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Deconstructing the concept of participation in participatory health research: Its limitations and opportunities

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ABSTRACT

This contribution explores the multiple, complex layers that are involved in establishing participation in research. Specifically, this contribution analyses the dominant conceptualization of participation in the field of participatory health research (PHR). The focus of this contribution is to analyze the dominant conceptualization of participation in the field of participatory health research (PHR) through the lens of five key aspects underlying participation in PHR: stakeholder engagement, relationships among participatory researchers, empowerment, capacity building, and knowledge transfer. By deconstructing the complex layers of the concept of participation, this contribution seeks to highlight both the limitations of the current conceptualization as well as new perspectives for successful participation in practice.

To do so, this contribution provides practical recommendations aimed at overcoming the identified limitations. These recommendations promote an alternative understanding of participation that supports a more responsive approach to challenges at both the structural and individual levels. Acknowledging the limitations and challenges of PHR enables stakeholders to engage in participatory research processes based on mutual respect and appreciation.

1. Introduction

The roots of participatory health research (PHR) can be traced back to the 1970ies, in which social movements pointed out that knowledge production was used to (re)produce social injustice (Roura, 2021). With its roots in social movements, PHR aims to empower patients and contribute to health equity by giving them a voice in the design of research studies as well as in the analysis and dissemination of their results through co-creation methods (e.g., Agnello et al., 2025; Evans & Potochnik, 2023; Hartung et al., 2025; von Unger, 2014; Wright et al., 2021). In contrast to the paternalistic structures that have traditionally dominated research and health care, the focus of PHR is on the needs and lived experiences of social actors with the aim to both give research greater relevance as well as to empower stakeholders (Clar & Wright, 2020).

The current conceptualization of PHR—with its emphasis on the co-production of the research process, outcomes, and impact as well as the assumption of shared decision-making authority among all stakeholders involved—places significant demands on researchers. In practice, departures from this idealized collaborative process are evident (Lenette et al., 2019). These high demands on all stakeholders—i.e., both the academic researchers and the co-researchers—arise mainly from the need to reflect on one's own role, the existence of different competences for participating in PHR, and a confrontation with the limits of one's own expertise (Wright, 2021). At the same time, challenges have been raised to the additional benefit of the knowledge generated by PHR projects and the empowerment they claim to produce. For example, it is questioned whether PHR in practice succeeds in capturing the lived reality of stakeholders or whether it constructs an image of others that does not reflect their actual lived reality (McLaughlin, 2016). If PHR fails to capture the reality of the patient's experience, its aim to empower the patient may break down with it.

The challenges outlined here are not new and are discussed in the literature. Yet, to us this highlights the need for a critical examination of

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the prevailing PHR framework. The main objective is therefore to shed light on the limitations of the currently dominant conception of PHR in addressing individual and structural challenges to participation, while also examining how reflecting on certain key features of PHR ideals can enable a more responsive implementation in practice. We propose to do so by deconstructing the existing conceptualization of PHR, i.e., to deconstruct the participatory research process. Rather than rejecting participation itself, deconstruction is used to uncover implicit assumptions, contradictions, and limitations within how participation is currently framed and practiced. By analyzing five key aspects—stakeholder engagement, researcher relationships, empowerment, capacity building, and knowledge transfer—this method helps identify areas where current approaches fall short and opens space for more responsive and inclusive alternatives. Although these five aspects of PHR are in practice intertwined with each other, we believe that separating them on the conceptual level—as we do in our deconstruction—benefits the understanding of PHR and how it can be implemented in practice.

Our deconstructive approach thus allows for a more nuanced exploration of challenges documented in the literature considering the actual practice of PHR. Through the deconstruction, this contribution aims to identify the limitations of participation that arise from the current theoretical conceptualization itself, and to offer suggestions for overcoming them. This deconstruction therefore serves as a basis for understanding and potentially improving the implementation of PHR in practice.

2. The current debate in PHR

The concept of participation is increasingly seen as a guiding paradigm in health research. The involvement of social actors whose lifeworlds are the object of research is cited as a binding recommendation in research proposals in the UK and is also becoming increasingly relevant in the allocation of funding in Germany (NIHR, 2018; BMBF, 2023). PHR can be understood as an extension of action research, whereby the focus in PHR is more on the aspect of participation in research studies and less on political action while upholding the aim of bringing about change in the lifeworld of stakeholders as well as increasing research impact (von Unger, 2014). The multi-perspective knowledge generated in the context of participatory research, through the combination of experiential and academic knowledge, should achieve greater applicability in society (Allweiss et al., 2021; Bär et al., 2021).

In the PHR ideal, results and interpretations should be developed jointly between academic researchers and patients, called co-researchers, so that the co-researchers have a voice in decisions that impact the outcome, the results, of the research (Bergold and Thomas, 2020). However, in the sense of a dialogical process, this right of co-determination also implies that co-researchers should be enabled to include their own objectives and relevant outcome measures in the development of assessment instruments or in the study design. It follows furthermore from understanding PHR as a social and dialogical process that it does not adhere to a linear scheme (von Unger, 2014). Rather, it is a process which needs to be actively shaped by all those involved (Wright, 2013). Particularly regarding existing orientations in health research and medicine, in which good scientific practice is mostly equated with adherence to certain methodological criteria, this characteristic of PHR can limit its implementation (Greenalgh et al., 2019; Wright, 2021).

For example, clinical indicators such as a reduction in disease symptoms or treatment adherence rates are commonly used to evaluate interventions. Patient-reported outcome measures (PROMs), on the other hand, are not yet extensively discussed and are only gradually gaining in importance (Steinbeck et al., 2021). A strengthened focus on PROMs within PHR could potentially improve the position of co-researchers in the sense of the PHR ideal. This necessary paradigm shift in health system quality assessment leads to a better understanding of the impact of diseases and the effectiveness of interventions from the perspective of those affected. PROMs should therefore be an important part of quality assessment in healthcare systems, in line with the aims of PHR.

