

Scottish Muscle Network (SMN) ANNUAL REPORT 2022/23

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Introduction

The Scottish Muscle Network (SMN) was established in 2004 to ensure that equitable, evidence based, patient centred care is provided for all children and adults with neuromuscular conditions, at each point of their care pathway. This is provided through the development and implementation of clinical guidelines, patient pathways, clinical standards, and information resources.

Neuromuscular conditions include muscular dystrophies, myopathies, mitochondrial diseases, peripheral neuropathies, and disorders of the neuromuscular junction such as myasthenia gravis. Although much progress has been made in the diagnosis and management of these diseases, neuromuscular conditions are largely progressive, debilitating and can frequently be life shortening. Patients commonly require complex and long-term management

Services for those affected by neuromuscular conditions are delivered across Scotland through a collaborative network approach. Care is routinely delivered as locally as possible, but travel may be necessary for diagnosis and to access specialist expertise or specialist facilities.

Current Position

38/42 Business as Usual objectives were achieved. Four related to meetings needing to be rescheduled to the start of 2023/24 due to clinical pressures on the service.

5/9 Service Delivery objectives were achieved. Two of the objectives relate to Strategic Planning which the network has prioritised for 2023/24.

Circumstances out with the Network control, have led to delays in the other two developments. The network agreed and submitted an SMA Core Dataset to CAS Developers in 2021/22 and still await a completion date which is not yet available. Piloting Newborn Screening (NBS) for SMA in Scotland remains an important aim for the network, however progress, whilst positive has been slow.

Lead Clinician Reflection

This report is based on activity within the Scottish Muscle Network from 2022-2023, reflecting on Year 5 of our established Workplan. Within the wider organisation of NHS Scotland, it is appreciated that this has been a year in which recovery from the pandemic has begun and we have seen many services struggle. Clinical pressures within the NHS are a particular issue and those involved with the Scottish Muscle Network see themselves challenged more than previously. We see several vacancies in our workforce, and this has potential to impact significantly on service delivery.

The Service Planning Review that took place in Year 4 of our Workplan is likely to form the basis of our Workplan for the next 5 years and we look forward to our rich collaboration in developing this further while being mindful of the challenging fiscal times we are faced with. Recent discussions within our Steering Group have been insightful into the need to develop for those who are directly involved in using the network for the benefit of their patients while maintaining an inclusivity that reaches across Scotland and to the various disciplines working with our patients. The benchmarking work done by colleagues in our DM1 subgroup collaboratively with the Team in Belfast has been a notable achievement. The approach to care of patients with Myotonic Dystrophy in Scotland is evidently of benefit and with the prospect of drug trials in Myotonic Dystrophy on the horizon, has Scotland well placed to be 'institutionally ready' for these developments. While the developments to the CAS database and PowerApp for audit of management of our patients with Myotonic Dystrophy has taken time, we hope this will allow us to audit with ease and better support this group of patients going forward.

We continue to strengthen our links with MDUK and other 3rd sector organisation and look to further patient engagement in collaboration with them. The 'Virtual Coffee Morning' that was

arranged for patients with CMT was a positive event and we plan to do this again and develop further from this for other patient groups. The ACP meeting, a collaborative event between the Neurology Framework Team and the SMN, was a thought-provoking example of patient engagement and insights from the meeting should help improve how we navigate these conversations and situations for our patients.

Educational events organised by the Network have been reviewed positively and we plan more going forward but are aware of the advantages of using our wider network across the UK to our advantage and hope that our website can be used to raise awareness of such events.

Undoubtedly the year ahead will have its own share of challenges, but we look forward to working together to support each other for the benefit of our patients and that the Network continues to provide the support for us to rise to these challenges.

Highlights

- **Service Development and Delivery**

Service Planning: Following the development of a vision for neuromuscular services and the gathering of service data to identify gaps, in 2023/34 the SMN will continue to have discussions with health boards on implementation.

