Scottish Muscle Network (SMN)
ANNUAL REPORT 2021/22

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Background

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

The Network has demonstrated good progress against the 2021/22 workplan to either deliver or progress most of its objectives. This was despite the continuing challenges resulting from the COVID-19 pandemic.

Progress against the workplan is detailed in Appendix 1.

Lead Clinician Reflection

The 2021-22 SMN Annual report reflects back on what is Year 4 of the Workplan that was developed following the independent review of the Scottish Muscle Network in 2018. This year has been one in which we have continued to see the consequences of the COVID-19 pandemic on our patients and changing challenges in delivery of their care.

A key objective for this time period has been the Service Planning Review that began early in 2020 and after stalling due to COVID redeployment we were able to gather data from across Scotland to illustrate the current provision of care to our patients with neuromuscular disease. The scope of this review has been broad and has attempted to capture activity as it is delivered in each locality, identifying good practice and aspects of patient care that could be improved. We have gathered information from all aspects of the patient journey, from diagnostics (pathology, radiology, genetics) to how ongoing care is delivered by orthotics, occupational therapists, dietetics, physiotherapists, nursing/care advisory staff and the various medical specialities, in particular Neurology. A document outlining the findings has been compiled and is currently under review within NSD with the aim of being used to inform Service Planning at a National Level. Outcome from this is likely to be discussed more fully in Year 5 of the Workplan.

A major piece of work for the DM1 subgroup has been the finalising of the DM1 database which has been in development for 2 years with colleagues from IMS and CAS. This replaces unsupported stand-alone databases in each centre and aims to improve delivery of our Care Standards and audit. There have been delays and teething problems, but these have now been addressed and as we move into the next audit cycle, data collection should be much easier to implement. Lessons from this have informed another CAS based project regarding patients with SMA and their treatment outcomes that we will be moving forward with in 2022-23.

There has been continued success with provision of educational opportunities, from events which were well received by our AHP's regarding Genetics to our Annual Conference and the Muscle Interest Group meeting. The website has had updates with recently reviewed leaflets for patients and professionals and there is evidence of increased visits to the website. Maintenance is ongoing and further changes are planned in the next year to keep it 'fresh'.

We have had the opportunity to collaborate with the 3rd sector regarding gaps in service highlighted in the MDUK 'Shining A Light' report in January 2022. This report reviewed the impact of COVID-19 and the future of care for people with a muscle-wasting condition in Scotland and has been shared widely. Concerns regarding how support for our patients around their mental health have been raised and this, along with project work around Anticipatory Care Planning, is likely to be an area for further work for the SMN in Year 5 of the Workplan.

Highlights

Effective Network Structure and Governance

Throughout 2021-22 all commissioning activities were progressed as business as usual; an Annual Performance Review (APR) took place and minutes were approved by the Steering Group (SG). SG membership and attendance at meetings was monitored throughout the year. The network continues to host the three subgroups on the same day as the steering group meetings and this works well with good attendance throughout the day and a contemporary feel to steering group discussions in the afternoon.

Service Development and Delivery

Service Planning: The network has now completed all the scoping work for the horizon scanning exercise exploring what is needed for neuromuscular services in the future. This has involved several meetings with various clinicians, gathering information and data on what resources (staffing, expertise, service model) they feel will be needed to deliver neuromuscular services in the next 5-10 years. This information has been captured in a report and has been submitted to NSD Commissioners.

Guidelines/Protocols/Pathways: During 2021/22, the Network continued to develop and review guidelines and care pathways in accordance with NNMS guidance. As such, two guidelines have been reviewed and updated, whilst another two are in the final stages awaiting final endorsement. These are all available on the SMN website http://www.smn.scot.nhs.uk

Benchmarking: One of the recommendations of the 2017/18 network review was to explore the use of benchmarking with UK services to measure performance of neuromuscular services in Scotland in the absence of recognised national UK guidelines for neuromuscular conditions. The network has previously been unsuccessful in progressing this due to difficulties in engaging with other UK neuromuscular services, however, a decision to focus on one condition, Myotonic Dystrophy, has enabled the network to re-focus and develop a revised plan which it will take forward.

Newborn Screening (NBS) for Spinal Muscular Atrophy: work is ongoing around assessing the possibility of a pilot to include SMA in National Newborn Screening in Scotland. A project is in planning, with grant application planned in the year 22/23, depending on review by the National Screening Oversight Research and Innovation Group within National Services Scotland.

Stakeholder Communication and Engagement

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. It also now includes different motivational quotes each week.

Patient Engagement: A questionnaire was sent to patients with DMD who have been on long-term steroids to find out if they understood the implications of long-term steroid use and the requirements of having appropriate investigations. Increased risks include infections (due their immunosuppressant effect), fractures (as bone health and growth can be affected) and possibly adrenal crisis (due to adrenal glands being 'switched off'). Data was gathered by Dr Gavin Langlands, a registrar who works with Dr Farrugia, and use in hospital of additional steroid treatment, in the context of illness was audited and discussed with the group. This information will inform patient information leaflets going forward. We expect that this audit will be repeated at a future date once adequate time has lapsed.

Education

Annual Conference: The annual conference was held virtually in September 2021, using MS Teams. 74 delegates attended the event with 35 (48%) returning feedback. This was a second time a major virtual event had been held by SMN and, like last year, was once again a success as the charts below demonstrate.

Delegate feedback reported that over 90% of respondants identified the event impacted on keeping them informed about neuromuscular conditions, whilst the same percentage felt it was effective on meeting their CPD purposes (see Figure 1 below).

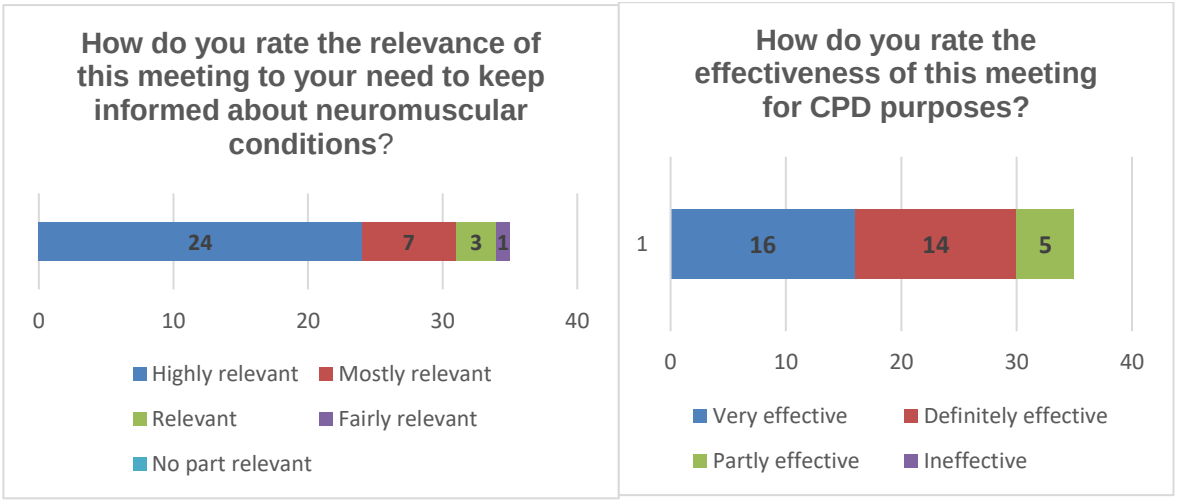


Figure 1- Annual Education Event Evaluation Results

Comments from delegates on impact on future practice included: -

- Better understanding of current developments in gene therapy and greater awareness and benefit from neuropsychology input for clients
- Increased my overall knowledge and lots of food for thought regarding efforts to get psych services improved and when discussing current and future SMA treatments

- Insight into other areas and transition planning. Many MCNs are all looking into creating transition pathways and standards and I do wonder if there is a need to try to create a national pathway with key elements for all areas of practice so that all practitioners are aware of the key areas for consideration in transition no matter the condition.
- Enhancing awareness in areas of drug treatments and update on care standards particularly of interest to own practice.

Muscle Interest Group Meeting: following the success of last year's events, the network held a virtual "Muscle Interest Group" (MIG) meeting on 5th May 2021. 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 meeting was attended by 27 delegates, evaluation response rate was 48% with 100% rating the education provided effective for their CPD purposes and 75% rating it important for their clinical practice going forward.

Again, useful comments from delegates regarding impact on future practice included**: -**

- New information about neuromuscular conditions, different aspects of management
- Discussion of difficult cases with expert colleagues
- This will change my practice in investigation of specific presentations of possible muscle disease
- Excellent presentations to re-orientate thinking in the field post maternity leave
- Being able to present unfinished cases for help

AHP Education Event: Dr Helen Gregory and Dr Elaine Fletcher delivered a successful education session on genetics for AHPs. Further sessions were to be explored with AHPs. This was recorded and placed on the SMN website. 29 delegates attended, with 16 returning evaluations, with 100% finding the session relevant to their education needs.

Comments included:

- It was good to get a refresher of the basic principles of genetics and it was presented in a way that was easy to understand and in a fun way
- Deeper understanding of genetics, which will be very helpful in my clinical practice.
- Some revision and new material which improves my understanding of the various issues surrounding the families we work with and the implications for them, their affected child, and their siblings. Helped give me the level of understanding I need for in my limited capacity as a visiting professional.
- Good to feel that I have a basic understanding of genetics to help when reading research and articles around children with specific genetic conditions. Also, as this field becomes increasingly at the front of diagnosis, it is important for physios working with children with a range of conditions to be aware of the basics.

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 so that it is ready for use. After a few false starts due to various faults identified and additional developments required, 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.

