Scottish Muscle National Managed Clinical Network

ANNUAL REPORT 2019/20

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1. Executive Summary

Following an independent review of the Scottish Muscle Network (SMN) in 2017/18 as part of national commissioning governance, the network was found to add value to healthcare and has an ongoing role in improving access to and quality of neuromuscular care in Scotland. The network was therefore commissioned for a further five years with a number of recommendations that the network should take forward. These were incorporated into a 5 year strategic workplan for the period 2018/19-2022/23. This report evidences progress in Year 2 of that workplan.

Measuring performance has again been a major objective for the Network during 2019/20 and although this has again been challenging, it has made some good progress. Two main conditions were previously prioritised, Duchenne Muscular Dystrophy (DMD) and Myotonic Dystrophy (DM1). The DMD workstream has agreed to focus on auditing endocrine tests recommended by the DMD MDT Pathway to develop key indicators whilst the DM1 sub group concentrated on developing a national database for DM1 patients hosted on CAS. The bi-annual audit of DM1 indicators from Care Standards was also measured in the period August 2018-August 2019 using data collected from the four DM1 genetic centres across Scotland. This, however, is a labour intensive task and has been challenging in previous years mainly due to local IT problems. A national database will improve both the efficiency and reliability of carrying out this audit. The network has worked with the genetics team from the Myotonic sub group and have made good progress with the database fields agreed and hosted on an excel spreadsheet. The next step will be to forward the spreadsheet to the CAS development team with the aim to have the data fields stored a CAS Core Dataset. This will be one of the network priorities in 2020/21.

The other major piece of work involved Spinal Muscular Atrophy (SMA.) Following the recommendations from the National Specialist Services Committee (NSSC) last year, SMN developed and published a care pathway for SMA aligned with a service mapping exercise across Scotland. In addition to SMA the network had raised concerns about the impact on new therapies on other services. As a result, the network undertook a piece of planning work to look at the future service needs for neuromuscular patients taking into account emerging treatments and population trends. When this is completed a report will be submitted to the National Planning Board identifying potential areas for development.

Provision of education and information remain a success for the Network, with the implementation of the education strategy which was developed last year. This aims to continue to build a range of resources for both professionals and stakeholders. Current resources are easily accessible through the website and provided at clinics.

The network has continued to develop and review both guidelines and patient information leaflets.

The main work priorities for 2020/21 will be focused on implementing Year 3 of the 3-5 year strategic workplan, including:

1. Reporting to the National Planning Board on potential developments for neuromuscular services in Scotland.
2. Reviewing and updating the SMA Pathway in line with new evidence.
3. Continued implementation of the Education Strategy.
4. Rolling out a programme of audit across Scotland against Key Performance Indicators for DMD.
5. Developing a National Database for DM1 patients to drive quality improvement.
6. Improving transition services through a QI Project
7. Revising the patient/carer experience questionnaire.
8. Continuing to update and add to the current portfolio of patients resources

2. Introduction

The Scottish Muscle Network (SMN) was first established in 1999 and originally funded by the Muscular Dystrophy Campaign, now known as Muscular Dystrophy UK. In 2004 it was designated as a national managed clinical network (NMCN), commissioned by NHS National Services Scotland on behalf of Health Boards and the Scottish Government Health and Social Care Directorate (SGHSCD). As stated in the Executive Report, the network was independently reviewed in 2017/18 as part of national commissioning governance. The outcome was that the network was found to have made satisfactory progress toward its objectives and was commissioned for a further five years. Recommendations arising from the review, were subsequently integrated into the strategic workplan.

It is estimated that there are more than 6,000 children and adults in Scotland affected by inherited and acquired neuromuscular disorders. Examples 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.

The Network has a remit to support services in Scotland to provide equitable and prompt access to high quality care for patients with neuromuscular conditions across their patient journey. Services for those affected by neuromuscular conditions are delivered across Scotland through a collaborative networked approach. Care is routinely delivered as locally as possible but travel may be necessary for diagnosis and access to specialist expertise or specialist facilities.

Since its inception the network has been effective at supporting neuromuscular services in Scotland to deliver evidence based, patient centred care for children and adults with neuromuscular conditions, through the development and implementation of clinical guidelines, patient pathways, clinical standards and information resources. In 2017, and award from Muscular Dystrophy UK recognised it among the first Networks of Excellence in the UK.

3. Report on Progress against Network Objectives in 2018/19

National networks have agreed core objectives that reflect the Scottish Government's expectations for managed clinical networks, as described in CEL (2012) 29[1]. The network's core objectives are:

1. Design and ongoing development of an effective Network structure that is organised, resourced and governed to meet requirements in relation to SGHSCD Guidance on MCNs (currently CEL (2012) 29) (Annex and national commissioning performance management and reporting arrangements; Annex C).

2. Support the design and delivery of services that are evidence based and aligned with current strategic and local and regional NHS planning and service priorities.

3. Effective Stakeholder Communication and Engagement through design and delivery of a written strategy that ensures stakeholders from Health, Social Care, Education, the Third Sector and Service Users are involved in the Network and explicitly in the design and delivery of service models and improvements.

4. Improved capability and capacity in neuromuscular disorder care through design and delivery of a written education strategy that reflects and meets stakeholder needs.

5. Effective systems and processes to facilitate and provide evidence of continuous improvement in the quality of care (CQI).

[1] Please see: https://www.sehd.scot.nhs.uk/mels/CEL2012_29.pdf

6. Generate better value for money in how services are delivered.

3.1. Effective Network Structure and Governance

The Network continues to be overseen by a multi-disciplinary steering group that is accountable for the delivery of the Network workplan. Through its terms of reference and sub-group structure, SMN meets the core principles of managed clinical Networks as set out in CEL (2012) 29.

Workplans and reports are published on the Network website, and any documents produced by the Network are publicly available for clinicians and patients to view.

The current SMN Lead Clinician is Ms Marina Di Marco, Specialist Neuromuscular Physiotherapist based in Glasgow. Her tenure is until November 2020. A list of steering group members can be found in Appendix 1.

The Network has a service level agreement with NHS NSS in place for 2017-2020. This is currently being updated

Steering Group meetings are chaired by Dr Steve Banham, Respiratory Consultant (retired), as independent Network Chair.

3.2. Service Development and Delivery

3.2.1 Guidelines

During 2019/20 the Network continued to develop and review guidelines and care pathways in accordance with NNMS guidance. As such, the following guidelines and care pathways have been reviewed:

- Anaesthetic Guidance Summary for patients with Myotonic Dystrophy (revised)
- Anaesthetic Guidance for patients with Myotonic Dystrophy (reviewed)
- The Duchenne Muscular Dystrophy Multidisciplinary Pathway

3.2.2 Benchmarking

In 2018/19 the network made initial contact with a number of neuromuscular services across the UK through liaison with Muscular Dystrophy UK to benchmark services. However, there has been little progress this year due to lack of availability of various centres around the UK to meet. SMN is currently exploring further opportunities to target one large UK centre and benchmark services.

3.2.3 SMA Service

The Network developed a Scottish Nusinersen Pathway for Spinal Muscular Atrophy (SMA) to ensure all children and adults have equitable access to this medication which was approved by the Scottish Medicines Consortium (SMC) in May 2018. Evidence is available which demonstrates that Nusinersen improves both achieving and maintaining physical milestones of SMA type 1 patients. Further evidence is currently in the process of being collected for patients with SMA types 2 and 3. Patients with types 2 and 3 can access Nusinersen through application via the SMC using the ultra-orphan drug therapy pathway.

The complex and evolving landscape of this medication means the SMN Pathway will have to be reviewed on a quarterly basis.

Neuromuscular services are currently under significant pressure as the treatment of Nusinersen is complex and requires a large multi-disciplinary team with clinical expertise to deliver this. In addition, there is currently inequality across Scotland for the level of service to adult neuromuscular patients due to lack of staffing resources. This is a serious concern as projections based on current SMA population in children and a projected increase of 5 new SMA cases per annum will mean that in approximately 15 years' time there will be an estimated 80 SMA, some of whom will have entered the adult service on one of the new novel therapies available. The eldest treated SMA type 2 patient in Scotland is currently ten years old and will transition to adult services in six years' time. Lack of resources in adult services will mean careful planning and consideration will be required for this cohort of patients well in advance of transition.

Following an unsuccessful bid by NHS GGC to NSSC for a designated national service based in Glasgow the network has been given a unique and exciting opportunity will work with the National Planning Board to explore what service is needed for the neuromuscular population into the future. The network would use all their expertise to undertake a horizon scanning exercise to scope what is coming and what might be coming as well as considering how the population will change over the next 5-10 years. Based on the findings from this project the network will submit a report to the National Planning Board in November 2020. This report will specify what resources will be needed to deliver this service. It will detail issues of levels of capabilities and capacity required, how this might be developed, where this could be delivered and how it would be connected. This will also inform future work plans for the network as it is recognised that some of this development is likely to be around reconfiguration of existing resource and building capacity though education, which SMN is well placed to support.

