

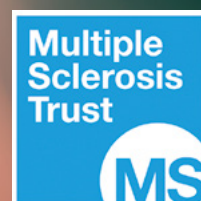


CASE STUDY COMPENDIUM

The QuDoS in MS Recognition Programme 2019

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The South East London Kent and Medway (SELKAM) Regional MS Nurse Advisory Group



Innovation in practice

Royal Wolverhampton Trust (RWT) MS Nurse Team



Outstanding MS nurse

Karen Vernon, Salford Royal NHS Foundation Trust

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INTRODUCTION & FORWARD

The QuDoS in MS – Recognising Quality in the Delivery of Services in Multiple Sclerosis – recognition programme is a pharmaphorum initiative supported by the MS Trust and sponsored by a number of pharmaceutical companies.

QuDoS in MS highlights innovation and excellence in MS care management and service delivery, recognising the valuable contribution of individuals and teams in improving the quality of life and experience of care for those with MS.

In this compendium you will find a range of QuDoS multiple sclerosis NHS case studies

taken from the winners and shortlisted finalists from the 2019 programme. Read on to find out more, including the challenges faced, how the shortlisted candidates overcame them and most importantly how you could implement these great initiatives.



David Martin
CEO, MS Trust

One of the great privileges of my role is meeting the inspirational specialist healthcare professionals who spend every day making the lives of people with MS better. Their commitment, expertise and dedication are worthy of celebration, so the MS Trust is delighted to again partner with pharmaphorum and our sponsors for the 2019 QuDoS in MS recognition programme. Whether you're an MS specialist nurse, physiotherapist, occupational therapist, physician, pharmacist or an allied healthcare professional involved in innovative practice, we want to hear from you!"

QuDoS Multiple sclerosis: NHS case studies 2019

Outstanding MS physiotherapist commendation

Name, job title and centre

Sarah Brenton, Specialist Neurological Practitioner, Dorset Healthcare University NHS Foundation Trust

Project / initiative name

Various initiatives, including establishing a 'duty' telephone service for MS patients, psychological support for team members and multi-disciplinary team working

Project start date

Range of services rolled out by the team across 2018 to 2019 and currently ongoing



Challenge

- Ongoing support is needed throughout the course of an MS patient's life, which is a long period of time to try and continuously maintain and improve quality of life; this requires a high level of support from MS teams
- Acute symptoms for infections (eg, urinary-tract infections) pose a continuous challenge
- Managing patient deterioration over time
- Carer management can also be challenging; there can be differences in terms of what the carer (frequently a close family member or spouse) believes is best for the patient and what the MS team would recommend

- Occasionally team members may be required to manage psychologically challenging issues (eg, suicidal patient interactions) when they are not trained specifically in the appropriate area (eg, mental health crises)
- Staff resourcing is always a challenge
- Responses to patient queries in short time frames

Solution

- A multi-disciplinary, flexible team has been developed that responds to patient needs quickly

Solution cont...

- 'Joined up' team working has been applied throughout the service; for example, where a patient meets a different healthcare professional each month, they are still part of the same multi-disciplinary team with regular communication between team members; this means that continuity of care can be experienced by the patient, without the entire need for support falling on just one individual (eg, nurse, therapist)
- In the case of carers, the multi-disciplinary team works closely with each other, speaking with both patient and carer (eg, in a group visit) and encourages positive changes that will improve the patient's life whilst also bringing the carer on-board with those decisions
- A telephone 'duty' service has been set up three times per week (two-hour slots each); a member of the professional care team is available to patients via the telephone and is ready to respond to any issues in real-time
- Psychological support is now regularly available for the multi-disciplinary team members, which is particularly helpful for those dealing with challenging patient mental health issues
- All team members have access to patient details, which further supports the 'joint team working' approach
- Networking between services has been increased, which has improved geographic coverage of MS services
- Hospitalised MS patients now receive rapid follow up after discharge
- The multi-disciplinary team is involved in equipment ordering (rather than solely being reliant on district nurses).

Results

- There has been positive feedback, especially related to team home visits (rather than patients having to go to clinics)
- There has been an increase in care support in terms of time spent with the patient and carers
- More cross-discipline information and insights has been gathered as a result of working as a multi-disciplinary team
- There have been improvements in working relationships with other services (eg, social services), which has allowed alignment of care plans and improved overall service for the patient
- Telephone 'duty' received a large patient uptake and positive response
- The psychological support has helped the care team to feel valued and supported in challenging scenarios
- There is now more communication between team members overall, which improves patient care continuity

Next steps

- Potentially launching the 'Attend Anywhere' initiative for virtual patient interactions (F2F but via a digital platform)
- Planned participation in MS Trust development courses, covering advance care planning and bladder scanning
- Insights gained from the MS Trust conference will be shared with the multi-disciplinary team, especially relating to management of PEGs and beginning patient conversations earlier (eg, discussing potential scenarios with the patient, such as in case of chest infections and palliative care decisions)
- Training to deliver botulinum toxin for patients with spasticity symptoms is also planned

What has been the biggest challenge?

