

# Cross-Party Group on Stroke

Monday 30<sup>th</sup> October 12:30-13:30

Minute

Present

MSPs

Gillian McKay MSP

Roz McCall MSP

Other members

Katie MacGregor (secretariat)

John Watson – Stroke Association [speaker]

Alan Flynn

Andy Wilson

Colin Oliver

Douglas Horn

Dr Amy Mulroue

Dr Charlie Chung

Dr Christine McAlpine

Dr Fergus Doubal

Dr Lesley Scobbie

Dr Sarah Keir

Eric Sinclair

Gillian Capriotti

Professor Frederike van Wijck

Professor Lisa Kidd

Susan Smith

## Invited speakers

James Bundy

Samuel Humphrey

### 1) –Welcome and Apologies

#### a) Chair – Gillian MacKay MSP [GM]

GM welcomes members to the meeting and gives a note of the apologies:

- Dr Matt Lambert
- Dr Jackie Hamilton
- Ian Lee
- Prof Mark Barber
- Prof Terry Quinn
- Prof Gillian Mead

### 2) **Topic: F.A.S.T. Stroke Awareness Campaign in Scotland**

GM introduces the topic and gives some context of stroke awareness in Scotland, particularly around the F.A.S.T. campaign.

The number of strokes in Scotland is rising year on year. There are over 12,000 hospital admissions for suspected stroke each year in Scotland. It's about 1 every 42 minutes.

Stroke is a medical emergency. Anyone experiencing stroke symptoms must be taken immediately to the right hospital, assessed and given the appropriate treatment as soon as possible.

It is so important that the general public – everyone - is aware of the signs and symptoms of stroke and calls 999 so someone having a stroke receives treatment, as quickly as possible.

The F.A.S.T test is essential to this.

With stroke, we lose millions of brain cells for every minute without treatment. The longer you wait, the less chance of speech, movement and other abilities returning. Acting F.A.S.T really is lifesaving.

NHS England has run an Act F.A.S.T campaign since 2009. It relaunched in 2021 despite Covid. This year – 2023 - NHS Wales and NHS Northern Ireland have also ran Act FAST campaigns.

Scotland is the only one of the 4 UK nations which has not done a FAST campaign.

F.A.S.T. has gained some media attention recently in Scotland due to the campaigning work of Councillor James Bundy from Falkirk is also one of the speakers today.

First speaker is John Watson. John is the associate director for Scotland at the Stroke Association.

a) *Speaker:* John Watson, Associate Director for Scotland, Stroke Association [JW]

JW provides some further context to F.A.S.T. and asks the question, what is the need we are trying to meet here.

JW lays out how response to stroke is time urgent. Time is brain is what is sometimes said. When blood supply is cut off part of the brain – brain cells – die fairly quickly.

Key thing about responding to a stroke is doing so as quickly as possible. Critical to that is the time taken to identify stroke symptoms and dial 999. Everything else on the pathway then needs to happen very quickly as well.

JW continues and makes clear that stroke can strike anyone. It can happen anytime, any place, anywhere. So the target for any stroke awareness campaign must be the general public.

JW describes what the F.A.S.T. test comprises of.

Important that the message is simple, so that it is broad and easy to communicate. More complex messages are harder to convey and less likely to be retained by the audience so it's a balancing act between ensuring the F.A.S.T. test is the most accurate model and also the most effective at being retained and implemented by the general public.

The F.A.S.T. test has high accuracy with about 85% of stroke involving a F.A.S.T. symptom. We don't want the test to be so broad that hospitals are inundated with suspected stroke patients as that will slow down the whole pathways.

Evaluation has shown that the F.A.S.T. test is cost-effective and results in people remembering what they are supposed to.

It's important to remember that 85% is only 85%. That's another 1500 strokes every year in Scotland that aren't picked up by the fast test. Important that we need to include that in any evaluation and ensure that the F.A.S.T. is updated when the evidence suggest it should be.

