Tackling myasthenia gravis – a consensus on the priorities co-developed by patients and clinicians

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Health Innovation Network South London

Inspired by **patients.** Driven by **science.**

Contents

Executive summary

Myasthenia gravis (MG) is one of several thousand known diseases affecting fewer than one in 2,000 people in the general population. It is, by definition, a rare disease and has not received the attention it deserves. The Health Innovation Network (HIN) was funded by UCB to lead a consensus development programme to build an understanding of what would be required to elevate standards of care for people experiencing Myasthenia Gravis in the UK.

This report details our approach and methods as well as the insights and recommendations about the key areas in which to focus to improve the standards of care for people with MG. These are framed around the four priority areas in the UK Rare Diseases Framework[1]:

- Helping patients get a diagnosis faster
- Increasing awareness of rare diseases among healthcare professionals
- Better co-ordination of care
- Improving access to specialist care, treatments and drugs.

Recommendations about helping patients get an MG diagnosis faster

- Review and update the Association of British Neurologists guidelines for MG. In addition, standards should be agreed and published, and articulate why early diagnosis and treatment is important.
- Update advice and guidance and roll-out nationally, highlighting the importance of voluntary sector collaboration in its development. Include a PDF for GPs, what to look out for and signposting. Links to validated information and patient information (eg Myaware).
- Neurologists and GPs should work in partnership to develop new pathways for diagnosis. Design a diagnostic algorithm for MG in primary care. Consider measures eg timeframe for patient to be seen and appropriate tests completed.
- Use of artificial intelligence to examine patient records (flagging 6-8 common symptoms might mean the patient has MG. Refer for MG testing).
- Provide link to Good Diagnosis Report, and recommend that diagnosis should be informed and

[1] Department of Health and Social Care. UK Rare Diseases Framework [Internet]. 2021 [cited 2022 Dec 05]. Available from: https://www.gov.uk/government/publications/uk-rare-diseases-framework

supported, collaborative and co-ordinated, respected and acknowledged.

Recommendations about increasing awareness of MG among healthcare professionals

- Review all existing information resources about MG and design a national awareness-raising campaign (as above, central repository of awareness-raising and training materials). Myaware should be appropriately funded to provide information to people living with MG and to healthcare professionals.
- Develop and roll-out a national awareness-raising campaign. People living with MG to be supported to become advocates/educators (prioritise opticians / pharmacists / GPs).
- Patient-held records/passports to support healthcare professionals where knowledge is limited but crucial to care eg A&E.
- Specialists to publish best practice and service developments in neurology journals.

Recommendations about better co-ordination of care

- Develop a database (Oxford registry) to include: number of people with MG, spread (geographically), the treatment they are receiving, and to measure outcomes and financial modelling to understand the resources required and where they would have most impact
- Develop an audit tool similar to the Parkinson's one. Co-produce the specification for an audit tool.
- Use data from database and audits to inform a service specification to standardise care for people living with MG. Key components are recommended in this report.
- Develop a standard business case for the role of MG Clinical Nurse Specialists across services, supporting primary care and ensuring people living with MG understand the breadth of their role.
- Standardise shared care agreements (ICSs are looking at this but they will need to be developed with GPs, not just specialists)
- All people living with MG should have access to their records (a reference pilot is taking place in Southampton – share pilot evaluation when this is available)

Recommendations about improving access to specialist care and drugs

- MG network to work with ICSs to develop evidence-based treatment pathways
- Measure access and outcomes to reduce variation
- An agreed framework to expand serviceability of treatments eg plasma exchange, to ensure they are more widely available
- Develop information for healthcare professionals about the use of 'off label' medications

Other overall recommendations

- Need for an MDT approach on diagnosis, role of CNS and Myaware to support access to social services and benefits, communications with schools, universities, etc.
- Specialists, GPs, Myaware and people with lived experience establish a formal network that can inform the development of the rare disease action plan and drive service improvements.

Introduction

Myasthenia Gravis is a rare long-term condition that causes muscle weakness. It most commonly affects the muscles that control the eyes and eyelids, facial expressions, chewing, swallowing and speaking. But it can affect most parts of the body. It can affect people of any age, typically starting in women under 40 and men over 60[2]. It is estimated that 15 in 100,000 people are living with MG in the UK.

People with rare diseases like MG often feel forgotten, unheard or misunderstood. The challenges they face can be magnified by isolation and worries around healthcare needs that are not being addressed.

The Health Innovation Network (HIN) was funded by UCB to lead a consensus development programme to build an understanding of what would be required to elevate standards of care for people experiencing Myasthenia Gravis in the UK. UCB is a global biopharmaceutical company focused on severe neurological and immunological conditions. UCB were not directly involved in the outputs of the consensus development.

The insights and recommendations from this consensus development programme are framed around the four priority areas in the UK Rare Diseases Framework:[3]

- Helping patients get a diagnosis faster
- Increasing awareness of rare diseases among healthcare professionals
- Better co-ordination of care
- Improving access to specialist care, treatments and drugs.

This report also contains spotlights on topics that fall outside the rare disease framework that were found to be of significance.

There is fragmentation in the MG landscape, with significant variation in diagnosis and service delivery which is impacting the lives of people living with MG. Those in the NHS and voluntary sector providing care for people with MG are

[2] NHS. Myasthenia Gravis. [Internet] 2020 [cited 2022 Dec 05]. Available from: https://www.nhs.uk/conditions/myasthenia-gravis/
[3] Department of Health and Social Care. UK Rare Diseases Framework [Internet]. 2021 [cited 2022 Dec 05]. Available from: https://www.gov.uk/government/publications/uk-rare-diseases-framework

committed to improving services and access to treatments, but there is currently no co-ordinated network that supports stakeholder engagement or can articulate a vision to develop MG services and pathways for the future. The neurosciences service transformation programme has developed new pathways and there is an opportunity to learn about how to improve MG services from this approach.

