Cross-Party Group on Stroke

Wednesday 23rd March, 12:30 – 13:30

Minute

Present

MSPs

Gillian MacKay MSP [GM]
Alexander Stewart MSP

Invited guests

Professor Martin Dennis (Speaker) [MD]

Non-MSP Group Members

Douglas Horn (speaker) [DH]
Mark Smith
Margaret Mitchell MBE
Dr Christine MacAlpine
Eric Sinclair
Dr Jackie Hamilton
Professor Andrew Elder (President Royal College Physicians Edinburgh)
Dr Amy Mulroue
Katherine Byrne (Chest, Heart and Stroke)
Joanne Graham (Scottish Stroke Nurse Forum representative)
Dr Chris Taylor
Professor Frederike Van Wyck
Matthew Walters MBE (RCPSG representative)
Dr Fergus Doubal
Dr Terry Quinn (BIASP)
Clare McDonald
Alan Flynn
Ian Lee
Dr Leslie Scoobie
Catriona Renfrew
Dr Stephen Makin
Dr Tony Byrne
Katherine Gillespie
Lizzie Edwards (RCGPG)
Katie MacGregor (secretariat, Stroke Association)
Colin Oliver
John Watson

Apologies

Professor Gillian Mead
Dr Matt Lambert
Professor Jesse Dawson
Dr Lisa Kidd
Colin MacFarlane

Agenda item 1 – Welcome and Apologies

Chair: Gillian MacKay MSP

GM welcomes members to the first wider meeting of the CPG Group and went through list of Apologies.

GM outlined the current number of people affected by stroke in Scotland and how there is a significant lack of awareness both politically and publicly of the impact of stroke. This provides the basis and need for this CPG. GM then highlighted the number of commitments in the 2019/20 programme for government. One of which was to develop a progressive stroke pathway, which will be the focus of today's meeting.

GM introduced the first speaker, Professor Martin Dennis - Chair of the National Advisory Committee on Stroke and Specialty Advisor on stroke to the Chief Medical Officer – who will present on the recently published Progressive Stroke Pathway document.

Agenda item 2 – Progressive Stroke Pathway (PSP)

Speaker: *Professor Martin Dennis*

MD outlined where this work has come from in the 2019/2020 P of G and subsequent Thrombectomy commitments in the 2020/2021 Programme for Government (PfG).

Through quality improvement and working with managed clinical network, there has been slow and uneven improvements in aspects of the delivery of stroke care. Important this is delivered well as it improves outcomes for patients, including survival and avoiding further stroke and minimising disability.

PSP, been in development over the last two years. The contents of this were informed by work that was sponsored by the national planning board, specifically a 'horizon scanning' project, where clinicians from across the pathway, tried to judge what is likely to happen in stroke care over the next 5-10 years. Used evidence guidelines from across the world, engaged with wide range of health care professionals, 3rd sector input and lived experience input via the National Stroke Voices (NSV).

MD describes the infographic on page five of the document. Starting at prevention and recognition of stroke through to long term support in community and, where

appropriate (10-20% of patient who enter hospital) end of life care. Please see info graphic for more information.

Over the next few months, there will be ongoing work to raise awareness of the PSP and will work with NHS boards to identify the gaps to deliver this progressive stroke service. This work will evolve into an Action Plan, to be published later this year. MD hopes to work with the Scottish Government to influence their wider policies which will help to deliver this plan.

MD highlighted that some health boards in Scotland are too small to deliver this service alone and will need support for elsewhere which is why more help with wider policies and NHS planners is essential.

MD acknowledges there are number of challenges to the delivery of this pathway vision, including: health and social care funding, health and social care staffing, ageing population, poor prioritisation within NHS, ineffective MCNs, siloed working, poor IT and lack of digital solutions.

MD then spoke about his hopes and expectations for the future. These include:

- Robust and sustainable 24/7 Thrombectomy and thrombolysis service across Scotland
- Improved access to imagining and other diagnostics through better prioritisation of what we currently have
- Improved access to specialists, making better use of telemedicine
- Ensuring better outcomes for patients which involves agreeing what a good outcome for patients is – through shared decision making and more valued outcomes

Agenda item 3 – Lived experience of Stroke

Speaker: *Douglas Horn, Co-Chair of National Stroke Voices (NSV)*

DH shared his stroke journey with the group.