This will be the key part of the network's work plan for 2020/21.

3.2.4 Research

SMN continues to develop Scotland as a base for neuromuscular research in order to sustain good access for Scottish patients to new studies. This will be increasingly important as other more established research bases such as Newcastle and London have reached saturation and are unable to take on new research projects and have a limited recruitment capacity for current research. Ongoing key research in Scotland includes an investigation into bone health and vertebral fractures in Duchenne Muscular Dystrophy (DMD) and the Troponin study of heart biomarkers in Myotonic Dystrophy patients. The FOR-DMD study in Glasgow, a satellite centre for Newcastle, has now coming to an end. Vision DMD, a trial investigating a steroid like drug with a better side effect profile than current steroid therapy, is now at its midpoint and has stopped enrolling, although recent communication indicates that it may be extended as global capacity has not been reached. Enrolment to the Tam DMD study, a study exploring the re-purposed drug Tamoxifen is now fully recruited and enrolment to Sarepta Essence, an exon skipping trial has been postponed due to the C-19 pandemic.

Collaboration is becoming increasingly important to develop, monitor and sustain evidence based best practice. This includes working in partnership across a range of bodies such as the NHS, charities, the pharmaceutical industry and research organisations. Through the Scottish Muscle Network, Scottish clinical services are very much a part of this process.

The Drugs and Therapeutics Intervention Group (DATIG) has been instrumental in discussing and reaching consensus towards new drugs and therapies whilst reviewing current literature.

3.3. Stakeholder Communication and Engagement

A communication strategy was developed by the network last year. The network progressed the following pieces of work aligned with this strategy:

3.3.1 Patient Engagement Events

On 17th September 2019, the Network participated in an event which was organised and hosted by the Prince & Princess of Wales Hospice in collaboration with DMD Pathfinders, Muscular Dystrophy UK and Yorkhill Muscle Fund who hosted a Young Adults' Forum. The event was for patients with Duchenne Muscular Dystrophy (DMD) and Spinal Muscular Atrophy (SMA), their families and healthcare professionals to offer a forum to share experiences and provide updates from the hosts. Three workshops were also delivered on:

- Assistive Technology
- Physiotherapist interventions
- Financial & Practical Support

50 people attended with positive feedback including:

"Great day with loads of information"
"Great to hear patient experiences"
"Excellent to bring in people affected with the condition"

The networks aim from the event were to:

- Raise the profile of the SMN with both the 3rd sector organisational and the families affected by these conditions
- Engage with these sectors and learn more about the charities roles in supporting these patients and families
- Learn more about the challenges and issues patients and families with these conditions face and whether the network can help them in any way

3.3.2 Transition Survey

The Network in collaboration with Muscular Dystrophy UK has developed a Transition audit to better understand the current service provision for young men with Duchenne Muscular Dystrophy (DMD) who have transitioned to adult services in the last three years. The results will allow the network to build a picture across Scotland for all young men with DMD that may help services improve. The audit has now begun with patients providing feedback through home visits.

3.3.3 Website

The network continues to raise awareness and increase the visibility of the SMN and its website www.smn.scot.nhs.uk to stakeholders through adding the website address to information sheets on various conditions for GPs, clinic letters, emails and liaising with other UK neuromuscular services. From April 2019 to March 2020 there were 171 more sessions (visits to the website) than the previous year and 632 more individual page views than the previous year.

Figure 1 below shows the increase in website usage.

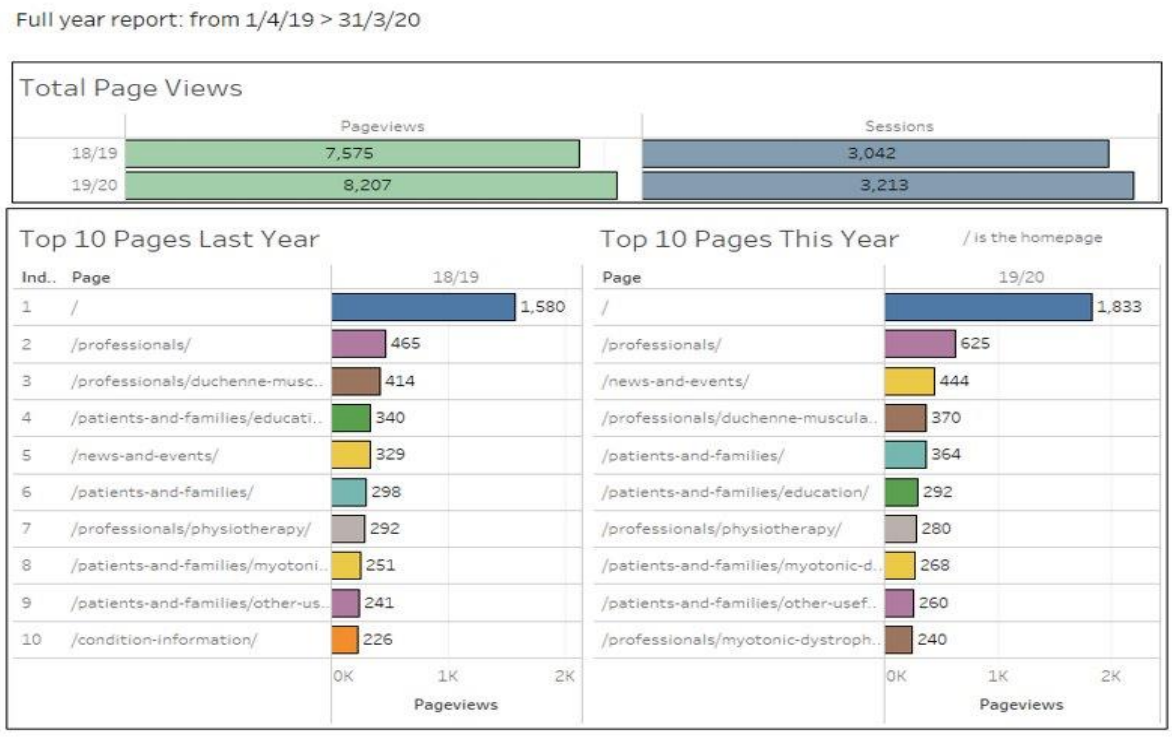


Fig. 1: SMN Website Usage (March 2019-March 2020)

3.3.4 Information materials

During 2019/20, 11 patient information leaflets have been updated by various steering group members and endorsed by the steering group.

- Oedema Management
- Bladder function and Continence care in DMD
- Continence care – bladder issues
- Postural management
- Non NHS registries for muscle conditions
- Considering a trial of Modafinil
- Starting a trial of Modafinil
- Information about fatigue
- Chest Physiotherapy support
- Managing falls
- Pain management

In addition, a new leaflet on Ankle Management for DMD patients was developed

3.3.5 Family Engagement

A draft questionnaire has now been completed which will be shared with the steering group. Once ratified the findings will be used to identify areas of patient experience that families feel can be improved. The network will then use these findings as planning tools to drive service improvement.

3.3.6 App

A new exercise protocol for DM1 (myotonic dystrophy) patients was previously developed by the SMN Myotonic Dystrophy (DM1) sub group and the group suggested the best way of delivering this to patients was through an app. However, this option proved not to be viable. The network is currently exploring other ways of making this information available to these patients.

3.4. Education

The network has an Education Strategy which included delivery of the following: The net

3.4.1 Multidisciplinary Meetings

Following the success of previous events, the network held “Muscle Interest Group” (MIG) meetings on 17th May 2019 (Perth) and 15th November 2019 (Glasgow). The aim of these meetings is to provide a forum for discussion of challenging neuromuscular cases, professional peer support, and dissemination of medical knowledge. The two meetings were attended by 18 and 31 delegates, respectively and included world experts from the field under discussion. This assisted clinicians throughout Scotland to ensure clinical governance surrounding the diagnosis and management of more challenging cases was in place. Evaluation response rate for both events combined was 60% with 100% of the delegates rating the education relevant to their CPD. The majority of delegates also reported that the education provided would impact their future clinical practice as figure 2 below shows.

