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Sipari, S., Vänskä, N., Lehtonen, K., Helenius, S., Harra, T., Kinnunen, A., Väisänen, S., & Jeglinsky, I. (2023). Participatory Research Partnership in Rehabilitation - Co-Development of a Model for Collaboration Process. *Disabilities*, 3(3), 410–425.

DOI: <http://dx.doi.org/10.3390/disabilities3030027>

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Article

Participatory Research Partnership in Rehabilitation—Co-Development of a Model for Collaboration Process

Salla Sipari ^{1,*} , Nea Vänskä ², Krista Lehtonen ², Sari Helenius ¹, Toini Harra ¹, Anu Kinnunen ³ , Sara Väisänen ² and Ira Jeglinsky ⁴

¹ Department of Wellbeing, Metropolia University of Applied Sciences, 00920 Helsinki, Finland; sari.helenius@metropolia.fi (S.H.); toini.harra@metropolia.fi (T.H.)

² Department of Rehabilitation and Examination, Metropolia University of Applied Sciences, 00920 Helsinki, Finland; nea.vanska@metropolia.fi (N.V.); krista.lehtonen@metropolia.fi (K.L.); saravaisanen93@gmail.com (S.V.)

³ Department of Future Health Care Services, Lapland University of Applied Sciences, 94600 Kemi, Finland; anu.kinnunen@lapinamk.fi

⁴ Graduate School and Research, Arcada University of Applied Sciences, 00550 Helsinki, Finland; ira.jeglinsky@arcada.fi

* Correspondence: salla.sipari@metropolia.fi; Tel.: +358-40-3342027

Abstract: *Purpose:* Collaboration that engages diverse stakeholders to actively participate in the rehabilitation research process is becoming a crucially important approach when the purpose is to promote well-being in everyday life. The aim of this study was to co-develop a partnership-based participation model for research with stakeholders such as researchers, rehabilitees, close ones, rehabilitation professionals and experts by experience. *Methods:* We applied an action research approach. The Participatory Research Partnership (PaRe) model was co-developed in a multi-phase process including a literature review, workshops and focus group discussions (64 participants). The model was tested, evaluated and further developed in a developmental training process with 50 experts in rehabilitation. *Results:* The PaRe model consists of five phases: (1) starting the research partnership; (2) building a research team; (3) reciprocal co-planning of research; (4) co-production of new research data; and (5) utilization of research data in everyday life. The model comprises examples and templates including developmental and ethical evaluation. *Conclusions:* The PaRe model enhances co-agency, interaction and co-learning in rehabilitation research and practices. Active participation of users and providers of rehabilitation services in scientific research promotes everyday accessibility and relevance of research-based knowledge. The model ensures that the research process and results are meaningful and empowering for the participants.

Keywords: participatory research partnership; rehabilitation; collaboration



Citation: Sipari, S.; Vänskä, N.; Lehtonen, K.; Helenius, S.; Harra, T.; Kinnunen, A.; Väisänen, S.; Jeglinsky, I. Participatory Research Partnership in Rehabilitation—Co-Development of a Model for Collaboration Process. *Disabilities* **2023**, *3*, 410–425. <https://doi.org/10.3390/disabilities3030027>

Academic Editor: Reinie Cordier

Received: 14 June 2023

Revised: 4 September 2023

Accepted: 5 September 2023

Published: 7 September 2023



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1. Introduction

Rehabilitation is a multidisciplinary and collaborative endeavor with the person undergoing rehabilitation and the rehabilitee's close ones, aiming to enhance their functional capacity in everyday life. It is a goal-directed process that is based on the needs of the rehabilitee [1]. Rehabilitation is conducted with the help and support of professionals. According to the World Health Organization's International Classification of Functioning, Disability and Health (ICF) framework, rehabilitation is a complex and interactive practical phenomenon [2]. Therefore, rehabilitation research should also have a multifaceted and collaborative approach.

Scientific research in rehabilitation is typically conducted by researchers and the topics are often based on existing theoretical premises and previous studies, repeating certain starting points. Lately, however, the democratization of research has generated

new research approaches especially concerning minorities, vulnerable and marginalized citizens. For these research approaches, several different concepts used in the literature can be found, e.g., inclusive research, co-research and participatory or peer research [3–6].

Researchers have enabled professionals, service users and citizens to participate as partners and knowledge producers through a variety of approaches and methods. Such research approaches include citizen science with its use of crowdsourcing [7] and various collaborative research orientations such as co-research [8]. An action research approach is commonly used and is characterized by the participation of members of a given community in the development of their own environment, thus emphasizing research participants as active agents of change in their own community [9,10]. The approach known as inclusive research, on the other hand, allows for the accessibility of research activities, i.e., active participation of people with disabilities in research [11].

The terminology and definition of concepts in participatory research varies across approaches and disciplines [6,11,12]. Among others, the literature review by Hoekstra et al. (2020) identified more than 30 different concepts related to participatory research approaches from 86 included articles [6]. Examples of terms used to describe participatory approaches include community-based research, community-based participatory research, participatory action research and public scholarship. The participatory approaches in research have a common characteristic: individuals with experience, expertise in the research topic or those whose lives are directly impacted by the phenomenon being studied are invited to actively participate. The underlying assumption is that the collaborative nature of these approaches will lead to a more comprehensive, enriched and enhanced understanding of the phenomenon under investigation [13,14]. The activity in the different participatory approaches is divided into “consultation”, “collaboration” and “patient-led”. In “consultation”, researchers define the focus and ask people with lived experience about their opinion of the phenomena; in “collaboration”, people with lived experience and researchers work as equal partners in the research process; and in “patient-led”, people with lived experience are in charge of the research process (sometimes with assistance from researchers) [13,15].

There has been an increasing interest in patient and public involvement in research [3]. Activation of public laypeople in research is characterized by a process whereby research is carried out together with or by clients and other stakeholders [16]. It is important that research activities are carried out by all parties affected by the research or who benefit from the results—that means research in collaboration. In collaborative research, all participants work together in a co-productive way on equitable premises. Collaborative research can be understood as the democratization of research, but it also concerns a question of epistemological issues. When it comes to such phenomena as rehabilitation and rehabilitation experiences, epistemology is always complex. The research of complex issues requires multidimensional and transdisciplinary viewpoints and methods. Additionally, information about experiences is subjective. This subjectivity also applies to the researchers, whose interpretations are always linked to their own life history and understanding [17,18].

In a process of different collaborative research approaches, it is typical that end users are enabled to participate in the definition of research topics, search for funding, planning, data collection and analysis, evaluation, publication and implementation of results as equitable research partners [3,5]. This means that research practices must be reformed in order to prevent stakeholders from only being research objects or informants in the data collection phase [10].

