

Participatory Research Partnership in Rehabilitation

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A jointly designed activity culture in scientific research
The Participatory Research Partnership model



Foreword

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This publication was made as a part of the REcoRDI project (Platform ecosystem for strengthening of RDI activities in multidisciplinary rehabilitation) and has also been published electronically and as a printed version in Finnish. The Finnish publication is called Osallistuva tutkimuskumppanus kuntoutuksessa. The project received funding from the Ministry of Education and Culture. The purpose of the project was to develop effective high-quality applied research in the field of rehabilitation. The project was carried out as a joint effort of JAMK University of Applied Sciences and Metropolia University of Applied Sciences in 2019–2022.

Welcome to learning more about **participatory research partnership!** This refers to the partnership-based participation of researchers, rehabilitees and their families, rehabilitation professionals and other stakeholders in collaborative activities at different phases of the research process.

The Participatory Research Partnership model described in this publication has undergone several phases of development. The development project was kicked off with a literature review of international rehabilitation studies. The first draft of the model was built on this scientific research evidence. Data collected in co-development workshops was used to fine-tune the model to match Finnish rehabilitation practices better. Content for the model was also produced by theses prepared in the Master's Degree Programme in Rehabilitation. This material was condensed into the second version of the model, piloted in a developmental training process. The model and its practical applications were explored through development tasks, which yielded useful data for evaluating the model. The Participatory Research Partnership model is the result of work carried out during the above phases.

We would like to extend our warmest thanks to everyone who took part in this project. The workshops included over 100 experts and the developmental training included 50 expert: rehabilitees and their families and a transdisciplinary group of rehabilitation professionals, developers, trainers, students, and researchers.

We'll start off with some background on why partnerships are needed, moving on to describe participatory research partnership and the values

// Moving towards a bright future through the collaborative use and generation of research-based knowledge



The Participatory Research Partnership model was developed as a part of the REcoRDI project (Platform ecosystem for strengthening of RDI activities in multidisciplinary rehabilitation), which was launched to promote effective and high-quality applied research in the field of rehabilitation.

The results from the REcoRDI project are outlined in [*the Strategic Roadmap for Applied Research in Rehabilitation \(Theseus\)*](#).



Tulevaisuudenkuntoutus.fi (in Finnish) is an interactive online platform, which collects rehabilitation research data and brings together researchers and other actors interested in research.

and guiding principles thereof. Then, we'll look at the Participatory Research Partnership model, explain the contents of its phases, and provide some examples. The final chapter describes the development of the model from the research perspective. We'll conclude by introducing the authors and listing our partner developers. The templates for practical application of the model are provided at the end of the publication. Separate editable and fillable versions are also available in the Theseus database.

We hope that the Participatory Research Partnership model and the tools supporting its adoption will create co-agency and collaboration in applied rehabilitation research and rehabilitation practices. Our goal is to create a bright future through the collaborative use and generation of research-based knowledge.

At the end of the Year of Research-Based Knowledge 2021,

Salla Sipari, Nea Vänskä, Krista Lehtonen, Sari Helenius, Sara Väisänen, Toini Harra



**PARTICIPATORY
RESEARCH
PARTNERSHIP**

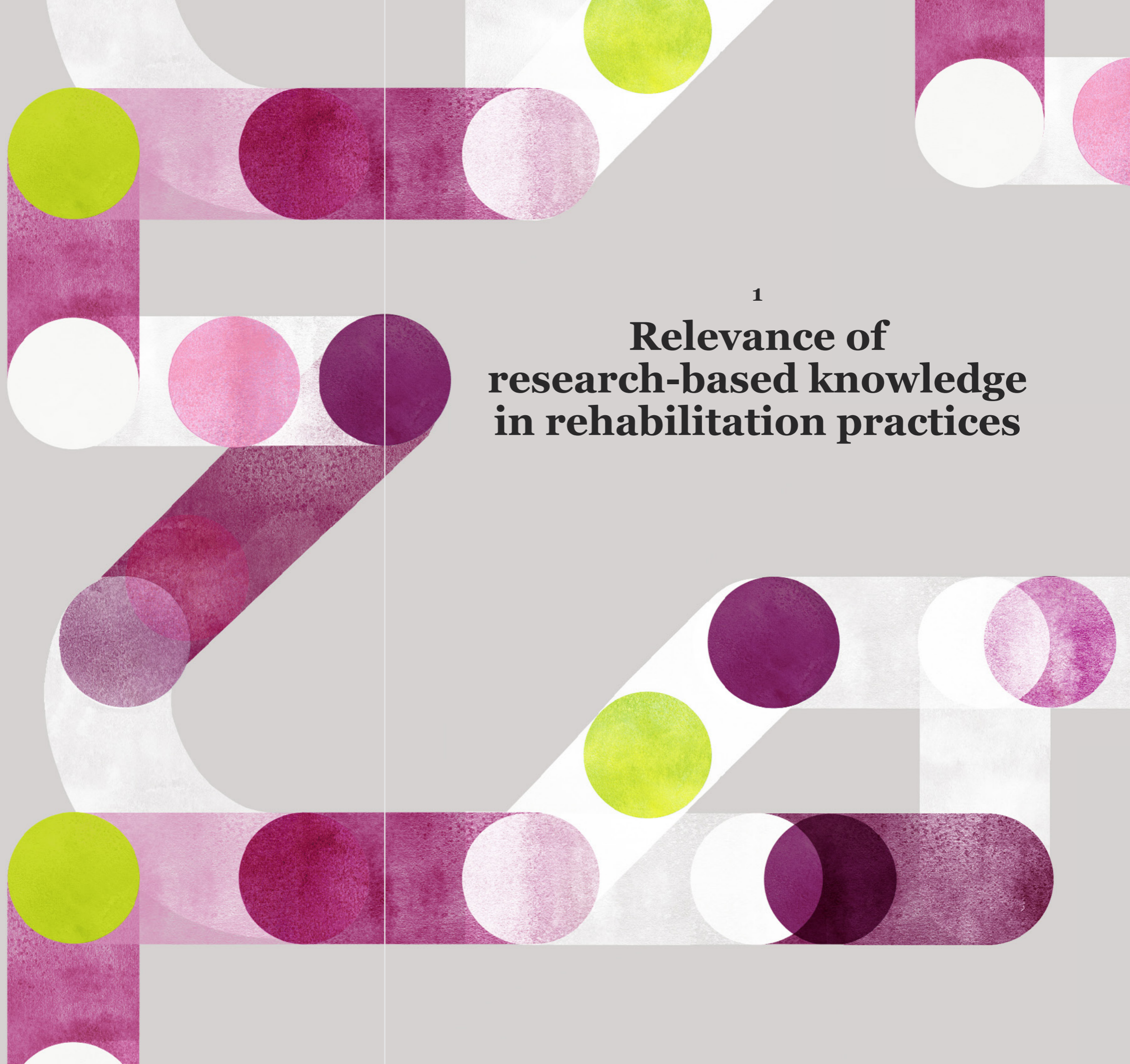


When using Participatory Research Partnership model, include this logo of the model.

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Relevance of research-based knowledge in rehabilitation practices



Subject or partner in scientific research?

The significance of research-based knowledge is highlighted when people try to secure a sustainable future in a rapidly changing world. In rehabilitation, research-based knowledge is needed for everyday solutions to promote well-being, work capacity and functioning. Active participation of users and providers of rehabilitation services in scientific research promotes the everyday usability and relevance of research-based knowledge. The accessibility and usability of research data are of crucial importance when verifying the suitability of research-based knowledge from the user's perspective.

It is important to identify how the participation of various actors in scientific research is enabled. Is a study planned around rehabilitees as research subjects, collecting data about their functioning with various measurements? Or do rehabilitation professionals and experts have the role of data producers only, answering surveys drafted by researchers or taking part in interviews or workshop tasks? What if rehabilitees, professionals, various stakeholders and researchers conducted research in the framework of partnership-based collaboration, which allows everyone to contribute in a way that suits them best? This is what participatory research partnership is all about.

Learn more about the idea of participatory research partnership from Salla Sipari's TEDxMetropoliaUniversity presentation (*in Finnish*): [Are you a subject or a partner in scientific research? \(YouTube\)](#)

Collaborative production and use of research-based data

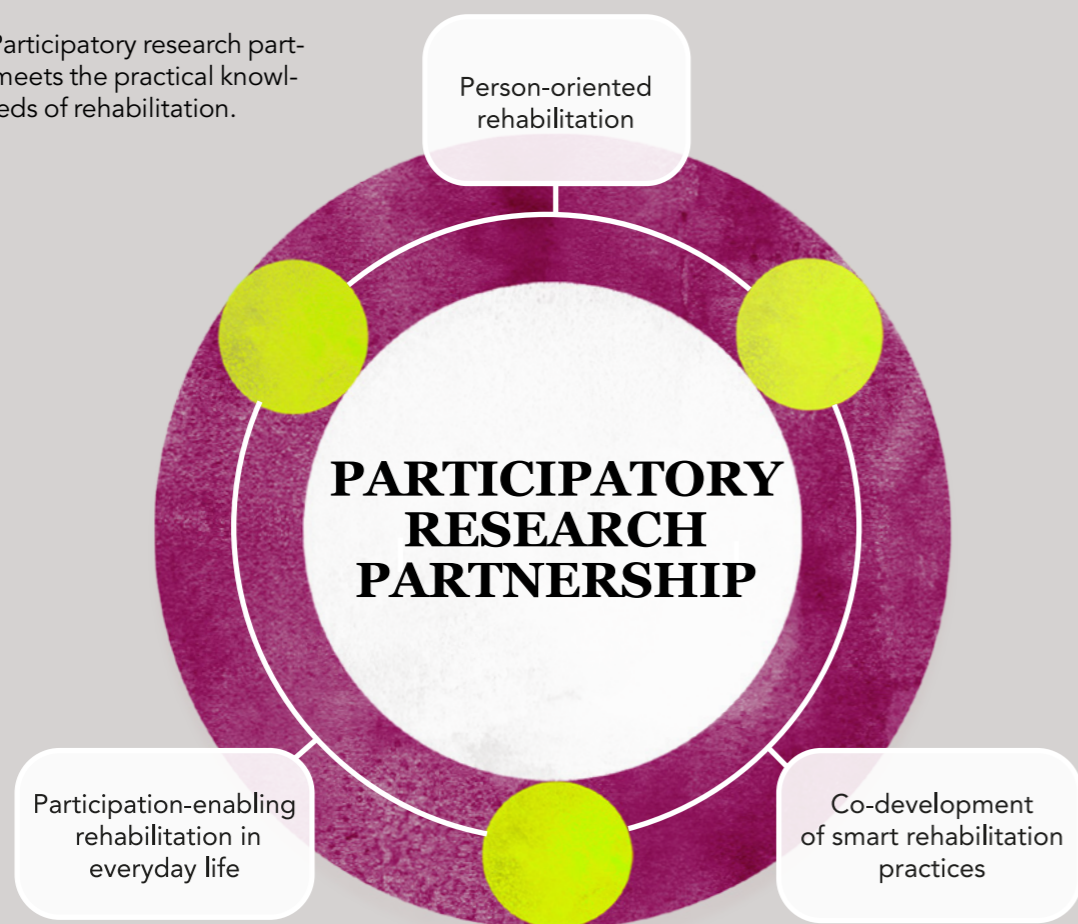
Participatory research partnership (PaRe) represents fresh culture in scientific research. It involves the deliberate construction of a collaborative partnership between different parties: researchers, rehabilitees and their families, and professionals. The aim is to produce and use data together, instead of simply transferring research-based knowledge over to practice. Benefits are reaped over the long term when partners working under constant change learn to produce and use research-based data to create a good future.

Participatory research partnership and rehabilitation research are a good match when rehabilitation is understood as a planned process of change between the rehabilitee and his/her environment. Rehabilitation concerns the relationships and interactive collaboration between the rehabilitee and the environment. All those involved, from rehabilitees and their families to professionals, have valuable expertise to share when research-based knowledge is co-produced.

/// All parties have valuable expertise to share when research-based knowledge is co-produced

Collaborative knowledge building means knowingly defining and refining meanings on a case-by-case basis. Building knowledge together is a gradual and iterative shaping of understanding. The construction of knowledge embodies an expanding informational entity in which new knowledge complements previous understanding.

Figure 1. Participatory research partnership meets the practical knowledge needs of rehabilitation.



Knowledge needs from the viewpoint of rehabilitation practices

As an activity culture in scientific research, participatory research partnership can respond to rehabilitation research phenomena, which are diverse, broad, network-like, systemic entities formed of many interwoven elements. Person-oriented rehabilitation is based on the needs and goals of the rehabilitee. Keeping these needs and goals in mind, the rehabilitee, close ones, and rehabilitation professionals co-develop smart rehabilitation practices and environments that enable meaningful participation and rehabilitation for the rehabilitee in his/her everyday life. Participatory research partnership allows different kinds of expertise to be combined in order to target the research at promoting rehabilitation. (Figure 1.)

Applied rehabilitation research utilises existing research data to develop rehabilitation practices. In addition to problem-solving, applied research involves future-oriented innovation activities. In applied rehabilitation research, it is important to identify and pursue collaborative research activities where the participatory research partnership is useful and serves a purpose.

2 Towards a good future of research-based knowledge as partners

Participation in a partnership

A participatory research partnership is a jointly shaped activity culture in scientific research. In such a partnership, stakeholders and the general public do not need to be trained researchers to participate in all steps of the research process as equal partners. Researchers, rehabilitees and their close ones, and rehabilitation professionals join forces to define meaningful forms and methods of **participation**.

What participatory research partnership is all about:

- democratic research, which means that everyone has the right to participate in matters that concern them – not the democratisation of research, which would allow citizens to make decisions about the results
- each actor being a member of a research team or community as befits his/her personal expertise – not citizens turning into researchers
- research expertise, i.e. those with research training being responsible for the quality and reliability of research – not all actors having identical skills and responsibilities
- advancing understanding of the subject matter together and sharing expertise through participation in research activities – not apparent inclusion or passive involvement
- collaborative activities that can be applied in a purposeful way in various research approaches – this is not a method or an approach.

// Researchers, rehabilitees and their families, and professionals join forces to define meaningful methods of participation

Participatory research partnership is about non-tokenistic involvement, i.e. researchers including actors who are the targets of the activity in the preparation of e.g. study protocols or, within the framework of applicable boundary conditions, in the publication of research results. **Participatory** research partnership is based on the active participation and collaboration of all actors.

What participatory research partnership requires:

- expertise in partnerships and collaboration and ability to apply this to scientific research
- partial reform of good scientific practices and related guidelines to clarify that the members of stakeholder groups are not just research subjects but partners who take part in carrying out the research
- evaluation of ethical solutions among researchers and partners in the research team.

