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East

Riding of

Yorkshire

North East

Lincolnshire

North

Doncaster

South Yorkshire ICB (pop ~1.4m)

Humber & North Yorkshire Health

& Care Partnership (pop ~5.5m)

West Yorkshire Health & Care

Partnership (pop~2.4m)

York

Leeds

Wakefiel

Developing a regional networked approach to care in Integrated Care Boards for Myasthenia Gravis

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Background

- Currently complex myasthenia gravis (MG) care is often not delivered close to home but in specialised regional centres leading to inequitable care and inefficiencies.
- This centralised model can lead to sidelining of referring centres from the decision-making process and disjointed ongoing patient care.
- Delegated budgets for integrated care boards (ICBs) and the NHS England neurology transformation agenda now open up new opportunities to neurology services to move to a multidisciplinary networked approach that will improve the delivery of integrated health and care services.

Aims

We brought together multi-disciplinary MG care teams across ICB areas that utilise the Sheffield and Birmingham regional MG services as exemplars to map current care delivery. This was carried out in 3 steps: development of an integrated care pathway for MG, systematically identifying the network of care, connect with commissioners in the ICB's to plan how multi ICB MG services will be delivered.

Methods

Using the model developed by the South West London and Surrey Heartlands Pathfinder NHS England neurology transformation pilot¹, neurology teams from the

Fig 2. Multi-ICB footprint of Sheffield and Birmingham MG regional centres

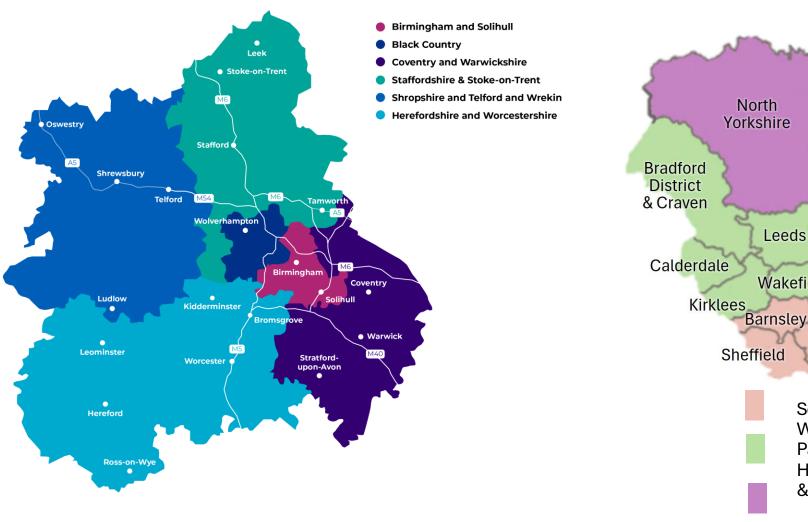
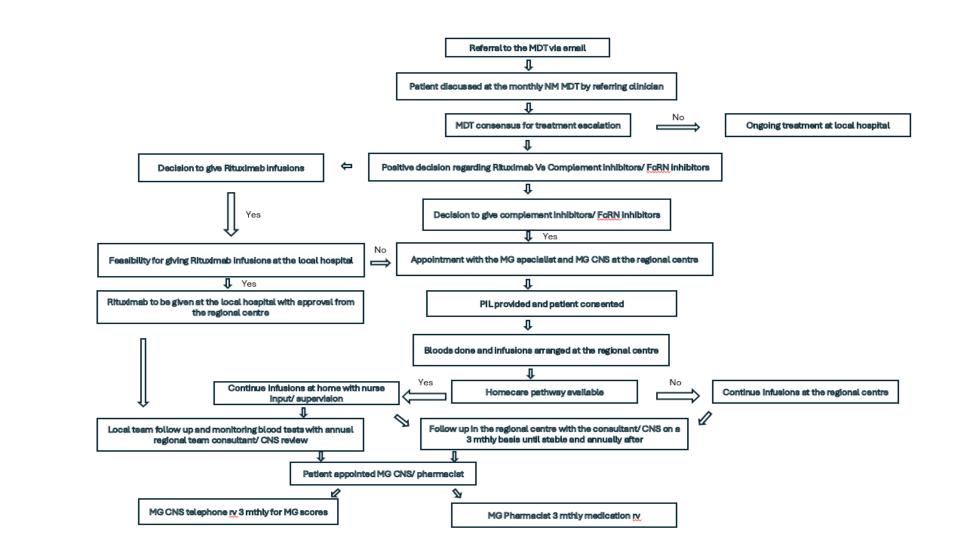


