

## Cross Party Group on Stroke Minutes

**Meeting:** Cross Party Group on Stroke

**Date:** 28 November 2017

**Venue:** Committee Room 5, Ty Hywel, National Assembly

### Chair

Dr Dai Lloyd AM (Plaid Cymru)

### Speakers

Dr Phil Jones, Consultant Physician, Stroke Lead for Wales

Dr Raza Alikhan, Consultant Haemotologist, Research & Development Clinical Lead, C&VUHB  
Rhodri Davies, Head of Influencing & Communications, Stroke Association

### Attendees

Dr Anne Freeman OBE, Hon Consultant ABHB, former Clinical Lead for Stroke, Wales  
Philippa Ford MBE, Chartered Society of Physiotherapy, Public Affairs & Policy Manager, Wales  
Dr Richard Dewar, Consultant Stroke Physician/Lead, Cwm Taf University Health Board  
Nicola Davis-Job, Acute Care & Leadership, Royal College of Nursing, Wales  
Nick Cann, stroke survivor, LAS Award winner, Wales Advisory Committee Member  
& Ambassador/fundraiser for the Stroke Association  
Rachel Jenkins, Local Account Manager, Pfizer  
Tommy Price, Account Director, Pfizer  
Martin Coombes, Policy & Gov Affairs, BMS  
Juliet Morris, Policy & Research, Care & Repair Cymru  
Stephen Ray, Healthcare Partnership Manager, Bayer plc  
Stephen Davies, Stroke and Neuro Conditions Implementation Groups Coordinator  
Irina Erchovaia, Research Assistant, Cardiff University, stroke survivor  
Chris Moore, Clinical Support Lead, WAST  
Sheila Tagholm, Chair, North Wales Reference Group; Committee Member (Stroke Assoc)  
David Fitzpatrick, stroke survivor & volunteer  
Jeff Harris MBE, a stroke survivor from Chepstow  
Haydn Canter, Volunteer & Ambassador at Stroke Association

### In Attendance

Llinos Wyn Parry, Head of Services (Mid & North Wales), Stroke Association

Matt O'Grady, Policy & Campaigns Officer, Stroke Association

Jillian Haynes, Minute Secretary, Stroke Association

### Apologies

Llyr Huws Gruffydd AM (Plaid Cymru)

Dr Shakeel Ahmad, Clinical Lead for Stroke, Training Programme Director for Stroke C&V UHB  
Ross Evans, Acting Director, Stroke Association

Dr Fiona Jenkins, Chair Nat Stroke Del Group, Exec Dir Therapies & Health Science, C&VUHB  
Sue Beckman, Director, Delivery Unit

Catherine Quarrel, Commissioning Manager, Powys Teaching Board

Ceri Williams, Policy & Public Affairs Lead, Social Care Wales

Caroline Walters, Policy Officer, Royal College of Speech and Language Therapists  
Joanne Oliver, Health Service Engagement Lead for Wales, British Heart Foundation  
Trudie Lobhan, Founder & CEO, AF Society  
Tina Donnelly, Director, RCN Wales  
James Barry, Clinical Lead, All Wales Cardiac Network  
Prof Chris Jones, Medical Director, Deputy Chief Medical Officer,  
Adam Fletcher, Head of BHF Wales  
Simon Hatch, Carers Wales  
Helen Hak, Strategic Clinical Lead Occupational Therapists for Stroke (ABUHB)  
Ele Hicks, Policy Manager, Diverse Cymru  
Louis Fligelstone, ABM ULHB Surgical Specialties  
Professor Reg Morris, C&V UHB Psychology Training  
Ruth Crowder, Policy Officer Wales, Royal College of Occupational Therapists  
Fiona Hillen, Cwm Taf LHB, Nutrition & Dietetics  
Professor Chris Burton, Head of School of Healthcare Sciences, Bangor University  
Lorraine Morgan, Consultant on Ageing  
Claire Butterworth, Clinical Specialist Physiotherapist in Stroke, C&V Physiotherapy  
Gary George, stroke survivor  
John Heaton, stroke survivor  
Sara Moran, Campaigns and Diabetes Voices Officer

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#### Purpose of the Cross Party Group on Stroke:

The CPG's priorities and required outcomes for 2017-8 were agreed as **post-acute care** (psychological and psychiatric support) and **prevention** (specifically, atrial fibrillation (AF)). There would also be a standing topic around **scrutiny of the implementation of the Stroke Delivery Plan** across health boards. It was the intention of this meeting to review progress on the above and consider responses received from the Cabinet Secretary to correspondence submitted by Dr Lloyd on behalf of the Cross Party Group on Stroke.

