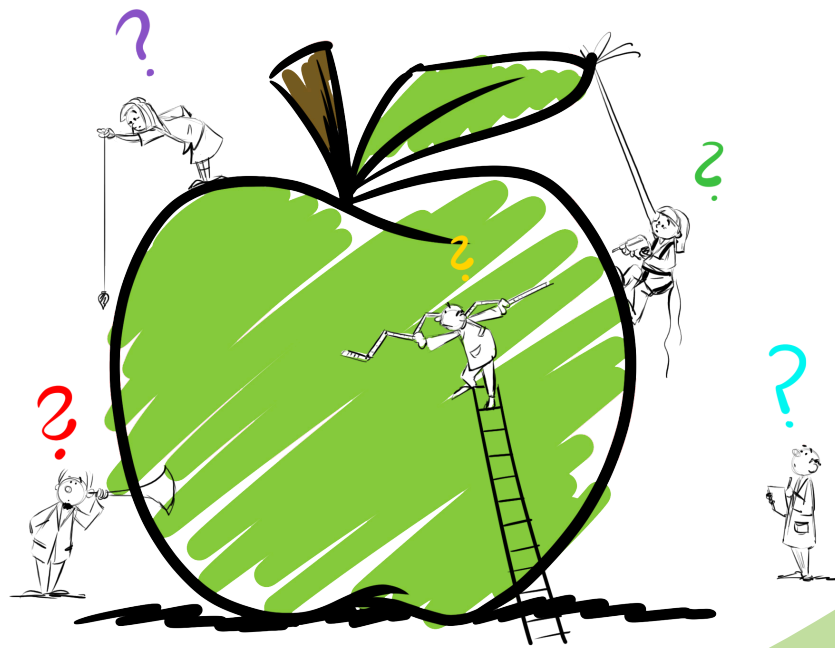


ANNEX 1

# LAB- BOOK

BRIDGING THE GAP

RESEARCH TOGETHER  
IN THE JUNIOR RESEARCH ACADEMY



Financed by:



LUDWIG  
BOLTZMANN  
GESELLSCHAFT  
Open Innovation in Science Center

Implemented by:



MEDIZINISCHE  
UNIVERSITÄT WIEN



COPEGROUP  
CHILDHOOD, ONCOLOGY, PSYCHOLOGICAL RESEARCH, EMPOWERMENT



Childhood  
Cancer  
International  
EUROPE



KURVENKRATZER



# Foreword

## Hello!

My name is Claire and I have a request. I would like people to have a better understanding 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.

This probably sounds familiar to some of you: If you are a patient or a patient's family member and you are participating in this workshop, you have probably taken a bite out of your own sour apple.

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, so that those people are the 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: Researchers - for example, from the fields of medicine, psychology, nursing, social work and many other fields.

Now we get to the heart 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 bring with them. Because only they 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 jointly developed **research questions with a high degree of relevance**. Scientific questions that include us patients and our relatives from the very beginning and take our experiences and needs seriously. And based on these, creating **project plans** to implement the research together.

This applies to all areas in which research is happening! Like a jigsaw puzzle, we have to take all the experiences relating to the body, the mind and the social sphere into account in equal measure 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 - also in the selection of experts.

Every apple tastes different!



In this workshop we address the specific topic:



I'm sure your moderation team has a good example of how PPIE has been used in your area.

# Foreword

You received this document in preparation for the workshop.  
It contains the following information:

- 🍏 What is **Patient & Public Involvement and Engagement** (PPIE)?
- 🍏 The workshop “**game rules**”
- 🍏 Expandable **PPIE dictionary** for the workshop
- 🍏 A **space for notes and thoughts**

Use your Lab-Book,  
so everything is in one place.



A basic requirement for working together well is that all participants, despite their diverse backgrounds, are able to participate on an **equal** footing. This is the only way to achieve the goal: 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. We all want to **improve research and care**.

