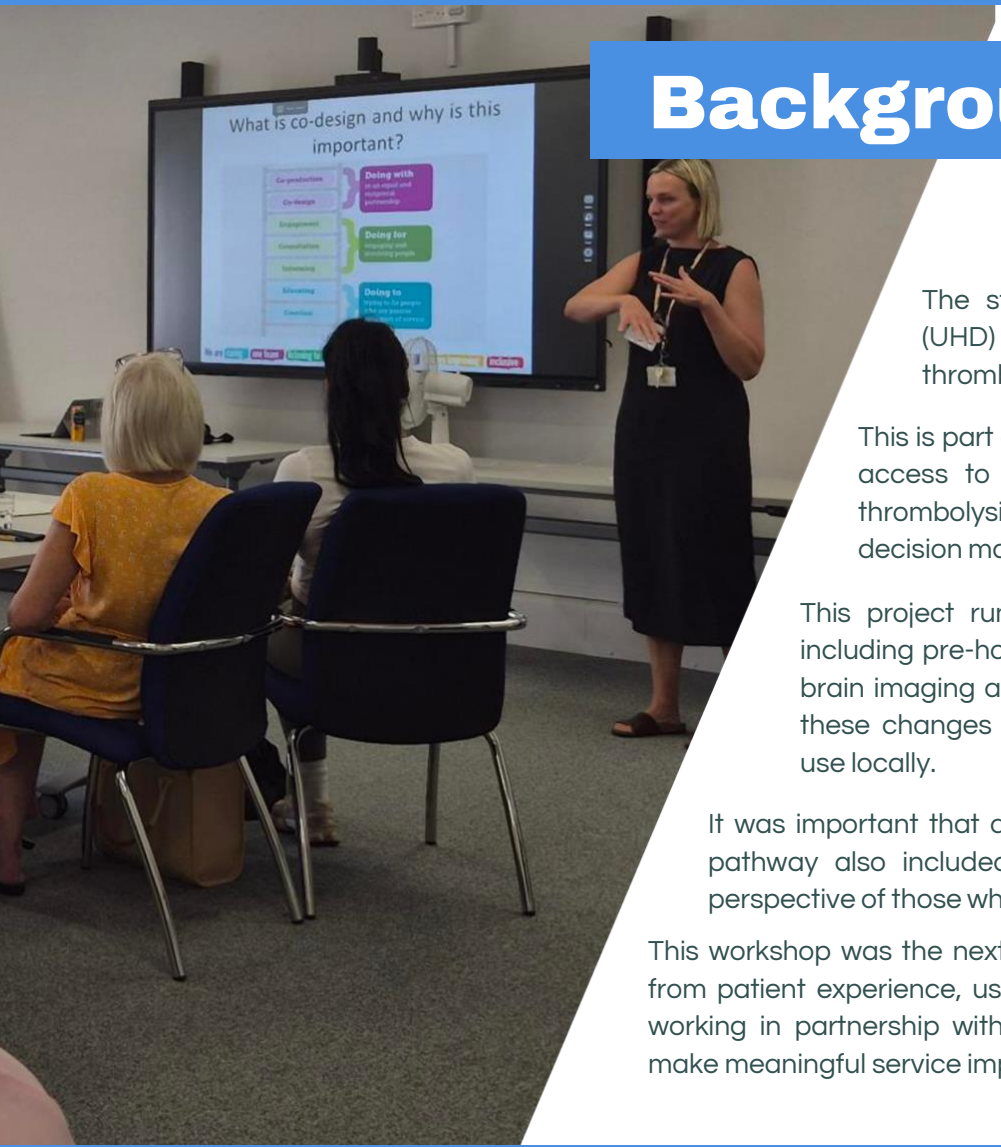
We are caring one team listening to understand open and honest always improving inclusive

NHS
University Hospitals Dorset
NHS Foundation Trust

Improving the UHD Stroke thrombolysis experience

Experience based co-design workshop



Background

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The stroke team at University Hospitals Dorset (UHD) are working to improve their stroke thrombolysis pathway.

This is part of a national programme of work to increase access to acute stroke treatment with clot busting thrombolysis drugs through better pathways and decision making

This project runs alongside other improvement initiatives including pre-hospital video triage, introducing new types of brain imaging and creating standardised practice. To date these changes have seen a 40% increase in thrombolysis use locally.