#### 1. Welcome, Apologies and Introductions:

The Chair welcomed attendees and introductions were made. Apologies are noted above.

#### 2. Approval of Previous Minutes:

The Minutes of 19 September were approved by Members as an accurate reflection of the meeting content.

#### 3. Update on Actions:

Actions agreed at the last meeting were discussed.

Dr Lloyd confirmed that he had written letters to the Cabinet Secretary around the establishment of **hyperacute stroke units** and **thrombectomy**.

He also reported that had received a formal response from the Cabinet Secretary, dated 24 September, and tabled for attendees' information, to his correspondence on **atrial fibrillation**.

The Chair had not, to date, received a response from the Cabinet Secretary to his correspondence around **psychological and psychiatric stroke services**.

4. Update on the Stop a Stroke Project by Dr Raza Alikhan

5. Discussion on AF: the next steps:

Dr Alikhan presented the key elements of the Stop a Stroke campaign.

Notable statistics relayed included: a person with AF would be five times more likely to have a stroke than a person without; females are 1.5 times more at risk than males. At November 2017, six thousand patients with AF were at risk of stroke (NWIS statistics). There had been a Welsh Government instruction for GPs to review patients on aspirin monotherapy by 31 March 2015. An audit tool was developed and deployed in November 2017; this showed that 82% of those with AF were on anticoagulants. One in five were taking aspirin or nothing at all however, and those people were to be highlighted as an area of concern.

The Cardiff and Vale Health Board was the first in the UK to be awarded an advanced service payment for GPs to identify patients with particular stroke requirements. This had been taken up by practices at various rates. Pathways were developed to support primary care services and teaching programmes were implemented. In 2012-5, certain patients were allowed to transfer from aspirin.

Dr Alikhan continued that there were many requests from English health boards to examine the results of work with primary care colleagues, and so the Stop a Stroke Project was born, and the website created, which contains useful information and statistics on stroke. It also has an interactive element where submitted queries would be answered within four days, although average response times were less than 24 hours.

David Fitzpatrick queried whether there were any alternatives to aspirin. Dr Alikhan replied that aspirin reduces the prospect of stroke by 19% but anticoagulants reduces prospects by 66%. It was imperative that a blood test was taken before commencement of an anticoagulant. NWIS deployed the audit tool in every group practice in Wales, gathering data by group clusters. From December, the dashboard would update every 24 hours, showing the prevalence of atrial fibrillation within every practice in Wales. It has been tested for eighteen months and is now available worldwide.

Ms Pippa Ford asked if there was similar work occurring in other parts of the UK which Wales could learn, from and share information with, to mutual benefit. Dr Alikhan replied that work was ongoing in the UK generally; there were areas of good practice in Wales which could share useful outcomes.

Mr Jeff Harris suggested that atrial fibrillation appeared to be difficult to diagnose. Dr Alikhan stated that he was keen to work with the Stroke Association to encourage pulse checks to detect such irregularities.

Matt O'Grady noted that the audit tool was available across Wales, but queried how widespread the publication of this work had been to health boards. Dr Alikhan advised that publicity had been sporadic, but he had made inroads into seeking champions to lead the way. When available, he was willing to be approached by anyone who was interested in discussing stroke. Dr Jones agreed that this had been exciting, ground-breaking work, and the Stroke Implementation Group had identified people to relay the information back to each health board.

Dr Dewar stated that the Stroke Implementation Group had identified and funded this work at a group practice in Cwm Taf and it had moved on to become a sustainable model. There was funding available for all areas to become involved. Dr Dewar was disappointed in the decision taken by the Cabinet Secretary regarding AF screening, especially as the procedure was cheaper than many other forms of stroke prevention. Checking each patient's blood pressure and pulse could avoid atrial fibrillation being undetected.

Rhodri Davies invited comments on what the Cross Party Group on Stroke could do in order to assist with awareness of Dr Alikhan's work and suggested that engagement with health boards would be essential.

Nicola Davis-Job suggested that engagement with the sixty-four cluster leads would be effective.