Participatory research partnership involves the deliberate construction of a collaborative relationship between researchers and stakeholders. Creating a participation-based culture plays a key role in this. The culture takes shape through discussion and concretisation of the specific situation. It is also associated with shared values, principles, goals, methods of action, understanding and experience of the subject matter.

Core values of participatory research partnership:

- **Openness:** each partner enriches and shapes collaborative activities by openly bringing their skills and expertise to the table.
- **Respect:** different viewpoints and skills are appreciated when interaction is based on trust.

Core principles of participatory research partnership:

- **Equality:** All members of the research team are equal partners. This also means equality in all interactions. The expertise of all actors is recognised, acknowledged, and utilised to achieve the shared aims and goals. Equality does not mean that all research partners have the same role or perform identical tasks during the research process.
- **Reciprocity:** Research team forms a community that is relevant to them. It allows them to influence and to become influenced by each other. In other words, each partner contributes to the course of the action and becomes also influenced by it. Reciprocity is not a barter. It means recognising the expertise of each partner and forming an understanding of everyone's roles and responsibilities together.

Activities are shaped jointly in a participatory research partnership so that the ownership of the research process becomes a matter of shared influence and responsibility.

Goals of participatory research partnership

The purpose of participatory research partnership is to produce new research-based data that will meet the practical knowledge needs of rehabilitation in the best possible way to promote and support functioning, work capacity and wellbeing. This is why it's so important to allow rehabilitees associated with the research topic, their close ones, professionals, and stakeholders to participate and help build and use research-based knowledge. This enables the production of data that will be truly meaningful to the users in their daily lives. In participatory research partnership, research activities are fully open, transparent, understandable, and meaningful for everyone involved.

Collaboration in participatory research partnership

Collaboration means that researchers and other partners of the research team, i.e. rehabilitees and their close ones, professionals, and other stakeholders, roll up their sleeves and work together at different phases of the research. Collaboration promotes co-agency as an interactive process, allowing everyone to become wiser through shared experiences and learn new things together.

Recognising the agency of collaborating actors is the cornerstone of co-agency. This requires getting to know your own skills, abilities, goals, needs and emotions, as well as those of other partners. The co-agency of the research team is built on resources identified together, a shared idea and understanding of the situation, and the research aim. Co-agency enables meaningful and purposeful participation in the activities of the research team for all stakeholders. It is made up of collaborative planning, decision-making, commitment, and shared responsibility. In co-agency, a shared vision of the goal and the methods used to reach it, is achieved through contemplative discussion and jointly made choices and decisions.

“I am involved in a research partnership where my unique skills are appreciated and we are achieving good things together.”

Wishing well to others, fairness and equity form the foundation of co-agency. The investments made in co-agency, and sharing its benefits and responsibilities, are based on mutual fairness. Co-agency also helps resolve unexpected conflicts and problems amicably and in an equitable manner.

Collaboration gives all partners the opportunity to bring their own experiences, observations, and feelings on the research topic to the table and the confidence that they will be heard and respected. Co-agency and collaboration provide participants with abilities and opportunities for action. They also promote wellbeing and a good life. •

Cornerstones of participatory research partnership:

- well-intentioned partnership: positive attitude, interest, and willingness to work with others
- defining the forms and methods of participation together
- mutual aims: commitment to working together towards jointly formulated goals.

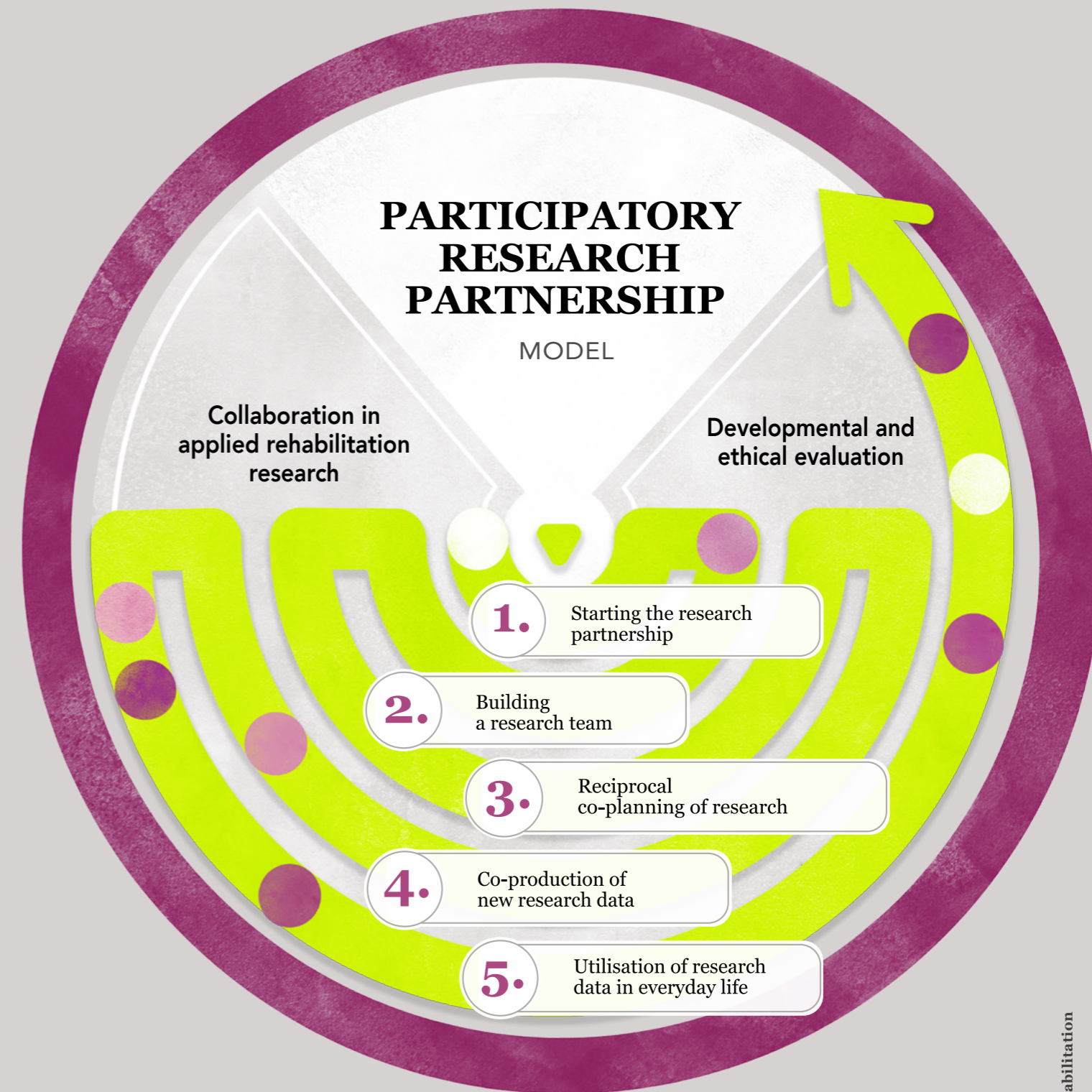
3 The Participatory Research Partnership model

The model as an interactive entity

The Participatory Research Partnership model should be visualised as an entity (Figure 2), where the different phases interact with each other and can also advance simultaneously. The phases are: starting the research partnership, building a research team, reciprocal co-planning of research, co-production of new research data, and utilisation of research data in everyday life. The phases include a description of partnership-based collaboration and enabling participation in it. A developmental and ethical evaluation applies to every step of the Participatory Research Partnership model.

Typically, the first steps of scientific research are getting to know the research topic and preparing a plan, which is done by researchers. A participatory research partnership, however, starts with reciprocal co-planning that includes all the partners involved. First, a partnership should be built between the actors and then a functioning research team formed. This is why participatory research partnership places more emphasis on the preparatory phase of research, and the research planning step is preceded by two phases that focus on building a true partnership. The research is based on the co-production of data. The aim of reporting and publishing results is to make the data accessible and exploitable in the everyday setting.

All phases of the Participatory Research Partnership model are carried out as a collaboration. Also, developmental evaluation is an omnipresent theme in the model. Its purpose is to ensure a meaningful research partnership and appropriate progress towards the jointly established goals. Ethical solutions relating to the participatory research partnership are interwoven with the developmental evaluation. The goal of the evaluation is to ensure equal participation from the beginning to the end of the research process.



Collaboration in all phases of the model is based on the belief that “our research will succeed better when you are a part of it and contribute to it”.

Figure 2. Overview of the Participatory Research Partnership model.

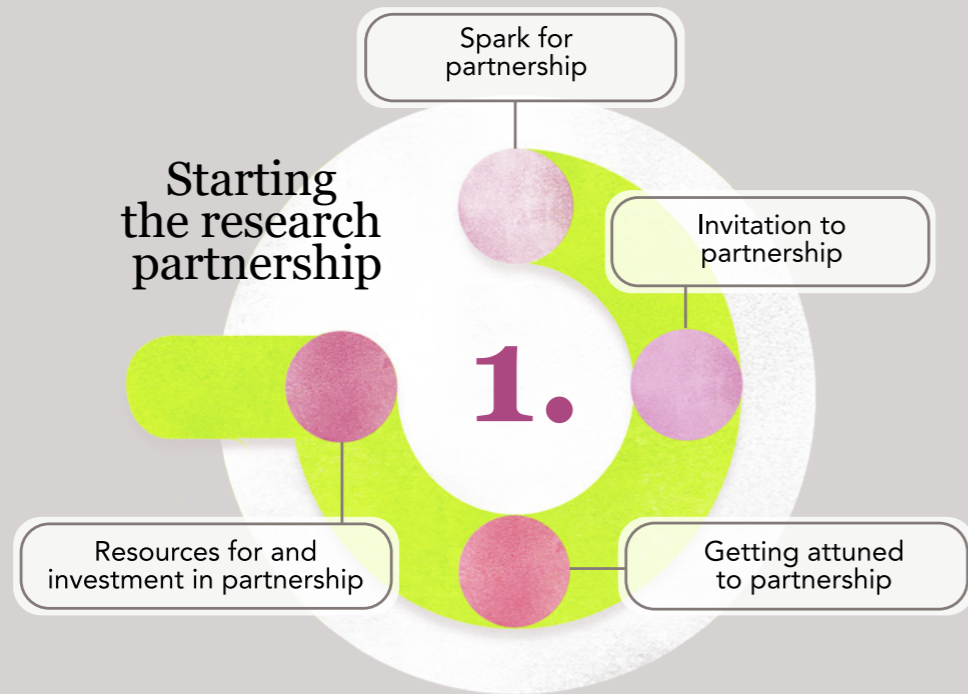


Figure 3. Key factors of starting the research partnership.

Starting the research partnership

Starting the research partnership includes the following steps: spark for partnership, invitation to partnership, getting attuned to partnership, and resources for and investment in partnership (Figure 3).

Spark for partnership

Identifying a research need serves as the spark for partnership and may be associated with e.g. an issue brought up by rehabilitees, a will to engage in collaborative research expressed in the partnership network, a challenge observed in rehabilitation practice, or an issue identified based on previous research. Identifying a meaningful research topic and prioritising topics may also

Identifying a research need serves as the spark for partnership

turn into a research project in the framework of the research partnership. Identifying the added value of partnership for the research may also spark interest in a partnership.



METHODS OF ACTION FOR IDENTIFYING RESEARCH NEEDS

Examples of ways to identify meaningful research needs and prioritise those that are the most topical or have the greatest importance to partners:

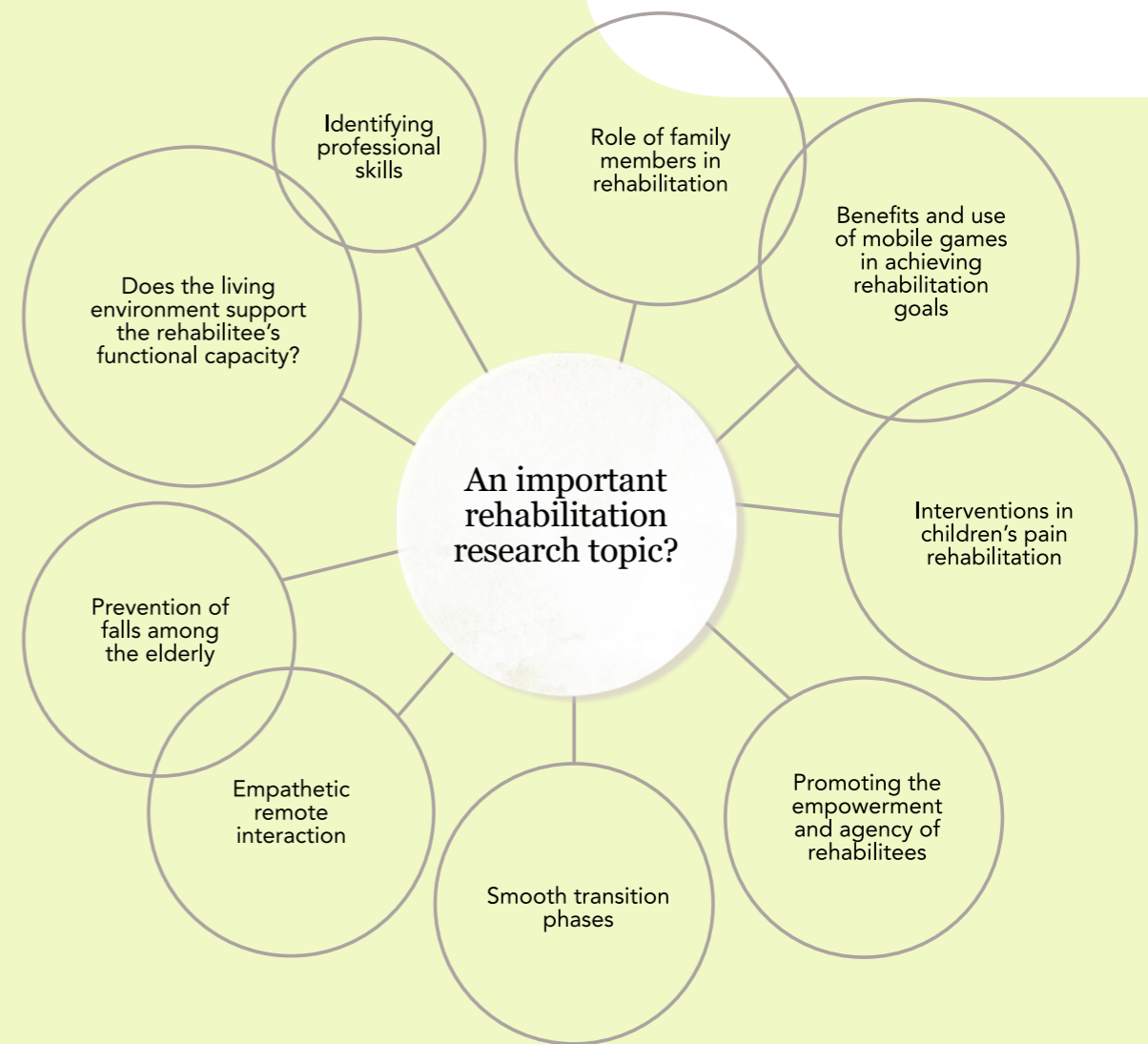
- workshops / small group sessions
- open discussion forum
- panel discussion and commenting
- literature review and discussing the results together

When identifying research needs, digital tools can be used to maximise participation. An example of important rehabilitation research topics collected on a digital platform is shown in the image.



