

## Decision Guide For Partnership Research: *To Partner or Not To Partner?* Information for Lived Experience Experts

Partnership research is about meaningful collaboration between researchers and people with lived experience of the topic. *Lived experience experts* might include patients or their family members. Partnership research is especially helpful for ensuring the study being conducted is relevant and valuable for the people it affects most.

Deciding to partner in research can be challenging for both the lived experience expert and the researcher. Taking time to consider some key areas can help you make an informed decision about whether partnering in a project is right for you. The following guide offers key information and prompts for reflection to help you make an informed decision.

**Begin by considering each question below and place an X along the sliding scale. Next, discuss your guide with your potential research partner.** The researcher should complete the *Researcher companion decision guide* and discuss their results with you as well.

### IMPORTANT FACTORS WHEN MAKING A DECISION ABOUT PARTNERING IN RESEARCH:

#### Role

The role and responsibilities involved in the project should be clear and fit for you.

#### Knowledge

You should have knowledge about the topic area and your lived experience should align in some way with the project.

You should also have training and support to develop the necessary skills to partner in the project.

#### Time

There might be a little or a lot of time required, depending on the project. Time is important to consider.

#### Values & Benefits

The project should align with your personal values and feel safe for you.

Your expertise might even be financially compensated.

### DID YOU KNOW?

There are a variety of involvement roles for lived experience experts in the research process.

These roles vary in the degree of time and participation required as well as your comfort level in sharing ideas.

**Think about these roles and decide, which feels best for you?**

| Involvement Role   |  | I am seeking ...  |
|--|--|--|
| <b>Listener</b><br>       | <b>The person in this role is given information</b><br>(e.g., researcher gives the lived experience expert a project plan to review)   |  |
| <b>Co-Thinker</b><br>     | <b>The person in this role is asked to give their opinion</b><br>(e.g., lived experience expert gives their opinion about an information letter for study participants)                  |  |
| <b>Advisor</b><br>        | <b>The person in this role gives both solicited and unsolicited advice</b><br>(e.g., lived experience expert proposes improvements to a survey or speaks up about an overlooked barrier) |  |
| <b>Partner</b><br>        | <b>The person in this role works as an equal partner</b><br>(e.g., lived experience expert and researcher write a grant or article together)   |  |
| <b>Decision Maker</b><br> | <b>The person in this role takes initiative and makes decisions</b><br>(e.g., lived experience expert develops a website about the project or presents results at a conference)          |  |

[www.participatiematrix.nl](http://www.participatiematrix.nl)

Be sure to ask the researcher what role they are seeking to ensure a good fit between yourself and the project.

**Do you understand your role and the role of others? What role fits best for you?**

1.

*I understand my role very well*

*I am unclear on my role*

2.

*I understand the role of other team members very well*

*I am unclear on the role of other team members*

3.

*After considering the different involvement roles and talking to the researcher, the role they are seeking matches for me*

*After considering the different involvement roles and talking to the researcher, the role they are seeking doesn't match for me*



**Do you have the necessary knowledge, personal connection, and training?**

4.

*I have a lot of knowledge about the topic*

*I have little knowledge about the topic*

5.

*I have a close personal connection to the topic*

*I have no close personal connection to the topic*

6.

*I or my family member are similar to the people the study is about*

*I or my family member are different from the people the study is about*

7.

*I have the training and support I need to partner in the project*

*I don't have the training and support I need to partner in the project*



**What further knowledge and skills might you need to partner in the research project (e.g., research ethics training, confidence speaking in a group, conflict management):**

---



---



---

**Do you have time?**

8.

*I have a lot of time to offer to the project*

*I have little time to offer to the project*

9.

*I have flexible days and times to offer*



*I only have specific days and times available*



**Are your personal values aligned?**

10.

*The research project aligns with my physical, emotional, and spiritual values (e.g., comfortable with the topic, content, intervention)*

*The research project does not align with my physical, emotional, or spiritual values (e.g., uncomfortable with the topic, content, intervention)*

11.

*I feel physically, emotionally, and spiritually, safe to talk about the research topic*

*I feel physically, emotionally, or spiritually unsafe to talk about the research topic*

12.

*The topic and partnering with researchers does not trigger negative feelings for me*

*The topic and partnering with researchers triggers negative feelings for me*



13.

*I would like to be financially compensated for my contribution to the project*

*I would like to contribute to the project without financial compensation*



What personal barriers might get in the way when partnering in the research project:

What personal facilitators might help when partnering in the research project:

---



---



---



---



---



---

After considering the role, knowledge, time, values, and benefits associated with the research project, it's time to decide!

14.

*Partnering in this research project is a good fit for me right now*

*Partnering in this research project is not a good fit for me at this time*

