

Cross Party Group on Multiple Sclerosis (MS)

Notes of Meeting on Wednesday 19th February 2020, held at Scottish Parliament in Room TG20/21.

In Attendance:

George Adam MSP, Stacey Adam, Luke Ashton, Mhairi Coutts, Mary Douglas, Becky Duff, John Finnie MSP, Joe Fitzpatrick MSP, Gerard Gahagan, Iain Morrison, Colette McDiarmid, Tanith Muller, Katherine Paterson, Keith Robson, Jonathan Sher, Morna Simpkins, Greg Stevenson, Craig Stockton, Phil Sully, Steven Tait, Janice Thomson, Chrissie Watters, David Wilson

Apologies:

Mark Bevan, Marion Butchart, Donald Cameron MSP, Pamela Devine, Angela Feharty, Neil Findlay MSP, Yasmin Fraser, Cat Johnson, Liam McArthur MSP, Angela McCormack, Judith MacSween, Sarah Mather, Rachel Morrison, Elizabeth Quigley, Karine Whitton, Jill Williamson

1. Welcome and introductions

John Finnie MSP took the chair as George Adam MSP was slightly delayed and welcomed everyone to the meeting of the CPG. It was great to have the Minister for Public Health, Wellbeing and Sport along to talk about the Neurological Framework.

2. Neurological Care and Support in Scotland: A Framework for Action 2020-2025 AGM

The Minister (MPHSW) updated the meeting on the Neurological Care and Support Framework.

- Clear vision for everyone to access services to live well with neurological conditions
- 35 early actions within the Framework
- 1 million people living with neurological conditions in Scotland
- No matter where live or what condition there should be seamless access to care and support
- Pleased that the Framework has been widely welcomed; the neurological community was involved in developing it
- £1m p.a. funding through to 2025-26
- Key component will be leadership and focus on person-centeredness
- Working with Healthcare Improvement Scotland (HIS) on Key Performance Indicators (KPIs) and self-evaluation tools for condition specific focus
- Critically important that involve key stakeholders

Q&A

GS: Need for robust data at local level to ensure invest, time, resources in right area.

MPHSW: The Cabinet Secretary is keen on research and data. The Scottish Government is keen that the Framework aligns with other areas of work and doesn't stand alone. It was clear during the consultation that our population data needs to be developed.

MD: Within remote and rural areas, people with neurological conditions have to travel miles to access treatment.

MPSHW: Crucial part of the Framework is appropriate support. The Framework works in with HIS Standards.

George Adam MSP took over the chair from John Finnie MSP.

GG: There are fourteen health boards as well as Health and Social Care Partnerships so how do we measure the standards in each area? Commitment to look at local networks. The first stage is each NHS Board region.

MD: Does that include transport?

MPSHW: Transport is wider than looking at neurological community.

IM: Revive have been involved in the 'Attend Anywhere' pilot programme supported by HIS. It was focussed on Lanarkshire and the Western Isles and is about to be rolled out across Scotland.

MPSHW: Visited Orkney last summer and saw technology in use and neurologist specialist visiting.

TM: Issues that Scottish Ambulance Service need to address. Wouldn't drop off [person living with Parkinson's] at home and at day centre five miles away.

GA: As a former Councillor used to know how much is spent on transport. Frustration in getting people to work together.

GG: Heard about lack of connectivity when developing the Framework. Been working at making those connections through leadership and health and social care partnerships.

ST: Highlight issue of transport in relation to mobility. Lack of mobility feeds into poverty. What will KPIs look like?

GG: We are meeting with HIS on 3 March to look at next steps. The Framework gives Scottish Government a foundation, as true measurement is not just the Framework and the Scottish Access Collaborative.

JS: It is clear that the Framework is all after the fact. There is nothing about preventative action. Why? And will it continue? Will the Scottish Government commit to B9 vitamin in flour? Fetal Alcohol Spectrum Disorder is nothing if not a neurological condition.

MPSHW: Absolutely committed to Folic Acid fortification. All devolved administrations support it and waiting on UK government decision. Will be difficult to do just for Scotland but may have to look at that.

FASD recently met with Adoption Scotland to discuss this. Crosses portfolio with Maree Todd (Minister for Children and Young People) and due to meet soon.

Happy to include JS in future discussions as this is second time he has been at a meeting and raised it.

CS: What KPIs are you looking for HIS to go with that are wider than just health?

GG: Looking to get expertise on self-evaluation and self-assessment based on broader health and social care standards with third sector input.

IM: Need for condition specific workstreams (standards) and framework and services.