3. Deconstruction of the concept of PHR

Looking at existing debates within PHR, there is an emerging trend of questioning what is to be understood as participation and which differences exist in regard of theoretical basis (Messiha et al., 2023), while the added value of PHR is also critically evaluated (e.g., Greenalgh et al., 2019; Wright, 2021). To address and frame these concerns, the current conception of PHR will in the following be deconstructed in five key aspects to highlight opportunities and challenges of PHR. As our aim is to improve the practice and implementation of PHR, we believe that the discussion of these five key aspects together provides the best opportunity to get the central possibilities to improve the practice of PHR in view (see for a summary Table 2 below). With this aim in mind, we take not only in focus the aims of PHR, but also the conditions and structural aspects successful participation.

3.1. Stakeholder involvement

The first aspect to be analyzed is stakeholder involvement. As emphasized above, the involvement of patients as co-researchers in the research process is a central characteristic of PHR (Aldred, 2008; ICPHR, 2013). Stakeholders are thus provided the opportunity to contribute their perspective on the research object and actively shape the research process (von Unger, 2014). PHR is thereby characterized by a multi-perspective view of the research object (Wright, 2013), placing the relationship between participants at the heart of a successful participatory process (Lenette et al., 2019).

Existing research also addresses the challenges of collaboration (e.g., Cornwall, 2008) but tends to remain at a superficial level of analysis, focusing primarily on the opportunities for action for academic researchers. The relationship between the actors involved is characterized by an emancipatory ideal associated with the PHR process (Bergold & Thomas, 2012; for a discussion of the emancipatory ideal, see section 3.3). Yet, social dynamics and conditions of academic researchers and co researchers with regard to their participating role is left out.

First, it is important to consciously acknowledge that academic researchers hold a privileged position in society, which comes with the ownership of the authority to define vulnerable groups (Aldred, 2008). Derived from this, it is possible to reflect and discuss whether social dynamics are reproduced in PHR (Wihofszky et al., 2020). Identifying and defining a social group as disadvantaged or vulnerable also involves attributing a sense of powerlessness and helplessness to the respective group. Such a view of social groups ascribes to them a recipient mode

Table 1
Overview of Competences for successful PHR-collaboration.

Academic Researcher	Co-Researcher
Communicative competencies and language competencies	Communicative competencies and language competencies
Professional competencies	Health Literacy (e.g., the reflective examination of science-related topics and evaluation of them, ability to proceed systematically in the research process)
Self-competence and reflection competence (e.g., development of ethical awareness, awareness of uniqueness and inequities, self-management)	Expertise (knowledge gained from personal/professional experience and the abstraction of this knowledge)
Social competence and empathy skills (e.g., cooperation skills, ability to deal with conflicts/criticism)	Decision-making competence (e.g., ability to make decisions based on relevant factors)
Flexibility and adaptability	Reflection competence

Table 2
Overview of the dangers and coping strategies suggested in this article to deconstruct the current conceptualization of PHR.

Key aspects PHR	Dangers revealed by deconstructing the current concept of participation in PHR	Coping Strategies: Goals, ideal conditions, structural aspects
3.1 Stakeholder involvement	Reproducing social dynamics (privileges of researchers)	Researchers gain sense of the lifeworld of social actors
	Unseen hierarchical structures within groups of disadvantaged people	Constant reflection that experiences may give a superficial impression of homogeneity
	False picture of multi-perspective picture	Seeking attitude: acquiring knowledge of social networks and lifeworlds of stakeholder groups
3.2 Relationship of participatory researchers	Superficial level of perceiving fair and productive power dynamics	Making power imbalances explicit
	Collision of different and unspoken expectations in collaboration	Consultation about wishes and negotiation about conditions of collaborative work: Participants have space and capacities to reflect on expectations and objectives Transparent communication of motivation for including stakeholders in PHR as co-researchers
	Inadequate representation of relationships and thus the type of representation varying in different phases of the project	Reflecting on different participation models at an individual and/or collaborative level and monitoring the intensity of participation
	Non-equal value of different types of knowledge: Hierarchy between everyday and scientific knowledge	Critical reflection whether a common language is spoken and can be spoken in the context of PHR
3.3 Empowerment	Stakeholders powerlessly accepting their circumstances	Evaluation of empowerment processes should be considered within the system in which stakeholders are to be empowered
	Marginalized social groups only get activated by privileged groups	
	External aspects, i.e. the sociocultural level of power, are not part of the analysis of opportunities and challenges in PHR	Consideration whether current framework conditions in the health research system create opportunities for stakeholders to discover their resources, such as their unique perspective on research topics
	Due to certain understandings of empowerment: Assignment of passive role to co-researchers in their relationship with academic researchers and in shaping their own lifeworld.	Sensitive and reflective approach for understanding power imbalances between researchers and co-researchers Enabling opportunity and space to act and influence co-researchers own life circumstances Engaging with existing structures in the health research system Critical investigation of goals involving co-researchers and linked forms of empowerment
	Missed pre-conditions of empowerment: Stakeholders have been able to gain experience of self-worth and	Fostering and building skills, for example by developing participative research formats that enable co-researchers to engage in and benefit from
3.4 Capacity Building	*Co-researchers and academic researchers* are missing the necessary competencies for participation in PHR	*Co-researchers* gained a sufficient level of health and scientific literacy, decision-making competencies and communication skills *Academic researchers* gained social skills and empathy in addition to methodological knowledge specialized in PHR Both are able to critically reflect the possible analytical dichotomy of reflection, the interaction and owns role
	Reproducing societal inequalities through defining participation too rich in competencies and prerequisites needed for its success	Rethinking and transparent communication about the co-research process and linked conception of PHR Openness to competences, that participants develop during the process and complement each other
	Missing preconditions for perceiving participation as a possibility to acquire and extend abilities and resources of participants	Promoting participants' experience of having the opportunity to learn and empower themselves during the research process Willingness to prepare people to engage in participatory processes and to address their needs
3.5 Knowledge Translation	Barriers for co-researchers to knowledge translation: Applying for funding requires specific academic and institutional skills, knowledge, and language Publishing in appropriate journals requires adherence to research quality criteria and topic-specific nomenclature Results of participatory research projects are usually prioritized for a professional scientific audience	Promoting forms of publication to establish themselves in science, allowing the combination of scientific and empirical lifeworld knowledge and the strengths of co-researchers to unfold

