

Minutes of the Cross Party Group on Stroke: 18 June 2019

First Evidence Session of the Inquiry into the implementation of the Welsh Government's Stroke Delivery Plan

1. Welcome, apologies and introductions

In attendance:

Cross Party Group Members

Dr Dai Lloyd AM

Nick Ramsay AM

Other Assembly Members

Mark Isherwood AM

Giving Evidence

Pip Ford, Chartered Society of Physiotherapy

Carol Bott, Stroke Association

Dr Alison Stroud, RCSLT

Other Attendees

Gareth Lee, NHS Delivery Unit

Katie Chappelle, Stroke Association

Matt O'Grady, Stroke Association

David Fitzpatrick, Stroke Survivor

Elaine Scale, Welsh Local Government Association

Belinda Done, Royal College of Speech and Language Therapists

Claire Butterworth, Chartered Society of Physiotherapy

Anurag Saxena, Noah's Ark Children's Hospital

Alexander Smith, Stroke Association Postgraduate Fellow

Nigel Howells, AMGEN

Stephen Davies, NHS Wales Health Collaborative

Sarah Griffiths, Royal Pharmaceutical Society

Jodie Williamson, Royal Pharmaceutical Society

Callum Hughes, NHS Wales Confederation

Iwan Williams, Social Care Wales

Alun Walters, Cardiff and Vale University Health Board

Tabitha Mansel-Thomas, Cardiff and Vale University Health Board

Emma Henwood, British Heart Foundation Cymru

Claire Thirsk, Noah's Ark Children's Hospital

Nick Cann, Stroke Survivor

Paediatric Neurologist – Name TBC

Via Video Link

Jill Newman, Betsi Cadwaladr University Health Board

Apologies:

Dr Phil Jones, Welsh Government Clinical Lead for Stroke

Dr Fiona Jenkins, Stroke Implementation Group

Paul Mayberry, Mayberry Pharmacy

Peter Carr, Aneurin Bevan University Health Board

Shelia Tagholm, Stroke Association Welsh Advisory Committee

Stephen Ray, Bayer/ABPI Representative to the Cross Party Group

Rachel Jenkins, Pfizer

Jeannie Wyatt-Williams, Welsh Local Government Association

James White, Cwm Taf Morgannwg University Health Board

Ann Lloyd, Aneurin Bevan University Health Board

Elin Edwards, RNIB Cymru

2. Approval of minutes

Approved by group

3. Update on progress from actions agreed from last meeting; the way forward

The British Heart Foundation has joined the Cross Party Group task and finish group.

4. Evidence session: Life After Stroke

Pip Ford, Chartered Society of Physiotherapy

In preparation for this, CSP sent a questionnaire to health boards; six provided information. They asked a wide-ranging set of questions around stroke services including;

- How have rehabilitation services improved since the introduction of the stroke Delivery Plan (SDP)?
- How have you developed Early Supported Discharge (ESD) services?
- Can patients access community rehab and day services?
- Can stroke survivors re-access physiotherapy?
- Do stroke survivors get a six month review?
- Do physiotherapy services refer out to other services?

Q - How have stroke services improved since 2017?

Some good examples from around Wales:

- Powys Teaching Health Board Community Neuro Rehab Team, positive feedback from survivors, self-referral available and team refer on, including to life after stroke services.
- Cwm Taf Morgannwg development of ESD, data shows they've cut length of stay. Access to reablement, patients can re-access physio, and importance of self-management.
- Betsi have moved to 7-day working since Jan 2018. Although not clear if this is made out of 5-day staffing. Regular family clinics, to manage recovery expectation, holistic goal-setting.
- Hywel Dda run a specialist service for spasticity. They would like to continue their stroke physio community outreach project post-March 2020 but funding is unclear. They're treating patients in their own homes and running specialist clinics.
- Cardiff and Vale – increased access to groups, increase community setting, increased staffing support for seven-day working. Group exercises and involvement in research studies.

Overall they identified what the CSP felt was some good work going on across Wales and encouraging seeing health boards pointing to self-referral.

Q – What are the reasons for a lack of progress?

