

Mainstreaming 'diversity'

Creative strategies adopted while developing a
complex intervention

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Representation in research

Most of the participants in the study were white, and few had low socioeconomic status - meaning more research is needed to see if the findings hold in other groups.

trial participation [41]. Secondly, our patients were predominantly white, middle-class men with low levels of social deprivation. Although we did not specifically assess the educational level or health literacy of our patients, it is likely that our patients are more highly educated than patients from more deprived socioeconomic backgrounds, and issues such as lack of support, financial worries and difficulties with transport may be less problematic for our patients in comparison to patients from socially deprived areas [42]. Despite this, it is concerning that 21 % of patients

What are the barriers?

Participant barriers to research participation

Especially looking at “hard-to-reach” / “underserved” / “seldom heard” populations:

- Lack of knowledge about research
- Fear, worry, mistrust
- Lack of confidence – language barriers / low social capital
- Practical concerns – costs, opportunity costs



Researchers' barriers

- Our methodological tools!
- Costs and extra resources
- Exclusion criteria
- Stereotyping and pre-conceptions



Developing the BP:Together
intervention
(leading to RCT)

Qualitative study: developing the intervention

- Population – People who have previously had a stroke or TIA
 - At risk of subsequent event
 - High blood pressure (BP) major risk factor
 - Current practice of BP management is inconsistent
- Intervention – Home-based BP management, every month
 - Take 12 readings over 1 week
 - Send readings to GP using SMS or via app

My role – field researcher interviewing stroke patients and GPs

Who gets stroke in the UK?

- >100k strokes every year
- 4th biggest killer
- Average age: women 73y, Men 68y

- Ethnicity and social deprivation...

(Stroke Association, 2018)

Ethnicity

- White people in the UK are more likely to have atrial fibrillation (a type of irregular heart beat) compared to other ethnicities.^{32 33} These are risk factors for stroke.
- Black people are almost twice as likely to have a stroke as white people.¹³
- On average, people of black and Asian descent in the UK have strokes 10 years earlier than white people.
- Studies suggest that black and Asian people have strokes 10 years earlier than white people.
- Research suggests this is because black and Asian people are more likely to have high blood pressure and diabetes, both of which are stroke risk factors.
- In the last 20 years, stroke incidence has decreased by 40% for white people, but not for black people.¹³
- Black people are also more likely to have sickle cell disease, which increases the risk of a stroke.³⁵
- South Asian people are almost twice as likely to develop diabetes (a risk factor for stroke) as the rest of the UK population,³⁶ and are likely to develop it at an earlier age.³⁸

Social deprivation

- In general, people from more deprived areas have an increased risk of stroke.³⁷
- People living with the greatest social deprivation are two and half times more likely to have a stroke than people living in the least deprived areas.
- Deprived areas are likely to have a higher prevalence of stroke.³⁹
- In Scotland, Wales and Northern Ireland, people living in the most deprived areas have strokes at least five years earlier in their lives than people living in the least deprived areas.
- People living in deprived areas in the UK are more likely to die from stroke than people from higher income countries.

- **Black people 2x more likely to have a stroke than White people**
- **Black, South Asian and people from deprived areas have strokes at younger ages**
- **People from more deprived areas suffer more severe strokes**
- **In the past 20 years, in London: 40% decrease in stroke incidence for White people but not for Black people**

So what did I do?

Initial recruitment plan

- Call sent out to practices in the local area for expressions of interest
- Participating practices agreed to run searches to identify stroke/TIA patients
- Sent out opt-in invitation letters with Participant Information Sheet

Yielded a very narrow demographic



Additional recruitment plan

- Mosques and churches
- Stroke group pub lunch
- Stroke Association meeting in deprived west London borough
- Stroke Association mailout

Mosques and churches

- First contact – a very resourceful pharmacist
- Contacted imams and pastors
- Attended Friday (mosque) and Sunday (church) prayers –
 - Dressed appropriately
 - Participated wholeheartedly
 - Did a semi-formal presentation about the study – and why I was there
 - Spoke Urdu where helpful
 - Took lots of BP measurements!
- Recruited 1 each from each prayer meeting



Stroke patient groups

Stroke group pub lunch –

- Council housing residents, meet every Tuesday
- Very happy to help
- Disability + aphasia
- Recruited 2 people



Stroke Association meeting in high-deprivation neighbourhood in West London

- Non-white, multiple health problems
- Recruited 2 people

Stroke Association mailout

- SA staff working in the community invited participants
- Recruited 3 people, non-white and/or from deprived boroughs of London

What did we find?