The consensus development programme described in this report brought together valuable perspectives from a range of relevant roles to review current MG care pathways and explore factors that impact on the current standard of care for people living with MG, including the Covid-19 pandemic. This programme collated insights from a range of experts from across the UK, including key opinion-leading clinicians, national, regional and local stakeholders and patients with lived experience of MG. An expert panel was then formed to review these insights on current MG care, identify areas that could be improved and reach a consensus on a series of recommendations to elevate the standard of care for patients.

Some of the frustrations articulated by people living with MG and healthcare professionals are not specific to MG as a disease; however, these could be eased through developing effective partnerships with other services and the voluntary sector.

This report details the approach and methods of this consensus programme as well as the insights and recommendations about the key areas on which to focus to improve the standards of care for people with MG.

Approach and method

MG consensus development

We took a phased approach to support informed deliberation and consensus building across patient, carer and professional stakeholder groups:

- Phase 1 focused on insight gathering from across different patient and stakeholder groups to identify the issues and potential areas for improvement
- Phase 2 drew on these insights into a deliberative consensus building panel comprising clinicians and patients to agree practical recommendations to improve the standard of care for people with Myasthenia Gravis

Phase 1 - insights gathering

The first phase was to engage with patients, key opinion-leading clinical, operational and commissioner stakeholders working in the Myasthenia Gravis area. We used the HIN's existing relationships with healthcare services to engage with consultant neurologists, specialist nurses, researchers, NHS England commissioners and other stakeholders, including those from the charity sector. People living with MG were invited to participate by their healthcare professional and Myaware (MG charity), who ran a promotion on their website. We also had plans to gain insights from commissioners but had less success in engaging with people in these roles. The activities used to gather insights were:

- In-depth interviews with key clinicians, using semi-structured questionnaires to scope their experiences, best practice and recommendations for creating consensus panel.
- In-depth interviews and a focus group with ten people who have lived experience of MG.

The key lines of questioning focused on:

- How to achieve consistency and reduce variation in access and clinical outcomes for MG patients.
- Contributing towards vision on implementing the priorities outlined in the UK Rare Diseases Framework, using MG as a proof of concept.
- How can Integrated Care Systems (ICSs) in England commission MG services at a local level following the transfer of the majority of specialised commissioning spend from NHS England?

Using the UK Rare Diseases Framework, we shaped our insights and recommendations into four key priority areas:

- Priority 1: helping patients get a final diagnosis faster
- Priority 2: increasing awareness of rare diseases among healthcare professionals
- Priority 3: better co-ordination of care

- Priority 4: improving access to specialist care, treatments and drugs

Phase 2- Consensus-building through collaboration

A 'deliberative' approach was taken to consensus-building that allows participants to

consider relevant information from multiple points of view. Deliberation enables participants to discuss the issues and options and to develop their thinking together before coming to a view, considering the values that inform people's opinions.

Following the development of insights through the interviews and focus groups we held two workshops with an expert panel comprising patients, (specialist and generalists), researchers and people from the voluntary sector. A summary of the insights generated in phase 1 was presented to the expert panel who then worked in smaller facilitated groups to reflect on what they had heard and discuss challenges and priorities and make recommendations.

The programme ran for 12 months:

- Interviews and focus groups (completed between March and August 2022)
- Insights questionnaire and analysis of feedback (completed July 2022)
- Focus groups and analysis of feedback (completed August 2022)
- Identification of expert panel (completed August 2022)
- Expert panel consensus development workshop 1 (September 2022)
- Expert panel consensus development workshop 2 (October 2022)

The outputs of the expert panel consensus development workshops were supplemented by further insights gathered from a range of sources including local and national guidance.
The recommendations in this report were generated through a synthesis of consensus development process.

Limitations and scope

This report's aim is to share insights, to support short, medium and longer-term recommendations across health, local authority and community partners. While a range of individuals were interviewed from different roles, organisations and geographic locations, it was not intended as an exhaustive process. We were unable to engage with commissioners in the way we had hoped and there may

be individuals that have contributed to the programme who do not feel their views are fully reflected in this document.

Spotlight on the impact of Covid-19

Covid-19 was a difficult time for people living with MG, as the condition put them at high risk of getting seriously ill from the virus. Some people talked about the fear of catching Covid-19 while travelling to and from hospital for treatment. However, MG services managed to continue with their treatments and many people were supported virtually.

There were and continue to be issues with capacity. Some healthcare professionals working in hospitals were redeployed to other areas and large numbers of staff had to isolate.

One MG trial had to be postponed due to Covid-19.

Covid-19 and the vaccine roll-out - as well as managing people with long Covid and the backlogs in management of other health conditions including COPD and diabetes - had a significant impact on primary care workload. As a result, there were reports of reduced capacity to manage ongoing treatment of MG.

Covid-19 has also had an impact on people's mental health and there is greater demand for mental health services. All of this is having a knock-on effect on MG services, particularly Clinical Nurse Specialists, who reported they are supporting and signposting individuals who have been unable to access their GP.

Myaware, the UK registered charity for MG, was also affected by Covid-19. Their staffing capacity was reduced and they had to stop the valued face-to-face support groups for people living with MG.

The pandemic also created some positive opportunities, in particular the wider adoption of new technologies. Healthcare professionals and people living with MG are now routinely using remote or telecare and virtual consultations. This enables people living with MG to attend appointments without the need to travel during Covid-19 and, while some people prefer to attend clinics, some find virtual consultations more convenient. Furthermore, healthcare professionals have adopted virtual multi-disciplinary team meetings and are looking to expand this to include GPs and patients.

One GP reported that Covid-19 improved their remote access to specialists.

There are opportunities to learn from the innovations developed during Covid-19 and to build on the successes and advancements in the use of technology.