Guidelines/Protocols/Pathways: During 2022/23, the Network continued to develop and review guidelines and care pathways in accordance with NNMS guidance. As such, five guidelines and one care pathway have been reviewed and updated, whilst another care pathway (the DMD MDT Care Pathway) is awaiting the development of the North Star and DMD UK pathway. The network will either adopt this pathway or adapt to be relevant for Scottish services once completed. All updated documents are available on the SMN website <http://www.smn.scot.nhs.uk>

Benchmarking: A review of the SMN in 2017/18 recommended exploring the use of benchmarking with UK services to measure performance of neuromuscular services in Scotland. This would also help to demonstrate value for money, as would measuring the cost of SMN resources used against the benefits that have been achieved.

An initial benchmarking exercise focused on myotonic dystrophy was carried out with Belfast Health and Social Care Trust in Northern Ireland (NI), which the network identified as a comparable service. This service operates as a Regional Neuromuscular Disorder service for all of NI. Key findings demonstrated high concordance between the Scottish and NI services in their approach to management of patients and performance in reference to the key Scottish Care Standards.

Overall, this benchmarking work was viewed as a highly valuable exercise by both services, highlighting areas for reflection and further service development work. It is anticipated that the Scottish and NI services will build on this collaboration with future work to audit and improve their models for service delivery.

Newborn Screening (NBS) for Spinal Muscular Atrophy (SMA): work is ongoing around assessing the possibility of a pilot to include SMA in National Newborn Screening in Scotland. The NSS Pregnancy and Newborn Screening Board newly formed Research and Innovation Group approved SMN's proposed research study in September 2022. It has taken until March 2023 to coordinate a meeting with the Heads of Midwifery across Scotland to ask for their support, which is now awaited Research grants are now being applied for.

- **Stakeholder Communication and Engagement**

Website:

The website has recently been re-formatted based on feedback from steering group members to make it easier to navigate with the aim of increasing use by stakeholders. Another important development has been the creation of an interactive Service Map on the Home page showing all neuromuscular services in each board throughout Scotland.

Newsletter: The network has also refreshed its newsletter format using SWAY technology supplying stakeholders with up-to-date information on the network's various workstreams.

Patient Engagement:

Transition Audit-This exercise was started a few years ago but held up due to the effects of the pandemic on staff capacity. It was finally completed earlier this year and results analysed. The main findings informed the network that access to psychology support was the main need for this cohort of patients. In response, the network developed a psychology leaflet and placed it on the SMN website. A questionnaire was linked to the leaflet to capture its impact.

CMT-the network planned a series of meetings with patients with Charcot-Marie-Tooth (CMT) disease as it felt that this was a group where patient experiences had not been fully explored. Four meetings were planned, the first held virtually in January 2023, and although only three patients attended, good feedback was obtained. This prompted the network to send several support links supplied by MDUK to the patients involved as well as placing them on the SMN website. The network reflected on its methodology in advertising the meeting and plans to hold the remainder in 2023/24 with support from MDUK.

ACP- Anticipatory Care Planning has been discussed often within the network as key to improving care for our patients. The network began by focusing on the DMD patient group, establishing how many adults with DMD had a documented Anticipatory Care Plan (ACP). A document was submitted by Sheonad Laidlaw, Prince and Princess of Wales Hospice (PPWH), Glasgow and Maria Farrugia from SMN, to Scottish Government to fund a pilot project in NHS GGC. Funding was approved in September 2022 and a Neurology Framework project team leader was appointed. In addition to auditing numbers of individual patients, the team leader's remit included engaging with SMN health professionals to develop a pathway to support clinicians in recognising when an ACP should be triggered and then steps required for the ACP to be progressed. SMN plan to work with the project team to develop a pathway in 2023/24.