Managing patient expectations about what the MS services can do (especially with lots of changes to the services).

How did you overcome this challenge?

The team has had lots of new ideas for supporting MS patients, especially by working with other services (eg, social services); communication has been key – patient issues are varied so team discussion is important. Patients (and their carers) feel supported and that their specific perceived needs are being met. Availability and responsiveness of the team has been crucial (especially for anxious patients and family) – often a reassuring response (via a phone call or visit) is all that is required. Being clear with patients about how they can be supported has worked well.

What would be your advice to others wanting to replicate your work?

- Work with colleagues that are already doing a role that you would like to offer, to gain first-hand expertise
- Establish close multi-disciplinary team working and communicate with colleagues
- Keep up-to-date in readiness for patient requests for information – be as informed as possible

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QuDoS Multiple sclerosis: NHS case studies 2019

Outstanding MS physician Barbara Chandler

Name, job title and centre

Dr Barbara Chandler, Consultant in Rehabilitation Medicine, Raigmore Hospital, Inverness

Project / initiative name

Neuro-Rehabilitation Project with Highland Hospice

Project start date

2019



Challenge

1. People with advanced MS can face a range of day-to-day issues caused by common symptoms such as fatigue, mobility problems, cognitive impairment and spasticity. Accessing services to help with these issues can be challenging.
2. While many of these issues can be dealt with in the community, patients can often benefit from a period of intensive, goal-oriented rehabilitation.
3. Competing demands for beds on the Highland Neuro-rehabilitation ward, such as emergency admissions, make admissions from the community very difficult to achieve.

Solution

1. Highland Hospice was keen to broaden its range of services at the same time as the Neuro-Rehabilitation team were exploring options to offer people periods of focussed in-patient rehabilitation.
2. Neuro-rehabilitation patients referred by Dr Chandler and the neuro-rehab team are assessed by the hospice team before being admitted on a 10-day intensive rehab programme.
3. Each patient has a different set of goals. Previous examples have included being more independent in a wheelchair, regaining the ability to self-feed and fatigue management.

Solution cont...

4. Each programme is tailored to meet the individual's needs and goals.
5. At the end of the rehab period, the patient is connected to relevant community organisations and services to help them continue with their progress.
6. Follow up over the next 12 months is with the neuro-rehab and palliative care teams.

Results

1. These rehab beds are not subject to competing emergency admission demands, meaning patients can plan for their stay.
2. From 9 admissions; 7 had multiple sclerosis of whom 3 partially and 4 fully achieved their goals. Follow up indicates ongoing goal engagement.

What was the biggest challenge?

We were concerned that patients might worry about the concept of going to a hospice, but in fact the staff are so rehabilitation focussed that individuals were immediately put at ease and unanimously felt positive about the rehabilitation programme.

How did you overcome the challenge?

Describing the project initially, often followed by a joint meeting with the hospice therapy staff and neuro-rehab team staff.

What would be your advice to others wanting to replicate this project?

Make contact with local palliative care services and find out if they are interested in developing links with neuro-rehabilitation and working with patients who have advanced disease.

This project initially came about because the team were already in regular contact to share experience and seek advice in both directions. The lack of NHS services had prompted the team to look outside the NHS for possibilities to improve neuro-rehab opportunities.

Testimonial quote



From a patient

The individuals who have been through the project to date have valued the time given to practice activities such as mobilising, transferring, upper limb functions. They have valued the time to focus on their rehabilitation needs with skilled staff and the opportunities to continue post discharge.

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QuDoS Multiple sclerosis: NHS case studies 2019

Outstanding MS nurse commendation

Name, job title and centre

Katie Hanson, Clinical Nurse Specialist for MS and Neurology for Paediatrics, Great Ormond Street Children's Hospital

Project / initiative name

Various projects, such as the establishment of a working group for paediatric MS team nurses and 'family days' for patients and their wider support network

Project start date

Projects running through 2019 to 2020



Challenge

- There is a lack of funding across the board for care services, which means that there is also a lack of resources
- An unmet need exists for tailored transition documents and advice for teenagers with MS in the region, specifically tailored to 'transition' (ie, the gap between MS care for children and adult services)
- There was a lack of communication and sharing of best practice between paediatric MS nurses from across different services, which meant little opportunity for learning from peers.