Priority 1: Faster final diagnosis

Insights

For people living with a rare disease, getting the right diagnosis is the first step towards the appropriate management of their condition. It can enable greater treatment choice and link individuals to vital information and support through patient organisations. However, getting the right diagnosis has been consistently highlighted as one of the most significant challenges faced by both the genetic and non-genetic rare disease community. The development of genome sequencing and piloting new approaches for people with rare undiagnosed conditions are priorities identified in England's Rare Disease Action Plan 2022.[4]

For people living with MG, the time taken for diagnosis varies across England, with some people reporting moving quickly from diagnosis to treatment, and others waiting years. There were different perspectives from patient and stakeholder groups about how long people waited for a diagnosis based on different understandings about when the process began: patients tend to count the time taken from when they first feel unwell; GPs start timing things after the elimination of common diseases, through diagnostics, to referral to a specialist; and from the specialist's perspective, the duration is from waiting for test results to confirmed diagnosis and treatment.

> *The clock starts ticking at different times, for the patient, the GP, the consultant*
>
> *- GP*

Lack of awareness of MG among healthcare professionals - including consultants, GPs, pharmacists and opticians - creates a risk that patients requiring expert/specialist input are not referred in a timely manner for disease progression. MG may not be life-threatening but it can have life-changing implications. Symptoms present differently, leading to individuals being

[4] Department of Health and Social Care. England Rare Diseases Action Plan 2022. [Internet] 2022 [cited 2022 Dec 5]. Available from: https://www.gov.uk/government/publications/england-rare-diseases-action-plan-2022

misdiagnosed. Patients presenting with 'typical' symptoms are more likely to receive a faster diagnosis than those with less typical symptoms.
People living with MG talked about the physical and emotional impact of being misdiagnosed, their symptoms not being taken seriously or an assumption that the cause was something else. The pathway to diagnosis can be stressful for the individual and involve many tests, some invasive.

> *When I was getting my diagnosis and because I was a teenager, I was labelled as just being lazy or just being a typical teenager or trying to, like, stay off school. […] just listening to patients and listening to their families because they always know best and they'll know what's wrong with their child*
>
> *- Person living with MG*

Healthcare professionals shared their frustration that the current pathways to diagnose rare diseases are not optimal and access to specialist services can be difficult. The system is designed to deal with common conditions and common pathways. People may therefore be treated for other conditions rather than getting a diagnosis of MG. GPs reported that unless they 'hit' the right pathway to refer, patients tended to end up back in their surgery without any meaningful progress. GPs also reported that they were uncertain about where to source a second opinion in cases where the presentation of symptoms was consistent with MG but initial investigation had not been able to confirm a diagnosis.

I was misdiagnosed – treated as a stroke. The specialists implied there was nothing wrong with me – however with my medical background I felt something was wrong. I asked a neurologist friend – sent a video and the friend diagnosed MG. I was referred to general neurology who then had to refer to specialist neurologist – all took time, took time to get right medication

- Person living with MG

People had different experiences on receiving their diagnosis. There may have been a timely diagnosis but no one to explain what that diagnosis meant to the individual, or how it might impact on their lives. People reported being given little information about their condition. One individual was told by a healthcare professional to 'google it'. As well as written information, people wanted to talk to others with the condition so they could learn from their experience about how others with MG had coped with life situations such as work and parenting. Patients also wanted to know more about the medication available, particularly where information on the medication prescribed to them related to other conditions but made no reference to MG.

People living with MG also talked about a lack of psychological support on diagnosis. This was highlighted in the report Out of the Shadows(2020)[5]. Information about or access to allied healthcare professionals to support with diet, exercise and speech was sparsely available and referral to social services was non-existent.

The Genetic Alliance Good Diagnosis Report[6] describes the diagnosis journey. They report that the speed of diagnosis is only one factor in determining the level of satisfaction with the diagnosis process. How a person is supported on their

[5] Judy Abel. Out of the Shadows [Internet]. 2020 [cited 2022 Dec 05]. Available from: https://www.neural.org.uk/publication/rare-condition-report/

[6] Genetic Alliance. Good Diagnosis [Internet]. 2022 [cited 2022 Dec 05]. Available from: https://geneticalliance.org.uk/gauk-news/news/good-diagnosis/

journey to diagnosis is equally important. People diagnosed with MG told us they were often left feeling unsatisfied with their healthcare experience and with the level of information and support that they received.

Components of good diagnosis for MG

We have used the Genetic Alliance's Good Diagnosis wheel to illustrate our findings.

> To receive a diagnosis is life-changing and the days leading up to and following a diagnosis are so important, because that is the beginning of the rest of your life.
>
> *- Genetic Alliance stakeholder*

Accurate and timely

A timely and accurate diagnosis and access to the right treatment would save money on unnecessary tests, treatments and appointments. Diagnosis measures may be helpful; for example, a timeframe for the patient to be seen and have appropriate tests completed.

In other rare conditions, national standards of care have been published. The Association of British Neurologists (ABN) guidelines for MG are used by neurologists and these should be reviewed and updated regularly. In addition, standards should be agreed and published, including guidance on which tests to carry out and information about the nuances and limitations of testing but articulating why early diagnosis and treatment is so important.

Overall, there was an expectation that general neurologists should be able to diagnose MG and if they are unsure, be encouraged to seek advice from a specialist before sending the patient back to the GP.

Advice and guidance about MG could include signposting to Myaware (the UK registered charity for MG) which has online resources for healthcare professionals and information for people living with MG.

> "The system needs a quicker, responsive pathway that serves the patient"
>
> *- GP*

Particular diagnostic signposting could be developed for opticians as some patients reported that it was their optician who picked up the symptoms.

There is a potential to use artificial intelligence (AI) methods to develop a diagnostic algorithm to support generalists with the diagnosis of MG. An approach could be to examine large quantities of patient records, identify 6-8 common symptoms that would indicate a possible diagnosis of MG, and suggest further investigation and tests. This tool could be linked to information and signposting about which organisations that can provide help.

This or other tools could be developed that could encourage communication between primary care and MG specialists to expediate referrals.

Informed and supported

Steps should be taken to ensure that care following the diagnosis should be informed and supported.