Looking at research practices through the Universal Declaration of Human Rights (United Nations 2006), this would mean at least the following [19]. Firstly, researchers have a moral obligation to redress the imbalance between those affected by the research and themselves. All stakeholders should have an equitable opportunity to participate in deciding on research that ultimately affects/would affect them. Secondly, bringing lived experience in research enhances the quality and the value of research. Thirdly, collaboration

with clients increases the transparency of research and implementation as well as attracting possible funding and other resources [10,20].

There are differences in the emphasis on participation in research between countries and, for example, in Canada and the UK, funders require the involvement of end users in applied research [21]. Partnership-based collaboration in research has been evolving with a focus on client-oriented care [22,23] and families in pediatric rehabilitation as active participants in the process [24]. In Finland, the involvement of end users/people with lived experience in research is in its early stages, and there is neither an established system nor a model for how to go about implementing it.

Enabling the participation of stakeholders in partnership throughout the research process challenges researchers' knowledge, social status, attitudes as well as the environment in which research is conducted [25]. Participation in collaborative research should therefore not be thought of as a methodological issue, but as a partnership-based orientation involving the entire process.

In summary, there are many different approaches and theories about participatory research, but a practical model for the implementation of partnership in all phases of the process in rehabilitation has been missing. Features in the collaborative process include shared decision-making and knowledge construction; sharing valuable skills and resources; utilizing findings and insights; open dialogues; and mutual learning [3,6,25].

The aim of this research process was to co-develop a model for collaboration of participatory research partnership in rehabilitation with these specified research questions:

1. What is the concept of participatory research partnership in rehabilitation according to scientific studies?
2. What is participatory research partnership within rehabilitation practices from participants' perspectives?
3. What does participatory research partnership in rehabilitation look like?

2. Materials and Methods

Action research was selected as a systematic inquiry approach that involved the collaboration of researchers and stakeholders aiming to bring positive change by co-developing a new model through a cyclic process of planning, action, observation and reflection [9]. The planning of action was carried out through a literature review and workshops. Implementing the action was conducted by piloting the model in a developmental training process. The developmental training process also included observation of the action by evaluation of the new model through developmental tasks. Reflection of the co-development constructed adjustments and improvements to the model throughout the iterative cycle. In this research process, iterativity was realized in a way that the results of the previous phase were utilized as the basis for data collection and analysis in the subsequent phase. The results were versions of the model that emerged from the synthesis of the data analysis answering the research questions. The multi-phase and multi-method development process involved a diversity of stakeholders in the rehabilitation context as participants in the research process (see Table 1).

Participants were recruited through an open invitation via social media and by email using research and rehabilitation networks. Inclusion criteria were experience in rehabilitation and/or expertise in research and voluntary participation in co-development. All the participants gave their informed consent after receiving both oral and written information on the research. The ethical rules of the research were followed in accordance with the Finnish code of conduct for research integrity [26], under which a code of ethics on consent was made. This is compulsory and a regular practice in research projects in higher education in Finland.

The research team consisted of interdisciplinary rehabilitation researchers with one expert by experience, so all in all, five members. In collaborative and practical action research, communication took place among the participants as well as with the research team. Participants were selected through an open invitation to become development

partners, which meant they were not acquainted with each other, nor would they attempt to influence data or what the ideal model should be like.

Table 1. The iterative co-development research process according to the research questions in each action research phase.

Research Question	Phase of Process and Data Collection Design	Description of the Participants and/or Methods and Data	Action Research Cycle and Results
1. What is the concept of participatory research partnership in rehabilitation according to scientific studies?	The first phase: Studies published in English in scientific journals	Descriptive literature review: $n = 17$ articles, including $n = 3$ reviews and $n = 14$ original articles.	Planning of action: Version 1 of the model
2. What is participatory research partnership in rehabilitation practices from participants' perspectives?	The second phase: Workshops	$n = 64$ health care, social work and education professionals, teachers, students, researchers and developers; $n = 5$ focus group discussions in co-creation workshops; 30 pages of transcribed data.	Planning of action: Version 2 of the model
3. What is participatory research partnership in rehabilitation like?	The third phase: Developmental training process	$n = 50$ participants: rehabilitees and their close ones and multidisciplinary professionals, researchers, developers, teachers; $n = 5$ remote training sessions including $n = 6$ focus group discussions in co-creation sessions; 38 pages of transcribed data; $n = 65$ developmental assignments; 255 pages of transcribed data.	Implementing the action and observation: Version 3 of the model

The first phase of the co-development process was based on the literature review describing participatory research in rehabilitation. The search was conducted in the CINAHL, PubMed/MEDLINE, Cochrane and ScienceDirect databases. Seventeen papers met the inclusion criteria: three reviews and fourteen original research papers. Inclusion criteria were as follows: article published after year 2000, full text available in English, rehabilitation related research study, rehabilitees and/or their close ones participated as research partners. Studies focusing on one singular service or therapy (e.g., physiotherapy), descriptions of a study or project protocol, and study participants that did not include rehabilitees and/or their close ones or they were not research partners were excluded. The first version of the model was co-created by the research team based on the results of the literature review as a starting point for further development. The literature review was published as a peer reviewed study by Lehtonen et al., 2020 [5].

The co-development process of the model continued in the second phase in five co-creation workshops in 2020 to co-construct the partnership-based participatory research in rehabilitation. In total, 64 rehabilitation experts, including rehabilitees, professionals, trainers, students, developers, researchers and system-level decision-makers, attended the workshops. Data were collected in the workshops with focus group discussions enabling dialogue and co-construction of knowledge of the participants [27,28]. The questions discussed in the workshops were the following:

- What is participatory research partnership needed for?
- What knowledge and skills are needed in participatory research partnership?

- What enables success in participatory research partnership? How could the challenges be turned into success?
- What does participatory research partnership mean in practice: how could a participatory research partnership in applied research in rehabilitation be built?

The workshops lasted 90–120 min, of which four were conducted online due to the pandemic. The discussions were documented as summaries, so the participants were able to revise and confirm the collected data. Researchers (S.S., N.V., K.L., S.H. and T.H.) used a content analysis method to analyze the data [29]. The researchers selected meaning units (a conceptual entity) inductively from the transcriptions that answered the analysis question: what is participatory research partnership in rehabilitation research practice? The meaning units were coded by simplifying them without losing their original meaning and combined with other similar units. The first version of the model (based on the results of the literature review in Table 2) was used as a scheme for conducting the analysis (basis for data analysis). Researchers classified units to the scheme to inductively form sub-topics. Inductively combining the sub-topics into topics was the result of the data analysis forming the basis for model version 2. During the analysis process, new topics also emerged, which were added to model version 2.