Solution

- A working group for paediatric MS nurses was established (currently a small group comprised of six members); the group get together regularly to share ideas and are creating an MS transition document for teenagers that is tailored to individuals in the service region
- The working group also meet up at various MS conferences thereby creating opportunities for peer learning experiences (ie, sharing of best practice between paediatrics-focussed MS nurses)
- These learning opportunities have led the working group to begin development of a new standards document for blood monitoring, specifically in children and teenagers with MS.

Solution cont...

- 'Family days' have been initiated, which are educational informative days for families of those with MS (eg, parents), with Q&A sessions and opportunity for discussion between the care team and the patient's wider support network.

Results

- Families have been keen, pro-active and appreciative of the family days
- The transition support provided fills a key unmet need by identifying and stopping patients from 'slipping through the system' when they move from paediatric to adult services
- The working group has allowed sharing of best practice between peers, improved communication across services and created learning opportunities for all those involved.

Next steps

More family days are planned for 2020: one in April and another two (covering separate neurological conditions) later in the year. The networking with other paediatric MS nurses will continue and transition documents will be finalised for roll-out later in 2020. Feedback will also be collected and incorporated.

What has been the biggest challenge?

It is challenging to be an MS nurse specialist in a region without a larger support team, especially when covering other neurological conditions too; plus, getting bloodwork can sometimes be challenging.

How did you overcome this challenge?

The MS Trust study day was helpful in terms of covering what to do with different bloodwork results; delegation across the available team to share care responsibilities has been crucial, plus teamwork and collaboration help. Speaking with other teams and developing 'how-to' documents has also been valuable.

What would be your advice to others wanting to replicate this project?

- Organisation and time management is important – time must be set aside for new initiatives and sharing of best practice. Getting a 'buddy' or support from other teams and specialist nurses from other services can help
- If considering initiating 'Family days' be sure to get parents' and families' insights and/or feedback on what they want from the day; family days should be tailored to what the unmet needs are for your particular service / region
- Collaborate – make it a team effort; the MS paediatric nurse working group has been valuable for insights sharing and support for new ideas

Testimonial quote



From a colleague

Katie helps prepare older teenagers to transition to adult services or go off to university. She is a nurse, but she also counsels them, treating each patient as an individual... She is [also] in the process of setting up a workgroup for MS nurses and teams from around the country. She has organised events during which all the members discuss treatments and new research. They also discuss how they work and talk about the systems in their centres in terms of diagnosis and treatment, particularly in paediatric MS. The idea is to share best practice and improve care by learning from each other."

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QuDoS Multiple sclerosis: NHS case studies 2019

Team of the year commendation

Name, job title and centre

Hertfordshire Neurological Service, Central London Community Healthcare NHS Trust (formerly West Herts Community Neuro Team Central London Community Healthcare)

Project / initiative name

A variety of MS treatment pathways were developed to provide overall 'joined up' MS care; pathways covered vestibular dysfunction, advanced MS, physiotherapy and exercise, palliative support, and social and mental health

Project start date

March 2019



Challenge

1. A need existed to ensure MS patients with differing care requirements were provided with specialist, optimal services by the healthcare professional with the most relevant expertise (eg, dietician, physiotherapist, speech therapist etc)
2. Separate, siloed team specialities and solo patient visits were putting pressure on healthcare professionals who were over-burdened and unable to deliver optimal care within their specific skillset
3. Care for patients with complex, interdisciplinary MS cases, which required the involvement of multiple specialist teams, was not always well-coordinated (eg, where a hip replacement for an MS patient required involvement from orthopaedics MS specialists and physiotherapists)
4. Service changes had previously resulted in risk of patients with complex cases being side-lined between services and lost to follow-up

Solution

- New care pathways were established through joint (multi-disciplinary) team working for patients where there was an unmet need (eg, MS patients with vestibular dysfunction, patients that haven't engaged with exercise or those whose quality of life could be improved with specific equipment)

Solution cont...