On diagnosis, healthcare professionals should provide information about MG and details of Myaware. This would provide immediate access to validated information and support. Patients would be able to connect with others with lived experience.

A central repository of resources about MG could be developed, including details about support groups, specialist services in the UK and their referral criteria and training materials for staff.

Collaborative and co-ordinated

Diagnosis should be followed by the allocation of a care worker or specialist nurse to provide information and make referrals appropriate to the needs of the patient. For example, psychological services, occupational therapy support, and

social services. Participants suggested people living a distance from their specialist service could receive this support remotely.

Respected and acknowledged

Different services in the NHS should have a clear understanding of the new diagnosis and its implications for the individual, and be able to react appropriately. Other organisations to which this information could be shared to include local government, education establishments and the workplace.

People with MG need support to understand their diagnosis, their symptoms and how their condition will be managed. Information should be provided to patients about access to psychological support for them and their families/carers, and details of third sector organisations.

Holistic care would improve quality of life and for some the ability to return to work.

The Genetic Alliance UK, Good Diagnosis Report recommends that each of the UK's rare disease action plans include a rare conditions good diagnosis patient rights charter. This charter should clearly communicate the standard of care people with rare conditions should expect to receive.

This charter should be championed by those responsible for all those involved in the care of people living with MG and include the identified Principles of the Good Diagnosis report.

Recommendations about MG diagnosis

- Review and update the Association of British Neurologists guidelines for MG. In addition, standards should be agreed and published, and articulate why early diagnosis and treatment is important.
- Update advice and guidance and roll-out nationally, highlighting the importance of voluntary sector collaboration in its development. Include a PDF for GPs, what to look out for and signposting. Links to validated information and patient information (eg Myaware).
- Neurologists and GPs should work in partnership to develop new pathways for diagnosis. Design a diagnostic algorithm for MG in primary care. Consider measures eg timeframe for patient to be seen and appropriate tests completed.
- Use of artificial intelligence to examine patient records (flagging 6-8 common symptoms might mean the patient has MG. Refer for MG testing).
- Provide link to Good Diagnosis Report, and recommend that diagnosis should be informed and supported, collaborative and co-ordinated, respected and acknowledged.

Spotlight on data

There are very few rare conditions in the UK where you could confidently put a number on the people living with that condition. That's obviously a massive disadvantage if you're trying to improve those people's lives
- Genetic Alliance stakeholder

The Oxford registry (currently in development) will be a national, sustainable, and manageable database for myasthenic disorders in the UK, fulfilling an unmet need for clinicians. It will focus on data regarding people with Myasthenia Gravis and in the future, it may be used to help design clinical trials and advise health authorities. The database is being developed by John Radcliffe Hospital, Oxford, and funded by Myaware.

There is currently a lack of adequate data on the incidence and prevalence of MG, leading to the potential under-commissioning of services. Data is not currently being used intelligently to accurately capture where individuals are being treated, or what medication they are on.

There are differences in the use of treatments across the country, yet no mechanism to support the collection of outcome data. This data would provide more insight into treatment efficacy for certain cohorts of clinical cases.

MG clinical leads reported that data is not currently routinely collected or analysed within services due to lack of clinical time and resources.

There is lack a of investment in data collection for rare conditions compared to other diseases. For example, the national cancer registration service employees more than 100 people to register cancer across England. The national congenital anomaly and rare disease registration service currently employs a whole time equivalent of four people.

There is potential to support the investment in genomic data collection with registration data. There is value commercially in both datasets, but more importantly would be the ability to count people with rare conditions and build services around that need.

Priority 2: Raising awareness among healthcare professionals and others

Insights

"

I was visited by many medical students when I was in hospital because I was such a rarity

- Person living with MG

"

There is limited knowledge about MG presentation and treatment among trainee clinicians and others who may encounter people presenting with the condition, including GPs, medics in A&E, opticians and allied healthcare professionals such as physiotherapists, occupational therapists and dieticians.

More broadly, there is also a lack of awareness of MG in bodies or organisations tasked with providing social support, such as agencies assessing people for financial support. The variability of MG and its impact on people's lives are not adequately understood, so there is a need for easily digestible information to help educate social workers and council workers. There is also a need to raise awareness about MG and the potential impact of the condition in schools, universities and the workplace.

Raising awareness of MG among healthcare professionals would improve the speed and accuracy of diagnoses, as well as ensuring patients receive the best possible clinical care, particularly in medical emergencies. However, with 7,000 rare diseases, it is not realistic for healthcare professionals to receive comprehensive training on every condition. Consequently, the challenge is to develop an education programme for generalists that provides enough education to support diagnosis and treatment but is realistic in terms of time taken given their many priorities.

GPs face multiple challenges. They are expected to refer patients early, but only when they have excluded everything else, which takes time. There are no definitive biomarkers of MG, so it is hard to have a diagnosis quickly. Lack of continuity of care adds to these challenges. When there are complex conditions, such as MG, there is a worry that patients may see different doctors, causing them to fall through the gaps.

> *In 34 years, I have treated one patient with Myasthenia Gravis*
> *- GP*

There are neuromuscular care advisors who educate and advise health professionals but this is not co-ordinated or available within all Integrated Care Systems.

People living with MG told us that while having a rare condition is a challenge, the comments from clinicians can make the experience even more isolating. 'You have a 'rare' condition, you are different, we do not know about it.' Raising awareness, perhaps through mainstream media, and changing that discourse may reduce that feeling of isolation.

People living with MG have powerful stories to tell that would raise awareness of the condition and support any campaign or education programme. Successful approaches that have involved people with living with particular conditions, such as diabetes, have included patients as teachers, expert patients and health coaches. There is a potential to develop and utilise these approaches for MG.

Through this programme, people living with MG and clinical experts recommended co-designing an MG awareness-raising campaign/education programme. This could be adapted to include targeted messaging, appropriate to the audience. A tiered approach to dissemination could be designed, targeting groups and organisations, for example through training, specialist centres, neuroscience centres and talking at GP events (potentially targeting GPs with a neurological interest).

