Cross-Party Group on Muscular Dystrophy

Thursday 23rd November, 13:00-14:00 (virtual)

Minute

Present

MSPs

Jackie Baillie MSP (Convener of the CPG on Muscular Dystrophy).
Annie Wells MSP (Deputy convener of the CPG on Muscular Dystrophy).

Invited guests

Dr Pauline Nolan (Head of Leadership and Civic Participation at Inclusion Scotland).
Dr Catherine McWilliam (Clinical Geneticist; Lead Clinician at Scottish Muscle Network).
Dr Sheonad Laidlaw (Specialty Doctor for the Transition & Young Adults Service at The Prince & Princess of Wales Hospice; chair of Muscular Dystrophy UK's Scottish Council).
Rob Gowans (Policy and Public Affairs Manager at Health and Social Care Alliance Scotland).
Steve Brown (Health Systems Partner at Roche products Ltd).
Dr Caroline Hutchison (Neurology registrar, with an interest in muscle at Aberdeen Royal Infirmary).
Gerry McMenemy (Trustee at Muscular Dystrophy UK; member of Muscular Dystrophy UK's Scottish Council).
Kirsten Patterson (Clinical Nurse Specialist, Clinical Genetics at NHS Scotland).
Amandeep Singh (person with lived experience).
Jon Watkins (person with lived experience).

Non-MSP Group Members

Rob Burley (Director of Campaigns, Care and Support at Muscular Dystrophy UK).
Daniel Huggins (Head of Policy & Campaigns at Muscular Dystrophy UK).
Jackie Munro (Head of Regional Support, Outreach, and Information, at Muscular Dystrophy UK).
Farhan Khan (Health Policy Manager at Muscular Dystrophy UK).

Apologies

None.

Agenda item 1

Welcome and introductions

Meeting chair and CPG convener Jackie Baillie MSP (JB) welcomed participants. The chair introduced the meeting agenda and external speakers.

Agenda item 2

Annual General Meeting

An AGM was held at the start of the meeting to elect office bearers.

The following were re-elected to continue in their current positions:
- Jackie Baillie MSP (Scottish Labour, Dumbarton) as convener.
- Annie Wells MSP (Scottish Conservative and Unionist Party, Glasgow) as deputy convener.

The following decided to stand down from their role(s):
- David Torrance MSP (Scottish National Party, Kirkcaldy) stepping down from the role of deputy convener. The MSP will continue as a member only.

There was also confirmation for Muscular Dystrophy UK to continue to be the secretary for the CPG.

Agenda item 3

Update on service provision in Scotland

Robert Burley (RB) updated attendees on local service provision challenges. There are concerns in parts of Scotland about posts not being filled and others remaining vacant. RB noted the need to highlight wider systemic challenges beyond issues in particular areas. These wider challenges are directly impacting on the muscle wasting and weakening community in Scotland.

RB provided an overview of Muscular Dystrophy UK's (MDUK) plans to produce a short policy report on current service provision. The report will look at how Scotland compares to the rest of the UK and how support for muscular dystrophy compares to that for other comparable conditions. It will also discuss the impact on the muscle wasting and weakening community and the strain experienced by different services. MDUK is scoping the report now and there is yet no fixed timeline. There is a desire to do it by the end of this financial year.

RB noted that the Scottish government's current neurological care and support framework for action runs until 2025 and it was a good time to be gearing up for the next version. RB updated attendees on MDUK's intention to engage to ensure there is another plan and that it adequately covers neuromuscular conditions, as the current one falls short.

ACTION: MDUK to update attendees of next CPG meeting on findings from the policy report.

Dr Sheonad Laidlaw (SL) reflected on challenges in Scotland. The community is losing significant support in child and adult services, with little clarity on what happens in terms of succession planning for full-time care advisers in Scotland. SL noted her disappointment with the lack of progress, which has led to a crisis point. There is going to be a significant emotional impact on individuals and families. SL expressed how the community needs to work together to advocate for more care advisers for neuromuscular conditions to improve quality of life, care and person-centered support across Scotland. SL recognised it will take time to increase numbers.

SL noted that care advisers trying to navigate individuals' transitions from child to adult services were increasingly under pressure due to rising numbers. For example, the lead professional involved in an individual's care might be well known in childhood, but this situation often will not translate in adulthood. The care adviser then becomes the first point of contact. The geography of Scotland does not lend itself to easy access to the care from care advisers, even though teleconferencing since the pandemic has been good. SL noted that at the hospice, they see a number of young adults in transition. If individuals are well, then care advisers are not contacted as often. But this does not negate the work that could be done proactively as support is not just about crisis support.

SL noted that Sue Ryder had previously looked at the safety and financial benefits of proactive vs reactive care for neurological conditions and queried if a future iteration could also include neuromuscular conditions.