Fig 3 Referral flows within Birmingham Regional Network



2024

2025

- ICB areas met to discuss their individual services. The tasks of this workshop included:
- 1. Identify existing service components to plot how care is currently delivered locally (including workforce capacity, patient flows, areas for improvement) and to map the geographic footprint.
- 2. MG care pathway development for the whole footprint, modelled on the new three-tier system for neurology care and using a network approach coordinated around the specialist regional centre.
- 3. Explore how the regional centre could support networked MG care to improve patient outcomes by linking the MG networks with their ICB commissioners.

The Sheffield regional centre provides MG care for a population of \approx 9 million people across a footprint of three ICBs (Fig 1). Care is provided across 20 hospitals including 3 N1, 5 N2, 3 N3 and 11 N4 sites. There are 3 ICBs South Yorkshire, West Yorkshire and Humber and North Yorkshire.

In the West Midlands the regional centre provides MG care for a population of 6 million (\approx 4.6 million adults) (Fig 1). Neurology services are provided across 12 NHS Trusts, 20 hospitals including 3 N1, 0 N2, 7 N3 and 10 N4. There are 6 ICBs Birmingham and Solihull, Black Country, Coventry and Warwickshire, Hereford and Worcestershire, Shropshire, Telford and Wrekin, Staffordshire and Stoke on Trent.



MG patient population ²	22,855
Regional MG services ³	25
Specialist MG neurologist	s 43
Specialist MG nurses	6

- Specialist MG nurses
- 42 Integrated care services

Fig 1. Myasthenia Care Pathway

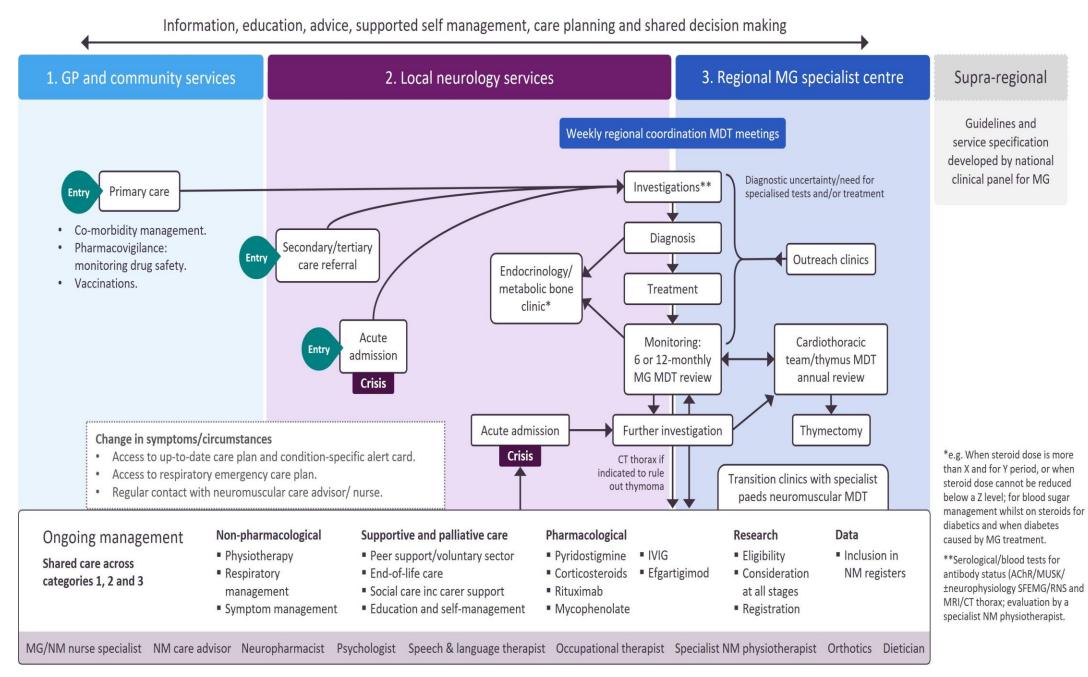


Fig 4. Case study: value of MDT shared care approach in MG Yorkshire Network

Background

Oct

Dec

Jan

July

Nov

Dec

2022

2023

- 74 yr female, diagnosed in Leeds in 1989 with generalised MG.
- AChR +ve, moderately affected (MG-ADL 10/24), thymectomy 1989.