Myaware is the UK registered charity for MG which provides information for people living with MG and healthcare professionals including clinical packs,

posters and videos. They would be a key partner in any awareness-raising activities.

Priority groups identified include opticians and ophthalmologists, GPs and allied healthcare professionals. The campaign/programme could also be adapted for schools, universities and the workplace. This would be an opportunity to disseminate literature and accessible resources.

We heard that Myaware's current webinars are helpful but do not replace the intimacy and 'safe space' that people experience in face-to-face meetings. Although social media is helpful, some felt that it could be a 'frightening' space and that perspectives put forth on social media might be imbalanced. One person told us that she had been terrified by some of the experiences of others with MG when she was newly diagnosed. Others were concerned about some of the discussions that took place among patients during the Covid-19 lockdown and during the first vaccination roll-out when there was so much uncertainty among people.

Raising awareness in medical school

RAREAware Glasgow is a university society set up by medical student Zainab Alani, who lives with MG, and her sister, a fellow medical student. The society raises awareness of rare diseases and their impacts.

RAREAware now has over 120 members, a full committee of 12 students, and has successfully hosted their first sold-out event. The society uses social media to raise awareness and promote RAREAware.

The society hopes to host more events in the future, including a collaboration with the British Sign Language (BSL) Society where they will be educating attendees about rare diseases which cause hearing loss while learning some basic BSL.

Patient-held records/patient passports could improve co-ordination of care and would support healthcare professionals where knowledge about MG is limited but crucial to care.

Specialists should be supported to publish best practice and service developments in a neurology journal or on service improvement platforms like Future NHS. They should also be supported to engage with the NHS neurosciences service transformation programme.

Inclusion of rare diseases in soaps and television dramas raises awareness of

conditions. For example, MG was portrayed on ITV's popular comedy-drama series, Doc Martin. Patients with MG told us how MG being on a popular TV show normalised the condition and that people started to talk to them about their condition, rather than avoiding it, or pretending it didn't exist.

Recommendations about raising awareness

- Review all existing information resources about MG and design a national awareness-raising campaign (as above, central repository of awareness-raising and training materials). Myaware should be appropriately funded to provide information to people living with MG and to healthcare professionals.
- Develop and roll-out a national awareness-raising campaign. People living with MG to be supported to become advocates/educators (prioritise opticians / pharmacists / GPs).
- Patient-held records/passports to support healthcare professionals where knowledge is limited but crucial to care eg A&E.
- Specialists to publish best practice and service developments in neurology journals.

Priority 3: Better co-ordination of care

Insights

People living with MG face multiple hospital appointments and are likely to require the expertise of different specialists. They may also require regular interaction with other services such as GPs and social care.

Co-ordination of care has been identified as an issue across all rare diseases. The NIHR-funded Co-ordinated Care of Rare Diseases (CONCORD) study (Morris, et al., 2022) looks at co-ordination of care for rare diseases This study published a landmark definition of co-ordination of care in rare diseases:

> *'Co-ordination of care involves working together across multiple components and processes of care to enable everyone involved in a patient's care […] to avoid duplication and achieve shared outcomes, throughout a person's whole life, across all parts of the health and care system …*
>
> *Co-ordination needs to be … family-centred, holistic (including a patient's medical, psychosocial, educational and vocational needs), evidence-based, with equal access to co-ordinated care irrespective of diagnosis, patient circumstances and geographical location.' (Morris, et al., 2022)*

The CONCORD study also explored the extent and impact of care co-ordination (or lack thereof), through extensive interviews with individuals affected by rare conditions (including undiagnosed conditions), and family members who have a caring role. The overall findings emphasise the importance of flexible care, which is capable of meeting patients'/carers' individual needs throughout their rare disease journey. The study lists a number of recommendations from participants, including being able to access professional support in co-ordinating care; adapting the location, scheduling, and services available at clinics and appointments; and improving communication using technology, care plans, accessible contact points, and multi-disciplinary team working.

Our insights support the findings in the CONCORD report, and we acknowledge that many of the issues raised by our contributors are more broadly relevant than

to MG and rare diseases alone. Despite best efforts, failures in the health and care system are impacting services and patient care. Healthcare professionals in secondary and primary care reported that lack of resource is impacting their capacity to deliver services; in particular, access to mental health support and the ability of primary care to take on the monitoring of people living with MG. The situation has deteriorated since Covid-19.

Patients are frustrated that they are unable to physically see their GP, and are therefore making appointments to see their consultant with conditions that are not necessarily MG-related, thereby impacting specialist service delivery.

People living with MG reported that the co-ordination of care had been left to them or their carers. They had to navigate the system themselves or were sent to different services such as GPs, specialist nurses or neurologists.

"

I felt like a ping pong ball being bounced around different healthcare professionals.

- Person living with MG

"

People living with MG said their care was not joined up and they did not believe they were seen as individuals. They were often left to relay information from one department to another, managing different consultants and medication. People talked about how stressful this was as they didn't yet have access to their patient records and had to try and remember everything and repeat their story again and again.

All those participating agreed that co-ordination of care was critical, yet they felt it was becoming increasingly fragmented. There is an expectation that ongoing management of MG can be provided by the GP; however, GPs report there is no capacity and there are concerns about capability.

"

GPs are there for the common diseases not the rare diseases – I feel strongly on this.

- Person living with MG

"

There is variation in the implementation of shared care protocols whereby GPs, in agreement with the initiating specialist, would be able to share care such as prescribing and monitoring medicines/treatments. Specialists reported that the lack of agreements resulted in duplication of effort taking up clinical time. They believe the GP could undertake these aspects and negotiate patient-by-patient shared care agreements. However, regional arrangements require access to multiple IT systems for patient records, letters and blood results, which is not currently possible and is challenging to address.

Some people living with MG believe that the GP should not be involved after the diagnosis as the management of medications can be complicated. If these drugs are not co-ordinated or administered according to individual need they may cause further difficulties.

