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Foreword

In March 2013, Muscular Dystrophy UK was awarded a three-year grant by the Department of Health, with the aim of securing neuromuscular service developments in the newly reformed NHS. To do this, the charity developed their Bridging the Gap project.

The objective of the Bridging the Gap project was to engage with key individuals and organisations to help support improved service commissioning in the NHS for people with muscle-wasting conditions.

It is pleasing to be able now to review this project report and to assess that Muscular Dystrophy UK has achieved this goal and so much more. In doing so, they have taken a great stride towards strengthening the care provided in England to people with muscle-wasting conditions.

By bringing together expert neuromuscular specialist clinicians, patients and NHS England commissioners, the project has helped drive forward the development of neuromuscular services, and secured increased investment in the support available to people living with muscle-wasting conditions.

In addition, the Bridging the Gap project has created new, award-winning and life-saving information resources, including alert cards that can help inform paramedics and emergency healthcare teams of the specific needs of patients with muscle-wasting conditions. The project has also launched the first-ever online map of neuromuscular services across the country, helping patients and health professionals to identify the best locations to receive specialist neuromuscular care.

I am delighted to see the highly positive impact that the team at Muscular Dystrophy UK has had in ensuring that the voices of people living with these rare conditions are heard and can in turn play a leading role in shaping the services they need.

Lord Prior of Brampton
Parliamentary Under Secretary of State for Health
Executive summary

NHS specialist care is a vital element in the lives of people affected by muscle-wasting conditions. It ensures the correct condition diagnosis and, by providing relevant and tailored ongoing care, helps to ensure the best quality of life possible.

However, because muscle-wasting conditions are so rare, they are often overlooked in the commissioning of NHS services. Muscular Dystrophy UK recognised that there was a need to give people with muscle-wasting conditions a voice in shaping the healthcare they receive.

In response, Muscular Dystrophy UK developed the Bridging the Gap project in order to improve:

- clinical capacity in NHS hospital trusts
- community health professionals’ knowledge of muscle-wasting conditions
- the support available to those who commission NHS services
- the tailored support and information available specifically to people with muscle-wasting conditions

In this review, we detail how the Bridging the Gap project has brought together patients, health professionals and NHS commissioners in England, to develop healthcare and support for people with muscle-wasting conditions.

Project summary

In 2013, the Department of Health awarded Muscular Dystrophy UK a three-year grant to develop expert-patient consultancy. This was to support the improved specialised commissioning for people with muscle-wasting conditions within the new NHS structures. Panels of people with these conditions, backed by clinical ambassadors, were set to advise new NHS commissioning bodies on commissioning effective, integrated services to meet the complex, specialised needs associated with muscle-wasting conditions.

Project aims

Throughout the Bridging the Gap project we have aimed to improve the healthcare, quality of life and independence that people with muscle-wasting conditions receive in England, through ensuring timely access to integrated health/social-care services responsive to their needs.

By improving co-ordinated preventative care, our aim has been to help reduce the number of emergency hospital admissions. This would lead both to significant savings for the NHS, and improved healthcare experiences for people with muscle-wasting conditions.

The key to achieving these care improvements has been ensuring people living muscle-wasting conditions, as well as their families, have a strong voice in the development of the NHS services they use. Patients are often the experts in the management of their conditions, and it has been vital to ensure patients have taken a leading role in the Bridging the Gap project.
Driving forward specialist care

Neuromuscular regional forums and emerging neuromuscular networks

In October 2013, we launched regional neuromuscular forums across England. These are made up of:

- neuromuscular specialist clinicians
- service users and family representatives
- NHS decision-makers and budget-holders, including NHS England specialist commissioners
- Strategic Clinical Networks
- other regional stakeholders.

The forums have identified the key service gaps for patients with muscle-wasting conditions living in each NHS England region. They also ensure that local examples of best practice are being shared across regional centres. In addition, the forum members work together in the delivery of neuromuscular healthcare across the region.

Over three years of the project cycle, the forums have grown and become a valued and respected part of neuromuscular service delivery. They have helped to secure 46 new NHS-funded neuromuscular roles and saved 15 existing roles that had short-term funding or were going to be discontinued. This amount equates to an investment of £3.6m in England.