Chris Moore stated that funding had been secured in 2015 to attach ECGs direct to selected patients' hearts in certain areas in Wales, and it was hoped that this facility would be transmitted to GPs' surgeries. David Fitzpatrick queried that as this procedure had been proved to prevent stroke, would it be possible to determine the key statistics, especially with regard to those who suffer from atrial fibrillation. Dr Dewar advised that there were additional questions to be asked around anticoagulants and atrial fibrillation. It would be very useful to prove that the above measures prevented stroke effectively.

Haydn Canter enquired whether it would be possible to detect AF as a lay person. It was advised that a person's pulse could determine irregularities and that NICE recommend a simple health check reader which connects to a mobile phone; an ECG reading could be determined within thirty seconds. Rhodri Davies advised that this facility is not available at Know Your Blood Pressure (KYBP) sessions in Wales, but is being trialled by the organisation in other parts of the UK. KYBP sessions, as organised by the Stroke Association, assist people by highlighting a high or low level blood pressure reading. A follow up GP visit may be recommended.

Irina Ercovaia enquired after how many experiences of atrial fibrillation someone would be advised to take anticoagulants, generally. It was explained that each patient would need to be risk-assessed individually and the benefit would need to outweigh the risks in the doctor's opinion.

**Action: The Chair agreed to write a letter of support to highlight the above suggestions and comments, and endorse the Audit Plus data capture system. He would discuss the issues further with Dr Alikhan and inform the Stroke Implementation Group in an effort to engage executive leads.**

## 6. Six Month Review Pilot in Cardiff: a Stroke Association presentation

Rhodri Davies, on behalf of Ross Evans Acting Director of Wales, informed the Group on the progress of six month patient reviews being integrated as a standard service for stroke patients following discharge in Cardiff and Vale UHB. The service was analysed from April 2016 to March 2017. By the end of the project, ie 31 December, it was envisaged that a total of 94 reviews would have been performed. Clinicians praised the work of the Stroke Association and their intervention in this area.

Mr Davies explained that the Cross Party Group on Stroke has a list of key priorities. Emotional support following hospital discharge is one of them, as evidence shows that a third of stroke survivors experience depression and over half suffered anxiety following stroke. Twenty percent felt that the emotional side of stroke was not addressed and ten per cent felt that they had not received the support they needed in order to accept their new situation.

In conclusion, there is an obvious funding need to provide this facility as a crucial follow up service in the community, as six month post-stroke reviews are expected to be carried out from the same funds alongside other, more visible, stroke services.

It was suggested that a six month review should be a holistic check-up and a discussion about general wellbeing. The Greater Manchester SAT tool identified 35 common problem areas of need following stroke, emotional support included.

It was also important to note that the need for support may become evident long after the six month review, and peer support/carer support groups could not necessarily fill the need.

The completed reviews were not able to be added to the SSNAP data, but the Stroke Association was responsible for the data and would submit to the Stroke Implementation Group as a report, and share the findings more widely.

Dr Anne Freeman suggested that a poster be written for the Wales Stroke Conference to be held on 3-4 July 2018, where the first six months post-stroke will be a discussion topic scheduled as a morning session.

**ACTION: Dr Lloyd would follow up the Cabinet Secretary's response to the correspondence sent on the psychological effects of stroke.**

## 7. Discussion on Psychological Therapies

Nicola Davis-Job enquired around the governance framework and the safety of clinical decisions. Rhodri Davies stated that he would pass her question to the Acting Director of the Stroke Association.

Matt O'Grady reported that the procedure would be that a copy of the six month review is forwarded to the GP and certain areas would be highlighted as a patient need, such as counselling.

Dr Anne Freeman asked if the system covered all aspects which were covered by the SSNAP six month review.

Irina Ercovaia praised the Stroke Association for bringing this issue to the attention of the Cross Party Group on Stroke and suggested that a longer term review would also be useful in addition to the six month review, as sometimes depression could emanate ten years post stroke. This gap is currently filled to an extent by peer group support.

## 8. Presentation on the Welsh Government's Stroke Delivery Plan

Dr Jones reported that Dr Fiona Jenkins was absent from the meeting as she was attending an event in London, having been nominated for the Guardian Public Service Award for Leadership Excellence.

He continued that the Stroke Implementation Group works closely with partners and organisations to promote healthy living (under the Living Well initiative) and progress the Stroke Delivery Plan.

