

Cross-Party Group Minutes

Meeting Minutes:

Cross Party Group Title:	Cross Party Group on Stroke
Date of Meeting:	12/10/23
Location:	Online (Teams)

In attendance:

Cross Party Group Members:

Huw Irranca-Davies MS (Chair)
Altaf Hussain MS (Vice Chair)
David Rees MS
Mark Isherwood MS

Presenters:

Frances Medcraft – The voice of lived experience
Sam Humphrey, Communication Manager, Public Health Wales
Angela Contestabile, Policy & Influencing Lead, Stroke Association
Katie Chappelle, Associate Director for Wales, Stroke Association

Other attendees:

Frances Medcraft
John Hunt
Judith Rees
Shakeel Ahmad (Cardiff and Vale UHB - Medicine)
Stubbs, Ed (Staff Cymorth yr Aelod | Member Support Staff)

Brennan, Shane (Staff Cymorth yr Aelod | Member Support Staff)
Thomas, Owen (Staff Cymorth yr Aelod | Member Support Staff)
Natasha Collins
Lynn Preece (Stroke Association)
Llinos Wyn Parry (Stroke Association)
Emma Burke (Stroke Association)
Katie MacGregor (Stroke Association)
Benji Williams (Cardiff and Vale UHB - Strategic & Service Planning)
Janine Gould (CTM UHB - Medicine)
Laura Thomas (Stroke Association)
Alexis Kolodziej (Stroke Association)
Colin Oliver (Stroke Association)
Alice Roblin (BCUHB - Clinical Psychology)
Sokina Miah (Stroke Association)
Annabel Jones
Kerry Morgan (CTM UHB - Community)
Cerrys Parker (Hywel Dda UHB - Stroke CNS/Day Hospital Manager)
Rees, Kirsty (Staff Cymorth yr Aelod | Member Support Staff)
Ryland
Som Shekar (Aneurin Bevan UHB - Stroke)
Annabel Jones
Cerrys
Karl Jackson (BCUHB - Stroke Unit)

Apologies:

Mabon ap Gwynfor MS
Jack Sargeant MS
Joel Williams MS
Eluned Morgan MS
Tracey Williams (Welsh Government)

Summary of Meeting:

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| <ol style="list-style-type: none">1. Welcome apologies and introductions.2. Annual General Meeting and re-establishment of Cross-Party Group on Stroke. |
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Huw Irranca-Davies introduces that we need to re-instate the group and that means nominating members.

Altaf Hussain MS and David Rees NS nominate Huw Irranca Davies MS as Chair. Huw Irranca-Davies MS is elected as Chair. David Rees MS and Altaf Hussain MS nominate Angela Contestabile (Policy and Influencing Lead, Stroke Association) as Secretariat and Angela Contestabile is subsequently elected as Secretariat. David Rees MS nominates Altaf Hussain MS and Huw Irranca Davies MS seconds. Altaf Hussain MS is elected as Vice Chair.

Huw Irranca-Davies MS 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.

Huw Irranca-Davies MS officially re-instates the Cross-Party Group on Stroke.

3. Stroke survivor stories and the importance of acting FAST

Huw Irranca-Davies MS introduces the first item: Lived experience of stroke and the importance of FAST. AC introduces Fran (a person with lived experience) 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 being admitted for her stroke because her mental health was going downhill, and she was physically able to leave the hospital. Since coming home, she has had support from Stroke Association and some private support including from Dr Ahmad at Spire Hospital.

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 recognised the signs and symptoms of her having a stroke. Her children know now that it can happen to anyone and the signs of a stroke and FAST. However, not many people do, and she feels more people need to know how to recognise a stroke and to act FAST (dial 999).

Huw Irranca-Davies MS 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.

Huw Irranca-Davies MS 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)

Huw Irranca-Davies MS 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.

Sam Humphrey 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. Sam Humphrey 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. Sam Humphrey 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). Sam Humphrey 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.

Sam Humphrey noted 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, PHW 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 Sam Humphrey 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. Sam Humphrey 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?

Huw Irranca-Davies MS thanks Sam Humphrey 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)

Huw Irranca-Davies MS introduces the next item: a summary of the recommendations from Healthcare Inspectorate Wales's (HIW) review of the stroke pathway. He apologizes that Health Inspectorate Wales could not attend and introduce Angela Contestabile, Policy and Influencing Lead from the Stroke Association to take the agenda item.