MEANINGFUL RESEARCH TOPICS MAY SPARK OFF PARTNERSHIPS

Peninsula Childhood Disability Research Unit (pencru.org) is a research unit in England that actively invites the families of children with special needs to be research partners in “the family faculty”. A manual describing, for example, different ways to participate in research and various activities, is available on the unit’s website. People can suggest research topics and sign up for activities through the website. The families participate in e.g. mapping out and prioritising meaningful research topics in collaboration with the staff of the research unit and other network members.



Invitation to partnership

When forming a research partnership to address a collective knowledge or development need, the first step is to invite actors into the research team. To this end, it is worthwhile to prepare interesting and accessible material for potential research partnership networks explaining what a participatory research partnership is all about. Using multiple communication channels is a good idea. The opportunity to participate can be broadcasted via various open forums, customer panels, networks of experts-by-experience, social media, and workplace visits. Communication may include e.g. answers to frequently asked questions and information on how to participate, what it entails and what kind of a timeframe has been envisioned.

A transdisciplinary and multi-perspective group of participants with ideas and skills (e.g. experience-based) relevant to the topic should be invited to join the partnership. Multiple methods can be used for extending the invitation.

These include e.g. an application process (see the example "Invitation to partner up"), an initial task, a group meeting or an online course that also serves as an introduction to participatory research partnership. This allows those interested in joining the partnership to make an informed decision about it.

When forming research partnerships, always keep in mind that the people involved should commit to the partnership, which is primarily linked to research activities. The number of partners and the composition of the team should be jointly considered, taking into account that a larger team will have more diversity but may also need more time to form a common understanding.

Getting attuned to partnership

When starting a partnership, the research team should get attuned to working together. Each member should be informed of the background

and course of the research process. The partners should jointly define what the participatory research partnership is about in this particular situation. Research partners should agree on the scope and methods of participation together. Participation is always voluntary, and any partner can withdraw if they wish to do so. If research partners are paid for participating, the consequences of withdrawal should be agreed upon in advance.

Starting a partnership is about building reciprocal relationships. This is why friendly interaction based on trust is important from the start, so everyone feels welcome. Getting acquainted on a personal level and recognising and acknowledging the agency, expertise, and values of other partners help build communality. This creates an atmosphere of openness and safety and a sense of solidarity. Identifying the partners' needs for individual support is important to ensure equal participation. Meaningful shared activities and an appreciative atmosphere improve commitment to collaboration.



GETTING ATTUNED TO PARTNERSHIP

When starting a research partnership, a shared digital platform can be created for the research team to facilitate open and reciprocal communication and interaction. A Teams platform was established during the developmental training process of the Participatory Research Partnership model to enable communication and interaction, such as the distribution of materials, in an easy, accessible, and time-independent way. Each research partner posted a presentation of themselves on the platform. In the developmental training process, the participants started preparing their presentation slides and viewing everyone else's slides before the first meeting. The skills, resources and viewpoints described in the presentation slides were summarised during the first meeting: what we are together.

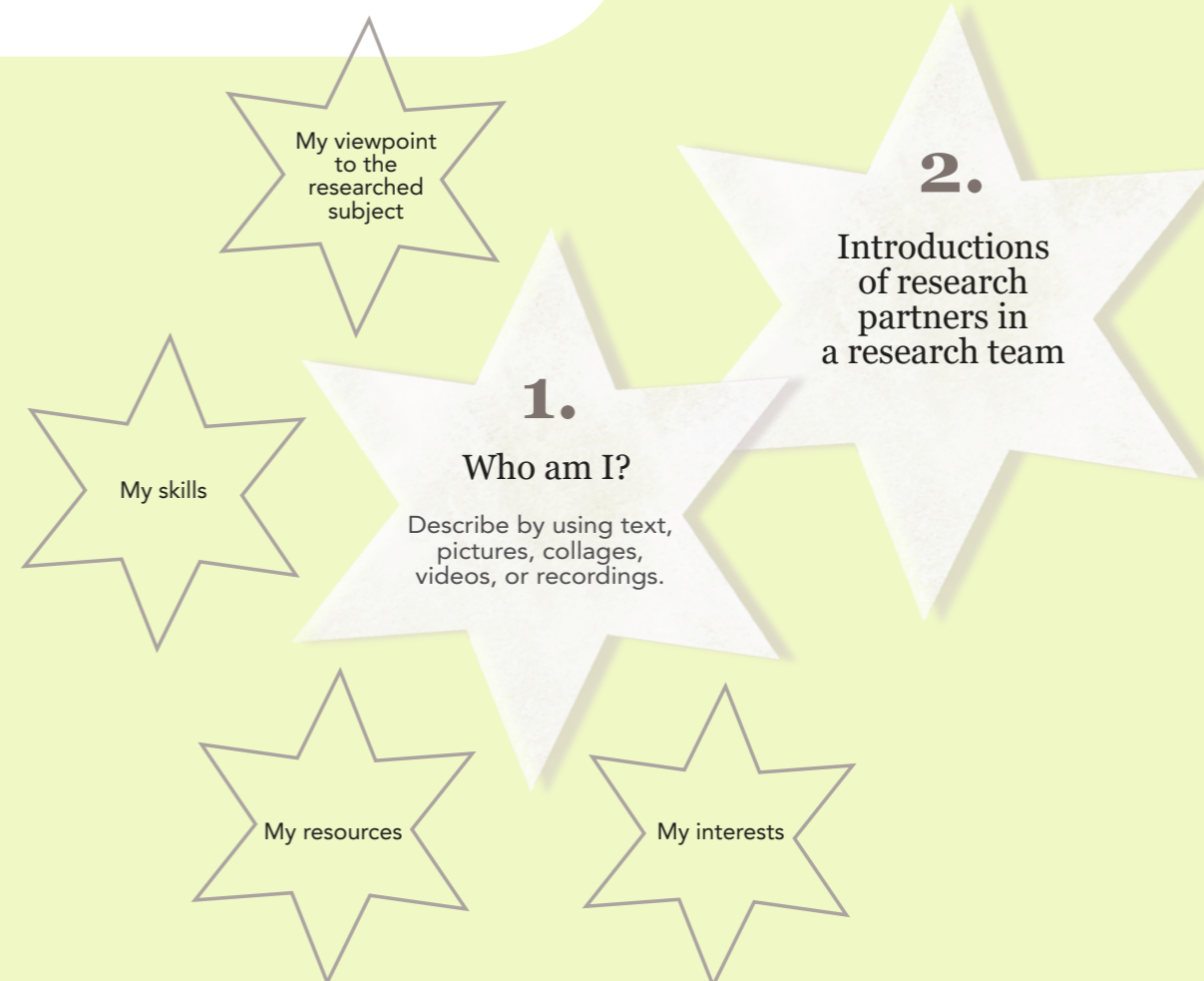


INVITATION TO PARTNER UP

Partners can be invited through an application process where potential partners are informed about the research partnership and can express their interest in taking part. Those interested can sign up e.g. by completing a questionnaire and describing:

1. which aspects of the participatory research partnership interest them, and
2. which skills or resources they can bring to the participatory research partnership, e.g. previous experience of development and research activities, personal experience with rehabilitation, or other types of expertise

If personal information (e.g. name, e-mail address) is collected on sign-up or application forms, it should be noted that the appropriate privacy statement is required to include.



Resources for and investment in partnership

When starting a research partnership, you need to identify the existing resources and contributions and determine what is needed to enable partners to participate. In addition to needs for support related to individual functioning, it is important to consider resources needed to the execution of activities. Financial resources may be needed for partners' travel expenses, working hours, facilities, or materials. Salary may be paid for working as a member of the research team. A participatory research partnership may also be launched as a voluntary activity. A partnership may have added value to the participants. For example, a research partner may have the opportunity to develop new skills that can be useful when looking for a job.

// You need to identify the existing resources and contributions and determine what is needed to enable partners to participate



STARTING THE RESEARCH PARTNERSHIP

- ❑ A research partnership is created around an identified, meaningful research topic.
- ❑ Research partnership networks and potential partners should be scoped out to invite suitable partners.
- ❑ Communication and information that is appealing to potential partners, presented via appropriate channels, support the search for partners. The materials and communication channels should be jointly planned and tested in advance.
- ❑ Networks and potential research partners should be told clearly and understandably what the participatory research partnership is all about when inviting them to join.
- ❑ The prerequisites for participation (e.g. resources, time requirements, voluntariness) should be described.
- ❑ The benefits of participation and possible financial support should be described.
- ❑ The purposeful size of the research team should be jointly considered.
- ❑ The criteria for selecting research partners and the selection process should be described.
- ❑ An application process should be used whenever appropriate.

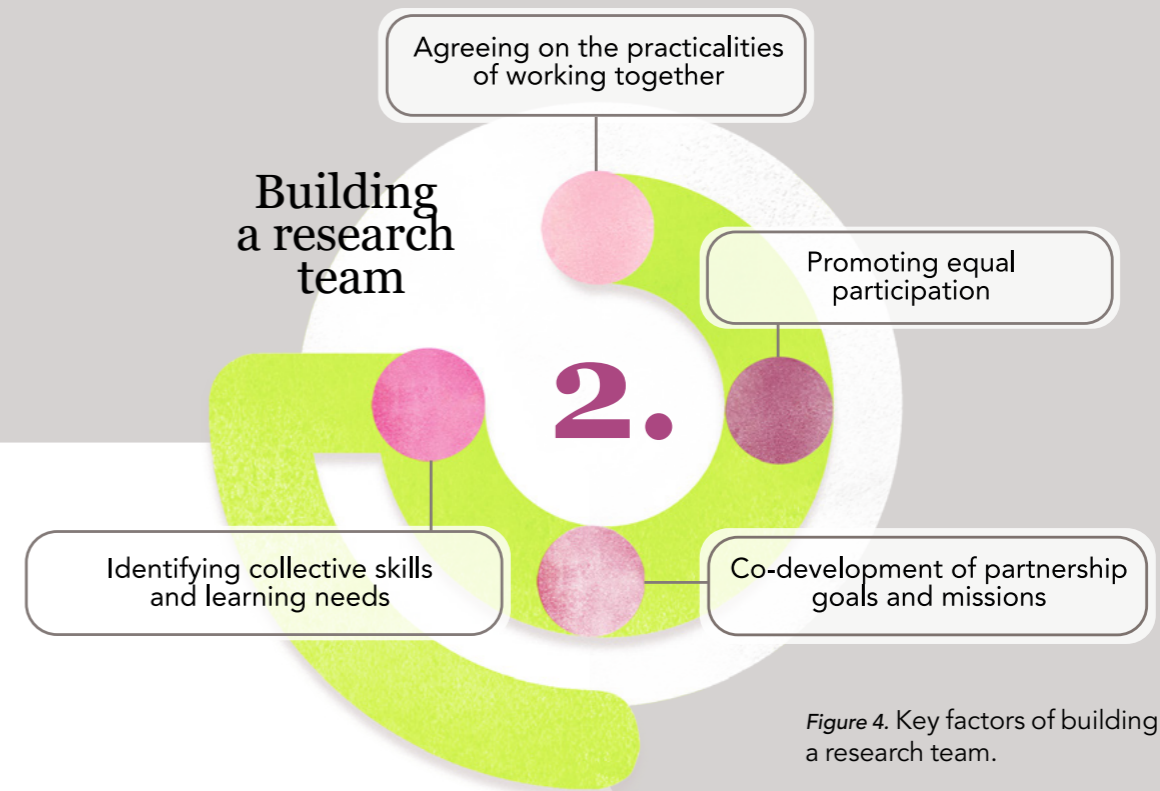


Figure 4. Key factors of building a research team.

Building a research team

Building a research team includes agreeing on the practicalities of working together, promoting equal participation, co-development of partnership goals and missions, and identifying the collective skills and learning needs of the team (Figure 4).

Agreeing on the practicalities of working together

The team members agree on the practicalities of working together, identify the prerequisites for collaboration, and create common rules for the activities. The agreement on the practicalities may include e.g. descriptions of the following:

- How will decisions be made?
- What kind of methods of action will be used?

- When will the collaborative activities be carried out?
- What is meant by equality and accessible interaction and communication?

The research partners jointly define the roles, tasks and responsibilities associated with the activities. A clear, understandable task description will be established for everyone through discussion and brainstorming in common meetings. Building collaboration, meaningful interaction and team spirit is of key importance. The ways of participating and the tasks of the team members take the individual resources and options of each team member into account.

The ways and roles of participating may change as work progresses, and jointly agreed practices can be adjusted when new things are learned

and developmental evaluations are performed. For instance, one member of the research team might be responsible for organising the team and coordinating the initial meetings, but if the team agrees, this responsibility could be passed on to someone else during the research process. The contributions of team members might vary in different phases of the research process depending on their personal lives, interests, and opportunities.

In a participatory research partnership, all members of the research team participate in decision-making. For partners to be able to participate in decision-making, adequate information must be available on, for example, the progress of the research process and ethical guidelines for the decisions.

Jointly agreed methods of action and areas of responsibility inspire trust and encourage team members to take responsibility. They also dispel prejudice and help create a shared understanding of the process and its goals. The organisation of the research team, including tasks and responsibilities, should be recorded. Keeping records allows the team to check what was initially agreed upon and make adjustments if needed.

Promoting equal participation

The process of shaping together the activities of the research team creates the foundation for equal, reciprocal participation. In a participatory research partnership, equality must extend past words to the actual methods of action. A true research partnership steers clear of tokenism, apparent or superimposed participation. Performing developmental and ethical evaluations in all phases of the research process helps ensure adherence with the principle of equal participation (see page 36).

Ensuring that environments and methods are both physically and socially accessible, and taking individual needs into account, helps promote equal participation. Accessible interaction is associated with diverse opportunities to present different viewpoints and taking different ways of communication into consideration. Other members of the research team may need to learn new ways to communicate in order to enable equal



TOOLS FOR ORGANISING THE RESEARCH TEAM AND DEFINING ROLES AND RESPONSIBILITIES

Patient-Centered Outcomes Research Institute (PCORI) is an institute located in the United States that strives to promote the inclusion of patients in research activities. The institute has developed a tool to improve the engagement of team members: [Updated Engagement Plan Template \(PDF\)](#).

