



**Meeting 1 – AGM and CPG to launch the campaign for a regular FAST
campaign in Wales**

Date of Meeting:

12 October 2023

Attendees:

Huw Irranca-Davies MS (the then Chair)

Altaf Hussain MS (Vice Chair, now sole Chair)

David Rees MS

Mark Isherwood MS

Sam Humphry, Communication Manager, Public Health Wales

Angela Contestabile, Policy & Influencing Lead, Stroke Association

Katie Chappelle, Associate Director for Wales, Stroke Association

Katie MacGregor, Stroke Association

Colin Evans, Stroke Association

Lynn Preece, Stroke Association

Llinos Wyn Parry, Stroke Association

Emma Burke, Stroke Association

Summary of the issues discussed:

1. Voting, welcome and apologies.

2. Annual General Meeting and re-establishment of Cross-Party Group on Stroke

Huw Irranca-Davies introduces that we need to re-instate the group and that means nominating members.

AH and DR nominate HID as Chair. Huw Irranca-Davies is elected as Chair. DR and AH nominate AC as Secretariat and AC is elected as Secretariat. DR nominates AH and HID seconds. AH is elected as Vice Chair.

HID welcomes everyone to the meeting. He explains that the meeting will be recorded and anyone who does not want to be in the recording to turn cameras off now.

HID officially re-instates the Cross-Party Group on Stroke.

3. Stroke survivor stories and the importance of acting FAST

HIW introduces the first item: Lived experience of stroke and the importance of FAST. AC introduces Fran and invites her to share her story.

Fran introduces herself and shares that she had a stroke 15 months ago and has been left with aphasia. She explains that this is a communication disorder. She also explains that she frequently experiences fatigue, headaches, and low moods after her stroke. She went to bed and then woke up in the middle of the night not feeling quite right. Her face had dropped. She did not want to disturb anyone in the household and decided to go back to sleep. Fran woke up on Friday morning and came downstairs and tried to speak to her husband.

Fran tried to speak, but her words weren't coming out. He could see the panic in her and knew something was wrong. He called 999 and they said it was a four hour wait. He took her to hospital. Luckily, she was seen straight away as it was quite early in the morning.

Fran needed rehab, but there were no beds available. She discharged herself 10 days after as her mental health was going downhill and she was physically able to

leave. Since coming home, she has had support from Stroke Association and some private support including from Dr Ahmad at Spire.

She had her stroke at 48. Many people think strokes only happen to older people. She was fit and healthy. If she had woken her husband that night, he would have seen her face and known to get help. She thinks that they could have acted sooner and that her husband would have recognized the signs. Her children know now that it can happen to anyone and the signs of a stroke and FAST. However, not many people do.

HID thanks Fran for sharing her story in such an honest and brave way. He reiterates the importance of acting FAST and making sure people know the signs of a stroke.

HID asks how the recovery is going for Fran, and congratulates her on sharing her story and acknowledges that this is part of the journey. She explains that recovery is very slow. It takes years rather than days. Talking does not feel natural and reading is also hard. She says she is tired but is doing well.

4. Presentation of the key findings of the Public Health Wales FAST campaign and recommendations for future campaigns (Samuel Humphrey, Public Health Wales)

HID introduces first presentation from Public Health Wales detailing the outcomes of the recent FAST campaign. He introduces Sam Humphrey, Communications Manager at Public Health Wales.

SH explains the campaign ran through May 2023. The main objective of the FAST campaign is to reduce the amount of time it takes for people to get to hospital and call 999. Uses a tried and tested method including catching imagery and the well-known acronym FAST.

Stroke disproportionately affects people of certain groups. Such as those over 50, those from BAME backgrounds for example.

The channels are particularly important. Many over-50s watch TV and radio so PHW utilized these methods, but did not neglect social media as other members of public need to be aware.

Had access to an advert and re-adapted this for Wales using a voice actor. SH shows the advert to the CPG. This advert has been tried and tested in England, but this challenge was making this equally impactful amongst Welsh speakers.

Worked with agency to come up with NESA. This translates to when stroke strikes, remember the NEXT steps. SH shows the Welsh advert to the CPG.

TV is a very powerful medium and video on demand ads were placed where they would reach disproportionately affected groups. They gained 5,127,227 impressions (300,000 for the Welsh ad). SH notes this is the number of times it was seen not the number of people. Some may have seen it multiple times.

