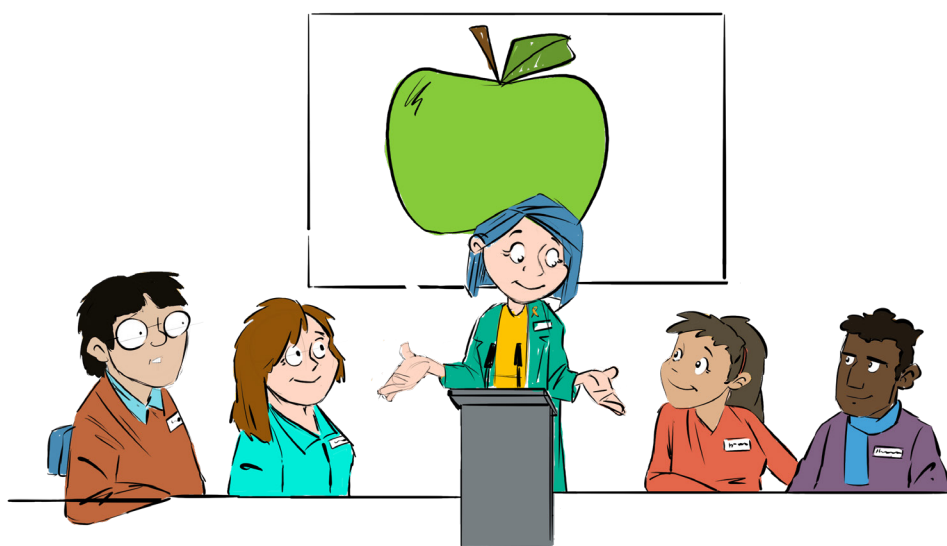# BRIDGING THE GAP

RESEARCHING TOGETHER

**Workshop for Serious
Involvement of Patients
in Research and Development**

Moderator Edition

Caution: practical guide
to joyful research ahead!

Foreword

Hello!

My name is Claire and I have a request.
I would like people to get a better idea of what it is like to bite into a **sour apple.**
Now many readers are probably wondering:
What is she getting at?

Well, the apple is my metaphor for cancer. I've survived it.
And my path to recovery has made me a real **expert**:
I know all about my particular sour apple.
Especially how it tastes.

> Each apple tastes different!

This leads me to the **vision** that my research team and I have:
To engage the public and patients in research. And to improve it by asking specific research questions and thereby making these people the main focus - the public and patients like me.

What does this have to do with the apple? Well, there are methods to measure, analyze and treat an apple. And there are experts who work on it with a lot of **know-how and enthusiasm**. Some people have already guessed it: Researchers working in the medical field, psychology, nursing, social work and many other fields.

Now we get to the core of the matter (and the purpose of this document):
In order to develop **effective diagnostic methods and therapies**, we not only need to take measurements, analytics and treatment into consideration, but also the experience that patients have gained. Because only treatments can really describe how the apple tastes. It is therefore a matter of involving patients in research, right from the start. This is also the focus of the **workshop** to which you were invited to. It serves as a tool that enables patients and research groups to work together on **developing highly relevant research questions**. Scientific questions that include us patients and our relatives from the very beginning and take our knowledge and experience seriously. Based on these, **project plans** are being created as well as implemented.

This applies to all areas in which research is happening! Like a jigsaw puzzle, we have to take all the expertise relating to the body, the mind and the social sphere to put equally into account in order to obtain an integrated picture at the end and to meet all the needs. A holistic, interdisciplinary approach according to the biopsychosocial model is therefore necessary. The same approach should be used when selecting experts.

> **In this workshop we address this specific topic:**

> Remember to provide participants with information on the workshop topic. This can be done through videos, literature or websites. It is best to send this information along with the lab book via email.

Foreword

With this document it will definitely work!
It is a **step-by-step** guide for the workshop moderators and contains lots of practical information: From preparation to implementation to evaluation and documentation. I myself also show up here and there to provide useful tips for participatory research.

A basic requirement for a good collaboration is that all participants, despite their diverse backgrounds, can participate on an **equal** footing. Only this way can the goal be achieved: Bridging the Gap! In other words, **building a bridge** between patients and researchers. Because we are all working towards the same goal: We want to understand the apple in all its facets. We also want to know how it tastes. Because we all want to **improve research and care**.

Enjoy the workshop!

Claire,
Patient Expert

You must have a good example for your participant, how PPIE was used in your field!

Content

SPACE FOR THOUHGTS

There will be many new impressions and thoughts in this workshop, which are best stored in this thought space. Have fun while filling it!

Intro

Why Patient and Public Involvement & Engagement (PPIE)?

Research without patients can be compared to a jigsaw puzzle in which one piece is missing. You can view and analyze many individual pieces, but without the missing piece, the overall picture remains incomplete - there is no certainty that all the connections have been understood. It is therefore an encouraging improvement that the **involvement of patients** in clinical research is gaining in importance.
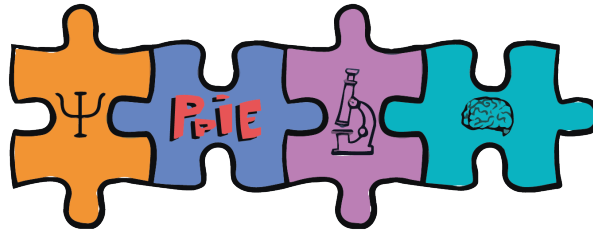
Those directly affected bring the value of lived experience with treatment methods and their side effects. Or - to stick with the metaphor of the apple - they don't just know what the apple looks like, but also what it tastes like. For too long this knowledge has not been considered enough in practice, which not only leads to frustration, but also diminishes the **validity of studies and thereby the quality**. And with it the quality of the treatment approaches being researched.

The answer to this discrepancy is called "**Patient and Public Involvement & Engagement**", or PPIE for short. Sounds bulky, but it's a minor revolution: it means that research and development in the health sector are carried out together WITH or even BY patients and representatives of the public, not ABOUT or FOR them. PPIE stands for a voice and active participation in research and development.

- **PPIE** goes beyond the most common forms of participation to date, which are mainly based on questionnaires, focus groups and interviews.

- In PPIE, patients are directly and **actively involved in research processes** from the very beginning: From phrasing the research question, to applying for funding, to to the collection and analysis of the data gathered.

- Thanks to the expanded, multidisciplinary approach, the research and the projects profited from **better research quality**.

- They are **more effective** overall because the needs of patients and their valuable experience are taken into account right from the start.

In other words, for research groups, serious patient involvement is the order of the day. This document is a **practical guide** to that. To ensure that all the pieces of the puzzle come together to form an accurate overview.

Let's put these instructions into action together! In my video, I share even more about PPIE.

SPACE FOR THOUGHTS

Workshop Preparation

How to Create the Optimal Preparations

It is a well-known fact that planning is half the battle - and it's what makes the process so much fun for everyone involved. Once a research project has been identified for which questions are to be developed, it's time for the organizational small (and big) stuff. Find a suitable co-moderator and participants, prepare methods and materials, secure a location for the workshop and define the rules of the game: This is how to prepare successfully.

> Schedule enough time for preparations.

Organizing Moderation

Two is better than one. This truism also applies to this workshop:
Dual facilitation promotes balance in the group.

Ideally, the workshop will be led by one person with thier experience regarding their own disease ("Patient Expert") and one with expertise in health care ("Health Care Professional") or with a scientific background. Experience with leading workshops is recommended, but not a basic requirement. In this case the co-facilitators play through the modules together in the course of the preparation until both feel confident and comfortable in their role. It is important that the co-moderators make joint decisions regarding planning, implementation and evaluation.

Choosing Space and Check Logistics

Cabin or ballroom? When booking the workshop room, the **needs of the participants** must be taken into account. The room must be easily accessible and, if necessary, barrier-free. As a lot of time will be spent in it, it should have sufficient daylight and a good indoor climate.

Logistics on site: Are there enough flip charts available? Is there a beamer to show a presentation? Are the right connections available for my laptop, or is there a PC on site? Do I need speakers? There are a handful of questions to look out for when booking a space.

Do not forget: **Food** must also be prepared. Must-have: sufficient (mineral) water for the participants. Nice-to-haves: coffee, tea, milk, sweetener, fruit, (healthy) snacks, etc. Depending on the venue, meals will be taken on site - e.g. if you are in a seminar hotel or a restaurant. In this case, the necessary **reservations** must be made

Workshop Preparation

Writing materials should be freely accessible. This way, the participants can take notes at any time.