GG: The meeting next month will look at exactly that.

RD: It's a win for the CPG in getting a meeting with HIS and a commitment to reconvene the working group. It's one meeting but it's a positive start.

We're setting up a MS Improvement Board – health professional group looking at Standards and the Framework's commitment. Running alongside that will be a patient group. The work will feed into the National Advisory Committee on Neurological Conditions (NACNC).

Important that there are condition specific spaces as MS is different from MND from Parkinson as from ME.

TM: Very pleased to see mental health commitments within the framework. Impact on quality of life day-to-day.

RD: What will be the biggest challenges to delivering the framework?

GG: Developing truly integrated model of care and why we involve chief officers.

RD: Framework gives us an opportunity to show how integration can work. Can have much wider impact than just the neurological community. Is there support from Ministers to get operational engagement at that level?

MPHSW: Need to work across Scottish Government where particular blockages exist.

IM: Framework has highlighted the positive input of the Third Sector and important role within partnership - not just a cheap option and part of the solution.

MD: What are the timescales for the 35 early actions?

GG: March 2021.

TM: Potentially the elephant in the room, do you think we have enough staff to support people living with neurological conditions?

MPHSW: Scottish Government recognise there is more to do but allocating resources

TM: Workforce strategy didn't reference neurological care and can it be retrospectively actioned?

MPSHW: Will look at that.

ST: Is there extra budget?

MPSHW: This year and then £1m per additional money to support delivery of the framework

RD: If MS Group came back and said we need 15 extra consultants how would that be received?

GG: Workforce planning colleagues helped shape the Framework. Hopefully that is reassuring.

The discussion drew to a close and the Convenor thanked the Minister for attending and his contribution. He would be welcomed back in the future to discuss progress of the Framework's development.

3. Matters Arising from previous meeting

A letter has been sent out on behalf of the CPG to Health Improvement Scotland (HIS) regarding the need for condition specific standards. Still awaiting a reply. Keith Robson made the group aware that conversations are taking place between the Neurological Alliance of Scotland and HIS on this matter.

KR mentioned that there would be protest outside of the parliament the following day by members of MS Society Council and volunteers on the 20m rule.

IM: Remember we are a cross party group.

DW stated that dignity, fairness and respect may be embedded in the Framework but across the general population the day to day life is different.

JF: Really important that no one should face stigma of living with a health condition.

GA: Nobody understands until they go through it, people don't know what day to day life is like.

RD: Would add that tomorrow we will have our MS kit do MSPs can find out what it is like with MS

JF: Have made progress, particularly in mental health but all have role to play in raising awareness.

The minutes were proposed by MD and seconded by JF.

4. Update on Treatments and Research

Fampyra

MC: The Scottish Medicines Consortium. The DMT is not life changing in terms of the disease but can make a difference to peoples' independence.

RD: It is tricky to measure walking speed. It is about mobility, independence and improved fatigue and continence.

Oxrelizumab

GS explained that MSC had approved the use of Ocrelizumab for use in the NHS in Scotland for adults with early primary progressive MS. The accompanying statement by SMC can be found [here](#).

HSCT

KR updated the meeting that Scottish Government officials are talking to Health Boards about setting up a centre of excellence in Scotland. It is estimated that there could be up to 18 patients per year receiving HSCT.

Access to treatments

KR fed back to the meeting that they had been receiving anecdotal evidence of Health Boards not adding DMTs to their list within the required timescales after approval for use by SMC.

RS: Whole premise of SMC is a one-for-Scotland decision based on clinical need and efficacy. The patient access scheme is in place to ensure that. Decision has already been made by SMC on cost and should not be a factor for Health Boards.

CW: The register has clinical data on patients offered DMTs. How long from primary care symptoms before getting a DMT? We have the incidence figures for the past ten years. This is perhaps something the CPG could take up.

JF: Will be interesting to see that data.

Agreed that item should be on the agenda for September

5. MS National Profile: MS as a Standard Specific Condition

As referred to in the discussions on the Framework there is a meeting taking place with HIS next month, which is directly because of the work of this group.

6. AOCB

- a) Primary Care in MS Conference - MC promoted the forthcoming being organised as part of MS Awareness Week. A link would be put in the minutes so people could find out more and register
- b) Braehead Curling Club – CW wanted to raise the issue of her local curling club, which is an inclusive club and its closure would have a massive impact. GA offered to meet with the General Manager to see what could be done. RD offered to write a letter of support from the MS Society.
- c) Future Dates of CPG – Agreed to cancel March's meeting and there would be a joint meeting with the CPG on Carers in June.