that does not do justice to their diverse experiences and suggests homogeneity (Cornwall, 2008). Accordingly, collaboration based on mutual respect and appreciation in PHR requires not only reflecting on processes within the research project but also ensuring that academic researchers gain a comprehensive and holistic sense of the lifeworld of social actors, while perceiving them in their heterogeneity. Indeed, hierarchical power structures may be reproduced in the very process of selecting potential stakeholders, which need to be considered when recruiting co-researchers.

Furthermore, the design of PHR is also linked to competencies that potential co-researchers may find demanding. Houwaart et al. (2021) emphasize that although in principle anyone can participate in PHR as a co-researcher, participation requires, among other things, the ability to aggregate one's own knowledge in order to formulate it as experiential expertise. This process of abstraction and role change requires competencies (see section 3.4), which can also initiate processes of exclusion within the stakeholder group.

Moreover, stakeholder groups are involved through representatives.

These representatives contribute a form of collective knowledge of the stakeholder group to the research process (Houwaart et al., 2021). It is thus debatable whether stakeholder collaboration can have a direct impact on the lifeworld of the individual members of the social group beyond the co-researchers involved. The current definition of stakeholders clearly does not aim to embrace all facets and experiences embedded within a stakeholder group. Rather, it aims to incorporate shared values as well as experiences through representatives (Herzberg, 2020). These representatives are given a 'gatekeeper' role through which their inclusion potentially reinforces the reproduction of a homogeneous image of the stakeholder group, creating the danger that sociocultural inequalities and divergent experiences are insufficiently represented. Common criticism of patient representatives is that they therefore have little descriptive representative character, as people with certain barriers (social, economic, cultural) are not (or cannot be) adequately considered from the outset. (Baumann et al., 2022). However, shared experiences may not be necessary to enable legitimate representation. Holetzek and Holmberg (2022) offer conceptual reflections on responsiveness and the characteristics of representative actors in representative-participatory settings and highlight different forms of dynamic representation beyond representative and represented sharing relevant disease characteristics and disease experiences. When working with representatives of different stakeholder groups, it is necessary to constantly reflect on the fact that their experiences may only give a superficial impression of homogeneity and that on closer inspection their heterogeneity is revealed (Fischer et al., 2020; Wahl et al., 2021). This 'seeking' attitude towards the diversity of the stakeholder group has so far been insufficiently incorporated in the concept of PHR and in building a relationship based on mutual respect and appreciation with the stakeholder group as a whole, and not merely with some of its representatives. The beginnings of a more nuanced view of stakeholders are provided by Wahl et al. (2021) in their elaboration of the roles of those involved in the research process, which will also form the basis for deconstructing the relationship of the involved actors within the PHR process in the next section.

3.2. Relationship of participatory researchers

In PHR, knowledge is produced through the interaction between co-researchers and academic researchers. But the knowledge of exactly what different forms of participation—such as consultation, collaboration or co-production—consist of and how they differ is currently being discussed (Price et al., 2022). Epistemically, this raises the question of how and in which social process knowledge is generated, and who has the power over this process. As it is not obvious how and also challenging to ensure productive and fair power dynamics, collaboration based on mutual recognition is considered essential for the implementation of PHR (Arnold et al., 2022; ICPHR, 2013). The aspiration to cooperate with co-researchers on an equal footing is not perceived in its complexity in the current conceptualization of PHR often but remains instead on the superficial level. This can be linked to the attribution of a general "willingness to cooperate" to the co-researchers, while academic research remains in power of the knowledge-producing process. Here is the risk of reproducing social dynamics and hierarchies by implicitly denying co-researchers power over the knowledge-production (Egid et al., 2021). This is important, as it influences the moment in which academic researchers start to involve stakeholders in the research process, which is often after a study is already designed.

Previous research on PHR so far excluded the analysis of the expectations of co-researchers' collaboration, while academic researchers' expectations, who usually pursue clearly defined objectives by involving co-researchers, are often equated with research objectives. Usually within PHR, no consultation about the wishes and expectations regarding the collaboration by co-researchers takes place and neither does negotiation of the conditions of collaboration (Lenette et al., 2019). As a result, different expectations can collide unspoken, which can be identified as a limiting factor. What is lacking in the literature is the idea that expectations of academic researchers should be linked to demands regarding cooperation by co-researchers.

This implies that co-researchers should have both the space and the capacities to reflect on their own expectations and objectives. This should be a precondition, as co-researchers should be empowered and encouraged to articulate their expectations of the collaboration before it begins. At the same time, academic researchers should transparently communicate their motivation for including co-researchers, so that power imbalances in this respect can be balanced by transparency and open discussion of the expectations and objectives regarding the cooperation.