Gathering Materials & Documents

For the Entire Duration of the Workshop:

- ☐ For each participant a "Lab-Book".
- ☐ Notepads (min. A5) & pens for the participants
- ☐ Enough Flipcharts
- ☐ Colored pens (felt pens for flipcharts)
- ☐ Moderation cards
- ☐ Different colored sticky notes
- ☐ Sticker dots and various other stickers
- ☐ Adhesive tape
- ☐ Name tags
- ☐ Small fabric ball
- ☐ Optional: pin board & pins or magnetic board with accessories
- ☐ _____
- ☐ _____

Tip: The digital tool **Mentimeter** can be used for feedback rounds or voting. This should be considered in the preparation! Website: mentimeter.com.

For the Individual Modules:

Module 1:

- ☐ Flipcharts with questions *(1. Arrival)*
- ☐ Flipchart with agenda & game rules *(3. Agenda & introduction)*
- ☐ Presentation PPIE *(3. Agenda & introduction)*
- ☐ Cards with workshop roles *(4. Workshop roles)*
- ☐ Avatar worksheet *(5. Creating an avatar)*

Building blocks (for example, the set "Lego Classic creative building set"), modeling clay, pipe cleaners and/or craft materials create a special workshop experience!

Module 2:

- ☐ Presentation research process *(11. The Research Process)*
- ☐ Optional: mini-presentation (guideline: 2 Slides) on the research topic *(10. Introduction to the research topic)*

Module 3:

- ☐ Invention Worksheet *(17. Inventor)*

Module 4:

- ☐ Presentation & Worksheets *(21. Study Design Guide)*
- ☐ ABC poster *(24. Reflection)*
- ☐ Feedback sheets or online survey with QR code *(25. Feedback)*

For the complete collection of materials and documents, go this way!

Workshop Preparation

Finding the Right Group

To stay with the apple metaphor: The best possible result is achieved by a group that looks at the apple from different perspectives. A **balanced relationship between science, medicine or psychology and those affected** is essential. An ideal group therefore consists of researchers, physicians, psychologists, nurses, patients and their relatives. Ideally the groupmembers should not know each other beforehand. This way, all participants start with the same basis.

Charge

All group members spend the same amount of time working on the project, this also applies to patients. They should be **compensated for their expertise and experience**. The **Fair-Market-Value-Calculator** can give orientation here: https://nationalhealthcouncil.org/fair-market-value-calculator/.

Tip: The costs for the workshop should be considered in the overall project design and included and budgeted accordingly during calls. The acquisition of funding is therefore a relevant stage of the project.

Contracts

If you say "clinical research", you also have to say "**informed consent**." Or "contract for work" - since patients are also experts in their respective fields. Each institution deals with such contracts differently. However, it is essential to draw them up in advance and to clarify the legal framework, if necessary with the legal department.
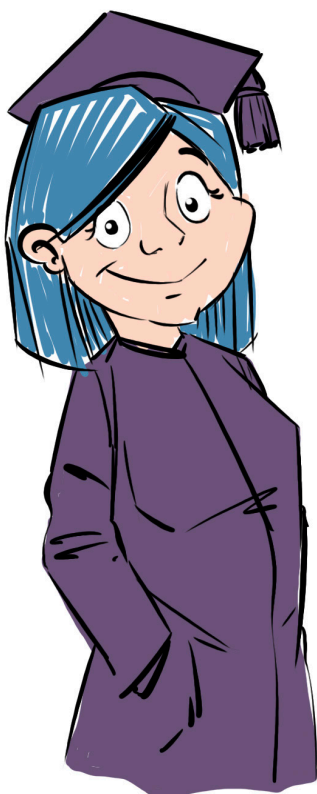
In many institutions there are already Patient Experts and Patient Advocates, who should be involved from the start.

Workshop Preparation

Consideration of Special Needs

Every team member has their own **perspectives** and **expertise**. This also applies to the group member's needs. The following considerations are part of **good planning**:

**?** Is accessibility necessary? If so, can the workshop location be in abarrier-free way? Likewise the sanitary facilities?

? Is the room within the building easy to find & sufficiently signposted?

? Is the presence of an assistant required?

? Can sufficient ventilation be provided?

? What are the lighting conditions in the location?

? Will food be provided (nuts, pastries, drinks)?

? What times and dates are convenient for all participants?

? Are breaks scheduled sensibly and, if necessary, generously?
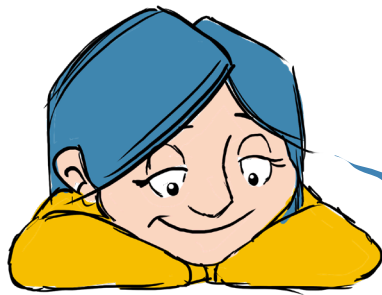
Find individual solutions for the participants, so that each person feels taken seriously and can work to their full potential!

In Case of Cognitive Impairments

Illness and therapy can lead to restrictions in concentration, memory, endurance or energy balance in individual participants. This must not become a -disadvantage. Therefore, the workshop should be adapted to this. This helps:

- **Adjust the pace:** Slow down processes and summarize content regularly and repeat

- Connect methods **with all senses** (seeing, hearing, feeling, tasting).

- The co-facilitation team should regularly encourage participants to **write down important content in their lab book** so that it can be read up on independently. The lab book serves as a note- and workbook and is handed out at the beginning of the workshop.

Workshop Preparation

Defining the Game Rules

Did you find your group member? Did you clarify any contractual issues? Very good. In order to get all participants on board as a co-moderation team, certain rules should be internalized before the start of the workshop.

- **At eye level:** consciously use technical terms and explain them if necessary. A PPIE dictionary, which the participants can add to themselves is useful here (see attachment). This gives them a sense of added competence and self-confidence.

- **First names first:** addressing people by their first names is a good way to work together. This loosens the atmosphere and promotes brainstorming and creative work.

10 Commandments for Good Cooperation

1. **"Engage with each other."** Let each other finish - every voice should be heard.

2. **"Treat each other with respect."** Respect each other and value the knowledge and achievements each member brings to the table.

3. **"Use solution-oriented language."** Avoids killer phrases. Instead of "It won't work anyway," prefer "Let's try!"

4. **"Be constructive."** Offer alternatives to any criticism.

5. **"Replace ‚but' with ‚and.'"** "A ‚but' has a more negative effect in communication than an ‚and'; it changes the mood of the room!"

6. **"Take responsibility."** Agree to share responsibility for the success of the workshop.

7. **"Stay in the here and now."** Turn off "distractors" such as smartphones and pagers on silent.

8. **"Work with an open mind."** PPIE means having the courage to think openly, to enable solutions outside of familiar conventions.

9. **"View diverse perspectives as an opportunity."** The workshop is an "open space" for exchange - take advantage of this opportunity, talk to each other, exchange your perspectives and show willingness to dive into each other's worlds.

10. **"Be confident."** The workshop, of course, means time and work. But the PPIE process is a real win for everyone involved.

Clear rules facilitate appreciative cooperation.

Psst, there is one more. Rule #11: Have fun!

Workshop Preparation

Preparation of the Participants

The more info, the better? Not in this case. The **right information** is the goal. In order not to overload participants with with information in advance and still create a good common basis, the info mail sent out in advance should contain the following:

- ☐ Time and place of the workshop
- ☐ Reason for the meeting (description of the research project)
- ☐ PPIE explanation and link to the PPIE video (Lab-Book – *see material collection*)
- ☐ Agenda (roughly)
- ☐ Inquiry about the needs
- ☐ PPIE dictionaryLab-Book – *see material collection*)
- ☐ Info on remuneration and contracts

Each participant receives a Lab-Book in the workshop. It can be found in the material collection and should be printed out by the co-facilitation team and distributed at the beginning of the workshop. The Lab-Book can also be sent in advance - it contains a **PPIE explanation** as well as the **PPIE dictionary**, which can be extended by the participants themselves, as well as enough space for their **own notes**.

