

CROSS PARTY GROUP ON MULTIPLE SCLEROSIS (MS)

Notes of Meeting on Wednesday 20 June 2018, held at Scottish Parliament

In Attendance:

George Adam, MSP
Clare Adamson, MSP (in part)
Mhairi Coutts, Revive
Mary Douglas, Council Member MS Society
John Finnie, MSP
Daniel Lafferty
Angela McCormack
Judith MacSween,
Iain Morrison, Revive
Mairi O'Keefe, Leuchie House
Keith Robson, MS Society Scotland
Niall Sommerville, MS Society Scotland
Greg Stevenson, Roche
Janice Thomson, MS Therapy Centre

Apologies:

Stacey Adam
Marion Butchart, Novartis
Cat Johnson
Elizabeth Quigley
Morna Simpkins, MS Society Scotland
Steven Tait, Council Member MS Society
Belinda Weller, Anne Rowling Clinic

MEETING

George Adam MSP welcomed attendees. Following an amendment to add John Finnie's apologies for the previous CPG meeting the minutes were agreed.

In respect of matters arising, George Adam informed the meeting that he along with Niall Sommerville of MS Society would be meeting with Aileen Campbell MSP, Minister for Health on 27 June.

George had received an email containing a series of questions regarding access to HSCT and it was agreed that they would be added to the agenda for the meeting with the Minister and Niall Sommerville would inform the civil servant.

Update on Treatments and Research

Niall Sommerville updated the CPG on the June meeting of the Scottish Medicines Consortium (SMC) where Ocrelizumab (Ocrevus) was considered. NS had given evidence from a Patient Group perspective. He expects to hear the outcome of the decision in July. Two other treatments are anticipated going to the MSC later in the year. There followed a discussion about the cost price of treatments. Greg Stevenson informed the CPG that it costs pharma companies between £50k and £100k for each submission to the MSC.

Action:

- Agreed to add questions re HSCT to discussions

MS Nurses: supervision and continuing professional development

Mairi Coutts, MS Revive, talked to the group about the need for MS Nurses to be supervised by someone qualified in their topic. Mairi also stressed the need for MS Nurses to keep learning, even amongst the more experienced nurses. The Academy sponsored by Biogen each year is really good. Looking at developing a formal course 'MS support nurse'.

MS Nurses: Scottish MS Register and National MS Nurse Assessment Tool

Chrissie Waters, talked to the group about the Scottish MS Register and the Nurse Assessment Tool.

The [Register](#) only captures confirmed cases. It is measured against clinical standard 15.2 and doesn't record resources, budgets, waiting times or staffing levels. Will be promoting the register with Mary Wilson acting as the 'public face'. Mary has MS and is a Para-Olympian.

Chrissie has met with MS Nurses across Scotland. Patients feel a real inequality of care. Working on the Scottish Health Assessment for MS which gives a structure to identify needs – nurses are currently doing it on borrowed time: evening; annual leave and TOIL.

Started to build electronic version, paper version is not being issued any longer. 8 Health Boards are represented. It will have electronic care package that patients will hold. It is accurate in measure incidence but not prevalence as lack of historical data makes it difficult. There was a discussion around the varied use of READ codes and difficulty in getting accurate statistics.

One MS Nurse reported waiting time of 27.83 weeks and not the 16 weeks as heard at consultation event today.

MS Revive have had to add a new 'pre-diagnosis' code as waiting times of diagnosis have increased. Patients are being seen by a general neurologist within the allocated waiting times and then have to wait for a specialist neurologist.

Reference was made to the [Health and Care \(Staffing\) \(Scotland\) Bill](#). Keith Robson informed the meeting that the Bill is at Stage 1 and the [Health and Sport Committee](#) has issued a [call for written views](#) by 1 August 2018. It brings into legislation existing regulations about safe levels of staffing and introduces a national formula for Health Boards to use in their calculations.

Chrissie concluded by saying that they are always looking for volunteers to get involved with the Patient Reference Groups.

Action:

- Agreed to add link to the Scottish MS Register [Report](#) in the minutes
- Agreed to add matter to discussions with the Minister
- Agreed to issue summary of the [Health and Care \(Staffing\) \(Scotland\) Bill](#) with the minutes and members can feedback comments to Keith

MS Nurses and Technology

Rachel Morrison, Specialist MS Nurse NHS Western Isles, gave a presentation on the use of technology in patient referrals. Using the MORSE app on her IPad Rachel can sit with patients in their homes allowing them to see the referral pathway. The information is stored and then automatically uploaded when connected with Wi-Fi. It saves 40% admin time giving more time to spend with patients. You can see colleagues' calendars on the app and can directly message colleagues. Rachel is able to sit with patients and complete assessments which they then see being sent off immediately. Don't have to wait until back in the office.

Florence

Is a national system that the Health Board bought and worked IT team to adapt to the information needed. It is a texting service and can be used to access data on : 'Blood Pressure and weight'; 'Pelvic floor exercises'; 'Sleep Studies'; 'Exercise Tracking and Weight'; 'medication Compliance' and 'Symptom Management'. It has shown improved compliance by patients in doing pelvic floor exercises.

BEAM

BEAM can be used to tackle social isolation. A patient with highly active MS uses BEAM within the house. It is an IPad on wheels and can be used as a community alarm and alerts the patient's husband/ambulance if assistance is required. Their 4 year old daughter knows how to operate it.

Attend Anywhere

Rachel gave the example of a fisherman who uses it when out on his trawler. It is a Face-time style app and Rachel has used it to get a second opinion for a patient.

Action:

- Agreed to circulate Rachel's presentation to the CPG

Future Work Programme

A discussion took place around the future work programme for the CPG. Mairi Coutts raised the issue of the Single National Formulary and wanted to discuss that at a future meeting as there are questions on the potential impact on access to treatments. Ian Morrison said that Revive MS are looking to hear patients voice on the issue and could feed in to any CPG discussion. Other topics suggested for consideration were: staffing/resources; succession planning and provision of social care.

Action:

- Agreed to talk outside of the meeting

A.O.C.B.

1. Niall Sommerville, MS Society, updated the meeting on the announcement by the Department for Work and Pensions (DWP) on the reassessment for PIP for people living with long term conditions.
2. Cannabis – Niall Sommerville, MS Society, updated the meeting on the Society's campaign for the legalisation of cannabis for medicinal use. It is a reserved matter however there is cross-party support within the Scottish Parliament.
3. PIP 20m rule – George Adam is trying to get an urgent question asked at First Minister's Questions following the report from the MS Society PIP: A step too far.
4. Neurological Standards: Concerns were raised that the outcome of the consultation on the standards has already been decided with generic standards which don't recognise specific conditions. If Health Boards don't have to report on MS neurological standards then they can potentially take a more generic approach with the level of care being diminished.

The meeting closed at 19:50