

# Patient involvement in health research and development- The role of patient representatives



Kiana Kiani, RN, Ph.D. student, Ida Björkman Ph.D., Elin Siira Ph.D. Catarina Wallengren Ph.D. & Axel Wolf Professor  
Institute of Health and Care Sciences and the Centre for Person-Centered Care - GPCC, Gothenburg University

## Background

Currently, there is insufficient knowledge about patient representatives' views on their role in collaboration with other stakeholders and when, where, and how to effectively involve them in health research and development. Patient representatives provide a unique perspective based on their lived experiences. This knowledge is crucial for those aiming to positively impact health research and development.

## Purpose

To explore patient representatives' views on their role in health research and development.

## Method

A survey involved 95 patient representatives recruited through the European Patient Academy on Therapeutic Innovation (EUPATI) in Sweden. They were asked about their role in health research and development, collaboration with different stakeholders, their understanding of patients' role in such collaborations, trust levels, and barriers to patient involvement. We analyzed the participant's answers through descriptive statistical analysis. Participants rated statements on a scale of 1 to 5.

The analysis primarily focuses on the following questions:

1. How often do you interact with different stakeholders? (Rated from 1=never to 5=very often)
2. How important is it to include patients as advisors to various stakeholders? (Rated from 1=not important to 5=extremely important)
3. Do you experience trust in different stakeholders? (Yes, no, hard to tell)

## Results

Most of the participants, primarily women aged over 40 (75%) with post-secondary education qualifications (82%), had ties to patient organizations. Table 1 illustrates the extent of participant collaboration with various stakeholders. Table 2 presents the significance of collaboration with other stakeholders from the participants' perspective, while Table 3 displays the level of trust participants have in some of these stakeholders.

## Conclusion

The findings suggest that there is little collaboration between patients or patient organizations and the stakeholders deemed important by survey participants. There are also uncertainties regarding collaboration, particularly with authorities, pharmaceutical industries, and decision-making bodies such as healthcare procurers. Further research is needed to study the experiences of other stakeholders in patient and public involvement (PPI), as well as the role of patient representatives in collaboration with various stakeholders. It is also important to explore any obstacles and opportunities for PPI as perceived by the different stakeholders.