Workshop Overview

The Lab-Book helps participants of the project to recall the results again at a later point in time!
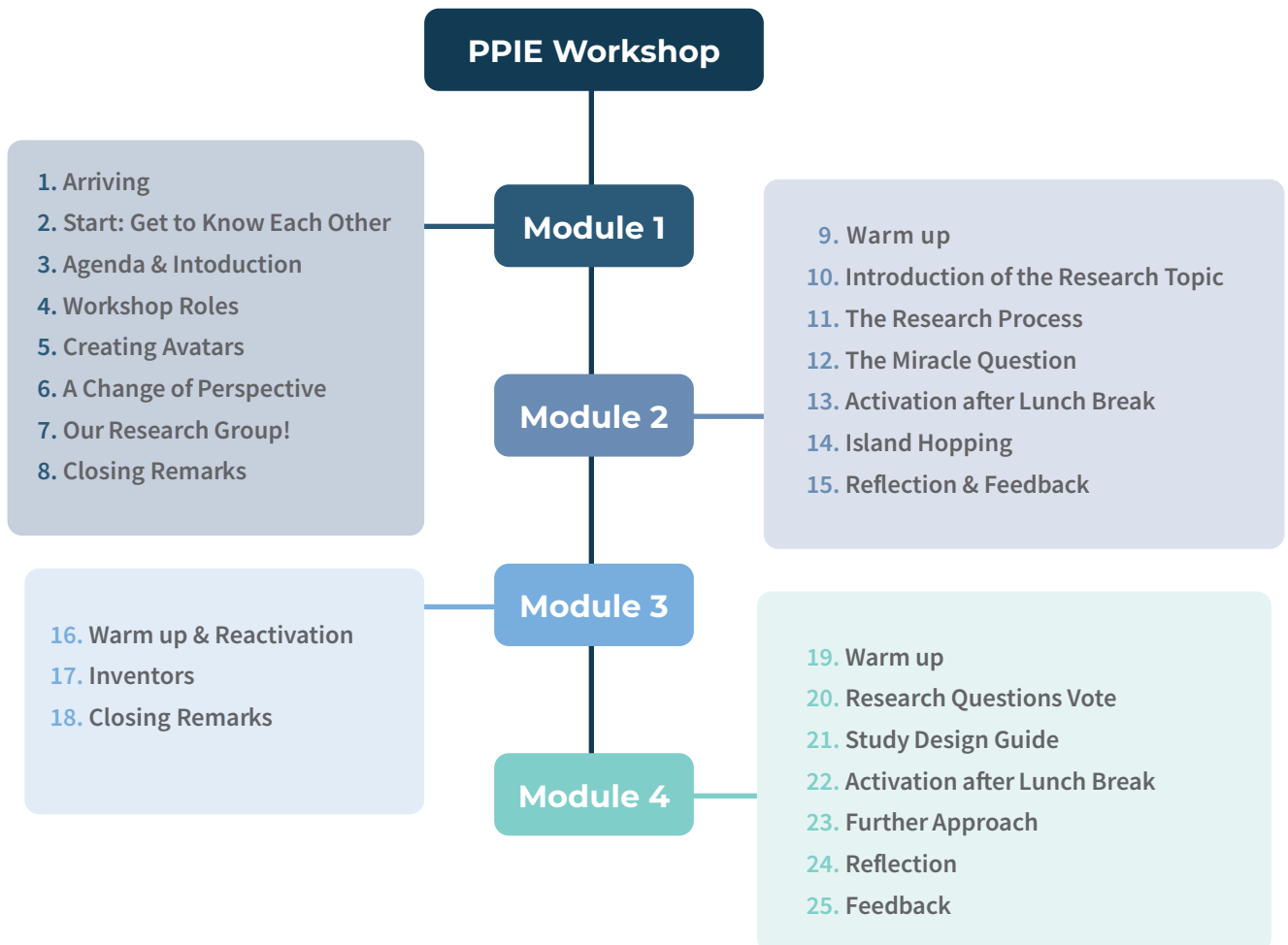
The Workshop

Roadmap for Modules 1-4

Now that everything is prepared, the best part begins: **the implementation**. To ensure that the methods presented here lead to the desired goal, a workshop period of meeting twice for one and a half days each and a division into four modules. Here is an example:

Module 1: Friday from 1pm-4:30pm
Module 2: Saturday from 9:30am-4pm
Module 3: Friday from 1pm-5pm
Module 4: Saturday from 9:30am-4pm

We recommend that you schedule two modules on a weekend, ideally Friday and Saturday. This way the group can also maintain social contact in the evenings, which strengthens the team spirit. It has proven useful to hold **modules 3 and 4 separately at a later date**, e.g. one month later. Successive workshop weekends are tiring, and new ideas often need a little time to grow. However, the time between the two workshop weekends should not be too long, so that the results achieved are still reasonably present.

PPIE Workshop

Module 1

1. Arriving
2. Start: Get to Know Each Other
3. Agenda & Intoduction
4. Workshop Roles
5. Creating Avatars
6. A Change of Perspective
7. Our Research Group!
8. Closing Remarks

Module 2

9. Warm up
10. Introduction of the Research Topic
11. The Research Process
12. The Miracle Question
13. Activation after Lunch Break
14. Island Hopping
15. Reflection & Feedback

Module 3

16. Warm up & Reactivation
17. Inventors
18. Closing Remarks

Module 4

19. Warm up
20. Research Questions Vote
21. Study Design Guide
22. Activation after Lunch Break
23. Further Approach
24. Reflection
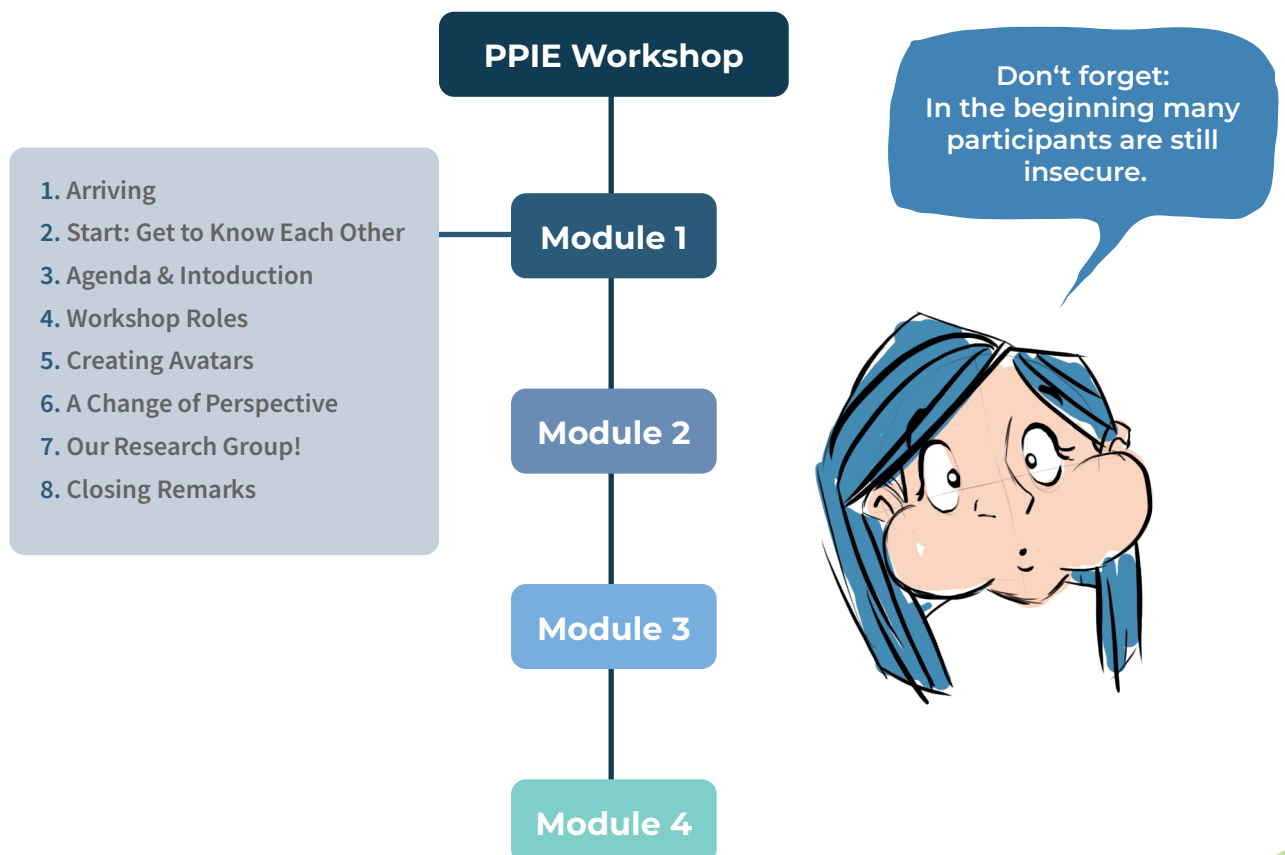25. Feedback

The Introduction

Preparation for Module 1:

☐ Flipcharts with questions *(1. Arriving)*

☐ Flipcharts with agenda & game rules *(3. Agenda & introduction)*

☐ Presentation PPIE *(3. Agenda & introduction)* - **see material collection**

☐ Cards with workshop roles *(4. Workshop roles)*

☐ Avatar worksheet *(5. Creating avatars)* - **see material collection**

Module Objectives: Getting to Know Each Other & Finding Group Identity

Let's go! The first step is to get to know each other. And we do this „at eye level": Everyone brings different expertise, which is essential for research and for the workshop. The chosen methods ensure that each participant finds a place in the (research) group with their personal strengths. This lays the foundation for collaboration - in the workshop and beyond.