- Joint triage was introduced to help identify MS patients where there was an unmet care need; the approach identified what the need was (eg, physiotherapy, orthopaedics etc), which specialism was needed (eg, speech therapist, dietician etc) and how the need could be addressed (eg, visits, equipment, access, education)
- Patient visits were optimised to include only those specialists whose expertise was needed in each case (a tailored approach)
- Working relationships were developed between specialisms to ensure that care teams were receiving the 'full picture' for each patient
- Care providers from all specialties were educated in multi-disciplinary team working (eg, learning how to identify at the referral stage who has the relevant specialist expertise)
- Specialist tools were developed to help identify patient needs; for example, the multi-disciplinary team developed a series of questions specific to vestibular dysfunction to enable accurate screening; patients identified as having vestibular dysfunction were then referred for specialist rehabilitation
- Liaison with other services allowed for better planning (eg, patient visits were arranged in parallel with visits from carers, health and social care, district nurses or mental health team colleagues)
- Close links were also established with local community groups, charities and businesses (eg, the local gym runs MS exercise classes in a 'toning suite' and collaborative working with the gym instructors has increased their knowledge and skills for supporting people with MS)
- Weekly joint team meetings were set up to discuss complex cases and share the burden of care across the multi-disciplinary team.

Results

- Burden of care was reduced overall for MS team staff
- Patients were provided with more specialist, tailored and relevant care
- More patients now have access to services that are of value to them (eg, the 'toning suite' at the local gym, standing frames etc)
- F2F conversations with specialists have led to patients being more able to understand care recommendations and therefore comply with their treatments (eg, where new equipment was recommended to improve their quality of life)
- MS team members now work closely with specialists which has led to improved cross-disciplinary knowledge; this translates to burden of care reduction for specialists in the long-term too
- MS team members are empowered to involve the relevant specialists immediately, whilst avoiding over-burdening other specialisms where there isn't a clear patient need.

Next steps

There are plans to improve team working further by strengthening existing links and increasing multi-disciplinary team F2F meetings (where of value), plus building connections with more specialties (eg, respiratory specialists, local hospice's and palliative care services).

What was the biggest challenge?

Service change and structural re-organisation was a major challenge, plus commissioning managers willingness' to support activities that were not a strictly specified part of their services remit.

How did you overcome the challenge?

Cross-disciplinary team working, plus increased specialist knowledge and understanding of MS has allowed development of the different care pathways. The team were able to demonstrate, using data and case studies, where there were clear unmet patient needs and then focussed in on those areas.

What would be your advice to others wanting to replicate this project?

- Identify which specialists are needed for individual patients as early on as possible
- Conduct joint triage with other healthcare professionals, if available – where resources are not available, have conversations with patients at the referral stage to encourage them to pursue specialist care (where there is a clear need or potential for patient benefit)
- Foster a good working relationship with other specialists and learn how to communicate clearly and assertively with colleagues about when a specialist should be involved (be direct with team members)
- Conduct multi-disciplinary group visits where appropriate but always ensure that there is a clear rationale for each specialist to be involved (to ensure best use of time)

Testimonial quote



**From a
wheelchair-
using MS
patient**

It helps for my care to be coordinated by three people coming together. I felt heard and understood, and confident my needs would be met."



**From an MS
patient**

"I've been using the training suite four or five times a week for about ten weeks... In addition to feeling stronger and having increased energy, the main benefit has been the great sense of well-being... this is helped by the very welcoming and professional, knowledgeable staff at the centre."

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Outstanding MS occupational therapist

Name, job title and centre

Susan Hourihan, Lead Occupational Therapist (Neuro-Sciences), National Hospital for Neurology and Neurosurgery

Project / initiative name

MDT transition clinics

Project start date

2008



Challenge

During my MSc in MS practice, I found that there was a group of patients who were transitioning between relapsing and progressive disease. These patients, who are hard to identify as there is no diagnostic criteria for transition, face a number of challenges:

1. Transition to progressive disease can be a challenging time psychologically. Some people find the diagnosis of progressive disease as difficult, or sometimes more difficult to adjust to than the original diagnosis of MS.
2. Transition to progressive disease may impact on a person's eligibility for disease modifying drugs.
3. Transition to progressive disease signals the accumulation of disability. This presents a number of practical challenges, such as applying for benefits or leaving/staying in work.
4. Progressive disease can lead to or enhance a number of disabling symptoms, such as spasticity and bladder issues.

We felt standard neurology follow-up appointments did not have the capacity or the resources needed to help people overcome these challenges.

Solution

1. Susan Hourihan, lead neuro-sciences occupational therapist, worked with neurologist Dr Jeremy Chataway and Bernadette Porter, Consultant MS Nurse to start an MDT transition clinic.
2. General neurologists and GPs refer patients they feel are transitioning to progressive disease into the team for a one-hour session.
3. The patient's medical history is first assessed for signs of transition to progressive disease.
4. If the team agree with the referring clinician's conclusion, the patient's needs are holistically assessed.
5. They are given general information on the progressive stage of MS and are referred into other services that may be relevant to them and their needs. That might be psychology, FES, upper limb electrical stimulation or splinting, fatigue management, vocational rehabilitation or bladder intervention.
6. The team have also upskilled themselves on issues surrounding benefits and housing in order to offer advice and signpost patients to appropriate outside services.