It is very difficult to get hold of comparative evidence between different stroke symptom awareness campaigns.

Important to be mindful that if the evidence changes, the recommendation changes, then then so will we. And again, it's that balance between missing strokes and finding too many strokes and focusing on what is the best overall outcome.

Of the four nations in the UK, Scotland's the only one that hasn't delivered a recent mass media campaign on F.A.S.T. We know that evaluation shows that fast messaging is effective. It continues to show that. I've seen evaluation from the recent campaigns in England and Northern Ireland, and I'm looking forward to hearing more from Wales today.

But getting stroke treatment faster means better outcomes for patients and we need to be I, I think reminding people all the time.

That results in shorter hospital stays. It results in reduced ongoing support needs. Yes, we want to spend money on this and money is very short in supply at the moment, but this is the kind of investment that actually helps our health and social care system work better and to cope with the pressure it's under. JW goes on to say that this is not a cost for us to look at. It's an investment in making the system work better in getting people into the system more quickly

so that it improves outcomes for them, but also that it reduces the ongoing pressure on the system.

a) *Speaker:* Julia Rout, General Manager Health Promotion and Advocacy, Stroke Foundation of New Zealand *[pre-recorded presentation]*

JR gives context of stroke in New Zealand. Around 9,500 strokes every year and it costs their economy around \$1.1bn.

JR described the F.A.S.T campaign history.

- 2014: campaign pilot
- 2014/15: first national campaign, primary audience being women 35-65
- 2016/2017: second national campaign, primary audience Maori and Pacific peoples
- 2018/2019: third national campaign, primary audience Maori and Pacific peoples
- 2019+: current campaign, funded until June 2024

3 c's are the foundation of their campaign: clear, concise and consistent. This is why they remain consistent with F.A.S.T and not change as yet to BeFAST/FASTER.

JR organisation, the Stroke foundation of New Zealand, have taken a really strong collaborative approach with their campaign. Work closely with the Ministry of Health and Health Promotion Agency. Power dynamics has shifted over the years and now is very equal.

Historically the campaign had a strong focus on TV, but has now evolved to social media, radio and print. Have also taken a regional approach with their clear priority approach.

Have taken a multi-level approach to their campaign. Engaging with the individual and family, work with community group, partner with St. Johns via their teaching with Children, engaged with community providers on how best to share FAST message in their area. Funding was given to support the delivery of those ideas. Work with housing New Zealand too to reach the people living in social housing. Ministry for social development also advertised the FAST message in their waiting rooms.

Visuals have evolved over time, started off as an animation and now using real people. Strong focus on story telling – having people who have experience of stroke share their experiences on what they saw and experienced.

JR shared examples of the social media posts that they had developed. The visuals used different places where people have a stroke; house, at work, on the rugby pitch etc.

JR shared the top line metrics from the 2022 campaign; 1.35 million views of content. People remember how you made them feel which is what they tried to get across in their campaign.

Also developed some training and workplace toolkit. Covered things such as: what is a stroke? Why is it important to take action if stroke is suspected? How to prevent a stroke and how to share the F.A.S.T message?

Very simple but easy to deliver. Plug and play information.

JR shared the results from their evaluation. 2 Key data sources have informed this: national survey for awareness of signs of stroke, and data from St John Ambulance 111 calls.

18% increase in stroke awareness (specially sudden numbness or weakness of the face, arm or leg” as signs of stroke) and 12% increase in knowledge of “sudden confusion, trouble speaking or understanding speech”.

Significant increase in numbers of calls to 111 during campaign periods.

Next steps for the campaign

- Continued focus on priority groups.
- Supporting community led approach.
- More stories.
- Training.

## **b) *Speaker:* James Bundy, Stroke Awareness Campaigner**

James (JB) shared his personal experience of stroke, the symptoms his father experienced and what he and his family are currently campaigning for.