With their stage model, Wright et al. (2010) provide an approach for reflecting on the distribution of power and collaboration, which, as described, also has a decisive influence on the negotiation of expectations and goals for the research. In doing so, they also define what constitutes participatory collaboration for them: the shared power to make decisions during the research project (Fig. 1).

The model provides reference points for assessing the level of participation and for developing methods to increase participation. The view of participation advocated here avoids a simplistic 'either/or' dichotomy and instead emphasizes the importance of a continuous process of development. This model focuses on the intensity of shared decision power as a quality indicator for PHR (Wright, 2021) and thus suggests that collaboration with mutual respect and appreciation is primarily based on creating opportunities for co-researchers to act and influence decisions and thus the research process.

In practice, however, the intensity of shared decision power as a quality indicator does not sufficiently capture the different starting positions and the heterogeneity of the stakeholder groups that are involved in PHR. Not all persons within a stakeholder group can participate immediately in decision-making or expect the quality and success of their participation to be measured by shared decision-making power. In addition, according to the PHR concept, collaboration is characterized by a change in roles, especially for the academic researchers involved (Wahl et al., 2021). This requires reflection on one's own role by academic researchers, which can be seen as a crucial determinant for building relationships in PHR.

Wahl et al. (2021) therefore place a different emphasis in their model of PHR, focusing on the roles of participants and describing in detail which groups of people interact in a participatory project and visualize their relationship in the model (Fig. 2). First, co-researchers are located within the inner ring and participants who are involved in a research phase without decision-making power are located within the outer ring. Furthermore, the authors argue that those roles directly involved in the research, also, academic scientists, co-scientists and professionals—in which one individual can have more than one role—within the health care setting need to be negotiated on their meaning of their role in the study, their relation to the institutions involved in the research, and the (shared) decision power. Lastly, the dashed lines indicate that the involvement of individuals may change, illustrating the flexible process and that role changes at different stages of a PHR-study.

This flexibility requires specific competencies and critical reflection on what constitutes one's own role, how it changes over time within one study, and to what extent one's main role can be discarded in the interests of equity and cooperation. It also requires critical reflection on the intersection of different roles. As it is not always possible to draw a distinctive line here, an intersectional perspective on the distribution of roles is required. Ultimately, it is also a matter of addressing and reconciling one's own expectations with those of the other participants (Wahl et al., 2021).

In contrast to the considerations regarding the stage model, in the model by Wahl et al. (2021) it becomes clearer that the intensity of involvement of co-researchers during different stages of PHR can vary. It becomes for PHR therefore relevant to monitor the intensity of participation in terms of decision power, as different intensities of involvement

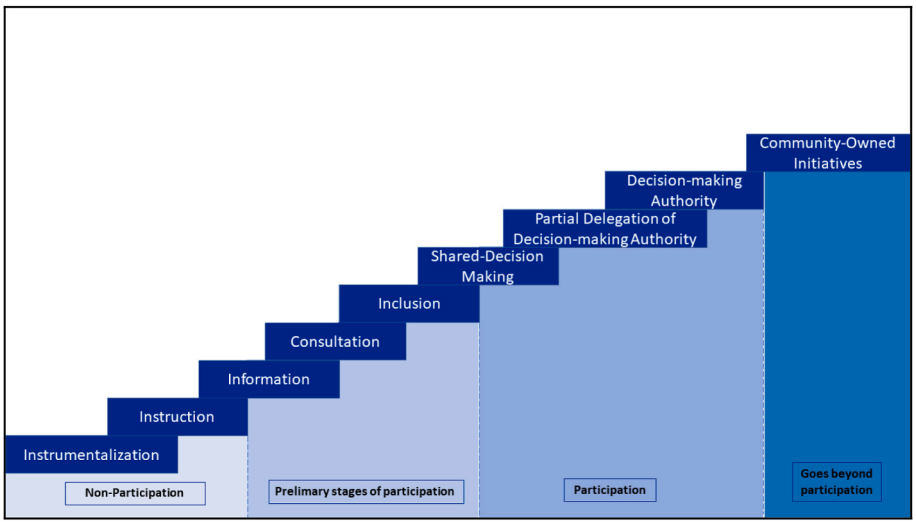

Fig. 1. Stage Model of Participation informed by Wright et al. (2010).

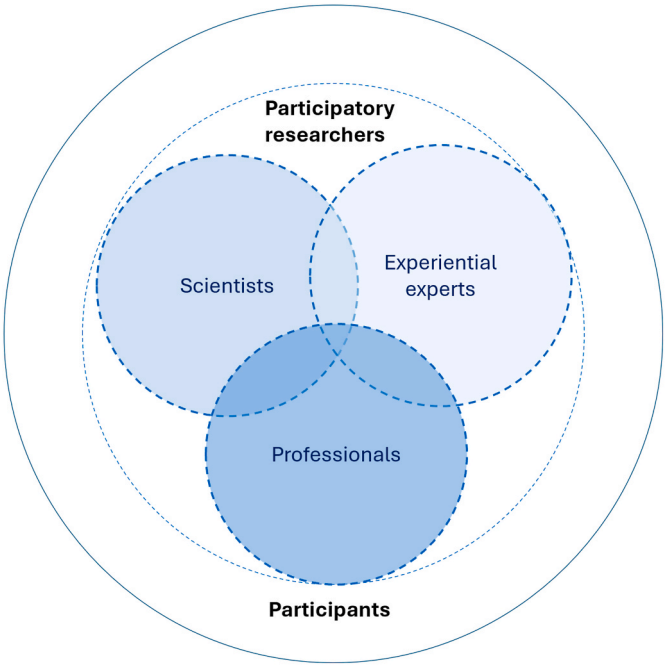

Fig. 2. Model of Participation informed by Wahl et al. (2021).

lead to different expressions of power relations between co-researchers and researchers over time within the collaboration. To summarize, it is necessary to reflect on and analyze the perception of equitable collaboration from the perspective of all parties involved.

