



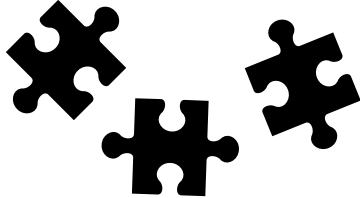
How to involve patients (people) with communication difficulties in stroke research

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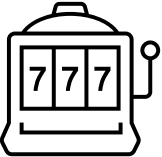
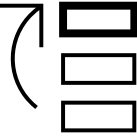


This presentation

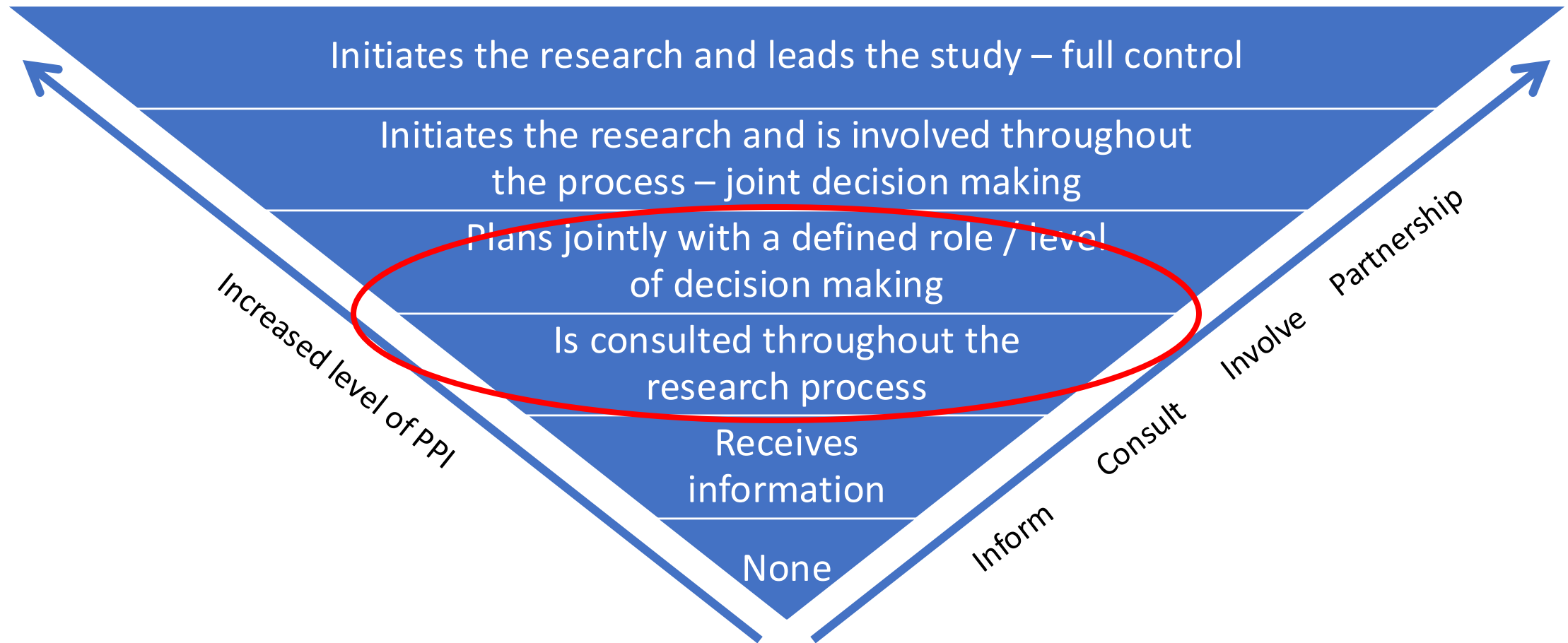
- **Why involve** people with communications difficulties in stroke research? 
- **How to involve** people with communications difficulties in stroke research? 
- A few **practical examples** 

This is about research participation
– what about public and patient involvement?

Why?

<p>It is big [1-3]</p> <p>+</p>	<p>It is serious [2, 4-9]</p> 
<p>It is systematic or is it systematic? [10-12]</p> 	<p>It is important [13]</p> 

Conceptual Model: Levels of Involvement



How? Preparation

- Learn about PPI
- Follow or be inspired by guidelines and frameworks
- Consider level of involvement
- Ethical considerations
- Funding for involvement
- Find people with communication disorders
- Find support to support them
- Enable them to take part
- Get to know each other

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Samtykkeerklæring
Interview til forskning

Hvad er formålet?

	Vi vil gerne lave et interview med dig. Vi vil gerne vide, hvilke behov dig og din familie havde efter, at du fik afasi. Når vi skriver <i>familie</i> , så mener vi dine nærmeste pårørende . Det kan derfor også være dine nære venner.
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Hvorfor deltage?