A direct result of this is that the voices and needs of people living with muscle-wasting conditions are being heard more clearly by NHS decision-makers. This has led to the successes listed above, since the start of the Bridging the Gap project.

Some of these forums have now evolved into NHS England-backed clinician-led neuromuscular clinical networks (London and South East Coast, North West and North East).

Martyn Blenkharn (pictured), who has facioscapulohumeral muscular dystrophy (FSHD), is a North West Neuromuscular Forum patient representative:

“It was great to be able to represent Muscle Group members from across the region at the Forum. I was impressed with the progress we were making and it was clear that we were making a real difference to the neuromuscular services in the region. It is important that we continue to make the case for better services and support for patients and families, and through these forums we will continue to see a clear improvement.”
Engaging with NHS decision-makers to improve care

Through the Bridging the Gap project, we have worked with a wide range of national and regional NHS organisations to improve the commissioning of neuromuscular health services, at both specialist and community level.

The groups include:
- NHS England regional service specialist commissioners
- NHS England Strategic Clinical Networks
- NHS England Clinical Reference Groups
- Clinical Commissioning Groups (CCGs).

Each of these groups has an individual remit in the commissioning of services, so engaging with each on different topics is important for service improvement.

Through this work, we have achieved the following:
- the creation of the first CCG policy on the commissioning of cough assist machines for people with muscle-wasting conditions
- the clustering of groups of CCGs to fund specialist NHS neuromuscular roles
- the setting up of neuromuscular networks backed by the NHS
- the creation of regional and national neuromuscular care pathways.

Muscular Dystrophy UK is a member of NHS England’s Paediatric and Adult Neurosciences Clinical Reference Groups (CRGs). Both of these groups are in place to ensure that the correct advice on the care needs of people with muscle-wasting conditions is given to NHS services. Being a member of these groups enables the charity to continue sharing best practice, which patients inform us about. CRG membership is not permanent, so re-application for membership is needed. In the past year, the Bridging the Gap team successfully re-applied to retain membership of both groups.

As members of the paediatric Clinical Reference Group, Muscular Dystrophy UK was tasked to write and secure commitment from NHS England to a revised version of the
paediatric neurology service specification. This was to ensure neuromuscular conditions were well represented within this document (previously not the case). The specification has been written and has been well received by NHS England commissioners. It is now being tested by stakeholders.

The service specification is expected to be published in 2016. It will contractually oblige all NHS Trusts in England that deliver neuromuscular services to provide a universally high standard of service to children with muscle-wasting conditions.

National audit of neuromuscular centres 2015

In 2015, Muscular Dystrophy UK audited the specialist care delivered at muscle centres in the UK. This was the second time such an audit was conducted – the first one took place in 2012. The purpose of the audit was to assess – and recognise – specialist centres that provide outstanding clinical care to people with muscle-wasting conditions. The audit results have given us a comprehensive overview and picture of clinical care provision at centres UK-wide. In addition, and perhaps more importantly, these audits have helped us identify the key challenges centres are facing in being able to provide the best possible service.

Muscular Dystrophy UK’s Services Development Committee sub-committee, who commissioned the audit, recommended that three neuromuscular centres be recognised as ‘Centres of Excellence’:

- Wessex Neurological Centre in Southampton
- Addenbrooke’s Hospital in Cambridge
- Robert Jones and Agnes Hunt Orthopaedic NHS Trust in Oswestry.

With the addition of these three centres, there are now 10 neuromuscular centres UK-wide that have been recognised as being excellent.

The sub-committee also recommended that two neuromuscular networks be recognised as being excellent:

- the South West Operational Delivery Network
- the Scottish Muscle Network.
Audit findings:

Changes in specialist care available at muscle clinics in the UK

Capacity in clinics:
The need for new roles to support patients with muscle-wasting conditions was the biggest finding from both the 2012 and the 2015 audits. In 2012, 44 percent of centres mentioned the need for more staff including consultants, physiotherapists, care advisors and occupational therapists. In 2015, this need was mentioned by more than half of the centres, who also highlighted the need for clinical nurse specialist roles and research fellows.

Care advisors:
Our 2012 audit showed that the participating centres had 16 care advisors and 10 specialist nurses/clinical nurse specialists in post. In 2015, the audit showed that the participating centres now have 30 care advisors, and 14 specialist nurses/clinical nurse specialists in post.

