

**Scottish Muscle Network (SMN)
Annual Report
2020/21**

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Background

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 Scottish Muscle Network (SMN) was established 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.

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.

Summary of Year / Current Position

NHS Scotland has understandably been heavily impacted by the pandemic with many networks having clinical resources diverted from network activity.

SMN has responded to these challenges by managing to either deliver or progress the majority of its objectives agreed in its 2020/21 workplan. A few objectives were either delayed or paused and will be progressed in 2021/22. This was a result of clinical staff involved in progressing these workstreams being redeployed from their primary role, or picking up duties of other staff members who were either absent, self-isolating or have been re-deployed.

The network continually posted updated relevant C-19 information for patients affected by neuromuscular conditions on the SMN website. This was to raise awareness amongst patients of various support mechanisms available to them.

Key Highlights

Guidelines/Protocols/Pathways: During 2020/21, the Network continued to develop and review guidelines and care pathways in accordance with NNMS guidance. As such, three guidelines/pathways were reviewed and updated. These are all available on the SMN website <http://www.smn.scot.nhs.uk>

A decision was made to archive the Spinal Muscular Atrophy (SMA) Care Pathway developed the previous year. This was based on ongoing uncertainty around the service infrastructure available to deliver these services at the standard endorsed by the network. This pathway may

be looked at again, depending on the outcome of the Service Planning Exercise outlined below.

Service Planning Following an unsuccessful bid by NHS GGC to NSSC for a designated national SMA Service based in Glasgow the network was given a unique and exciting opportunity to work with the National Planning Board to explore what service is needed for the neuromuscular population into the future. The network would use their expertise to undertake a horizon scanning exercise to scope what is coming and what might be coming as well as considering how the neuromuscular population will change over the next 5-10 years. Based on the findings from this project the network planned to submit a report to the National Planning Board during the year, specifying what resources will be needed to deliver this service.

The impact of Covid-19 delayed the progress of this project during the first half of the year, as key staff were unavailable. The network has however recently progressed this major piece of work.

The network has also developed and distributed a questionnaire to clinical staff treating SMA patients across Scotland. The feedback will be used to inform the network what treatment is being offered patients in each centre, if all patients in Scotland have access to the new drug therapies and if they do, are they being monitored etc. This information will be used to aim for equity of treatment for all SMA patients cross Scotland.

Communication and Engagement

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 2020 to March 2021, there were 877 more sessions (visits to the website) than the previous year and 1,035 more individual page views than the previous year. (Fig 1)

