Cross-Party Group on Stroke

Friday 23rd June, 12pm-1pm

Minute

Present

MSPs

Roz McCall MSP (RM)
Jenni Minto MSP (JM)

Invited guests

Anne Marie Gahagan
Katrina Brennan [KB]

Non-MSP Group Members

Katie MacGregor (secretariat)
Colin Oliver (CO)
Calum Rosie
Ian Lee
John Watson (JW)
Clare McDonald
Kylie Barclay
Kym Kestell
Amy Mulroue (AM)
Tessa Stanley
Eric Sinclair (ES)
Douglas Horn (DH)
Sophie Bridger (SB)
Catriona Renfrew
Lesley Scobbie (LS)
Jackie Hamilton
Fergus Doubal (FD)
Jacqui Morris
Margaret Mitchell MBE
John Wilson
Mark Barber (MB)
Andy Wilson
Angela MacLeod
Lisa Kidd (LK)
Christine McAlpine (CM)
Maggie Lawrence

Apologies

Alan Flyn
Alexander Stewart
Emma Young
Fiona Dickens
Gillian Capriotti
Gilllian Mead
Martin Dennis
Matt Lambert
Pam Duncan-Glancy

Agenda item 1 – Welcoming Members and Minister

Chair: Roz McCall MSP

RM welcomed members and introduced Jenni Minto MSP, Minister for Public Health and Women's Health.

JM outlines the Scottish Government's position on thrombectomy and its commitment to a high quality, clinically safe thrombectomy service in Scotland.

Agenda item 2 – Progressive Stroke Pathway (PSP)

RM opened a period of pre-selected questions from members directed to JM.

1. JW: It was very welcome to see your foreword to the Stroke Improvement Plan reaffirm that stroke is a priority. Unfortunately, this is not how it feels for the stroke community in Scotland. We could see for example that the very next day a cancer 'strategy' (which is rather more than a plan') was announced, with considerably more fanfare.

Would you agree that compared to some other conditions and treatments, stroke does not receive the prioritisation that it merits? - in terms of numbers of people affected, it's impact on individual people and their families, and the huge economic costs on the health and social system? If so – can we work together to define what stroke as a priority would mean and what it would look like in practise?

JM: When I read your question and I did the very logical thing strategy versus plan, you're right. Strategy is the big document, but under the strategy you have plans and the plans are what you follow to make things happen. I think they are two different things.

The cancer strategy is 10 years and looking at shorter periods of time to reach certain goals. I think what we've done with the stroke plan is laid these goals out straight away and I think that's really positive.
And I think because organizations like yours and others have been working very closely in collaborating, and I think I'm going to use the word collaborating a lot because I think that's how we're going to ensure that we raise the awareness, we

inform more and more people about what it's like to live with the stroke, which is why I highlighted the event that was in Parliament.

So I think I have got a priority for stroke and the Scottish Government does as well. And I know that you do. And I think it's that collaboration that will work. And I think that my responsibility is to have direct engagement with the health boards to ensure that stroke and care and recovery is a key priority for them as well.

2. FD: We have seen how thrombectomy can transform the lives of our patients presenting with potentially devastating strokes but are distressed when we have to tell patients from the "wrong" area or who present after hours or on a Saturday that we cannot offer them treatment. The Scottish government has prioritised stroke, and specifically the delivery of thrombectomy but we see little evidence of this within NHS Boards. Many more patients could benefit if NHS Boards appropriately allocated their available resources.

How will the Government ensure that NHS Boards give the same priority to stroke care as the government does?

JM: Apologies for that and I completely understand how frustrating this must be for people like yourselves and your wider teams.

I was on the ferry home and I was speaking to a friend whose father, sadly during lockdown, had a stroke. But because he was on an island, it wasn't possible to get him to the mainland soon enough, so I absolutely understand where you're coming from.

And I'm hoping that you recognize within the Improvement Plan that that's where we're hoping to move and that these discussions, as I said in my introduction, and we'll be doing a timetable for a more detailed plan and to further develop the thrombectomy services.