Physiotherapy:
In 2015, there were 60 neuromuscular specialist physios working across the 28 centres that completed the audit. By comparison, only 25 physios were listed in the 2012 audit of 17 centres. In other words, in 2012 there were an average of 1.45 physiotherapists at every centre, and in 2015 there were 2.13 per centre.

Psychology:
Many centres said the provision they did have was either stretched or at full capacity. In 2015, nine muscle centres had a neuromuscular psychologist on their staff. This was an increase from 2012 when only three muscle centres had a psychologist as part of their multi-disciplinary team.

Dr Simon Hammans, a lead consultant neurologist at the Wessex Neurological Centre, said:
“lt’s fantastic for our patients to see their hospital recognised as one of the country’s leading centres for neuromuscular conditions, with a desire to maintain clinical excellence.”
Audits of neuromuscular services and unplanned admissions

The UK’s first Neuromuscular Complex Care Centre (NMCCC) based at the National Hospital for Neurology and Neurosurgery, Queen Square, London opened on 9 September 2014. The NMCCC has been designed to provide a one-stop multi-disciplinary assessment of people with neuromuscular conditions.

In 2016, the NMCCC carried out an (anonymous) patient experience survey. Findings included:

- 89 percent of service users felt the co-ordination of care had improved since the launch of the NMCC
- patients felt that the NMCCC provided a single point of access for multi-disciplinary assessment in an environment that was sensitive to their complex needs
- most patients (76 percent) felt that the NMCC had enabled them to access new services
- 50 percent of patients noted a drop in the number of acute hospital admissions
- patients have had access to new services, such as dietitian, psychologist, which were not previously available for them
- the inpatient experience was perceived as more relaxed when compared to a general ward environment.

We also worked alongside the John Walton Muscular Dystrophy Research Centre in Newcastle and NHS England on a separate audit of emergency admissions in the North East. The audit covered admissions between 2013 and 2016 and showed that only 21 percent of admissions were potentially avoidable with increased co-ordination of patient care. This compared to the finding of a similar audit in the South East in 2012, where 40 percent of admissions were found to be preventable.

This difference illustrates how well-co-ordinated neuromuscular care at a centre that has streamlined multi-disciplinary provision, can help reduce patient admissions and save the NHS money.
Improving the provision of cough assist machines

In 2014, Freddie Kemp – a young man from Cornwall – died after being turned down for a cough assist machine by his local NHS Clinical Commissioning Group (CCG). The cough assist machine would have helped to keep his lungs clear.

The poor commissioning of cough assist machines was identified by health professionals, as well as families living with muscle-wasting conditions, as a major issue across the UK. Both the CCGs and NHS England saw it as the responsibility of the other. Muscular Dystrophy UK highlighted this service gap at two meetings with health ministers, as well as via eight parliamentary questions.

The Bridging the Gap project team led a joint venture with Walsall CCG, and came up with a best practice commissioning policy for cough assist machines.

The ‘Walsall policy’ has now been adopted by seven CCGs in the West Midlands. It is currently being disseminated across all CCGs in the country through NHS England networks.

Naima Ali-Khan from Coventry said:

“My daughter has been in need of a cough assist machine since her respiratory weakness resulted in her needing night-time ventilation. The cough assist machine would help her to clear the extra secretions produced by overnight ventilation, which she struggles to clear herself. This has led to weight loss, as she is unable to manage to eat well in the mornings and last year she was hospitalised after getting a chest infection. As a parent, it is so frustrating that confusion over who is responsible for funding is preventing my daughter getting this vital equipment.”
Reaching and supporting more people with muscle-wasting conditions

Over the three years, 2,680 people with muscle-wasting conditions have directly benefited from the activities of the Bridging the Gap project.

The charity has also seen a 33 percent increase in the number of people we support: from 10,972 to 14,622.

Between 1 January 2015 and 1 July 2016, we engaged with 1,990 new people with muscle-wasting conditions. Comparing that figure with the same time period in 2012/13, we reached 884 people. Of those newly in contact with the charity, more than 1,400 approached us for support through the Bridging the Gap project.