Full year report

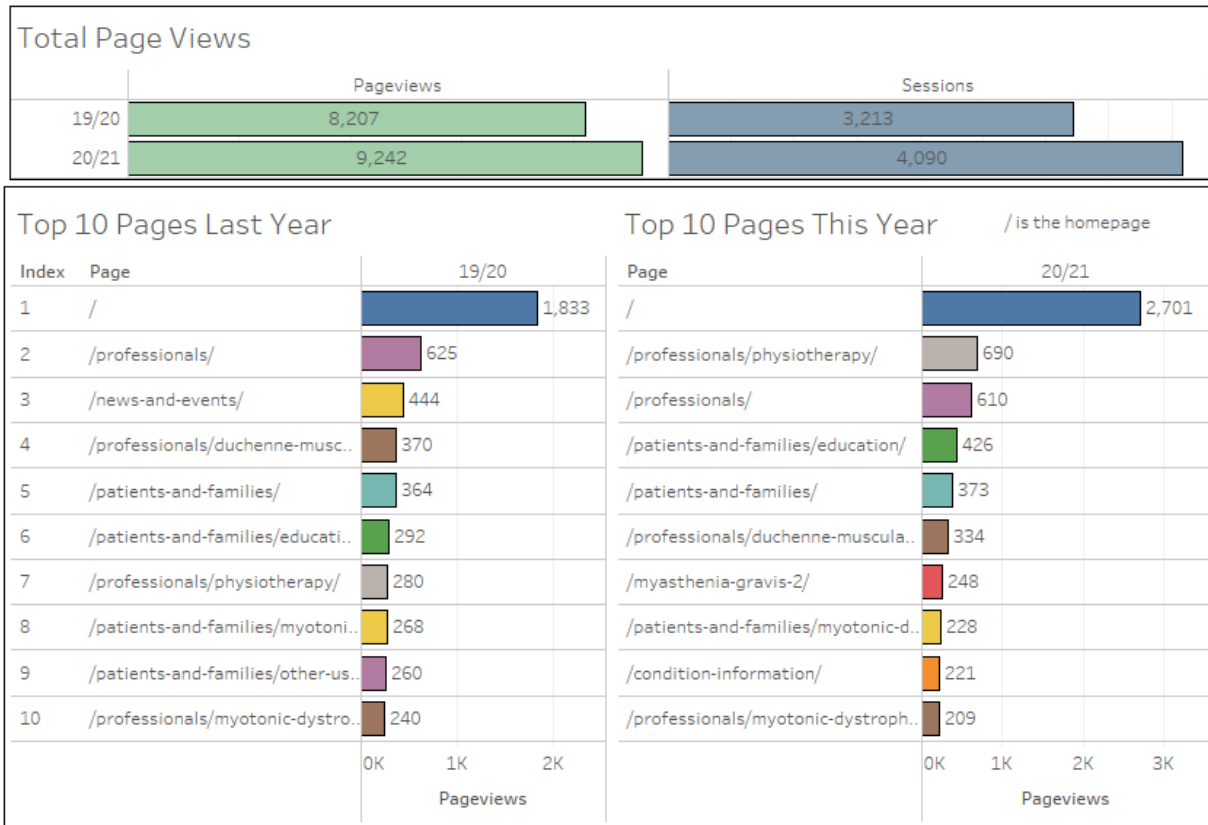


Fig 1 Website viewing increase over the year

Education- the network continues to prioritise the provision of education to stakeholders with the implementation of the education strategy, developed last year.

The annual conference was held virtually in September 2020, using MS Teams. 88 delegates attended the event with 50 (57%) returning feedback. This was the first time a major virtual event had been held by SMN and it was a great success as the charts below demonstrate.

Delegate feedback reported that over 90% rated the virtual event a success (excellent or very good) whilst the same percentage of respondents identified the event impacted on keeping them informed about neuromuscular conditions (see Figure 2 below).

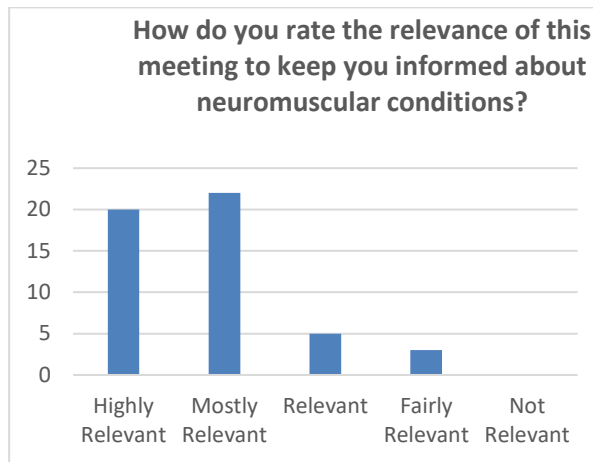
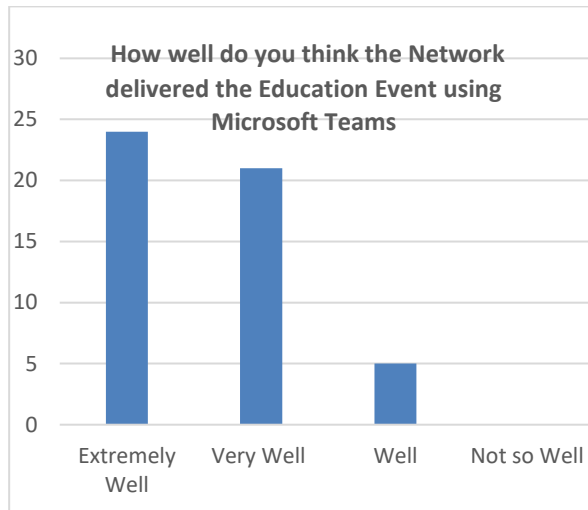


