



# Patient and carer experience of centralised stroke care pathways: intentions, concerns and outcomes

Presentation to UKSF

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## Innovations in major system reconfiguration in England:

a study of the effectiveness, acceptability, and  
processes of implementation of different  
models of stroke care

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# Study team



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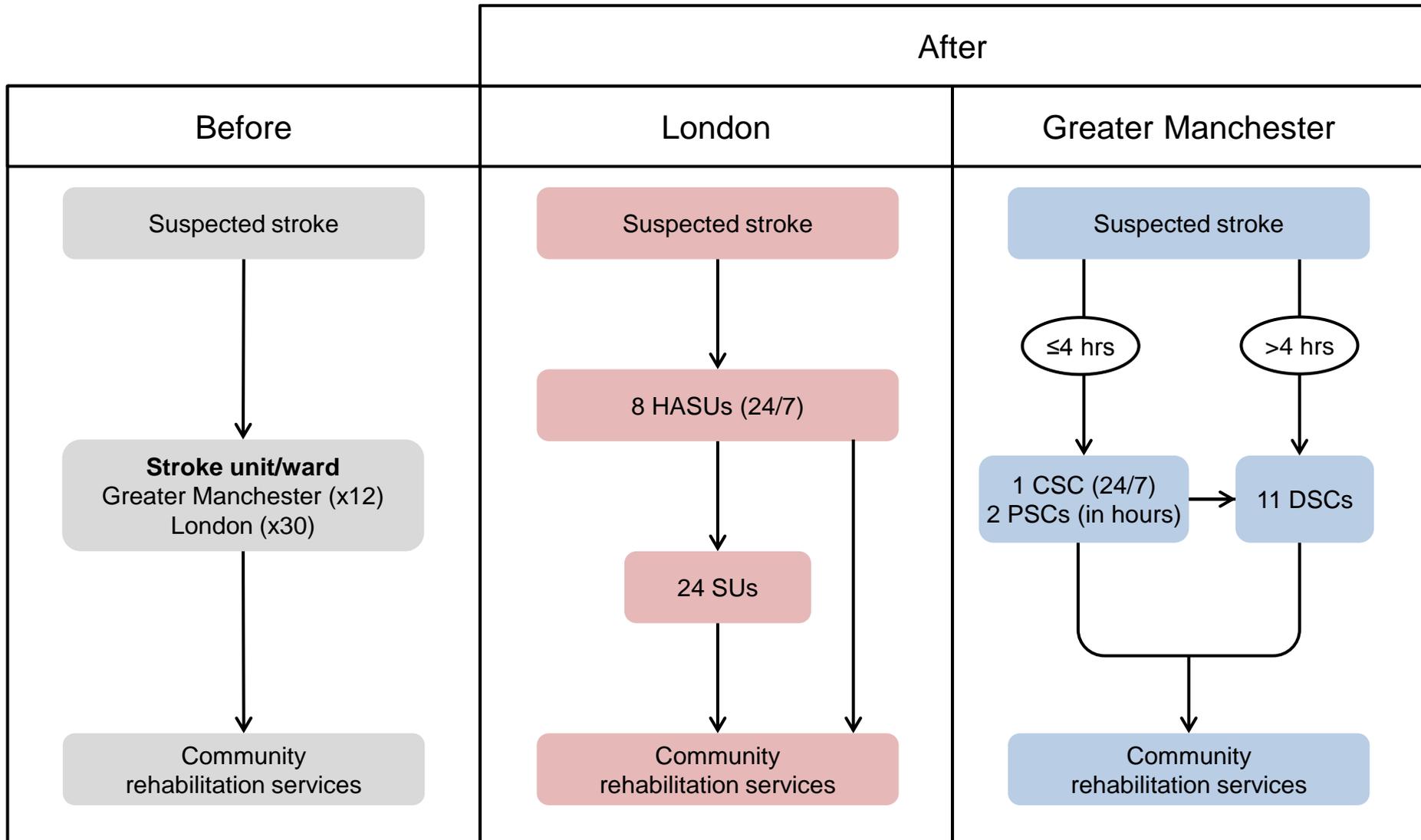
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# The changes



# Background

The centralisation of stroke care services was intended to improve the quality of care for patients

- **Research question:** what is the experience of patients and carers of the reconfigured stroke care pathways in Greater Manchester (GM) and London?
- **Focus of this analysis:** to explore patient and carer experience of the stroke care pathway in relation to the original **intentions** of, and **concerns** about, the new care pathways

# Background

In GM and London there were specific **intentions** articulated, by those planning the changes, in relation to the patient experience of the stroke care pathway



## GM

Quality of the patient experience was to guide all elements of project delivery: *'get the patient perspective right and then the rest of it will sort itself out, but if we get the patient perspective wrong we'll never get it correct'* (GM05).