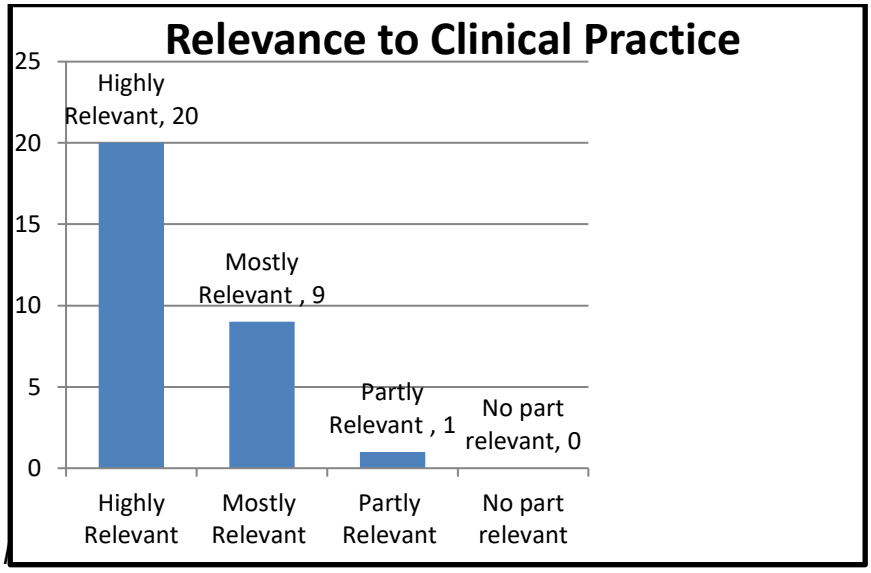


Fig 2-Relevance to Clinical Practice of 2 MIG Education Events

A sample of comments by delegates include:

- Hugely helpful– ability to receive advice on how to investigate my patients
- Could not do my job properly without this meeting

3.4.2 Allied Health Professional (AHP) Education

Two masterclasses on neuromuscular respiratory education were held in November 2019 at Glasgow and Edinburgh following the identification of need at a previous AHP education event. 24 and 21 delegates attended respectively with a 75% response rate to feedback. Similar to the two Muscle Interest Group (MIG) meetings, 100% of the delegates found the education relevant to their CPD. With regard to impact on clinical practice 85% of delegates found the education highly relevant as shown in figure 3 below:

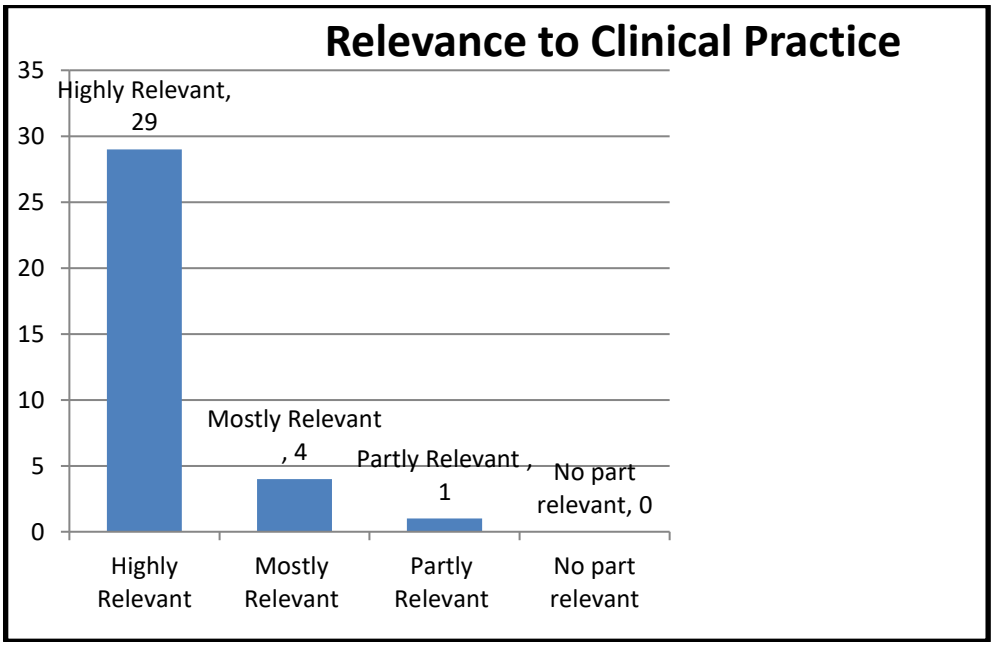


Fig. 3: Impact on Clinical Practice from two Neuromuscular Respiratory Education Events

A sample of comments by delegates include:

- Reassured about practice and learnt a few additional facts and practice points.
- Confidence in how to manage neuro-respiratory questions with families updated from the professionals
- Feel more confident with techniques; breath stacking
- Improved knowledge of devices and respiratory care of neuromuscular conditions
- Tips on ambubag use. Stretch – thoracic

3.4.3 Annual Conference

The annual conference was held in September 2019 in Dundee. 57 delegates attended with 43 (75%) returning evaluation feedback.

A breakdown of delegate designation is shown in figure 4 below

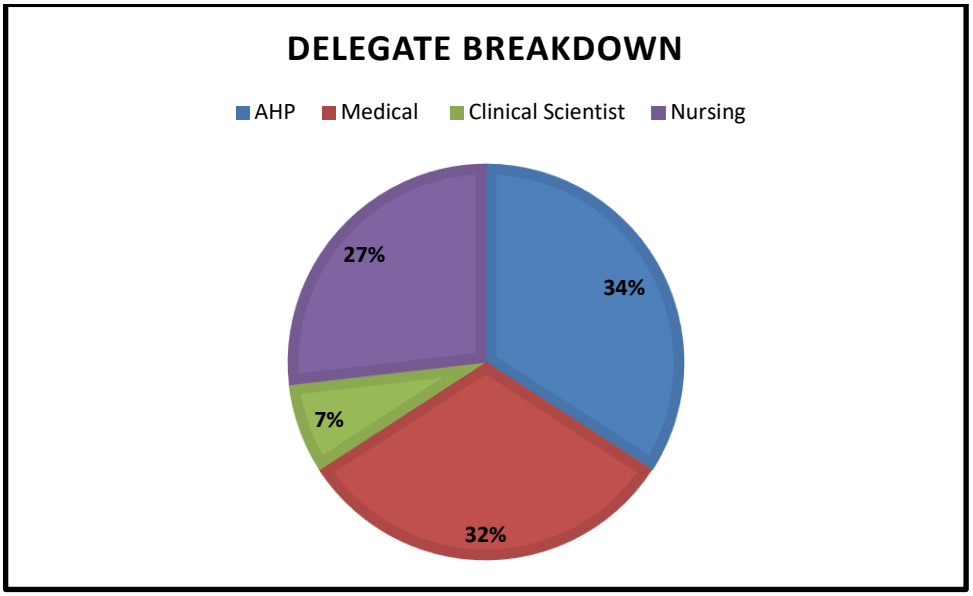


Fig. 4: Delegates at SMN Annual Conference by designation

Delegate feedback reported that over 95% of delegates rated the quality of education provided as excellent or very good whilst 80% reported that the meeting was effective for their CPD purposes. Most importantly, feedback indicated a number of areas where delegates felt the education provided will impact their clinical practice (see Figure 5 below).

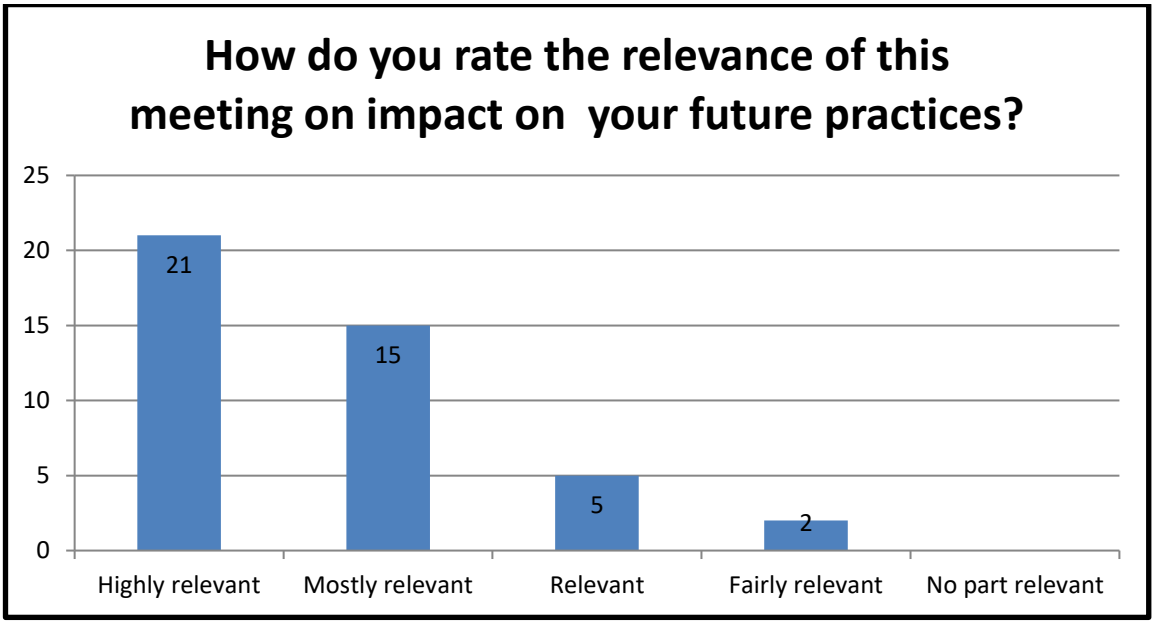


Fig. 5: Impact on Clinical Practice from Annual Education Conference

.Comments included:

- Will give advice to families re driving and lycra. Better understanding of cognitive function in DMD
- Need to explore Orthotic access
- Leaned how testing for Rhabdomyolysis is important-will now be aware of this
- Hopefully better and more rounded holistic approach to patient care
- To further improve MDT working and widen knowledge of information
- More aware of the importance of nutrition
- It has given me a clear insight into the services involved in a patient's life and how each service can be tailored to their needs
- Definitely change discussions on future treatments for children whilst asymptomatic e.g. PEG feeding

3.5. Audit and Continuous Quality Improvement

3.5.1 CAS

Due to increasing work pressures for Network members and ongoing uncertainty regarding the need to finalise the terms of the General Data Protection Regulations (GDPR) with regard to consent there has been very little progress on building the database during the past year.

Plans are now in place to re-invigorate this exercise.

3.5.2 Audit

- **DMD**

The Network has made progress in developing key performance indicators for DMD, which will be used to measure service performance during 2020/21. The network has agreed to use a number of endocrine tests as a basis for KPI's and plan to pilot measuring performance against these for a number of patients in the West of Scotland. If successful, this programme will be rolled out more widely to other centres. The aim will be to identify areas where improvements can be made to services provided for these patients.

- **DM1**

DM1 is the other main priority for audit. Since 2010, management of most adults with DM1 in Scotland has been delivered through specialist clinics run by four Regional Genetic Services (Aberdeen, Dundee, Edinburgh and Glasgow). Patients are offered an annual review, and common clinical data are recorded in each centre. Local variation in service delivery may lead to difference in practice at each centre; however, the SMN DM1 Care Standards (shown in Appendix 4 and available at www.smn.scot.nhs.uk) aim to ensure DM1 patients across Scotland receive equitable care. These standards were agreed upon in 2009 using SIGN methodology and are updated biannually by the DM1 sub group. The sub group perform a biannual audit, the most recent one covering August 2018-19, using data captured from the four databases. Results of the audit are shown on Appendix 3, (figures 6-11). Analysis of findings show:

1. The number of patients referred to a Specialist Management Clinic shows steady increase over the past 6 years.
2. The % of patients receiving their annual review falls below standard of 90% apart from in Glasgow- reasons for this are currently under review.
3. The %of patients receiving their reviews at 18 months, 24 month and 36 months mainly meets the 90% standard apart from East and Tayside which did not meet the 24 months' standard. However, the trend over the past 6 years shows that more patients are receiving their reviews faster than before, although it must be noted that West of Scotland had no data available for the 2016/17 audit due to IT problems.
4. Clinical testing and monitoring in the following categories has met recommended standards across all four regions:
    a) Molecular diagnosis when seen at a Specialist Management Clinic.
    b) Cardiology (ECG)
    c) Respiratory (Epworth Sleepiness Score)
    d) Endocrine (Glucose and Thyroid)
5. Appropriate support and Information provided to patients has met standards across all four regions

Information Management Services (IMS) have worked closely with genetics on an ambitious project to identify and capture a core dataset of key information that would be placed on a national database. This work is now almost completed and when finalised will be put forward to the CAS Development Team. The aim would be to have a single national DM1 database which will be used to audit more efficiently.

3.6. Value

The SMN has been supporting NHS services in providing better value in the following ways:

1. Linking a wide range of service providers at local, regional and national level in a collaborative network that promotes the sharing of best practice and provides a forum for developing common solutions that can be applied effectively and efficiently (e.g. facilitating a common approach to the use of novel, treatments such as Nusinersen for children with SMA).
2. Engaging with patients, families and the third sector to identify service user views on how neuromuscular care and support could be improved
3. Agreeing and reviewing guidelines and patient care pathways, that detail the kinds of services that patients/families should have access to
4. Auditing care in Scotland against agreed standards (e.g. Myotonic Dystrophy) and demonstrating a positive impact on direct patient care
5. Professional education to achieve greater awareness of best practice among Scottish clinicians
6. Perceived economies of scale as the network has been operating at national level.

In addition, SMN is committed to ensuring that for every Network sub-group meeting and, in as far as possible, for all education events there is an opportunity to link in via videoconference. This enables staff

from around Scotland to participate in network business and education while avoiding unnecessary pressure on clinical commitments.

4. Plans for the Year Ahead

Key priorities for 2020/21 include:

1. Develop neuromuscular services in Scotland through working with National Planning
2. Deliver a programme of audit against Key Performance Indicators for DMD patients.
3. Developing a National Database on CAS for DM1 patients to allow audit against clinical standards
4. Hold a joint family event with MD-UK for patients with DMD and SMA
5. Improving the quality of neuromuscular services through analysis of feedback and a Transition QI Project.
6. Continue to develop and review clinical protocols, guidelines and information leaflets, for both professional and patient groups.
7. Continue to take forward the recommendations from the Network Review

Risks/Issues include:

1. *New Therapies*– Network members continue to be concerned about the impact of new treatments and the workload implications of supporting patients to access this, in particular:
    a) Impact on other neuromuscular services as resources are diverted to focus on developing SMA services where new treatments are available.
    b) Even with additional investment, rrecruitment of appropriately skilled staff and then succession planning will also be a challenge.
    c) There is currently inequality across Scotland for the level of service to adult neuromuscular patients with currently no neurologists in either the North or East of Scotland with an interest in neuromuscular diseases, and only one consultant (Dr Maria Farrugia) in the West. There is no specialist adult neuromuscular physiotherapy service for the North and east of Scotland
    This is a serious concern as projections based on current SMA population in children and a projected increase of 5 new SMA cases per annum will mean that in roughly 15 years' time there will be an estimated 80 SMA patients alive in Scotland. Within six years, the eldest current SMA patient will commence transition to adult services with others following. Local service planning will need to reflect how these patients will be cared for. This will be looked at as part of the ongoing work on SMA service provision.
    d) SMA was only the 'tip of the iceberg'. Many other new interventions including gene therapy would soon be available for other neuromuscular conditions, e.g. DMD which would put a further additional strain on resources that are already over-stretched.

COVID-19

Since February 2020, understandably NHS Scotland priority has been to prepare for and deal with COVID-19 impact and this has seen clinical and other resource diverted from network activity. The network has undertaken an exercise to not only capture the impact of this unprecedented situation on the current reporting period but also to assess the likely impact on delivery of the 2020/21 workplan.

Key areas include:

1. Undertake a Service Planning exercise to consider the future service needs for the neuromuscular population based on developments in neuromuscular care and the wider environment. Workshpos

planned may have to be delayed plans to look at alternative ways to engage with key staff are currently being looked at.

2. The Management of DM1 in Adults was due to be reviewed in April –will be postponed until later in the year.
3. 2 questionnaires planned for distribution to patients will need to be delayed
4. Education events including Muscle Interest Group and Annual Education event planned are currently at risk.
5. A Family Event planned for later in the year is at risk

5. Detailed Description of Progress in 2019/20

Key

RAGB status	Description
RED (R)	The network is unlikely to achieve the objective by the agreed end date.
AMBER (A)	There is a risk that the network will not achieve the objective by the agreed end date but progress has been made.
GREEN (G)	The network is on track to achieve the objective by the agreed end date.
BLUE (B)	The network has been successful in achieving the network objective to plan.