In the third phase of the co-development process (2021), the model was piloted and evaluated in the developmental training process with 50 experts in rehabilitation (rehabilitatees and their close ones and multidisciplinary professionals, researchers, developers, teachers). The participants familiarized themselves with the model (basis for data collection) and applied it to practice by performing developmental assignments in their context and environments. Evaluation of the model by co-creation in focus group discussions was carried out during five remote training sessions. The analysis of the data was carried out similarly as in the second phase using content analysis, but the second version of the model was a schema for analysis and the analysis question was the following: what could be improved upon in the model? The results of the pilots and evaluations were used in the co-production of the third and final version of the model. The final version of the participatory research partnership model is an open access publication [18].

3. Results

The results depict the development of a collaborative process model within a participatory research partnership in rehabilitation. These findings are presented in alignment with the various stages of the research process. Firstly, the results describe the conceptual model of participatory research partnership in rehabilitation based on scientific studies. Secondly, the results present the practical model of participatory research partnership in rehabilitation practices from the participants' perspective. Thirdly, the result is a piloted, evaluated and refined model of participatory research partnership.

(1) Results from literature review: model version 1

The descriptive literature review (Lehtonen et al., 2020) resulted in a description of the phases and participatory practices used in research partnership in rehabilitation [5]. The phases in the research process were building the research partnership, drawing up a research plan together, doing research together in practice, and participatory reporting, utilization of results and evaluation. Building the research partnership as the first phase involved recruiting and selecting partners, establishing an interactive relationship, forming a team, and providing equal participation. The second phase jointly involved defining the research topic and agenda, formulating research questions, and planning and selecting specific research methods, as well as managing research materials and obtaining necessary permissions. During the third implementation phase, participants for the research were recruited, data were collected and interventions were implemented, followed by the analysis and interpretation of results. The fourth dissemination phase of the research results included reporting, presentations and implementation of the results in practice. In the final phase, the importance of evaluating research partnerships and the implementation of research findings was underlined, although best practices in this area were not reported.

Equity in participation and meaningful collaboration was emphasized at each phase of the process. The participatory practices and roles of the participants varied between the studies and also during the research processes depending on individual and study resources, applied methods and the context of the study. One key aspect of the participatory research partnership is that roles and forms of participation are agreed upon together. The findings of the literature review highlight the significance of a preparatory phase in the research process that encompasses recruiting appropriate partners and establishing an equitable, genuine partnership, as well as forming a functional research team.

Based on this first phase of the iterative co-developmental process, a first version of the model was co-produced. To build a meaningful and equitable partnership and to highlight the importance of several tasks in the beginning of the partnership-based research process, the following steps replaced the first phase in the model (building the research partnership): (1) establishing a relationship with partners and (2) organizing to support the partnership (see Table 2).

Table 2. The first version of the model.

Establishing a relationship with partners	<ul style="list-style-type: none"> • Comprehensive, multichannel, equal recruitment • Selection/application process • Building an equal and personal relationship
Organizing to support the partnership	<ul style="list-style-type: none"> • Jointly agreed upon working methods and practices in the team • Clear roles, tasks and shared decision-making and responsibilities • Education • Clear research communication
Drawing up a research plan together	<ul style="list-style-type: none"> • Prioritization/selection of the topic of study and joint determination of direction • Ethical assessment from the perspective of the rehabilitee and family • A common goal • Funding procurement • Producing meaningful and clear research material
Doing research together in practice	<ul style="list-style-type: none"> • Diverse and collaborative methods supporting participation • Collecting data together, acting as a researcher • Joint analysis, interpretation of the results and conclusions
Participatory reporting, utilisation of results and evaluation	<ul style="list-style-type: none"> • Reflective dialogue between rehabilitees and different stakeholders • Creating articles and presentations together • Writing practical summaries

(2) Results from co-creation workshops: model version 2

As a result of the stakeholder co-creation workshops, the need for partnerships, the key elements of a successful partnership and good practices to tackle the potential challenges were described. Additionally, the findings completed the model with an understanding of what elements, knowledge and skills are required to apply the model in rehabilitation research practices.

“Collaboration already in the planning phase is central. The study topic should be interesting and emerge from both clinical work and everyday life of the clients”.

“I think that in participatory research partnership, stakeholders who should genuinely be involved need to be identified, and methods for their inclusion are determined together. This requires time and good communication skills to build trust and commitment throughout the process. Also, skills related to networking are needed”.

“The rehabilitee can, e.g., consider what meanings the results hold from the perspective of their own experiences, determining whether these results have value. Statistical expertise is not necessary, but a strong understanding of evaluating the results’ significance is useful”.

The results from this iterative co-developmental process phase highlighted that evaluation is not a separate and final phase in the model, but rather that a continuous and proactive evaluation is needed throughout the research process to steer co-production of research knowledge and develop the partnership. The evaluation helps to align the partnership towards achieving the common goals by identifying the promoting and hindering factors.

“Need to identify factors that promote and hinder achieving the goals in partnership”.

“Continuous evaluation that guides actions in partnership in real time, not just evaluating after the fact”.

Based on the findings, a developmental evaluation was integrated into each phase in the second version of the model, and the wording was refined to underline partnership at each step in the model. Model version 2 included the following phases: (1) launching a research partnership; (2) building up the research team; (3) reciprocal planning; (4) co-production of a new knowledge; and (5) using knowledge in everyday life (Figure 1). The second version of the model was conceptualized to describe the partnership-based collaboration at each phase of the research process.