- Poor health (recurrent strokes, mental health problems)
- Some younger people (stroke in 30s)
- Disability affecting practicalities of participating in the intervention
- Diversity in the organisation of their care – e.g. multigenerational support and advocacy, social care, role of community

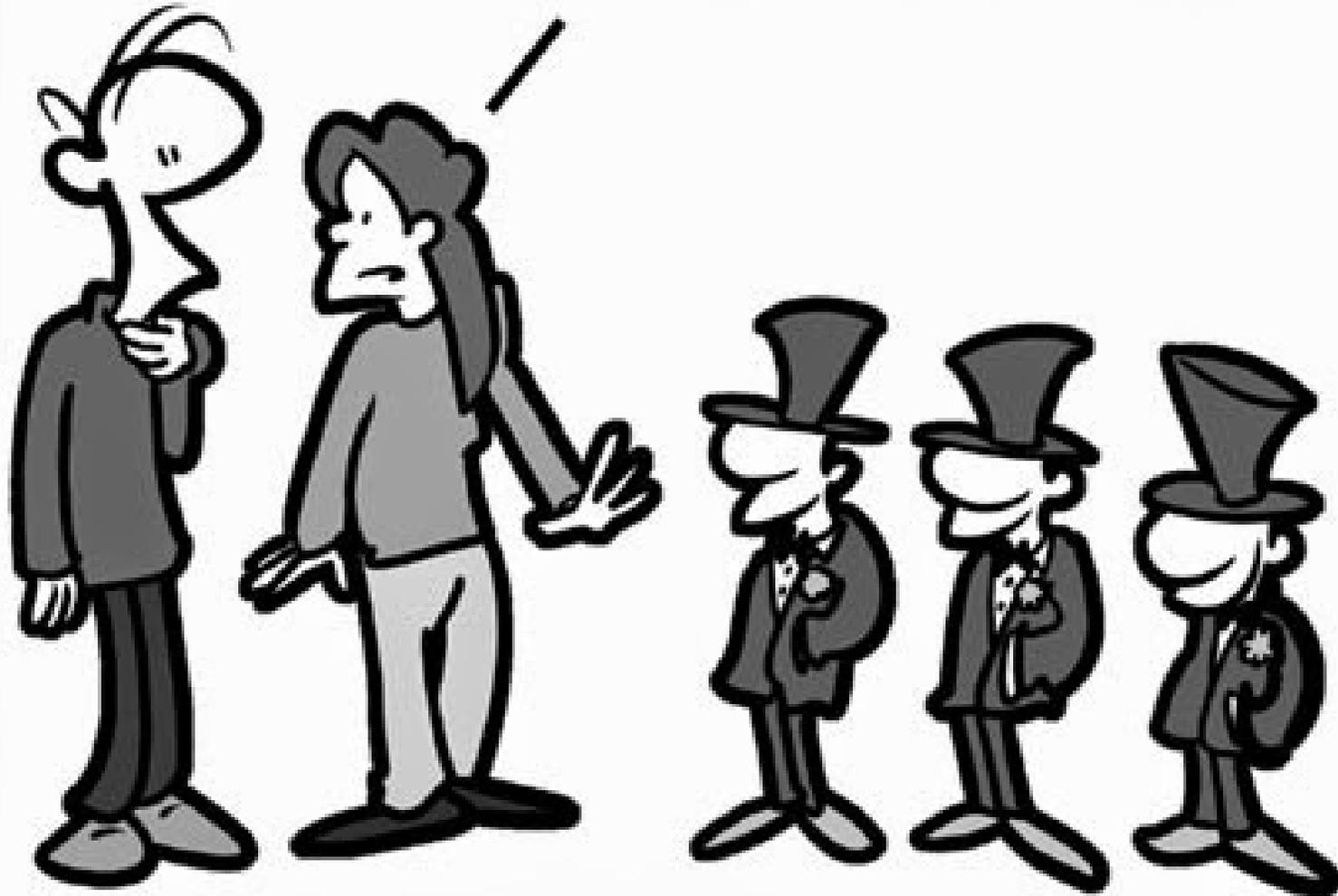
How they viewed me!

Going forward

How do involve under-represented people in research?

- Look at the data (e.g. NIHR business intelligence data and prevalence heatmaps, NIHR INCLUDE programme)
- Identify some initial key gate keepers
 - They will lead to more
- Social demographics – where do people hang out?
 - Any ongoing youth clubs, community groups?
 - Who run them?
- Other institutions / charities working within community
 - Healthwatch?
- Local radio / social media
- Participate in social and community activities...! (pssst...it's fun)

BUT THEY WERE SELECTED RANDOMLY



Making sense of research results

- Inconsistent measurement and reporting of SES and ethnicity data
 - not mandatory even though part of CONSORT
 - NIHR INCLUDE framework may change that....
- Greater reflection needed on how study sample composition affects external validity of results (Furler 2012)
 - Underestimate intervention effects (marginal or no benefit)
 - Missed opportunity for potentially larger benefits to those with higher baseline risk
- US style NIH reporting of ethnicity, gender – policy level

Conclusion

Using alternative, creative recruitment methods can help match research participation with relative burden of disease:

- Fits with wider recognition of importance of public engagement in research
- Makes for better science
- Aligns with NHS principles of equity, fairness and providing high-quality healthcare for all.

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Any questions or comments?

Thank you for listening!

Please contact me if you have any questions or comments to share:

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