**Enjoy the workshop!**

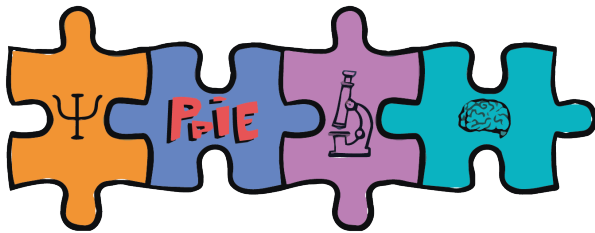
**Claire,  
Patient Expert**



# 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.



If you're wondering about the meaning of some terms you are unsure of, go to your PPIE dictionary on page 7.

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 been barely taken into consideration in practice, which not only leads to frustration, but also diminishes the **validity of studies**. And with it the quality of the treatment approaches being researched.

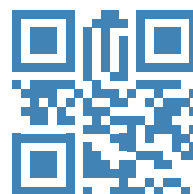
The answer to this discrepancy is called "**Patient and Public Involvement & Engagement**", short PPIE. Sounds bulky, but it's a minor revolution: it means that research and development in the health care sector are carried out together WITH or even BY patients and representatives of the public, not 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 the collecting and analyzing of the data gathered
- Thanks to the expanded, multidisciplinary approach, the research and the projects developed benefit from **better research quality**
- They are **more effective** overall because the needs of patients and their valuable experiences 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.



In my video I tell you even more about PPIE!



# GAME RULES

## How do We Want to Work Together?

You now know the goal of this workshop. Then let's briefly consider how we work together, so that everyone can have fun and contribute optimally.

- **At eye level:** Use technical terms consciously and explain them. The glossary, which you can add terms to yourself, is useful here (next page).
- **First names first:** addressing people by their first names is a good way to work together. This loosens the atmosphere and you can more easily find common ideas and work creatively.

## 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 each one brings to the table and their achievements.
3. **“Use solution-oriented language.”** Avoids killer phrases. Instead of “It won't work anyway,” use “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.

You feel there is a rule missing? Share your thought with the group!



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



# NAME TAG



**bend here**

Space for your name:





# PPIE Dictionary 01

**Specific fields need specific terms. And they are usually quickly explained - even when it comes to diagnostics, treatment and research of an oncological disease. So to make sure we all speak the same language in the workshop, we have prepared a glossary. The special feature: You can expand it yourself.**

**This is how we deal with it in the workshop:** If a technical term occurs, the person who uses it should also explain it. In addition, one participant will make sure that this actually happens, (we will determine who will take on this role together on site). We will document the given explanation, furthermore you can enter it in this **personal glossary**.



## MY PPIE DICTIONARY

**PPIE:** Stands for Patient and Public Involvement & Engagement.

It sounds bulky, but it is a small revolution: This approach means that research and development in the health sector should be carried out **WITH or even BY** patients and representatives of the public, not **ABOUT** or **FOR** them. PPIE stands for a democratization of research and development.

**Participation:** An essential first step when it comes to patient involvement. It is a **partial participation** of patients in studies through questionnaires, interviews, focus groups, etc.

**Engagement:** This refers on the one hand to **raising awareness** about a topic, such as spreading information about research via (social) media, science festivals, workshops or open house days. On the other hand, it also means the active participation of patients in the research process by taking on tasks.

**Involvement:** The real thing! This refers to the active, full involvement of patients in research projects. **What's meant** here is the joint identification of research topics, phrasing of research questions, submission of proposals. Patients are members of steering committees, help in the development of information materials, in conducting interviews, etc.

**Patient Advocates:** These are individuals - often former patients - who serve as **advocates** for the interests of patients - towards institutions, healthcare professionals, the pharmaceutical industry, politicians, in various committees as well as in public.

# PPIE Dictionary 02

**Patient Organisation Representatives:** Representatives of organizations that advocate on behalf of patients. They represent the views of their respective patient organization.

**Patient Experts:** The name says it all: These patients are real experts! They are people who on the one hand have valuable experience as patients. On the other hand, they have specialist expertise in one or more areas through appropriate further training. This enables them to actively participate in research & development, health policy, etc.

**Individual Patient:** Refers to the individual patient. Those, who had to take a bite from the sour apple, have also gained a lot of experience. For many areas of research, this knowledge is a valuable contribution.