Challenge of staffing combined with no permanent increase in funding. Funding for pilots and short-term funding only, with no substantive increase. Maternity leave and sickness create challenges.

Health boards are reviewing and redesigning, although one comments; “We started these discussions six years ago, there's been no improvement.”

Challenge to deliver a seven day service but also to deliver and support an early supported discharge, although other outreach services available.

Q- How do you see the future of the SDP post-2020?

There needs to be a focus on stroke, otherwise it will be lost as a speciality area. SDP has forced LHBs to focus on service delivery. Some investment came with SDP and Neuro Delivery plan. Warning that the focus is too often on the acute side and rehab seems to be forgotten. CSP concerned about short-term funding.

Q – How does research fit in?

This is vital. However there are concerns we don't have capacity to release people from their workload to do more research.

Other comments:

Physiotherapists are found in fast effective care, end of life – it's everywhere, not just rehab.

Three recommendations:

- Rehab needs a much greater focus – prioritise
- Organisations needs to address therapy staffing levels for rehab
- There needs to be a focus on stroke rehabilitation in whatever comes post-2020

Dr Alison Stroud, Royal College of Speech and Language Therapists

They also surveyed their members, including clinical excellence network for speech and language therapy and stroke. Feedback showed that generally, there's been an increased investment due to the SDP. More of this investment has been at the acute end, but general agreement is that this has led to increased capacity

There was concern that SSNAP targets are driving productivity rather than quality. SALTs using outcomes measures which are not just about impairment but about managing risk of harm and preventing functional impact. A recommendation was made that any future delivery plan should focus on PROMs and PREMs, not just productivity outcomes.

There are only 100 speech and language therapists working in adult services around Wales, this doesn't leave a lot for stroke. SSNAP does not highlight whether there is a SLT in and ESD team.

An example of positive work was given of Cardiff Met using Stroke Association as student placements – but the challenge of balancing rehab against an acute sector which keeps grabbing attention. SALTs are 'upset at being constantly used' to do lots of swallowing risk management and speech and language is not always prioritised by others. There needs to be more interdisciplinary training at undergraduate levels, so SLT don't have to deal with swallowing etc.

The research element of the SDP was felt to be useful – for example the 'head' screening tool which has been implemented across the whole of Wales.

Good outcomes could be facilitated by new technology but progress is too slow. A parallel piece of work on augmented assistance has received Welsh Health circular guidance, but still waiting on guidance for stroke patients.

Carol Bott, Stroke Association

The Stroke Association works in an increasingly difficult environment, commissioned income is decreasing, we're competing for voluntary income in a competitive market.

Our stroke recovery service provides tailored one-to-one support, and operates in all but two LHBS. We also support neuro cafes, Phoenix Project etc. for working-age

stroke survivors and can signpost to a helpline. However there are gaps and more investment is needed. Our Lived Experience of Stroke research out today surveyed 600 people in Wales. 94% said they experienced a cognitive effect from their stroke proving that, despite the commitments of the SDP, many people aren't able to access to support they need.

Gaps we've identified include;

- 93% of stroke survivors at Prince Charles access SLT at least once – only 20% at Morriston Hospital. Stroke survivors mention SLT to us the most.
- Hywel Dda – significant gaps in rehab. In some areas, no ESD available, despite SDP saying it should.
- 6 month reviews are ad hoc cross Wales.
- Role of peer support recognised by SDP, but current commissioning means these are likely to decrease.

Questions from Cross Party Group to the panel:

JN said there is a huge desire to engage more in life after stroke with patients. Betsi Cadwaladr are working with third sector organisations to enable patients to enjoy life after stroke. Agree with the importance of medical and clinical care after stroke, but third sector need to be enabled to support patients and their families.

SD said he is aware some patients can't tolerate 45 minutes of therapy. Is this an issue? PF said this is a problem with SSNAP data. Some people just aren't able to take 45 minutes of treatment.

AS responded that this is one of the issues with SSNAP data and target is based on SALT research for a specific speech impairment, this has become a target for everything, not always appropriate.