It was important that any improvement to our stroke thrombolysis pathway also included improving experience of care, from the perspective of those who use our services (patients and their family).

This workshop was the next stage in a focused project, understanding from patient experience, using it to inform areas for improvement and working in partnership with patients and their families to design and make meaningful service improvements.

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What do we mean by co-design?

To achieve meaning change in the NHS we need to work together as one team, with people who had used our services.

As health professionals we have one type of knowledge and experience, but we won't necessarily know what it feels like to experience stroke or be on the receiving end of stroke care.

Working together as one team, with patients and their families makes sense. NHS experience tells us this partnership is proven beneficial, it is cost effective and has proven to result in better outcomes.

We are using experience based co-design principles in this work. This isn't about tokenistic involvement, it is about working with and including patients and their families from the beginning, to learn from them and help us to identify where change needs to take place and to design what that change needs to look like. For this project we are choosing a one team approach - because we know we can go further and work better, when we work together.

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What had we already learnt?

In late 2026 three people who had received thrombolysis treatment at UHD kindly volunteered to share their treatment experiences.

Each individual met with Tony (Stroke Nurse Consultant) and talked through the treatment pathway, listening to understand how if felt to be on the receiving end of care at UHD.

Thank you to Anne, Martin and Robert for saying yes and helping us begin this work. From their detailed accounts we listened and identified several themes for improvement.

We selected three key themes from their narratives to inform the focus of the co-design workshop. Our aim was to use the collective knowledge and experience of the group, posing each theme as a question to be solved - how do we make this better for future people using our services?

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Three Key Themes:

Please scan the codes below to hear open and honest accounts of thrombolysis treatment from Anne, Martin & Robert. This narratives (taken from longer discussions) were used to inform the focus of the workshop.

Identifying stroke symptoms & calling 999

Conversations pre-treatment to gain consent

Debriefing on the ward after treatment

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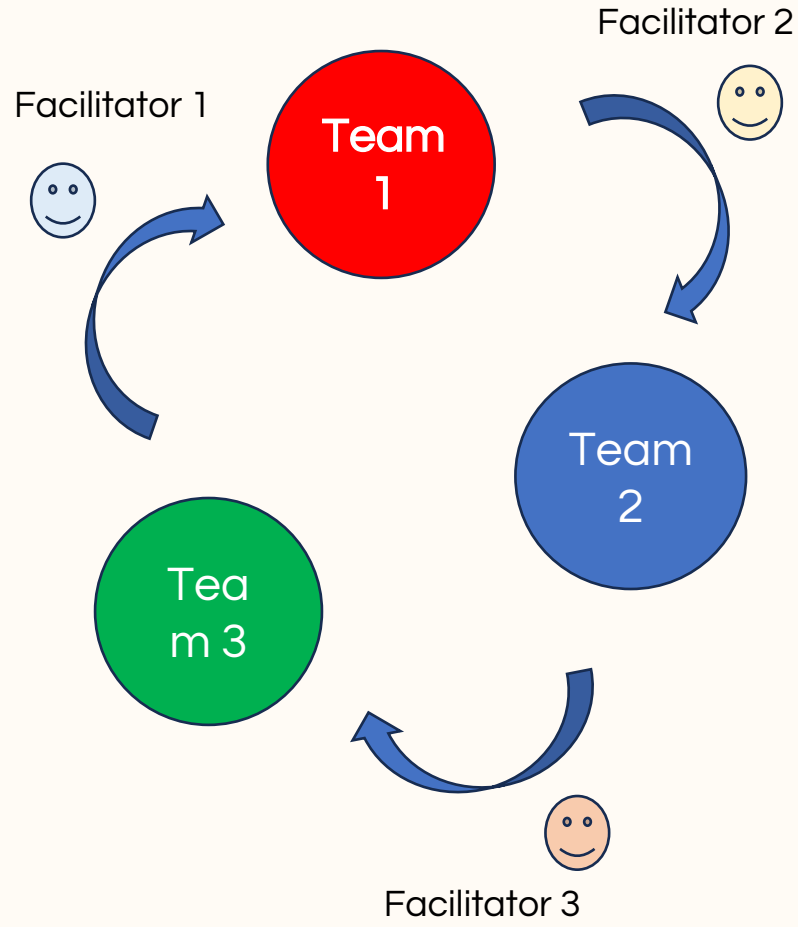
Who was in the room?