Furthermore, the collaboration between co-researchers and academic researchers is characterized by the different types of knowledge—experiential vs. academic knowledge, respectively—they give into the research (Bergold & Thomas, 2012; Jull et al., 2017). Although PHR emphasizes the equal value of different types of knowledge in terms of a multi-perspective approach, there still exists a hierarchy between every-day and scientific knowledge in research practice that is already (implicitly) communicated during the education of future scientists. Furthermore, scientific knowledge is more established in scientific discourse and can therefore be associated with power—including the ability to communicate research findings and results (Wihofszky et al., 2020). The distinction between different types of knowledge is directly related to the language in which knowledge is described and transported (Roura, 2021). Here, critical reflection by all parties is needed to determine whether a common language is spoken and can be spoken in the context of PHR (Richter et al., 2019). The cooperation of co-researchers and academic researchers throughout the research process—and thus also in the phase of publication and communication of research results—is again imposed with power imbalances. The ability to acknowledge different types of knowledge and languages and to perceive them within the dialogic process that defines PHR can therefore be seen as essential for the collaboration between co-researchers and academic researchers.

Previous efforts to attain power balance in PHR encounter challenges concerning the relationship between co-researchers and researchers. These difficulties stem from the perceived rigid boundaries between co-researchers and academic researchers in PHR (von Unger, 2014; Wahl et al., 2021). Addressing the degree to which these boundaries are diminishing in PHR is necessary to address the named challenges in participatory practice. Moreover, in terms of the academic profession, it also requires reflection on the extent to which the differentiation of co-researchers is necessary to define oneself as a profession in the processes of PHR. Consequently, it is necessary to rethink and redefine the role of the academic researcher to establish a process with co-researchers in which expectations, roles, and power balances are negotiated.

3.3. *Empowerment*

The dialogical process in which the "worlds" of co-researchers and academic researchers meet, and the conditions of the cooperation are (ideally) negotiated, has been called an act of "boundary work" (von Unger, 2014, p. 9). In PHR, it is this boundary work that should foster empowerment and enable co-researchers to actively shape the conditions of their lives by promoting the personal resources of co-researchers (Wright, 2013, 2021). It is important to emphasize that empowerment is both an outcome of PHR and a process within PHR itself (Egid et al., 2021; ICPHR, 2021). Through its procedures, PHR aims to create frameworks for co-researchers to discover, become aware of, and promote their own abilities (Bär et al., 2021; Roura, 2021). Establishing these frameworks requires a relationship based on mutual respect and appreciation between the stakeholders.

In this third step of the deconstruction process, the purpose is to analyze the understanding and presence of empowerment in PHR processes. One of the difficulties with the concept of empowerment is that the definition as well as the goals of empowerment are vague (Brandes & Stark, 2021; Bröckling, 2003). Despite the absence of a unified

definition, when looking at prominent attempts to define empowerment, we can identify two factors linking the various definitions.

a. The intention of empowerment practices is to encourage individuals to recognize their own strengths and to support them in developing self-determination and life autonomy to shape their own life path (Herriger, 2020).
b. However, this is also accompanied by the perception of a scarcity of resources and the perceived powerlessness of disadvantaged groups (Herriger, 2020).

In the context of PHR, empowerment is mainly understood as a practice that provides people with the resources to take responsibility for their own lives and opens up spaces of possibility in which they can experience their own strength and explore patterns of networking in solidarity. Therefore, we understand empowerment in line with this as the encouragement of co-researchers to discover their own resources and strengths to support themselves in the self-determined and autonomous shaping of their lifeworld (Blank, 2012; Herriger, 2020). This subsection will further highlight the limitations of this ideal of empowerment, which arise primarily from the limits of the empowerment conception itself.

The existing critical voices in the debate on PHR mainly refer to the statement that no person can empower anyone other than themselves (Bröckling, 2003; Herriger, 2020). Whether this to be true—and the aim to empower stakeholders through PHR thus must be given up—can only be answered by going one step further in operationalizing the concept of empowerment in more detail.

The prevailing understanding of empowerment seems to reproduce existing power-imbalanced social dynamics by placing academic researchers in a position to empower others, while other social groups are attributed with the need for empowerment by external agents. In this way, stakeholders appear to be in a state of 'powerlessly accepting their circumstances' (Borde, 2015). In addition, the assumption underlying PHR seems to be that the process to empower a stakeholder group is necessarily to be activated by a privileged group, i.e. academic researchers, as the marginalized social groups of co-researchers would otherwise not have become aware of its disadvantaged position in society and would not have recognized opportunities to transform their own circumstances (Blank, 2012).

It thus becomes clear that power imbalances can be derived from the perception of a social group as disadvantaged or particularly vulnerable. Furthermore, this attribution and homogenization of what is a heterogeneous group can result in a process of disempowerment of individuals meant to be empowered, as they are perceived as victims of the social conditions they live under (Blank, 2012). The decision by external experts—i.e., academic researchers—whether and how a person can be empowered does not do justice to the self-determination of individuals in the respective social group.

This underlying power imbalance, which characterizes the concept of empowerment, is more in line with a paternalistic attitude towards co-researchers and contradicts the values that the empowerment approach seeks to represent within the PHR debate. Empowerment thus is made into something that is about external control over individuals and at the same time about the reproduction of existing (perceived) powerlessness in society (Blank, 2012; Roura, 2021). Contrary to the concept of PHR, which sees empowerment as a central aspect and outcome of the collaborative research process, the current understanding of empowerment once again ascribes a passive role to co-researchers in their relationship with academic researchers and in shaping their own lifeworld.