Objective Number	Smart Objective	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at March 31st 2020	Anticipated Outcome	RAGB status
1. Effective Network Structure and Governance [linked to Quality Dimensions 3,4,5,6]						
2019-01	Network continues to be overseen by multi-disciplinary steering group with Lead Clinician and Chair. Network has Service Level Agreement and workplan in place	April 2019/ March 2020	Steering Group	Steering Group in place with LC and Chair which oversees workplan. The Network has a service level agreement with NHS NSS in place for 2017-2020. This is currently being updated	Effective delivery of the SMN work plan to ensure continuation of progress.	**G**

	Network meets core principals of managed clinical networks as set out in CEL (2012) 29.					
2019-02	Organise 3 Steering Group meetings to ensure effective delivery of the 2019/20 workplan	April 2019/ March 2020	Steering Group	Steering Group Meetings: 11 June 2019 31 October 2019 11 February 2020	Effective delivery of the SMN work plan to ensure continuation of progress.	**B**
2019-03	The network will meet reporting requirements: - Mid-year Report - Annual Report	31/10/19 31/05/20	Lead Clinician/ Programme Manager	Mid-Year Report available Annual Report available	There are effective governance arrangements in place.	**B**
2. Service Development and Delivery **[linked to Quality Dimensions 1,2,3,4,5,6]**						
2019-04	Scope development clinical pathways for development of MDT to support Spinal Muscular Atrophy (SMA) service.	April 2019/ June 2019	Iain Horrocks/ Maria Farrugia/ Hugh Kennedy	SMA Pathway Developed and published on website .	Develop service for SMA	**B**
2019-05	Explore benchmarking opportunities against rest of UK	April 2019/ March 2020	Hugh Kennedy	Not progressed-new plan in place to target one neuromuscular centre in England c/fwd	Measure SMN neuromuscular services against other UK services	**R**

2019-06	Update guidelines/pathways in line with review timetable: DMD MDT Care Pathway	April 2019/ March 2020	Hugh Kennedy/ Laura Craig	Successfully completed and published on website	Ensure all clinical information is relevant and current	**B**
3. Stakeholder Communication and Engagement **[linked to Quality Dimensions 1,3,4,5,6]**						
2019-07	Hold a joint patient engagement event with DMD Pathfinders and Prince & Princess of Wales Trust	August 2019	Marina Di Marco/ Laura Craig	Event held in September 2019. See section 3.3.1 for details	Facilitate provision of better support for young people and adults with DMD/SMA	**B**
2019-08	Revision and distribution of patient experience questionnaire	April 2019/ March 2020	Hugh Kennedy/ Wilma Stewart	Draft prepared. Will be distributed next year. c/fwd	Direct input of parents/patients and family priorities into SMN objectives	**A**
2019-09	Update /review 11 patient information leaflets in line with review schedule	April 2019/ March 2020	Marina Di Marco	Successfully completed-see section 3.3.4	Ensure all network documents are reviewed in line with NNMS guidance	**B**
2019-10	Develop new patient information leaflet on Ankle Management for DMD	April 2019/ March 2020	Marina Di Marco/Steering Group	Successfully completed-see section 3.3.4	Provide information and support for patients with DMD	**B**
2019-11	Progress the improvement in the transition process through investigation of experience of a number of patients who have transitioned to adult services during	April 2019/ March 2020	Marina Di Marco/Jackie Munro	Questionnaire developed – feedback ongoing-see section 3.3.2 for details c/fwd	Improve service to adult patients with a neuromuscular condition	**A**

	the past three years. Develop questionnaire to capture this feedback					
2019-12	Develop app to support exercises for Myotonic Dystrophy patients	April 2019/ March 2020	Cheryl Longman/ Hugh Kennedy	Project proved not be viable Network will look at alternative ways to support this group of patients. c/fwd	Support for Myotonic Dystrophy patients	**R**
2019-13	Review information currently on SMN website and ensure it is relevant and up to date	April 2019/ March 2020	Laura Craig	Website up to date www.smn.scot.nhs.uk	Improved engagement with both patients and professionals	**B**
4. Education **[linked to Quality Dimensions 1,2,3,4,5,6]**						
2019-14	Hold annual education conference	Sep 2019	Laura Craig/Marina Di Marco	Successful event held in September 2019. See section 3.4.3 for details	Improved knowledge in neuromuscular disorders for relevant healthcare professionals that either reinforce existing best practice or results in changes in practice	**B**
2019-15	Hold 2 bi-annual Muscle Interest Group Meetings	May and November 2019	Laura Craig/Maria Farrugia	2 successful meetings held. See section 3.4.1 for details	Improved knowledge in neuromuscular disorders for relevant healthcare professionals that either reinforce existing best practice or results in changes in practice	**B**

2019-16	Hold AHP Education Meeting	April 2019/March 2020	Laura Craig/Marina Di Marco	AHP group wanted more specialised education on respiratory issues in neuromuscular patients- two respiratory master classes held. See section 3.4.2 for details	Improved knowledge in neuromuscular disorders for relevant healthcare professionals that either reinforce existing best practice or results in changes in practice	**B**
5. Audit and Continuous Quality Improvement [linked to Quality Dimensions 1,2,3,4,5,6]						
2019-17	Collect meaningful data on DMD patients by developing 5-6 KPI's based on North Star scoring	April 2019/March 2020	Mike Gunn/ Hugh Kennedy	6 KPI's developed and agreed. Plans in place to measure in 20120/21 c/fwd	Identified service improvements for patients with DMD	**G**
2019-18	Explore options for Myotonic Dystrophy (DM1) national data collection	April 2019/March 2020	Mike Gunn/Kelly Maxwell Brown/DM1 Leads	Good progress to date. Database fields agreed compiled on excel spreadsheet. Plan to submit to CAS developers for costing c/fwd	Identified service improvements for patients with DM1	**G**
2019-19	Continue the bi-annual audit the four DM1 standards across the four tertiary centres. Use August 2018-August 2019 data collected.	April 2019/March 2020	Catherine Mc William	Audit successfully completed. See section 3.5.2 and Appendix 3 for details	Identified service improvements for patients with DM1	**B**
6. Value [linked to Quality Dimensions 1,2,3,4,5,6]						

None						

6. Proposed Workplan in 2020/2021

Key

RAGB status	Description
RED (R)	The network is unlikely to achieve the objective by the agreed end date.
AMBER (A)	There is a risk that the network will not achieve the objective by the agreed end date but progress has been made.
GREEN (G)	The network is on track to achieve the objective by the agreed end date.
BLUE (B)	The network has been successful in achieving the network objective to plan.

Objective Number	Smart Objective	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at March 31st 2020	Anticipated Outcome	RAGB status
1. Effective Network Structure and Governance [linked to Quality Dimensions 3,4,5,6]						
2020-01	Update and endorse Network Service Level Agreement so that Network continues to meet core principals of managed clinical networks as set out in CEL (2012) 29.	April 2020/ March 2021	Programme Manager /Lead Clinician		Effective delivery of the SMN work plan to ensure continuation of progress.	

Objective Number	Smart Objective	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at March 31st 2020	Anticipated Outcome	RAGB status
2020-02	Organise 3 Steering Group meetings to ensure effective delivery of the 2020/21 workplan	April 2020/ March 2021	Steering Group		Effective delivery of the SMN work plan to ensure continuation of progress.	
2020-03	The network will meet reporting requirements: - Mid-year Report - Annual Report	31/10/20 31/05/21	Lead Clinician/ Programme Manager		There are effective governance arrangements in place.	
2. Service Development and Delivery [linked to Quality Dimensions 1,2,3,4,5,6]						
2020-04	Scope developments in all Neuromuscular Services in Scotland through identification of impact of new therapies on services: • Workgroup to scope project • Short life working group to progress and finalize proposal • Business Case to be submitted to NSSC	April 2020/ March 2021	Workgroup		Development of neuromuscular services	
2020-05	Review SMA Pathway quarterly	April 2020/ March 2021	Hugh Kennedy		Ensure SMA Pathway is relevant and current	
2019-05	Explore benchmarking opportunities against a UK neuromuscular centre	April 2020/ March 2021	Hugh Kennedy		Measure SMN neuromuscular services against other UK services	

Objective Number	Smart Objective	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at March 31st 2020	Anticipated Outcome	RAGB status
2020-06	Review existing guidelines/care pathways in line with NNMS Review Timetable: 3 will be reviewed: • Management of DM1 in adults • DMD Physio profile • Generic Neuromuscular Pathway	April 2020/ March 2021	Hugh Kennedy/ Laura Craig		Ensure all clinical information is relevant and current	
3. Stakeholder Communication and Engagement [linked to Quality Dimensions 1,3,4,5,6]						
2020-07	Organise and host a joint patient engagement event with MD-UK for SMA and DMD Patients	August 2020	Marina Di Marco/ Laura Craig		Facilitate provision of better support for young people and adults with DMD/SMA	
2019-08	Revision, distribution and audit of patient experience questionnaire	April 2020/ March 2021	Hugh Kennedy/ Wilma Stewart		Direct input of parents/patients and family priorities into SMN objectives	
2020-08	Update/Review 13 patient information leaflets in line with review schedule Complete patient information leaflet on Trismus in SMA / DMD	April 2020/ March 2021	Marina Di Marco		Ensure all network documents are reviewed in line with NNMS guidance	
2019-11	Progress the improvement in the transition process through	April 2020/	Marina Di Marco/Ja		Improve service to adult patients with a	

