

Patient and Public Involvement in Stroke Research: The BEFORE Recommendations

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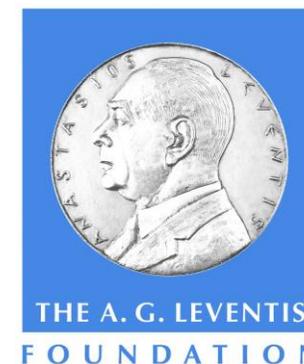
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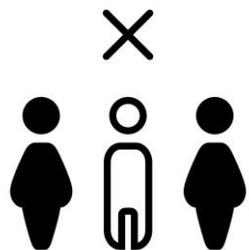


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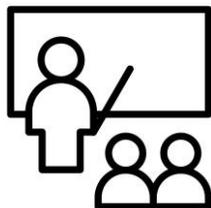
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Background



People with stroke and aphasia are often excluded from studies

(Charalambous et al., 2020)



If they do, their engagement is characterized as tokenistic

(McMenamin et al., 2022)

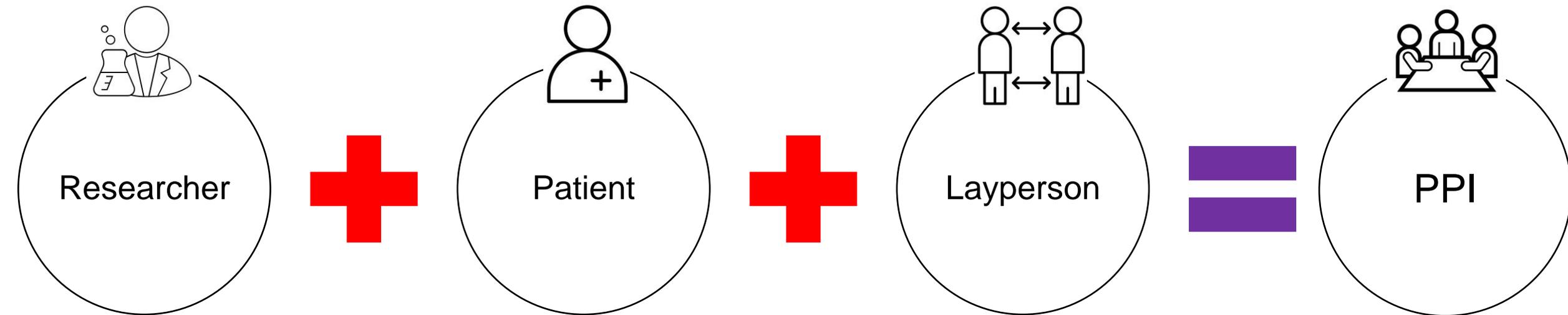


The mandate from funders is to actively involve patients in scientific teams

(Jayes et al., 2021)

Patient and Public Involvement (PPI)

is the active collaboration between researchers, patients and laypeople
in the processes of creating research



Objective



to explore the views and perspectives of people who live with chronic stroke on their potential involvement as research partners

Participants

8 people with chronic stroke (4 with aphasia and 4 without)

6 European countries



Criteria:

- Stroke diagnosis
- Chronic Phase (> 6 months post stroke)
- Speak & Understand English
- Socially active
- Research experience

PPI Method

- The research team included a person with chronic aphasia
- We followed the Dialogue Model (Abma et al, 2015)
- Semi structured interviews were subject to thematic analysis (Braun & Clarke, 2006)



The **BEFORE** recommendations

For researchers to consider *before* commencing PPI research, are as follows:

1. **B**uild rapport, explain commitments and offer information prior to involvement
2. **E**stablish communication needs and barriers
3. **F**oster a robust support system
4. **O**ffer accessible training courses on PPI research
5. **R**einforce the use of tailored resources
6. **E**ncourage patient partners to participate in support groups

BEFORE

1. Build rapport

Organize one to one meetings with patient partners:

- Explain project commitments & provide timetable

“Time is always an issue. You see I have my work and family also. Maybe not full-time research partner” (person with stroke, Switzerland)

- Offer options of transport

*“I cannot take the car...nor the bus. It takes time [...] tired. Maybe do meetings online”
(person with stroke, Cyprus)*

“I need someone to take me to places, with aphasia is difficult to drive [...] home visit is better for research” (person with aphasia, Greece)

BEFORE

2. Establish needs and barriers

Proceed with patient partners detailed case history interview:

- Assess communication needs

“Involved, that can bring something to the people with aphasia. It... ammm... making it easier for them to communicate? ...So that I can help them with whatever the problem is... a bit communicate, a bit the family, a bit at the workplace, whatever it maybe hopes to contribute a little bit to”(person with stroke, Portugal)

- Explore barriers to active involvement

“I think what is very difficult to me to be in a group. I had the stroke and I came back I was lucky that I had very light consequences, but I have to manage somehow my real state of fatigue. It’s difficult to attend long meetings... it makes me more tired” (person with stroke, Norway)

3. **F**oster a support system

- Employ communication partners + facilitators

“I can write it but I.. I can ..I need to reread, reread, reread, reread, and I send my documents to my father, my girlfriend, my sister [...] to examine” (person with aphasia, France)

- Suggest compensatory strategies

“People with aphasia can help other people with aphasia to understand and speak in the team” (person with aphasia, Cyprus)

BEFORE

4. Offer training courses

- Use simplified vocabulary and aphasia-friendly formats on terminology, design and methodology

“ I having difficulty in participating in the group when reading something scientific [...] if it's a difficult, for example article, I can read them but I will need much more time.. Emm when I find a word is unknown, I will search for it and I find its translation in Greek or English, online with a computer”
(person with stroke, Greece)

5. Reinforce the use of tailored resources

- Technological support

*“...I used to do all the lectures on a speech recognition program. And it’s a bilingual program ...English, German, French, Greek. And I dictate to the program [...] the computer then types the text into the file”
(person with aphasia, Switzerland)*

- Contextual resources

*“I can read. I can read with the images, the pictures. I can have a pattern that I would... that someone can help. I would like to...It’s also difficult for me to understand in English. For me it’s more or less bullet points”
(person with aphasia, France)*

6. Encourage support groups participation

- Practice communication skills

“I would like to be with someone with the English very good to help me with the team [...] like the student in the aphasia group [...] to help with the group things to do in the team” (person with aphasia, Cyprus)

- Outcomes dissemination

“I can send to my French aphasia group... the research, the questionnaires also, the results” (person with aphasia, France)

Take home messages

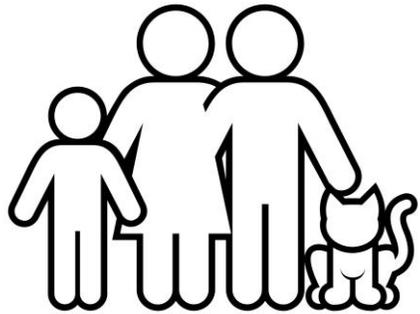
- People experiencing chronic stroke and aphasia are willing to be involved as PPI partners **if** the research team provides the necessary support.

“And also, I would like to be more in research for stroke and aphasia. I don’t know why, but [...] because I was in Erasmus, I have friends all over Europe and I would, I would like to be more in touch with the research. I would like to be part of a European team” [...] I would like to [...] go to see it and I would like to make connections for the aphasia groups” (person with aphasia, France)

- It is important to create of a **robust support system**, before the appointment of patient partners

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and their families



Thank you for your attention

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Research Involvement
and Engagement

RESEARCH ARTICLE

Open Access



The views of people living with chronic stroke and aphasia on their potential involvement as research partners: a thematic analysis

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Abstract

Background: Patient and Public Involvement (PPI) is the active partnership between researchers, patients and laypeople in the process of creating research. PPI in stroke aphasia research aims to ensure equal opportunities for informed decision-making and guarantee democratic representation of patient partners within the research team. Yet, little is known about the factors that hinder and/or promote the autonomous involvement of people with aphasia in stroke and aphasia PPI projects. This study aimed to explore the views and perspectives of people who live with chronic stroke, with and without aphasia, with experience in research prior to stroke, on their potential involvement as research partners.

Methods: The research team included a PPI partner with chronic stroke-induced aphasia. Semi-structured interviews were conducted online with people with chronic stroke (n = 8), four with aphasia and four without. Interviews were subject to thematic analysis.

Results: Inductive thematic analysis generated four themes: (1) the kinds of *Restrictions* that make involvement in research difficult, (2) the preferred levels and ways of *Involvement* during the research process, (3) the *Support* required for active and collaborative involvement, and (4) the *Impact* of their involvement and how it benefits the study's outcomes.

Conclusion: People experiencing chronic stroke and aphasia are willing to be involved as PPI partners if the research team provides the necessary support. Recommendations for researchers to consider before commencing co-produced research with people with stroke and aphasia are provided.