Kenniscentrum Revalidatiegeneeskunde Utrecht is a centre of excellence located in the Netherlands that has developed an involvement matrix tool for structuring research partnerships: [Involvement Matrix \(PDF\)](#). This tool helps outline the various roles and tasks of actors in the research team, but it can also be used for monitoring the advancement of the project and for reporting on participation. The tasks of the actors in different phases of the research, and what the tasks specifically involve, are described in the matrix.

connections allow people to participate regardless of location and distance.

Flexible and proactive methods, such as having the opportunity to prepare for team meetings and get oriented with the help of e.g. materials distributed in advance, promotes equal participation. A proactive approach makes it easier to account for people's different rhythms. Visual and illustrative methods, such as digital presentations, wall posters and written materials, support participation and improve understanding. The challenges of participation should be discussed openly, and solutions should be sought together.

When shaping the activities of the research team, research partners work their way towards a shared set of values, trust, and communality through discussion. Building trust may take time, and getting to know each other in a relaxed, informal setting is a good idea. Open and respectful interaction in the team is of key importance. The research team might come up with a suitable name for the team and design a team symbol or logo, for example. It is important to ensure that

everyone feels like they are a part of the team, their expertise is appreciated, and they have something to contribute.

Co-development of partnership goals and missions

When shaping the activities of the research team, realistic expectations for the partnership should be determined and agreed upon. The goals, tasks and schedules for the team's activities should be jointly determined, e.g. by using co-development methods. The key thing is to work towards a shared understanding of what the participatory research partnership should achieve.

Many tools are available for the planning of co-development and network-like development activities. For example, ["The project is over, now what?" online publication available in the The-seus database \(2021\) \(in Finnish\)](#) lists tools for ensuring that social innovations take root, e.g. by locating multi-actor networks.

// True research partnership requires equal participation

participation. A family member or assistant may sometimes need to support a team member's interaction and participation.

Avoiding research jargon and difficult concepts is important, because obscure terminology can lead to misunderstandings and exclude participants from discussion and activities. Setting titles aside when making introductions and settling down in a shared space without anyone obviously standing in front of the group can help promote participation. Digital solutions and remote



PROMOTING EQUAL PARTICIPATION

- ❑ The environment should be physically and socially accessible to participation.
- ❑ Individual needs for support should be taken into consideration.
- ❑ All partners should have the opportunity to express their opinions.
- ❑ Everyone should be able to understand the language being used.
- ❑ Appropriate digital and visual solutions should be used.
- ❑ Accessibility of interaction, communication and materials should be taken into account (see e.g. [saavutettavasti.fi](#) (in Finnish)).
- ❑ Partners should be able to prepare for activities with the help of e.g. materials distributed in advance.
- ❑ Flexible, proactive, and diverse methods of action should be used.
- ❑ Opportunities for participation should be co-developed.

Identifying collective skills and learning needs

When shaping the activities of the research team, the skills of the team members and any new skills required for research activities in the participatory research partnership should be identified. The team should ensure that everyone has the opportunity to express what they can do and which skills they want to develop. Training or mentoring, for instance, can be organised if needed. Training on the following subjects might be needed in a participatory research partnership: equal participation and interaction in the team, research methods and ethics in different phases of the research process, or team communication and presentations.



IDENTIFYING COLLECTIVE SKILLS

A digital whiteboard may be a useful tool when identifying collective skills as it allows the addition of text, images, links, etc. It can be used to document the results of team discussions and brainstorming sessions. Team members should be allowed to express their thoughts anonymously on the whiteboard, which also allows it to be used for individual work if needed. An example of the results of co-development is given in the image.



JOINT TRAINING

Getting ready for a research partnership through joint training may be necessary. For example, the Canadian *CanChild research centre* offers an online training program, *Family Engagement in Research*, which is targeted at researchers, clinicians, other stakeholders, and rehabilitees and their families.

Reciprocal co-planning of research

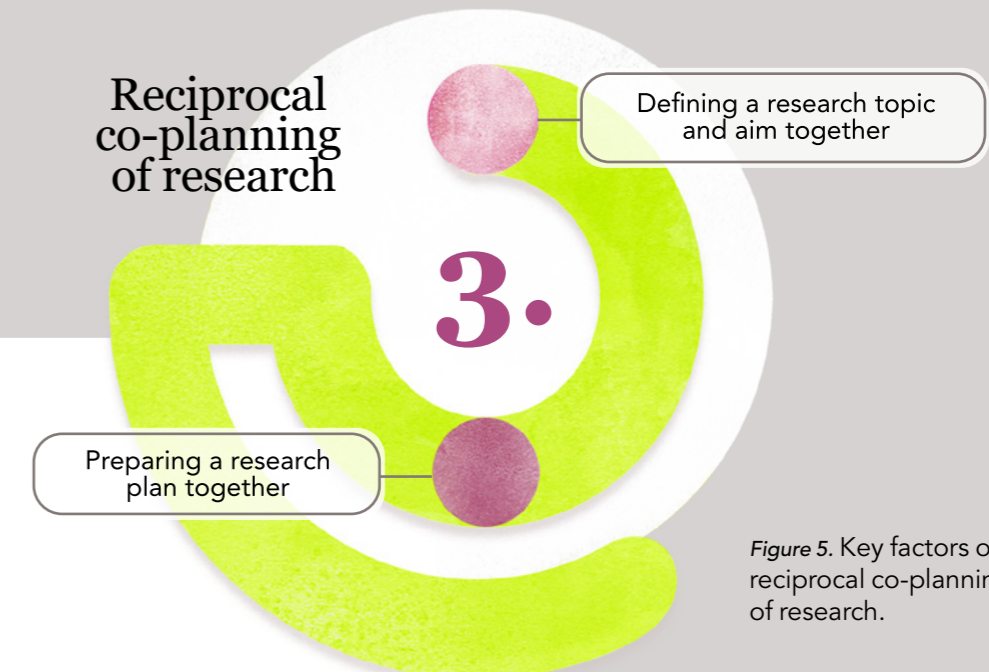


Figure 5. Key factors of reciprocal co-planning of research.

Reciprocal co-planning of research

Reciprocal co-planning of research includes defining a research topic and aim together and preparing a research plan together (Figure 5).

Defining a research topic and aim together

The research partners are connected by a specific topic or phenomenon they wish to develop or have more research-based data about. To paint a multidimensional picture, reciprocal planning initially involves open discussion about a preliminary topic or aim and related experiences and viewpoints. In addition to topics of common interest, the research partners may initially have

different ambitions, expectations and wishes.

If the topic and aim are of personal interest, team members may be willing to commit to a long research process. For this phase to succeed, partners must make sure that equal participation is enabled and the discussion gradually specifies the research topic and aim better. This helps improve shared understanding of the topic under investigation and the different viewpoints associated with it.

The idea for the research topic and aim may spring from the needs of one or several partners, but it is the task of the whole team to fine-tune and possibly adjust and clarify it. The research



THE TIMEOUT METHOD

The Timeout method, developed by Sitra, can be used to promote dialogue. Timeout is a method that allows you to bring together people from different backgrounds and engage in equal dialogue, also with individuals who are often easily left out of discussions. It is best suited for groups of 6–25 people. Ideally, the participants should sit in a circle facing each other, but a remote meeting is also a possibility. Timeout is a facilitated discussion, and the facilitator ensures that the discussion moves along and remains constructive and equal. Ground rules for a constructive dialogue, made by Timeout, are available to support the planning and implementation of discussions.

All participants should first express their own ideas and interests, and the discussion should then proceed to creating a shared understanding of the research topic. To ensure a realistic, multi-perspective approach that is the result of a joint effort, the participants need to be able to accept and give space to the different views of others. Recognising silent signals and needs, and understanding their significance, requires particular sensitivity and attention.

topic can be clarified, specified, adjusted and limited on the basis of open dialogue.

Reciprocal planning of research involves discussing the prerequisites of achieving goals and performing the research. These include e.g. the time and skills available, funding opportunities, the amount of work required, equipment, methods and environments, and also other networks and actors involved in the project, if known. The tasks related to conducting the research and a continuous ethical evaluation are interwoven in reciprocal planning.



EXAMINING AND DEFINING A RESEARCH TOPIC TOGETHER

- ❑ Everyone should have the opportunity to explain his/her understanding of and needs relating to the topic freely and in different ways.
- ❑ In the planning phase, preliminary aims can be expressed in various ways with creative methods, such as drawing, writing, or giving a physical presentation, and also through other means of communication, e.g. emotion cards or photos.
- ❑ Topics and aims should be documented so that they can be reviewed together by using e.g. mind maps or interrelationship diagrams.
- ❑ Discussions may also lead to the co-discovery of new aims.
- ❑ Partners need enough time to examine and consider the aims before any decisions or solutions are made.
- ❑ Jointly agreed aims should be presented in a way that is similarly understood by all.



PREPARING THE RESEARCH PLAN

To an increasing degree, international and national financiers appreciate and occasionally require research partnerships with experts-by-experience and citizens who have a stake in the research topic.

Preparing a research plan together

Preparing the research plan should be a joint effort. The plan describes the design and conduct of the research, taking into consideration the aims and conditions of the financier. The research methods are selected and adapted together. If the plan has already been prepared and the authorisations or funding needed to launch the research have already been obtained prior to starting the partnership, a detailed action plan will be made together. This helps ensure that all research partners are on the same page about the research aim and the contents of the research plan.

Reciprocal co-planning places emphasis on agreeing on matters in such a way that the viewpoints of each research partner are heard and given due consideration. When drafting the plan, the team should think about the ways in which each member can participate in conducting the research. The advantage of participatory research partnership is that each partner is different, and different phases of research require different skills and roles. Therefore, it is not necessary for everyone to have the same skill set or participate in every activity.

- ❑ All research partners should share an understanding of the key concepts, purpose, aims, and methods of the research.
- ❑ The research team can attend training on the required methods and instruments, if needed.
- ❑ When describing the inclusion and exclusion criteria for study participants, the skills and diversity of the team should be fully exploited to ensure that the criteria are appropriate and participation based on functioning is enabled.
- ❑ The team's knowledge should be used in order to explain how suitable study participants can be found and invited in, and what the best way to select participants is.
- ❑ The ways of involvement of study participants should be evaluated, and the use of methods supporting meaningful participation should be ensured. From the viewpoint of study participants, it is a good idea to evaluate and develop the meaningfulness of the practical implementation of research, e.g. as regards stress or the time taken up by participation.
- ❑ The research environment should also be taken into consideration, as it can be restrictive or encouraging depending on e.g. the atmosphere, familiarity, language, and culture.
- ❑ Strategic solutions enable the adoption of multiple methods, multiple perspectives, different accessible ways of collecting data, and expedient production of data within the research team.

The knowledge of rehabilitation professionals and rehabilitees is useful e.g. when choosing jointly which methods of action would allow people with variable competences to participate in the research as informants. These include, for example, sign language skills and the ability to use various communication devices and image communication.

When preparing the research plan together, ethical aspects and quality should be considered to ensure the plan meets the criteria for scientific research. Like other types of research, research conducted in a participatory research partnership must abide by the principles of good scientific practice and related ethical guidelines. The necessary documents, authorisations and consents should be reciprocally planned in line with *the guidelines of the Finnish National Board on Research Integrity*, please see *Responsible conduct of research and procedures for handling allegations of misconduct in Finland (PDF)*.

The research team should also review the guidelines issued by the Office of the Data Protection Ombudsman regarding *data security and data protection in scientific research (tietosuoja.fi)*, which need to be taken into account in the research plan. In scientific research, the personal information of participating data providers is protected by the General Data Protection Regulation, which also gives them more control over the processing of their data. The regulations concerning processing and the exceptions thereto are meant to support and promote scientific research activities.

Reciprocal co-planning supports ethical research solutions, especially when it comes down to understanding the viewpoint of the study participants. The research team can prepare clear and easy-to-understand information letters, information sheets and consent forms for people invited to participate in the research. When planned together, the research materials will combine multiple perspectives, which may improve their intelligibility, clarity, and usability. Since people should be able to participate in the research with minimum effort and discomfort, being able to take the study participants' viewpoint into consideration as early as possible during the planning process is very valuable.

Functional methods of collecting data may include various creative methods. For example, methods that combine photos, drawing, and activities may improve the meaningfulness of participation. The use of online resources or technology may further improve the opportunities for participation. Teenagers are not the only ones who regard digital solutions with increasing interest, and the developing AR/VR and XR technology, social media, and chats may be used to collect data. Preparing and reviewing interviews or survey questions in the framework of reciprocal planning and pre-testing helps make the questions easier to understand and more meaningful for the research participants. *The methods and tools for co-development (innokylä.fi)* can be used in the collection and analysis of data.

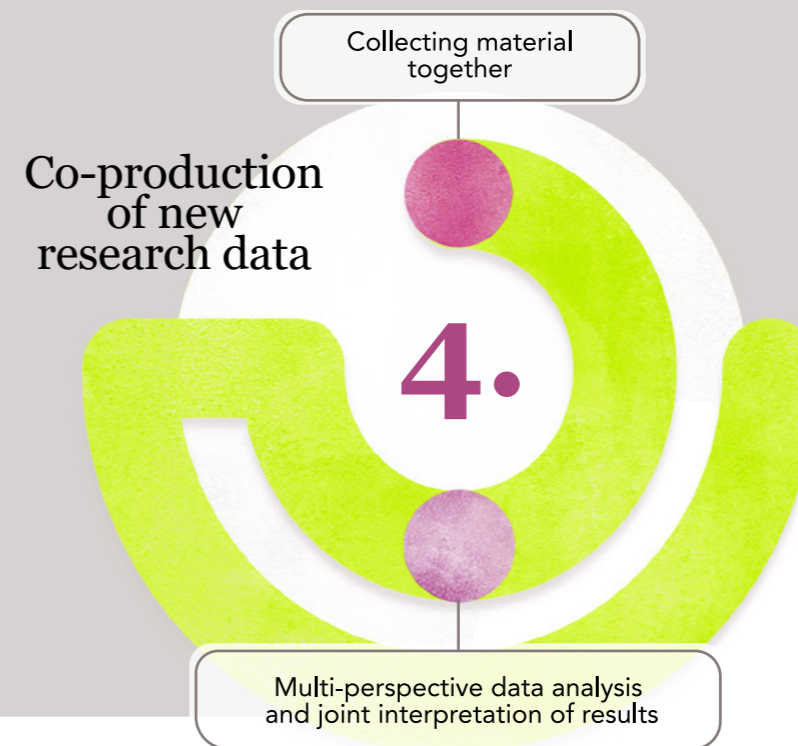


Figure 6. Key factors of co-production of new research data.

Co-production of new research data

Co-production of new research data involves the collection of data together and the analysis and interpretation of data together in a transdisciplinary way (Figure 6).

Collecting material together

Participatory research partnership places emphasis on using multiple methods to collect data, utilisation of functional data collection methods, collaboration between partners and utilising the opportunities of working online.