Radio ads also performed really well. Used some specific radio stations to target Wrexham and the Vale. Some global radio stations such as Classic FM also covered and so did Wales Online.

Social media gained almost 4 million impressions, with most people seeing the ad 4 times. 1 million people saw the ads and we had 6,000 link clicks to the stroke page on NHS 111 website.

Shared assets and digital toolkit with health boards and third sector. Engagement was requested in person sometimes, such as Women's Connect First in Grangetown.

After the campaign, questions were included in the regular survey for Talk Public Health Panel. 38% of respondents had seen the campaign during May.

SH notes this was a representative sample of the population so not just the targeted demographics, so demonstrates a good robust set of evidence for the impact the FAST campaign can have.

Recommendations for the future include more time to plan and evaluate the campaign better. For example, running a survey before and after the campaign. Also could have partnered with WAST more for evaluation and planning before the campaign.

What more could be done: Excellent feedback from engagement session in Grangetown. HIW suggests community engagement around stroke awareness and SH highlights FAST could be a good medium to do this. Some printable assets might be useful for displaying in GP surgeries.

Public Health Wales suggests that FAST will need refreshing soon. SH would also suggest that the ads and content need to be as Welsh specific as possible. For example: Does the ad target the groups in Wales we need to be targeting?

HID thanks SH and reflects on the lessons we can learn from this to take forward.

5. Key findings of the Health Inspectorate Wales National Review of Patient Flow (Stroke Pathway) and recommendations on FAST (Angela Contestabile, Policy & Influencing Lead, Stroke Association)

HID introduces the next item: a summary of the recommendations from HIW's review of the stroke pathway. He apologizes that Health Inspectorate Wales could not attend and introduces AC from the Stroke Association to take the agenda item.

AC explains that HIW is the equivalent of OFSTED but for health. She outlines that stroke was used as a case study to assess patient flow. HIW asked: How did PHW consider engaging with people to raise awareness of stroke? And where can it make the biggest difference?

BAME groups are more likely to experience a stroke or for people for whom English is not a first language. HIW noted that imagery from NHS is often not representative of these groups. In recent data (2018-2020) the demographic of Wales is represented as 95% identifies as white, and 5% as of BAME backgrounds.

Important that health boards and Welsh Government find ways to meaningfully engage with disproportionately affected groups and those from lower socioeconomic backgrounds.

Recommendations from HIW included better collaboration and sharing of good practice, improve stroke awareness and prevention alongside FAST. Additionally, they should work closely with people disproportionately affected by stroke to ensure better health outcomes.

What needs to happen next? We need commitment from the Minister for Health and Social Services to run the campaign every 2 years. Commitment from the Minister for national awareness campaigns for stroke and prevention. Also need to make sure that all necessary stakeholders are involved from initial planning stages through to evaluation.

HID thanks AC. HID highlights that the Cross-Party Group will take these insights and translate them into action and make some recommendations for the future.

6. Where we are now in Wales and recommendations for the next steps (Katie Chappelle, Associate Director for Wales, Stroke Association)

HID introduces Katie Chappelle, Associate Director for Stroke Association.

KC thanks HID and explains that Stroke Association is a charity that supports stroke survivors and also acts as a voice for them to hold systems to account (such as Welsh Government and the NHS).

The number of stroke survivors is expected to increase by 50% in the next 20 years. We know that this will include more working-age people as people will work for longer. We want to see people properly supported and able to manage their own care when appropriate to do so.

We all know how important it is to look after our health, but we need to make sure people have access to the things that allow them to live well. These include access to housing, clean air, green spaces and preventative care. We often see more people presenting to A&E with suspected strokes and they may not have the health literacy to advocate for themselves or their family member at the A&E reception desk.

The solutions to some of these issues can be simple and cost effective. We need to see the FAST campaign given the time it needs to reach the people it needs to have the most impact. KC highlights that HIW recommended that the stroke awareness campaign needs to be run alongside a FAST campaign. This also needs to coincide with focus on BAME communities and address health inequalities.

There is a recommendation for all NHS members to be aware of the FAST campaign and the Rossier tool. Everyone needs to be trained in this tool, including receptionists at A&E. This will ensure better patient flow and better outcomes for stroke.

HID thanks KC for sharing some further information and highlighting the messages and action we can take to improve outcomes for stroke patients in Wales.

7. Questions and discussion

HID opens the floor for questions and passes to John Hunt.