Duration: approx. 3,5 hours (e.g. Friday 1pm-4:30pm)

PPIE Workshop

1. **Arriving**
2. **Start: Get to Know Each Other**
3. **Agenda & Intoduction**
4. **Workshop Roles**
5. **Creating Avatars**
6. **A Change of Perspective**
7. **Our Research Group!**
8. **Closing Remarks**

Module 1

Module 2

Module 3

Module 4

Don't forget:
In the beginning many participants are still insecure.

Method 1: Arriving
3 Questions, 3 Walls

Why? Smoothing the arrival in the workshop + An initial discussion of the content of the topic.

Duration? Upon arrival of the first participants until start (approximately 10 minutes)

Materials:

- 3 flip charts with questions
- pens
- sticky dots

Description

Shy looks, nervous silence, beads of sweat on the forehead: Arriving at a workshop is often a bit uncomfortable. To make this phase easier for the participants, three posters are hung up, each with a question. The co-moderation team greets the participants personally and asks them to go from poster to poster. They can use pens to write their answers to the questions or mark a pre-written answer with a sticky dot. Soft music can be played to lighten the atmosphere. The answers on the posters can later be integrated into the workshop, e.g. by referring to them during the introduction.

Possible Questions for the Flip Charts:

? **"Have you ever heard of Patient & Public Involvement and Engagement?"**

   (prephrased: yes/no)

? **"Have you ever been involved in research?"**

   (prephrased: yes/no)

? **"What do you expect to get out of this workshop?"**

   (let participants write in their answers)

Method 2: The Start: Getting to Know Each Other
Room Setup

Why? The participants get to know each other.

Duration? 10 minutes

Description

A typical introduction that is also fun! After a brief „hello", things get started right away: Participants line up in the room in response to questions from the co-facilitation team. How about, for example, a line-up by birthplace on a fictitious map? In a short round of dissolution, the participants tell why they have positioned themselves the way they did. While searching for their own place, first communication between the members is already taken place, which promotes the process of getting to know each other. The process should be repeated three times.

Highly Recommended Tasks:

? **"Where were you born?"**

(list on fictitious map)

? **"How intensively have you dealt with the topic of the workshop so far?"**

(scale placement between "very much" and "not at all")

? **"How much time have you spent in medical facilities recently?"**

(scale placement from "a little" to "a lot")

Who is who?
In which room will the workshop take place? The Lab-Book is best suited when participants want to take notes!

MODULE 1

Method 3: Agenda & Introduction
Lecture & Discussion

Why? Orientation, rules of the game, level of knowledge alignment.

Duration? 30 minutes

Materials:

- prepared flip chart,
- powerpoint presentation

Description

1.Welcome & Agenda:

Now the group has briefly met. Time to welcome everyone and introduce the agenda! First, the co-moderation team explains the **goals of the workshop** and the project in a few sentences. The agenda for the next day and a half is briefly introduced. The most important points are on the agenda, which was previously written down on a flipchart. Not too detailed..

Tip: The introduction can be creative, e.g., using an example, a story or referring to the flipcharts that the participants filled out when they arrived.
Duration: approx. 10 minutes

2. Game Rules:

Everything clear so far? Then it is all about working as a team now. How, will be answered during the presentation of the game rules. These are also written on a flipchart (e.g. on the agenda chart).
Duration: approx. 5 minutes

Allow your pariticipants to speak.

3. Introduction:

What is PPIE? The co-moderation team immediately passes this question on to the participants - what do they already know about „Patient & Public Involvement & Engagement"? Short plenary discussion. Then, using 3 PowerPoint slides, the most important pillars are succinctly explained and all participants are brought to the same level of knowledge.
Duration: approx. 15 minutes

Method 4: Workshop Roles
Quick Impulse

Why? Incorporation, distribution of tasks.

Duration? 10 minutes

Materials:

- cards or sticky notes

Description

Before the content of the workshop starts, the moderators assign roles to volunteers. Why? In this way, the workshop becomes a joint effort with shared responsibilities, which also distributes the burden on the co-moderation team. The following roles are each written on a card in advance, then explained and assigned. The assignment should not be dead serious, but can be designed humorously (e.g. like at a fair!).

The following roles are each written on a card in advance, then explained and assigned:

Timekeeper

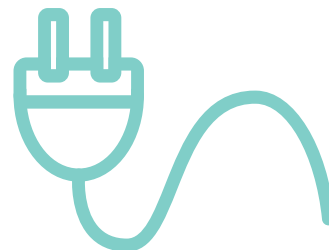Make sure that the time frame is not exceeded

But-Guard

Intervenes when someone says „but" in a discussion and turns this into an „and".
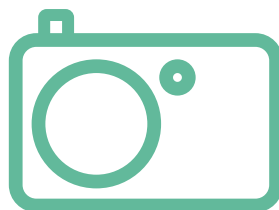
Walking Dictionary

Notes technical terms and explanations on a chart. Reminds the group, to explain technical terms if they forget.

Charger

Pays attention to the energy level in the room and calls for breaks if it is too low.

Photographer

Takes pictures of the results, takes pictures of the group and transmits them to the co-moderation team after the meeting.

Method 5: Create Avatars
Create Avatars

Why? Presentation of strengths, knowledge, expertise.

Duration? 1,5 hours

Materials:

- building blocks
  (*e.g. Lego Classic set*)
- possibly pipe cleaners
- Play-Doh
- avatar worksheets
  (see material collection)

Description

Now handiwork is required! Working with your hands triggers creative processes in your mind and enables free thinking. The different creations can be used wonderfully as metaphors. This exercise is divided into four parts:

1. Preparation:
To begin, all participant:s are given building bricks, pipe cleaners, or Play-doh. Or all of these. The materials are on tables in the room or handed out directly to the participants. Important: There are no limits to creativity, there is no right or wrong! Which the co-moderation team emphasizes right at the beginning.
Duration: 10 minutes

2. Building:
With the help of the materials, the participants build their avatar: a figure that represents them. The avatar should symbolize their own strengths, knowledge and expertise.
Duration: 15 minutes

3. Describe:
The participants now take their avatar worksheet. On it, they describe their avatar:

- What are your strengths?
- What expertise do you bring to the table?
- What special qualities do you have?

Duration: approx. 20 minutes

⏰ *20 minutes break.*

Don't forget to put the avatars on the worksheets and take pictures! The co-facilitators can also do their own crafting.

4. Sharing:
Now the participants present their avatars to each other, including their strengths, knowledge and expertise. Each participant gets the same amount of time for this!
Duration: 30 minutes

Method 6: A Change of Perspective
Putting Yourself in the Shoes of a Stakeholder

Why? To make competencies visible

Duration? 40 minutes

Materials:

- flipcharts
- pens

Description

Thanks to the exercise with the avatars, everyone in the room now knows the personal strengths of the other participants. Great! The next step is to put yourself in the different **roles of the project participants**. To do this, empty flip charts are set up in four places in the room, each poster represents a stakeholder of the research project. In other words, a group of people who are involved in the project in any way: patients, researchers, physicians, nurses.
Duration: approx. 10 minutes

The participants are divided into **four groups**. For example, by counting from 1 to 4. Each number forms its own small group (make sure that the groups are well mixed). The small groups distribute themselves among the posters, discuss the given questions and record the answers on the flip chart:

? What **expertise** does the role bring to the research process?

? **What** needs to happen for the project to be successful from their perspective?

? What is their **wish** for the research team?

Duration: approx. 15 minutes

Finally, each group briefly presents „their" perspective.
Duration: approx. 15 minutes

Method 7: Our Research Group
Plenary discussion

Why? Strengthen the group identity.

Duration? 20 minutes

Materials:

- flipcharts

Description

Time for a summary. The co-moderation team „presents" to the group what strengths their members have. These have already been made visible during the avatar creation. In a brief group discussion, the **new research group** is defined, which the participants will form together from now on. They can also form several smaller groups. As an orientation, the following points are written down, discussed and recorded in writing on a poster:

- **What is our goal as a research group?**
- What are our **strengths?**
- **What knowledge** do we all bring to the table?
- **What defines** us as a group?
- **What name** do we give our research group?
- What is our **logo/symbol?**

Method 8. Conclusion
Flash

Why? Closure, reflection.