The members of the research team coach each other and learn together. For example, rehabilitees can share their knowledge and understanding of the best way to proceed with data collection from the viewpoint of study

participants, and which questions are meaningful and easy to understand. Researchers bring to the partnership their knowledge of how to approach data collection from the perspective of research. Pairing up can also be useful in some situations. Interviews are one example of this, as the interviewers can ask questions and supplementary questions from different perspectives.

Discussing the interview experience together may be necessary to process the thoughts and emotions provoked by the situation. If rehabilitee, close one, or professional is hosting a co-development session or acting as a peer interviewer in an interview study, it is particularly important to consider how the interviewer's background will influence the interview and the analysis of the data.

Multi-perspective data analysis and joint interpretation of results

In a participatory research partnership, several members of the research team participate in the data analysis, bringing multiple viewpoints to the table. The different perspectives of the

research partners may help identify meaningful contents in the data that are important to the analysis questions and might otherwise escape notice. When analysing the data, the team can make use of e.g. joint workshops and multiple analysis rounds, which will allow them to discover and verbalise different interpretations of the data together.

Participatory research partnership focuses on the practical significance of the results when interpreting them. The results can also be reviewed

in open forums, which makes it possible to evaluate, deepen and expand the practical significance of the results. A multi-perspective approach allows for a more in-depth interpretation, which increases the reliability of the research.

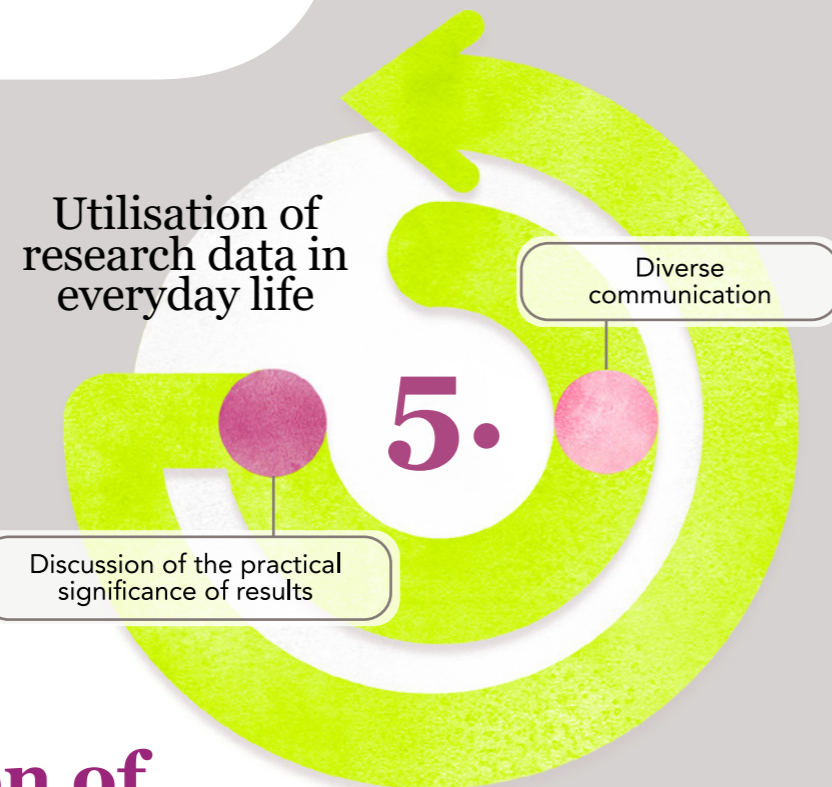


Figure 7. Key factors of utilising research data in everyday life.

Utilisation of research data in everyday life

Utilisation of research data in everyday life includes diverse communication and discussion on the practical significance of the results (Figure 7).

Diverse communication

Communication in a research partnership seeks dialogue and favours networking. A communication plan is prepared during the planning

process to ensure that all relevant parties are taken into account, and that the best publication channels and forms for the target audience are selected. The plan describes who the communication is targeted at, and the roles and responsibilities of the research team. A decision on the authors of the publications should be reached as early as possible during the planning process. The strengths, skills and networks of the research team members are used to diversify communications.

Transparent and consistent documentation of the jointly executed research process and inference chain is crucially important for the reliability of the research. When reporting results, attention should be paid to clarity and comprehensibility to ensure accessibility for different parties and data users. The accessibility of communications can be ensured by using different types and channels of communication, or signs and text equivalents if needed.

When presenting and sharing results, things that are meaningful to the rehabilitees and their close ones in everyday life should be highlighted and used to link the results to rehabilitation practices. The poignancy of the results to different stakeholders can be ensured when the research partner is familiar with the language, concepts and needs of the target group and addresses them in the communications. Visibility can be ensured by using multiple communication networks and channels



INSTRUCTIONS AND TOOLS FOR REPORTING

BMJ, a publication channel, has provided pointers about things that should be described in the report of a partnership-based study involving rehabilitees and their families: [*Reporting patient and public involvement in research \(PDF\)*](#).

Another useful tool for reporting research partnerships is the [*GRIPP2 tool \(in English, PDF\)*](#) (GRIPP2-LF and GRIPP2-SF forms, Staniszewska et al. 2017). GRIPP2-SF is shorter and can be used even if the partnership played a minor role in the research activities. GRIPP2-LF is longer and a better choice for significant research partnerships. The long form can also be used as a checklist during the planning and evaluation process. A related [*article and the forms are available on the website of BMJ*](#).

Peer-reviewed studies that allow stakeholders to participate in all phases of the research are published in the journal [*Research Involvement and Engagement*](#). The journal is co-produced by all key interest groups, including rehabilitees, researchers, decision-makers, and service users.



DIVERSE CHANNELS AND FORMS OF COMMUNICATION

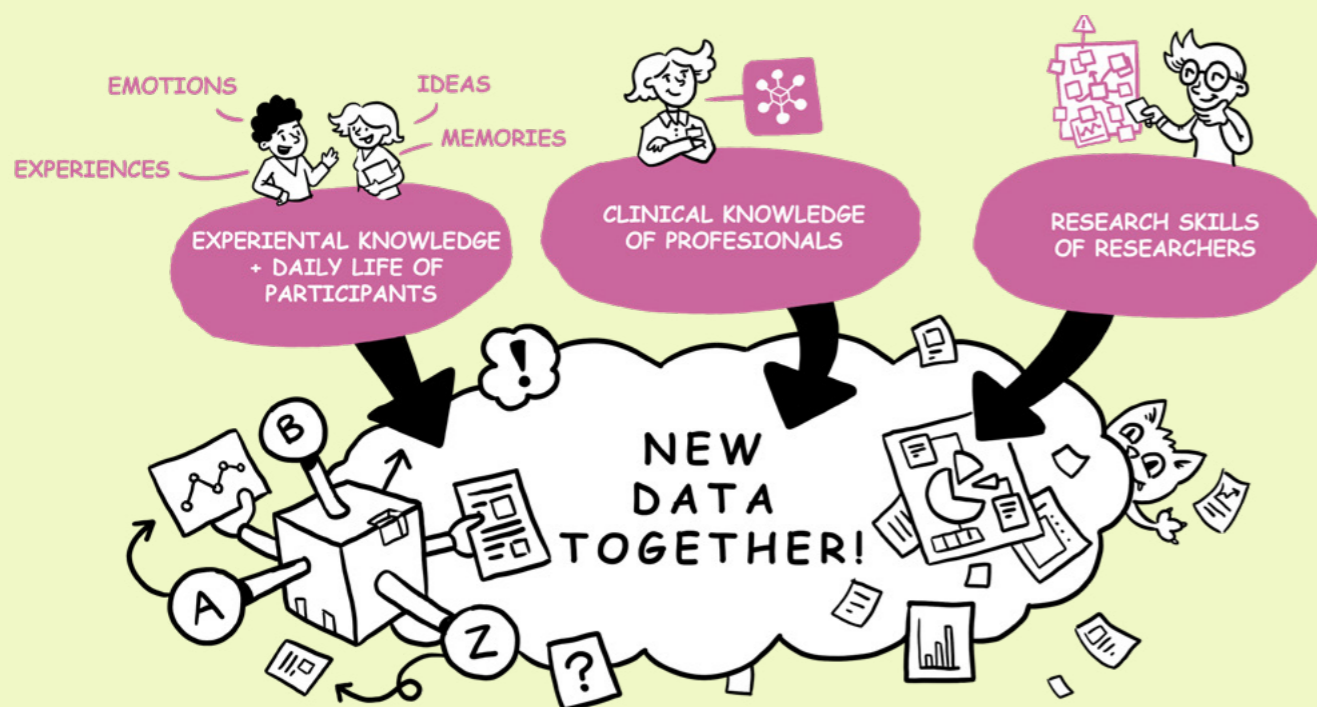
- communicating with target groups and networks via different social media platforms and e-mail
- online blogs, posts on websites and articles in online publications
- peer-reviewed publications
- articles and stories in society publications, professional journals, newspapers, periodicals, and websites
- presentations in seminars, webinars, discussions, and public events
- training sessions and workshops
- panel discussions and events targeted at decision-makers
- posters, videos, infographics, easy language summaries, podcasts, cartoons, story-based or image-based messages, policy briefs



Research partners can co-author research articles and other publications on research results and their significance. Other team members can be reviewers or commentators depending on the situation and needs. Research partners can present results together at events and conferences. Rehabilitees and their close ones can also serve as peer communicators of new information. New creative and accessible ways of presenting results, such as videos or cartoons, can be jointly developed.

CRYSTALLISING AND VISUALISING DATA

Live illustration was ordered for the developmental training process on participatory research partnership. It helped visualise the dialogue on the requirements and benefits of partnership that took place during co-development (two images as examples). Live illustration can be used to communicate the results of co-development efforts.



Tussitaikurit



COMMUNICATION AND REPORTING

- ❑ A communication plan should be prepared to direct communication and reporting.
- ❑ The team members' roles and responsibilities in communication should be defined and agreed upon based on their strengths and skills.
- ❑ The target groups of communication should be defined.
- ❑ The channels and forms of publication need to suit the target groups.
- ❑ The accessibility of communication should be taken into account (see e.g. [saavutettavasti.fi](#)).
- ❑ The research process and inference chain should be transparently and consistently documented.
- ❑ The presentation of the research results should be jointly planned and evaluated by research partners to ensure comprehensibility.
- ❑ Things meaningful to rehabilitees in everyday life and related rehabilitation practices should be brought up when sharing and presenting results.

research partners should jointly determine which results will be shared, by whom, where, and in which format. Understanding of the content, significance, and implementation of the results in everyday rehabilitation should be built together.

Discourse and the possibility to contemplate the practical significance of the results from the viewpoint of the individual, community and society promote the implementation of the results. There should be extensive discourse between the users of the research results and the results should be examined with a critical eye. The opportunity to ask questions and discuss promotes the creation of a shared understanding and opens up new perspectives to the significance of the results and new research needs. How the results apply to each rehabilitee's individual situation should also be discussed.

Applying research results to rehabilitation practices and individual situations always requires a critical appraisal of the results and their applicability. Engaging in such contemplative dialogue is possible e.g. in work communities, network meetings, or other events. In addition to dialogue, co-development methods can be applied to allow all stakeholders to participate. Co-development can also facilitate the planning of concrete changes in rehabilitation practices based on the results.

Applying the results to everyday life can be made easier e.g. by:

- training as a mentor or a change agent
- arranging extensive training events in organisations that bring together different kinds of actors
- collaboration with universities, i.e. making collaborative reflection on research results a part of courses in the framework of basic studies, continuing education and open university studies.

Discussion of the practical significance of results

A collaborative approach to the dissemination and instillation of research data promotes the use of data in everyday rehabilitation in a way that helps improve shared understanding. The



CO-DEVELOPMENT OF DIVERSE RESEARCH COMMUNICATIONS

To ensure maximum usefulness and usability of research results, team members can co-develop types of research communication e.g. by discussing good publication and dissemination methods that already exist, and others that may be needed in the future. Co-development may include e.g. the following steps:

1. Independent work (___ min): Recall or come up with a good method for disseminating or publishing results. You can add your example on the electronic platform as an image, link, and/or text.
2. Work in small groups (___ min): Discuss and brainstorm how the research results should be published and disseminated to ensure easy adoption into use. Add notes about your discussion on the electronic platform. Summarise a few key points to bring to the joint discussion.
3. Joint discussion and a summary of the results (___ min).

Developmental and ethical evaluation

A developmental evaluation is a collaborative learning process focusing on the future. The aim of a developmental evaluation is to promote the dissemination of information and the shaping of a shared understanding, and to help us learn. The purpose of the evaluation is to produce data that can be used to develop the participatory research partnership in the framework of each study.

A developmental evaluation produces new collective knowledge that can be used to develop research activities and improve the quality of research. A developmental evaluation promotes the use of evaluation results and empowers partners to seek constructive solutions. It helps us strategise how things could be done better in the future instead of getting stuck in the past or focusing on the problems of the present.

In scientific research, the results achieved and the influencing factors are often evaluated after the research process. A developmental evaluation touches on every phase of the partnership and supports the achievement of goals set for the research. As the evaluation is done jointly, it helps develop the participatory research partnership in every phase of the research process, and the benefits are easily identifiable.

Purpose of the evaluation of the participatory research partnership:

- to predict and guide the future phases and progress of the project
- to describe resources that already exist and those that are needed

Developmental evaluation is well suited for participatory research partnership, because it involves continuous development based on interaction and trust and improves shared understanding of the subject.

// We need to strategise together how things could be done better in the future

- to promote the usability and coverage of networks
- to promote the implementation of different methods to achieve goals
- to promote the usability and development of methods during the process
- to identify benefits and disadvantages from the viewpoints of the individual, research team and research
- to identify promoting and inhibitory factors
- to identify the participation of partners, and factors influencing their involvement
- to improve risk management
- to improve the quality of research

The methods used in the developmental evaluation are planned jointly by the research team in line with the evaluation targets and questions. The evaluation is multidimensional and typically involves a flexible multi-method approach. The developmental evaluation moves along with and anticipates the phases of the participatory research partnership.

In a participatory research partnership, special attention is paid to ethical aspects in all phases of the research process. Ethical evaluation is constantly present and linked to the developmental evaluation of the participatory research partnership.

Like collaboration, developmental and ethical evaluation is cross-cutting and necessary at all stages of a participatory research partnership process.

Examples of questions to ask during a developmental and ethical evaluation:

1. How can we ensure that all members of the research team are respected and heard equally?
2. How can we enable meaningful participation and engagement of all research partners?
3. How can we create and maintain a sense of community and reciprocity?
4. How can we ensure that decisions are based on dialogue and consideration and that guidelines on research ethics are followed?
5. How can we summarise the results of co-development efforts in such a way that all partners can understand and accept them?
6. How can we ensure accessible real-time communications within the research team and with other parties?