Results

We regularly collect feedback from our patients. They frequently tell us that before they attended the transition MDT, they thought they had "reached the end of the line" in terms of intervention options. They tell us that they feel reassured and supported, and that the sessions helped them to see they had a future.

Next steps

We are now looking into offering people one MDT annual review clinic slot a year.

Many people have told us that their needs frequently change in the years after transiting to progressive disease. Annual reviews would allow us to make sure they are connected to all and any help that is available.

What was the biggest challenge?

The biggest challenge was the logistics of lining up everybody's diaries and finding available rooms.

How did you overcome the challenge?

All the staff involved in the project understood the value of offering this support and were keen to make it work.

We also built strong links with the staff responsible for booking rooms in the hospital. We explained what we were trying to achieve and over the course of two sit-down meetings were able to find a room that was available at the right time and was big enough to accommodate all the members of the team.

What would be your advice to others wanting to replicate this project?

1. Make sure this is a service that your patient group would benefit from.
2. If you do not have a huge caseload, you might not need a separate transition clinic. Transition clinics can be carried out in a regular MDT clinic, but make sure you have the right skills in the room.
3. Be aware of what services people in this phase of the disease are likely to need: psychology, help with parenting, help with staying in work, fatigue management, help with managing bowel and bladder problems, help maintaining mobility and keeping active, orthotics, electrical stimulation and symptom management.
4. Make links with the services you are likely to refer into.
5. Understand which areas you may need to upskill in.
6. Be aware that the clinic is just a part of the process – it can take just as much time to make and follow-up on the referrals.

Testimonial quote



From a patient

Once I found out that I was going to be supported in the transition clinic, I suddenly felt so much better and I was going to be taken care of. I don't know how I would have coped without it."

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QuDoS Multiple sclerosis: NHS case studies 2019

Outstanding MS nurse commendation

Name, job title and centre

Iris Hume, South Eastern Trust

Project / initiative

Set up of a new MS service

Project start date

Initial launch of MS service in January 2017



Challenge

1. Setting up a completely new MS service where previously there had been none was the main challenge
2. There was a lack of understanding of MS and the specific needs of MS patients, particularly in other medical teams; for example, fatigue in MS was not well understood by either MS patients or other healthcare professionals, despite how overwhelming and disabling it can be for a patient
3. Patient expectations and perceptions were also a challenge

Solution

1. 'Newly diagnosed' MS courses, and progressive MS days have been rolled out to increase awareness and aid understanding
2. There have also been MS society courses in fatigue management and progressive MS, with high attendance from healthcare professionals
3. Patient accessibility was a key target in developing the new service; the team now keep one appointment slot available at the end of each day so that acutely unwell patients can be helped quickly
4. A telephone clinic was also rolled out – patients are able to ring the secretary and are given a date and time when they will be called back; this means that patients are able to better plan the rest of their day without waiting by the phone. They are also given the telephone number that will call so that patients can recognise the caller; there is an email address for more general patient queries too

Solution cont...

5. An audit was conducted that identified key areas of unmet patient need (eg, fatigue management); this meant that the team were able to focus on areas identified as of relevance to their patients.

Results

1. The telephone service was found to be reassuring to patients because it gave them a specific time to schedule in their call with an MS team member (eg, MS nurse)
2. The end-of-day appointment slot was also reassuring to patients because it meant that they knew if they suddenly felt unwell then they wouldn't have a long wait to see someone; this level of accessibility avoids stressful situations for MS patients and family members
3. Other access options were also found to be reassuring to patients and their families – the patients felt that they were able to get help when they needed it
4. The 'newly diagnosed' course was particularly successful in terms of providing more information for patients and sign-posting them to other organisations that could help; patients also fed back that it helped avoid feeling isolated, gave them an opportunity to make new friends in the MS community / meet the MS nurses and prompted sharing of useful information
5. As a result, patients were better able to self-refer to other services and had more confidence in asking for help or extra support.

Next steps

There are plans to conduct more audits and provide more courses, plus get more involved in the education of both patients and other healthcare professionals.

There are also plans to set up a website so that patients can be more easily sign-posted to other services that they might need.

What was the biggest challenge?

Creating a new service completely from scratch was a huge challenge.

How did you overcome the challenge?

The team just stuck their head down and tried stuff out! Having a supportive team behind you is crucial, plus the management team at the South Eastern Trust have been fantastic.

What would be your advice to others wanting to replicate this project?