And I think I've referenced a couple of times the event in the Parliament and I think anybody who was there couldn't help be moved and actually understand the importance of thrombectomy treatment when Adam Henderson shared his story.

So I think we absolutely need to see the development of this service, and getting it in the right place and the right time is so important. And we're also working with, as you may know, the National Services Division within the NHS and government to ensure that the decisions taken on expanding the service take account of the needs of patients across Scotland.

And I think that's really important because one of the words I think that is used most often since I've come into this role is ensuring that we meet the inequalities that are across Scotland. And so that's one thing that I always head in into meetings with that word and the top of my brain. And I think I said earlier that I will be working with the health boards to ensure that they recognize the importance of that.

And then we've also got the progressive stroke pathway, which we work with the NHS boards with as well.

So my guarantee to you is that I will raise this with the health boards when I meet them, and I would also underline as well the importance of the relationship that the health boards have, and Scottish Government also have, with third sector organizations.

So we're in the process of establishing a forum to help identify common challenges. So there is a lot of work going on. It's an iterative process, but you have my full support for moving this forward, and I also know the officials in my team are very much working in that direction as well.

3. LS: It's fantastic the Scottish Government will strive to develop ways in which we can measure the provision of rehabilitation alongside Public Health Scotland.

Can the Minister offer us any further details as to what this process might look like and if/ how we can help?

JM: So as I understand it, and I'm sure any of my officials that are here will jump in if I get any of this wrong, the rehabilitation subgroup from the Scottish Stroke Care audit meet next month to specifically look at the elements of rehabilitation care that are most suited to being measured and audited, and annual board reviews carried out by the Stroke Improvement team using the new Improvement Plan and Stroke Care audit will access rehabilitation performance against refreshed, nationally defined targets and defined performance markers such as access to acute therapy, access to inpatient stroke therapy, access to community stroke therapy and six month reviews are being included in the annual reviews of stroke services.

And Leslie, if you've got any specific suggestions and actually anybody else in this virtual room, any suggestions would be very much appreciated. So if you want, if you've got any ideas, then I'm really willing to hear because I think as I said earlier, I think collaboration is going to be one of the key ways of ensuring the that we get this right.

4. **AM: Do you know someone who has had a stroke?**

If so, what has been the emotional and cognitive impact for them and their family, and how were they supported?

JM: Thanks Amy. I remember I met you, we had a really good conversation at the event in Parliament, and I think I said to you then that one of the things that really struck me about Adam's story was actually when he was asked about what he thought, if he hadn't had the thrombectomy and he actually commented that he didn't really begin thinking about that until a few months down the line, which to me just showed that you have the stroke, but there's also, then, that period as well where you're working things through in your own mind. And then it's probably at that point or at some point that you will then need some more support to help you through it.

And I do have experience of stroke. My gran when I was growing up, she had a series of small strokes, if that's the correct terminology, and these really impacted on her

onset of dementia, and also onto my Papa, her husband, who was her prime carer. They had both been living very independently on their own in Saint Andrews, but then we suddenly realized that things were changing. And so as a family, we had to make the decision and thankfully we were able to and we built a granny flat onto our home. So we had three generations in the one house working together. Now we got really great support from the health services, but I know it played a huge toll on my Papa who basically reached his 80th birthday and felt that he'd gone far enough and there wasn't anything more he could do, which was quite difficult for us all. But we did recognize the support as a family we got from the wider health service and those involved in my Gran's care.

And then actually more recently - I say recently, it was probably about 10 years ago - an acquaintance, she's the unofficial dog fosterer where I live and I met her through getting our first collie. And she not long after I met her had one stroke, followed very quickly by a second stroke. Now you would have no idea that anything had happened, but the impact that it had on the wider community was really quite telling and certainly from my perspective, because she was only in her 40s, so she was kind of the same age as me, I found that quite shocking.

And I think it's these stories that are so important; that was why Adam was such a spark, in my thoughts. And actually when I was there I met a girl I used to work with in the BBC as well that had experienced stroke.