Fig 2 Evaluation Feedback from SMN Annual Conference

More importantly, when asked about impact on future clinical practice, a number of delegates responded with positive comments. Examples of actual comments include-

- *More consideration re importance of sleep with patients and what could be affecting this. Also, more aware of mechanics of sleep and how this can be improved. Becoming more aware that with treatment advancements that more complex patients will be transitioning into adult services*
- *It has given me a greater understanding of the respiratory effects of genetic muscle disease on individuals and how their respiratory needs may be met*
- *More informed to signpost and advise pt group. Increased clinical knowledge and awareness to inform deeper discussion with medical colleagues. Increased awareness of issues in adult population to inform discussion in childhood and answer questions more accurately*
- *Highlighted that the earlier the diagnosis and treatment re SMA the better the outcome. Therefore, being mindful when assessing my developmental/motor delays*
- *Better informed about current treatments in neuromuscular disease*
- *Very useful for General Paediatrician in a District General Hospital*
- *Hugely insightful thoughts re SMA and outcome measures. Food for thought for the future!*

The network also delivered a successful virtual Muscle Interest Group (MIG) meeting in September 2020 attended by 18 people. The aim of these meetings is to provide a forum for discussion of challenging neuromuscular cases, professional peer support, and dissemination of medical knowledge. This assisted clinicians throughout Scotland to ensure clinical governance surrounding the diagnosis and management of more challenging cases was in place. Feedback from 7 (39%) was favourable as demonstrated in fig 3 below

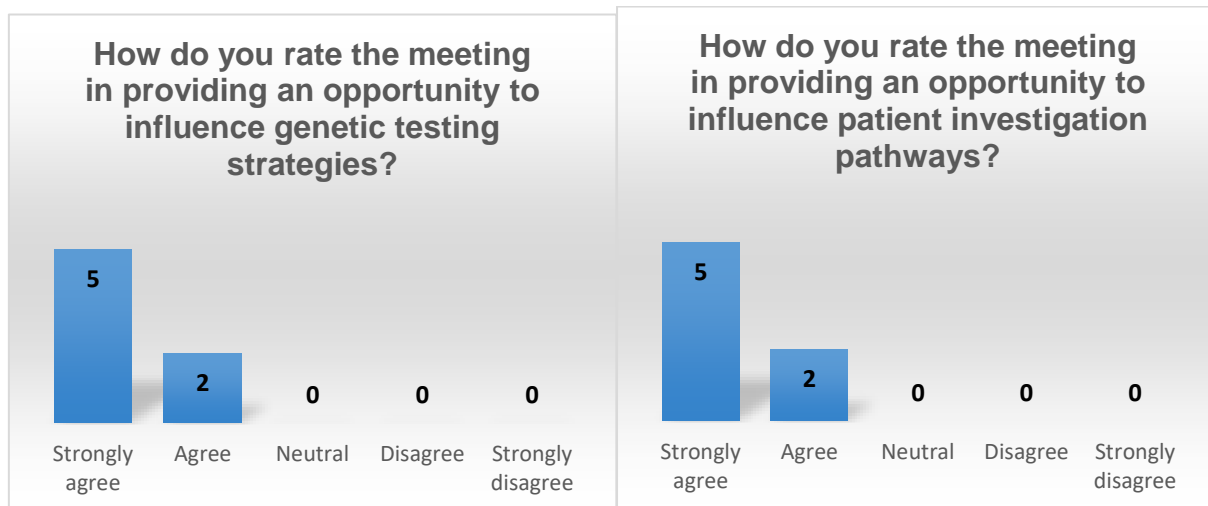


Fig 3-Feedback from MIG

Data collection and Audit-measuring performance has again been a major objective for the Network during 2020/21, although this has again been challenging. Two main conditions were previously prioritised, Duchenne Muscular Dystrophy (DMD) and Myotonic Dystrophy (DM1).

The DMD workstream had agreed to focus on auditing endocrine tests recommended by the DMD MDT Pathway, measuring performance against key indicators using CAS. A pilot exercise was started with a handful of patients in Glasgow. Despite some practical challenges of using CAS in a busy clinic and IMS developing a workaround, the network then decided to divert its focus on SMA. The main reasons were that DMD Care UK planned a national UK wide audit of DMD over the next year. The decision to choose SMA was that it was a condition where service performance that never been audited. This will be one of the priorities going forward.

