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# Absent Patients: The Ambiguous Positioning of Patients as Stakeholders in Health Research Collaboration

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## Background:

# Research collaborations with public and private stakeholders

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### Focus:

Stakeholder collaborations  
in brain health research

### Importance:

Public & Patient Involvement  
Including the patient perspective

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### Prior research:

Influence in stakeholder relationships shaped by the ways in which actors engage in discursive practices to construct meaning and values. Challenges of legitimacy in voicing opinions or becoming an agentic collaborator (Halme, 2020; Hardy & Phillips, 1998).

### Prior research:

Inclusion of lay stakeholders in the health research process has been increasingly emphasized in the health sector (e.g., Graham, Rycroft-Malone, Kothari, & McCutcheon, 2022; Greenhalgh et al., 2019; Johnson, Bush, Brandzel, & Wernli, 2016).

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### GAP:

Relational aspects focusing on the role of lay stakeholders in health research stakeholder collaborations

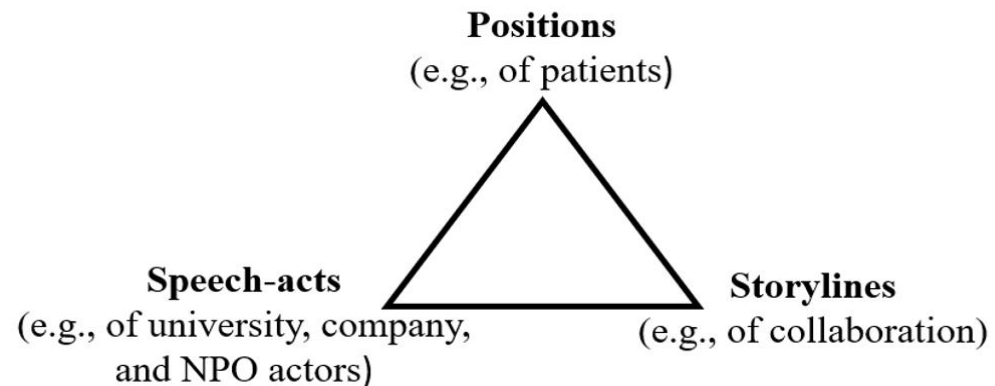
### WE ASK:

How HR stakeholders position patients as a part of their research collaborations?  
How the rights and duties associated with different positions represent the power dynamics of stakeholder collaborations?



# Theoretical framework

- Relational perspective on stakeholder collaborations (Civera & Freeman, 2019)
  - Critical discursive perspectives on stakeholder relations (e.g., Reynolds & Yuthas, 2008; Zakhem, 2008): stakeholder collaboration as relational, dialogical and constantly negotiated activity bound to the moral aspects of collaboration.
  - Emancipatory aspects of critical approaches have emphasized the importance of identifying social inequalities and engaging in inclusive and participatory processes that may allow marginalized stakeholders to have a voice (Painter, Pérezts, & Deslandes, 2021).
- Positioning theory (e.g. Harré & Van Langenhove, 1999)





# Research context

- It has become a common requirement in research proposals, especially for external funding, that health researchers must indicate how they will involve the public and patients in their research (den Oudendammer et al., 2019; Nimmegern, Norstedt, & Draghia-Akli, 2017; O'Donnell & Entwistle, 2004; van Bekkum & Hilton, 2014).
- In the Finnish brain research context, research collaborations have become increasingly cross-disciplinary and interdisciplinary and have extended from neuroscientists to academic experts of biomedicine, biology and data science and to medical physics and engineering.
- No regulation exists in Finland on how academic researchers can or should collaborate with patients in any other roles than research objects, for which specific legislation exists. When patients are research objects, they participate in health research, but do not have power to influence on how the research is done.
- Health firms that apply for regulated certification for their products and services are required to involve patients in their research and development projects as users of these products and services.



# Data and methods

- Our study focuses on stakeholder collaborations in brain health research between multiple actors as part of two recently established neuroscience research communities in two Finnish regions
- Qualitative interview data (n = 44) collected as part of a research project focusing on stakeholder relationships in neuro health research.

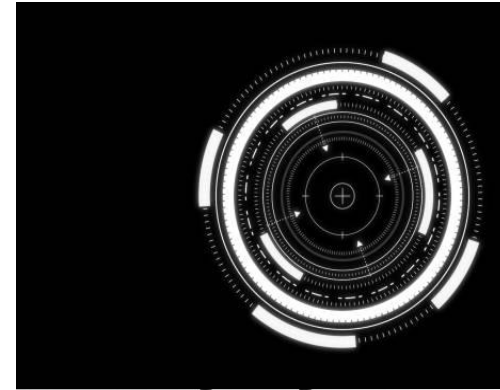
Type of stakeholder	Interviewees	Examples of actors
Scientific	19	Basic & clinical neuroscience researchers
Business	13	Start-ups and spin-offs
Non-profit organisation	12	Hospitals, patient organisations, and innovation ecosystems,

- Qualitative content analysis, explicit subject positions in terms of self-other positioning, storyline analysis, identification of rights, duties and responsibilities.



# Findings

- Positions of active and passive agency
- Positions of targets of care and research
- A variety of frames concerning stakeholder collaborations





# Conclusions

1. Ideals of **democratic science have challenged** the traditional views of scientific collaboration, highlighting how patients should have more rights to participate as collaborators in scientific research (Gibson et al., 2012).
2. **Imbalance** between expectations of PPI and collaborative stakeholder research practices.
3. Understanding how patients are positioned in scientific stakeholder collaborations is crucial because it reveals **why and how certain ideals become a part of the organisation of novel scientific work.**
4. Adds to the previous literature on stakeholder collaborations by expanding the discussion to an **explicit investigation of positioning dynamics in relation to moral orders** (rights and duties) and **power relations** in stakeholder collaborations in terms of intersecting moral orders.
5. Even if the overall goal of involving patients in collaborative research is guided by the intention to “shift from paternalistic and hierarchical, to more collaborative and egalitarian relationships between medical experts and patients/research participants” (Siffels et al, 2021: 1), as this study suggests, the **more traditional roles continue to guide stakeholders’ understandings of how patients are understood as serving collaborative research processes.**



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**Thank  
you!**

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