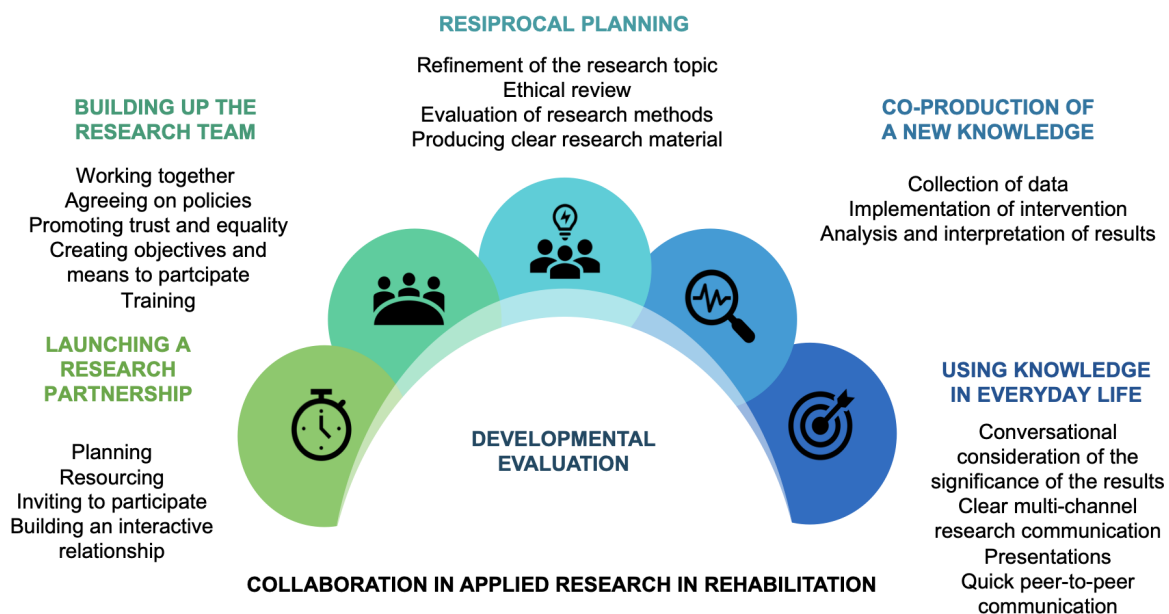


Figure 1. The second version of the model.

(3) Results from the developmental training process: model version 3

The findings from the developmental training process confirmed the applicability of the model in rehabilitation research practices. According to the results, the model guides actions with partners through genuine and inclusive interaction. The findings

have demonstrated that the ethical dimensions of partnership are intertwined with the developmental evaluation.

“The model appears as a genuinely inclusive way of functioning, enabling participation, where all stakeholders are seen as equally important, without focusing on titles or professional roles. An interactive, dialogical approach is essential if genuine research partnership is desired, fostering a mutual trust-based approach to research collaboration”.

“In partnership, everyone gradually establishes their own position throughout the entire process, and this is openly discussed and openly structured in an equitable manner, with ethical considerations as a foundation”.

The results show the importance of each partner to commit to the core values of openness and respect in participatory research partnership and to the core principles of equity and reciprocity. A safe, creative and open atmosphere was mutually built. According to the findings, diverse ways of enabling participation are needed to foster a partner’s agency within the group and achieve genuine equality. Additionally, the results highlighted the need for practical tools facilitating and evaluating the partnership throughout the research process.

“A permissive and safe atmosphere, encompassing creativity, openness, and respect for others’ opinions, is central in partnership”.

“What is important is the opportunity to participate and the different ways to enable participation, to be able to realize active agency as part of the working group. Building equality is a fundamental aspect”.

In the third and final version of the model, the descriptions of practices related to the model’s phases were refined and redundancies were eliminated. In the wording of the model, emphasis was placed on research partnership in terms of a co-agency to ensure that the goal of producing and utilizing researched knowledge together is not missed. The results from the developmental training process provided examples of good practices for the model, such as the application of co-creation methods to co-create shared goals for the research partnership. The model’s descriptive illustrations were generated as an interactive whole to highlight that equitable and reciprocal collaboration is built and developed at each step of the process with ethical and development evaluation. Additionally, six tools that support and guide the construction of meaningful collaboration were co-produced. The tools are templates that are used to facilitate partnership and evaluation throughout the process, as well as to support the implementation of the model.

As an output of the co-developmental process, the third and final version of the model is described in Figure 2 and as an open access publication (Sipari et al. 2022) [18]. Figure 2 of the PaRe model highlights the interactive nature of the phases and the complexity of the process. The model is not linear in nature, but its components are interactive when implementing the model into practice.

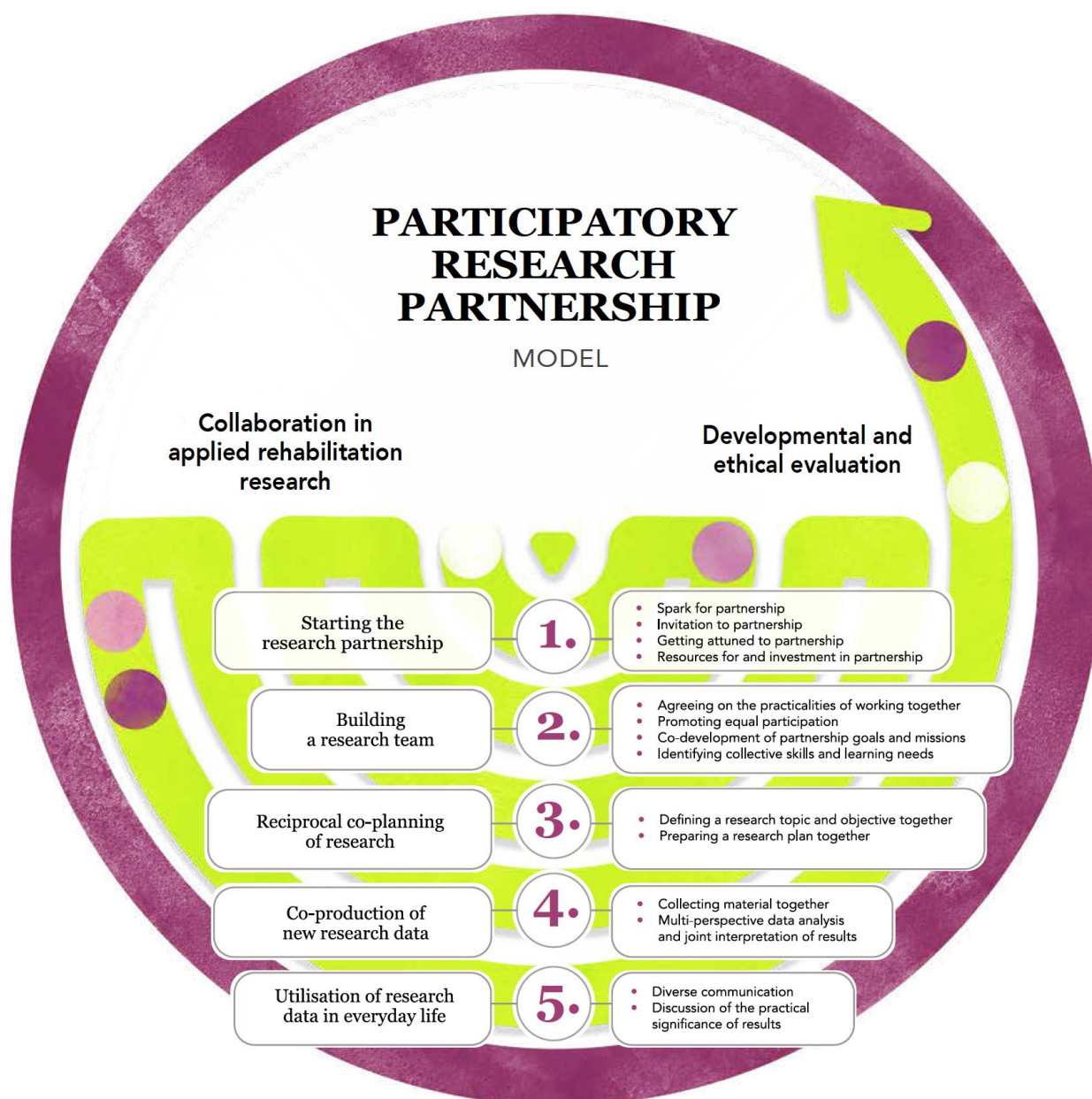


Figure 2. The third and final version of the model (Reprinted with permission from Ref. [18]. Copyright 2022 Metropolia University of Applied Sciences).