Finally, CAS has continued to be populated with neuromuscular patients. Fig 4 shows the overall position to date. It is estimated that there are more than 6,000 children and adults in Scotland affected by inherited and acquired neuromuscular disorders. To date 1,050 patients (17.5%) of this figure have been registered on CAS. However, it is important to note two major limitations regarding the SMN Register on CAS:-

- patients are recorded on the CAS as part of an ongoing process to build up capacity within the network for collecting and utilising data to inform the network’s programme of work. To date, progress has been steady but incremental and as a result, there is as yet not a comprehensive register of the Scottish neuromuscular population

- not all people with neuromuscular conditions in Scotland are known to specialist services, in particular in the adult population, which in turn impacts on the completeness of the neuromuscular patient register.

CAS Patients by Condition and Patient Treatment Centre

All Treatment Centres	Ayrshire & Arran	Edinburgh - RHSC	Edinburgh - WGH	Forth Valley	Glasgow - QEUH	Glasgow - RHC
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Patient Treatment Centre

All

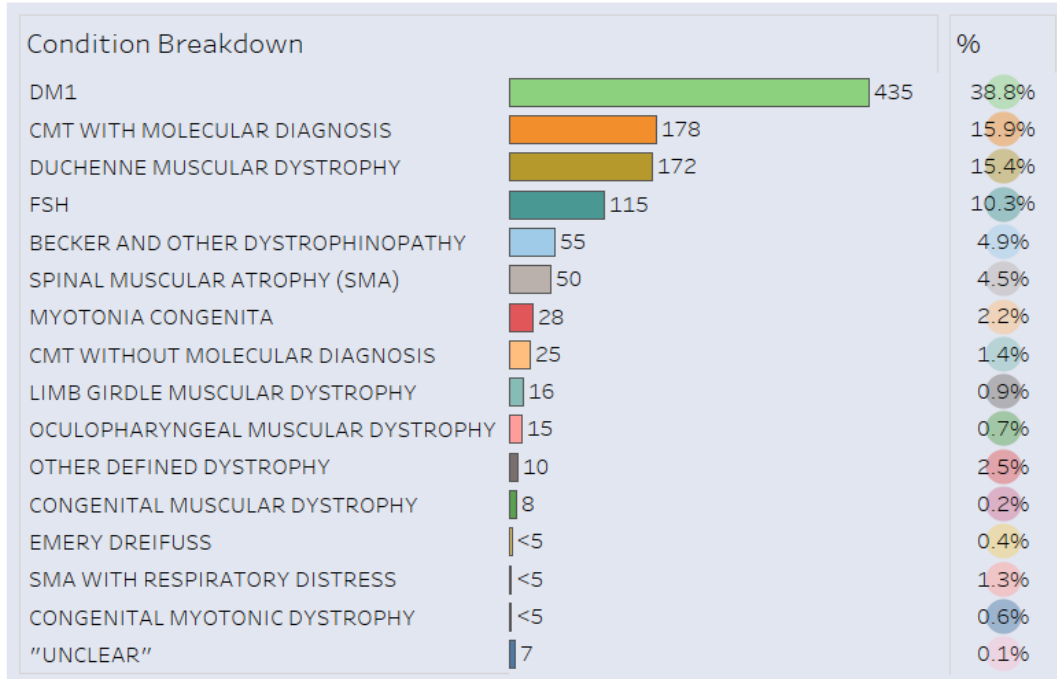


Fig 4-Neuromuscular patients on CAS –All Scotland

Exceptions

The following objectives were not delivered as, given the situation caused by the pandemic, the network was keen to minimise the burden on clinicians.