Overcoming this passive role attribution to co-researchers requires a sensitive and reflective approach to the power imbalances between researchers and co-researchers. As stated at the beginning, PHR aims to give people the opportunity and space to act and influence their own life circumstances. To create these opportunities, academic researchers need to look critically at what their goals are in regard of involving co-researchers and what form of empowerment is linked to their goals. Looking at the current conceptualization of PHR, participatory processes mainly refer to the strengthening of individual autonomy.

In the discussion on empowerment in PHR, it is often overlooked that there are other empowerment models that can be applied in participatory processes. In addition to individualistic empowerment, Prainsack (2017) [1] distinguishes between instrumental, democratic, and emancipatory empowerment. According to Prainsack (2017), empowerment can pursue different aims, e.g. to strengthen the capacities and self-determination of individuals (individualist model) or providing better information and resources (instrumentalist model). Empowerment can therefore be individualistic as well as promoting democratic and deliberative processes (democratic model) or improving the quality of life of marginalized groups (emancipatory model). The choice of a specific empowerment model has implications for the collaboration in research projects. If PHR is aiming for the emancipatory model of empowerment, then it is important to broaden the range of meaningful practices that co-researchers, i.e., patients, can engage in, so that current rationales within the health system can be challenged. Furthermore, there needs to be an awareness that the empowerment of co-researchers through participation in PHR projects may mean something different for each project. This should also be reflected in the conception of PHR, which so far does not sufficiently differentiate between the individual empowerment models. At the same time, there must be an awareness that these genuine empowerment processes are time-consuming. This is particularly important considering the currently limited funding periods for research projects, which constitute an extra barrier for PHR.

A PHR conception that includes empowerment as one of its objectives must therefore also consider whether the current framework conditions in the health research system create opportunities for co-researchers to discover their resources, such as their unique perspective on research topics. At the same time, the question arises as to how academic researchers have so far supported co-researchers on this journey of discovery. Genuine support goes beyond addressing a relevant research question or participating as an interviewee in an interview study. Rather, it is about fostering and building skills, for example by developing workshops or other participative formats that enable co-researchers to engage in, and benefit from, the research. Empowering processes can only take place where stakeholders have been able to gain these experiences of self-worth and active creative power, of encouragement and social recognition. In consequence, stakeholders feel less vulnerable to their environment and gain the courage to intervene proactively by drawing on the positive capital of these experiences (Herriger, 2020). However, it is not the brief, one-off collaboration with a research team, but such positive life experiences, in which people find security and self-worth, which develop an empowering force (Herriger, 2020). This perspective should also be considered in further discussions on the ideal of PHR and related evaluation standards.

3.4. Capacity building

While empowerment refers to the enhancement of opportunities for action and the development of competencies for self-determined change in one's circumstances, the following chapter identifies and outlines the necessary competencies for participation in PHR (Houwaart et al., 2021). It is important to note that all participating actors—both academic and co-researchers—need competencies to be able to engage in PHR. This aspect has not been sufficiently addressed in the literature, leading to the impression that only co-researchers need to acquire competences to participate successfully in PHR. As is stated in a recent article in regard of "coproduction competencies" in community-based

[1] This article only presents the model by Barbara Prainsack (2017). The model will not be critically evaluated.

participatory research: "[…] there is a lack of frameworks and guidelines that identify the ideal competencies and conditions that all research partners need to make a meaningful and equitable contribution." (Ozano et al., 2024, p. 1).

The aim of this subsection is to highlight the power imbalance that exists in this context, and to suggest strategies to reduce this imbalance. Co-researchers need to have a certain level of scientific literacy and decision-making competence for participation in participatory processes as well as a sufficient level of health literacy and communication skills (Houwaart et al., 2021; Nieke & Eicher, 2022; von Unger, 2012; Ozano et al., 2024). Academic researchers need to have social skills and empathy in addition to methodological knowledge, which should be specialized for PHR (Bergold & Thomas, 2012; Heeg et al., 2021; von Unger, 2012; Ozano et al., 2024). One competence that should be acquired by both academic researchers and stakeholders is the competence of reflection (Gilstad, 2014; von Unger, 2012). This competence refers primarily to the ability to reflect on the interaction between academic and co-researchers, as well as on one's own role against the background of social processes (Wihofszky et al., 2020). This includes the ability to work in the most inclusive way, but also the ability to create safe and inclusive spaces for multidirectional knowledge and skills sharing (Ozano et al., 2024). Table 1 provides an overview of the competences that can be useful for the joint development of collaborations based on the cited literature.

Houwaart et al. (2021) argue that these competencies are not only crucial for the success of participation processes, but they are also a decisive factor for which members of a stakeholder group can be recruited. Reflecting on this a step further, it becomes clear that there are processes of exclusion in the background of participatory research regarding the diversity of a stakeholder group: A conception of participation that is so rich in the competencies and prerequisites required for its success runs the risk of reproducing societal inequalities.

One such mechanism for reproduction is that a self-selection process takes place within the stakeholder group (compare section 3.1). There are individuals who, because of their social demographics and their perception of their own resources, are more likely to see themselves as able to participate in participatory research projects (Houwaart et al., 2021). Others, who experience themselves as powerless, will less likely participate as co-researcher. This experience is potentially reinforced by academic researchers who see such competencies as prerequisite for participation (Kümpers et al., 2021). Yet, against the background of the social process and mutual learning that characterizes PHR, it does not seem necessary for an involved person to possess all the competences presented as examples in Table 1. Rather, it seems sufficient for the competences of different persons to complement each other and for capacity building within the group process that the co-production of scientific insights is to remain relevant, but with a much more individual interpretation and adaptation. Thus, to attribute greater self-confidence to the co-researchers, a fundamental openness to the capacities and competences that co-researchers can develop during the process is required, while rethinking the research process so that such competencies can be learned during the collaboration.