In response to a question by JB, SL clarified that the reason for reduced hours and cutbacks was essentially funding. JB suggested the CPG ask the minister to attend a meeting early in the new year.

Dr Catherine McWilliam (CM) expressed a lack of surprise at having reached this point, where there has been an increasing number of patients without a corresponding recognition of the increased burden on the NHS. CM expressed that they had tried to raise awareness around this and any support would be very appreciated.

CM noted the need to nurture different aspects of the workforce and consider the long time it takes to do this. For example, a neuromuscular consultant neurologist has years of experience before becoming a consultant. As a result, there is a need to look at trainees as well, although this is difficult to do when everyone is struggling to meet current service commitments. CM acknowledged that while pressures were acute, they were not unique to muscle services.

Agenda item 4

Update on Scottish Spinal Muscular Atrophy (SMA) newborn screening pilot

CM highlighted emerging evidence that early intervention and treatment before babies present with SMA is the way to ensure the best outcomes. Early treatment is why screening is so important. More treatments are now available and more patients are coming through services, but there is a need to treat them in the best way to maximise the benefit of these new drugs.

In Scotland, newborn screening is dictated by a national committee that decides what conditions are screened for. This is a very rigorous process, which is why there is a limited number of conditions screened for in the UK. A review for SMA started last year. The UK National Screening Committee has decided that the way forward would be to have an economic modelling project and an in-service evaluation (which CM noted is a lot like a pilot).

CM discussed work looking at what is needed to implement newborn screening in Scotland. This work is looking at the impact on the NHS, impact on midwifery colleagues, diagnostic capacity, cost of clinical genetics and the cost of treatment.

CM and colleagues put forward a proposal to determine the effectiveness of screening for SMA in newborns in Scotland. This was approved by NHS Scotland. CM is waiting to hear on funding application, as there is a need for more funding for the pilot study to proceed. There should be more details in December. CM hopes to begin screening by this time next year. There will be questions around how to keep the work going and how to campaign around that so that the gains are not temporary.

Agenda item 5

Update on social care support for disabled people and the community

Dr Pauline Nolan (PN) introduced Inclusion Scotland.

PN remarked how independent living means all disabled people having the same freedom, dignity, choice and control as other citizens at home, at work and in the community; and not about fending for yourself, which is what is often talked about.

PN discussed the Self Directed Support (Scotland) Act (2013) and the state of self-directed support. Things are not working as they should. There is a lack of focus on outcomes, no training for social workers and a lack of funding means there are no resources to put around it. Eligibility criteria and charges create further issues. There is also a postcode lottery of good practice around Scotland.

PN discussed the Government funded Inclusion Scotland People-led policy panel, as an example of coproduction to come up with the most important things people with lived experience thought were needed in adult social care. PN referred to the Feeley review of adult social care, its recommendations and how it spoke to the Inclusion Scotland panel.

The Scottish government is now working on the National Care Service bill, which has been quite delayed because of oppositions and other agreements which have been made. Some people in the panel do not trust local authorities with social care support after having experienced poor services. They hoped the new national framework would improve things. They are therefore not happy with the Verity House agreement about sharing accountability with the Government.

Agenda item 6

Open discussion and questions

JB noted the confusion around the National Care Service and limitations in what it could do. The implementation gap identified in the Feeley review continues.

JB noted that social care staff recruitment is impossible because salaries are not increasing. There are regular discussions with Government about what the salary should be. More broadly, as long as social care is a Cinderella service, then it will not get to where people need it to be: a service provision of equal status to the NHS. Until then, there is the sense that actions are merely sticking plasters. There is a need to work very hard to shape something that will be an answer to the real challenges being seen today, because JB is not sure we have that answer yet.

PN reinforced that supported people want good conditions and pay for the people who support them, so it is critical that they are recognised and valued. JB shared that these issues make a regular appearance in budget asks and will continue to do so next year.

Attendees raised concerns around how a long-term focus was not helping people that continue to slide into crisis now. PN shared that Government had been listening to concerns but that PN didn’t really see much improvement. The sense of a lack of improvement was exacerbated by the scale of cuts being considered by local government and the potential impact on social care.

JB initiated a discussion around the role of the CPG to demand change and keep muscular dystrophy on the Government’s agenda. JB suggested RB and others get together to consider what can be done, what information is needed and what the best way would be to continue raising awareness. A small group could be set up to form a plan for the CPG, including looking at the upcoming MDUK report and support needed for newborn screening, but ultimately focusing on social care, where the real urgency is. Rob Gowans is interested in participating in this working group.

ACTION: MDUK to pick up discussions offline around future CPG influencing plans.

Agenda item 7

Summary and closing remarks

JB thanked all speakers for their presentations, reiterated next steps to move forward on campaigning and closed the meeting.