Building trust between the research partners is of key importance if the evaluation is to be performed in a constructive, honest, and open manner. The evaluation is a joint effort but performing an anonymous one should also be an option if needed. The implementation of the evaluation and the tools used should be jointly agreed upon.

It is important to emphasise that the evaluation focuses on the research partnership, not on anyone's individual performance. However, in addition to the joint evaluation, team members should be given the opportunity for individual discussions and feedback. The evaluation results should be documented in a way that is accessible to all partners, which allows them to be used for the development and orientation of the participatory research partnership. •

4

Developing the model from the research perspective

A multi-phase development process

The evidence-informed Participatory Research Partnership model was co-developed in multiple phases (Table 1). The first phase was carried out in 2019 and involved a descriptive literature review of international studies focusing on research partnerships, research participation and collaborative research. The material comprised 17 articles, which provided information about the course of a research process carried out as partners, and the ways and good practices of working in such a partnership. The review described how a research partnership can be established with rehabilitees – both children and adults – and their close ones, and experts and researchers representing different fields and parties. The information obtained from the review was used to prepare the first preliminary version of the Participatory Research Partnership model.

// **The review describes how a research partnership can be realised in rehabilitation research**

Process and results of the literature review:

Lehtonen, Krista & Vänskä, Nea & Helenius, Sari & Harra, Toini & Sipari, Salla 2020. *Participatory co-research in applied research in rehabilitation - a literature review. Kuntoutus 43 (3). 6–19. (journal.fi)*

Results/input used in the development of the model	A description of the participants/collection of data	Phases of the development process
A. International literature review	<ul style="list-style-type: none"> Articles n=17, including reviews n=3 and original articles n=14 	Version 1: Global perspective
B. Co-development events (n=5)	<ul style="list-style-type: none"> Attended by over 100 health care, social work and education professionals, teachers, students, researchers and developers 	Version 2: National perspective
C. Studies (theses) from the Master's Degree Programme in Rehabilitation (n=2)	<p>Thesis 1 (Kaipainen 2020)</p> <ul style="list-style-type: none"> Theme interviews of rehabilitees: 6 participants Group interview of rehabilitation professionals 9 participants Co-development project by a development network: 12 participants <p>Thesis 2 (Nurmi 2021)</p> <ul style="list-style-type: none"> A literature review of 24 studies 	
D. Round table discussion	<ul style="list-style-type: none"> Experienced rehabilitation researchers, developers, and experts, 5 participants 	
E. Developmental training process	<ul style="list-style-type: none"> 50 participants (rehabilitees, their families and multidisciplinary professionals, researchers, developers, teachers) 7 remote training sessions/events 6 co-development projects 80 development tasks 	Version 3: Practical tests and developmental evaluation

Table 1. Phases of the participatory research partnership development process.

/// The Participatory Research Partnership model was enriched by its practical application

The model was revised in five co-development events in 2020. Over a hundred rehabilitation experts attended, including rehabilitees, professionals, trainers, students, developers, researchers, and system-level decision-makers. This helped fine-tune the model for better compatibility with Finnish rehabilitation practices. Co-development was a useful tool in finding answers e.g. for the following questions:

- Which things pave the way to success in a participatory research partnership?
- How can potential challenges in a participatory research partnership be turned into victories?
- What is participatory research partnership needed for?

The co-produced answers were documented as summaries, which allowed the participants to check and confirm them. These were then used in the process of preparing the second version of the model.

Useful content for developing the model was also provided by studies carried out in the Master's Degree Programme in Rehabilitation. *In the study by Kaipainen (2020) (Theseus)*, rehabilitees and professionals developed practices to support co-research in applied rehabilitation research. *The study by Nurmi (2021) (Theseus)* described factors that support or prevent co-development based on a Finnish literature review.

The model was also presented to experienced rehabilitation developers, researchers, and decision-makers in a round table discussion. This

presentation launched the co-development process around the following questions:

- How can we build participatory research partnership in applied rehabilitation research?
- What kind of know-how does a participatory research partnership require?

The round table discussion was documented, and the results were used in the model's development.

A developmental training process on the second version of the model was organised in the spring of 2021. The training process brought together 50 rehabilitation experts throughout Finland, including rehabilitees, professionals, trainers, students, developers, and researchers who shared an interest in the model and its development. The training was worth 5 credits and included five training sessions and four development tasks. The training took place online in Teams.

The learning goals in the developmental training process were:

- to produce shared definitions and understanding
- to paint a bigger picture of the situation
- to create a common working culture
- to apply functional methods and good practices
- to utilise developmental evaluation in the production of new knowledge

The participants got to know the model but also applied it directly into practice by performing development tasks linked to their operating environments. The development tasks and co-development carried out during the training sessions (see the example "Visualising the future to form a shared idea") provided useful evaluation data on the model. The input was used in the development of the third and final version of the Participatory Research Partnership model described in this publication.

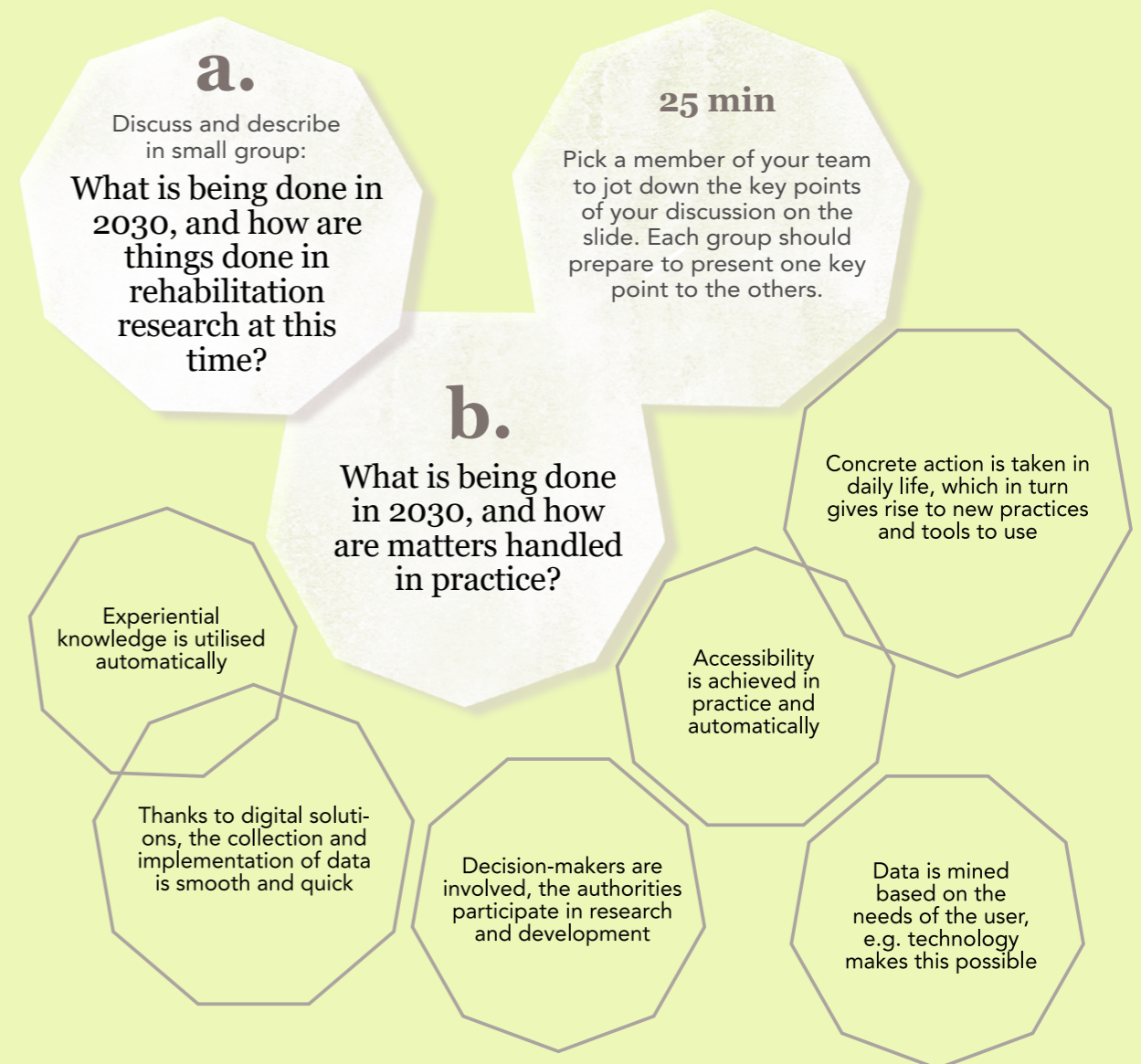


VISUALISING THE FUTURE TO FORM A SHARED IDEA

In the participatory research partnership development process, a future visualisation exercise was used in the first session of developmental training. The goal was to come up with a solid, shared idea of what a participatory research partnership means in practice and how it might change existing research practices.

The exercise was easy to do remotely online, and it produced a multi-perspective overall picture of the topic. Future visualisation was carried out in nine small groups, and each group prepared a slide presenting their results. An example of the results of one group is given in the image:

It is 2030, and the participatory research partnership model has been adopted into use.

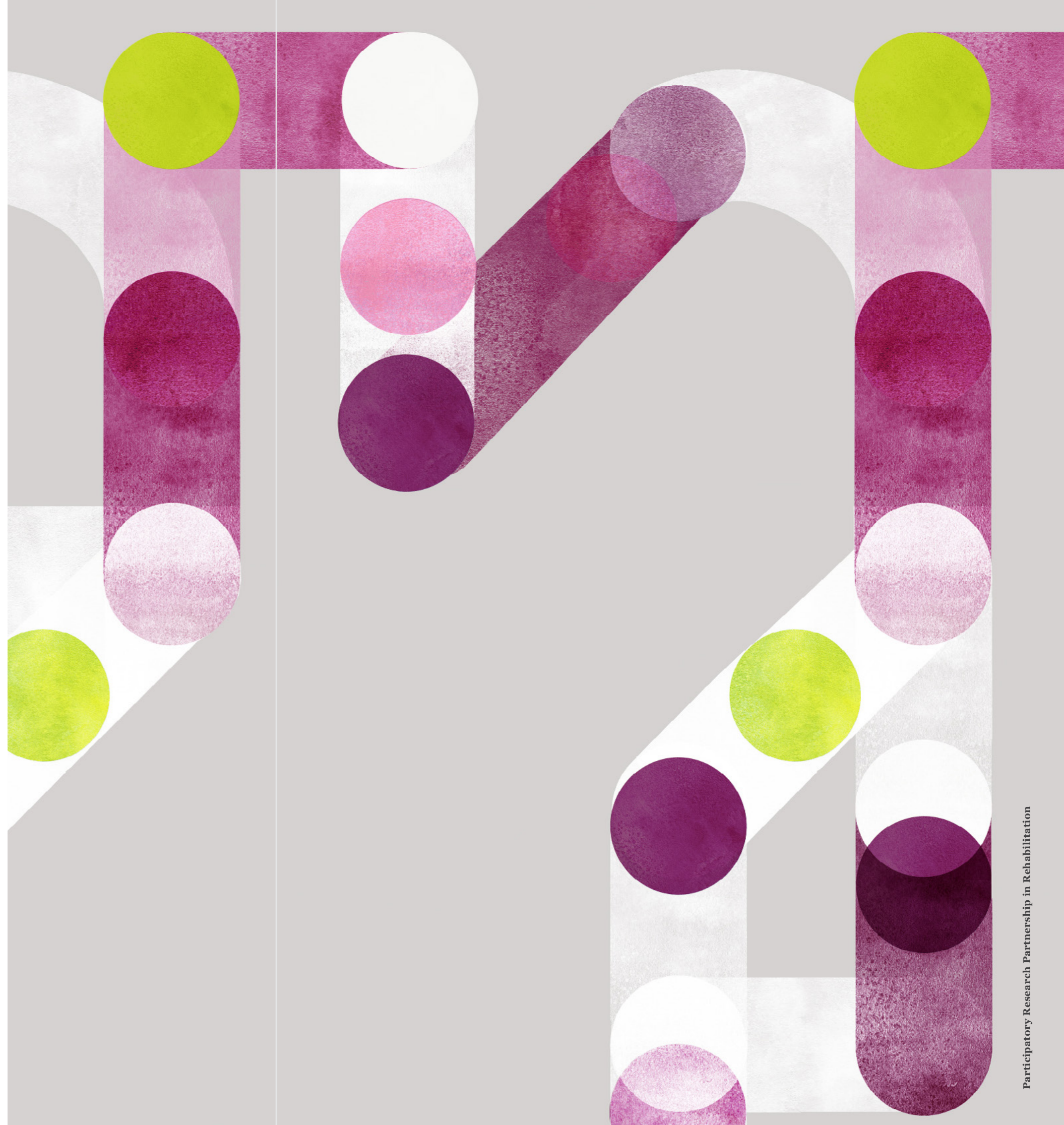


A model that constantly develops through the contribution of its users

A participatory research partnership is not a method that is used in the exact same way in every situation. It involves the creation of a new kind of research culture, offering a knowledge base founded on scientific development and a process model that can be applied in various research contexts. The Participatory Research Partnership model is meant to be constantly re-shaped and developed through the contribution of its users in different situations.

Participatory research partnership emphasises in a new way the importance of the preparatory phase of scientific research and the conscious building of a reciprocal and equal partnership. This idea can also be applied to rehabilitation practices, when the goal is to form a developmental partnership involving professionals and rehabilitees. A brilliant example of this is *the Charter of Janakkala Family Centre (in Finnish)*. Involving rehabilitees as partners in research and development in the framework of both rehabilitation practice and scientific research supports the empowerment of rehabilitees and their active role as contributors to a bright future.

Participatory research partnership promotes ethically sustainable research through multi-perspective and interactive collaboration. Mutual aims agreed upon by various actors involved in the research, a common goal, a culture of dialogue based on trust, and methods and structures enabling collaboration ensure the quality of research activities. Participatory research partnership supports the effectiveness of research when research activities and their results are meaningful and can be used in everyday life. •



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Authors and partner developers

Author introduction

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Salla has researched and developed good rehabilitation practices with a special focus on collaborative activities and co-development.

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Templates for the model

Templates - instructions -

Six templates have been prepared to support the implementation and application of the Participatory Research Partnership model. The numbering of the templates reflects the recommended order of use, with the exception of the sixth template, which can be used throughout the participatory research partnership. The templates can be used alone or in parallel, meaning that following the numerical order is not mandatory.

The first template helps the team members get attuned to the research partnership by getting to know each other and describing the research team. The second template helps identify the individual agency of research partners and build co-agency in the research team. The third template helps define common practices in the research partnership. The research partners can use the fourth template to agree on tasks and responsibilities. The fifth template promotes reciprocal planning of the research. The sixth template is a tool for performing a developmental evaluation of the research partnership.