Rather than focusing on how people can be empowered through the PHR process, it is necessary to take a step back first, or so we argue. Furthermore, academic researchers should take a step back and perceive the PHR process as a possible way to strengthen their own abilities and resources, as this can only be achieved as well through participation (Bröckling, 2003). It should therefore be less important that requirements for certain levels of participation are met in the sense of a "rating scale" before engaging in participation, but rather that all involved experience themselves as part of the participatory process in which they can learn and empower themselves (Heeg et al., 2021). For PHR to be more inclusive for co-researchers whose capacities are limited, e.g., by mental illness, medical history, disability, or simply due to time constrains, it is important to re-conceptualize PHR away from an emphasis on capacities and more towards a shared experience of cooperation (in which capacity *building* has its role). In this way, capacity building can take place in the background and the experience of successful and emancipatory collaboration can come to the fore.

3.5. Knowledge translation

This section highlights two interrelated issues that warrant careful consideration in the context of PHR: first, the need for potentially revised criteria for evaluating participatory research and, second, the imperative for academic researchers to reassess research dissemination considering the participatory ideal.

PHR is characterized by its focus on knowledge translation, with the aim of having a direct impact on the lifeworld of stakeholders (ICPHR, 2013; Wright, 2013). Knowledge generated through PHR processes, it is claimed, is inherently more applicable and relevant to stakeholders, providing an unparalleled opportunity to initiate change at the individual, group, and potentially institutional level (Wright, 2021). The aim of PHR is to improve societal circumstances and health prospects, particularly for disadvantaged groups (Wright, 2021). Consequently, PHR is driven by the aspiration to increase the impact of research and stimulate social change by bridging the existing gap between research and its adoption in society (Allweiss et al., 2021; Gilfoyle et al., 2022; Jull et al., 2017).

With this goal and the joint production of shared knowledge, PHR processes challenge the distinction between "scientific knowledge" and "experiential knowledge" as well as the assignment of ownership of each type of knowledge (Davies et al., 2008; Wahl et al., 2021). This reorganization would thus require that both types of knowledge are placed seen equal and not on a continuum between disorganization (everyday knowledge) and systematization (scientific knowledge). This links directly to the challenges of a collaboration based on mutual respect and appreciation between co-researchers and researchers (see section 3.2), of which has been argued is limited by a hierarchization of knowledge types.

In practice, however, there are several examples where the equal value of coexistence of experiential knowledge and scientific knowledge is being challenged. One example is applying for funding from a funding organization. Looking at the application processes, it quickly becomes apparent that applying for funding requires specific skills, knowledge, and language that academic researchers develop through their institutional training (Kümpers et al., 2021). To meet the expectations of the funding agencies and to initiate research projects, experiential knowledge alone does not suffice. Regarding the ideal of PHR the question arises: how can co-researchers exert sufficient influence on the design of a research project?

This gap also persists when it comes to the scientific outputs of projects, which are intended to increase the impact of research. When considering the success of PHR projects, researchers primarily rely on scientific publication channels such as academic journals, as this is the currency for acquiring future funding as well as advancing scientific careers (Wright, 2021). Yet, publishing in appropriate journals requires adherence to research quality criteria and topic-specific nomenclature that often excludes co-researchers (Döring und Bortz, 2016). It follows quite naturally that the results of participatory research projects are usually prioritized for a professional scientific audience and that the competences of academic researchers are also primarily addressed. The downside is that participation opportunities for co-researchers, and thus the research's impact on their lifeworld, are still limited and often not recognized. This calls for a rethink: in the context of PHR, more creative forms of publication should increasingly be allowed to establish themselves in scientific practice, allowing the combination of scientific and experiential knowledge to become mixed also in the output of a PHR-project and allowing the strengths of co-researchers to unfold. It therefore remains to be discussed what role experiential knowledge can play in PHR and how this ultimately informs the publication or, more generally, the output of collaborative research projects. This may mean

that PHR cannot always achieve the highest research impact, while also aiming to give place to the co-researchers' views in co-creating the output of a project. How this can offer the promise of challenges to existing rationales within both the health system and the scientific community is something to be further discussed considering the debate on the added value of PHR and the limitations of the concept of knowledge translation (e.g., Allweiss et al., 2021; Cruz Rivera et al., 2017).

4. Practical implications

From the deconstruction of the concept of participation in this approach, practical implications can be derived that do justice to a concept of participation that is based on mutual respect and recognition of all stakeholders. These practical implications include addressing power structures, removing structural barriers and emphasizing the stakeholder perspective. Table 2 provides an overview of the discussed key aspects in PHR, i.e. the dangers, which were revealed by deconstructing the current concept of participation in this article, while putting the recommended coping strategies in juxtaposition.

In the context of the five key aspects of PHR presented in this paper, it is clear that embedded power structures are inherent constraints. For example, the power imbalance in the relationship between researchers and co-researchers has a significant impact on the ability of co-researchers to participate in the dissemination of research findings, which are often aimed at an academic audience. This example simultaneously underlines the different importance attached to experiential and scientific knowledge in PHR practice. There is thus a need to realistically adjust the possibilities within the conception of PHR and the impact that PHR can have on society. Lastly, it is important to recognize that without critical reflection on their own research practices by academic researchers, they run the risk of perpetuating unfavorable social dynamics that they wish to counteract by engaging in PHR.