At the end of the project, membership of Muscle Groups (patient support groups) has grown to 2,337 members. This is an increase of approximately 1,300 since July 2013. Muscle Groups have several functions: an opportunity for support and for meeting people in similar circumstances, as well as a key forum for members to feed in updates and concerns about services in their area.
Peer support network

Our new peer-to-peer support network is now operational, with 40 people with muscle-wasting conditions who have been trained to provide emotional support to other people in similar situations. This is the first time MDUK has been able to offer this service; our expert information team can now signpost individuals and families to others who have first-hand experience of living with muscle-wasting conditions. Feedback on the effectiveness of this network is proving very positive from individuals and health professionals who signpost families to the peer-to-peer support. To date, we have linked up 30 individuals with peer-to-peer supporters.

Elly Miller, from Stockport, said:

“I want to be a peer support volunteer to help others at the time of diagnosis. I felt quite isolated, when I was diagnosed with congenital myopathy, and would have benefited from having someone to talk to who had been through a similar experience. I’m also aware that getting a diagnosis can be a lengthy and frustrating process, and sometimes we don’t get a definite answer.”

Supporting diverse communities

Our Awaaz group was launched in Bradford in 2014 and continues to welcome new families at the regular group events. The peer support group, for South Asian families living with muscle-wasting conditions, now has more than 50 participants who come together to provide advice and friendship.

Meetings have featured themed discussions, as requested by the families involved, on topics such as:

- getting the right wheelchair
- support and days out at local hospices
- accessing disability sport
- adapting properties.

We will continue identifying communities facing additional barriers, particularly on account of ethnicity.
Awaaz group member Nazma Chowdhury said:

“I cannot tell you enough how much this group means to people. It can be incredibly isolating having a child who has a condition that people know little about. Navigating the health system and negotiating all the NHS services can be extremely daunting. We hope this new forum will be the missing link for many families in the area. This group, as well as being a community for families, will help to break down the barrier of language and culture that may prevent some people getting the best support available.”

The Hub and online map of neuromuscular services

We launched the first-ever online map of neuromuscular services and support that is available across the UK. ‘The Hub’, as the portal is known, includes a searchable database of:

- all muscle clinics
- hydrotherapy pools
- Changing Places toilets
- useful places to access mobility equipment and other useful resources
- best practice information on neuromuscular conditions for specialist and non-specialist health professionals.

This resource extends our capacity to offer practical advice and signposting far beyond personally answering queries.

The Hub has had 27,000 visits in the first two years. Families, commissioners and clinicians have found The Hub to be extremely useful.

Sulaiman Khan, from London, who has congenital muscular dystrophy, said:

“The Hub brings together information for people with muscle-wasting conditions, for health professionals and for NHS commissioners. It is a great one-stop-shop for anyone to find information about muscle-wasting conditions. For me personally it has been a great resource that allows me to quickly and easily find information where previously I was unable to find any of these resources all in one place.”
Supporting young people through transition

Many young people have told us that they didn’t feel supported when they went through transition from children’s to adult neuromuscular services.

Transition can be a difficult time both for young people with muscle-wasting conditions as well as their families. So it is essential that they have access to all the information they need to get the best health and social care possible.

We are creating a new guide for young people that explains the process of transition. We have also launched new online resources for young people, to help give them the information they need at this time of transition.

Laura Bizzey, who has minicore myopathy, said:

“The new young people’s section of the website has information, tips and reassurances specially created for young people with muscle-wasting conditions – whether they are newly diagnosed or just reaching new stages of their lives. Discovering these new resources make me really happy, because when I was diagnosed at eight years of age, in (roughly) 2005, there was very little information and support out there for young disabled people.”

Condition specific and multi-disciplinary team videos

We have created short information videos on Duchenne muscular dystrophy, Becker muscular dystrophy, facioscapulohumeral muscular dystrophy (FSHD), myotonic dystrophy and Charcot-Marie-Tooth disease (CMT). We have also created a short video outlining the specialist healthcare that families and individuals with muscle-wasting conditions can expect from a specialist multi-disciplinary team. These videos, which are available online and have been viewed over 12,000 times, feature people living with muscle-wasting conditions, neuromuscular care advisors, consultant neurologists and geneticists, physiotherapists, cardiologists, and researchers.