An important part of this work was being inclusive to help ensure the right people were part of the conversation. We wanted solutions to come from being one team, with that team including people who have used our services.

We invited 82 people to participate in the workshop and were pleased to be joined by 24 people with first hand experience of receiving thrombolysis, family members involved in care and treatment conversations and people with experience of stroke and insight into wider peer experiences. Lived experience made up almost 50% of workshop attendees. Clinical staff involved in stroke thrombolysis made up 50% with 2 people representing team management to help us progress and drive forward change.

It was essential workshop space was accessible for people with mobility issues/using aids. Family and carers were invited to support or stay (with/without participating based on their preferences). Participants were divided into small mixed groups, discussion encouraged all voices to be heard and different views welcomed.

Workshop structure



After an introduction to the topic, the three key themes and how we identified these we began table top discussions. Each team of participants were able to contribute to discussions on every theme. Facilitators moved between each team, focusing conversation on one theme at a time and capturing feedback. We tried to establish an understanding of what 'good' looked and felt like for each theme, identifying change ideas and details of how improvement could be progressed.

Notes were taken to record discussion and commitments for support to progress this work.

Teams were provided with refreshments and rest breaks during different topics.

01

"It didn't cross my mind I was having a stroke"

Recognising Stroke Symptoms and calling 999

Participants of the workshop agreed that awareness of stroke symptoms and action required is essential to ensure timely treatment of stroke. Participants felt current messaging doesn't fully match real-world experiences. The FAST campaign is widely known (Face drooping, Arm weakness, speech problem, Time to call 99) but the group highlighted important limitations. For example, several patients did not present with classic FAST symptoms, which can delay people calling 999.

It was also shared that stroke should be seen as a medical emergency, with any sudden change in neurological symptoms requiring immediate action. Having someone present at symptom onset was seen as crucial as they often provided the push to call 999 quickly. Hesitation to call 999 due the current pressures on emergency services was reported by some patients. Participants shared that public education must reinforce that stroke symptoms always justifies an emergency call.

Participants noted a major shift in how people consume information, with fewer people likely to see a mainstream TV advert. Future campaigns will need to adapt to other platforms now being used such as social media. Education was seen as essential, but participants agreed that we needed to look at how, when and where this should be delivered.

You said...

01

Where should education be delivered?

- Education in schools, workplaces, GP practices and community groups, sports clubs were suggested.
- Targeted public awareness in GP surgeries and specialist clinics may be more effective in reaching high risk audiences.
- The more people who understand the symptoms of stroke the more people who will get urgent treatment. Reinforcing the role of the bystander with encouraging timely emergency calls.

02

How should education be delivered?

- With the decline of mainstream TV any public awareness will need to be adapted to platforms the public now use.
- Education resources should be adapted into new user-friendly formats such as short videos, social media content, infographics and interactive tools which are likely to reach larger audiences than traditional leaflets or TV adverts

03 Public awareness and communication

- To expand symptom education beyond FAST and promote the importance of calling 999 even when symptoms appear mild or uncertain.
- To explore ways to reinforce the message of stroke as an emergency with messaging comparable to cardiac arrest campaigns.

Consent - pre treatment conversations

Participants recognised that consent for thrombolysis takes place during one of the most stressful and time-critical moments. Most patients described feeling frightened, vulnerable and unable to fully process information, with many recalling very little of the conversation itself. Despite this, they generally felt reassured by the calm, organised and confident manner of the stroke team, and placed considerable trust in clinicians to recommend the treatment that was in their best interests.

Participants consistently felt that simple, practical explanations were more helpful than percentages or numerical risk estimates. They preferred information that explained what treatment aimed to achieve, what the main risks were, and what could happen with or without treatment. There was also broad agreement that conversations should be adapted to the individual, recognising differences in stroke severity, communication difficulties, cognitive impairment and the role of relatives in supporting understanding.

Perhaps the strongest message was that patients and relatives wanted the opportunity to revisit the conversation once the immediate emergency had passed. They wanted to better understand why treatment had been recommended, what had happened during their care, and what to expect next, recognising that much of the information shared before treatment was difficult to absorb at the time.

02

"I just wanted the experts to tell me what was best"

You said...

01

What matters most in the conversation?