- Take your time – you need to crawl before you can walk and walk before you run! Don't do too much too soon; it's better to do it right rather than rush in
- Involve someone who is good with IT – electronic records are useful for multi-functional team working and cross-team communication.

Testimonial quote



from a patient

I just wanted to thank you for my care during my recent bout of unwellness. Your regular phone calls make me feel supported and cared for during this unnerving time. It was reassuring to know a health professional was monitoring my condition and my family were pleased to know of this too."

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QuDoS Multiple sclerosis: NHS case studies 2019

Outstanding MS pharmacist

Name, job title and centre

Joela Mathews, Highly Specialist Pharmacist - Neurosciences Lead, Barts Health NHS Trust

Project / initiative name

UK Neurology Pharmacists Network

Project start date

November 2013



Challenge

1. Neurology pharmacists faced with designing procedures and protocols for new MS drugs were working in isolation.
2. Best practice was not being shared between people working in similar positions across the country.
3. Education and career development opportunities for neurology pharmacists were lacking.

Solution

1. The UK Neurology Pharmacists Network was established by contacting all the neuro pharmacists in the UK and inviting them to a regular meeting.
2. Originally, these meetings were backed with pharmaceutical company funding, though the network now works independently.
3. The network holds two face-to-face meetings a year and members keep in regular contact via email.
4. The network works with partner organisations, such as the UK Clinical Pharmacists Association and the Neurology Academy, to develop and deliver education and career development opportunities. Examples include the Neurology Academy's Neurology Pharmacist's training course and a UKCPA-backed research day.

Results

1. A total of 16 people graduated from the inaugural Neurology Academy Neurology Pharmacist training course in 2019. The network works with the academy to develop and deliver the curriculum.
2. The role of the neurology pharmacist has grown in scope and prominence since the network was established.
3. Neurology pharmacists feel better supported in their roles, more confident in their ability to develop effective protocols and procedures, and more integrated into the wider MS multi-disciplinary team.

Next steps

We would like to work withECTRIMS to add a pharmacist-focused session to its annual meeting agenda. This would allow us to share best practice Europe-wide.

What was the biggest challenge?

When the network first started, some members were forced to take annual leave in order to attend.

How did you overcome the challenge?

We soon realised that this was because management did not understand the value of the project. To overcome this, we added a general discussion session to the agenda, during which people were encouraged to share problems they faced in day-to-day practice. Because of the nature of the group, members were able to share and develop practical solutions that could be easily implemented once they were back at their centres. This approach allowed members to quickly demonstrate the value of attending the meetings.

What would be your advice to others wanting to replicate this project?

Get on and do it!

Book a room and a date around six months in advance to give everyone a chance to get it in their diaries and send regular reminders. Make it clear that everyone is invited. Don't worry too much about having a formal agenda or getting funding – all you need to do is get people with a similar passion and a problem to solve in the same room. Most hospitals will have a room you can book for free and people are usually happy to pay for their own coffee and lunch if they can see the value in what you are doing.

Testimonial quote



**A delegate quote
from the first
Neuropharmacist
masterclass**

This helped to understand how the pharmacist role can develop in an area, improve service and be developed to support day to day management of patients."

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QuDoS Multiple sclerosis: NHS case studies 2019

Innovation in digital services

Name, job title and centre

UHS MS Team, UHS My Medical Record team and NIHR CLAHRC Wessex

Project / initiative name

My Medical Record

Project start date

Launch: August 2018



Challenge

1. NHS neurological care can be fragmented, with barriers to access and communication.
2. Caring for people with MS is complex, with an increasing number of disease-modifying drugs (DMDs) and multi-disciplinary input.
3. Empowering people to develop self-management skills and set their own goals can boost outcomes.
4. Every year, we have almost 300 new patients, yet the staff numbers are not increasing. This is the same across the country – we simply do not have enough clinic spaces and appointments to see all our patients.

Solution

- My Medical Record is a digital patient-held record available to patients of the University Hospital of Southampton (UHS). It was first developed for cancer patients.
- It gives patients access to their clinical letters, appointments and blood results, and provides access to healthcare teams. It enables the coproduction of health goals and provides a research evidence base for improving care planning.
- Working collaboratively, the UHS MS Team, UHS My Medical Record team and NIHR CLAHRC Wessex, with the backing of the Neurology Alliance, adapted My Medical Record for MS.