DH explained what the NSV group was created. Shared how he became involved with the group. Explained what the selection process was; for both stroke survivors and carers of stroke survivors. Each story is unique, and each treatment has been unique. There is no one answer to stroke care. Each stroke survivor has their own journey. There are around 20 members; ranging from teenagers to retirees; it does not exclusively happen with old people. A diverse group. Hope to continue to ensure the group is as diverse as can be going forward.

The group have been grateful to be able to pull together a view and contribute to the final version of this document. They are pleased to see the groups' view be incorporated in a meaningful way, especially in the post-stroke/rehab section.

DH raised importance of public awareness of F.A.S.T as a means to identify people having a stroke.

Now hope to be involved in the implementation of this pathway document. Patient voices need to be continued to be involved in these discussions.

Agenda item 4 – Q&A opportunity.

Q1: community rehab and pressure around Health and Social Care Partnership, will there be additional funding?

MD: While some areas will require additional funding, many services, such as community rehab, early supported discharge and follow up, could be bolstered through better prioritisation of existing resources. A concern going forward is that even if we have the money, we do not necessary have the things to spend it on that we would like.

Q2: Workforce concerns

MD: There are going to be struggles across health services and social care with numbers of people, there needs to be a decent workforce plan – there isn't currently one for stroke. This is to ensure that we are training the right number of people in the right areas and we can attract and retain the staff and offer then good CPD. A lot of work is needed here to retain the staff. Lots of specialist staff have left the stroke services during COVID due to stroke units being closed for a short time. There will be need for more funding, clever workforce planning and clear prioritisation and making our staff go further with decent digital support.

Q3: Involving stroke survivors carers and family members in their after-care and decision as part of the stroke pathway, specifically around speech and language in ever day life

MD: There are examples when this has been done well and speech and language therapists are often good at involving stroke survivors and their families/carers to help the patient communicate in their everyday life. There are stroke group which some people can access, good online help to aid people communicate after their stroke. This support is very patchy though, either because not available in their area of because they are not directed to them. Need to map the availability of these services, and ensure that wherever you are you are at least made aware of these services and directed to them.

Q4: Life after stroke services

MD: Very patchy services across the country. People (those working in stroke care) are now involving themselves in setting up these services so that people have easy access into specialist services when they need it – not necessarily just when they have had an acute event but when they need extra support. Particularly accessing specialist care in the community.

DH: NSV place emphasis here on having a dedicated stroke nurse to be able to identify what help a patient might need. SN needs to be well embedded into a well-integrated

system so that is a robust service and isn't prone to failing the patient and family because specific SN isn't available.

Q5: Raising awareness of PSP and next steps

MD: We will be revising the Stroke Services improvement plan and report back in that; currently only reaches those working in stroke. Need to get message out further and engage wider stakeholders. MD & others will be working with NHS boards to identify the gaps of what we hope to be delivering in the future and what they are currently delivering now.

DH: NSV keen to lend support here to raise awareness of report, possibly through community engagement opportunities.

Q6: What can MSPs do both on this and wider stroke services

MD: MSP can have influence at two levels – at NHS Boards (challenge is that stroke is not high up prioritisation in NHS boards); keen to strengthen the Stroke MCNs within boards – have senior members of NHS boards responsible and accountable for this plan – MSP can lend support here.

On a national basis, there are number things that should be happening in NHS generally and are not. We need better prioritisation – Thrombectomy a key example of this – this should have become a rapid priority and wasn't; demand to have proper workforce planning (e.g. a stroke training post was removed by the deaneries last year with no consultation with stroke community); IT systems are very poor NHS – very lengthy process to change which results in having multiple systems that don't speak to each other. Stroke care needs to be managed across all areas to be delivered really well.

DH: MSPs can bring it up in the chamber, attend stroke café/club

Actions from meeting

Action 1: CPG write to each board and ask who the named individual will be from their SMT?

Action 2: Write to the cabinet secretary for Health and Social Care, following publication of the vision doc when the refreshed SIP will be published?

A.O.B

Katie (secretariat) will write to members with minutes and next meeting dates and topics.