**Carers (or Caretakers):** This term stands for all persons who are close to the/a patient and accompany them on their treatment path: Relatives, friends, trusted persons.

Further terms can be added at will!

Caution! Now the content of the workshop starts. What type are you?

**The information-seeking typ:** Already looking at the upcoming pages, or the **adventurer:** Looking forward to the surprise and only starts reading the upcoming pages during the respective session.



# PPIE Dictionary 03

Remember to bring your Lab-Book to the workshop



Further terms can be added at will!

A large, empty rectangular box with a thin green border, intended for writing or drawing terms to be added to the dictionary.

# SPACE FOR THOUGHTS

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



# My Team 01

**Workshop Title:**

**Meeting Point** (adress/institution):

Exchange your contact details to stay in touch

**Which role are you and your team members taking on?**



**Timekeeper** – makes sure that the time frame is not exceeded.



**Photographer** – takes pictures of the results and the group and sends them to the co-moderationteam afterwards.



**Walking dictionary** – notes technical terms and explanations on a chart. Reminds the group to explain technical terms if they forget.



**But-Guard** – intervenes when someone says “but” in a discussion and turns this into an “and”.



**Charger** – pays attention to the energy level in the room and calls for breaks if it is too low.



## The Moderating Team and its Supporters

**NAME/ROLLE**

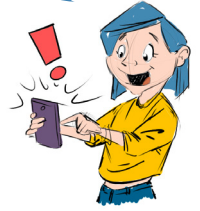
**CONTACT DETAILS**

Feel free to write down, what roles your teammates take on.

NAME/ROLLE	CONTACT DETAILS
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# My Team 02

Exchange your contact details to stay in touch.



## Workshop Participants:

NAME / ROLE

CONTACT DETAILS









































NAME / ROLE	CONTACT DETAILS
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# My Team 03

Exchange your contact details to stay in touch.



## Workshop Participants:

NAME / ROLE	CONTACT DETAILS
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# SPACE FOR THOUGHTS



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# Avatar Worksheet

## BUILD YOUR AVATAR



### 1. Build

 Space for your avatar

### 2. Describe

1. What are your strengths?

2. What expertise do you bring to the table?

3. What special qualities do you have?

4. What 5 important milestones have you achieved/experienced so far?

### 3. Share Your Avatar With the Group

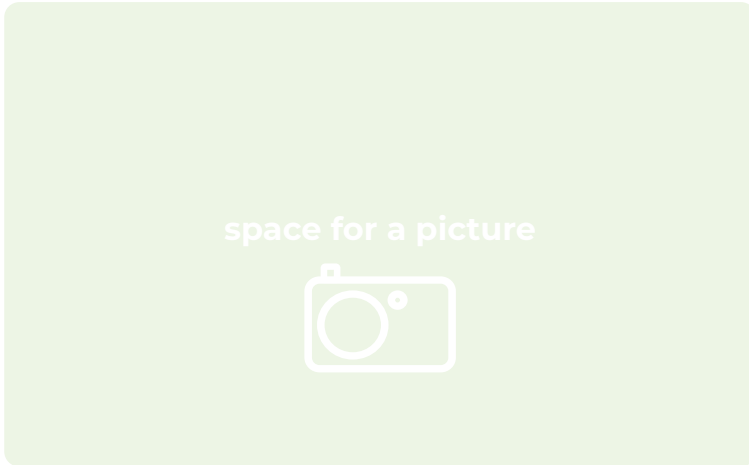
# SPACE FOR THOUGHTS



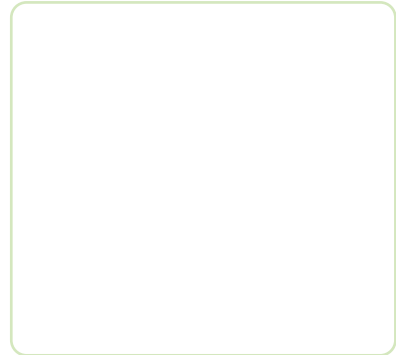
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# My Research Group

Name:



This could be our logo:



This is our goal:

A large, empty white rectangular box with rounded corners and a thin green border, intended for writing the group's goal.