Duration? 5-10 minutes

Put notes on the research group also into the Lab Book!

Description

Done! The first module is over. The group has found itself, all strengths are on the table, the team even has a name. Before the first day of the workshop ends, the mood of the group should be briefly captured, also leaving **space for feedback**. The co-moderation team asks each person to say one sentence about how they are doing after the first module. There should be no response to the statements. The co-moderation team also participates.

Afterwards, farewells are said and, if necessary, **organizational tips** are given on the subject of dinner and accommodation.
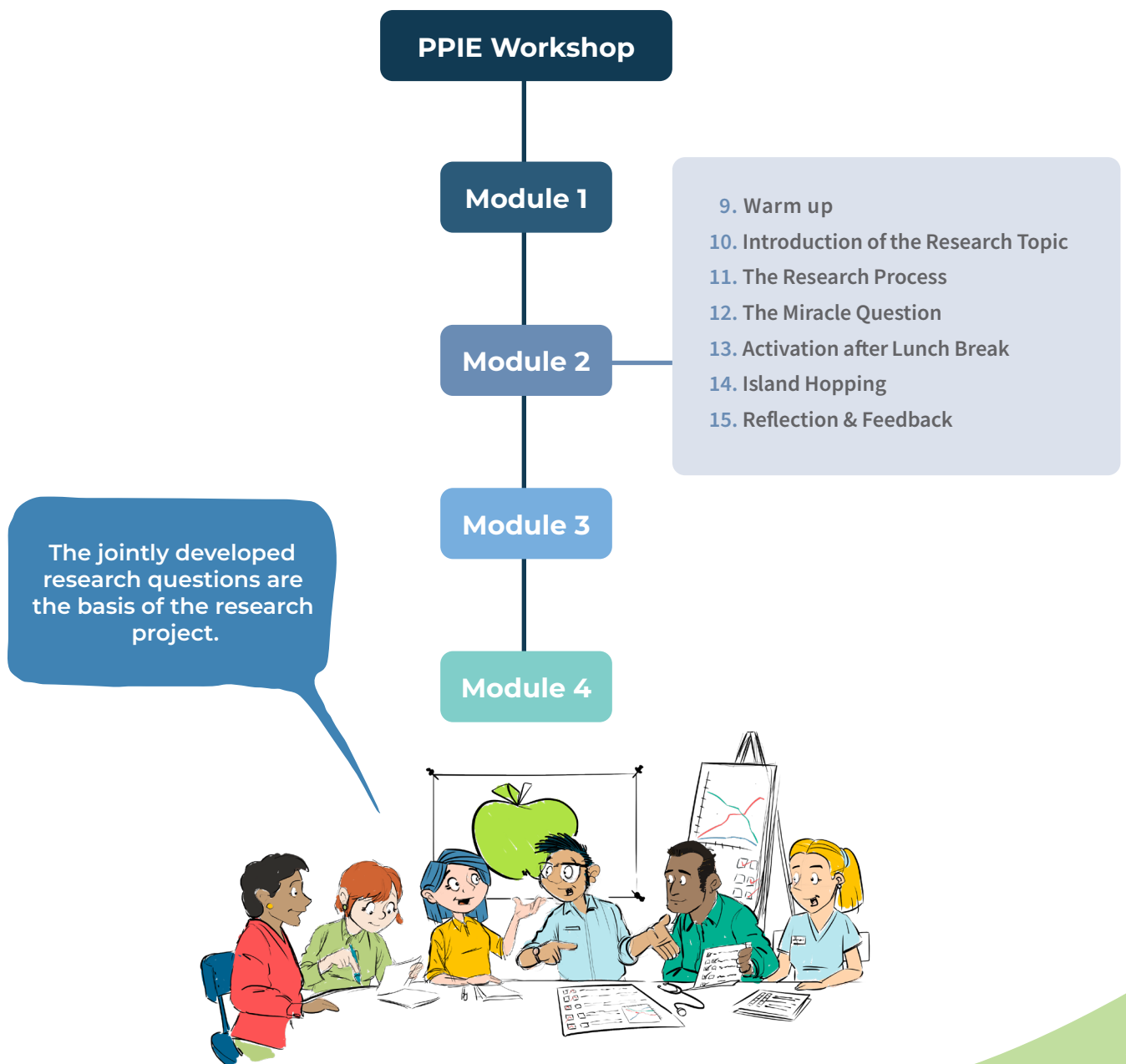
Finding Research Questions

Prepare for Module 2:

☐ Presentation Research Processs *(11. The Research Process)* - **see material collection.**

☐ Optional: mini-presentation *(guideline: 2 slides)* on the research topic *(10. Introduction to the research topic)*

Module Objectives: Finding Research Questions

Spent a nice evening together and adequately recovered? Great! Then you can start joint work on the research topic. The planned methods allow a creative development of first research questions.

Duration: 7,5 hours(e.g. Saturday 9:30am-4pm)

PPIE Workshop

Module 1

Module 2

9. **Warm up**
10. **Introduction of the Research Topic**
11. **The Research Process**
12. **The Miracle Question**
13. **Activation after Lunch Break**
14. **Island Hopping**
15. **Reflection & Feedback**

Module 3

The jointly developed research questions are the basis of the research project.

Module 4

MODULE 2

Method 9: Warm up
Two Truths One Lie

Why? Activation & deepened getting to know each other

Duration? 20 minutes

Description

The participants already know each other a little after the first day. But how well really? That's what in this fun activation game: each participant thinks of **two truths and one lie** about themselves. It can be something funny or private or related to the topic. The others must now guess which statement is the lie. To increase the pace, the person whose turn it was last determines the next one.

Method 10: Introduction to the Research Topic
Impulse Lecture of the Co-Moderation Team

Why? Establish the same level of knowledge on the research topic

Duration? 15 minutes

Materials:

- mini presentation on the research tropic *(optional)*

Description

The content of the meeting starts now: Up to now, the main focus has been on getting to know each other and on the teambuilding of the research group. Now all participants should be brought to a similar level of knowledge of the basic topic that is the reason for the meeting. These questions should be answered:

? What is the **subject area** (psychology, medicine, neuropsychology, pharmacology, social work)?

? **What exactly** is to be researched or developed?

? How does the **workshop** contribute to this?

? What is the role of the **workshop group** in the project?

MODULE 2

Method 11: The Research Process
Brainstorming, Impulse Lecture, Free Association

Why? To get to know the research process and your own points of contact with it.

Duration? 1 hour

Materials:

- sticky notes
- flipchart
- colored sticky dots
- research process template
  (see material collection)
- *optional*: presentation

Description

1. Brainstorming:
Participants consider what touchpoints they have already had with research. Each of their touch points should be written down on a sticky note and collected. These will be used in step 3.
Duration: 15 minutes

2. Impulse Talk:
Now the co-facilitation team gives a brief overview of the research process. This can be done with the help of a poster or a presentation. The outlined research process can also be used for orientation (see material collection).
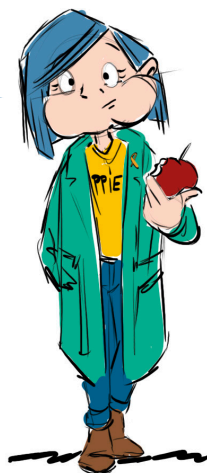**Duration: 15 minutes**

3. Free Association:
Now that the participants are well informed about the research process, they put their previously collected points of contact (sticky notes) on one or more flipcharts in a chronological order based on the research process. Here collaboration is encouraged! Additions, which occurred to them after the impulse lecture are welcome and should also be attached to the flipchart with a sticky note.
Duration: 25 minutes

This is where personal experience is called for!

⏰ *20 minutes break*

Method 12: The Miracle Question
Miracle Question: What if..?

Why? Activate creativity and optimism

Duration? 45 minutes

Materials:

- cards or sticky notes
- flipchart
- pens
- Lab-book *(optional)*

Description

Now it's time to get creative again! The participants brainstorm possible solutions to the basic research problem of the project. The co-moderation team asks the following question: "Imagine you wake up and the **problem is solved**. How would you recognize that?"

To illustrate the question, examples of situations can be described: A patient wakes up cured, a researcher has solved a tricky research question, a Patient Advocate was able to achieve an improved treatment approach in the patient's interest.
Duration: 5 minutes

Each participant should think about the **answers** to the following three questions and write them down on cards or sticky notes. (Duration: 10 minutes):

? **How** would you know that this miracle has happened?

