

# EMBEDDING THE PATIENT VOICE IN PARKINSON'S RESEARCH

## THE WHO, WHAT, WHY AND HOW OF ENGAGING PATIENT RESEARCHERS

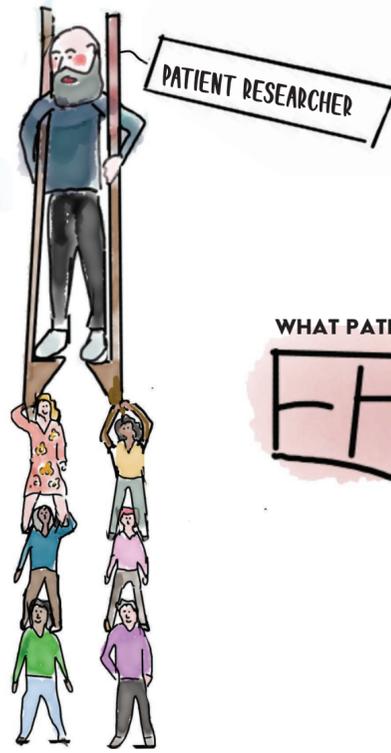
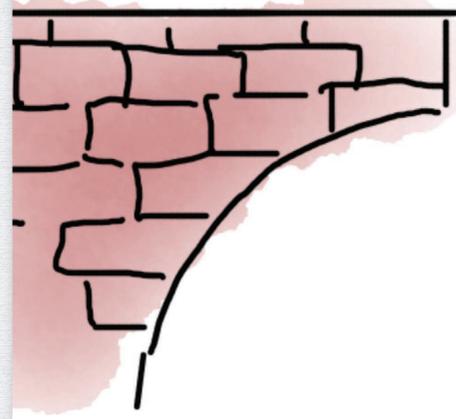
This is the visual interpretation by Marina Noordegraaf of the article by Meinders, M. J., Donnelly, A. C., Sheehan, M., & Bloem, B. R. (2022). Including People with Parkinson's Disease in Clinical Study Design and Execution: A Call to Action. Journal of Parkinson's disease, <https://doi.org/10.3233/JPD-223190>.

### WHO

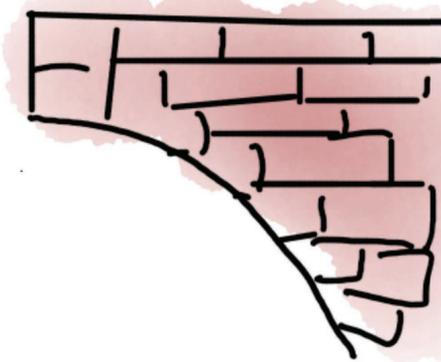
Patient researchers represent the patient voice in clinical research, from inception until implementation. They have Parkinson's or are loved ones of someone with Parkinson's. They are interpreters and translators between the language of science and the language of lived experience.

*think that patients*

WHAT RESEARCHERS WANT

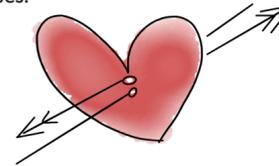


WHAT PATIENTS WANT



### WHY

Participation of patient researchers bears the following promises:



#### FUN AND WORTHWILE

Embedding patient researchers in your research project makes research more enjoyable, worthwhile. You are reminded whom you are doing it for.

#### EFFICIENT

Successful engagement of patient researchers in your research project ensures a better fit between what patients want and what researchers (think patients) want. It increases the chance that the research is relevant, feasible, accessible and useful to the patients that patient researchers represent.

### HOW

Successful involvement of patient researchers is not self-evident. To keep up to the promises and make a suitable match, the researchers give the following tips:



#### ANTICIPATE

Support patient researchers. Include costs for patient researchers in funding proposals. If needed, offer training to patients to be able to represent the patient voice.

#### EXCHANGE EXPECTATIONS

Actively discuss motivations and expectations. What role is envisioned for patient researchers in what research phase? Lead, assist, advise? In what ways and how often is participation useful? How much time will it take?

#### TUNE-IN INTO PARKINSON'S

Parkinson's may come with reduced mobility, a soft voice, obstacles in thinking (e.g. problems multitasking), diminished organisational skills, small or illegible handwriting, fatigue, depression, etc. Ask which symptoms hinder someone and what they need to make the voice of the patients they represent heard as loud as possible.

#### MAKE IT ACTIONABLE

Make arrangements to circumvent mentioned obstacles. Discuss the best location and timing for meeting, e.g. only discuss research during on-time, in the morning when fatigue hasn't kicked in yet, prepare handouts to help keep an overview, summarize, etc

Make arrangement about compensation. How are patient researchers reimbursed for their expenses and time?

#### ADJUST

Evaluate the value of the collaboration and adjust course along the way, if necessary.

#### DO RESEARCH

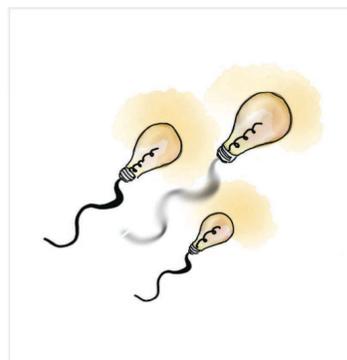
Conduct follow-up research into success factors for valuable patient researcher participation.



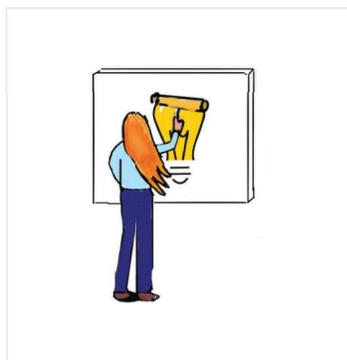
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### WHAT

Patient researchers ask questions and give tips from the patient's perspective. This can make sense in all research phases, from the idea to implementation in daily practice. Examples of questions are shown below.



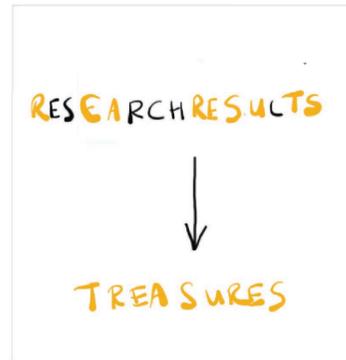
**From research to research question**  
How is the idea relevant to patients? What research priorities do people with Parkinson's (PwPD) have?



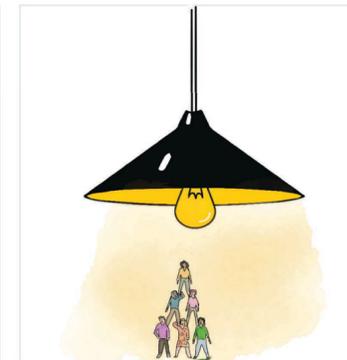
**From design to fit**  
What outcome measures matter to PwPD? Is the study protocol tailored to patients' possibilities and restrictions?



**From recruitment to engagement**  
How to truly engage research participants? What drives PwPD to participate? What matters to them?



**From data to meaning**  
How should we understand the data? How can we translate the results to the patient community in a way they can connect and interact?



**From results to impact**  
How do we stay focused on implementation? How to make sure the patient community benefits?