Tracey Franklin from Humberside, whose 19-year-old son Jack has Duchenne muscular dystrophy, said:

“This short film is amazing and really informative. I wish this had been available when Jack was diagnosed. It was also fantastic to see the variety of health professionals explain clearly what they do.”
Supporting health professionals

At our Muscle Groups, regional forums and social media, Muscular Dystrophy UK often hears about major gaps in the knowledge of health professionals supporting people with muscle-wasting conditions.

Through the Bridging the Gap project, we have run neuromuscular upskilling events for more than 1,800 health professionals, with many more future events planned.

Online training courses for physios working with adults with muscle-wasting conditions

We developed a new online training course for physiotherapists. Developed by patients and specialist neuromuscular physiotherapists for their community-based peers, the course has been completed by more than 700 physios to date. We have started work on developing a similar online course for physiotherapists working with children with muscle-wasting conditions.

In addition, we have worked alongside specialist neuromuscular teams across England over the past three years, and have run regional upskilling events for 448 physiotherapists.

Bettina, a community physiotherapist from London said:

“I really enjoyed the lectures, I feel I have learnt a lot. I have been working in a community neurology team for over a year now, having previously only worked in hospital settings and mostly in stroke. This course has really helped me in my understanding of neuromuscular conditions and will help me a lot in the areas of assessment, choosing suitable outcome measures, exercise prescription and overall management of these patients. It is great that this course is available online for free. I will definitely recommend completing this course to other members of my team.”

Online training courses for GPs and training GPs in the community through CCGs

We worked alongside specialist neuromuscular consultants, patients and the Royal College of General Practitioners to launch an online course for GPs on their role in the care of people with muscle-wasting conditions. The course has proven very popular with GPs and we have already seen over 600 GPs complete the module to date. To help maximise the impact of the course, we joined with CCGs across England and held seven protected learning events for GPs. Each event was attended by approximately 100 GPs, and included presentations from regional neuromuscular specialists.

Dr Sheonad Laidlaw, a GP from Glasgow, who has a daughter with spinal muscular atrophy (SMA) said:

“Although neuromuscular disorders are rare, and many GPs will have very few patients with these conditions throughout our careers, we play an important role in identifying and supporting the 70,000 people in the UK who live with a muscle-wasting condition. We need to
know when and where to refer these patients and be confident in managing acute complications, such as respiratory infections. These conditions are life-limiting and the individuals affected deserve the best quality of life possible through good holistic care. This course will help GPs recognise and manage some of the more common neuromuscular diseases.”

Alert cards

In late 2014, we launched the first of our new alert cards and care plans. We have developed alert cards for 12 different muscle-wasting conditions, as well as one for undiagnosed muscle-wasting conditions. This has positioned Muscular Dystrophy UK as a source of information on specialist care in emergencies, respected and trusted by those affected as well as health professionals.

The alert cards, designed to inform health professionals in times of emergency, contain the vital and specific issues that affect adults and children with a range of conditions. We have alert cards for people with:

- Duchenne muscular dystrophy
- spinal muscular atrophy (SMA) types 1,2 and 3
- Charcot-Marie-Tooth disease (CMT)
- myotonic dystrophies types 1 and 2
- limb girdle muscular dystrophy 1 and 2
- Becker muscular dystrophy
- undiagnosed muscular-wasting conditions
- facioscapulohumeral muscular dystrophy (FSHD)
- congenital muscular dystrophy.

The cards have been valuable to families affected by muscle-wasting conditions, with 52 percent of people in our national patient survey saying these resources had been useful to them. More than 8,000 cards have now been requested by people living with muscle-wasting conditions, and neuromuscular specialist clinics. The cards have also been highly commended by the BMA as a patient resource that improves healthcare.

Our new care plan for people with muscle-wasting conditions is also proving helpful for neuromuscular specialist teams and people living with muscle-wasting conditions. We have had almost 1,300 requests for the care plan since its launch last year.

Jacqueline Burns from Corby, whose son James (pictured) has Duchenne muscular dystrophy, said:

“James always carries this card on him. He gave the card to the ambulance team – as they were giving him dangerous levels of oxygen. They immediately lowered this – as the paramedics had no knowledge of the risks for people with DMD. James made it to A&E and the resuscitation team who met him said he would have certainly had a fatal heart attack had the ambulance staff not been given the card, and acted quickly.”
Ambulance flagging

When treating patients with muscle-wasting conditions in a health crisis, paramedics need access to specialist information, so they can prioritise these patients. This was illustrated when a young man in London died because an ambulance crew failed to reach him in time.