JB explained that his father didn't have the common F.A.S.T symptoms and neither the ambulance staff nor the emergency staff within A&E picked up on them. This ultimately led to the JB's father not receiving the treatment that he needed for his stroke within enough time.

JB outlined that the F.A.S.T test does not detect around 8-10% of strokes. The acronym BEFAST would be more effective in these situations and hopefully lead to better outcomes for those stroke patients. 8 to 10% would equate to around 750-950 stroke in Scotland per year.

JB emphasises that at bare minimum it's vital that front line medical staff are aware of BEFAST and the other stroke symptoms.

JB has submitted a petition to the Scottish parliament website and he is also meeting with MSPs from across all political parties to ensure cross-party support.

## **a) *Speaker:* Samuel Humphrey, Communications Manager at Public Health Wales**

Sam (SH) introduces himself and what him and his team are responsible for at Public Health Wales. They delivered a campaign in May this year and have since evaluated it. SH will share the evaluation today.

The ambition of the campaign was to reduce the amount of time between someone having a stroke or signs appearing and them arriving in hospital and using that F.A.S.T. acronym, to increase knowledge and increase intention to act quickly.

They took a population wide approach with a focus towards reaching over 50s, particularly those in deprived areas and those from black African, black Caribbean and south Asian descent as they are at a higher risk of having a stroke.

SH explains that they used quite traditional channels with majority of budget being spent on TV, video on demand and radio ads.

They didn't neglect social media, which is obviously an incredibly important channel and quite a cost effective one. They did some traditional media engagement and a lot of stakeholder engagement as well. Overall, a collaborative approach similar to the one described in New Zealand.

Given the short time frame they had to deliver the campaign, they were able to have access to the existing creative content from NHS England.

SH explained how they worked with an ad agency to develop a new Welsh F.A.S.T. acronym – NESSA – which means next in Welsh.

The TV ads proved to be very successful thanks to it provoking an emotive response. Ads on TV gained over 5million impressions over a month.

Adds on video on demand platform gained over 300,000 impressions.

Radio ads also proved very successful. Gained 10 million impressions, mainly through radio stations like Absolute Radio and Magic FM, but they also used more local digital channels to reach people in places like Wrexham and the Vale of Glamorgan. Also utilised community channels which can be really good at targeting specific audiences.

Good strong case study from colleagues at the Stroke Association helped achieve coverage in print media too.

In total they reached almost half a million people aged over 50 in Wales. And many many more if you include under 50.

SH also created a campaigns toolkit which they shared with over 40 stakeholders (esp colleagues in health boards, local authorities and 3<sup>rd</sup> sector).

Following on from that there was some local community engagement activity too, particularly in ethnically diverse areas of Wales.

Following the campaign, they used their 'time to talk' public health panel, which is run by Public Health Wales' Knowledge team, which asks a set of questions to represent a sample of the population of Wales every couple of months.

- 38% of that sample said they'd seen the messages.
- They also in the same population panel, asked a number of questions about their knowledge of the F.A.S.T. test. 79% have heard of it and over 90% of those knew what the letters stood for.
- Although arms and time were less likely to be known than face and speech.
- 89% of people knew that they should call 999 in the event of a stroke.

In terms of learning and recommendations,

- The main limitation with this campaign is that they were asked to deliver it at really short notice. So if they were going to make one recommendation, it would be give yourself plenty of time and that would have led to a much better, more robust evaluation, which they think is just really important in showing the impact that they could have done some; e.g. pre and post campaign surveys to measure the knowledge.
- earlier engagement with colleagues in the ambulance service would be absolutely key.
- Do more face to face engagement with key audiences.
- Make more printed materials available for places like GP surgeries and other settings.
- Review the creative content regularly.
- need the evidence to inform the campaign – who to focus on and how best to reach them.

- Would be great to do an act fast campaign that is tailored to Wales. Be as specific and targeted as possible and ask yourselves whether the people in the creative content are representative of the people they're trying to reach.