Templates for the model

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

Template 1

Getting to know your research partners

When starting the research partnership, it is important for the members of the research team to attune themselves to the partnership by getting to know each other and forming an overall picture of the team.

The template has two parts. You can use just one part, if needed. The template includes some example questions. All descriptions are valuable, but it is not necessary to answer all the questions. In addition to written descriptions, you can also add photos, videos, drawings or audio recordings to the template.

- A. In the first part (A) the research partners prepare a free-form description of themselves, and the descriptions are shared with the team.
- B. The second part (B) involves forming an overall picture of the research team. The answers from the first part can be used as reference.

Using your imagination and creativity is encouraged!



The results obtained from this template (1) can be useful when describing agency in the research partnership in template 2.



Template 1

A Description of you

Participant

What kind of things are meaningful to you?

!
Add e.g. an image, video link, drawing or audio recording about yourself, your everyday life or a topic that interests you.

What would you like to tell the research team about yourself in particular?

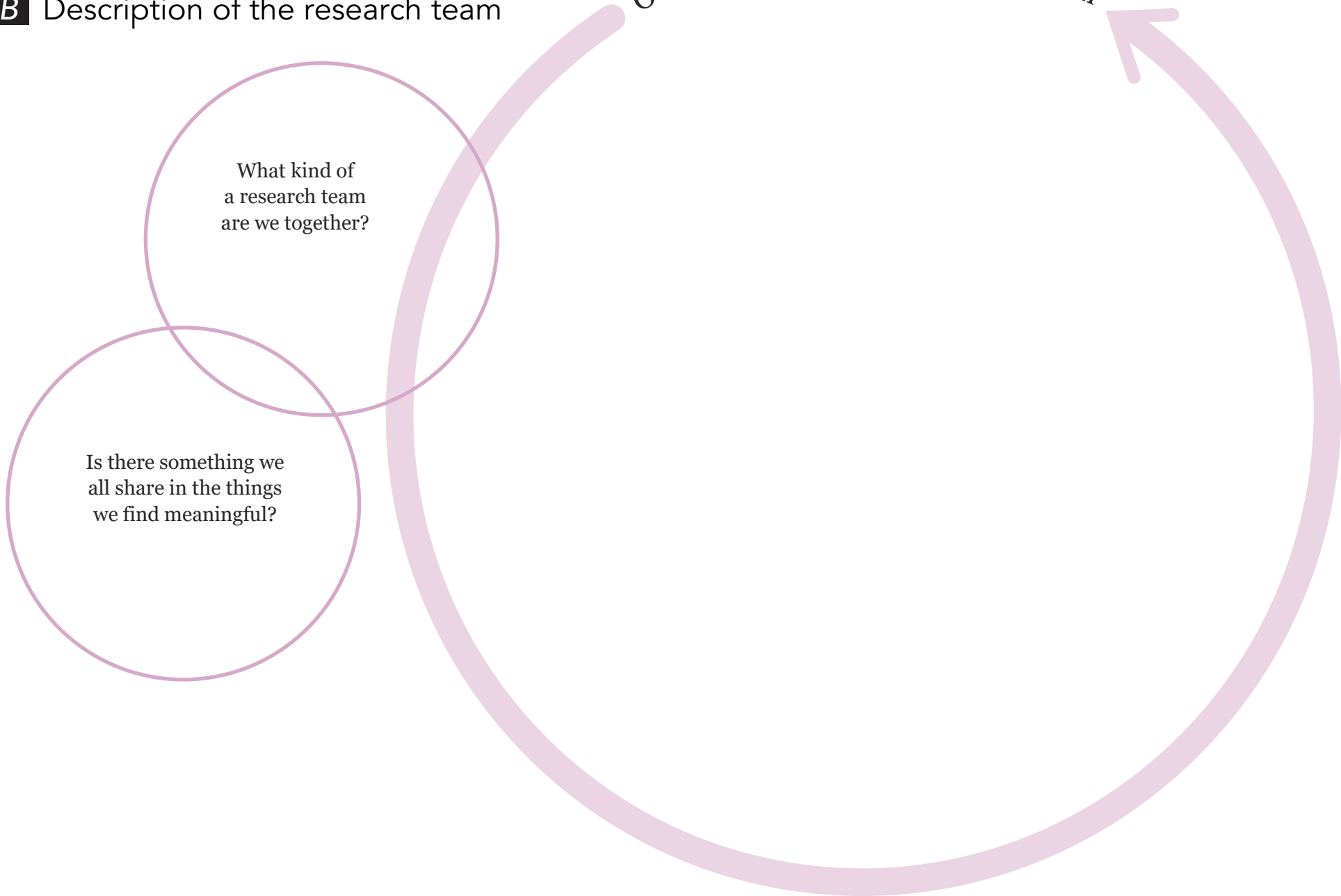
What motivates you to take part in the research partnership?



A

Template 1

B Description of the research team





B

Template 2

Agency in the research partnership

Interest in the joint research, skills, resources, learning needs and enabling participation are the cornerstones of agency when building the research partnership.

The template has two parts. You can use just one part, if needed. The template includes some example questions. All descriptions are valuable, but it is not necessary to answer all the questions. You can also add photos, videos or recordings to the template e.g. by using links.

- A. In the first part (A) each partner thinks about the key aspects of agency that concern them personally in the research partnership. Any questions and concerns can also be listed here.
- B. The second part (B) involves discussion of the cornerstones of co-agency and summarising the shared vision of the research team. The answers from the first part can be used as reference. The name, acronym, identifier or logo of the research team should be placed at the heart of the template. The research team can jointly tackle the questions that came up in part A.



The results obtained from template 1 may be useful when completing this template.

The results obtained from this template (2) may be useful when defining the practices in template 3 and planning the research in template 5.





Template 2

A Personal agency in
the research partnership

Name

What research topic are you interested in? What would you like to explore?

What skills, experience, resources do you have: • in connection with the subject of the study? • in connection with research and development activities?

*Why is the subject you describe important to you?
What emotions does the research evoke in you?*

What do you want to learn, do you need support for: • in connection with the subject of the study? • in connection with research and development activities?

*Which things enable your involvement in the research partnership (e.g. remote meetings, interpreter, training, schedules)?
Which challenges do you think your participation may involve? Any other questions?*



A

Template 2

B Co-agency in the research partnership

Research team

Research topic, general interests:

Group skills and resources:

Defining the significance of the research topic together:

Group learning/support needs:

Prerequisites for participation – things that enable participation:

Questions answered together:



B

Template 3

Defining the practices of the research partnership

The practices of the research partnership are jointly defined by the members of the research team, who deliberate and agree on the purpose and principles of the collaboration and the rules directing the activities. This is the time to hear the thoughts of each research partner, giving space and encouraging everyone to bring their individual expertise to the table – including different, even opposing ideas.

Co-development methods can be used in deliberative judgment. The process of co-deliberation and the jointly made agreements should be described in the template.



The results obtained from template 2 may be useful when completing this template.

The results obtained from this template (3) may be useful when agreeing on tasks in the research partnership in template 4.



Template 3

Research team (participants):

Collaboration practices in the research partnership

A. How is deliberative judgment carried out?

B. What was jointly agreed?

1.
Purpose of the activities:
Why is collaboration important in this specific research? What is the purpose of the activities?
E.g.

- creating a multi-perspective network
- enabling the participation of research partners before preparing a plan

a.

b.

2.
Principles and rules directing the activities:
What is equal and reciprocal interaction like? How does the operating environment promote flexible and meaningful methods of participation? How are decisions made together? How are successes and handled together? What kind of a schedule is used in joint activities?
E.g.

- enabling proactiveness and advance preparation
- ensuring the adequacy of information by different means (images, videos)

a.

b.

Template 3



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Template 4

Agreeing on tasks in the research partnership

The research partners define and jointly agree on the research tasks and related responsibilities to carry out research activities.

The template has two parts. You can use just one part, if needed.

- A. The first part (A) includes a description of partner-specific tasks agreed on. Things related to e.g. the distribution of tasks, schedules, or the meaningful performance of tasks can be jotted down as needed. In participatory research partnership, members of the research team can work in pairs or small groups, for instance.
- B. The second part (B) includes a description of the common tasks of the research team that all team members share.



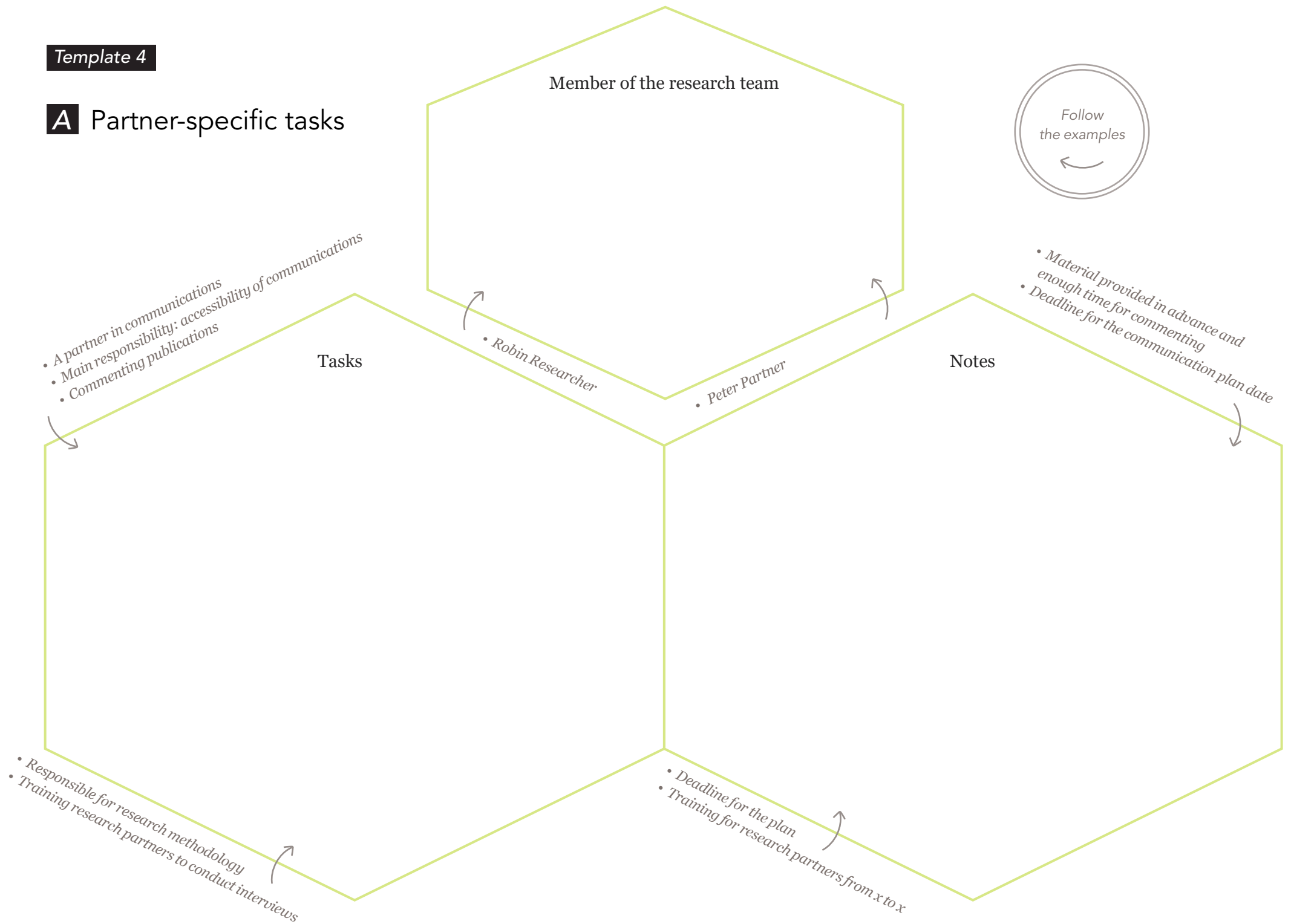
The results obtained from template 3 may be useful when completing this template.

The results obtained from this template (4) may be useful when planning the research in template 5.



Template 4

A Partner-specific tasks





A

Template 4

B Common tasks of the research team

Tasks of the research team

Which are the common tasks of the research team that all team members share?



B

Template 5

Planning in the research partnership

Research is planned reciprocally in the research partnership. This is the time to hear the thoughts of each research partner, giving space and encouraging everyone to bring their individual expertise to the table – including different, even opposing ideas.

The way in which deliberative reasoning is carried out, and the results of the deliberation, should be described in the template. Co-development methods can be used in deliberative reasoning. The template includes the key aspects of research planning divided into steps. You can complete the parts of the template that apply to you and are meaningful for your research.



The results obtained from template 2 may be useful when completing this template.

The results obtained from this template may be useful when preparing a research plan.



Research team (participants):

Preparing a research plan together

A. How is deliberative judgment carried out?

B. What were the results of the deliberation?

<p>1. <i>Narrowing down and specifying the research topic</i></p>	<p>a.</p>	<p>b.</p>
<p>2. <i>Defining the aim of the research</i></p>	<p>a.</p>	<p>b.</p>
<p>3. <i>Key research concepts</i></p>	<p>a.</p>	<p>b.</p>
<p>4. <i>Reviewing the <u>guidelines on research ethics (tenk.fi)</u></i></p>	<p>a.</p>	<p>b.</p>
<p>5. <i>Describing, inviting and informing the data producers</i></p>	<p>a.</p>	<p>b.</p>
<p>6. <i>Forms of participation of study informants and evaluating the burden and benefits of participation</i></p>	<p>a.</p>	<p>b.</p>



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Preparing a research plan together	A. How is deliberative carried out?	B. What were the results of the deliberation?
7. Study design and conduct	a.	b.
8. Selecting the methods and tools for the collection and analysis of data, and skills and training required for these as necessary	a.	b.
9. Using methods that promote participation in the collection and analysis of data, interpretation of results and communications	a.	b.
10. Research environment (e.g. atmosphere, values, familiarity, language, culture, and other characteristics)	a.	b.
11. Research schedule	a.	b.



Template 6

Developmental evaluation of the research partnership

A developmental evaluation can be used to predict, direct and develop the participatory research partnership throughout the research process. The evaluation improves shared understanding of the subject. The template emphasises the identification of factors that promote the research partnership, benefits of the research partnership, and new and unexpected issues. This helps direct the activities in line with the aims.

The template includes the evaluation topics and some examples of evaluation questions. These progress alongside the different phases of the research partnership. The methods, materials, and results of the evaluation should be described in the template.

You should approach the evaluation from a positive viewpoint by considering which things promote the research partnership, and what kind of benefits you are getting out of the research partnership. The example questions are anticipatory in nature and can also be changed to past tense, in which case they can be used to evaluate activities that have already taken place.



This template (6) can be used in all phases of the participatory research partnership. The results obtained from other templates may be useful when completing this template.