Objective Number	Smart Objective	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at March 31st 2020	Anticipated Outcome	RAGB status
	investigation of experience of a number of patients who have transitioned to adult services during the past three years.	March 2021	ckie Munro		neuromuscular condition	
2020-09	Review information currently on SMN website and ensure it is relevant and up to date	April 2020/ March 2021	Laura Craig		Improved engagement with both patients and professionals	
2020-10	Maintain the Service Map and other information on the website	April 2020/ March 2021	Laura Craig		Improved engagement with both patients and professionals	
2020-11	Staff newsletter to be developed distributed during the year to network members and hosted on SMN website	April 2020/ Sep 2020	Laura Craig		Improved engagement with professionals	
4. Education **[linked to Quality Dimensions 1,2,3,4,5,6]**						
2020-12	Organise and host an annual education conference	Sep 2020	Laura Craig/Marina Di Marco		Improved knowledge in neuromuscular disorders for relevant healthcare professionals that either reinforce existing best practice or results in changes in practice	
2020-13	Organise and host 2 bi-annual Muscle Interest Group Meetings	May and November 2020	Laura Craig/Mar		Improved knowledge in neuromuscular disorders for relevant healthcare	

Objective Number	Smart Objective	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at March 31st 2020	Anticipated Outcome	RAGB status
			ina Di Marco		professionals that either reinforce existing best practice or results in changes in practice	
2020-14	Organise and host AHP Education Meeting	April 2020/March 2021	Laura Craig/Marina Di Marco		Improved knowledge in neuromuscular disorders for relevant healthcare professionals that either reinforce existing best practice or results in changes in practice	
5. Audit and Continuous Quality Improvement **[linked to Quality Dimensions 1,2,3,4,5,6]**						
2019-17	Measure against KPI's developed 2019/20 to evidence quality improvement for DMD patients	April 2020/March 2021	Kelly Maxwell-Brown/ Hugh Kennedy		Identified service improvements for patients with DMD	
2019-18	Continue to develop national database for DM1 patients: Core dataset developed and agreed. To be submitted to CAS Developers. Core dataset on CAS to be tested before going live.	April 2020/March 2021	Kelly Maxwell-Brown/ DM1 sub group		Identified service improvements for patients with DM1	

Objective Number	Smart Objective	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at March 31st 2020	Anticipated Outcome	RAGB status
2020-15	Audit Malignant Hypothermia Pathway	April 2020/March 2021	Catherine Mc William/Cheryl Longman		Identified service improvements for patients with MH	
2020-16	Continue to populate CAS with neuromuscular patients	April 2020/March 2021	Laura Craig		Service improvements for neuromuscular patients	
2020-17	Complete a Quality Improvement Strategy for SMN	April 2020/March 2021	Hugh Kennedy		Quality improvements for neuromuscular patients	
6. Value [linked to Quality Dimensions 1,2,3,4,5,6]						
None						

Appendix 1: Steering Group Membership

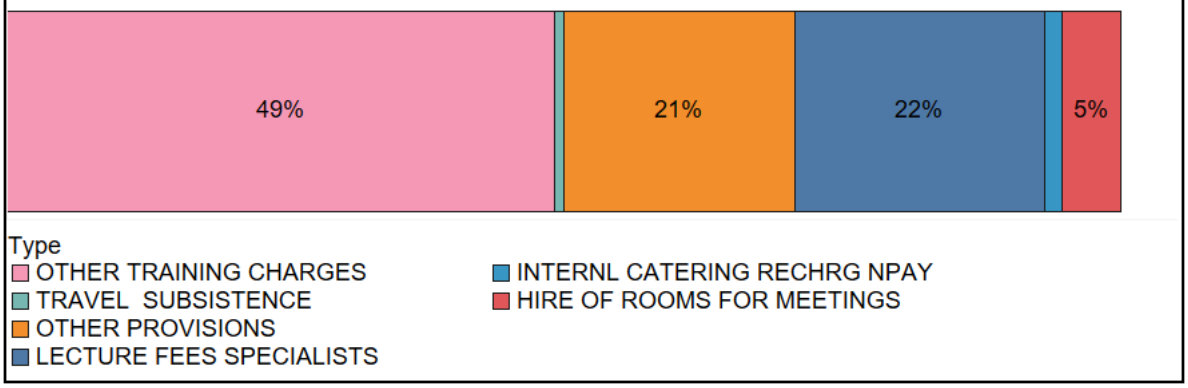
Name	Designation	Health Board Area
Dr Steve Banham	Consultant Cardiologist (Chair)	NHS Greater Glasgow & Clyde
Dr Anthony Bateman	Consultant in Respiratory Medicine	NHS Lothian
Dr Alex Baxter	Consultant Paediatrician	NHS Lothian
Dr Katie Brennan	Consultant Neurologist	NHS Greater Glasgow & Clyde
Julie Burslem	Paediatric Physiotherapist	NHS Highland
Dr Scott Davidson	Consultant in Respiratory Medicine	NHS Greater Glasgow & Clyde
Dr Phil Davies	Consultant Paediatric Respiratory Physician	NHS Greater Glasgow & Clyde
Marina Di Marco	Lead Clinician / Principal Neuromuscular Physiotherapist	NHS Greater Glasgow & Clyde
Jen Dunne	Neuromuscular Clinical Nurse Specialist	NHS Greater Glasgow & Clyde
Clare Eadie	Paediatric Physiotherapist	NHS Lothian
Dr Maria Farrugia	Consultant Neurologist	NHS Greater Glasgow & Clyde
Dr Helen Gregory	GP	NHS Grampian
Dr Iain Horrocks	Consultant Paediatric Neurologist	NHS Greater Glasgow & Clyde
Dr Shuko Joseph	Clinical Research Fellow	NHS Greater Glasgow & Clyde
Dr Cheryl Longman	Consultant Clinical Geneticist	NHS Greater Glasgow & Clyde
Dr Catherine McWilliam	Consultant Clinical Geneticist	NHS Tayside
Dr Kenneth McWilliam	Consultant Paediatric Neurologist	NHS Lothian
Gill Mitchell	Neuromuscular Liaison Nurse	NHS Lothian
Fiona Monaghan	Orthotist	NHS Borders
Jackie Munro	Advocacy & Information Officer	MDUK
Dr Karen Naismith	Consultant Paediatrician	NHS Tayside
Denise Oxnard	Genetic Counsellor	NHS Greater Glasgow & Clyde
Yvonne Robb	Genetic Neuromuscular Nurse	NHS Lothian
Dr Nicola Scott	Clinical Psychologist	NHS Ayrshire & Arran
Tracey Sharp	Project Manager	NHS Forth Valley
Lesley Snadden	Genetic Counsellor	NHS Greater Glasgow & Clyde
Wilma Stewart	Neuromuscular Care Advisor	NHS Greater Glasgow & Clyde
Robbie Warner	Parent representative/Muscular Dystrophy UK rep	n/a