Myotonic Dystrophy Audit: 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 Management of Adults with Myotonic Dystrophy Care Standards (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 subgroup, most recently in January 2022. The subgroup performs a biannual audit, the most recent one covering August 2020-August 2021, using data captured from the four databases. Results of the audit are shown on Appendix 3, (figures 3a - 3h). Highlights of this audit which was undertaken during the pandemic include: -

- The number of patients referred to a Specialist Management Clinic with a molecular confirmation of diagnosis remains above target (Graphic 3a).
- Within the audit period, the % of patients receiving their annual review within 12 months falls well below standard of 90% in all regions (avg 55%) although differences between how reviews were conducted e.g., face- to- face / telephone / virtual appointment may explain the variation across centres.
- The % of patients receiving their reviews at 18 months, 24 month and 36 months mainly meets the 90% standard apart from East and North which did not meet the 18 months' standard. However, the trend over the past 8 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 (Graphic 3c).
- Clinical testing and monitoring in the following categories which can be assessed by telephone / virtual appointment have met recommended standards across all four regions:
  a) Molecular diagnosis when seen at a Specialist Management Clinic (Graphic 3a).
  b) Respiratory (Epworth Sleepiness Score) (Graphic 3d and 3e).
  c) Pedigree Reviewed and updated (Graphic 3g).
  d) Anaesthetic /sedation risk awareness of patients attending specialist management clinic (Graphic 3g).
  e) Patients attending clinic can produce an alert device (Graphic 3f)
  f) Care is documented and managed via electronic record with embedded clinical guidelines (Graphic 3h).

  However, the following categories have not met standards, particularly in Glasgow: -
  a) Cardiology (ECG) (Graphic 3d and 3e).
  b) Random Blood Glucose and Thyroid (Graphic 3d and 3e).

  This likely represents the difficulties that were experienced due to the pandemic in other services. Patients who in the past would have been seen Face2Face and had ECG and bloods done at that appointment may have had a telephone or virtual appointment in and subsequent appointments made for ECG and bloods at other locations under challenging circumstances.

- Appropriate support and Information provided to patients has met standards across all four regions (Graphic 3g), this is easily given over the phone or by virtual appointment.

Annual Audit: CAS has continued to be populated with neuromuscular patients. Appendix 4 shows the overall position to date by condition with some additional useful analysis in other

graphics. To date 1,314 patients have been recorded on the system, an additional 289 from last year.

Graphics 4b and 4c showing boards numbers by HoP (HoP is based on Standardised Age-Specific prevalence rates.) is much better than actual figures as it highlights variances that need further investigation. e.g. Lothian adult numbers are low.
Graphics 4d and 4e highlights age ranges by both region and condition which will be useful to inform transition planning within the network

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. This data could also be used later to benchmark against the standards of care that the SMAReach project will be developing going forward. This has been sent to CAS Developers

Exceptions

A few workstreams have been slow to progress because of the pandemic, e.g., Service Planning Exercise, Benchmarking, DM1 Database, SMA Audit, CMT Patient Engagement Event and Transition Survey. However, these have now all progressed later in the year, none now remain stalled.

Looking forward

The 2022/23 Network objectives are outlined in the workplan in Appendix 2.

Priorities for the network in the coming year include:

- Developing neuromuscular services in line with the outcome of the Service Planning document
- Populating 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.
- Completion of Transition Survey to develop transition experiences for neuromuscular patients Experience.
- Continuing to gather evidence to submit an application for SMA Newborn Screening.
- Developing a Quality Improvement Strategy to support the Networks approach to service improvement.

Finance

Due to the restrictions in place and the continued use of virtual meetings, costs normally associated with face-to-face meetings and education events have not been incurred this year. The network has not spent in any other area.

Appendix 1. Detailed Description of Progress in 2021/22

Core Principle	Description of Work/Activity	End of Year Update	Start Date	End Date	Q4 RAG Status
Effective Network Structure and Governance	Core Team meets regularly	Core Team met fortnightly during 2021/22 apart from the few months at the start of 2022 due to covid restrictions.	01/04/21	31/03/22	**C**
	Hold 3 Steering Group Meetings	Steering Group Meetings held on Aug, Nov, and March 2022	01/04/21	31/03/22	**C**
	Subgroups meet regularly	Paeds, Adults, Education and Audit, Myotonic Dystrophy and DATIG Subgroups have taken place regularly during 2021/22.	01/04/21	31/03/22	**C**
	Annual Report	Submitted 31/05/21.	01/04/21	31/05/21	**C**
	Mid-Year Report	Mid-Year Report submitted on 31st October 21	01/09/21	31/10/21	**C**
	Quarterly monitoring of finance spreadsheet	No finance data provided. Network holds local record for budget spend.	01/04/21	31/03/22	**N/A**
	Purchase Orders received at the end of each quarter	No finance data provided. Network holds local record for budget spend.	01/04/21	31/03/22	**N/A**
	2022/23 Workplan Objectives	Objectives drafted for discussion at March 2022 SG Meeting	01/04/21	31/03/22	**C**
	Service Planning Exercise to be completed	Report completed and submitted December 2021	01/04/21	31/03/22	**C**
	Review and update the following guidelines and care pathways: Management of DM1 in Adults Guideline Management of Mitochondrial Disorders	 Guideline updated and endorsed Jan 2022. Now on SMN website. Guideline updated and endorsed March 2022. Now on SMN website	01/04/21	31/03/22	**C**
	Review and update the following guidelines and care pathways: Malignant Hypothermia Pathway	All in draft, will be carried forward to 2022/23 workplan.	01/04/21	31/03/22	**A**

Service Development and Delivery	Myasthenia Gravis - medicines that may affect patient's guideline				
	Develop a Quality Improvement Strategy	Quality Improvement Strategy scheduled to be developed following development of SMA KPI's	03/11/21	31/3/22	**C**
Stakeholder Communication and Engagement	Development of website	Website updated on an ongoing basis.	01/04/21	31/03/22	**C**
	Review And Update of following Information Leaflets: Vertebral Fractures Ankle Management in DMD Patient Admission Information Leaflet	All completed	01/04/21	31/03/22	**C**
	Review And Update of following Information Leaflets: 11 Myasthenia Gravis Patient Information Leaflets	All in draft stage. Will be carried forward to 2022/23 workplan.	01/04/21	31/03/22	**A**
	Patient /Family Engagement	CMT Engagement Event in planning stage, delayed due to covid 19 Development of patient focus group progressing	01/09/21	31/03/22	**A**
	Patient Experience Surveys	Patients on Long Term Steroids- feedback analysed. Transition -progress in collecting information has been slow due to impact of covid on staff. Will be carried forward to 2022/23 workplan.	01/04/21	31/03/22	**A**
Education	Host Annual Educational Event	Education Event held on 18th September 2021. Evaluation shown in main body of report	01/04/21	30/09/21	**C**
	Organise and host two Muscle Interest Group Meetings	One held May 2021, the other cancelled due to Covid pressures	01/04/21	31/03/22	**A**
	Organise and host AHP Event	Genetics Education event held and was a success	01/04/21	31/03/22	**C**

Audit and Continuous Quality Improvement	Continue to populate CAS with neuromuscular patients	Additional 289 patients added 2021/22	01/04/21	31/03/22	**C**
	Continue to liaise CAS Developers to complete DM1 Database on CAS	Now live with all changes successful	01/04/21	31/03/22	**C**
	Agree dataset for SMA and forward to CAS Developers	Dataset agreed with both SMN and IMS. Sent to CAS Developers	01/04/21	31/03/22	**C**
	Complete Biannual DM1 Audit, covering period Aug 2020-Aug 2021	Audit completed	01/04/21	31/03/22	**C**

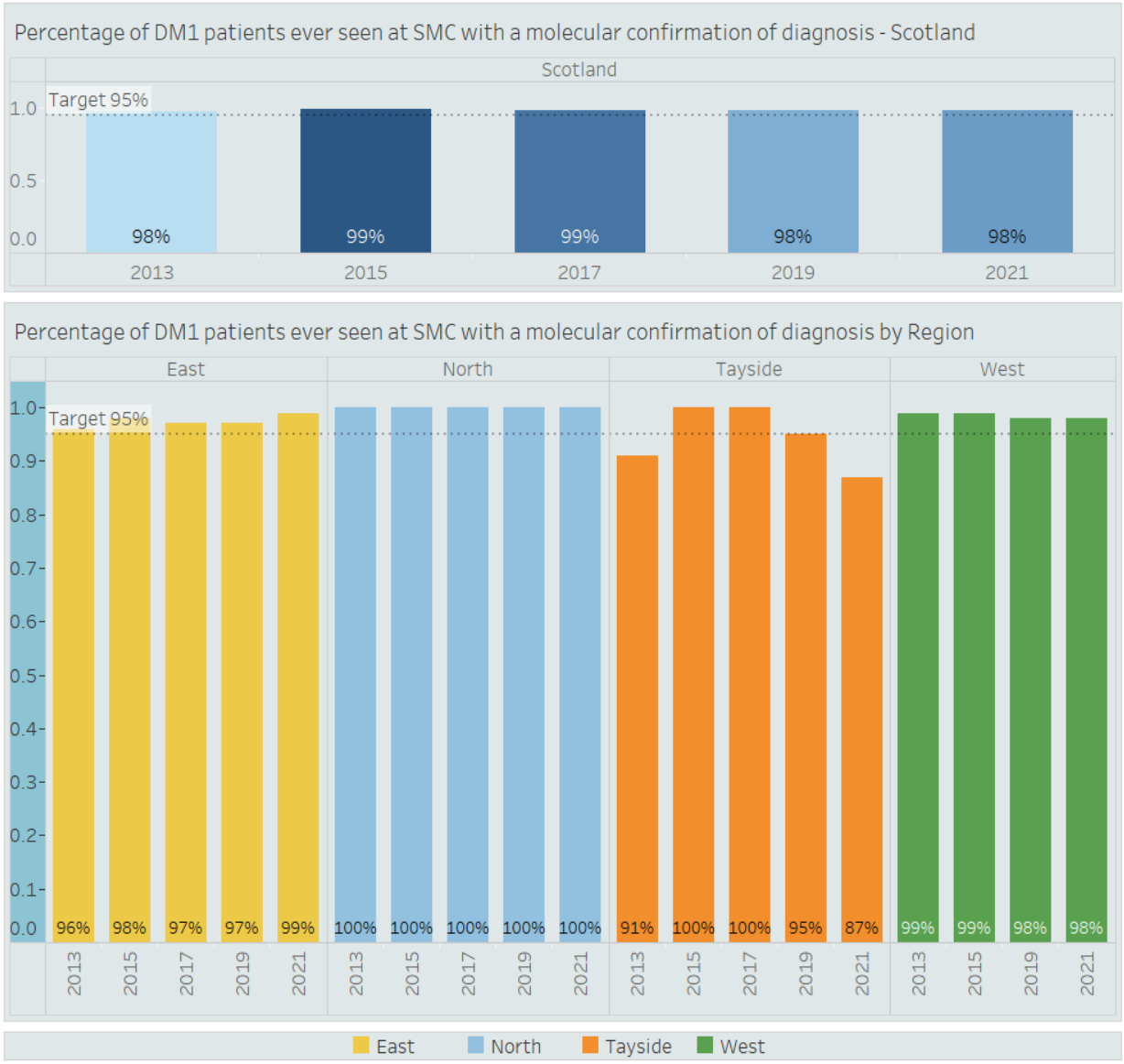
Appendix 2- Proposed Work Plan for 2022/23