GM thanked all the speakers, especially JB for sharing his deeply personal experiences.

### 3) Opportunity for Q&A

**Charlie Chung (CC)** – Thanked all the speakers. Shared a story of his own that echoed James' situation whereby someone wasn't recognised to be having a stroke until much time after presenting with symptoms.

CC went to their managed clinical network and had a conversation with the Scottish Ambulance Service. SAS recognise that there are additional protocols and additional questions that they can put in.

CC shared some anecdotal stories about 999 calls and FAST positive symptoms. Question is do we have statistics to show that in the situation where people with milder strokes, their family members or neighbours have less of a tendency to call 999, in which case the campaign is missing some of these people? And if so, is there a need for a national campaign? The current communication materials also focus on severe stroke symptoms, burning in the brain etc.

**GM:** I think that's a really important reflection there, Charlie, actually. And how do we communicate that sort of spectrum of severity of symptom and make it accessible and make people take it seriously at the same time, I think that's definitely something that we need to we need to feedback there.

**JW:** Important to be clear, concise and consistent but we are clearly missing people and it's a difficult balancing act to reach everyone and make sure we're targeting those we are missing.

Was struck about what is happening even when patients are reaching the health system. Is there more of a sophisticated test that could be developed for those working in the health system?

So how do we get the maximum benefit out of a campaign that's aimed at the public who are bombarded with messages all the time.

**Sarah Keir [SK]:** Thanked all the speakers for their contributions.

Clearly there is an opportunity to move this story forward. Spoke about how when FAST was first developed, overall stroke awareness was extremely low. Things have changed now so there is a need to develop the story on. Time to think about the maturity of the messaging.

- That comes in that might not be stroke, but the important thing as we know is we're not getting enough strokes. We're not getting them when we need to see them. So frankly, a few more that we can happily send away as a clinician, I'm perfectly happy with.
- So let's maybe start a dialogue around whether we move the dial on whether it's just F.A.S.T. or B.E.F.A.S.T.

**Douglas Horn (DH):** Shares how this is an area of interest to the National Stroke Voices group too. Particularly with the younger members.

- National stroke voices are saying that when they presented at hospital, the clinicians are asking the question of 'what have you taken' rather than looking at the possibility of it being a stroke.
- But having be F.A.S.T. for clinicians would certainly seem to be a more appropriate line for us to be working with clinicians to look at for stroke recognition. So thank, but and also thank you to all the speakers and all of us that have put lots of time and emotions into where we're going with stroke in Scotland.

**Alan Fynn (AF):** James' story was very affecting to listen to because it was actually very similar to his own stroke, which was seven years ago. Luckily for him, his outcome was much better than James' father's. But I think that was luck. I had the severe nausea, my eye trim was trembling. I didn't present with the regular fast symptoms. But the paramedics took me to hospital anyway despite thinking it was a migraine initially.

Agrees with the others that effort should be put into developing another, more advanced test.

**GM:** Thanked Alan and shared reflections on how we could perhaps engage with the SAS and call-handlers to ensure their responses are always accurate too.

**JB:** Shared personal reflections on what could have been his Dad's experiences had the F.A.S.T test been more broad and included his symptoms. Made comparisons with the Covid pandemic and how the public reacted well to ever-changing public health messaging so it's important that we keep that in mind when thinking of developing any new potential messaging.

JB reiterated that we trust the people of Scotland. Trust them to remember information that could save their lives, save the lives of a loved one. I think if it's two letters they can do that. JB also reiterated the point that Scotland is lagging behind and can either play catch up and run a F.A.S.T campaign or it can take the lead and develop new, more effective public health messaging.

**GM:** Closed the meeting and secured agreement from the group on the following action:

*Work with Cross-Party Group MSP colleagues to secure a parliament debate on national stroke public awareness campaign and the need for it to be publicly funded.*

**Meeting close 13:30pm.**