? **What** problems/difficulties would have disappeared as a result?

? **Who else** would recognize that this miracle has happened and that your problems have disappeared?

Afterwards, the results are presented individually in the **plenary session** and pasted or written on to a flipchart. **The participants can also transfer their thoughts into their Lab-Book.**
Duration: 30 minutes

⏰ *1 hour lunch break*

MODULE 2

Method 13: Activation after Lunch Break
Zip-Zap-Boing

Why? Activation after lunch break

Duration? 5-10 minutes

Description

Eaten well? Hopefully! After lunch, it is important to briefly reactivate the brain again. The funny game "Zip-Zap-Boing" is perfect for this.

The group members stand in a circle. An **impulse goes through the group**. It is passed on to the left by turning to the left, clapping hands and saying "**Zip**" loudly. To the right, the impulse is passed on by turning to the right, clapping hands, and saying "**Zap**". Finally, there is the "**Boing**" command: with this you pass the impulse to any one of the players in the circle (but not to the immediate neighbors). You look at the person, make a movement with your hands as if you wanted to hit an invisible volley-ball over to them, and say "Boing" loudly and clearly.

As soon as the impulse reaches a teammate, they can choose which of the three commands to use to pass on the impulse. The **goal of the game** is to make the impulse travel as quickly as possible without anyone making a mistake.

Activation exercises raise the energy level of the group! But pay attention to the needs of the participants.

Method 14: Island Hopping
Island Hopping / World Café

Why? The participants formulate 3 research questions together.

Duration? 2,5 hours

Materials:

- cards
- flipcharts
- pens
- pinboard and pins *(optional)*

Description

Now it's time to get serious. You could say that all the steps so far have prepared the group for this exercise, namely working out research questions together. This is why enough time should be scheduled for this exercise.

Step 1:

Participants individually consider what specific questions they have about the session and write them down on cards. These cards are briefly presented in the plenary and then pinned on a pin board. There, under the guidance of the co-facilitation team, the questions are summarized into topics (e.g. "side effects", "quality of life", "diagnosis phase","therapy", "rehab"), "therapy", "rehab" or "aftercare", etc.).
Duration: approx. 40 minutes

Step 2:

From the topic clusters, 3-4 are selected, e.g. by voting. The co-moderation team must ensure a balance between the views of health care professionals and patients. The topics are written on posters and distributed in the room, like islands in the sea. One person per poster is chosen to "take care" of the poster. They are the island owners.
Duration: approx. 10 minutes

Step 3:

The remaining participants are now divided into small groups and go from island to island (approx. 10-15 minutes per poster). At each station, they formulate questions and reflections on the particular topic. The owner of the island takes notes and then gives a short summary to the next group. Attention: When dividing the groups, make sure there is a good mix of the participants!
Duration: 50-60 minutes

⏰ *20 minutes break*

Give enough time and allow discussions.

Step 4:

The island owners now present their posters or the questions and comments on their topics in a plenary session. Under the guidance of the co-moderation team, the plenary votes for three of these of these questions, which in their view are most relevant for the concrete research project. These are now the research questions that will be worked with further. The other questions can be „parked" in an idea parking lot. A new flip chart is suitable for this.
Duration: 30 minutes

MODULE 2

Method 15: Reflection & Feedback
Train Compartment

Why? The participants actively deal with what they have learned. The verbalization of these experiences supports the practical transfer.

Duration? 20-30 minutes
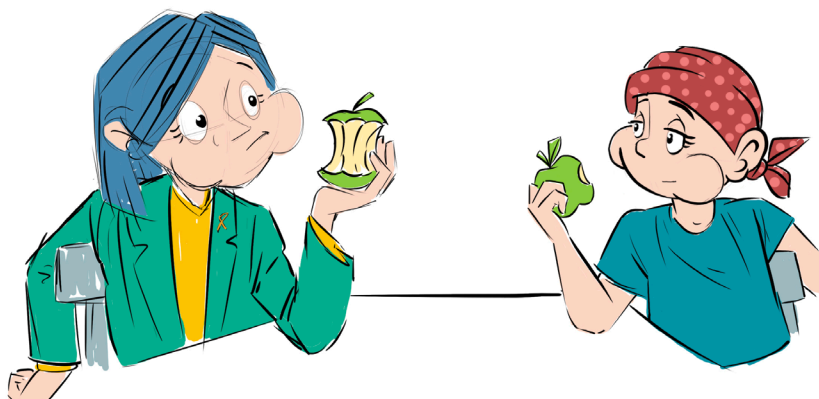
Materials:

- 6 chairs

Description

Done! At the end of the second day, the workshop participants and the co-moderation team are satisfied: they have accomplished a lot together! Before everyone goes home, however, there is still time for reflection.

The co-facilitation team sets up six chairs **facing each other**. As if they were in a train compartment. Participants enter the „train compartment" as they wish, if seats are available, and talk freely with the other „passengers" about what they have thought of the workshop so far, what they would like to get off their chest, what they remember particularly about the workshop, etc.

Finally, the **co-moderators** board the train as conductors and also give a brief final feedback to the group.

Do not forget to take a picture of the results of the second day!

SPACE FOR THOUGHTS
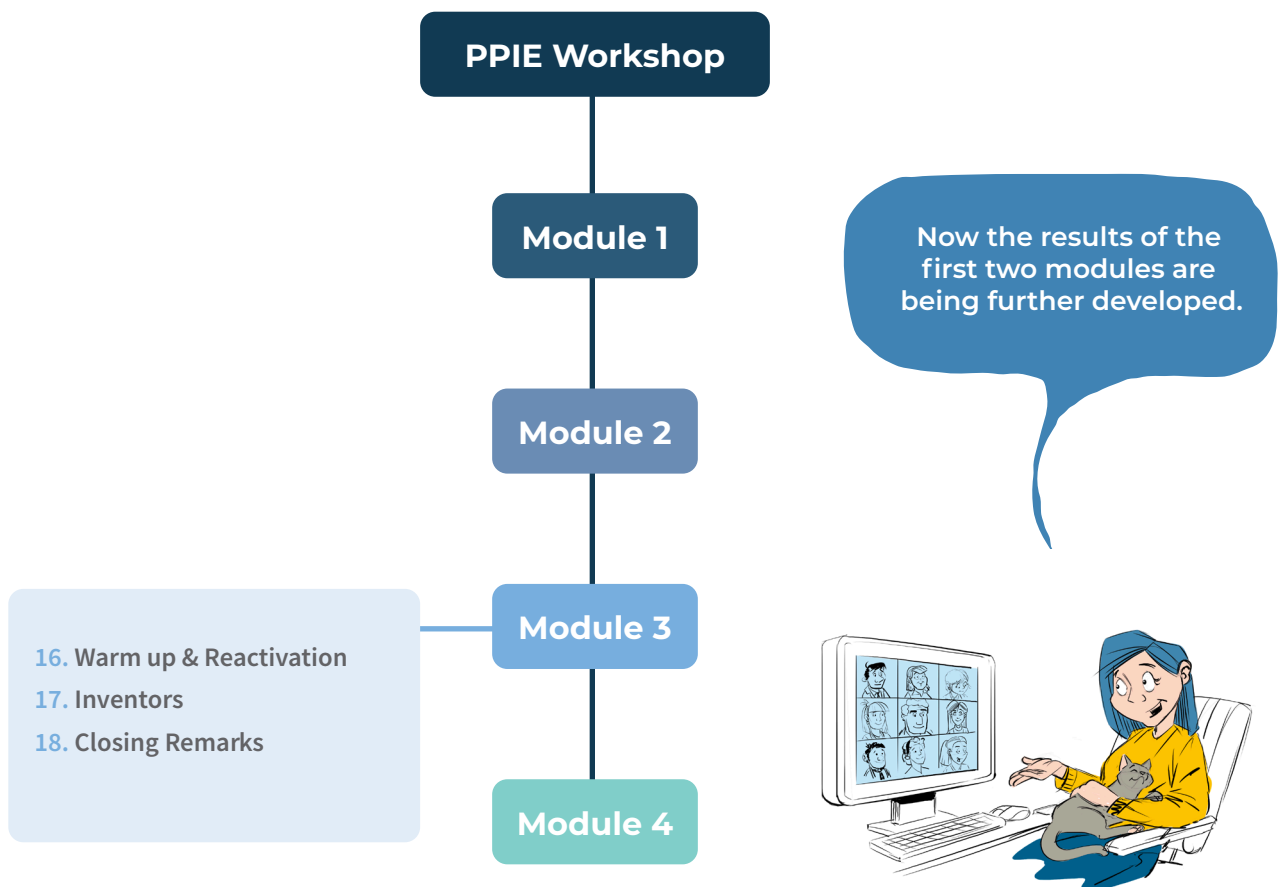
Finding Creative Solutions

Preparations for Module 3:

☐ Inventions worksheet*(17. inventors) - **see material collection***

Objective of the Module: Develop Approaches to Solutions

Finally we are moving on! A few weeks have passed and after the positive workshop experience of the first two modules, the participants are looking forward to the continuation. The research questions have been formulated, now the group gets creative: they develop "**problem solvers**". In order to make it easier to get back to work, it is important to have a **prepared summary** of the results so far.