Core Principle	Activity	Start Date	End Date
Network Structure and Governance	Core Team Meets Regularly	01/04/2022	31/03/2023
	Hold 3 Steering Group Meetings	01/04/2022	31/03/2023
	Subgroups meet regularly to drive forward workplan	01/04/2022	31/03/2023
	Ensure governance in place for Guidelines/Pathways	01/04/2022	31/03/2023
	Ensure all finance requirements are met	01/04/2022	31/03/2023
	Submit Annual Report	01/04/2022	31/05/2022
	Submit Mid-Year Report	01/10/2022	31/10/2022
	Develop 2023/24 Workplan	01/01/2023	31/03/2023
	Develop 3 -5 Year Strategic Workplan	01/02/2023	31/03/2023
Service Development and Delivery	Influence the development of neuromuscular services using the findings of the Service Planning Exercise	01/04/2022	31/03/2023
	Develop/review the following Guidelines and Care Pathways in line with NSS policy: - <u>Carried Forward from 2021/22 workplan:</u> Malignant Hypothermia Pathway Myasthenia Gravis -medicines that may affect patient's guideline <u>Due in 2022/23:</u> Anaesthetic Guideline Summary Anaesthetic Guideline for DM1 DMD -MDT Care Pathway	01/04/2022	31/03/2023
	Pilot NBS for SMA in Scotland	01/04/2022	31/03/2023
	Develop Networks Quality Improvement Strategy	01/04/2022	31/03/2023
Stakeholder Engagement and Communication	Continue to capture information to improve Transition experience for patients	01/04/2022	31/03/2023
	Continue to update and develop the website to ensure that it is a useful resource for patients/HCPs	01/04/2022	31/03/2023

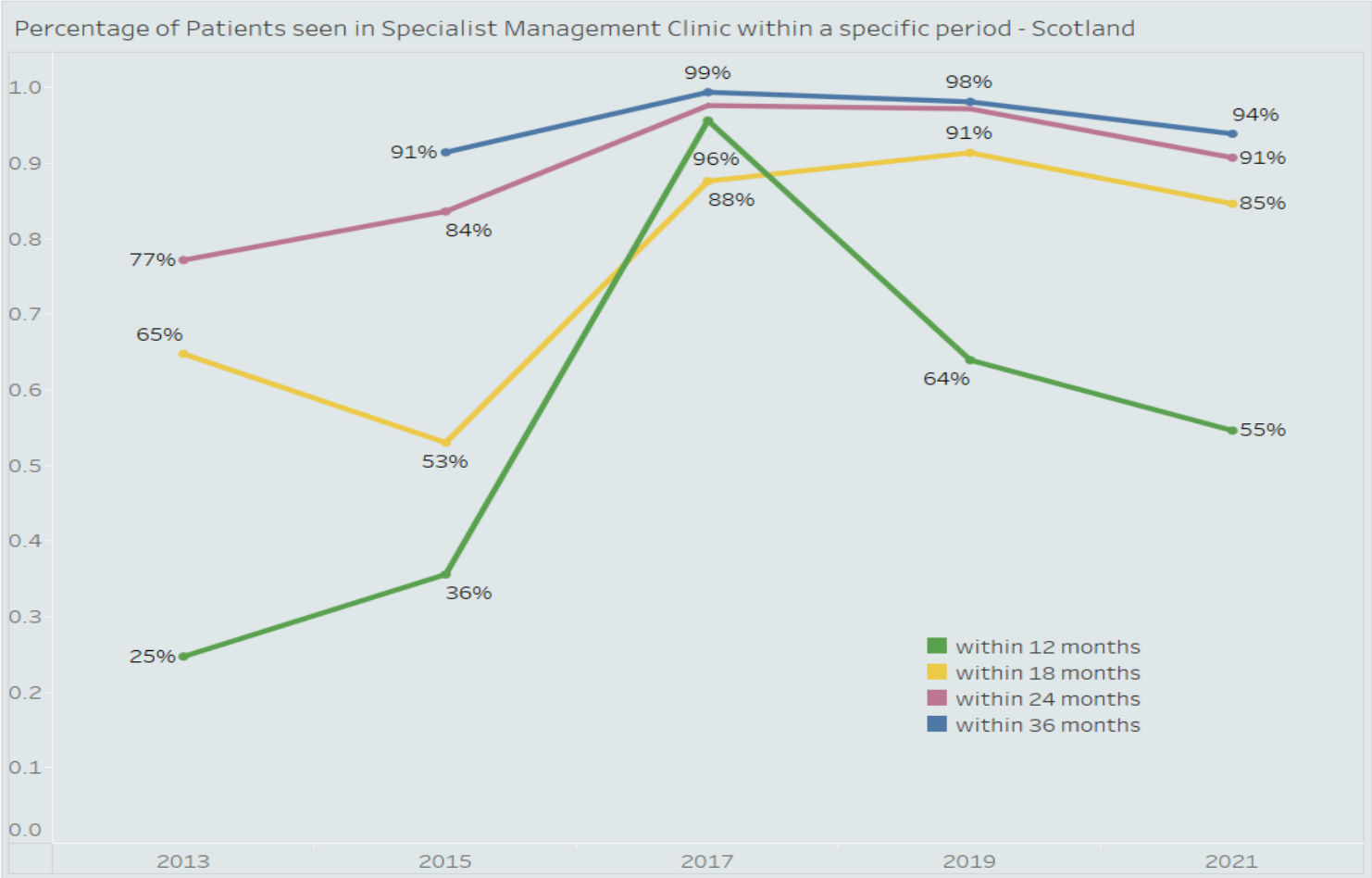
	Review and update the following Patient Information Leaflets based on review schedule: <u>Carried Forward from 2021/22 workplan</u>: 11 Myasthenia Gravis leaflets <u>Due in 2022/23:</u> Bladder function and Continence Care Continence Care-Bladder Issues Postural management Non -NHS Registries for muscle conditions Modafinil - considering a trial Modafinil - starting a trial Pain Management	01/04/2022	31/03/2023
	Issue at least 2 Newsletters	01/04/2022	31/03/2023
Education	Host Annual Educational Event for HCPs	01/04/2022	30/09/2022
	Host Two MIG Meetings	01/04/2022	31/03/2023
	Host Educational Event for AHP's	01/04/2022	31/03/2023
Audit and Continuous Quality Improvement	Produce quarterly audit reports by health board, treatment centre and condition using CAS	01/04/2022	31/03/2023
	Populate the DM1 database	01/04/2022	31/03/2023
	Populate the SMA Core Dataset page on CAS to capture useful information on these patients	01/04/2022	31/03/2023

