

Decision Guide For Partnership Research: *To Partner or Not To Partner?* Information for Researchers

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 lived experience expert partner. The lived experience expert should complete the *Lived Experience Expert* companion decision guide and discuss their results with you as well.

IMPORTANT FACTORS WHEN MAKING A DECISION ABOUT PARTNERING IN RESEARCH:

| Role | Knowledge | Time | Values & Benefits |
|---|---|--|--|
| <p>The role and responsibilities involved in the project should be clear and fit for you.</p> | <p>You should have knowledge about the partnership research process and the lived experience experts' background should align in some way with the project.</p> <p>You should also have training and support to develop the necessary skills to partner in the project.</p> | <p>There might be a little or a lot of time required, depending on the project. Time is important to consider.</p> | <p>The project and idea of partnership research should align with your personal values and feel safe for you.</p> <p>You should think about financial compensation for the lived experience expertise you are seeking.</p> |

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 their comfort level in sharing ideas.

Think about these roles and decide, which role are you seeking for your project?

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

Be sure to ask the lived experience expert what role they are seeking to ensure a good fit.

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. *I would like to liaise and work directly with the lived experience expert as the researcher* | *Someone else on the research team will liaise and work directly with the lived experience expert*

4. *After considering the different involvement roles and talking to the lived experience expert, the role I am seeking matches* | *After considering the different involvement roles and talking to the lived experience expert, the role they are seeking doesn't match*



Does the lived experience expert fit? Do you have the necessary knowledge and training for partnership research?

5. *The lived experience expert has a lot of knowledge and a personal connection to the topic* | *The lived experience expert has little knowledge and/or personal connection to the topic*

6. *The lived experience expert is similar to the people the study is about* | *The lived experience expert is different from the people the study is about*

7. *I have the training I need to partner with patients and families in research* | *I don't have the training I need to partner with patients and families in research*



What further knowledge and skills might you need to partner in the research project (e.g., group facilitation skills, collaborative communication, conflict management, patient engagement training):

Do you have time? What Time is Required?

8. *I have a lot of time to devote to relationship building and collaborative partnership within this project* | *I have a little time to devote to relationship building and collaborative partnership within this project*

9.

The time I require from the lived experience expert is flexible



The time I require from the lived experience expert requires specific days and times



Are your personal values aligned?

10.

The idea of partnership research aligns with my physical, emotional, and spiritual values (e.g., comfortable with the idea of partnership research)

The idea of partnership research does not align with my physical, emotional or spiritual values (e.g., uncomfortable with the idea of partnership research)

11.

I feel physically, emotionally, and spiritually safe to engage in partnership research

I feel physically, emotionally, or spiritually unsafe to engage in partnership research

12.

Partnering with lived experience experts does not trigger negative feelings for me



Partnering with lived experience experts triggers negative feelings for me



13.

I am able to offer financial compensation to the lived experience expert



I am unable to offer financial compensation to the lived experience expert



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 partnering in research, 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