According to the synthesis of the results of the co-development process, the core components of the model can be outlined as follows:

Phase 1. Starting the research partnership includes a spark for partnership, invitation to partnership, getting attuned to partnership, and resources for and investment in partnership. The need for research is identified by any of the partners, e.g., from everyday life or rehabilitation practices, and serves as a spark for partnership. Various stakeholders are invited to join the research team, sometimes through an application process. It is highly important to invite partners widely in order to build a team that is representative of all the groups concerned. Common and individual goals for partnership should be discussed to define shared understanding. Getting to know each other also on a personal level enhances equity and reciprocal relationships. The expertise of all participants should be acknowledged.

Phase 2. Building a research team includes the following: agreeing on the practicalities of working together, promoting equitable participation, co-development of partnership

goals and missions, and identifying the collective skills and learning needs. Enough time should be allocated to team building to ensure equitable involvement and to avoid tokenistic participation. Equally important is to discuss and agree on the roles and responsibilities in the team, taking into account different capabilities and expertise.

Phase 3. Reciprocal co-planning of research includes defining a research topic and aim together and preparing a research plan together. The research topic and the specific purpose should be clarified and possibly adjusted in an open dialogue. Reciprocity in the research plan supports the ethics of the research solutions, especially in how different perspectives, skills and working methods of the participants in the implementation of the research are taken into account also in the selection of methods for data collection and analysis.

Phase 4. Co-production of new research data includes collecting material together and multiperspective data analysis and joint interpretation of the results. The members of the research team coach each other and learn together. The rehabilitees bring to the table their expertise on, e.g., how to ask relevant clarifying questions in an interview and researchers share their knowledge of how to perform data collection from the perspective of research. The multiperspective interpretation of the results, e.g., in a joint workshop, increases the reliability of the results.

Phase 5. Utilization of research data in everyday life includes diverse communication and discussion on the practical significance of the results. Multiperspective and multi-channel research communication enhances the dissemination and implementation of the results. Experts by experience and rehabilitation professionals can be early ambassadors of research information in their various, also non-formal, networks.

The following six templates were developed as part of the model as practical tools to facilitate and evaluate the research partnership throughout the process.

Template 1: Getting to know your research partners

Template 2: Agency in the research partnership

Template 3: Defining the practices of the research partnership

Template 4: Agreeing on tasks in the research partnership

Template 5: Planning in the research partnership

Template 6: Developmental evaluation of the research partnership

The PaRe model underlines developmental and ethical evaluation in all phases of the research. The purpose of the developmental evaluation is to ensure a meaningful research partnership and appropriate progress towards the jointly established goals. Ethical solutions related to the participatory research partnership are interwoven with the developmental evaluation. The goal of the evaluation is to ensure equal participation of all participants from the beginning to the end of the research process.

4. Discussion

4.1. Findings and Their Implications

This study described the co-development of a participatory research partnership (PaRe) model in applied research in rehabilitation. The iterative co-development process proceeded with several phases that explored the specific features of collaboration in rehabilitation research from the literature, participants' perspectives and in practice. In the discussion, we focus on the novel PaRe model, the particular attributes of participatory research partnership rehabilitation research and the methodological considerations of the co-developmental process.

The specific contribution of this study to collaboration in participatory research partnership was the evolvement of a PaRe model of collaborative interaction with developmental and ethical evaluation of collaboration through action research. The model depicts the nature of collaboration, introducing new dimensions to the process by emphasizing the initiation phase of research and its systemic process. The PaRe model highlights equitable and reciprocal participation in collaboration throughout the whole research process. The collaboration described in the model emphasizes the acknowledgement of human agency

and unique experiences and expertise of each partner as well as co-agency between partners. Thus, the PaRe model is based on true partnership where all partners' roles in the production and utilization of research knowledge are enabled. The traditional position of rehabilitees, their close ones and professionals, as well as other stakeholders, changes from being an object in the research to being equitable partners and the status change to being a member of the research team. This value-based starting point has also been recognized in other participatory research models, such as the community-based research partnership model (CBPR) which underlines the importance of a collaborative, equitable partnership involving an empowering and power-sharing process [30–32].

In the PaRe model, the beginning of the process includes phases that are not usually described in research processes conducted only by researchers. Participation as partners from the very first steps in the research process leads to a new focus and emphasis in the preparation phase through inviting partners, combining different and complementary expertise from stakeholders, and building reciprocal relationships between partners. The emphasis on building meaningful collaboration requires not only focus but also new skills in research to establish reciprocal relationships between partners. For example, in the PaRe model, common and individual goals for partnership should be discussed and getting to know each other on a personal level enhances equity and a reciprocal relationship. This finding is similar to the Roberts et al. (2022) study which identified that researchers must work collaboratively to identify shared values, goals, vision and priorities based on the research team's overall mission as well as the research topic and participant population. Identifying and communicating values is likely to be an iterative process [33].

Partnership-based participation in research means a cultural change, which was also found in the Potzniak et al. (2021) study. Engagement of rehabilitees and close ones constructs a change in new research culture, whereby the research is carried out by those it concerns [34]. The co-development of the PaRe model has led to an even deeper understanding of cultural change, identifying that the action culture of research can be continuously and consciously co-constructed through collaboration throughout the research process. Findings from the co-development of the PaRe model are described as templates and tools and examples, which seem to be helpful in building a new research culture and contributing new practical applications to this research field [18].

The nature of partner engagement is intricately connected to the practical effects of research [12]. The development of rehabilitation and decision-making in rehabilitation is supposed to be based on research, but at the same time, research is perceived as being disconnected from the real needs of citizens or the results are too opaque to be assimilated [35]. Collaboration according to the PaRe model could have the potential to bridge these two premises. Combining research-based knowledge and experience from different expertise is likely to increase the potential for innovation in scientific research, rather than simply developing existing methods separately. In rehabilitation, e.g., end users of assistive devices have contributed to the relevance of research in practice [36]. Thus, the partnership-based research process has the potential to bridge the gap between knowledge production and research use and thus to increase the impact of research in society at large [10,37].