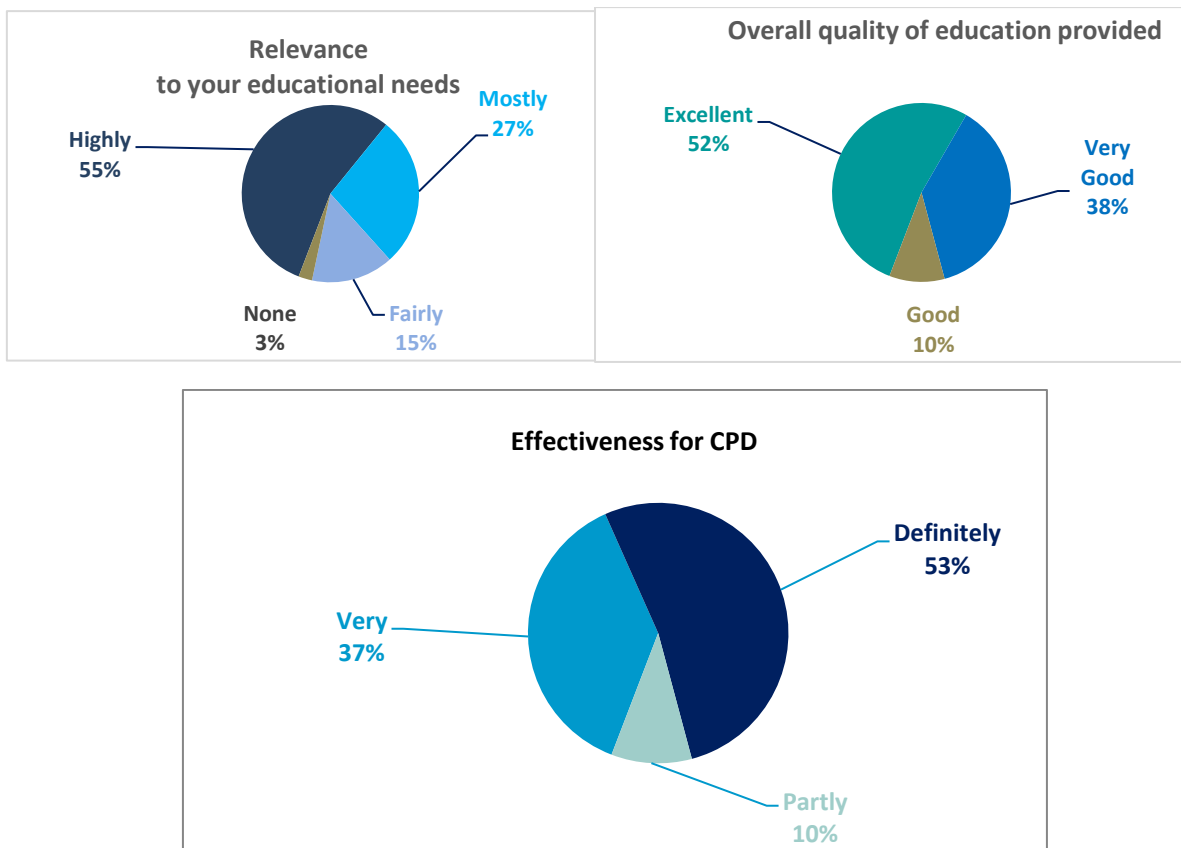
The network also organised a face-to-face meeting with PPWH, the project team and a small group of patients in March 2023. The aim was to scope the level of knowledge of ACP's that existed amongst patients with DMD. Feedback from that meeting has prompted the Framework Team Lead to circulate the SMN website link to the patients for feedback and the network awaits a final report from the Framework Team around this valuable work.

Patient Information-SMN continues to review its information leaflets in line with NNMS guidance. 14 leaflets were successfully reviewed and updated where required during the past year. The updated versions are posted on the SMN website.

- **Education**

Annual Conference: The annual conference was held in September 2022 at Edinburgh Training and Conference Venue. This was a hybrid event with 30 delegates attending in person, and 60 on-line using MS Teams.

Delegate feedback response rate was 50%. 82% identified the event as relevant for their education needs and impacted on keeping them informed about neuromuscular conditions, 90% felt the quality of education was good or very good as well as being relevant for CPD purposes as shown below.