- The project was funded by the Health Foundation.
- The project team included consultant neurologists, MS nurse specialists, IT developers and quality leads. Therapists from the community neurological rehabilitation team were also involved, to make sure the platform supported patients throughout the disease trajectory.
- Patient focus groups were held to inform the development of the MS-specific platform. They were asked if they thought it would be useful and how they thought it might support them to manage their condition.
- Care plans, basic disease information and what to do in the event of a relapse were added to the MS-specific platform.
- My Medical Record is already available in other conditions. This means there were no concerns over ethics, compliance or data protection as the platform has already been approved.
- Since the platform was launched in August 2018, every patient seen in clinic has been offered access to My Medical Record.
- A patient satisfaction survey was carried out after the launch of the platform.

Results

As of October 2019, more than 600 patients have registered and are using the platform. They can now:

- Monitor their own blood results.
- Access their clinical letters and appointment bookings.
- Digitally access MS information and affiliated MS charity links.
- Securely message their MS teams in the acute and community setting, improving access to care teams between appointments.
- Upload their information and share with other providers, families and GPs.
- Complete online diaries and health questionnaires noting changes in their condition which they can share with their clinical care teams.
- Co-produce online care plans to include personalised goal setting.
- Register for local research studies via the site.
- The MS team now routinely ask patients to contact them via the messaging system rather than by phone or email. This allows better message monitoring, and the team can save messages directly to the patient clinical record when clinically relevant.

Feedback from a patient survey showed:

- patients immediately valued the fact that the platform allowed them to manage practical aspects of their condition through providing copies of clinical letters, being able to access and change upcoming appointments, and see their test results
- they felt that in the longer term, added functionality would help them to communicate with their care teams, understand their condition and, through elements such as care plans and diaries, improve their self-management.

Next steps

The next phase of the project will focus on helping the MS team to support and monitor patients on DMDs.

What was the biggest challenge(s)?

The biggest challenge was the time it took to register patients. That includes the time it took to explain the concept to people and for staff to physically set people up on the system. For data protection reasons, team members had to register their own patients, and this took a little time at the start.

How did you overcome the challenge(s)?

We found better ways to describe the system. When someone has children, for example, we liken it to the physical records pregnant women are given. We also have a leaflet about data protection. Setting people up on the system got quicker with practice.

What would be your advice to others wanting to replicate this project?

- Make connections with your IT team, they will be your biggest champions on a project like this.
- Contact the My Medical Record team at UHS who will be more than happy to meet your team, together with the other stakeholders, to demonstrate the platform
- Find a handful of your patients who would be willing to champion this for your service

Testimonial quote

“
“
from a patient

I am able to stay connected to my MS team via MyMR even though I live in the Falklands. I still see them face-to-face yearly, which is a feat on its own, but I am confident that I can access them when I need them in between. I can also download my blood monitoring on MyMR so my team can advise my local team here if needed.”

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QuDoS Multiple sclerosis: NHS case studies 2019

Outstanding MS physician commendation

Name, job title and centre

Dr Jonathan O’Riordan, Consultant Neurologist, Tayside and NE Fife Regional MS Unit

Project / initiative name

Multiple initiatives delivered, focussed around the development of the specialist MS service for Tayside

Project start date

Services covering ~20 years



Challenge

- Tayside has one of the highest incidences of MS in the world, which means that there is a large patient pool for the MS service to cover
- Originally there was no specialist MS service, which meant a lack of diagnosis and communication with patients about their diagnosis; there were also few treatment options other than episodic steroids
- Delivery of preventative treatment in a safe and appropriate environment is a challenge; healthcare professionals should be conscious of the potential for multiple interactions with polypharmacy

Solution

- The specialist MS service was developed and a multi-disciplinary team on-boarded (physiotherapist, social worker, MS coordinator etc.)
- The service has championed a patient-centred approach by focussing on improvements in patient quality of life, relapse prevention and providing access to palliative care.
- Identification of specific patient population needs allowed for creation of tailored services, such as the rollout of a dedicated pelvic health clinic
- Treatment focuses on symptom management by offering options such as acupuncture, lidocaine infusions, access to hyperbaric chambers and home physiotherapy

Solution cont...

- There has been exploration of non-drug means of symptom control through a balance of pharmaceutical means and non-pharmaceutical means
- Preventative strategies have been implemented; for example, clinics and educational events are held on topics such as acute relapse, lower urinary-tract dysfunction, pain management and spasticity management
- A collaborative approach to patient care has been introduced by scheduling regular multi-disciplinary team meetings, encouraging regular communication between team members and encouraging team discussion
- A pharmaceutical monitoring service has been developed for patients on DMTs (to ensure management of symptoms)
- Lastly, there has been a focus on clinical research (eg, MS epidemiology, the application of MRI for clinical and prognostic purposes, MS prevalence, symptomatic therapies such as cannabinoids and preventative therapy); this has helped to inform strategies for managing symptoms in real-world practice