Template 6

Phase 1 Starting the research partnership

Object of evaluation	Examples of evaluation questions	A. Evaluation methods and materials	B. Evaluation results
1. Spark for partnership	<ul style="list-style-type: none"> How do you identify the need for participatory research partnership? Why is participatory research partnership needed? 	a.	b.
2. Invitation to partnership	<ul style="list-style-type: none"> How do you form a multi-perspective and diverse research team? 	a.	b.
3. Getting attuned to partnership	<ul style="list-style-type: none"> How do you create an atmosphere of openness and safety, and a sense of communality and solidarity? 	a.	b.
4. Resources for partnership	<ul style="list-style-type: none"> Which resources are available, and what is still needed? How are the resources used? 	a.	b.
5. Other, please specify	<ul style="list-style-type: none"> How are unexpected issues solved? 	a.	b.



Phase 1

Template 6

Phase 2 Building a research team

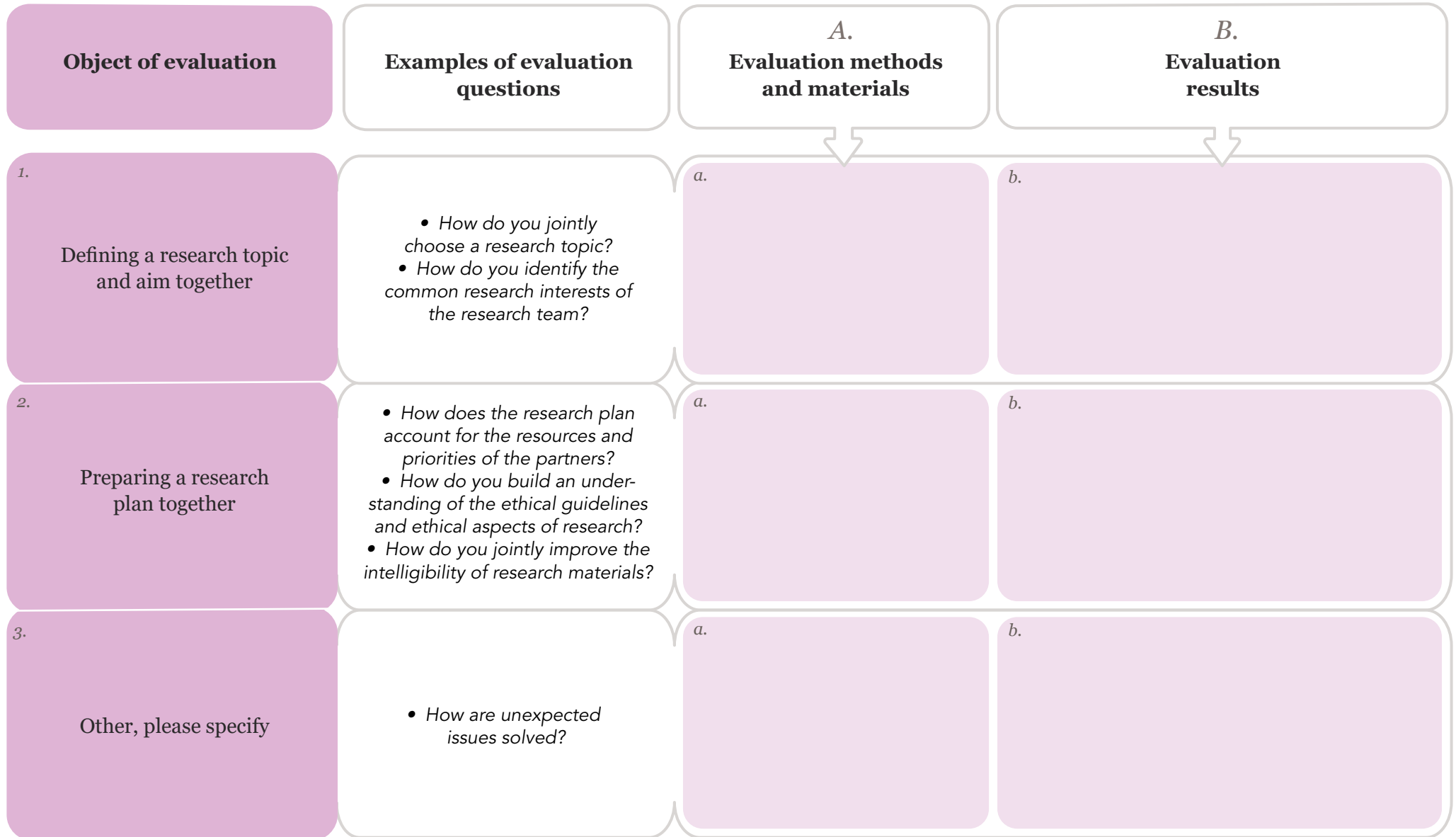
Object of evaluation	Examples of evaluation questions	A. Evaluation methods and materials	B. Evaluation results
1. Agreeing on the practicalities of working together	<ul style="list-style-type: none"> • What is mutual respect like? • What kind of rules are needed for joint activities? 	a.	b.
2. Promoting equal participation	<ul style="list-style-type: none"> • How do you make sure that everyone is able to participate? 	a.	b.
3. Co-development of partnership goals and missions	<ul style="list-style-type: none"> • How do you jointly determine the purpose and goal of the partnership? 	a.	b.
4. Identifying collective skills and learning needs	<ul style="list-style-type: none"> • Which skills do the members of the research team have, and which new skills are needed? • What kind of training is needed, and how is it planned? 	a.	b.
5. Other, please specify	<ul style="list-style-type: none"> • How are unexpected issues solved? 	a.	b.



Phase 2

Template 6

Phase 3 Reciprocal co-planning of research

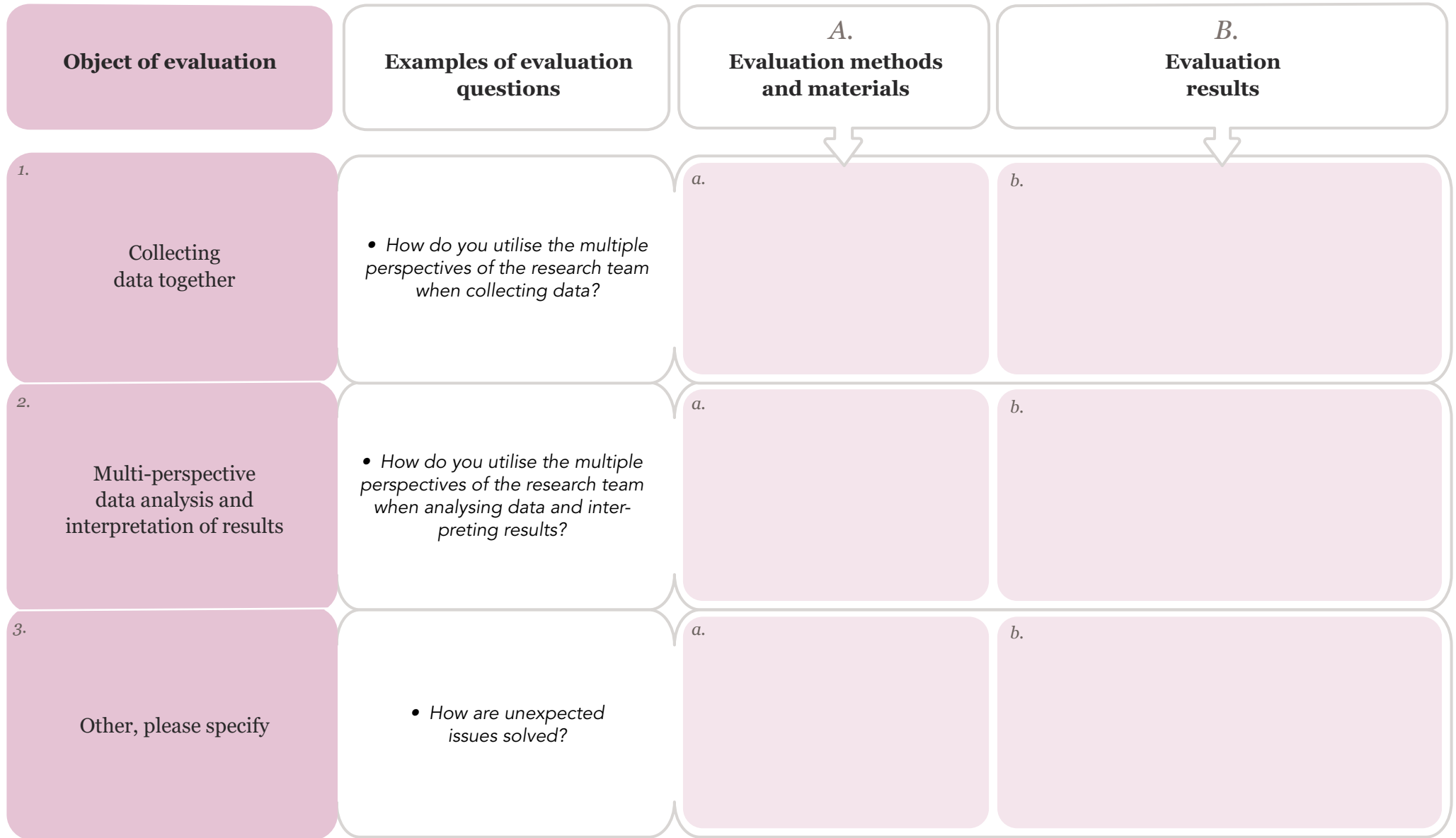




Phase 3

Template 6

Phase 4 Co-production of research data





Phase 4

Template 6

Phase 5 Utilisation of research data in everyday life

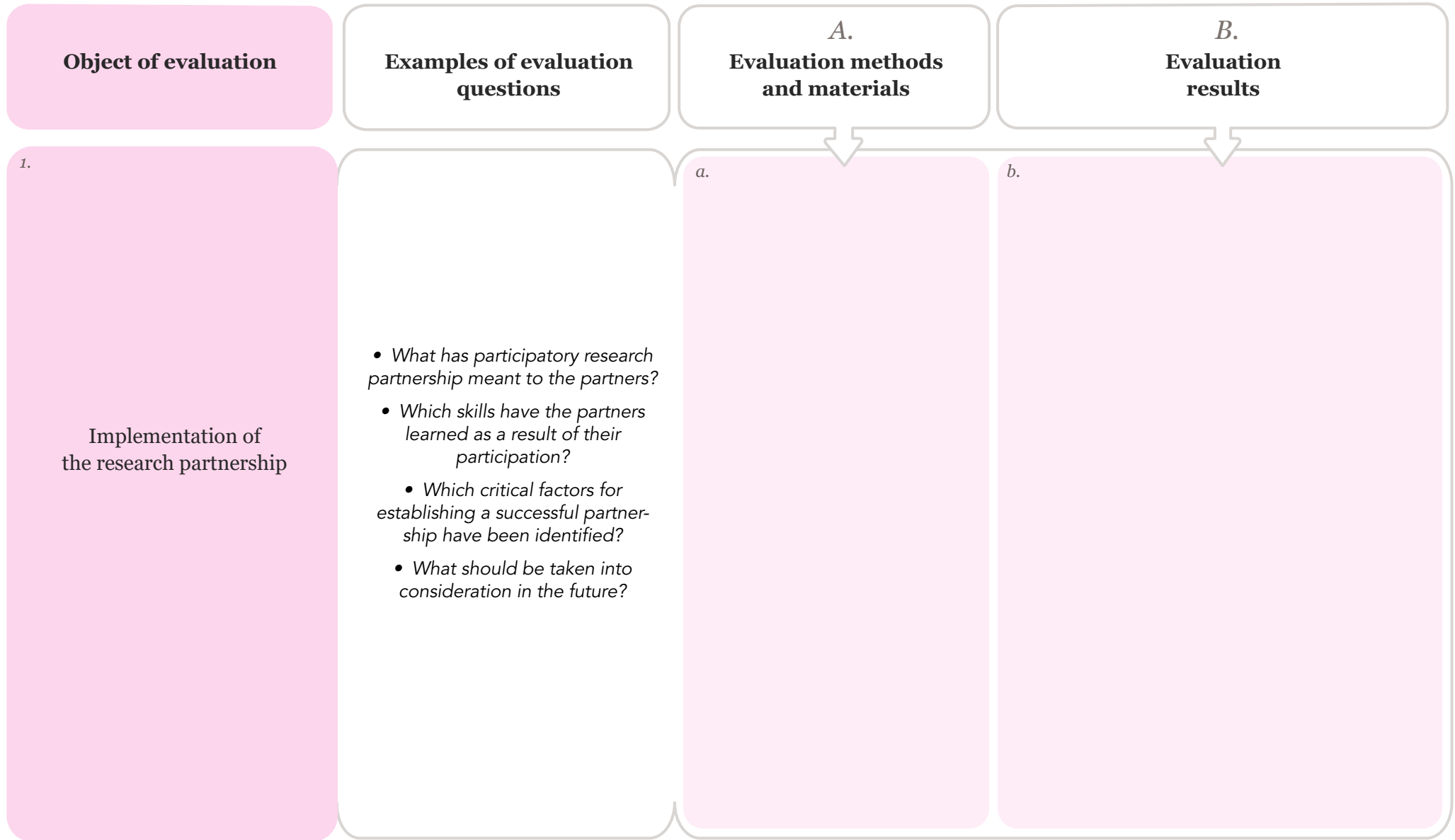
Object of evaluation	Examples of evaluation questions	A. Evaluation methods and materials	B. Evaluation results
1. Diverse communication	<ul style="list-style-type: none">• How to utilise the diversity of the research team in communication?• How to strengthen the attractiveness and accessibility of communication?	a.	b.
2. Discussion of the practical significance of results	<ul style="list-style-type: none">• How do you engage in multi-perspective dialogue with users of the research results?• How do you promote the application of results in everyday life?• What kind of methods of action and communication methods and channels are needed?	a.	b.
3. Other, please specify	<ul style="list-style-type: none">• How are unexpected issues solved?	a.	b.



Phase 5

Template 6

At the end of the research process, you can evaluate the following:





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The importance of utilising research-based knowledge increases with every leap of technological advancement, service system reform and unexpected upheaval. This rings particularly true in the everyday setting. Collaboration that allows stakeholders and citizens to actively participate in the rehabilitation research process is becoming a crucially important approach. In a collaborative research team, all members are seen as equal and reciprocal partners.

This publication presents the idea, premise and development process of the Participatory Research Partnership model. The model describes collaboration in every phase of the research process, including developmental and ethical evaluation. In this model, research partners may be rehabilitation professionals, rehabilitees and their family members, or other actors whom the research topic concerns in some way.

The model can be applied to a variety of approaches and methods of jointly conducted research. It is targeted at building a brighter future together and improving the relevance and accessibility of research data to help promote well-being, work capacity and functional capacity. •



PARTICIPATORY
RESEARCH
PARTNERSHIP