- Keep Explanation simple and concise
- Explain risks in practical terms rather than percentages
- Focus on the potential benefits as well as risks
- Tailor the conversations to the individuals needs

02

Who should be involved?

- Involve relatives wherever possible
- Use relatives to support understanding when appropriate
- Avoid making relatives feel responsible for the decision
- Stroke specialists should lead treatment discussions

03

How should we communicate?

- Use clear, jargon-free language
- Avoid overloading patients with information
- Visual prompts may help some patients
- Confidence and reassurance from staff are important
- Adapt communication for aphasia and other communication difficulties

04

When should information be provided?

- Start conversations as early as possible if feasible
- Consider providing information for relatives whilst scans are underway
- Accept that patients may retain very little during the acute phase
- Revisit the discussion once the immediate crisis has passed

05

What helps patients most?

- Trust in the stroke team
- Feeling the pathway is organised and efficient
- Knowing why treatment is recommended
- Understanding what happens next

03

"I felt scared and I couldn't think fast enough"

Debriefing conversations on the ward post treatment

Participants at the workshop agreed that debriefing conversations on the ward after treatment were essential. When these occurred they were highly valued by patients and their families. When these were missed or perceived to be suboptimal this felt to contribute to a 'gap' in knowledge, understanding and created additional anxiety.

The workshop participants recognised there would be no 'one size fits all approach' to debriefing. People will naturally have different needs and preferences for receiving information.

Participants felt it was therefore important that we had both consistency (in terms of a toolkit for approaching debriefing conversations, quality of conversational skills, knowledge and messaging related to treatment) but also be tailored and personalised in how and when this is delivered based on individual need.

You said...

01

We need a shared ethos?

- As a team we need to check in, encourage questions and meet people where they are at
- As standard, we will offer to talk to family with you (they should not have to ask to talk to us)
- We will try to be both consistent in our approach/resources used but tailored to your needs/preferences
- We won't use jargon

02

What is it important for staff to say /patients to hear?

- Recap what has happened, what we know and what we don't know (it's okay for stroke team to acknowledge uncertainty, we would rather hear this)
- A short term plan is helpful (what is happening over the next few hours and why)
- Beyond short term, ask us how much we want to know now

03

When do we offer this?

- Regular touch points, rather than 1 conversation
- Invite relatives to first morning ward round
- Aim for daily updates (with a prompt on ward round paperwork)
- Early check in after discharge to home

04

What are common questions I may want answering?

- What happened? - check my understanding of event and treatment
- What will happen next?
- What is common/what should I expect (e.g. fatigue)

05

Who should be involved in this?

- Stroke consultants doing ward rounds
- Stroke Outreach team (revisit the next day)
- Ward doctors

06

What else could help?

- Written resources (must be aphasia friendly)
- Provide short summary of discussion (to jog memory)

Quick Wins

We care about the experience of people using our services. There are some of the changes we can quickly make, based on what we learnt from the workshop.

1. Reaching out to our wider supporting teams including paramedics, radiology and ED to stress the benefits of next of kin staying with the patient throughout the thrombolysis pathway.

2. To submit a press release, sharing the highlights and key learning from the co-design event. Providing an opportunity to increase awareness of stroke symptoms and the urgency in calling emergency services.

3. Embedding an orientation to the thrombolysis pathway on arrival so patients and next of kin know what to expect.

4. Updating the ward leaflet to include information on attending the first consultant ward round post thrombolysis treatment.

5. To add a prompt on the ward round paperwork to ensure an opportunity for post thrombolysis debriefing and question from patients and their families.

Next steps

We care about making meaningful commitment to codesigning our services.

These are some of the changes we want to progress in the next phase. We plan to continue to work with people with stroke and their families to codesign the following solutions:

1. Stroke awareness education tools to be used in local GP surgeries and high-risk clinic areas.

2. A 'plain English' and aphasia friendly thrombolysis decision aid.

3. Aphasia friendly information on thrombolysis for patients and their relatives, to include what thrombolysis is, the risks, benefits, potential complications and monitoring post treatment.

4. A thrombolysis 'debrief guide' for staff – sharing good practice tips.

5. Workforce training focused on consent and debrief conversations delivery in local and national acute stroke pathways.

THANK YOU!

Remember to keep in touch with this project, see our project update page:

Project leads

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