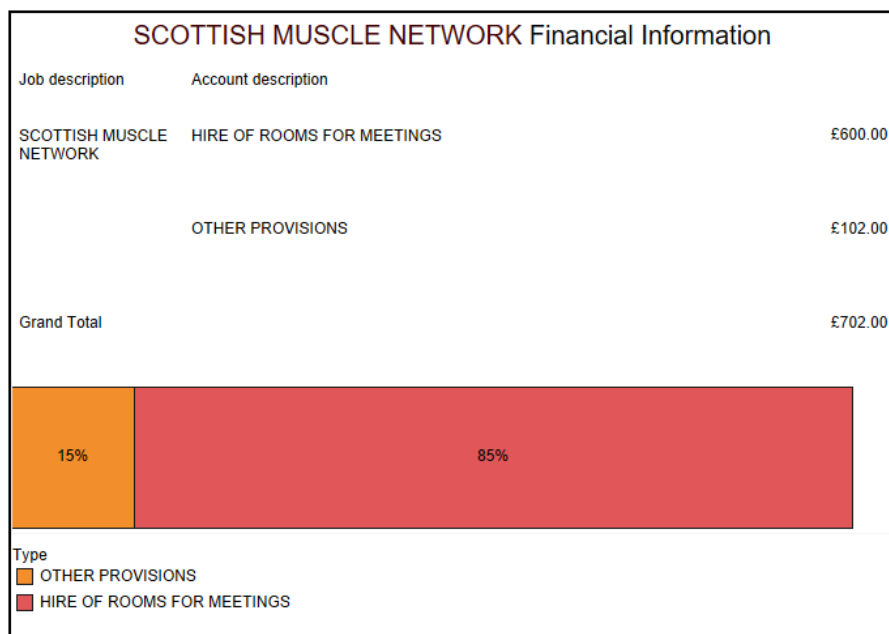
Benchmarking –the network had planned to benchmark Scottish neuromuscular services with neuromuscular services provided in South Wales, as they seemed the most relevant in the UK to compare. However, this workstream was paused to 2021/22 as the network decided that other priorities took precedent.

AHP Education Event-this was paused to minimise the burden on clinicians.

Patient/Family event: All face-to-face events were cancelled for 2020/2021.

Finance

The Network spend has been minimal in this reporting period. The costs shown relate to an event that took place in 2019/20 and reasons why it has been charged to this budget are being investigated.



Looking forward

The main work priorities for 2021/22 will be focused on implementing Year 4 of the 3-5 year strategic workplan, including:

- Reporting to the National Planning Board on potential developments required to deliver future neuromuscular services in Scotland (this will be priority).
- Continued implementation of the Education Strategy.
- Rolling out a programme of audit across Scotland against Key Performance Indicators for DM1 and SMA.
- Gathering useful feedback from the transition and long –term steroid use questionnaires and informing patients the networks plans to act on it.
- Implementing the patient/carer experience questionnaire.

Over the course of 2021/22 SMN will also work with its stakeholders to support, where possible, the remobilisation of all neuromuscular services in Scotland.

Appendix 1 – Annual Workplan

SMN Workplan April 2020- March 2021

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.

Key

Objective Number	Smart Objective	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at March 31 st 2021	Anticipated Outcome	RAGB status
1. Effective Network Structure and Governance <small>[linked to Quality Dimensions 3,4,5,6]</small>						
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	Now complete	Effective delivery of the SMN work plan to ensure continuation of progress.	B
2020-02	Organise 3 Steering Group meetings to ensure effective delivery of the 2020/21 workplan	April 2020/ March 2021	Programme Manager /Lead Clinician	First meeting /APR held on Aug 2020. Further meetings held in Dec 2020 and March 2021	Effective delivery of the SMN work plan to ensure continuation of progress.	B
2020-03	The network will meet reporting requirements: - Mid-year Report - Annual Report	31/10/20 31/05/21	Lead Clinician/ Programme Manager	MYR completed. AR planned	There are effective governance arrangements in place.	B
2. Service Development and Delivery <small>[linked to Quality Dimensions 1,2,3,4,5,6]</small>						
2020-04	Scope developments in all Neuromuscular Services in Scotland through identification of impact of new therapies on services: <ul style="list-style-type: none"> 3 workgroups established-Paed's, Adult and Diagnostic Scope Current Pos'n and SWOT Analysis 	April 2020/ March 2021	Workgroup	This major piece of was delayed due to COVID -19. However, this has now been picked up recently and is progressing through MS Teams. Plan to complete by June 2021	Development of neuromuscular services	A