## London

Interviewees spoke about *'making sure that the pathway that was being designed for the patient was appropriate and manageable'* (Lon06) and that there should be *'a seamless pathway for the patient'* (Lon01).

# Background

In GM and London there were various **concerns** expressed in relation to how patients might experience the new stroke care pathway

- Whether a seamless pathway of care was achievable
- Transporting patients to a more distant HASU (journey times, impact on patient and family)
- Repatriation
- Cultural needs

# Patient and carer experience

## Interviews with patients and carers

- Patients were recruited from 3 case study sites in Greater Manchester and 4 sites in London



	Greater Manchester	London
Females	7 (2 with family member)	10 (5 with family member)
Males	8 (6 with family member)	11 (4 with family member)
Age range	41 years – 87 years	38 years – 90 years
Total	15 (23)	21 (30)

# Analysis

- With the permission of participants, interviews were digitally recorded
- Transcribed interviews were uploaded onto NVivo software
- Thematic analysis was carried out, using a deductive approach guided by a framework developed from the literature about stroke patient experience, as well as inductively from the data
- We then developed a framework of themes focussed on intentions and concerns related to the patient pathway

# Findings relating to intentions and concerns

Original intentions and concerns	Themes (taken from the overview framework and developed)
<b>Transporting patients to a more distant HASU</b>	Transfer by ambulance to HASU Transfer from DSC/SU to HASU Impact on patients and families
<b>Repatriation</b>	Relatively smooth Confusion Delays
<b>Seamless pathway of care</b>	Ambulance to HASU Within hospital (including weekends/evenings) HASU to DSC/SU Hospital to home and community follow-up Therapy
<b>Cultural needs</b>	

# Transporting patients to a more distant HASU

## Transfer by ambulance to HASU



Initially some concerns were expressed, particularly by relatives

*We're going further, that's going to take longer, what happens if it gets worse on the way there? (GM, family member)*

*They said we're taking you to (HASU) because they've got a specialist stroke unit there, effectively, and I said, "well that's fine" (GM, patient)*

However, once it was explained that transfer was to a specialist unit, fears were usually allayed

# Staying at a more distant HASU

## Impact on patients and family

Patients were generally happy to be at the HASU

*It was a bit awkward being so far away (GM, patient)*

*I mean, I can imagine it would affect people if they were in Kent or somewhere like that (London, patient)*



However, visiting for families and friends was raised as a slight issue

# Repatriation to local stroke unit

## Transfer relatively smooth, however.....

Some confusion experienced in relation to which hospital a person would go back to and when this would happen

*Somebody told us that she would definitely be going at one time, then she didn't go and then somebody else said no, no.....you know it was a little bit confusing (London, family member)*

*We weren't very happy if you recall at the time with transfer from HASU to SU, because it took six hours, which left both of us in a very het up and upset state (London, family member)*

Some delays experienced in waiting for a bed at a stroke unit, or for transport to go there

# A seamless pathway of care?

## Ambulance

- For the majority of people the ambulance came quickly
- Ambulance staff were informative, giving clear information about likely diagnosis (in contrast to earlier studies)

*You went in and they were so ready for him, I know they'd radio-ed through, I know they were prepared for him (GM, family member)*



## Hospital

- People were pleased with the reception they received on arriving at hospital
- Timely investigations and treatment received
- Perception that stroke was treated as a priority (in contrast to earlier studies)

# A seamless pathway of care?

## Within hospital

- Most people perceived that they received clear explanations about their care, and they knew who was treating them (in contrast to previous studies)
- Some lack of continuity reported at weekends (as previously)
- Transfer of care from HASU to local stroke unit was not an issue



*It's unclear even to me today what's going to happen with physiotherapy in the future because apparently there is... a waiting list and I've not heard much from them (GM, patient)*

## Hospital to home

- Communication between hospitals and GPs happened effectively
- Some people were not clear about their follow-up once home (as previously)

# Conclusions

- Concerns about the new pathways (transfer to a more distant HASU/repatriation) were not generally realised
- Service users in GM and London reported similar experiences
- Centralised pathway can work from the patient perspective?
- Importance of clear explanations
- Seamless pathway of care?
- A less seamless pathway at the latter stages may reflect
  - focus of reconfigurations on hyper-acute care
  - inequalities in ESD and community therapy services across GM and London
- Those planning service centralisations may wish to consider integration with ongoing care