JH expresses concern around targeting over 50s and those with other conditions and un-healthy lifestyle factors. He suggests that we need to focus on fit and healthy groups as well to mitigate the common assumptions about stroke.

DR agrees with JH that we need to also focus on other age groups too with future campaigns. He mentions that we need to focus on this as he met a young stroke survivor recently who shared his story.

AH also shares his reflections. AH thinks we should be talking about education from school age. Ambulances also need to be focused on. He is going to take this away and speak with the Minister, Stroke Association and other colleagues to suggest some solutions.

HID recommends that the fellow Members of the Senedd put together the actions and recommendations from the meeting and share with all Members.

MI mentions visiting the group in Buckley Flintshire. He raises that stroke survivors there also mentioned the need to work cross-border with hospitals in England that many stroke survivors will access.

HIW passes over to Alice Robin from BCUHB. AR raises that a lot of people do not always present with FAST campaign. AR mentions that VFAST is also possible as it highlights the visual symptoms people may experience. AR also raises ambulance response times and the fact that in Wales there is no time target for reaching people in Amber category. AR recommends that we consider this as part of any work going forward.

HID invites Shakeel Ahmad, Clinical Lead for Stroke to speak. SA highlights that we need to be focusing on each area in the stroke pathway. HiW report did focus on flow and systems are under huge pressure. There are many challenges on this, and causes a lot of issues at the front door. There are a lot of complexities that this causes for FAST and self-presenting patients. We need to focus on rehab in the community. Explains the trial happening in Cardiff on pre-hospital video triage. This is in the pilot stages but will allow us to learn from this and hopefully roll out across Wales.

HID invites Debbie to share her thoughts. Debbie is a stroke survivor and agrees with JH's points around young stroke survivors and how we can make sure they are aware too in the general public.

Johanna Brown (ARCH) suggests that we target certain groups in their own languages – especially in GP surgeries with high populations of people with English not as their first language. Additionally, the slots we use for the ads need to maximize reach – example given of English speaking show with Welsh speaking FAST ad and it is just not maximizing the reach it could have and maybe needs looking at for further campaigns.

Lynda Kenway, National Stroke Programme Manager thanks everyone for being here and their comments. LK explains the work being carried out by NHS Executive on the whole stroke pathway, including the back-end as well as front end. Important to make sure people recognize the symptoms and can act as fast as possible. WAST are in a difficult situation at the moment and staff are trying their best, but we are

falling behind. LK explains that they are engaging with charities currently and stroke survivors will engage in the programme work and is looking forward to working in partnership with CPG.

Judith Rees highlights concerns around NHS mixed messaging in the media – often hear about people being told not to attend A&E due to extreme pressures and we need to refocus this and make sure we tell people which things are an emergency and when they should be seeking care.

JH picks up on AR's point and highlights that the category for stroke is Amber because that is the most appropriate vehicle for stroke. If it were red, vehicles can be sent that are not suitable to deal with a stroke. JH also highlights that we need to make sure stroke survivors are valued after their stroke and seen as if their life is worth living.

SH highlights that he agrees with JH. In response to JB, SH says that they trialed other languages for Covid vaccines and found the resources were not used. However, for these groups face to face engagement and trusted messengers in those communities worked the best and so could do more outreach and engagement in future.

8. Concluding remarks: Katie Chappelle and Huw Irranca-Davies MS

HID invites KC to come in to conclude and respond to comments.

KC agrees on the FAST campaign re: other symptoms, but suggests we need to get that strong message embedded and then we can add to the campaign and flesh out the message.

KC asks the CPG to write a letter to the Minister for Health and Social Services to highlight the need for a stroke awareness campaign and a FAST campaign at least once every two years.

HID asks AC as Secretariat if she can draw together the main points so Senedd Members involved in the CPG can send a letter. HID also suggests that they look at how Senedd Members approach their own local health boards and can also include some information and ask them to join the Cross Party Group on Stroke. HID will also make sure that Senedd Members are asked to meet with stroke survivors and stroke association and health boards to learn about stroke.

HID makes concluding remarks and thanks his colleagues for accepting roles on the CPG and those with lived experience for sharing their story. HID explains the meetings will run quarterly and the group will be consulted on the agenda as much as possible beforehand.

HID passes onto AC who thanks all the presenters and HID for chairing the meeting.

HID brings the meeting to a close.

You can watch the YouTube recording of the Cross-Paty Group here:

<https://www.youtube.com/watch?v=TvvQh1xFokQ>