If primary care is successfully to manage people with MG, GPs need to be engaged in the development of shared care guidelines, be provided with reliable information and have immediate access to a point of contact when they have a concern.

> *GP practices will say well, we don't have a shared care agreement for this condition, so … you are always negotiating with the GPs. For one patient I've been going back and forth for six weeks with the GP practice. In the meantime the patient is still on the same dose of the drug and under-controlled.*
> *- Clinical Lead, neurology*

There was criticism regarding communication between secondary and primary care; it was viewed as cumbersome, too slow, lengthy, and either lacking in detail or containing too much detail.

What's working well

Some people living with MG and healthcare professionals in primary and secondary care reported that the increased use of technology during Covid-19

had improved communication, supporting access to consultants and virtual multi-disciplinary team (MDT) meetings.

One hospital described their rapid access service for GPs, where all enquiries are recorded in one portal rather than sent to individuals. This central portal is staffed daily for all neurology and other specialities, so that GPs received a response within 24 hours.

Remote or telecare is also popular; for example, in one service 50 per cent of follow-up patients used a telephone review. Some services provide video consultation if needed or preferred, and there have been discussions about including GPs in virtual consultations where appropriate.

Services and people living with MG who have access to a Clinical Nurse Specialist (CNS) reported benefits supporting co-ordination of care across services and signposting to wider support. Contributors said there were opportunities to learn from specialities such as rheumatology that have well organised systems in place provided by nurse specialists. Myaware is supporting a network of Clinical Nurse Specialists. This network is valued.

"

The CNS is key point of contact for the patient, co-ordinating role, liaison between services such as GP and local hospitals, referring to other teams etc. The CNS has be 'a jack of all trades'.
- Consultant Neurologist

"

What's not working well

People living with MG talked about feeling very isolated and finding the infrequency of support challenging. There is no consistent care pathway or help with navigation of the health and care system.

Spotlight on networks

The effective management of MG relies on patients being able to access specialist care, which may involve services beyond those immediately local to the patient. As such, regional and national collaboratives are key to providing consistently high standards of care.

While adoption of these networks is not yet uniform, a number of approaches were highlighted during the programme as showing the potential to improve patient care in MG.

National networks and collaborations

Rare disease collaborative networks (RDCNs) are an important part of NHS England's provision to support patients with rare diseases. RDCNs are made up of providers (rare disease collaborative centres) who have an interest in a particular rare disease and are committed to working together to progress research, increase knowledge and improve patient experience and outcomes.

A Juvenile MG RDCN has been established and is informing the development of the rare disease action plan. However, there is currently no corresponding RDCN for adult services.

Local networks and collaborations

There are currently several MG collaborations within the acute sector that are supporting improvements in patient care. By working together, services have been able to influence commissioners, for example, getting early access to new types of treatment. Some trusts are working together and networks are looking at different aspects of their practice, making sure they are in alignment with other tertiary centres and thinking about where they should be setting standards of care.

> "We should think about how we roll-out what we've been doing, such as publishing stuff and doing a case study of patients."
> *- Consultant Neurologist*

South west London and Surrey have established a network of 200 people affected by neurological conditions, which is looking at how to involve people affected by neurological conditions in their service improvement initiatives. Current projects for this network include running a pilot for future commissioning models under the ICS structure. This network also has the support of medical directors in the region, who help to advocate for change at an ICS level.

Establishing a rare disease collaborative network for MG and wider opportunities for influencing

There are opportunities to develop and co-ordinate existing collaborations and networks into an RDCN for MG, which could include GPs with a specialist interest

in neurology, people with lived experience and researchers. Working together, an RDCN would be in a good position to influence the rare disease action plan and high-level commissioning decisions.

The RDCN for MG could focus on collaboration and share learning, publishing new initiatives and case studies.
Outside of the RDCN, other opportunities to influence could be presented through:

- The clinical reference group for neurology. This is currently being reformed by NHS England, and Dr Niranjanan Nirmalananthan has recently been appointed as National Clinical Director for Neurology.

- The neurosciences service transformation programme. This project is underway and three optimal pathways have been developed for neurology. They are hosting webinars and there are opportunities for networks to learn from, influence and showcase improvements.

Other related conditions have established networks such as the British Peripheral Nerve Society and British Myology Society. These groups of clinicians have their own active communities and may present the opportunity for raising awareness of MG-specific issues, given the overlap in clinical interest.

Areas for development

Standardise care for people living with Myasthenia Gravis

Integrated Care Systems need to understand national and local prevalence and develop an economic model for MG. This would help identify resources required and where the input of those resources would have most impact. The work underway on the Oxford registry, will support this.

Creating a large dataset could be the way forward for clinicians to gain rapid access to informatics. Nationally, the healthcare system and those commissioning services need to know the numbers of patients, the spread of patients, what treatment they receive and how this is working for them. This includes the number of patients who aren't in specialist centres.

MG care of a specific patient may start with a treatment approach but this may need to change with the development of the condition, so there is a need for co-ordinated pathways of care for different levels of MG. There is learning from the UK's Parkinson's audit, the recognised quality improvement tool for Parkinson's

services. This audit allows measurement of practice against evidence-based standards and patient feedback in a continuous cycle of improvement. Using this approach would support the development of a national MG Audit.

A stakeholder group consisting of people with lived experience of MG and healthcare professionals should convene and in the next twelve months co-produce the specification for an MG audit tool. This should include developing questions and the audit process, and ensuring follow-up and reporting. Included within this, people with MG would be audited to identify whether they were referred to Myaware. This information would support the development of a service specification (developed with specialists, generalists in primary and secondary care and people living with MG) to improve co-ordination of care.