The results indicate that the PaRe model has the ability and agility to address complex research objectives and phenomena in rehabilitation in real-world settings. When partners working under constant change learn to produce and use research-based data to create a good future, long-term benefits can be created together. Hence, the PaRe model combines a research-based innovation and a collaborative learning process, which shakes up the boundaries of scientific research. The participatory research partnership enables continuous learning in research when, e.g., citizens, professionals and students are invited to participate in research activities. Participatory research partnership can be built into a collective learning process, whereby new resources arising from networks are co-produced from the combination and multivoicedness of different expertise. Empowerment in collaboration is not hierarchical (power over) but collective (power with), based on common goals [38] and a well-intentioned partnership [39].

This study highlights the partnership-based participation of researchers, rehabilitees and their close ones, rehabilitation professionals, and other stakeholders in collaborative activities at different phases of the research process involving those who the research concerns. The aim of the PaRe model is to produce and use the knowledge together, initiate, and embed the research knowledge production from and into the daily life of rehabilitees and practice in rehabilitation. The key elements of partnership between researchers and stakeholders related to the research topic appear to involve meaningful participation, learning and shared decision-making, facilitated by ethical practices and knowledge co-production methods [6,12]. In research activities, it is essential to identify what different actors are thought to be involved, how participation is implemented and what kind of influence is created in the research and development process [12,37]. In line with Hoekstra et al. (2020) [6], the ethical issues of collaborative research activities were underlined in the PaRe model. The findings of this co-development process indicate a pressing need for continuous developmental and ethical evaluation throughout the entire research process. Furthermore, a novel contribution is the collaborative nature of this developmental and ethical reflection, involving all stakeholders.

4.2. Methodological Limitations

The reliability, strengths and limitations of this action research are discussed with regards to participation in co-development, methodological solutions in co-development as well as achieved changes [40]. The strength of this action research is that the findings and the new model can be applied to another context, as the current situation was described through a literature review, the participants involved in the development were from many different backgrounds and the model was not developed in a specific community or organization. The co-development process and the results are carefully documented for the practical application of the model [18].

An obvious limitation is that this research relies on the participants' perspectives and researchers' interpretation related to the aims of the co-development. However, the research team confirmed that the researchers' subjectivity and personal interests did not produce biased results. In the co-development phases two and three, the study produced participants' perceptions of reality, which were constantly constructed through action and speech. These perceptions included not only personal experiences but also understandings and meanings of how participatory research partnerships could be implemented in collaboration. Thus, the results of the study describe the desired state of participatory research partnerships. In particular, the third phase of the action research cycle helped clarify the terms, fine-tune the phases of the model and support the development of practical tools and developmental and ethical evaluation which are included in the model. Examples of good practices, such as the application of co-creation methods to co-create shared goals for the research partnership, were identified. At this phase, the model was revised collaboratively with multiple stakeholders who participated in the co-development process. The research team identified aspects and factors that complemented the model being developed. The model was continuously reflected by the research team in relation to the theory and the produced data [41].

The action research process lasted for three years with regular and continuous reflection providing learning with insights and new perspectives that might not have been apparent initially. This iterative reflection led to a deeper understanding of the collaborative process. On the other hand, the final version of the model and the conclusions represent the research group's collective interpretations derived from their research process. Therefore, it is recommended to apply and further develop the model in various contexts with different adaptations. Implementing the action research cycle and the iterative co-development process required significant time and resources during the process, and at another time and with other participants, the results could be different. The participants in the study exhibited a high level of diversity, and their backgrounds were not described in detail as the selection criteria were also lean. This decision was motivated by the aim of including

diverse perspectives to enrich the co-development of the new model. This approach may introduce a potential limitation to the reliability of the findings.

The coherence of the results was influenced by an iterative process in which the findings from the previous phase were carried forward into the next phase, to address the research aim in several phases with multi-method and multiperspective settings. This iterative process represents both a strength and a limitation of the study. The research team's extensive experience of both the co-development process and rehabilitation provided strengths in terms of ethical considerations, control over external variables affecting the findings, and the feasibility of conducting action research.

4.3. Future Directions

This action research approach emphasized the co-development of a new model that is both applicable and valuable for improving practices and promoting transformation. This research project included one cycle and further research is needed for the second cycle. Implementation research is needed to understand the adoption of the model and to investigate its effects. The participatory research partnership model could be further piloted and developed beyond the applied research in rehabilitation and social and health care fields.

The developmental training process enabled the testing of the model in various rehabilitation practice contexts and a multifaceted evaluation of the model. The developmental training process generated new results evolving the model, emphasizing the initiation of partnership, and transforming it from a linear model into a more holistic and systemic one. With the enrichment of the model, the developmental training process seems to be a promising good practice in co-development and implementation. It could be conceptualized for international transdisciplinary training. The results also suggest that the research topics arising from people's everyday lives are phenomenon-oriented and often require expertise in fields such as technology, business and culture.

Based on the results, the future perspective of research is the research knowledge accumulated from people's everyday lives and the understanding that is developed and shaped from it together. The results of this research can be used in the development of a new kind of participatory research partnership culture strengthening the ethics, practical benefit, and democracy of research activities and quality. In the future, the power of networks will be strengthened, societal change requires the development of a new kind of network competence and the participatory research partnership model brings a new perspective.

5. Conclusions

The co-development of the participatory research partnership resulted in a systemic model that emphasizes the value and quality of interactions, rather than a linear task-oriented process model. The model emphasizes the preparation and initiation of research and the results contribute an enriching perspective to this phase of research. The co-development resulted in novel insights into the developmental and ethical evaluation of collaboration. Equally distinctive is the description of how collaboration is implemented throughout the entire extended research process. The participatory research partnership model holds the potential to foster a new research culture in embedding transdisciplinary and people's daily lives in meaningful collaboration.

Author Contributions: Conceptualization, S.S., N.V., K.L., S.H., T.H., A.K., S.V. and I.J.; Methodology, S.S., N.V., K.L., S.H. and T.H.; Writing—Review and Editing, S.S., N.V., K.L., S.H., T.H., A.K., S.V. and I.J. All authors have read and agreed to the published version of the manuscript.

Funding: The participatory research partnership model was co-developed as a part of the REcoRDI project (platform ecosystem for strengthening of RDI activities in multidisciplinary rehabilitation), which aimed to promote effective and high-quality applied research in rehabilitation. The project was carried out during 2019–2022. The project received funding from the Finnish Ministry of Education and Culture (OKM/173/523/2018).