Duration: approx. 4 hours (e.g. von 1pm-5pm)

PPIE Workshop

Module 1

Now the results of the first two modules are being further developed.

Module 2

Module 3

16. **Warm up & Reactivation**
17. **Inventors**
18. **Closing Remarks**

Module 4

Method 16: Warm up & Re-Activation
Speed Dating & Think-Pair-Share

Why? Reactivation of the group, repetition of the previous contents.

Duration? 45 minutes

Materials:

● cards or notebooks

Description

Did everyone arrive well? Then let's start with a repitition. Namely, with a **repetition of the previous workshop**. The exercise consists of three steps:

1. Step

First, a short "**speed dating**" session takes place. The participants are divided into pairs, for example, by counting them. Each pair takes turns asking each other questions for five minutes to discuss what they know and what they have learned in the first two modules. Possible questions would be: "What were the most important insights for you from the first part of the workshop?" or "What questions are still open?"
Duration: 10-15 minutes

2. Step

Now the pairs change and the second part starts, the so called **think-pair-share method**. The participants sit down with another person in order to exchange their thoughts and insights and write them down. Each participant can draw from the insights gained in the previous round. Some participants may have new ideas after the previous workshop module, and these can now be recorded as well.
Duration: approx. 10 minutes

3. Step

Then, the individual pairs are asked to share their most important insights or ideas **with the whole group**. The new ideas can, for example, be written on an "idea parking lot" poster. The moderators add content from the module that may not have been mentioned by the small groups.
Duration: approx. 20 minutes

Pairs should be well mixed.

MODULE 3

Method 17: Inventors
Inventors

Why? Discover new approaches to solutions

Duration? 2,5 hours

Materials:

- building bricks
  (e.g. lego classic set)
- pipe cleaners, play doh *(optional)*
- inventions worksheet
  (see material collection)

Description

The next exercise is really fun: The participants become inventors! There are no limits to their creativity. By working with their hands, creative processes are triggered in their minds and enable free thinking. The different building blocks can be wonderfully used as metaphors. This method is divided into four areas:

1. Preparing:
At the beginning, participants will be divided into **three groups**: one for each research question developed in Module 2. The groups are given building blocks, pipe cleaners, or play doh or all of the above. The materials are placed on tables in the room or handed out directly to the participants. Important: There are **no limits** to creativity, there is no right or wrong! The co-moderation team emphasizes this right at the beginning.
Duration: 20 minutes

2. Constructing:
Referring to the research questions and related problems discussed during the island hopping, inventions, so-called "problem solvers" are now developed. With the help of the materials, the groups build their invention(s). These may be completely completely made up and detached from physical laws.
Duration: 90 minutes

3. Describing:
Now the participants take their worksheet and describe their inventions on it.

? What **problem** does your invention solve?

? What **features** does your invention have?

? What is the **name** of your invention?

Duration: approx. 10 minutes

⏰ *20 minutes break*

> Don't forget to copy the results onto the worksheets and take pictures! In this exercise, it's okay to think ‚out of the box'.

4. Sharing:
Now the groups present their inventions. Each participant should get approximately the same amount of time.
Duration: 30 minutes

Method 18: Conclusion
Flashlight

Why? Conclusion & reflection

Duration? 5-10 minutes

Description

Done! After the creative work we let the workshop day come to an end. Before that we should briefly capture the mood of the group and give the **opportunity for feedback**. The co-moderation team asks each participant to tell them one sentence about how the person is doing after the third module. There should be no response to the statements. The co-moderation team also participates.

Afterwards farewell and possibly **organizational hints** on the topics dinner and accommodation.
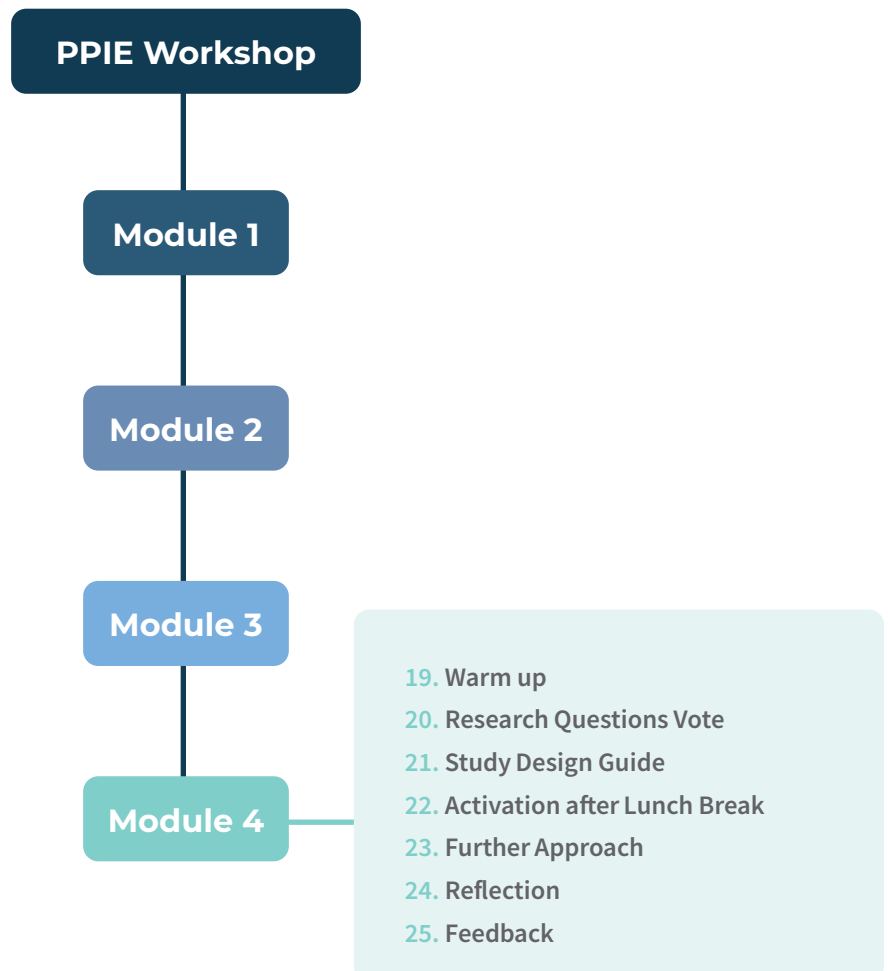
Develop Study Design

Preparing for Module 4:

- ☐ Presentation & Worksheets *(21. Study Design Guide))*
- ☐ ABC poster*(24. Reflection)*
- ☐ Feedback sheets or online survey with QR code *(25. Feedback)*

Module Objective: Development of the study design.

The research questions have been formulated and various creative approaches to solving them have already been established. Now the group learns about the **study design** and applies it to their own results. Finally, the co-moderation team gives an outlook on the time after the workshop.

Duration: approx. 7,5 hours (e.g from 9am-4:30pm)

PPIE Workshop

Module 1

Module 2

Module 3

Module 4

19. **Warm up**
20. **Research Questions Vote**
21. **Study Design Guide**
22. **Activation after Lunch Break**
23. **Further Approach**
24. **Reflection**
25. **Feedback**

Method 19: Warm up
Best Picture Contest

Why? Activation, Tuning back into the topic.

Duration? 30-40 minutes

Materials:

- cell phones of the participants

Description

The last workshop day starts creatively. The participants become photographers and have the task of expressing the workshop so far in **one picture**. It does not matter if they take a photo or research on the internet. However, it is important that the picture reflects how they feel about the results they have achieved so far (research questions, inventions).
Duration: Approximately **10 minutes** are sufficient for the photographs/research.

The results are then presented to the group and discussed if necessary. Each participant starts with the sentence "I chose this picture because...".

Method 20: Voting of the Research Questions
Vote

Why? Reducing to one research question in preparation of the next work step (study design)

Duration? 10-15 minutes

Materials:

- flipcharts or sticky dots
- Menimeter voting

Description

For the development of the study design it is beneficial to focus on one research question. This is done in this step: First, the three research questions that were already developed in Module 2 are recalled by hanging the posters next to each other. Now the group decides which research question is **most relevant to the project**. This can be done e.g. by assigning sticky dots, or by voting with the digital tool "**Mentimeter**".