Appendix 2: Finance

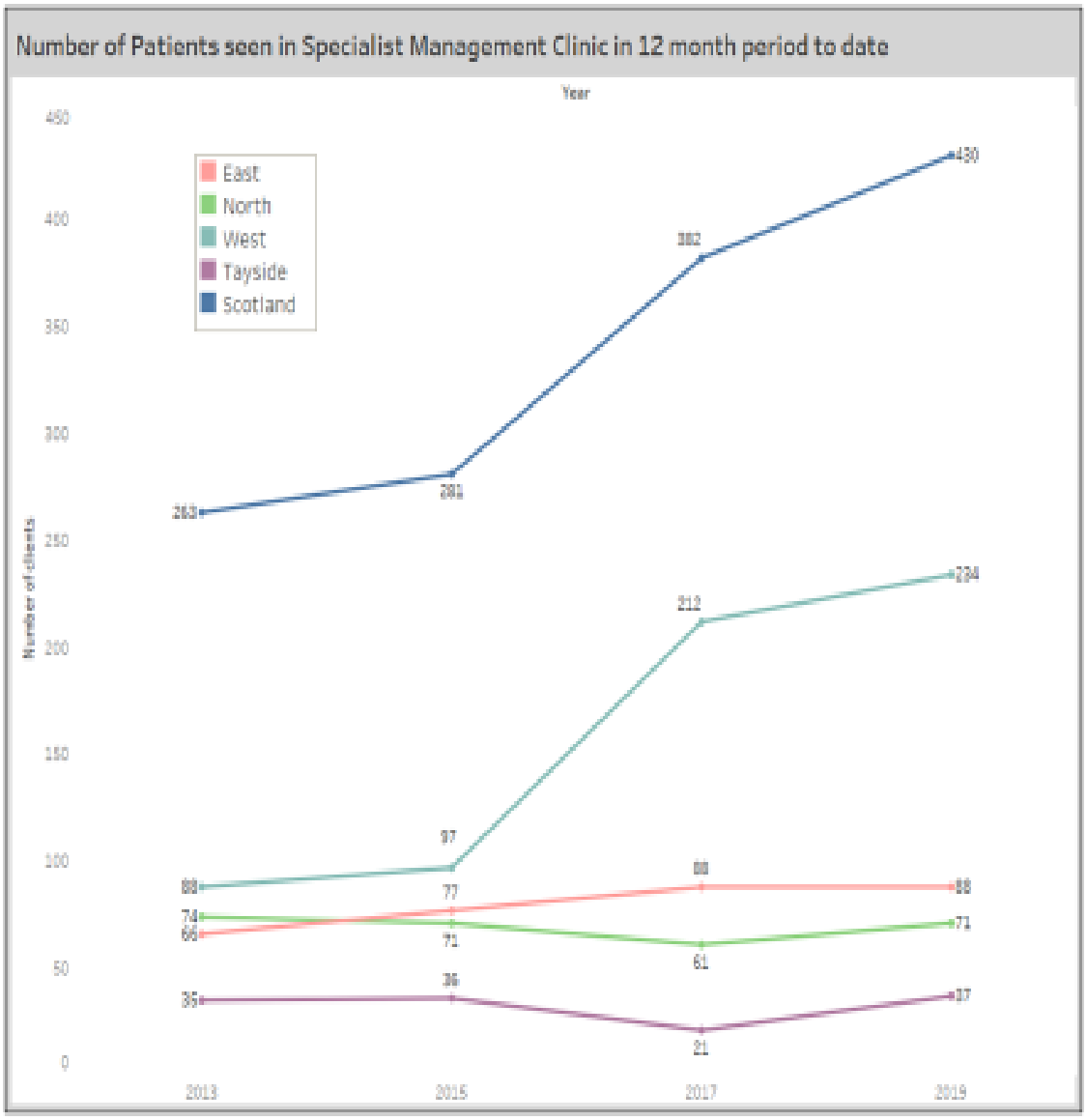
During the reporting period SMN were allocated a budget of £5000, the chart below contains a breakdown of how this was spent. The network held their annual education event in Dundee which was a significant spend at £2333.33, 49% of the overall spend. The other main expenditure was related to travel/accommodation for the guest speakers at the annual conference at a cost of £1065.73. Other network spending included; meeting room bookings, catering and travel. The network final position was an underspend of £256.84.

SCOTTISH MUSCLE NETWORK Financial Information

Job description	Account description	
SCOTTISH MUSCLE NETWORK	HIRE OF ROOMS FOR MEETINGS	£250.00
	INTERNL CATERING RECHRG NPAY	£74.65
	LECTURE FEES SPECIALISTS	£1,065.73
	OTHER PROVISIONS	£984.45
	OTHER TRAINING CHARGES	£2,333.33
	TRAVEL SUBSISTENCE	£35.00
Grand Total		£4,743.16

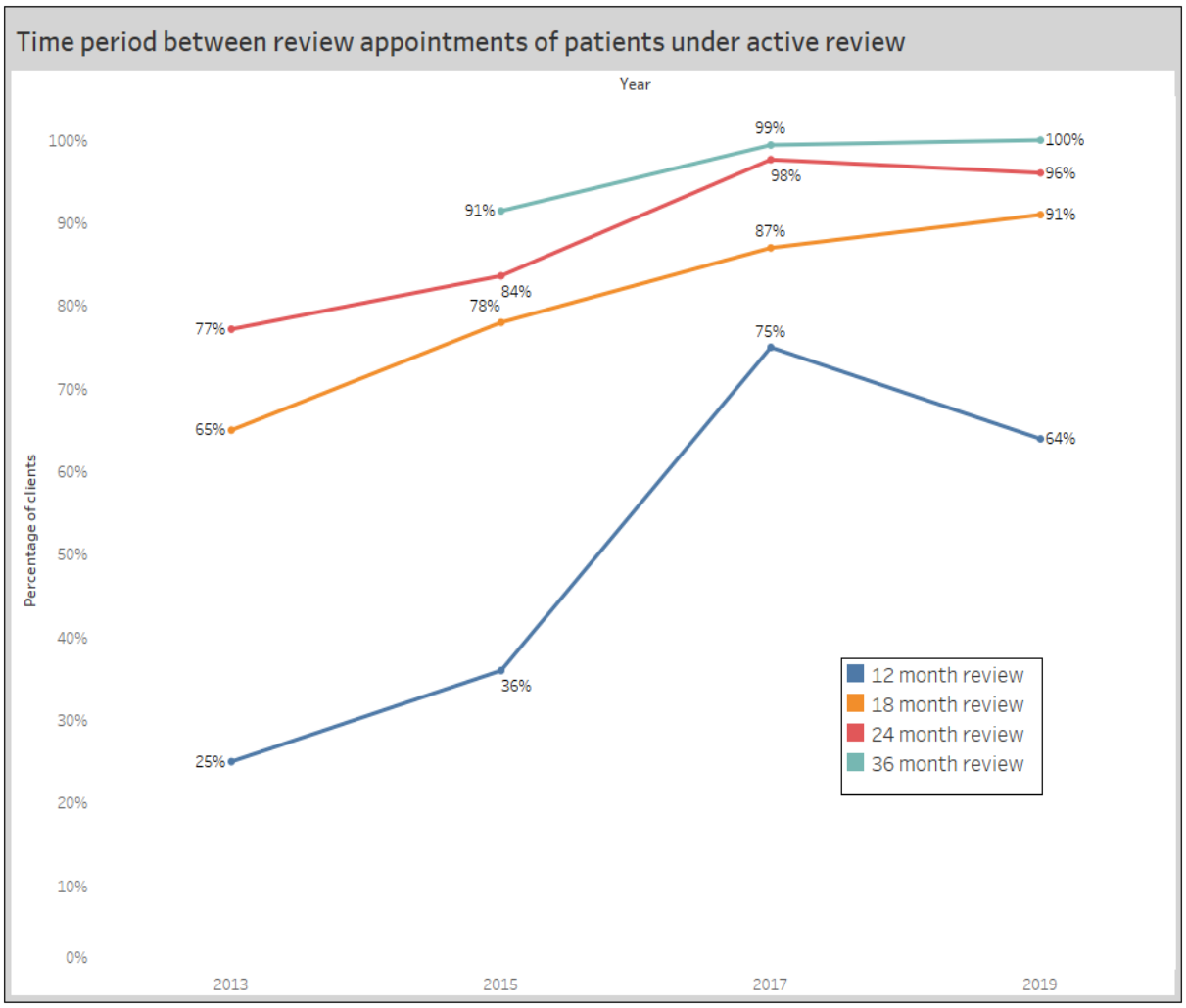


Appendix 3: Results of DM1 Audit



Standard Statement 2: Patients with DM1 have an annual review at a clinic that follows the SMN Management Guidelines: Management of Adults with Myotonic Dystrophy

Figure 6-Number of patients seen in Specialist Management Clinic in 12-month period to date



Standard Statement 2: Patients with DM1 have an annual review at a clinic that follows the SMN Management Guidelines: Management of Adults with Myotonic Dystrophy

Figure 7-Time period between review appointments of patients under active review

Time period between review appointments of patients under active review - by Region

Measure name	Region	Year 2013	2015	2017	2019
12 month review	East	47%	60%	57%	38%
	North	16%	21%	41%	31%
	Tayside	0%	3%	61%	19%
	West	25%	39%	93%	91%
18 month review	East	80%	91%	81%	88%
	North	73%	79%	95%	93%
	Tayside	26%	41%	95%	86%
	West	63%	74%		93%
24 month review	East	88%	91%	97%	97%
	North	81%	86%	98%	99%
	Tayside	31%	58%	100%	97%
	West	84%	86%		95%
36 month review	East		94%	99%	100%
	North		96%	100%	100%
	Tayside		72%	100%	100%
	West		94%		96%

Standard Statement 2: Patients with DM1 have an annual review at a clinic that follows the SMN Management Guidelines: Management of Adults with Myotonic Dystrophy

Figure 8-Time period between review appointments of patients under active review by region by RAG status

Green-achieved target

Amber-achieved half-way or above to target

Red-achieved below half- way to target

Standard Statement 3: Patients with DM1 receive appropriate monitoring and referrals according to the SMN Management Guidelines: Management of Adults with Myotonic Dystrophy

Figure 9-Specialist Management Clinical Outcome Measures-Scotland Total by RAG status