Institutional Review Board Statement: The JAMK University of Applied Sciences, which was responsible for the REcoRDI project, stated that no approval was required as the study did not involve the health or functional capacity of the participants, but rather focused on the advancement of research activities. In Finland, research with human participants must comply with the guidelines of the human participants and ethical review in the human sciences in Finland. Finnish National Board on Research Integrity TENK guidelines 2019.

Informed Consent Statement: All the participants gave their informed consent after receiving both oral and written information on the research (original documents are in Finnish).

Data Availability Statement: The data presented in this study are not available due to participant privacy.

Conflicts of Interest: The authors declare no conflict of interest.

References

1. Ministry of Social Affairs and Health. Rehabilitation. Available online: <https://stm.fi/en/rehabilitation> (accessed on 1 August 2023).
2. Karhula, M.; Saukkonen, S.; Kinnunen, A.; Heiskanen, T.; Xiong, E.; Anttila, H. ICF—luokituksen yksilötekijöiden kuvaus on osa toimintakyvyn laaja-alaista arviointia: Kartoittava kirjallisuuskatsaus ICF-yksilötekijöitä käsittelevistä tutkimuksista. [The ICF personal factors are part of a comprehensive assessment of functioning—A scoping review of ICF personal factors in the rehabilitation studies. *Kuntoutus* **2021**, *44*, 9–24. (In Finnish) [[CrossRef](#)]
3. Harrison, J.D.; Auerbach, A.D.; Anderson, W. Patient stakeholder engagement in research: A narrative review to describe foundational principles and best practice activities. *Health Expect* **2019**, *22*, 307–316. [[CrossRef](#)] [[PubMed](#)]
4. Ketelaar, M.; Smits, D.W.; Meeteren, K.; Klem, M.; Alsem, M. Involvement of young people and families in all stages of research; what, why and how? In *Participation, Optimizing Outcomes in Childhood-Onset Neuro-Disability*; Imms, C., Green, D., Eds.; Mac Keith Press: London, UK, 2020; pp. 105–118. ISBN 978-1-911-61216-2.
5. Lehtonen, K.; Vänskä, N.; Helenius, S.; Harra, T.; Sipari, S. Osallistuva tutkimuskumppanus kuntoutuksen soveltavassa tutkimuksessa. Kuvailuva kirjallisuuskatsaus. [Participatory co-research in applied research in rehabilitation—A literature.]. *Kuntoutus* **2020**, *43*, 6–19. [[CrossRef](#)]
6. Hoekstra, F.; Mrklas, K.J.; Khan, M.; McKay, R.C.; Vis-Dunbar, M.; Sibley, K.M.; Nguyen, T.; Graham, I.D.; SCI Guiding Principles Consensus Panel; Gainforth, H.L. A review of reviews on principles, strategies, outcomes and impacts of research partnerships approaches: A first step in synthesising the research partnership literature. *Health Res. Policy Syst.* **2020**, *18*, 51. [[CrossRef](#)] [[PubMed](#)]
7. Eitzel, M.V.; Cappadonna, J.L.; Santos-Lang, C.; Duerr, R.E.; Virapongse, A.; West, S.E.; Kyba, C.; Bowser, A.; Cooper, C.B.; Sforzi, A.; et al. Citizen Science Terminology Matters: Exploring Key Terms. *Citiz. Sci. Theory Pract.* **2017**, *2*, 1–20. [[CrossRef](#)]
8. Kulmala, M.; Spišák, S.; Venäläinen, S. (Eds.) *Kanssatutkimus: Ihanteet ja Käytännöt [Co-Research: Ideals and Practices]*; Tampere University Press: Tampere, Finland, 2023; Available online: <https://urn.fi/URN:ISBN:978-952-359-042-7> (accessed on 1 June 2023). (In Finnish)
9. Lawson, H.A. Introducing participatory action research. In *Participatory Action Research*; Lawson, H.A., Caringi, J., Pyles, L., Jurkowski, J., Bozlak, C., Eds.; Oxford University Press: Oxford, UK, 2015; pp. 1–34.
10. Domecq, J.P.; Prutsky, G.; Elraiyah, T.; Wang, Z.; Nabhan, M.; Shippee, N.; Brito, J.P.; Boehmer, K.; Hasan, R.; Firwana, B.; et al. Patient engagement in research: A systematic review. *BMC Health Serv. Res.* **2014**, *14*, 89. [[CrossRef](#)]
11. Nind, M. *What is Inclusive Research?* Bloomsbury Academic Collections; Bloomsbury Publishing: London, UK, 2014; ISBN 978-1-7809-3851-6.
12. Vaughn, L.M.; Jacquez, F. Participatory Research Methods—Choice Points in the Research Process. *J. Particip. Res. Methods* **2020**, *1*, 1–13. [[CrossRef](#)]
13. Jennings, H.; Slade, M.; Bates, P.; Munday, E.; Toney, R. Best practice framework for Patient and Public Involvement (PPI) in collaborative data analysis of qualitative mental health research: Methodology development and refinement. *BMC Psychiatry* **2018**, *18*, 213. [[CrossRef](#)]
14. Greenhalgh, T.; Hinton, L.; Finlay, T.; Macfarlane, A.; Fahy, N.; Clyde, B.; Chant, A. Frameworks for supporting patient and public involvement in research: Systematic review and co-design pilot. *Health Expect.* **2019**, *22*, 785–801. [[CrossRef](#)]
15. INVOLVE, the National Institute for Health Research. Briefing Notes for Researchers. Available online: https://www.invo.org.uk/wp-content/uploads/2014/11/9938_INVOLVE_Briefing_Notes_WEB.pdf (accessed on 1 August 2023).
16. NIHR (National Institute for Health and Care Research). Available online: <https://www.nihr.ac.uk/> (accessed on 1 August 2023).
17. Hoppania, H.-K.; Venäläinen, S. Kanssatutkimuksen tietoteoreettiset taustat [The Theoretical Background of Co-Research]. In *Kanssatutkimus. Ihanteet ja Käytännöt. [Co-Research. Ideals and Practices]*; Kulmala, M., Spišák, S., Venäläinen, S., Eds.; Tampere University Press: Tampere, Finland, 2023; pp. 32–46. Available online: <https://urn.fi/URN:ISBN:978-952-359-042-7> (accessed on 1 June 2023). (In Finnish)