Angela Contestabile explains what HIW is and why it conducted its National Review into Patient Flow. She outlines that stroke was used as a benchmark to assess patient flow. HIW asked: How did PHW consider engaging with people to raise awareness of stroke? Where can it make the biggest difference?

Black and Minority Ethnic (BAME) groups are more likely to experience a stroke or for people for whom English is not a first language. HIW noted in its report that imagery from the 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% from 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 FAST/NESA campaign every 2 years. Additionally, we need commitment from the Minister for national awareness campaigns for stroke and stroke prevention. Also need to make sure that all necessary stakeholders are involved from initial planning stages through to evaluation.

Huw Irranca-Davies MS thanks Angela Contestabile. Huw Irranca-Davies MS highlights that the CPG 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)

Huw Irranca-Davies MS introduces Katie Chappelle, Associate Director for Stroke Association.

Katie Chappelle thanks Huw Irranca-Davies MS and explains that Stroke Association is a charity that supports stroke survivors and 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. Katie Chappelle 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 targeting these campaigns at BAME communities and address health inequalities.

There is a recommendation for all NHS members to be aware of the FAST campaign and the ROSIER 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.

Huw Irranca-Davies MS thanks Katie Chappelle for sharing this information and for highlighting the messages and subsequent action that we can take to improve outcomes for people affected by stroke in Wales.

7. Questions and discussion

Huw Irranca-Davies MS opens the floor for questions and passes to John Hunt.

John Hunt 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.

David Rees MS agrees with John Hunt 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.

Altaf Hussain MS also shares his reflections. Altaf Hussain MS 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.

Huw Irranca-Davies MS recommends that the fellow Members of the Senedd put together the actions and recommendations from the meeting and share with all Members.

Mark Isherwood MS 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 where many stroke survivors must access their care.

Alice Robin from BCUHB raises that a lot of people do not always present with FAST campaign. She mentions that VFAST is also possible as it highlights the visual

symptoms that people may experience. Alice Robin also raises the issue of ambulance response times and the fact that in Wales there is no time target for reaching people in the Amber category of their response model. Alice Robin recommends that we consider this as part of any work going forward.

Huw Irranca-Davies MS invites Shakeel Ahmad, Clinical Lead for Stroke to speak. Shakeel Ahmad highlights that we need to be focusing on each area in the stroke pathway. The HIW report did focus on flow and highlighted that systems are under huge pressure. There are many challenges on this, and this 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 there is a pre-hospital video triage pilot currently happening in Cardiff. This is a trial but will allow us to take away learnings and hopefully roll out across Wales.

Huw Irranca-Davies MS 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 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 maximise reach – example given of English-speaking show with Welsh speaking FAST ad and it is just not maximising 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 for their comments. Lynda Kenway 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 recognise the symptoms and can act as fast as possible. WAST are in a difficult situation now and staff are trying their best, but we are falling behind. Lynda Kenway explains that they are engaging with charities currently as well as stroke survivors and both will engage in the programme of work. Highlighted that she 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.

John Hunt picks up on Alice Robin'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. John Hunt also highlights that we need to make sure stroke survivors are valued after their stroke and seen as if their life is worth living.

Samuel Humphrey highlights that he agrees with John Hunt. Samuel Humphrey also says that PHW trialled 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

Huw Irranca-Davies MS invites Katie Chappelle to come in to conclude and respond to comments.

Katie Chappelle 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.

Katie Chappelle 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.

Huw Irranca-Davies MS asks Angela Contestabile, as Secretariat, if she can draw together the main points so Senedd Members involved in the CPG can send a letter to the Minister for Health and Social Services. Huw Irranca-Davies MS wants to highlight the importance and encourage Senedd Members to meet with stroke survivors, the Stroke Association and health boards to learn about stroke and its impact on those affected by it.

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

Huw Irranca-Davies MS passes onto Angela Contestabile who thanks all the presenters and Huw Irranca-Davies MS for chairing the meeting.

Huw Irranca-Davies MS brings the meeting to a close.

Dates, time, and details of next meeting will be shared in due course.