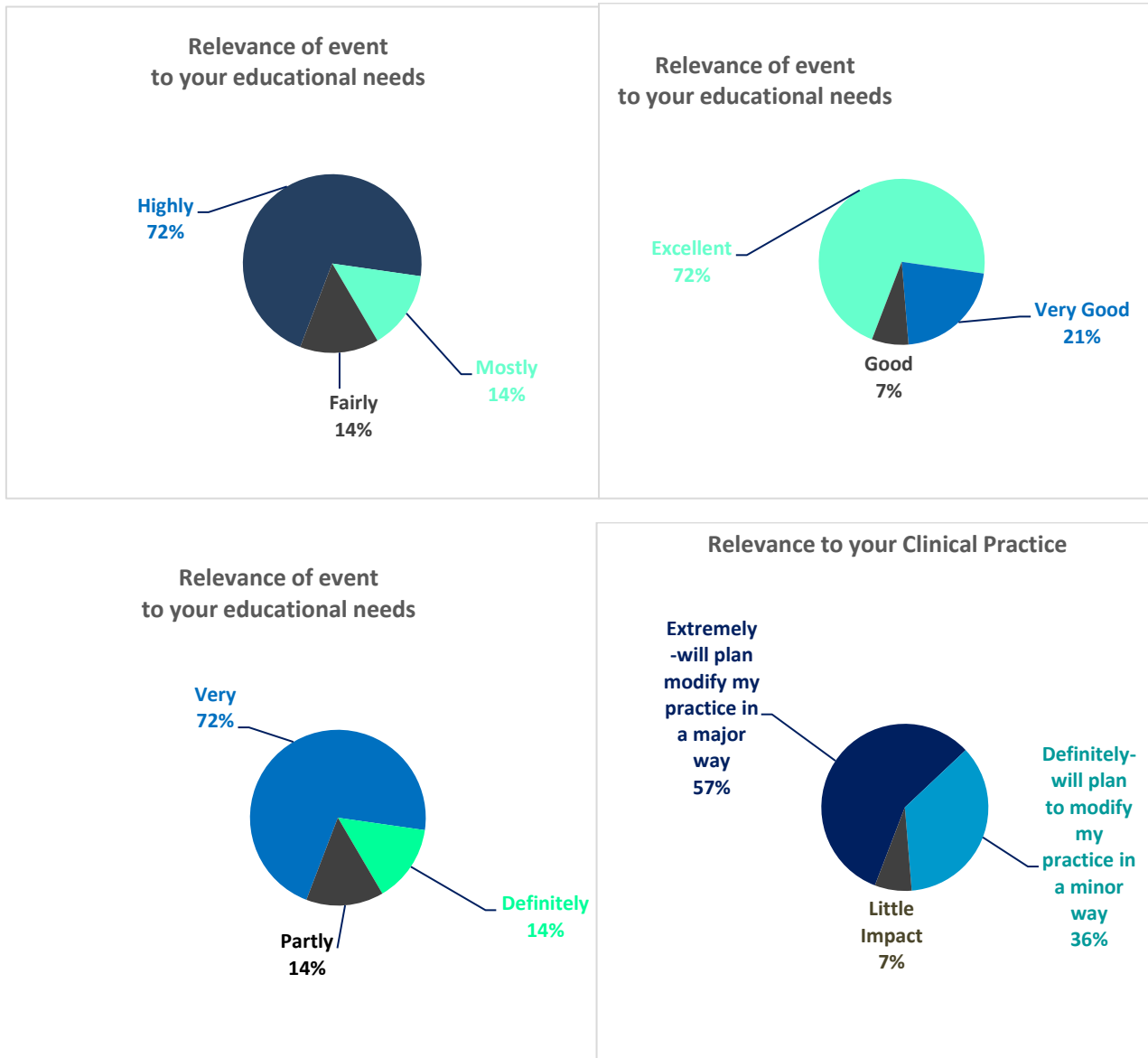


When asked for comments on impact on future practice respondents identified nutrition in DMD as the main learning theme that would influence their practice going forward.