This is the research project we are pursuing:

A large, empty white rectangular box with rounded corners and a thin green border, intended for describing the research project.

These are the strengths and expert knowledge we bring to the table:

A large, empty white rectangular box with rounded corners and a thin green border, intended for listing strengths and expert knowledge.

# SPACE FOR THOUGHTS

A large grid of small dots for writing thoughts.



# The Miracle Question



**Imagine, you're waking up and the problem**

**is solved.**

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

**Which problems/difficulties would be solved through your research project?**

**Who else would recognize this miracle and that your problem no longer exists?**



# SPACE FOR THOUGHTS



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# Invention Worksheet

## BUILD YOUR INVENTION



### 1. Build



Space for  
your invention

### 2. Describe

1. Which problem does your invention solve?

2. Which features does your invention have?

3. What's your invention's name?

**3. Share Your  
Invention With the Group**

# SPACE FOR THOUGHTS



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# How Does Research Actually Work?

## 1. Starting Point, Idea, Goal

What problems are being observed?  
 What shortcomings exist?  
 What questions arise?  
 What is necessary in order to create/use the invention?



## 2. Literature Research, Collaborations

What do we already know?  
 Who are the experts?



## 3. Scientific Research Questions, Forming Hypothesis

Which question can be precisely investigated?



## 5. Planning the Study

Who can participate/who cannot? How many people should participate? When/Where/How long should be examined? What is reasonable? What methods are to be used? what is the research project's time frame? Are they fair/repeatable? Are they really measuring, what they claim to measure? Are there confounding factors? Is there a control group? Is there an external control authority (ethics committee)?



## 4. Operationalization

How do I pose my research question to have measurable answers?  
 How do I recognize success/failure/change?



## 6. Data Collection

What tools are being used? Are there standards or norms?



## 7. Data Analysis and Interpretation

Is the data protected (no personal data!)? Are the data controlled? Are there "biases" (systematic errors) in the data? Which statistical evaluation methods can be applied?



## 8. Publication, Dissemination, Implementation

Where should the results be published? In which medium and with which quality criteria (peer review)? Are the results accessible (Open access)? Are the results applicable in practice?

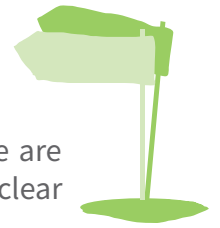


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# The Study Design Guide 01



We have the research question and creative approaches for solutions. Now we are going to create a **study design**. Now try to answer each question. Note any unclear points.



Here you can write down the research question we agreed on in Module 4.

## Planning

1. What information do I need to be able to answer the question?

2. What methods/strategies to gather information do I know?  
What are the advantages and disadvantages?

## Methods

## Sampling

3. Which group of people has the information I need to answer my question?  
Is it several people? How many?

## The Study Design Guide 02

**4.** When is the right time to gather this information? Should it be gathered once or more often?  
Should I collect data/information for a longer period of time?

**Collection**

**5.** What questions/points are still unclear after taking point 1-4 in consideration?  
Who do I need to ask/include/talk to/.. to answer my questions? What risks are there?

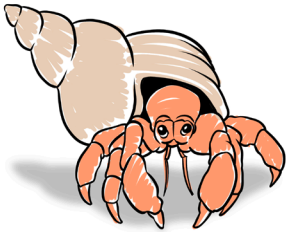
**Open questions**

**Space for  
Notes**

# Here's How We Continue

In our joint workshop, we have gathered **valuable knowledge** and developed great content together. As a team, we are already making an **important contribution to PPIE**.

I'm interested now though:  
What do you wish for regarding the further course of this project?



Here you can ask how the project will continue and whether you will be informed automatically about the further course of the project.