Objective Number	Smart Objective	Planned start/end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at March 31 st 2021	Anticipated Outcome	RAGB status
	<ul style="list-style-type: none"> Have Brainstorming session to find out realistic horizon scanning Prioritise horizon scanning ideas Final Report to be submitted to National Planning 					
2020-05	Review SMA Pathway quarterly	April 2020/ March 2021	Steering Group	This workstream now not required as infrastructure not in place across Scotland to make it a realistic aim	Ensure SMA Pathway is relevant and current	R
2020-06	Develop and distribute questionnaire to map SMA across Scotland	April 2020/ March 2021	Steering Group	Questionnaire completed and distributed to all centres	Support Service Planning	B
2019-05	Explore benchmarking opportunities against a UK neuromuscular centre	April 2020/ March 2021	Hugh Kennedy/Laura Craig	Work delayed due to COVID - 19. Plan to pick up 21-22	Measure SMN neuromuscular services against other UK services	R
2020-07	Review existing guidelines/care pathways in line with NNMS Review Timetable: 3 will be reviewed: <ul style="list-style-type: none"> Management of DM1 in adults DMD Physio profile Generic Neuromuscular Pathway 	April 2020/ March 2021	Hugh Kennedy/Laura Craig	All completed apart from Management of DM1 in Adults which has been reviewed and near completion	Ensure all clinical information is relevant and current	A
3. Stakeholder Communication and Engagement <small>[linked to Quality Dimensions 1,3,4,5,6]</small>						
2020-08	Organise and host a joint patient engagement event with MD-UK for SMA and DMD Patients	August 2020	Marina Di Marco/Laura Craig	Delayed due to COVID-19. However, Network members have engaged with various charities such as MD UK and Action Duchene to deliver zoom virtual seminars and patient and carer question time As a result, this workstream has now been replaced by looking to focus on patients with Charcot –Marie-Tooth (CMT)disease and organise a	Facilitate provision of better support for young people and adults with DMD/SMA	R

Objective Number	Smart Objective	Planned start/end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at March 31 st 2021	Anticipated Outcome	RAGB status
				patient engagement event 2021/22		
2019-08	Revision, distribution and audit of patient experience questionnaire	April 2020/ March 2021	Hugh Kennedy/ Laura Craig	Questionnaire complete and initially distributed. Plans in place to re-distribute using QR code. The network has agreed to leave progressing this piece of work until 2021/22 to focus on the other two questionnaires	Direct input of parents/patients and family priorities into SMN objectives	A
2020-09	Update/Review 9 patient information leaflets in line with review schedule Contenance Care - Bowel Spinal Fusion Importance of Sleep Stretches & Activities Fatigue in Myasthenia Gravis Postural Management & Stretches in adult DMD (PCT leaflet) Jaw Tightness (Trismus) Wellness Journey Respiratory care in nm conditions New Leaflet Complete Care Advisor Leaflet	April 2020/ March 2021	Marina Di Marco	All up to date in line with review schedule:- All Completed	Ensure all network documents are reviewed in line with NNMS guidance	B
2020-10	Audit DMD patients on long-term steroids	April 2020/ March 2021	Marina Di Marco/Maria Farrugia	Questionnaire complete and initially distributed. Plans in place to re-distribute using QR code to get better return	Improve service to this cohort of patients	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 the past three years.	April 2020/ March 2021	Marina Di Marco/Jackie Munro	Survey ongoing through home visits but progress slower than planned due to COVID-19 with two of the three health professionals involved being re-deployed	Improve service to adult patients with a neuromuscular condition	A