If the group decides to continue with multiple research questions, **prioritization** can be done in the same way.

⏰ *20 minutes break*

Method 21: Study Design Guide
Placement Method

Why? Embed research questions in a study design.

Duration? 80-90 minutes

Materials:

- Lab-book worksheet & presentation "Study Design Guide" *(see Lab-Book + collection of materials)*
- moderation cards (5 colors)
- flipcharts
- pens
- magnets or adhesive tape to hang up cards

Description

We have the research question, and creative approaches to solving it. Now the group has to develop a study design for it. In order for everyone to be able to contribute well, the unit consists of 5 sequential steps: individual work, group work, plenary discussion, opinion overview, documentation.

1. Individual Work:
Each participant has a worksheet with five questions in the Lab-Book. These can be projected on the wall or written on a flipchart (topics: Planning, Methodology, Sample, Survey, Open - *see Lab-Book and material collection*). During individual work, the participants try to answer each question as best as possible **in relation to the research question** and also to note down uncertainties in their Lab-book.
Duration: approx. 45 minutes

2. Group Work:
Now 3-4 small groups are formed. Important: In each group different expertises should be represented! The **5 questions are now discussed together**, with each person contributing the results of the respective individual work. The goal is to find one or more common answers, ideas, concerns or suggestions, throught the group. These are written on moderation cards. If desired, the co-moderation team can specify a particular color of card for each question.
Duration: approx. 60 minutes

⏰ *1,5 hours lunch break*

Method 22: Activation after Lunch Break
Thunderstorm Alarm

Why? Activation after lunch break

Duration? 5-10 minutes

Description

We already know this from the previous module: After lunch, the energy level is very low. Time for a short activation exercise. Here's how it works: The participants form a circle. A moderator stands in the middle and leads as followed:

- **"Sunshine"**: friendly smile

- **"The calm before the storm"**: concentrated calm and silence.

- **"The leaves rustle in the wind"**: rub fingertips together

- **"The rain is coming"**: rubbing hands together

- **"The first drops are falling"**: slowly snap the fingers of one hand together

- **"The rain is getting stronger"**: snap the fingers of both hands firmly and quickly

- **"The rain is pattering"**: clap quickly

- **"Thunder starts"**: additional stomping, 1-2 participants lie down on the ground

- **"Climax of the storm"**: everyone claps and stomps.

Then rebuild the storm in reverse order until the sun shines again!

MODULE 4

Method 21: Study Design Guide (Continuation)
Consensus-Building Process

Why? Embed research questions in a study design.

Duration? 80-90 minutes

Materials:

- Lab-book worksheet & presentation „Study Design Guide" *(see Lab-Book + collection of materials)*
- moderation cards (5 colors)
- flipcharts
- pens
- magnets or adhesive tape to hang up cards

Description

3. Plenary Discussion:

The groups have discussed the study design in detail, during the lunch break there was probably further discussion. Now it is time to take the results to the plenum and discuss them there. **Each group presents their results** and sticks their cards to the respective question (previously written on flip charts or pinboards by the co-moderation team). In an open discussion, the results are then clustered and prioritized, if necessary. In this way, five posters with the most important ideas, suggestions and also questions about the study design are created. **Important**: The co-moderation team ensures that all voices are heard and the exchange is respectful (reference to the "game rules").
Duration: approx. 60 minutes

4. Opinion Piece:

After the discussion, the co-moderation team asks the participants to express their agreement or disagreement with each of the five posters. To avoid peer pressure, it is recommended to use a digital voting tool such as "**Mentimeter**". Alternatively, participants can vote by "blindly raising their hands": Participants keep their eyes closed. The goal is to reach a consensus that all group members are happy with.
Duration: 10-20 minutes

5. Documentation:

The study design decisions made should be recorded to ensure that all participants have the same understanding and can reconstruct the decisions later. Additionally, participants can record the results in their Lab-Book. For this some extra time must be scheduled.

⏰ *20 minutes break*

Method 23: Further Procedure
Impulse Lecture

Why? The participants receive information on the next steps

Duration? 30 minutes

Description

What happens next? That depends on the project! Therefore this sequence has to be created individually by each research project. In a short impulse lecture, the co-moderation team informs the participants about how to proceed. Afterwards, based on the questions of the participants, it will be discussed together what will happen with the results. In any case, the following questions should be answered:

? What will happen with the **results** of the workshop?

? How will the project **continue**?

? Will the group remain **involved**? If yes: How?

> The participants want to know what happens next!

Optional: if participants are involved in the further course of the project, they should actively consider how. In a short sequence (**approx. 10 minutes**), they write down in their Lab-Book what ideas they have about this. Afterwards, the group discusses and the next steps are defined (**approx. 20 minutes**). One person can also remain involved on behalf of the group.

Method 24: Reflection
ABC Method

Why? Reflecting and solidify the workshop content.

Duration? 15-20 minutes

Materials:

- prepared materials
- pens

Description

We are approaching the end and review of the workshop. On a pre-made poster, the co-moderation team (or a helper from the group) has written down all the **letters of the alphabet** in three columns, with enough space between them. Now the participants are asked to write a term for each letter that relates to the workshop. These can be technical terms as well as atmospheric terms. The goal is to find at least one word for each letter. It is explicitly desired that there is more than one term for each letter.

Tip: There is more space on the poster in landscape format!

Method 25: Feedback
Weather Forecast & Feedback Forms

Why? Atmospheric and anonymous Feedback.

Duration? 15 minutes

Materials:

- prepared online (or printed) survey
- cotton ball

Description

The workshop was a great success, everyone goes home happy. Right? That's what the participants themselves should say. Therefore, there is a short feedback round at the end: a so-callen **weather report**. The co-moderation team introduces the task as follows: „Imagine you are giving feedback on this day. Do this in the form of a short weather report!" Whoever's turn it was nominates the next feedback giver (e.g., by tossing the ball). According to experience, some participants will add a few personal sentences to their „weather report", which is totally fine. The co-moderation team also participates.

Afterwards, **5 minutes** should be planned for anonymous, written feedback.

Then: Farewell, conclusion. Done!

> **Filling out the feedback forms should take place during the workshop!**

What is Needed after the Workshop

I also welcome feedback on the workshop and this guide!

CONTACT:
office@ccieurope.eu

Conducting the Evaluation

After the workshop is before the next workshop. To strengthen strengths and learn from weaknesses, a precise **analysis of the feedback** from the participants is recommended. Important: Take points of criticism seriously and evaluate objectively whether they require adjustment in the event of further workshops.

Unwinding the Documentation

During the workshop, the results should be **documented photographically**. If a participant is commissioned to do this, they should not forget to send it **to the co-moderation team** at the end of the workshop. The photos can be named and filed systematically, so that they can be clearly assigned later when the research group is working with them.

If the documentation - or parts of it - is made available to the participants, the corresponding photos can be compiled and transmitted, e.g. in a PDF file.

What Happens Next?

Whatever happens next, **the workshop participants want to know**. And for good reason: They have invested two weekends to support the project. How the workshop results are implemented in the further research process may vary from project to project. We recommend to give the workshop participants an outlook and to answer the following questions:

? What will happen to the **research group**? Will it remain in existence?
Will there be further projects for them? Was this a one-time research trip?

? How will the group continue to be involved if the **project continues**?
Where do they need to be involved?

? Are there continuing projects where the group itself can be **involved**?

? What happens to the **outcome** of the workshop?

? How will the group be **informed** about the results of the research?

Let's look at the future together!

SPACE FOR THOUGHTS

At the End

Hello, it's me again.
Did you enjoy the workshop?
I hope so!

Congratulations to the entire workshop group. By participating and conducting this workshop pioneer work has been done. Toward truly inclusive research and development. Or, to stay with the image of the apple from the introduction: The research group now not only knows the size and weight and other measurable data - it now also takes taste into account as a key characteristic. Simply put: The research group integrates the **expertise of patients** into the project from the very beginning.

And that has many advantages:

- The research questions are more **precise**.

- The research findings are **high quality and relevant**.

- There is a **serious focus on the needs** of patients.

- Research and care **become more comprehensible and more important**.

Apple or not: Through the workshop, everyone contributed to the common goal: **To improve research and care**. So that the apple tastes less sour.

Until next time!
Claire, Patient Expert

SPACE FOR THOUGHTS

At the End

Further Literature

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