	Vi kan få mere viden om, hvilke behov der er vigtige for familier med afasi .
	I fremtiden kan det hjælpe andre familier med afasi .

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Hvad skal du gøre?

	Du skal deltage i interviewet.
	Interviewet varer ca. 30 minutter.

Hvad bruges filmen til?

	Vi optager interviewet på video .
	Vi kigger på videoen Vi laver en analyse og skriver en artikel .
	Forskere fra hele verden kan læse artiklen.
P. Jensen	Du er anonym i artiklen.

How? During project

- Plenty of time
- Make sure it is meaningful
- Careful preparation: all materials being developed/adapted in an aphasia friendly manner
- emails, documents, props etc.
- Adapted communication during meetings
- On-site communication support
- Communication, communication and more communication

All this potentially creates power imbalances

- Clear agreements of decision-making power
- Clear agreements of workload incl. homework or not
- Salary, reimbursement (or at least clarity about if not)



Example 1

Supporting people with aphasia in health communication

Small regular qualitative study exploring how people with aphasia are/are not supported in communication with healthcare professionals (acute/subacute wards) – and their perceptions hereof.

Advisory board (three people with aphasia). Joint work:

- Tweaking RQs, aphasia friendly informed consents, interview guide incl. support material, friendly disseminations



Example 2

LiFT – Life with aphasia, a family intervention

Bigger project with two PhD students focusing on development and feasibility test of interventions for families living with aphasia

Some PPI elements:

- Running consultations with advisory board
- Recent "test" of methods for involvement (Lego Serious Play)



Some thoughts and concerns maybe for later discussion

A risk of...

- The same crowd of people with aphasia being involved in everything happening in aphasia research / service improvement in DK
- A bad representation of the people living with aphasia (we tend to work with people that are Danish, high educational levels, relatively young, living around bigger cities)
- Much of the involvement really is qualitative data collection without using rigid methods

Good places to start

- PAOLI framework [14]
- Element zero – PPI from pre-start [15] →
- AUS Stroke Foundation has a tool for researchers setting up PPI
- AUS Stroke Foundation has a tool for PPI contributors incl. ppl. w. aphasia
- How to make aphasia friendly information materials for research [16-17]

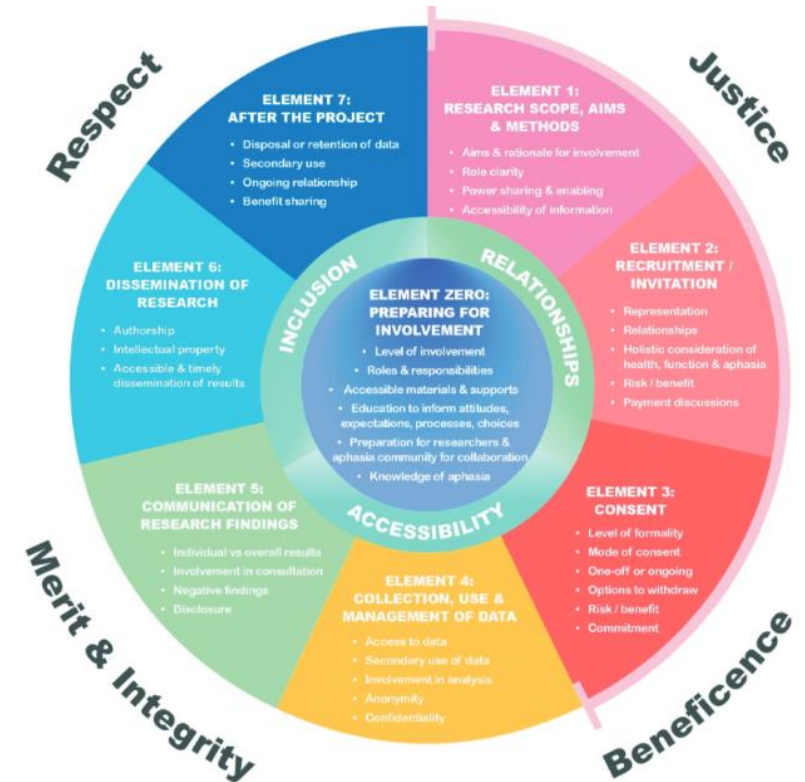


Figure 1. Ethics and PPI Research Lifecycle Model.

Take home messages

- If people with aphasia can be involved (and they can 😊), most people can be involved
- Know the population you want to involve properly (e.g. use an advisory board to open up a new field including providing knowledge about this field)
- Adapt your activities, materials etc. to your population
- Treat your collaborators as collaborators, not as instruments in making your research better
- Do it (PPI)! – it is the most mindblowing part of my research
- Don't do it (PPI)! – if you are not willing to change your mind and ideas

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