Objective Number	Smart Objective	Planned start/end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at March 31 st 2021	Anticipated Outcome	RAGB status
2020-11	Review information currently on SMN website and ensure it is relevant and up to date	April 2020/ March 2021	Laura Craig	Continuously updated	Improved engagement with both patients and professionals	B
2020-12	Maintain the Service Map and other information on the website	April 2020/ March 2021	Laura Craig	Service Map completed	Improved engagement with both patients and professionals	B
2020-13	Staff newsletter to be developed distributed during the year to network members and hosted on SMN website	April 2020/ Sep 2020	Laura Craig	Delayed due to COVID-19-will be progressed 21-22	Improved engagement with professionals	A
4. Education <small>[linked to Quality Dimensions 1,2,3,4,5,6]</small>						
2020-14	Organise and host an annual education conference	Sep 2020	Laura Craig/Marina Di Marco	Successful virtual conference held in September 2020 with good feedback reported in Highlight report.	Improved knowledge in neuromuscular disorders for relevant healthcare professionals that either reinforce existing best practice or results in changes in practice	B
2020-15	Organise and host 2 bi-annual Muscle Interest Group Meetings	May and November 2020	Laura Craig/Maria Farrugia	May meeting cancelled due to COVID-19. Virtual meeting held in November. Feedback in Highlight report	Improved knowledge in neuromuscular disorders for relevant healthcare professionals that either reinforce existing best practice or results in changes in practice	A
2020-16	Organise and host AHP Education Meeting	April 2020/March 2021	Laura Craig/Marina Di Marco	Delayed due to COVID-19	Improved knowledge in neuromuscular disorders for relevant healthcare professionals that either reinforce existing best practice or results in changes in practice	R
5. Audit and Continuous Quality Improvement <small>[linked to Quality Dimensions 1,2,3,4,5,6]</small>						
2019-17	Measure against KPI's developed 2019/20 to evidence quality improvement for DMD patients	April 2020/March 2021	Kelly Maxwell-Brown/	Data was originally collected for DMD in GGC as pilot. Plans recently changed to use	Identified service improvements for patients with DMD	A

Objective Number	Smart Objective	Planned start/end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at March 31 st 2021	Anticipated Outcome	RAGB status
			Hugh Kennedy	SMA as national audit planned for 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	Database finalised on CAS. User Acceptance Testing (UAT) completed. DM1 group happy with system with a couple of tweaks, which have been put back to CAS Developers. Plan to begin using in June 2021	Identified service improvements for patients with DM1	B
2020-17	Audit Malignant Hypothermia Pathway	April 2020/March 2021	Catherine Mc William/Cheryl Longman	Near completion, delayed slightly due to effect of Covid on DM1 group priorities	Identified service improvements for patients with MH	A
2020-18	Continue to populate CAS with neuromuscular patients	April 2020/March 2021	Laura Craig	Ongoing, see graphic in main body. This will be important for Service Planning Exercise	Service improvements for neuromuscular patients	B
2020-19	Complete a Quality Improvement Strategy for SMN	April 2020/March 2021	Hugh Kennedy	Draft Completed	Quality improvements for neuromuscular patients	A

Appendix 2 – Annual Workplan

SMN Workplan April 2021- March 2022

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.

1. Effective Network Structure and Governance <small>[linked to Quality Dimensions 3,4,5,6]</small>						
2021-01	Organise 3 Steering Group meetings to ensure effective delivery of the 2020/21 workplan	April 2021/ March 2022	Lead Clinician/ Programme Manager	First meeting /APR held on Aug 2021	Effective delivery of the SMN work plan to ensure continuation of progress.	
2021-02	The network will meet reporting requirements: - Mid-year Report - Annual Report	31/10/21 31/05/22	Lead Clinician/ Programme Manager	MYR and AR planned	There are effective governance arrangements in place.	
2. Service Development and Delivery <small>[linked to Quality Dimensions 1,2,3,4,5,6]</small>						
2020-04	Scope developments in all Neuromuscular Services in Scotland through identification of impact of new therapies on services: 1. 3 workgroups established-Paedrs, Adult and Diagnostic 2. Scope Current Posn and SWOT Analysis 3. Have Brainstorming session to find out realistic horizon scanning 4. Prioritise horizon scanning ideas 5. Final Report to be submitted to National Planning	April 2021/ March 2022	Workgroup	Sections 1, 2 and 3 complete through MS Teams. Plan to complete exercise by June 2021	Development of neuromuscular services	