Appendix 3 – Myotonic Dystrophy Biannual Audit Results

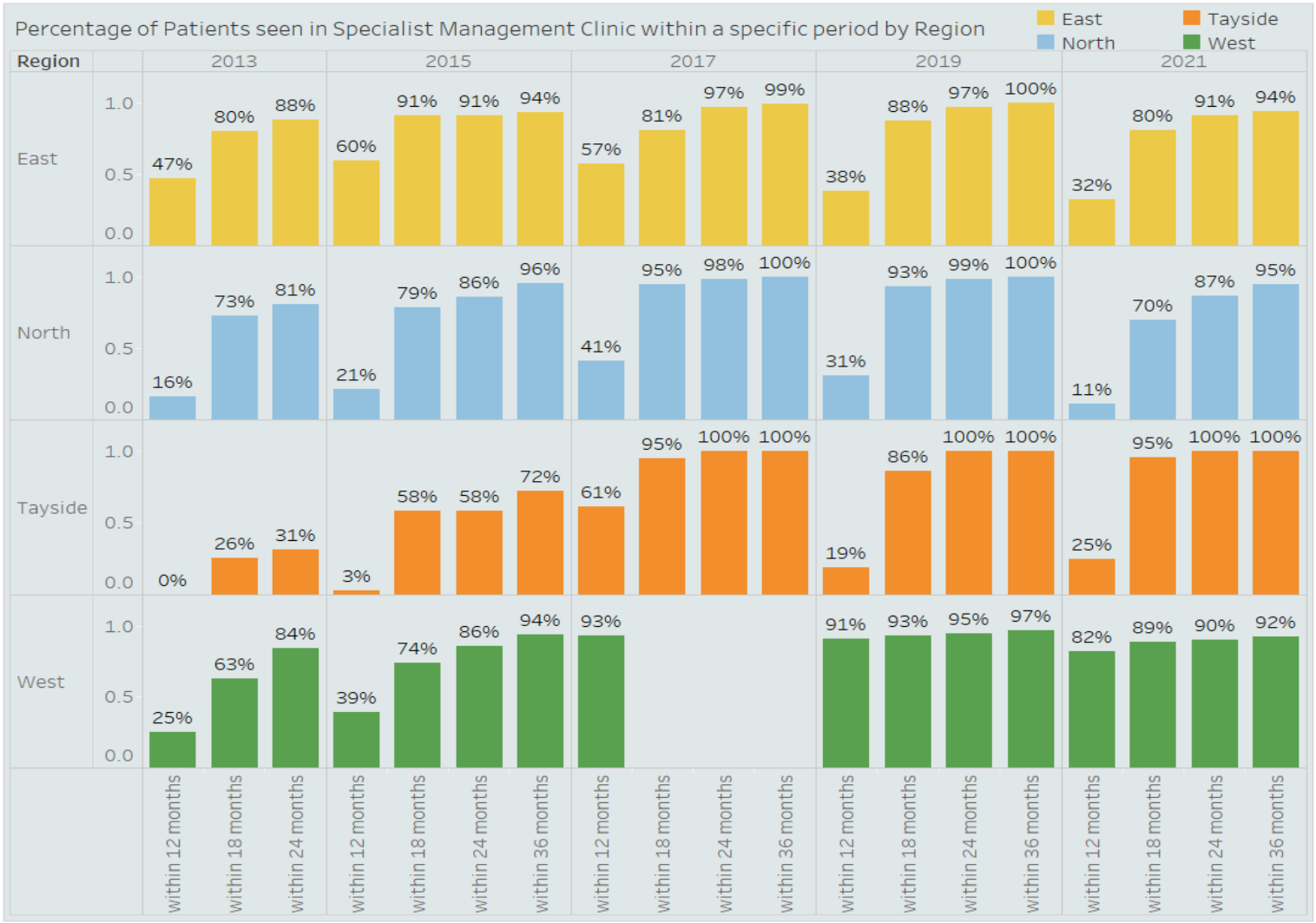
Aug 2020-Aug 2021



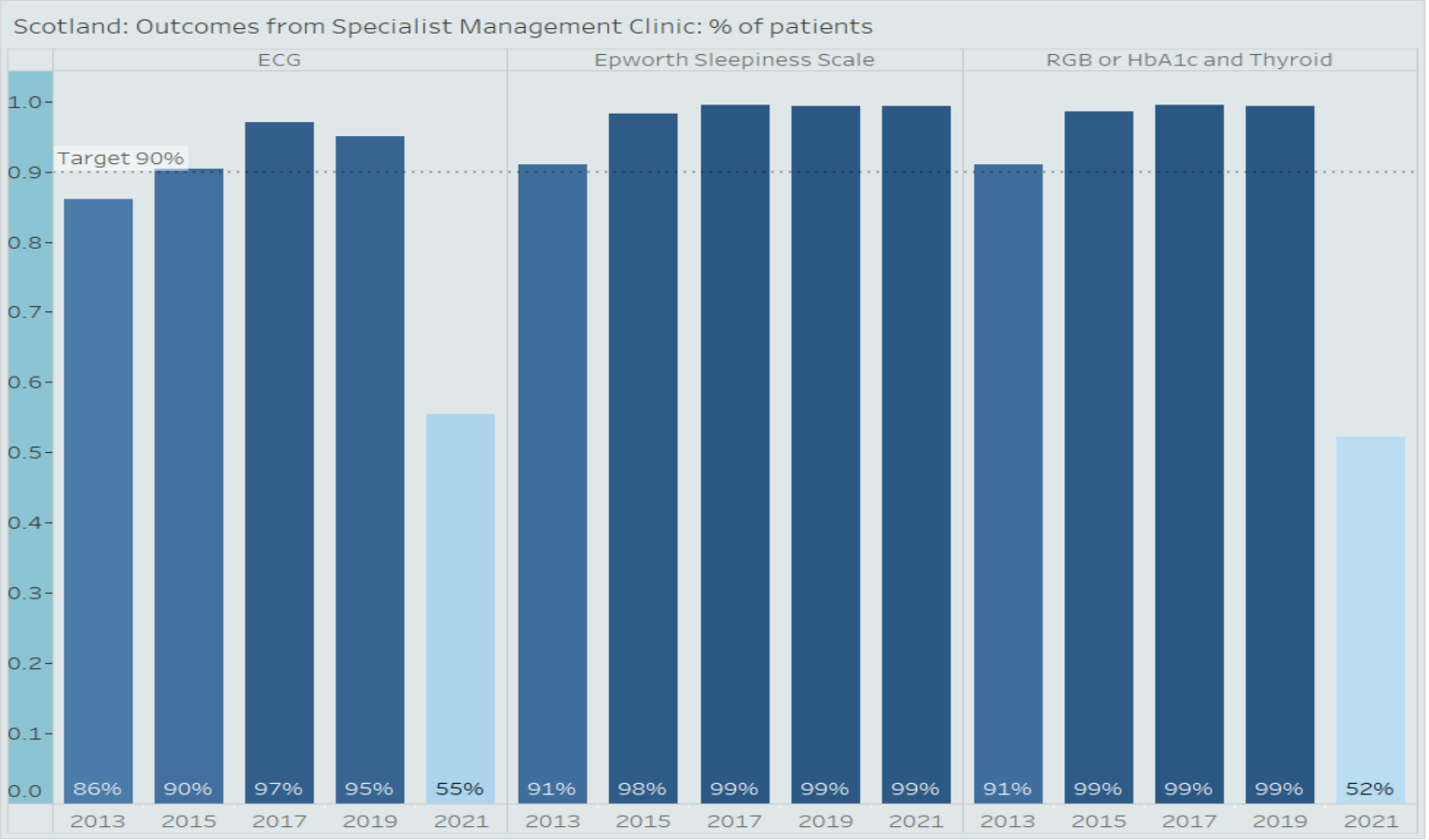
Graphic 3a


Percentage of Patients seen in Specialist Management Clinic within a specific period - Scotland
1.0
0.9
0.8
0.7
0.6
0.5
0.4
0.3
0.2
0.1
0.0
2013
2015
2017
2019
2021
99%
98%
94%
91%
91%
96%
91%
88%
85%
84%
77%
65%
53%
64%
55%
36%
25%
within 12 months
within 18 months
within 24 months
within 36 months