1st referral to Sheffield MDT: mycophenolate 1g

BD, steroid slow \blacktriangle 40mg, pyridostigmine 60mg qds.

MG crisis: IVIGs - post-infusion symptoms improve.

Shared care agreed. Discussions re deteriorating MG

Review. Rituximab discussed. Wait 6 months for

further steroid sparing effect of mycophenolate.

Clinic review: steroids **VMG-ADL score**

MG crisis – IVIGs steroids ▲ 40mg

most treatment options offered

Rituximab-low white cell count

complement inhibitory clinical trial.

5/24. ▲ mycophenolate seemed effective,

MDT discussions throughout - patient unkeen on

IVIGs planned 4 weekly. Waiting recruitment to

EMG indicates possible mild lower limb peripheral

- Symptom control difficult.
- Complications with azathioprine and methotrexate.

MDT referral to consider rituximab.

- candidate for clinical trial:

lymphocyte count $\mathbf{\nabla}$.

- Key for activity carried out by:
- Leeds neuromuscular MDT Sheffield specialist MG MDT
- Shared care between teams
- IVIGs planned. Rituximab considered but low Feb lymphocyte count persist and CD19. MG-ADL score 12/24.
 - MDT discussion: IVIGs, trial plans and options.
- Continued IVIGs given. June
- Aug-Screened for C5 inhibitory trial but screen failed Sep based on blood tests.
- MDT discussion: Efgartigimod Oct Continued IVIGs given Ongoing discussions at weekly MDT meeting
- Stop IVIGs in prep for efgartigimod. Communication Nov with GP, Leeds team and research nurses.
- 1st cycle completed: 4 weeks efgartigimod infusion 10mg/kg/week, 4 weeks monitoring.
 - IVIG stopped as counteractive to efgartigimod.
 - Weekly monitoring of Ig levels and MG-ADL required in 1st cycle and thereafter depending on response.
- Severity scores improving after 2nd dose (MG-ADL ▼ 2p. MGC ▼4p, MG-QOL15 ▼3p).
- 2nd cycle planned end Jan 2025 (homecare service) infusions).
- Blood monitoring and emotional and clinical support.
- Continued shared care and up date at the MDT

Results

neuropathy.

Ongoing shared care.

By mapping services and linking the regional networks of neurologists and the multidisciplinary MG care team services can reduce unwarranted variation in care delivery and improve multiple aspects of patient outcomes in MG.

- The model can increase capacity within specialist MG services and overall ٠ reduce economic burden by providing prompt care closer to home.
- An integrated MG network can be the basis to improve diagnosis and care for people with MG and is a transferable model of care other regional services could adopt.

Acknowledgement

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References

1. https://future.nhs.uk/neurologyservicetransformation/view?objectID=38682384; 2. Myaware (2025) www.myaware.org/specialists-in-myasthenia; 3. Carey IM, Banchoff E, Nirmalananthan N. Prevalence and incidence of neuromuscular conditions in the UK between 2000 and 2019: A retrospective study using primary care data. PLoS One. 2021 Dec 31;16(12):e0261983. doi: 10.1371/journal.pone.0261983. PMID: 34972157; PMCID: PMC8719665.

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*Or NMNS where MGNS unavailable.

a) Sheffield Teaching Hospitals NHS Foundation Trust, Sheffield. Sheffield Institute for Translational Neurosciences (SITRAN), University of Sheffield; b) University Hospitals Birmingham NHS Foundation Trust, Institute of Immunology and Immunotherapy – University of Birmingham; c) St George's University Hospitals NHS Foundation Trust, London; d) Neurology Academy, Sheffield.

▲ =increase, ▼=decrease, AChR=acetylcholine receptor, BD=twice daily, EMG=electromyography, ICB=Integrated Care Board, IG=immunoglobulin, IVIG=intravenous IG, MDT=multidisciplinary team, MG=myasthenia gravis, MG-ADL=MG activities of daily living (scale), MGC=MG composite (scale), MGNS=MG nurse specialist, MG-QOL15=MG quality of life scale 15, MGII=MG impairment index, NM=neuromuscular, NMNS=neuromuscular nurse specialist, p=point, pt=patient, qds=4 times a day.

N1 Neuroscience Centre, N2 Neurology Centre with in patients N3 DGH Neurology sentre without inpatients, N4 Visiting neuplogist only