We have established a partnership with the London Ambulance Service, and all neuromuscular centres in London. This is to run an emergency flagging system for people with muscle-wasting conditions who have been identified by their specialist consultant as requiring priority support in a health crisis. The new system will mean that ambulance crews have information about a patient’s condition prior to arriving at their home. We now aim to replicate this system with other ambulance services across the UK.

Ravi Mehta from London, who has Duchenne muscular dystrophy, said:

“My respiratory problems can be frightening, and to know that a medical team will have full access to my medical records in an emergency is a huge relief.”

A new network of health professionals for adults with Duchenne muscular dystrophy

Together with specialist health professionals, we have set up the first-ever national network of neuromuscular specialists supporting adults with Duchenne muscular dystrophy.

The North Star Adult Network is made up of neuromuscular expert consultants, physiotherapists and other allied health professionals, and Muscular Dystrophy UK. We are working together to improve the standards of care and support available to adults across the UK who have Duchenne muscular dystrophy.

The Network is in the process of developing groundbreaking guidelines for standards of care for adults with Duchenne muscular dystrophy. There are also plans to develop a database of information on Duchenne muscular dystrophy in adults, which will be a major driving force towards the future potential for clinical trials for young men with the condition.

Dr Ros Quinlivan, a consultant at the Centre for Neuromuscular Diseases at the National Hospital for Neurology and Neurosurgery, chairs the Network. She said:

“It is so valuable to be able to bring together specialists in the care of adults with Duchenne from across the UK and to hear how our services are similar and also differ in the ways we deliver care for our patients. We will all be working hard over the coming months to create these new guidelines that will drive forward the care for adults living with Duchenne muscular dystrophy.”
Recognition for the Bridging the Gap project

The co-chairwomen of the Yorkshire Awaaz group received President’s Awards – as Charity Champions – at the Muscular Dystrophy UK National Conference. They received these awards from charity President, Sue Barker, for their leadership in supporting other families from South Asian backgrounds in West Yorkshire.

The life-saving alert cards have been highly commended at the British Medical Association (BMA) Patient Information Awards 2016.

The Hub was shortlisted by the Health Service Journal Awards for an award in 2015.

Neuromuscular champion, Tracey Franklin, was recognised for her work as an ‘expert service user’ at the national NHS Excellence Awards 2014.
The next steps...

Muscular Dystrophy UK is determined to maintain the momentum for developing neuromuscular services that has been achieved through the three-year Bridging the Gap project. We will continue many of the highly effective programmes.

New projects planned for the immediate future include:

- expanding the reach of regional neuromuscular forums and clinical networks to include more local NHS commissioners and increase the involvement of people living with muscle-wasting conditions
- playing a leading role in the national commissioning of neuromuscular services through membership of the adult and paediatric neurosciences CRGs
- working ever closer with neuromuscular clinical teams, using a partnership approach to ensure people with muscle-wasting conditions have access to the charity’s information and advocacy resources
- highlighting the need for increased specialist neuromuscular support and driving forward the case for new clinical roles across the UK
- developing an online training module for allied health professionals working with people with muscle-wasting conditions
- creating an online training module for physiotherapists working with children with muscle-wasting conditions
- working with clinicians and health economists to benchmark best practice for the number of patients seen by neuromuscular consultants, care advisors and physiotherapists
- developing an app to help individuals and families organise and co-ordinate their care in an integrated way
- co-ordinating the development of the first-ever national care guidelines for the support of adults with Duchenne muscular dystrophy
- improving the quality of care delivered to people with high-risk muscle-wasting conditions in a health crisis, by flagging their vital information with ambulances services across the UK
- improving the support we provide to families from diverse communities across the UK
- creating alert cards for further muscle-wasting conditions.
Muscular Dystrophy UK is the charity bringing individuals, families and professionals together to beat muscle-wasting conditions.

- We are supporting high-quality research to find effective treatments and cures, and leading the drive to get faster access to emerging treatments for UK families.
- We are ensuring everyone has the specialist NHS care and support they need, with the right help at the right time, wherever they live.
- We are providing a range of services and opportunities to help individuals and their families live as independently as possible.