# SPACE FOR THOUGHTS



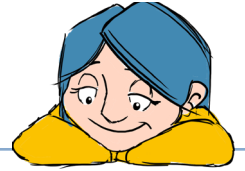
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# NOTES



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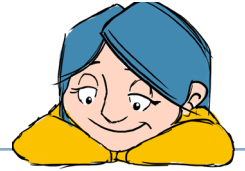
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**That's the core message I take away:**

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# NOTES



**I take notes on this method:**

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**That's the core message I take away:**

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# NOTES



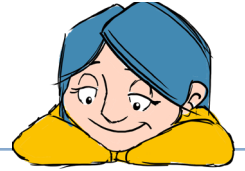
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# NOTES



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## Imprint

**A project of the Medical University of Vienna with the COPE Group in cooperation with CCI Europe supported by Kurvenkratzer, NF Kinder, EUPATI Austria and Survivors Austria, funded by the LBG Open Innovation in Science Center.**

**Medical University of Vienna**, University Hospital for Pediatrics and Adolescent Medicine, Comprehensive Center for Pediatrics, Währinger Gürtel 18-20, 1090 Vienna, [www.meduniwien.ac.at](http://www.meduniwien.ac.at).  
**CCI - Childhood Care International Europe**, Handelskai 94-96, 1200 Vienna, [www.ccieurope.eu](http://www.ccieurope.eu)

**Illustrations by Bone Buddrus, graphic design and design by Kurvenkratzer.**

**Project Team:** Living PPIE means thinking in an interdisciplinary and holistic way. In order to bring in a variety of perspectives, the project team was deliberately composed of people with diverse expertise, each of whom made their contributions at different stages of the project.

### Project Management:

**Liesa J. Weiler-Wichtl**, *Clinical and Health Psychologist, Medical University of Vienna/COPE Group.*  
**Carina Schneider**, *Psychologist, Patient Expert, CCI Europe*

### Conception and Implementation:

**Ulrike Leiss**, *Clinical and Health Psychologist, Medical University of Vienna/COPE Group*  
**Hannah Gsell**, *Psychologist, Patient Expert, CCI Europe, Survivors Austria*  
**Anna Maletzky**, *Clinical Psychologist, Medical University of Vienna*  
**Johannes Gojo**, *Physician, Medical University of Vienna*  
**Anita Kienesberger**, *Patient Advocate, CCI Europe*  
**Claas Röhl**, *Patient Advocate, NF Kinder, EUPATI Austria*  
**Martina Hagspiel**, *Patient Advocate, Kurvenkratzer*  
**Albina Hyseni-Bocelli**, *Project Coordinator, CCI Europe*  
**Lena Horvath**, *Project Coordinator, Kurvenkratzer*  
**Florian Lems**, *Workshop Concept Developer, Kurvenkratzer*  
**Tanya Kaindlbauer**, *Editor, Kurvenkratzer*  
**Lena Kalinka**, *Graphic Designer, Kurvenkratzer*  
**Bone Buddrus**, *Illustrator*  
**Nicola Unterecker**, *Translation*  
**Regina Elias**, *Proofreading*

### Involved Individual Patients & Carers and Other Project Staff (Public Involvement):

**Bettina Baldt**, *Psychologist*  
**Lisa Cate**, *Patient Expert*  
**Monika Czajka**, *Individual Carer*  
**Sabine Karner**, *Patient Expert*  
**Anna Lämmerer**, *Patient Expert*  
**Rita Hansl**, *Research Assistant*  
**Maximilian Hopfgartner**, *Research Assistant*  
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**Delphine Heenen**, *Patient Advocate, Content Advisor*  
**Alice Gerbaux**, *Patient Advocate, Content Advisor*

**Daniela Koczera**, *Individual Patient*  
**Marie Therese Gubi**, *Individual Patient*  
**Maria Willomitzer**, *Individual Carer*  
**Valentin Willomitzer**, *Individual Patient*  
**Anna Zettl**, *Patient Expert*  
**Sybille Zettl**, *Individual Carer*  
**Stefan Pinczolits**, *Individual Patient*  
**Doris Schober**, *Individual Carer*  
**Florian Müller**, *Individual Patient*  
**Manuel Hauer**, *Individual Patient*  
**Maria Hauer**, *Individual Carer*  
**Aisa Jusic**, *Individual Patient*

*And many more  
Individual Patients  
& Carers.*

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