MO asked regarding the reasons behind the variations in the number of people receiving the RCP recommended 45 minutes per day. At Bronglais it's 5.1%, at Glan Clwyd 37.2% what are the reasons behind wide variations, it can't all be down to clinical reasons?

PF indicated that it is often a staffing issue. Treatment can be labour intensive, sometime requiring two/three people. This is an issue. Also if it's a seven-day service you can't deliver such high-levels of staffing.

DF said the effects are so vastly different. Six weeks support is the maximum. It was good support, but it wasn't enough for him. As he had a minor stroke so some things weren't available. The assessment of the individual and treatment varies.

AS highlighted that this is why PREMs are important, we want to move towards treating people quickly who can benefit from a small amount of therapy e.g. minor stroke – this is where we should invest the money.

A question was asked regarding waiting times vs community support. Investment into the community can drive improvement, we need to get out to the patients e.g. breast screening.

BD explained the process of leaving hospital and ESD team picking up. Developments in neuro and stroke community services mean a more seamless transition to community groups. Various groups support on issues including fatigue etc. community services means hospital waiting lists have significantly reduced.

SG said pharmacists pick up a lot of issues with medication and it's difficult to sort as pharmacists aren't in the stroke team, meaning therapists can get caught up in sorting medications etc. They would like to see shared decision-making with patients. For an example a patient was discharged with medication that didn't take into account their cognitive problems, this was difficult to pick up in the acute setting. 'Your medicines at home' team is a community-based team that can do this.

A point was made that there are disparity between teams in waiting times. The example was used that Cardiff and Vale don't really have an ESD service, so patients are waiting 14 weeks for outpatient appointment.

PF said only two LHBs recognise they're delivering ESD. RE. Access in the community, there are a wide range of follow-up services through community resource teams – not always a stroke specialist, but some team members will have specialist expertise. However the focus is often on the acute sector, drawing resources in to community services is a problem.

It was highlighted that the SDP doesn't have childhood stroke as a term of reference. But those that survive and will become adults stroke survivors. Life after stroke in childhood is a long process and problems might arise in long-term future. I have difficulty in transitioning these survivors to adult services. Some psychologists won't accept them until 18 for example and some children's psychologists stop at 16. How can we best support children who've had a stroke?

CB said the Stroke Association offered to work with the team on this. The SDP has a small section on childhood stroke, but it's not enough detail. CB noted this is not currently high on the agenda. MO highlighted that childhood stroke is mentioned in the SDP but in very little detail.

MO stated that the SDP picks out the importance of six month and annual reviews. Does this happen?

BD and AS said that SALTs had open access self-referral to all patients, this goes above six month and yearly reviews. But trying to get people engaged with SALT is difficult – they feel the referral needs to come from a health professional. Six month and 12 month reviews could also be too prescriptive, we try to focus on the individual patient. SALTs also work with loved ones and carers to continue SALT at home. PF

said the annual review seems to be done by nursing specialists, rather than therapists.

NC and DF said as Stroke survivors they never had a review. CB mentioned this echoed in Stroke Association research that found 45% of survivors say they have feelings of isolation after discharge. SG mentioned pharmacy has the potential to be involved in the medicine review element of six month reviews.

JN responded that the Stroke Association do deliver reviews on our behalf, there are different modes of this review. Agreed there's value in looking at this holistically.

PF said there is feedback that psychological support is an area lacking in resource. LHBs fund the Stroke Association and therapists rely on this area of support, particularly when it comes to psychological support. Stroke Association services are crucial to the future yet there's a risk of no long-term funding.

The Chair noted the forthcoming retirement of PF and expressed his gratitude for her work.

Terms of reference for the Inquiry into the Stroke Delivery Plan

Circulated to the group. The Chair reiterated that evidence can be fed in to the inquiry at any time, not just during oral evidence sessions.

The Chair updated the group that a call for written evidence will be issued during the summer period and Local Health Broads will be asked to input. The Chair invited the group to email him or Matt with any further questions and/or comments.

Dates, time and venue of next meeting: 15 October, 12.30-13.30. Room TBC.

Topic for next meeting: Preventing Stroke

Meeting ends