So it's all these things, it's case studies that really focus people -it's the personal stories and the understanding. And I know Roz, you do that a lot in the Chamber in your speeches, and I think that's really important and I think Roz would agree with me that it is one of the huge privileges that we have in our roles as MSPs to be able to add the colour, add the experience, add the people to various conditions that we have to do as much as we can to try and help.

5. SB: What are your priorities for building the stroke workforce, and how will you support the third sector and NHS to work more closely together?

Thanks Sophie. I said inequalities was one of my top things that I always went into meetings with. I think the other thing is, and I know from experience from my own constituency, the huge importance of a collaborative working between the NHS, universities and also the third sector. That is so important given the circumstances that we are in. I think that the relationship between these three is incredibly - and actually I should bring in the Scottish Government as well. So we've got four corners that the pool together to ensure that we get the right service, the right research, the right care, the right after care.
And so I very much am of the view that ensuring that we work closely together is the right thing. Collaboration.

6. LK: The commitment made in the new Stroke Improvement Plan to person-centred holistic rehabilitation is encouraging and quite frankly necessary if we are to manage, support and care for stroke survivors and their families in a meaningful, dignified and respectful way. This will require a system and culture change to support staff to think critically about how they can best

respond to individuals' needs in a flexible and personalised way since the system we work in so often compromises and constrains how person-centred we can actually be. Therefore, I wanted to ask:

How will staff be supported to work flexibly in implementing person-centred care, how they will be supported (both through financial investment and freeing up capacity/ study time to engage in training) and what changes in systems and processes of care will be considered in order to ensure staff can consistently be person-centred in their approach to delivering post-stroke and longer term care?

JM: Thanks, Lisa for that.

We have a 'Once for Scotland' rehabilitation approach and that's the one that we will absolutely be focusing on.

But if I can reflect, and I'll give you the written answer to this, but I don't know if any of you attended the NHS day in Glasgow on Monday, this was something that came through, really importantly, in Gregor Smith's annual report: how important patient-centred care was, and not just in the hospital, but outwith.

And so I took that as one of my takeaways from that, and actually looking at how we have to look at all the processes that we're in across the board, because one of the sessions I was at was the 'NHS in 2043', so 20 years on, how will it look? And I think there's a lot of really good work that's being done within Public Health Scotland, for example. But you're absolutely right, the way that we're going to do that change is by connecting with all the wonderful, wonderful staff that are working in the NHS and in the third sector as well to support people.

So I'll give you my proper written answer, but I think it was just important for me to give you some of my reflections from Monday on that as well.
But the 'Once for Scotland' and 'Getting it right for every patient' I think is absolutely key to that, and getting it right for the staff as well.

Agenda item 4 – Q&A opportunity.

RM opened up discussion to attendees to share thoughts on the Q&A with the Minister.

- DH stressed the importance of using the voices and unique and varied stories of those with experience of stroke when working with Ministers to ensure individual's experiences are heard and that stroke care is tailored to the individual.

- ES asked for an update on tackling the uneven provision of community rehab across Scotland and how it is measured; CO answered that the audit report will be released on Tuesday 27th June which will contain the answers to ES' question. MB explains it is very difficult to measure how uneven access to rehabilitation is across the country and much work is being done on figuring out the best way to do so.

- SB confirmed that the data on access to rehabilitation is poor and agrees it is important that a way to gather more data without putting a strain on clinicians that also covers the topics that are important to patients. SB also said that the diversity of rehabilitation care makes gathering data difficult.

- SB recommends that this CPG returns to this topic in the future and suggests inviting the Royal College of Speech and Language Therapists to future meetings.

- CM agrees that stroke care services, including rehabilitation, are inconsistent across Scotland, and suggests data to be gathered from areas that are doing well in order to compare with areas that are struggling in order to learn what can be done better and how.

- DH mentions stroke fatigue, its impact on stroke survivors returning to work, and the importance of educating employers on stroke fatigue, particularly because stroke affects every age including those of working age.

- LS mentions that a number of research projects focusing on stroke fatigue are underway due to the voice of stroke survivors emphasising its importance.

- RM mentions her husband's experience with stroke and stroke fatigue and agrees with DH's statement that more education around stroke fatigue is needed.

A.O.B