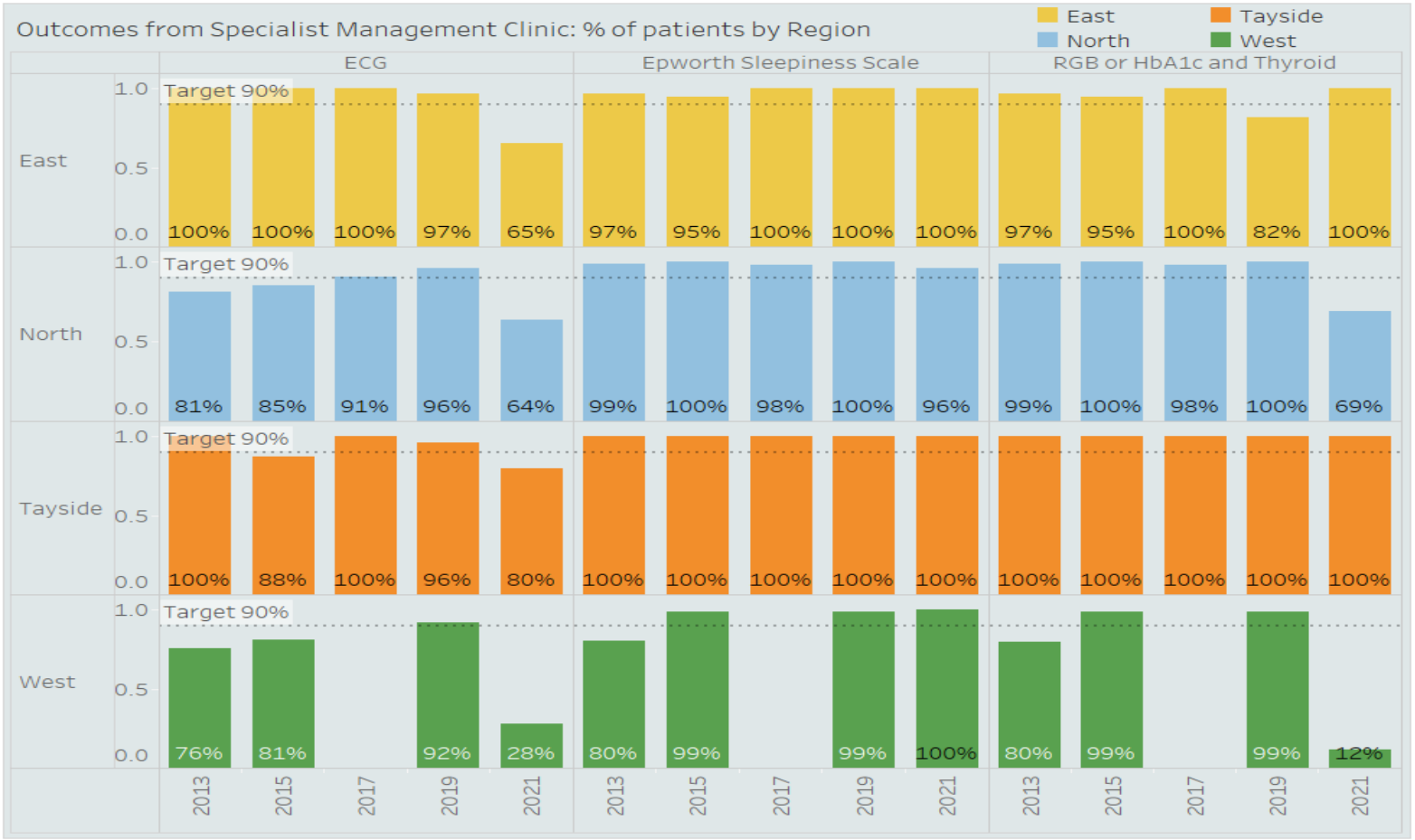
Graphic 3b


Percentage of Patients seen in Specialist Management Clinic within a specific period by Region
East
North
Tayside
West
Region
2013
2015
2017
2019
2021
East
1.0
0.5
0.0
47% 80% 88%
60% 91% 91% 94%
57% 81% 97% 99%
38% 88% 97% 100%
32% 80% 91% 94%
North
16% 73% 81%
21% 79% 86% 96%
41% 95% 98% 100%
31% 93% 99% 100%
11% 70% 87% 95%
Tayside
0% 26% 31%
3% 58% 58% 72%
61% 95% 100% 100%
19% 86% 100% 100%
25% 95% 100% 100%
West
25% 63% 84%
39% 74% 86% 94%
93%
91% 93% 95% 97%
82% 89% 90% 92%
within 12 months
within 18 months
within 24 months
within 36 months

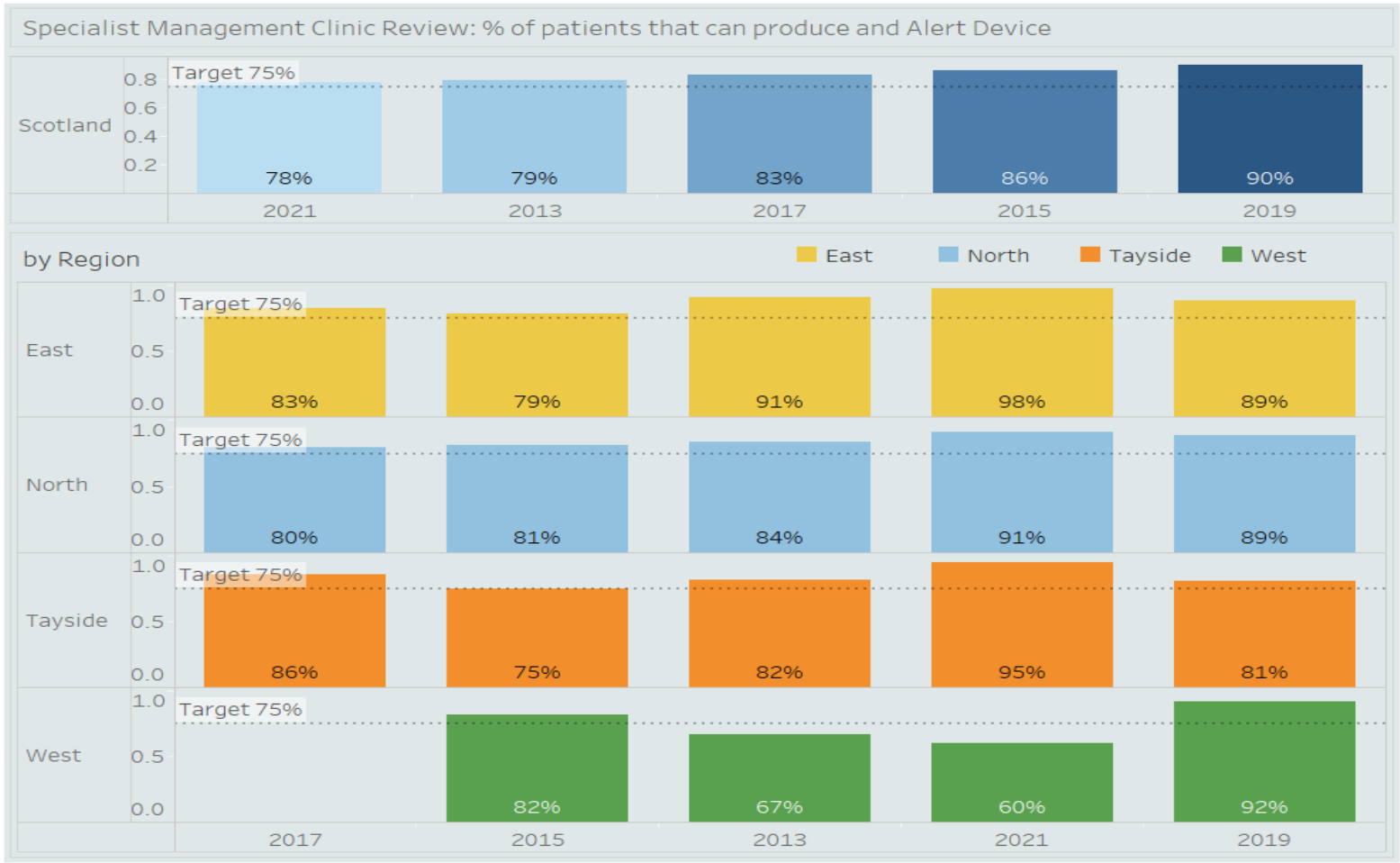
Graphic 3c


Scotland: Outcomes from Specialist Management Clinic: % of patients
ECG
Epworth Sleepiness Scale
RGB or HbA1c and Thyroid
Target 90%
1.0
0.9
0.8
0.7
0.6
0.5
0.4
0.3
0.2
0.1
0.0
86%
90%
97%
95%
55%
91%
98%
99%
99%
99%
91%
99%
99%
99%
52%
2013
2015
2017
2019
2021

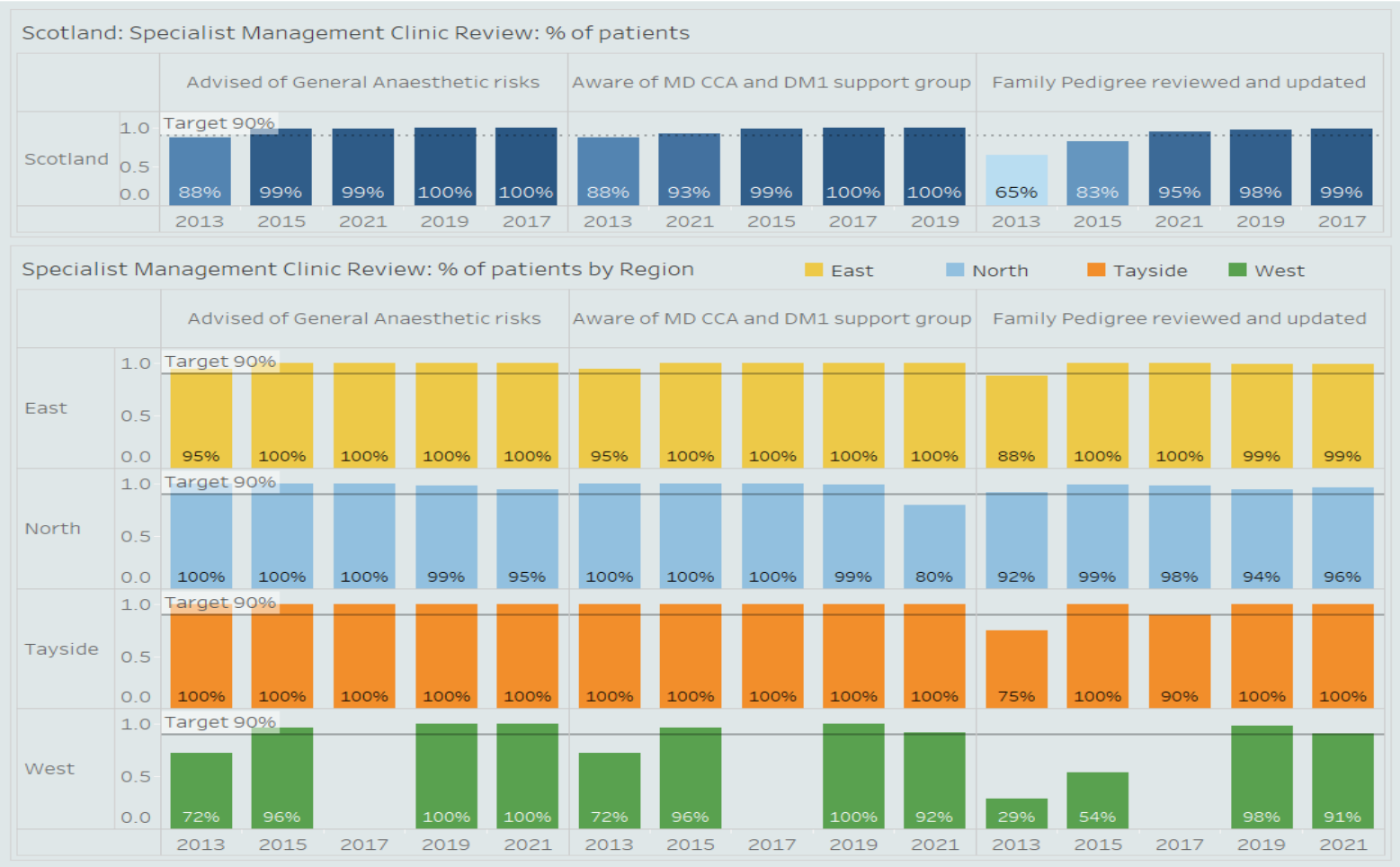
Graphic 3d


Outcomes from Specialist Management Clinic: % of patients by Region
East
Tayside
North
West
ECG
Epworth Sleepiness Scale
RGB or HbA1c and Thyroid
East
North
Tayside
West
1.0
0.5
0.0
Target 90%
100% 100% 100% 97% 65% 97% 95% 100% 100% 100% 97% 95% 100% 82% 100%
81% 85% 91% 96% 64% 99% 100% 98% 100% 96% 99% 100% 98% 100% 69%
100% 88% 100% 96% 80% 100% 100% 100% 100% 100% 100% 100% 100% 100% 100%
76% 81% 92% 28% 80% 99% 99% 100% 80% 99% 99% 12%
2013
2015
2017
2019
2021