The specification should consider recommendations identified through the consensus development programme:

- adoption of a hub-and-spoke model for local or regional services, with access to a tertiary centre that has more specialist advice;
- establishment of a complex co-morbidity service comprising different healthcare professionals that could review complex patients and medications;
- development of guidelines to standardise care and monitoring of care. These guidelines should be designed in a way which is accessible to patients and could also include specific suggestions from the consensus development programme, eg designing a flagging system to keep the patients safe.
- making supplementary information available on NHS websites providing information about diet and exercise;
- the adoption of a multi-disciplinary team approach to MG care to provide:
    - Access to psychological support to help with general holistic care recommended as part of assessment and treatment. This could include managing fatigue and need to pace self, integrating work and family.
    -
    - Access to specialist allied health professionals such as occupational therapists, physiotherapists, dietitians in the same way other neurological conditions do, such as multiple sclerosis and motor neurone disease.
    -
    - Access to a navigator / CNS for MG to help navigate the system.
    -
    - Access to obstetricians and midwives who specialise in high-risk pregnancies

This MDT approach should be informed by the learnings of other similar services who make use of virtual MDTs to discuss cases with other services, inviting generalists including GPs where appropriate. For example, St George's has set up a virtual MDT discussion of complex cases. Imperial College hold digital consultations among clinicians and are looking at expanding this service for

patients. Southampton have a surgical MG MDT where cases are reviewed before surgery, including a complex MG MDT where clinicians discuss complex cases with their neuromuscular consultant.

Digital solutions

While it was noted that digital interventions will not work for everyone and concerns were raised about digital exclusion, the recommendation was to build on the momentum of accessibility to specialist treatment and the development of virtual MDTs and virtual consultations/meetings made during Covid-19.

People can access services remotely via video or telephone and many felt that video rather than telephone calls can be easier to access.

There should be a clinical code to identify MG in primary care patient record systems. This could be used to provide data on numbers of people at a practice and ICS level. It could provide important data on where people are being treated, their medication and outcomes.

Clinical Nurse Specialists

Services and people living with MG that have access to a Clinical Nurse Specialist reported benefits supporting co-ordination of care across services and signposting to wider support. The consensus was that the specialist nurse is critical for MG and there are examples (Liverpool) where a neurospecificity nurse has helped to co-ordinate care.

There were discussions about whether this needed to be condition-specific for each ICS. Decisions would need to be made based on prevalence data and economic modelling. The role should be standardised and should support services and people in hospital and the community.

> *The CNS role could be shared across the sector, not just available to the tertiary centre but accessible to the GPs and hospital. A community-based role.*
>
> *- Consultant Neurologist*

The British Association of Neuroscience Nurses (BANN) may be able to champion and support the development of this role and provide guidance on the number of patients per nurse. There is learning from multiple sclerosis (usually 100 - 200 patients per nurse).

It was recommended that the business case for a Clinical Nurse Specialist, developed by Queen's Square, could be shared with all services to expediate the implementation of this role in the UK.

Implementation and management of shared care protocols

While some healthcare professionals and people living with MG believe that while they are stable they should be managed by their GP, others felt very strongly that MG should be managed by specialists.

New national documents for shared care are currently being developed. It is important that any concerns are addressed prior to implementation and that they are co-produced with primary care workers and people living with MG.

It would be valuable if GPs could have peer contact details and an agreed expectation of response time from specialists.

Shared care records

There was consensus that shared digital health records were a positive way forward and that all people diagnosed with MG should have access to their medical records. People living with MG said they want to take control of their data via diaries, or an application that would integrate with IT systems so they could upload information into their medical records. These could in turn potentially be linked to the Oxford registry work. Digital records could be developed to identify issues related to low mood and provide signposting to mental health support.

> *The best data sets are held by the patient*
>
> *- Clinical Lead, Southampton*

Southampton is currently piloting shared care records, giving patients digital

access to their medical records, with the ability to upload their symptoms and scores of their symptoms. People living with MG can track their symptoms in real time, work out what is happening and let the specialist know when things are not going well. The evaluation of this pilot should inform further development and roll-out so it is available to all.

Myaware has developed a healthcare passport, which provides details of the individual's care team. It is held by the individual and can be used by other healthcare professionals to aid treatment decisions; for example during an emergency, when the person living with MG may be incapacitated.

Healthcare passports would include:

- a letter from the consultant explaining the condition and impact on health
- general information about MG (from Myaware) and
- a letter from the individual providing a personal perspective.

For some people it can be hard to find work, and support with life skills may help with employability.

Recommendations about co-ordination of care

- Develop a database (Oxford registry) to include: number of people with MG, spread (geographically), the treatment they are receiving, and to measure outcomes and financial modelling to understand the resources required and where they would have most impact
- Develop an audit tool similar to the Parkinson's one. Co-produce the specification for an audit tool.
- Use data from database and audits to inform a service specification to standardise care for people living with MG. Key components are recommended in this report.
- Develop a standard business case for the role of MG Clinical Nurse Specialists across services, supporting primary care and ensuring people living with MG understand the breadth of their role.
- Standardise shared care agreements (ICSs are looking at this but they will need to be developed with GPs, not just specialists)
- All people living with MG should have access to their records (a reference pilot is taking place in Southampton – share pilot evaluation when this is available)

Spotlight on access to wider support and care

As with better co-ordination of care, access to wider support and care is a challenge that is not confined to MG and rare diseases. There is a lack of partnership working within the health and care system and it is difficult to navigate.

Maintaining good mental health is difficult for many people who receive a life-changing diagnosis, but people diagnosed with MG are not routinely referred to psychological services and referrals to Improving Access to Psychological Therapies (IAPT) are via GPs.

Unlike other neurological conditions such as multiple sclerosis and motor neurone disease that take a multi-disciplinary approach, people diagnosed with MG often do not have access to specialist allied health professional services such as an occupational therapist, physiotherapist or dietitian. Services currently refer patients to local therapy services via their GP.

Some people had received little or no support or information on diagnosis about MG: they reported finding out about their condition through Myaware. There is no identified social worker or care provision in the community setting. This makes it more difficult to consider and address the wider needs of individuals as part of their care.