2020-06	Complete Service Mapping of SMA patients across Scotland, including types of SMA from feedback from questionnaire to capture their current and future medical needs	April 2021/ March 2022	Steering Group	Information gathering has begun	The questionnaire was to capture a snapshot of the current medical needs of the Scottish SMA population and also to help plan for future services.	
2019-05	Explore benchmarking opportunities against a UK neuromuscular centre	April 2021/ March 2022	Hugh Kennedy/ Laura Craig	Plan to progress	Measure SMN neuromuscular services against other UK services	
2021-03	Review existing guidelines/care pathways in line with NNMS Review Timetable: <ul style="list-style-type: none"> • Management of Mitochondrial Disorders • Myasthenia Gravis-medicines that may affect patients • Management of skeletal health in boys with DMD • Secondary adrenal insufficiency and long term steroid use in DMD 	April 2021/ March 2022	Hugh Kennedy/ Laura Craig		Ensure all clinical information is relevant and current	
3. Stakeholder Communication and Engagement <small>[linked to Quality Dimensions 1,3,4,5,6]</small>						
2021-04	Organise and host a joint patient engagement event for CMT patients	April 2021/ March 2022	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 2021/ March 2022	Hugh Kennedy/ Laura Craig	Questionnaire complete and initially distributed. Plans in place to re-distribute using QR code in January 2022 as network feels other two questionnaires are priority	Direct input of parents/patients and family priorities into SMN objectives	
2021-05	Update/Review of patient information leaflets in line with review schedule: 11 leaflets on Myasthenia Gravis	April 2021/ March 2022	Marina Di Marco/DM 1 sub group		Ensure all network documents are reviewed in line with NNMS guidance	

	<p>Plus-information for GP's:-</p> <ul style="list-style-type: none"> • "At a glance" - DM1 • "At a glance" - Becker Muscular Dystrophy • "At a glance" - DMD • "At a glance" - FSHD • "At a glance" - LGMD • "At a glance" - Mitochondrial disease • "At a glance" - CMT • "At a glance" - LGMD type 1B 					
2020-10	Audit DMD patients on long-term steroids	April 2021/ March 2022	Marina Di Marco/Maria Farrugia	Questionnaire complete and initially distributed. Plans in place to continue survey using QR code	Improve service to this cohort of patients	
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 the past three years.	April 2021/ March 2022	Marina Di Marco/Jackie Munro	Ongoing –Plan is to have roughly 20 patients feedback docs to complete	Improve service to adult patients with a neuromuscular condition	
2021-06	<p>Review information currently on SMN website and ensure it is relevant and up to date. Plan for :</p> <ul style="list-style-type: none"> • Synopsis of what SMN intend to do with feedback from various strands of questionnaires that have been distributed 'You said, We did' • Maintain Service Map 	April 2021/ March 2022	Laura Craig	Continuously updated	Improved engagement with both patients and professionals	
2020-13	Staff newsletter to be developed distributed during the year to network members and hosted on SMN website	April 2021/ Sep 2022	Laura Craig	New format will be progressed 21-22	Improved engagement with professionals	

4. Education [linked to Quality Dimensions 1,2,3,4,5,6]

2021-08	Organise and host an annual education conference	Sep 2021	Laura Craig/Marina Di Marco	Event planned for September 2021	Improved knowledge in neuromuscular disorders for relevant healthcare professionals that either reinforce existing best practice or results in changes in practice	
2021-09	Organise and host 2 bi-annual Muscle Interest Group Meetings		Laura Craig/Maria Farrugia		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]

2021-10	Measure against KPI's developed to evidence quality improvement for SMA patients	April 2021/March 2022	Kelly Maxwell-Brown/Hugh Kennedy	Plans to explore what can be measured from SMA patients against best practice and use CAS Core Dataset page to measure	Identified service improvements for patients with DMD	
2021-11	Populate DM1 database and use to complete biannual audit against standards	April 2021/March 2022	Kelly Maxwell-Brown/DM1 sub group	UAT complete. Plan to begin populating June 1 st 2021	Identified service improvements for patients with DM1	
2020-17	Audit Malignant Hypothermia Pathway	April 202/March 2022	Catherine McWilliam/Cheryl Longman	Will be completed at start of year	Identified service improvements for patients with MH	
2021-12	Continue to populate CAS with neuromuscular patients	April 2021/March 2022	Laura Craig	Ongoing	Service improvements for neuromuscular patients	
2020-19	Complete a Quality Improvement Strategy for SMN	April 2021/March 2022	Hugh Kennedy	Ongoing	Quality improvements for neuromuscular patients	