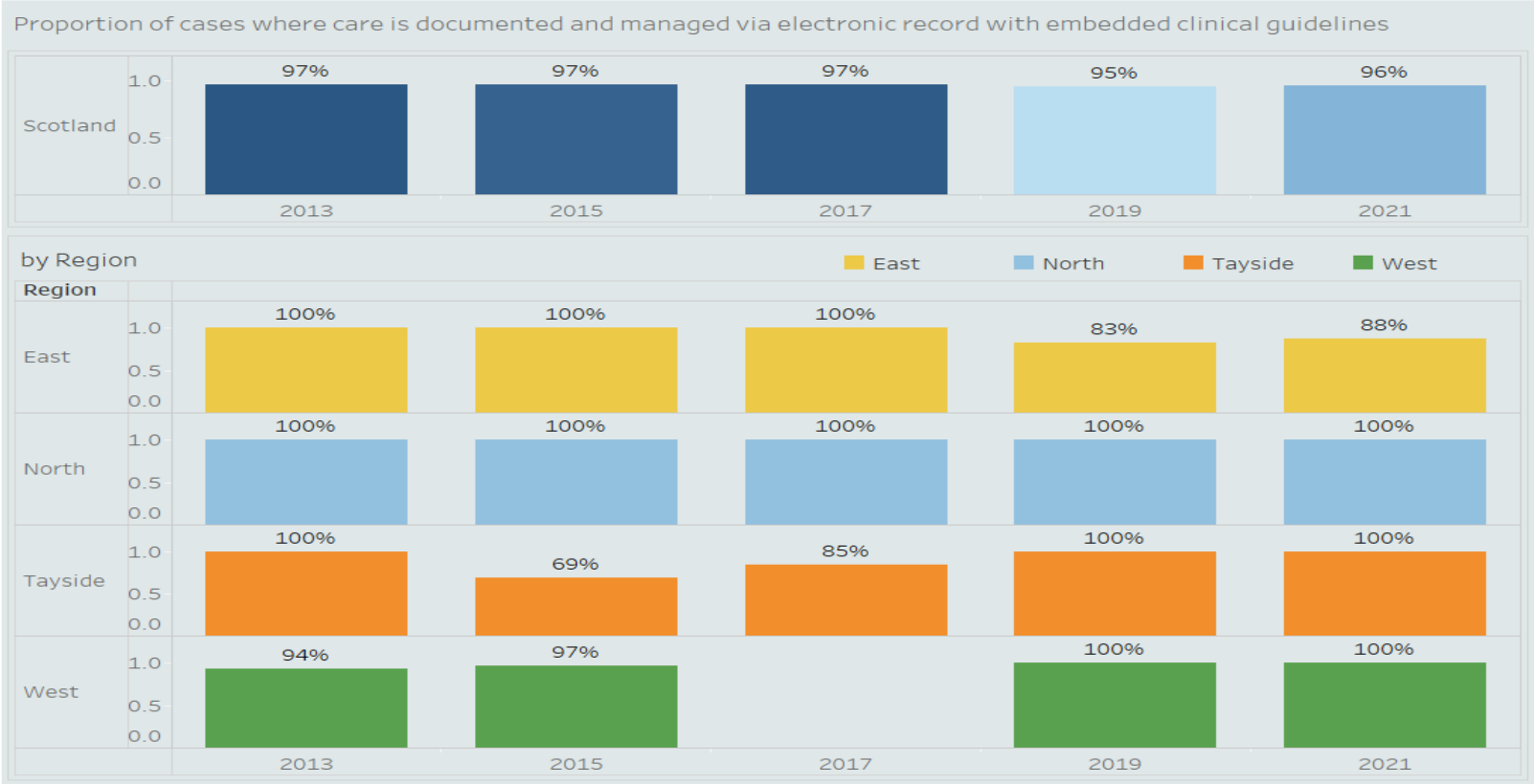
Graphic 3e


Specialist Management Clinic Review: % of patients that can produce and Alert Device
Scotland
Target 75%
0.8
0.6
0.4
0.2
78%
79%
83%
86%
90%
2021
2013
2017
2015
2019
by Region
East
North
Tayside
West
East
1.0
0.5
0.0
Target 75%
83%
79%
91%
98%
89%
North
1.0
0.5
0.0
Target 75%
80%
81%
84%
91%
89%
Tayside
1.0
0.5
0.0
Target 75%
86%
75%
82%
95%
81%
West
1.0
0.5
0.0
Target 75%
82%
67%
60%
92%
2017
2015
2013
2021
2019

Graphic 3f

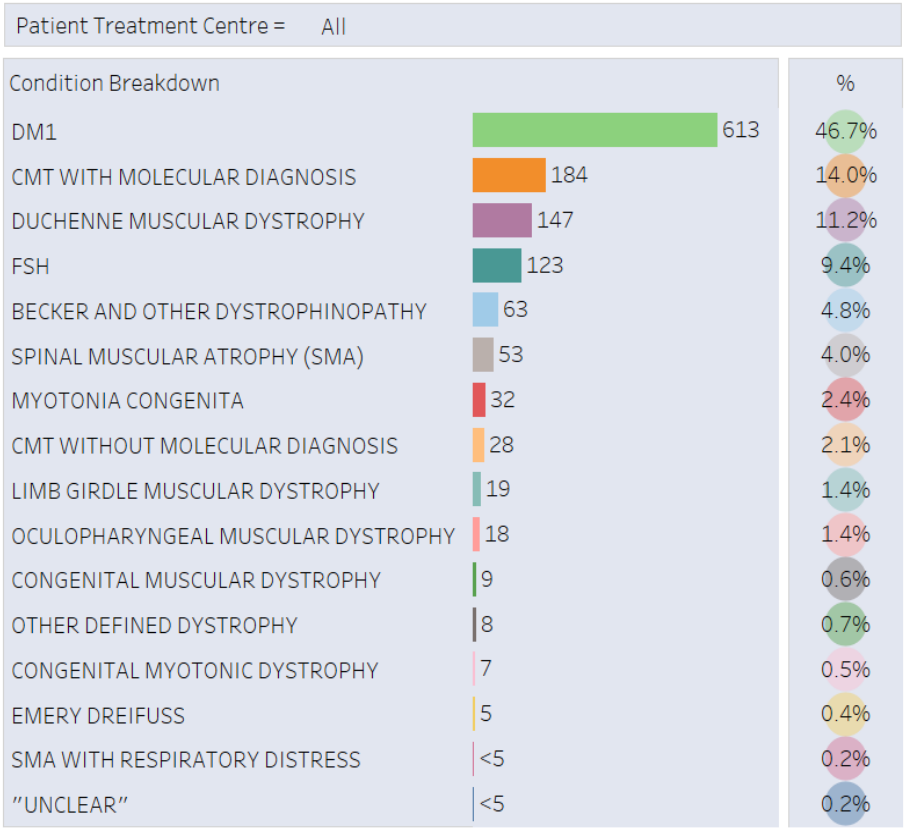

Scotland: Specialist Management Clinic Review: % of patients
Advised of General Anaesthetic risks
Aware of MD CCA and DM1 support group
Family Pedigree reviewed and updated
Scotland
Target 90%
1.0
0.5
0.0
88% 99% 99% 100% 100%
2013 2015 2021 2019 2017
88% 93% 99% 100% 100%
2013 2021 2015 2017 2019
65% 83% 95% 98% 99%
2013 2015 2021 2019 2017
Specialist Management Clinic Review: % of patients by Region
East
North
Tayside
West
Advised of General Anaesthetic risks
Aware of MD CCA and DM1 support group
Family Pedigree reviewed and updated
East
95% 100% 100% 100% 100%
95% 100% 100% 100% 100%
88% 100% 100% 99% 99%
North
100% 100% 100% 99% 95%
100% 100% 100% 99% 80%
92% 99% 98% 94% 96%
Tayside
100% 100% 100% 100% 100%
100% 100% 100% 100% 100%
75% 100% 90% 100% 100%
West
72% 96% 100% 100%
72% 96% 100% 92%
29% 54% 98% 91%
2013 2015 2017 2019 2021