Communication with schools, universities and places of employment following a diagnosis is not routine and not always supported by healthcare professionals. There is a lack of understanding about the impact of MG and people said that they had experienced discrimination in education settings and the workplace, being labelled as lazy.

Neurologists working in services that employ a CNS and people living with MG that attend those services both agreed that CNSs support effective co-ordination of care across services and signposting to wider support and care, such as financial support.

Healthcare professionals and people living with MG talked about charities taking an active role as advocates and supporting people with MG accessing social services and benefits. They discussed if there were opportunities for charities to be funded to provide this support

It was recommended that all people diagnosed with MG should be signposted to Myaware who were often the broker between the patient and social services.

Communication with schools, universities and places of employment following a diagnosis should become routine and supported by healthcare professionals. Myaware has information about the condition that would support schools and the workplace but there is currently no mechanism for this to happen automatically.

One person shared her story about how she provided her university with information and it was recommended that a template be developed that could be adapted for individuals and sent to schools, universities and employers.

Priority 4: Improving access to specialist care and drugs

Insights

The range of treatments for people living with MG is currently limited compared to other neurological conditions, but those that do exist can be life-changing, significantly improving an individual's quality of life. There is variation in treatment pathways and access in different parts of the country. For some, it can take many years to be seen in a specialist centre; one of our contributors waited for two years.

Specialised commissioning is moving from a regional level to align with ICSs. This will provide a local focus and these new organisations are currently reviewing all diseases. Some will remain with NHS England.

There is a concern that some of the novel treatments are not available in the UK because of the high costs. There is lack of consistency in prescribing oral drugs. Currently, only commissioned centres can prescribe certain drugs and there is no framework that would facilitate broadening accessibility. MG specialists are working with NHS England to create a process that allows other providers to be considered and are providing guidance on setting up more NHS plasma exchange units.

The Early Access to Medicines Scheme (EAMS) helps to give people with life-threatening or seriously debilitating conditions early access to new medicines that do not yet have a marketing authorisation but where there is a clear unmet medical need. A number of MG specialists have met to discuss this scheme and plan to meet regularly to support early access where appropriate. Administration support would help facilitate this ambition

There is variation across the country with some people needing to travel significant distances to access specialist centres. There is a higher concentration of neurologists in London and the south east. Outside of London, patients are more likely to have to travel.

The variation is unfair. You should get access to the same treatments and expertise whether you live in London or mid Wales. That's where the virtual clinics are so important. The first meeting face-to-face to establish a relationship but virtual after that

- GP

Community services for therapy are not set up for chronic conditions where patients potentially need less frequent but more long-term treatment and advice. For some, the delay in accessing occupational and physiotherapy meant that muscle weakness was already severe.

However, the challenge is broader than the cost of the drugs. It also involves managing people on those drugs, patient expectations and minimizing side effects. Examples of drug side effects include developing diabetes, osteoporosis muscle weakness; though it can be unclear if symptoms are a result of MG or medications.

People living with MG are given drugs to manage their condition but are not always fully informed of the implications of these drugs (specifically steroids, which can make MG worse). Some felt that they were unable to discuss the implications of their drugs with the neurologist, and others struggle to understand how cases can vary. People living with MG often present treatments that they have researched during appointments with their clinicians, and it can be difficult for some healthcare professionals to explain why they may not be eligible for a treatment.

Lack of awareness of the condition by some clinicians is a challenge, particularly when patients present in A&E. Due to their condition, they may be unable to advocate for themselves and, if they are under specialist care, their records may not be available out of hours.

The management of MG in the elderly (75+) is challenging when individuals have complex co-morbidities. Following treatment guidelines may impact other conditions and little has been published on this subject.

There is a lower level of understanding by clinicians outside of centres of

excellence about treatment pathways and prescribing drugs 'off label', with people reporting that they had to be their own advocates and persuade healthcare professionals to prescribe.

GPs reported that they do not know enough about the disease and its complexities to be able to give sufficient advice without specialist input, particularly where there is late onset of MG and patients are on other drugs. GPs report that in the current climate it is beyond their capacity and capability to monitor and they need access to support and advice.

MG in childhood is quite rare and there is variation in practice among neurologists about how MG should be managed in children. There is a lack of funding for treatment with high-cost drugs available in the USA but not approved by NICE.

There are challenges in delivering low-volume, high-cost treatments. A network approach (hub-and-spoke model) may provide scale that will overcome some of the efficiency challenges but provision needs to be identified at ICS level.

There are disadvantages for some people who may have to travel long distances and there is need for some local care, particularly for people with frailty. MG specialists are working with NHS England to create a process that allows other providers to be considered and are providing guidance on setting up more NHS plasma exchange units. An agreed framework would expand serviceability of treatments and ensure they are more widely available.

The Early Access to Medications Scheme has started and is facilitating access to certain drugs for MG treatment. This scheme has got people talking, and informal networks are being created between centres, which have generated a lot of enthusiasm and knowledge. Administration support to develop these networks would be helpful.

An MG network of specialists, generalists, the voluntary sector and people living with MG should work with the ICSs to develop evidence-based treatment pathways and consistent access to specialist care and drugs.

Recommendations about improving access to specialist care and drugs

- MG network to work with ICSs to develop evidence-based treatment pathways
- Measure access and outcomes to reduce variation

- An agreed framework to expand serviceability of treatments eg plasma exchange, to ensure they are more widely available
- Develop information for healthcare professionals about the use of 'off label' medications

Other overall recommendations

- Need for an MDT approach on diagnosis, role of CNS and Myaware to support access to social services and benefits, communications with schools, universities, etc.
- Specialists, GPs, Myaware and people with lived experience establish a formal network that can inform the development of the rare disease action plan and drive service improvements.

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This report includes anonymised quotes contributed by people who participated in our semi-structured interviews and focus groups. Some of these people are named below and those who contributed the expert panels are indicated with an asterisk. We have not named our patient contributors in this document but are especially grateful to them.

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