These limitations currently hinder the practical implementation of PHR. However, this does not mean rejecting the involvement of stakeholders as co-researchers in research projects. Rather, it highlights the need for self-reflection within the project, transparent communication and alignment of internal resources and goals for co-researcher involvement. If participatory research is to become the standard, a clear definition of what constitutes participatory research and what is feasible in the context of the health research system is crucial. For this reason, the debate is increasingly focusing on appropriate quality criteria for measuring the quality of participatory processes that go beyond determining the level of participation. In addition, an increasing number of handbooks, e.g., from the BMBF (2023) or the DLR (Schütt et al., 2023), present the practice of participatory health research and provide guidance on how to increasingly ensure the quality of participatory processes.

These developments are necessary if stakeholder involvement is not to be reduced to a mere box-ticking exercise in funding applications. This includes raising the awareness of research groups to critically question their research goals in terms of stakeholder involvement. It is essential to include the heterogeneity and experiences of co-researchers throughout the research process and to adapt it to their needs. If the potential of PHR is not reflected and improved upon in the actual research practice, the empowerment aim may inadvertently not reach those who may not be able to do so by themselves. Current structures can disempower people and reinforce disadvantageous social dynamics.

Another important task is to remove structural barriers that hinder participatory processes in the development and implementation of health research projects. Researchers and practitioners cannot single-handedly drive sustainable health equity efforts without more cohesive and structured institutional support (Papageorgiou et al., 2023; Sanchez-Youngman et al., 2023). The lack of opportunities to pay co-researchers or the insufficient funding duration of projects due to the prevailing norm of time-limited, professionally managed projects often leaves little room for genuine participatory work. To promote a more inclusive approach to health research, funding programs need to become more flexible and allow projects to integrate participatory processes into their research plans from the outset. Building lasting collaboration between stakeholders requires a significant investment of time and resources, allowing patients and other stakeholders to take the initiative and bring about meaningful change under participatory conditions.

These structural deficits currently pose a risk to the development of a relationship of trust and equity in which participation is truly possible and feasible. Academic institutions can and should play a transformative role in addressing structural barriers. Therefore, we join the calls for new attention to the role of institutional practices and processes to support and sustain participatory health research (e.g. Sanchez-Youngman et al., 2023). Furthermore, to comprehensively address the opportunities and challenges in the conceptualization of PHR, future research must place greater emphasis on the stakeholder perspective. Their perceptions offer invaluable insights into the meaning of research participation. Shifting the focus to stakeholder perceptions is in line with the core objective of PHR, which is centered on social actors and their interests. This approach paves the way for a redefined understanding of participation that considers the complex dynamics between stakeholders, academic researchers, and the health research system.

The conceptual analysis in this research work can serve as a constructive basis for further ethical tools and guidance that support the ongoing evaluation of mentioned key aspects: Self-reflection of stakeholders within the project, transparent communication and alignment of internal resources and goals for co-researcher involvement. There are guides which already offer concrete suggestions for independently reflecting on successful participation (PEDRI, 2025; ICPHR 2023; Lloyd-Evans et al., 2023; Schaefer et al., 2022; PRAM et al., 2015; Popay and Collins, 2014) and in regard of relevant ethical aspects (Page, 2022). Future handouts can benefit from structuring and framing of the processes and aspects of PHR and framing addressed in this paper. The participatory research project ORIENTATE can serve as such a best practice example (Duda et al., 2024a, 2024b) by drawing attention to central dos and don'ts with regard to stakeholder participation in the individual phases of a research project. As part of the project, a publicly available collection of brief and illustrated handouts, ready-to-use workshop material and two podcast episodes were created (Wöhlke et al., 2024). This is intended to encourage researchers to actively involve co-researchers in their research processes and give them the opportunity to play an active role in shaping them.

5. Conclusion

In summary, the deconstruction process of the concept of participation in PHR presented in this study has a twofold outcome. First, it provides valuable insights into the practical implementation of PHR. Second, it raises critical issues that should inform the design of participation in the context of the challenges discussed. These two aspects are linked by identifying structural limitations inherent in the current theoretical design of PHR. Five key aspects of PHR—stakeholder engagement, relationships among participatory researchers, empowerment, capacity building, and knowledge transfer—were discussed as perspectives for identifying dangers in current participation concepts, and corresponding practical implications were recommended (see Table 2). With regard to the key competencies identified by the theoretical deconstruction that co-researchers and academic researchers need, we see a need for further (empirical) studies. Furthermore, due to the theoretical scope of the article, there is a limitation regarding the implementation of concrete, practical approaches to meet the identified challenges. Although hinted at, suggestions regarding institutional and political approaches for practical solutions are brief and can be explored in greater depth in further research.

In conclusion, given its conceptual limitations, the deconstruction process presented challenges PHR as a concept and academic

researchers to be self-reflective and aware of their capacity to influence the lifeworld of co-researchers. Understanding and acknowledging the limitations and challenges within PHR is essential to promote equitable stakeholder engagement in future health research projects in practice.

CRediT authorship contribution statement

Lea Koop-Meyer: Writing – original draft, Visualization, Conceptualization. **Henk Jasper van Gils-Schmidt:** Writing – review & editing, Supervision, Conceptualization. **Sebastian Rosenbaum:** Writing – review & editing, Visualization. **Sabine Wöhlke:** Writing – review & editing, Supervision, Funding acquisition.

Data statement

There was no raw data used required to reproduce the above findings.

Ehical statement

Ethical approval is not applicable to this manuscript.

Declaration of the use of AI

Authors did not use AI for any part of the work related to the manuscript submitted.

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The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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