Graphic 3g

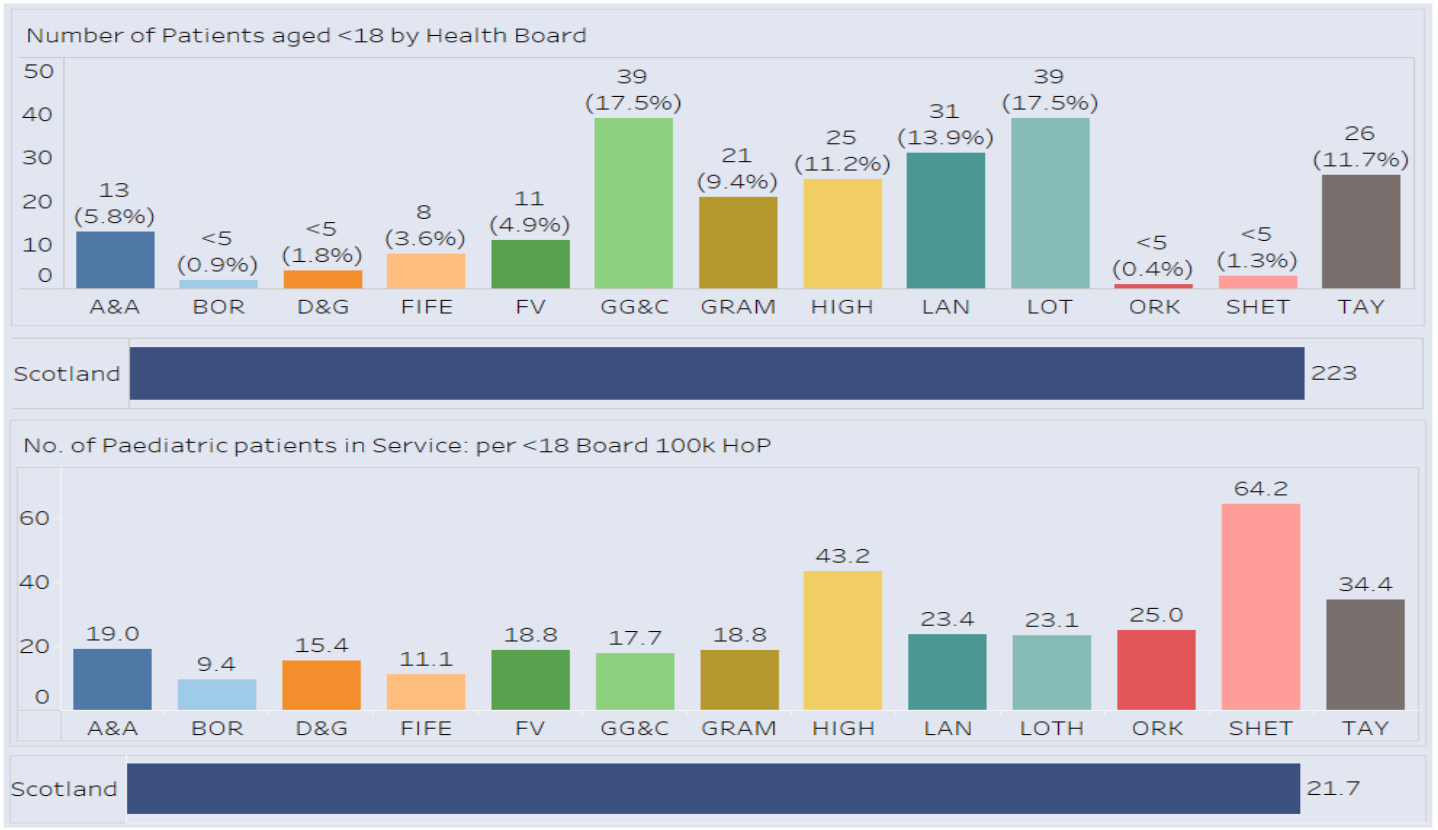

Proportion of cases where care is documented and managed via electronic record with embedded clinical guidelines
Scotland
1.0
0.5
0.0
97%
97%
97%
95%
96%
2013
2015
2017
2019
2021
by Region
East
North
Tayside
West
Region
East
100%
100%
100%
83%
88%
North
100%
100%
100%
100%
100%
Tayside
100%
69%
85%
100%
100%
West
94%
97%
100%
100%
2013
2015
2017
2019
2021

Graphic 3h

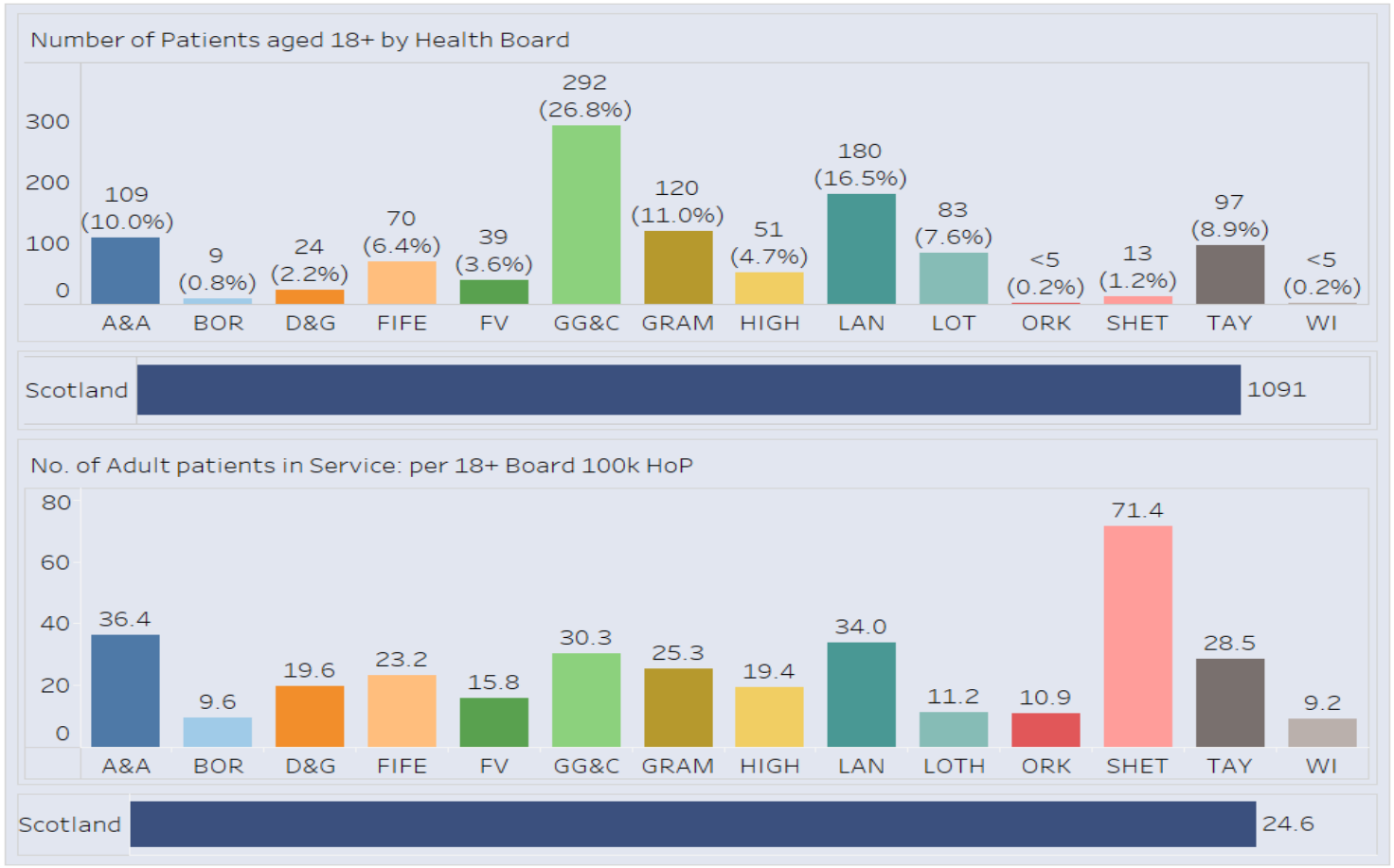
Appendix 4 – CAS Audit Results as at March 31st, 2022