The Stroke Implementation Group had collaborated with the Inverse Care Law programme to target certain demographics and had funded a successful media campaign in Cwm Taf in connection with stroke prevention, reaching 41% of the health board population.

The Stroke Implementation Group had also funded the Stop a Stroke project in the Cardiff and Vale UHB, as described above, to evaluate the processes of identifying people known to have atrial fibrillation. This was an agreed priority in 2016-7. It was hoped that the atrial fibrillation prevention initiative would be rolled out to health boards and further supported by primary care and the cardiac network in 2018-9, in partnership with the Royal Pharmaceutical Society. Transient Ischaemic Attacks were not recorded, but would be in 2018, and this was to be discussed at the Stroke Implementation Group on 12 December.

The reconfiguration of stroke services to include the development of hyperacute stroke units was a key topic of discussion. It was noted that performance against the SSNAP measures had improved in Wales and in September 2017, Wales had four units achieving a B grade for overall stroke care.

The Stroke Implementation Group had also worked with the Neurology Implementation Group to support the development of community rehabilitation and a new service, based in Merthyr Tydfil, had been developed.

A new reference book had been developed entitled 'Rebuilding Your Life After Stroke' in conjunction with stroke survivors and psychologists.

Development of a stroke research infrastructure/network had recently been launched in conjunction with Cardiff Metropolitan University in the form of a hub.

Dr Jones further reported that analysis of patient experience and outcome measures was on schedule to be completed in December 2017 and he summarised the national priorities for 2017-8.

Martin Coombes suggested that national screening for atrial fibrillation would not necessarily be effective in supporting stroke prevention. He suggested that supporting group practices to raise awareness in detection would be more effective.

Dr Alikhan invited suggestions as to how the population could be encouraged to perform their own pulse checks; perhaps at GP practices and pharmacies. Addressing the Cabinet Secretary's response to the Chair's letter discussing atrial fibrillation, Rhodri Davies replied that he is unaware of any work happening between the Stroke Association, PHW and the Royal Pharmaceutical Society, as stated in his response. However, he added that the Stroke Association is now part of a Wales-wide atrial fibrillation workstream group, including representatives from the health service and third sector. All agreed that raising the profile of atrial fibrillation is key.

Haydn Canter shared that his stroke was due to high blood pressure but that he had no idea that this was a condition from which he suffered, as he had experienced no symptoms.

It was suggested that the Stroke Association's Know Your Blood Pressure events could take place in sports arenas and stadia.

Jeff Harris enquired whether a person needed to be in atrial fibrillation at the particular time of the reading in order to be detected. Dr Alikhan replied that sustained atrial fibrillation would be present constantly.

Irina Ercovaia had observed that a procedure was available for monitoring atrial fibrillation via a device inserted subcutaneously. Dr Alikhan replied that this would be a risky procedure in some patients. Eighty percent of patients were prescribed anti-coagulants.

David Fitzpatrick noted that personal data sharing/communications appeared to not be in place effectively between health care professionals. Dr Alikhan advised that the Welsh clinical portal was now live and would combat this issue. This was revolutionary in Wales, but not available in England. Dr Dewar also advised that the system would show all correspondence between professionals, and Dr Lloyd stated that both primary and secondary care notes would be included.

Matt O'Grady enquired whether the thrombectomy paper would be presented to the Welsh Health Specialised Services Committee as a public paper.

Rhodri Davies added that a good atrial fibrillation toolkit was available.

It was suggested that the above presentation be uploaded to the website, if possible.

**Action: Jillian Haynes to check with the Table Office if it is possible to upload the presentation to the website.**

**9. Any Other Business:**

Rhodri Davies tabled a paper on the Wellbeing Care Plan. He asked that the information be disseminated to as many people as possible. The information can be found here: <http://www.nhsdirect.wales.nhs.uk/LiveWell/LifestyleWellbeing/Winterhealthplan>

No other business was discussed.

The next Cross Party Group on Stroke would be held on 6 March at 12:00 in Committee Room 5, Ty Hywel (to be confirmed). The topic for discussion would be Speech & Language Therapy. The meeting would also serve as the Annual General Meeting.

Dr Lloyd directed that the National Assembly's website shows the dates, times and venues scheduled for future meetings, as well as Minutes of all previous meetings.

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Minutes approved by Dr Dai Lloyd AM as a true reflection of the content of the meeting held on 28 November 2017:

Signed: ..... Date: .....

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