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## How PPIE is informing and shaping my research


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## In this presentation

- Background to my research
- Timeline of my PPIE activities



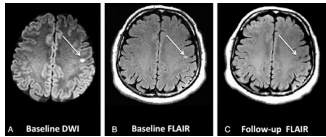
My key Learning Points

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## Background to my research

- **Improving follow-up care for people after minor stroke: development and feasibility testing of a complex intervention.**
- What is a minor stroke?



A Baseline DWI    B Baseline FLAIR    C Follow-up FLAIR

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## Why bother about minor strokes?

- 1.2 million stroke survivors in the UK
- £26 billion annual societal cost
- 25% are under 65 years
- Third to a half experience a 'minor' stroke
- Increased risk of further stroke



High unmet information needs, hidden impairments experienced, difficulties with adjustment to life after stroke.

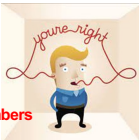
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## Patient, public involvement and engagement

Who does this involve?

- Patients and family or carers
- Public




AVOID Echo chambers

- Colleagues - local but also other geographies
- Management
- Funders - £££
- Voluntary sector – Stroke Association
- Government – policy, priorities
- James Lind Alliance

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## Key Learning Points!


- It is not a one-off exercise
- Different layers and types of engagement
- It is not unidirectional

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**My PPIE activities**

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- Pt story



I wasn't doing anything in the hospital that allowed me to flag up that I had these problems.


The First time I cooked at home, my brain wasn't ready ... it is not just about the mechanical I had to learn to split my brain again

- Joint service improvement project with CNRT

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**Another pt story**

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whilst on the ward, you really do not do much, you walk to the bathroom and back and have brief conversations. I did not even have a shower. When I got home I realised that whilst I had made a good recovery, I had problems with my co-ordination eg shampooing my hair, using a knife and fork, walking longer distances


I had lots of neurological symptoms and called for advice. I was told simply to see my GP or attend A+E. I informed them I am a GP and no further useful advice was forthcoming

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**Another pt story**

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Recommendations:



- Follow-up phone call after 5 days, referral for rehab.
- More information on discharge about what to expect.
- No one mentioned fatigue on the ward



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**Colleagues and Managers**

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➤ **Developed a post stroke cognitive clinic**

- Joint with stroke consultant, colleagues involved
- Met with trust business managers and CCG
- MDT tariff needed for the clinic

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**NIHR | National Institute for Health Research**

**Stroke Association**

Flowship

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**An occupational therapy led two-week post minor stroke telephone review with online cognitive assessment: What did this reveal?**

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Introduction: 1. Patient and public involvement

2. Clinician questions

3. Methods

4. Results


5. Implications for practice

- Older participants less likely to complete the online cog ax
- Digital inequality can exacerbate health inequalities

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**Stroke Advisory Group**


- RDS enabling involvement fund
- Invited 13 participants, 6 agreed
- Co-facilitator
- Preparatory questions
- Met 3 times




- Shaped intervention, sense checked the psychological theory, identified appropriate outcome measures

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**Key Learning Points!**



- Need to gather demographic formation.
- My group did not reflect the stroke demographic
- Groups don't suit everyone!



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**Most people are not WEIRD**

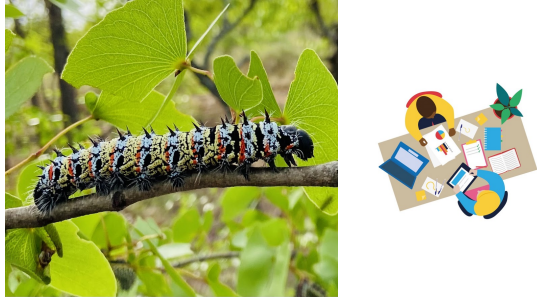
**Western Educated Industrial Rich Democratic societies**

will not necessarily align with those from other cultures and communities. Research results may not reflect the population of interest.

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**Concept of research**

not understood, is unfamiliar



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**Building Research Collaborations**



Improving transitions of care for Stroke and TIA: the time is now!

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**Is this just a London problem?**

What about other services geographies?

#OTalk

How can Occupational Therapists best assess, treat and support self-management of hidden impairments after TIA and Minor stroke? Hosted by @JenniferNCrow

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**PERC community outreach programmes**  Imperial College Healthcare NHS Trust


- MOSAIC community trust
- Preparatory meeting
- Two meetings attended



- Feedback on PIS and consent form
- Accessible supplementary information
- Feedback forms


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 **Key Learning Points!**

- Language and literacy
- Distrust, suspicion, fear of authority figures
- Stroke brings shame on families
- Community health worker model
- Importance of touch in healing


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**Brent and Hounslow events**  Imperial College Healthcare NHS Trust


 **Key Learning Points!**

- FUBU
- Natural and herbal remedies important
- Different health belief systems
- Elders are important
- Avoid focusing on what is bad about different cuisines

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- Building relationships with communities takes time
- Doing PPIE properly takes time

 **Key Learning Points!**


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**Harrow Event** 


- Pre-meeting
- Feedback forms




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**Imperial Stroke Public Involvement Group**  Imperial College Healthcare NHS Trust

- A team is important
- Preparation is key – recruitment, venue, materials
- Contact details and EDI
- Reimbursement
- Takes time

 **Key Learning Points!**

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### Resources

**IMPERIAL STROKE PUBLIC INVOLVEMENT GROUP**  
Why are we asking for this information?  
This information is used to help us understand a range of people in the group.

Please tick the response that applies to you

Have you had a stroke?  
Yes   
No

Are you currently taking any medicines for your stroke?  
Yes   
No

What type of stroke?  
TIA   
Ischaemic   
Haemorrhagic   
Other

How long since you had your stroke?  
Within 3 months   
3-12 months   
1-5 years   
More than 5 years   
Never had a stroke

What is your ethnicity?  
White British   
Black British   
Asian British   
Hispanic   
Other   
Any other ethnic group including none   
Prefer not to say

What is your gender?  
Male   
Female   
Other   
Prefer not to say

**IMPERIAL STROKE PUBLIC INVOLVEMENT GROUP**

ATTACHED INFORMATION

Name: \_\_\_\_\_

Tel: \_\_\_\_\_

Public Member: \_\_\_\_\_

Please provide contact details for follow-up where possible

Stroke Public Involvement Meeting: Yes   
No



Stroke Public Involvement Survey: Yes   
No

Stroke Public Involvement Focus Groups: Yes   
No

Other: \_\_\_\_\_

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### In Conclusion



- Underrepresented groups
- Allow sufficient time
- Keep listening, ask questions, follow-up
- Be curious, don't make assumptions
- Consider using PERC impact log
- Say yes to opportunities

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### Questions?



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### UKSF Workshop - main auditorium



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