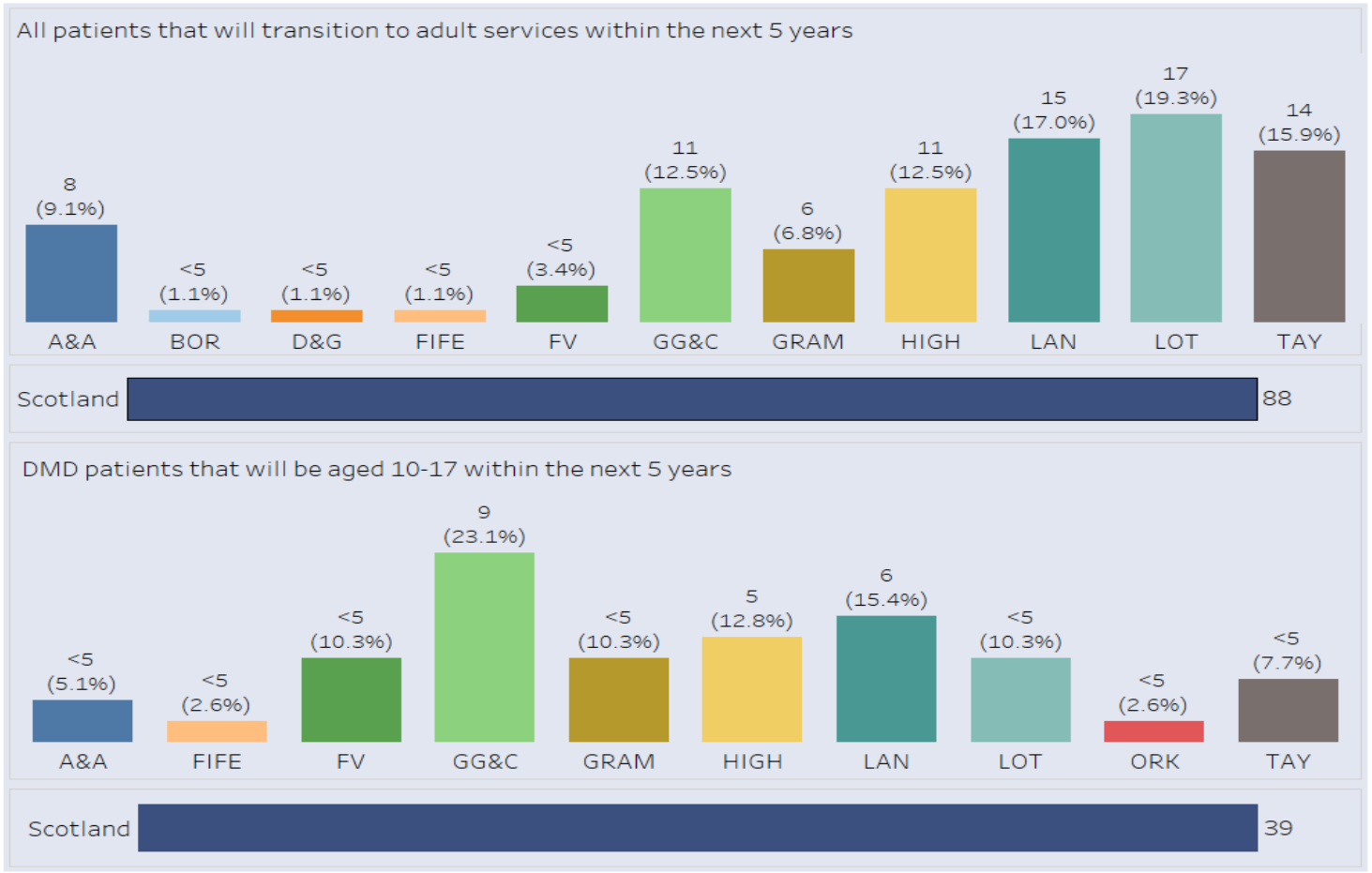
Graphic 4a


Number of Patients aged <18 by Health Board
50
40
30
20
10
0
13 (5.8%)
<5 (0.9%)
<5 (1.8%)
8 (3.6%)
11 (4.9%)
39 (17.5%)
21 (9.4%)
25 (11.2%)
31 (13.9%)
39 (17.5%)
<5 (0.4%)
<5 (1.3%)
26 (11.7%)
A&A
BOR
D&G
FIFE
FV
GG&C
GRAM
HIGH
LAN
LOT
ORK
SHET
TAY
Scotland
223
No. of Paediatric patients in Service: per <18 Board 100k HoP
60
40
20
0
19.0
9.4
15.4
11.1
18.8
17.7
18.8
43.2
23.4
23.1
25.0
64.2
34.4
A&A
BOR
D&G
FIFE
FV
GG&C
GRAM
HIGH
LAN
LOTH
ORK
SHET
TAY
Scotland
21.7

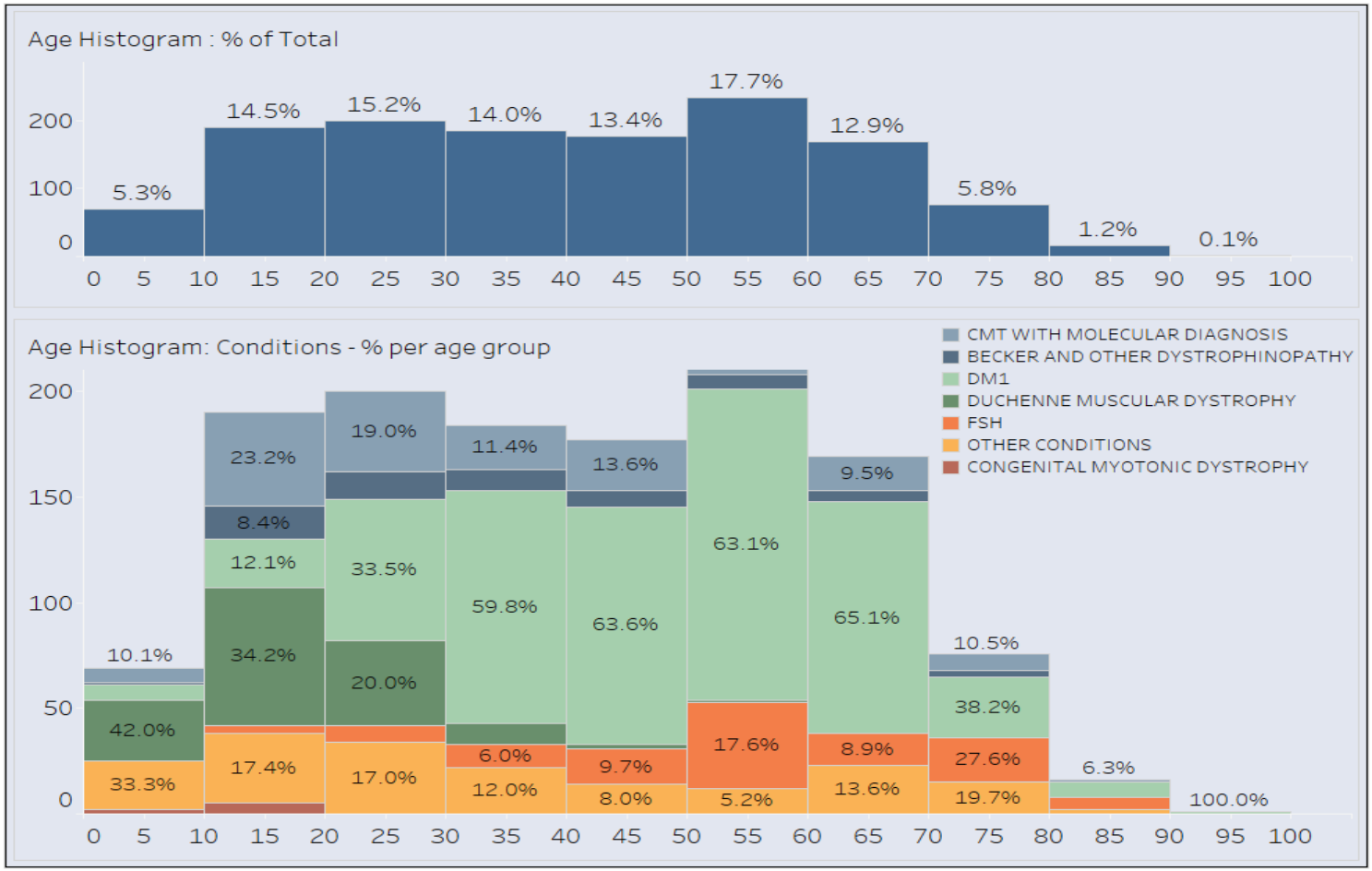
Graphic 4b


Number of Patients aged 18+ by Health Board
300
200
100
0
109 (10.0%)
9 (0.8%)
24 (2.2%)
70 (6.4%)
39 (3.6%)
292 (26.8%)
120 (11.0%)
51 (4.7%)
180 (16.5%)
83 (7.6%)
<5 (0.2%)
13 (1.2%)
97 (8.9%)
<5 (0.2%)
A&A
BOR
D&G
FIFE
FV
GG&C
GRAM
HIGH
LAN
LOT
ORK
SHET
TAY
WI
Scotland
1091
No. of Adult patients in Service: per 18+ Board 100k HoP
80
60
40
20
0
36.4
9.6
19.6
23.2
15.8
30.3
25.3
19.4
34.0
11.2
10.9
71.4
28.5
9.2
A&A
BOR
D&G
FIFE
FV
GG&C
GRAM
HIGH
LAN
LOTH
ORK
SHET
TAY
WI
Scotland
24.6

Graphic 4c


All patients that will transition to adult services within the next 5 years
8 (9.1%)
<5 (1.1%)
<5 (1.1%)
<5 (1.1%)
<5 (3.4%)
11 (12.5%)
6 (6.8%)
11 (12.5%)
15 (17.0%)
17 (19.3%)
14 (15.9%)
A&A
BOR
D&G
FIFE
FV
GG&C
GRAM
HIGH
LAN
LOT
TAY
Scotland
88
DMD patients that will be aged 10-17 within the next 5 years
<5 (5.1%)
<5 (2.6%)
<5 (10.3%)
9 (23.1%)
<5 (10.3%)
5 (12.8%)
6 (15.4%)
<5 (10.3%)
<5 (2.6%)
<5 (7.7%)
A&A
FIFE
FV
GG&C
GRAM
HIGH
LAN
LOT
ORK
TAY
Scotland
39

Graphic 4d


Age Histogram : % of Total
200
100
0
5.3%
14.5%
15.2%
14.0%
13.4%
17.7%
12.9%
5.8%
1.2%
0.1%
0 5 10 15 20 25 30 35 40 45 50 55 60 65 70 75 80 85 90 95 100
Age Histogram: Conditions - % per age group
CMT WITH MOLECULAR DIAGNOSIS
BECKER AND OTHER DYSTROPHINOPATHY
DM1
DUCHENNE MUSCULAR DYSTROPHY
FSH
OTHER CONDITIONS
CONGENITAL MYOTONIC DYSTROPHY
200
150
100
50
0
10.1%
42.0%
33.3%
23.2%
8.4%
12.1%
34.2%
17.4%
19.0%
33.5%
20.0%
17.0%
11.4%
59.8%
6.0%
12.0%
13.6%
63.6%
9.7%
8.0%
63.1%
17.6%
5.2%
9.5%
65.1%
8.9%
13.6%
10.5%
38.2%
27.6%
19.7%
6.3%
100.0%
0 5 10 15 20 25 30 35 40 45 50 55 60 65 70 75 80 85 90 95 100

Graphic 4e