Muscle Interest Group (MIG) Meetings: following the success of last year's events, the network again held two MIG's in May and November 2022. The former was virtual with 24 attendees, the latter a hybrid event with 21 virtual and 11 in person. The aim of these meetings is to provide a forum for discussion of challenging neuromuscular cases, professional peer support, and dissemination of medical knowledge. Combining the two meetings, evaluation response rate was 58% with 86% rating the education provided effective and 93% rating the quality of education as excellent or very good. 86% of responders also said the education was relevant to their CPD, whilst 93% planned to modify their clinical practice as a result of the education. These results are shown graphically below.

Benefits of Attending included:

- Guidance with patient investigation.
- Discussion of clinical cases.
- Useful to discuss difficult cases across multiple disciplines (neurology/genetics/pathology).
- Chance to discuss patients with experts in the field.
- Better understanding of variable phenotypes and complexities of collagenopathies



• Audit and Continuous Quality Improvement

Myotonic Dystrophy Database: The network previously worked with IMS and the CAS developers in finalising the Myotonic Dystrophy (DM1) database, the system successfully went live on March 31st, 2022

This development will allow data to be collected more efficiently across the four Regional Genetic Services (Aberdeen, Dundee, Edinburgh, and Glasgow) for the purpose of audit against

the SMN DM1 Care Standards which will help ensure DM1 patients across Scotland receive equitable, optimal care.

A proposal was submitted to NSS Digital and Security (DaS), through IMS, by the network to do a test run of the reporting ability of the powerapp, using 6 months data (April-Sep 2022). The aim is to ensure that when the next biannual audit is taking place, covering the year August 2022-August 2023, the system is robust and fit for purpose. Database overview to date is also being looked at by a SLWG, led by Dr Richard Petty and including main users of the system to look at the following:-

- data collected-what is superfluous and what is missing
- practical Issues -use in clinic/difficulty in accessing previously entered data whilst seeing patients and families in clinic
- generation of forms/letters etc
- reporting for audit against Management of DM1 in Adults Standards

Audit of Spinal Muscular Atrophy (SMA) Patients: Various Scottish centres (Glasgow, Dundee, and Aberdeen) already submit data on their SMA patients to the SMAReach database as part of a UK research project involving 16 UK centres. However, access to this data is challenging for the SMN network. The network therefore agreed a core dataset of data that could use to identify the demographics, current therapies, specific disease rating scores and likely trajectories for the Scottish services. Given that the therapies for these patients are novel and have such a high cost, the network feel it is critical that it has oversight around progress in this patient group and that gathering this data is the best way to inform development of services for the future. This data could also be used later to benchmark against the standards of care that the SMAReach project will be developing going forward.

This was sent to CAS Developers in November 2021 and is still awaiting approval.

- **Climate Sustainability**

The Network continued to make use of technology and remote communications to progress work this year. This has continued to be effective, saving time on travel and promoting economic and climate friendly practices.

- **Looking forward**

Priorities for the network in the coming year include:

- Development of a Strategic Plan. The network is meeting on June 7th, 2023, to focus on what workstreams the network wants to prioritise going forward over the next 3-5 years.
- Influencing the development of neuromuscular services in line with the outcome of the Service Planning document
- Continue to populate the DM1 database with a view to using it to audit against standards for the 2022/23 biannual audit which will cover the period Aug 2022 to Aug 2023.
- Populating the SMA Core Dataset on CAS to capture relevant SMA data.
- Continuing to collaborate with colleagues from genetics and NBS laboratories to gather evidence to submit an application for SMA Newborn Screening.
- Continue to work with colleagues to develop an ACP pathway for DMD patients.
- Developing a Quality Improvement Strategy to support the Networks approach to service improvement.

- **Finance**

The itemised costs and total spend for 2022/23 is given below.

| Item | Spend |
|---|---------------|
| Venue Hire/Catering for Annual Event and one Muscle Interest Group meeting. | £2,260 |
| | |
| TOTAL SPEND | £2,260 |

Risks & Issues

None identified