Specialist Management Clinic Outcome Measures - by Region

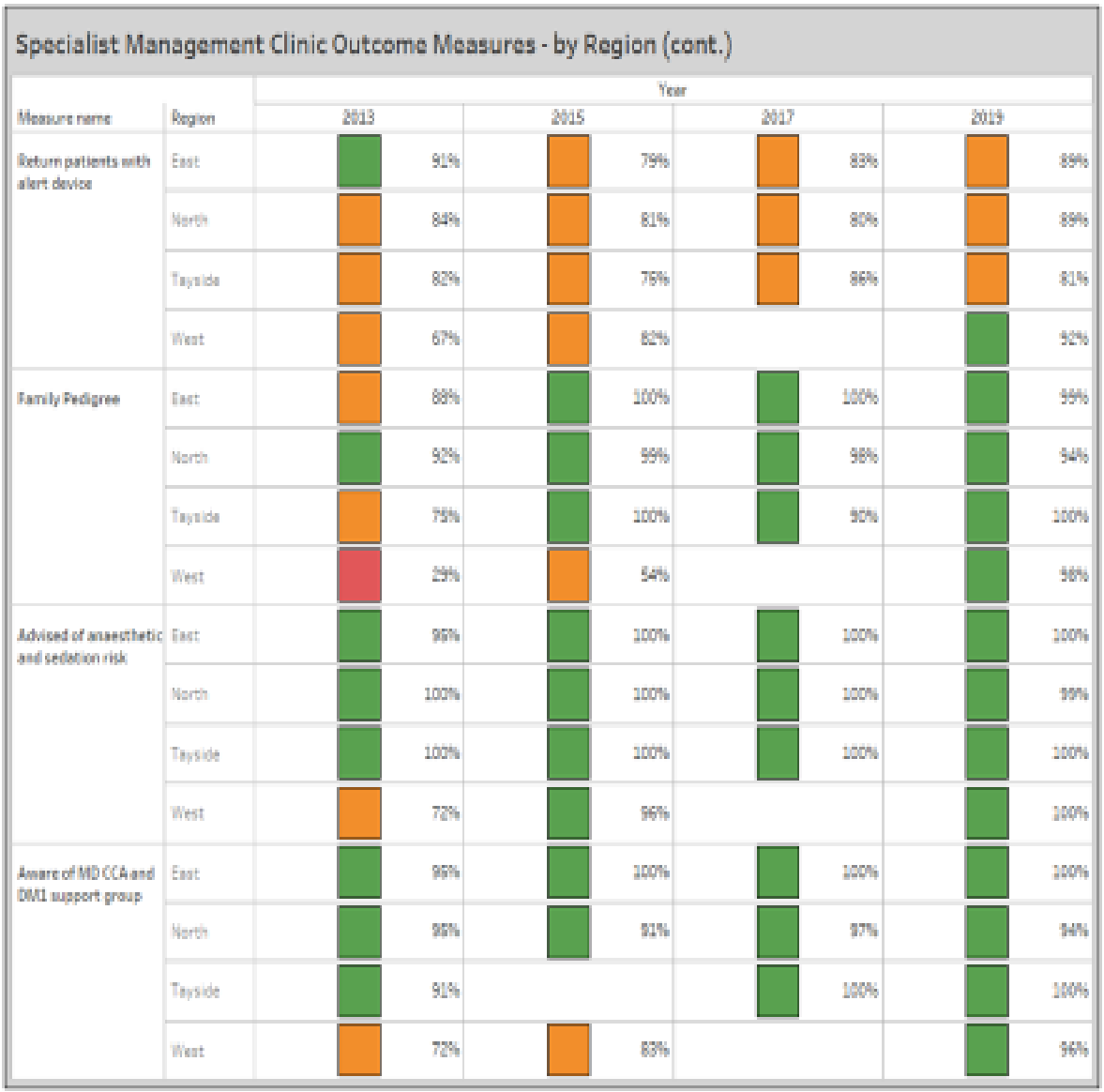
Measure name	Region	2013	2015	2017	2019
Molecular DM1 diagnosis	East	96%	98%	97%	97%
	North	100%	100%	100%	100%
	Tayside	91%	100%	100%	95%
	West	99%	99%		98%
Cardiology	East	100%	100%	100%	97%
	North	81%	85%	91%	96%
	Tayside	100%	88%	100%	96%
	West	76%	81%		92%
Respiratory/Sleep	East	97%	96%	100%	100%
	North	99%	100%	98%	100%
	Tayside	100%	100%	100%	100%
	West	80%	99%		99%
Endocrine	East	89%	79%	88%	82%
	North	78%	86%	93%	93%
	Tayside	90%	100%	95%	97%
	West	93%	94%		97%

Standard Statement 3: Patients with DM1 receive appropriate monitoring and referrals according to the SMN Management Guidelines: Management of Adults with Myotonic Dystrophy

Essential Criteria:

1. Cardiac. 90% of patients attending a specialist management clinic receive an automated ECG. (Exclusions: Patients with a pacemaker, ICD or other implantable cardiac device, who are reviewed in a pacemaker clinic or other cardiology clinic. Patients who have seen a cardiologist in the 12-month period preceding the clinic and whom the cardiologist plans to review.)
2. Respiratory. 90% of patients attending a specialist management clinic have their Epworth Sleepiness Score (ESS) assessed
3. Endocrine. 90% of patients attending a specialist management clinic have a random blood glucose (RGB) and/or* HbA1c, and thyroid function, recorded. (Exclusions: Patients known to have diabetes or thyroid disease, respectively) (*HbA1c preferred if available locally)

Figure 10-Specialist Management Clinical Outcome Measures-by region



Specialist Management Clinic Outcome Measures - by Region (cont.)

Measure name	Region	2013	2015	2017	2019
Return patients with alert device	East	91%	79%	83%	89%
	North	84%	81%	80%	89%
	Tayside	82%	79%	86%	81%
	West	67%	82%		92%
Family Pedigree	East	88%	100%	100%	99%
	North	92%	99%	98%	94%
	Tayside	75%	100%	90%	100%
	West	29%	54%		98%
Advised of anaesthetic and sedation risk	East	98%	100%	100%	100%
	North	100%	100%	100%	99%
	Tayside	100%	100%	100%	100%
	West	72%	96%		100%
Aware of MD CCA and DM1 support group	East	98%	100%	100%	100%
	North	98%	91%	97%	94%
	Tayside	91%		100%	100%
	West	72%	83%		96%

Standard Statement 3: Patients with DM1 receive appropriate monitoring and referrals according to the SMN Management Guidelines: Management of Adults with Myotonic Dystrophy

Figure 11-Specialist Management Clinical Outcome Measures-by region (cont.)

Appendix 4- DM1 Clinical Standards Version 2017

Standard Statement 1: All patients with a clinical diagnosis of DM1 should have molecular confirmation of diagnosis

Essential Criterion: 95% of patients who have ever attended a specialist management clinic have a molecular diagnosis of DM1.

Standard Statement 2: Patients with DM1 have an annual review at a clinic that follows the SMN Management Guidelines: Management of Adults with Myotonic Dystrophy

Essential Criterion: 90% of patients attending a specialist management clinic are reviewed annually (Specialist Management Clinic: A clinic where the SMN Management Guidelines "Management of Adults with Myotonic Dystrophy" are used and data is collected electronically to contribute to national audit. Genetic clinic appointments purely for the purpose of genetic counselling are excluded) (Reviewed annually: The proportion of patients attending clinic in the preceding year, for whom their prior appointment was less than 12 months earlier. Patients who do not have two attendances on the electronic database are excluded.)

Standard Statement 3: Patients with DM1 receive appropriate monitoring and referrals according to the SMN Management Guidelines: Management of Adults with Myotonic Dystrophy

Essential Criteria

Cardiac. 90% of patients attending a specialist management clinic receive an automated ECG. (Exclusions: Patients with a pacemaker, ICD or other implantable cardiac device, who are reviewed in a pacemaker clinic or other cardiology clinic. Patients who have seen a cardiologist in the 12-month period preceding the clinic and whom the cardiologist plans to review.)

Respiratory. 90% of patients attending a specialist management clinic have their Epworth Sleepiness Score (ESS) assessed

Endocrine. 90% of patients attending a specialist management clinic have a random blood glucose (RGB) and/or* HbA1c, and thyroid function, recorded. (Exclusions: Patients known to have diabetes or thyroid disease, respectively) (*HbA1c preferred if available locally)

Standard Statement 4: Patients with DM1 are given details of appropriate information and support

Essential Criteria

4a. 90% of return patients attending a specialist management clinic can produce an alert device at clinic. (Alert devices include DM1 care card, alert card, alert key fob, alert jewellery.)

b. 90% of patients attending a specialist management clinic have family pedigree reviewed and updated. (Definition: The family pedigree should have been seen by a Clinical Genetics clinician at clinic, and if the Consultant identifies individuals who have not been seen for counselling or affected individuals who have not been seen for management, the consultant should have been reminded to advise them of this.)

4c. 90% of patients attending a specialist management clinic are advised of general anaesthetic and sedation risks.

4d. 90% of patients attending a specialist management clinic are given details of the neuromuscular disorders support services* and the DM1 support group (*neuromuscular support services vary regionally and may include regional care advisor)