18. Sipari, S.; Vänskä, N.; Lehtonen, K.; Helenius, S.; Väisänen, S.; Harra, T. *Participatory Research Partnership in Rehabilitation*; OIVA-Series 55; Metropolia University of Applied Sciences: Helsinki, Finland, 2022; Available online: <https://urn.fi/URN:ISBN:978-952-328-342-8> (accessed on 10 June 2023).
19. United Nations. United Nations of Human Rights 2016. Available online: <https://www.un.org/en/about-us/universal-declaration-of-human-rights> (accessed on 1 August 2023).
20. Esmail, L.; Moore, E.; Rein, A. Evaluating patient and stakeholder engagement in research: Moving from theory to practice. *J. Comp. Eff. Res.* **2015**, *4*, 133–145. [[CrossRef](#)]
21. Government of United Kingdom. UK Research and Development Roadmap. Available online: <https://www.gov.uk/government/publications/uk-research-and-development-roadmap/uk-research-and-development-roadmap> (accessed on 1 June 2023).
22. Canadian Institutes of Health Research CIHR. *Canada's Strategy for Patient-Oriented Research Improving Health Outcomes through Evidence-Informed Care*; Her Majesty the Queen in Right of Canada: Ottawa, ON, Canada, 2011; Available online: https://cihr-irsc.gc.ca/e/documents/P-O_Research_Strategy-eng.pdf (accessed on 17 May 2023).
23. Skovlund, P.C.; Nielsen, B.K.; Thaysen, H.V.; Schmidt, H.; Finset, A.; Hansen, K.A.; Lomborg, K. The impact of patient involvement in research: A case study of the planning, conduct and dissemination of a clinical, controlled trial. *Res. Involv. Engagem.* **2020**, *6*, 43. [[CrossRef](#)]
24. CanChild. Family Engagement. Available online: <https://www.canchild.ca/en/research-in-practice/family-engagement> (accessed on 1 June 2023).
25. Van Schelven, F.; van der Meulen, E.; Kroeze, N.; Ketelaar, M.; Boeije, H. Patient and public involvement of young people with a chronic condition: Lessons learned and practical tips from a large participatory program. *Res. Involv. Engagem.* **2020**, *6*, 59. [[CrossRef](#)] [[PubMed](#)]
26. Finnish National Board on Research Integrity TENK 4/2023. Available online: https://tenk.fi/sites/default/files/2023-05/RI_Guidelines_2023.pdf (accessed on 1 August 2023).
27. Barbour, R. Doing focus groups. In *The Sage Qualitative Research Kit*; Flick, U., Ed.; Sage Publications: New York, NY, USA, 2007.
28. Krueger, R.A.; Casey, M.A. *Focus Groups: A Practical Guide for Applied Research*, 5th ed.; Sage Publications: Los Angeles, CA, USA, 2015; pp. 1–7. ISBN 978-1-4833-6524-4.
29. Elo, S.; Kääriäinen, M.; Kanste, O.; Pölkki, R.; Utriainen, K.; Kyngäs, H. Qualitative Content Analysis: A focus on trustworthiness. *Sage Open* **2014**, *4*, 1–10. [[CrossRef](#)]
30. Israel, B.A.; Parker, E.A.; Rowe, Z.; Salvatore, A.; Minkler, M.; López, J.; Butz, A.; Mosley, A.; Coates, L.; Lambert, G.; et al. Community-based participatory research: Lessons learned from the Centers for Children's Environmental Health and Disease Prevention Research. *Environ. Health Perspect.* **2005**, *113*, 1463–1471. [[CrossRef](#)] [[PubMed](#)]
31. Berge, J.M.; Mendenhall, T.J.; Doherty, W.J. Using Community-based Participatory Research (CBPR) To Target Health Disparities in Families. *Fam. Relat.* **2009**, *58*, 475–488. [[CrossRef](#)]
32. Gonzalez, M.; Ogourtsova, T.; Zerbo, A. Patient engagement in a national research network: Barriers, facilitators, and impacts. *Res. Involv. Engagem.* **2023**, *9*, 7. [[CrossRef](#)]
33. Roberts, M.K.; Evans, A.E.; Willover, L.K.; Ehde, D.M.; Alschuler, K.N. Patient-Centered Framework for Rehabilitation Research in Outpatient Settings. *Arch. Phys. Med. Rehabil.* **2022**, *103*, 1684–1692. [[CrossRef](#)]
34. Pozniak, K.; Buchanan, F.; Cross, A.; Crowson, J.; Galuppi, B.; Grahovac, D.; Gorter, J.W.; Hlyva, O.; Ketelaar, M.; Kraus de Camargo, O.; et al. Building a culture of engagement at a research centre for childhood disability. *Res. Involv. Engagem.* **2021**, *7*, 78. [[CrossRef](#)]
35. Leavy, P. Introduction to The Oxford Handbook of Methods for Public Scholarship. In *The Oxford Handbook of Methods for Public Scholarship*; Leavy, P., Ed.; Oxford University Press: Oxford, MS, USA, 2019; pp. 3–16. ISBN 9780190274481.
36. Young, R.; Sage, K.; Broom, D.; Broomfield, K.; Church, G.; Smith, C. Using nominal group technique to advance power assisted exercise equipment for people with stroke. *Res. Involv. Engagem.* **2021**, *7*, 68. [[CrossRef](#)]
37. Camden, C.; Shikako-Thomas, K.; Nguyen, T.; Graham, E.; Thomas, A.; Sprung, J.; Morris, C.; Russell, D.J. Engaging stakeholders in rehabilitation research: A scoping review of strategies used in partnerships and evaluation of impacts. *Disabil. Rehabil.* **2015**, *37*, 1390–1400. [[CrossRef](#)]
38. Järvikoski, A.; Martin, M.; Autti-Rämö, I.; Härköpää, K. Shared agency and collaboration between the family and Professionals in medical rehabilitation of children with severe disabilities. *Int. J. Rehabil. Res.* **2013**, *6*, 30–37. [[CrossRef](#)] [[PubMed](#)]
39. Harra, T.; Sipari, S.; Mäkinen, E. Hyvää tahtova kehittäjäkumppanuus. [A Well-Intentioned Developer Partnership]. In *Asiakkaasta Kehittäjäksi ja Vaikuttajaksi. Asiakkaiden Osallisuuden Muutos Sosiaali—Ja Terveyspalveluissa. [From Client to Developer and Influencer. Transforming Client Participation in Social and Health Services]*; Pohjola, A., Kairala, M., Lyly, H., Niskala, A., Eds.; Vastapaino: Tampere, Finland, 2017; pp. 147–164. ISBN 978-951-768-597-9. (In Finnish)

40. Potvin, L.; Bisset, S.L.; Waltz, L. Participatory Action Research: Theoretical Perspectives on the Challenge in Research Action. In *The Sage Handbook of Qualitative Methods in Health Research*; Bourgeault, R., Dongwall, R., de Vries, R., Eds.; Sage Publications: London, UK, 2010; pp. 433–453. ISBN 9781847872920.
41. McNiff, J. *You and Your Action Research Project*, 4th ed.; Routledge: London, UK, 2016; pp. 216–224. ISBN 978-1-138-91004-1.

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