projects have proven that researchers may indeed overlook questions of relevance to stakeholders, and that answering these questions not only satisfies stakeholders' needs, but also results in more effective research translation. A systematic analysis of the extent to which research priority setting generates scientific but most importantly societal impact is yet missing.

5   REFERENCES

[1]   H. Lifshitz-Assaf, "Dismantling knowledge boundaries at NASA: the critical role of professional identity in open innovation," *Adm. Sci. Q.*, vol. 63, no. 4, pp. 746–782, Dec. 2018, doi: 10.1177/0001839217747876.

[2]   A. King and K. R. Lakhani, "Using open innovation to identify the best ideas," *MIT Sloan Manag. Rev.*, vol. 55, no. 1, pp. 41–48, 2013.

[3]   V. Ramaswamy, "Competing through co-creation: innovation at two companies," *Strategy Leadersh.*, vol. 38, no. 2, pp. 22–29, Mar. 2010, doi: 10.1108/10878571011029028.

[4]   M. Mazzucato, "Governing missions in the European Union," 2019. [Online]. Available: https://ec.europa.eu/info/sites/default/files/research_and_innovation/contact/documents/ec_rtd_mazz ucato-report-issue2_072019.pdf

[5]   OECD, "OECD Due diligence guidance for meaningful stakeholder engagement in the extractive sector," Paris, OECD Publishing, 2017. [Online]. Available: http://dx.doi.org/10.1787/9789264252462-en

[6]   WHO, "Exploring patient participation in reducing health-care-related safety risks," 2013. [Online]. Available: https://www.euro.who.int/__data/assets/pdf_file/0010/185779/e96814.pdf

[7]   P. Wilson *et al.*, "Research with patient and public involvement: a realist evaluation – the RAPPORT study," *Health Serv. Deliv. Res.*, vol. 3, no. 38, pp. 1–176, Sep. 2015, doi: 10.3310/hsdr03380.

[8]   A. Tong *et al.*, "Reporting guideline for priority setting of health research (REPRISE)," *BMC Med. Res. Methodol.*, vol. 19, no. 1, p. 243, Dec. 2019, doi: 10.1186/s12874-019-0889-3.

[9]   R. F. Viergever, S. Olifson, A. Ghaffar, and R. F. Terry, "A checklist for health research priority setting: nine common themes of good practice," *Health Res. Policy Syst.*, vol. 8, no. 1, p. 36, Dec. 2010, doi: 10.1186/1478-4505-8-36.

[10]   A. Boaz, S. Hanney, R. Borst, A. O'Shea, and M. Kok, "How to engage stakeholders in research: design principles to support improvement," *Health Res. Policy Syst.*, vol. 16, no. 1, p. 60, Dec. 2018, doi: 10.1186/s12961-018-0337-6.

[11]   C. A. Lindeman, "Delphi survey of priorities in clinical nursing research," *Nurs. Res.*, vol. 24, no. 6, pp. 434–441, 1975.

[12]   K. Staley, S. Crowe, J. C. Crocker, M. Madden, and T. Greenhalgh, "What happens after James Lind Alliance priority setting partnerships? A qualitative study of contexts, processes and impacts," *Res. Involv. Engagem.*, vol. 6, no. 1, p. 41, Dec. 2020, doi: 10.1186/s40900-020-00210-9.