Results

- There is now a cohesive specialist MS service treating upwards of 1,400 patients
- The service is patient-oriented, providing holistic care with a multi-disciplinary team that is responsive to patient needs
- Patient interactions are increasing; daily clinics are now being run and they have received positive feedback
- The service has repeatedly attained high levels of achievement in all national standards
- The holistic approach to treatment has empowered patients to better manage their symptoms and reduce pharmacological medication overuse

Next steps

The team is currently working in collaboration with the Scottish National Ballet to set up ballet classes for MS patients (aiming to start in the Spring of 2020); the effects of these classes will be monitored in terms of symptom improvement, positive social impact, and pain and fatigue reduction, with the aim of determining whether these factors influence the requirements for pharmacological medication use.

The team will also continue to focus on symptom prevention and relapse management, whilst also looking at how to address unmet patient needs that are specific to deprived areas.

Lastly, there are plans in place to expand the work related to the pelvic health clinic, whilst monitoring its use and benefit for continuous optimisation.

What have been the biggest challenges?

Firstly, providing relapse-prevention therapy in a safe manner is a high priority and, secondly, meeting patient expectations is a continuous challenge.

How did you overcome these challenges?

To ensure safe provision of preventative therapy, the team has put in place a mechanism whereby treatment provision is monitored very closely. A comprehensive patient database has been set up with recommended monitoring timeframes and patient results (each with recommended parameter values); this has allowed a greater understanding of the different therapies being used and the patient's individual suitability. Plus, it ensures that everyone on the team is kept up to date on what to look for out for and how to respond to different patient results.

Meeting patient expectations regarding relapse prevention has improved due to symptom management and relapse prevention strategies (outlined above). Expectations in terms of disability progression are managed by increased team awareness of what can realistically be achieved, the limits of different treatments, and careful consideration of whether medication will be worthwhile (ie, in terms of benefit versus side effects).

What would be your advice to others wanting to replicate this work?

- A multi-disciplinary team approach is important; developing a flexible team that is responsive to patient needs, open to new treatments and ideas, and that has good communication and listening skills, is critical
- Specialist MS nurses are valuable in the development of a working team and should be brought on-board, where possible
- Establish two-way trust between all team members and aim to create a working environment that allows for open discussion; each team members' opinion should be valued

Testimonial quote



from a
colleague

Dr O'Riordan strives to provide the best patient care possible... Tayside has one of the highest incidences of MS in the UK and Dr O'Riordan prioritises his clinical work, ensuring that every new MS patient is seen quickly and receives personal clinical care. He has been responsible for developing the multi-disciplinary team and training all new MS nurse specialists and speciality doctors. Throughout, Dr O'Riordan has been innovative in his ideas for broadening the MS service, thus ensuring the MS patients in Tayside receive patient-centred holistic care."

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QuDoS Multiple sclerosis: NHS case studies 2019

Outstanding MS physician commendation

Name, job title and centre

David Paling, Consultant Neurologist (MS Lead), Sheffield Royal Hallamshire Hospital

Project / initiative name

Multiple initiatives and improvements to the MS service over recent years



Challenge

1. The number of MS patients has been steadily increasing year-on-year, which means that services like blood monitoring are increasingly needed
2. The complexity of MS treatments has increased, and the treatment options are becoming more varied each year
3. Despite the above, available resources have remained the same – the service has more patients, with more complex treatments, and more treatment options than ever before, but the level of staff and resources hasn't increased in parallel
4. The service covers a large geographic area which means that patients have long distances to travel for treatment – this is especially challenging for patients who require blood monitoring

Solution

- Solutions have focussed on improving efficiency and responsiveness across the service
- A new DMARD co-ordinator was brought on board to streamline processes and free up time for nurses and consultants to do more clinic-based tasks (ie, spend more time with patients)
- MS Consultant led outreach clinics have been set up in most local district general hospitals and MS nurse led clinics have been set up in GP surgeries
- Blood monitoring services have been set up at local GP practices, which means that patients do not have to travel as far
- Staff aim to see patients as close to home as possible.

Results

- Feedback from patients has been very positive; they much prefer local services because it means less travel time, it's more convenient, and it can be a less daunting experience for them
- Travelling far for services can also be particularly challenging for patients from deprived settings; local services has helped a lot in this respect
- Finally, local services also help towards reducing the environmental impact of regular travelling for blood monitoring and other treatment visits.

Next steps

There are plans to speed up processes even further – working groups have been established to help with streamlining practices. The team is also working together to help with the increased workload in the infusion unit. There are plans to set up more symptom-based clinics (eg, for bladder, bowel, fatigue and pain issues), and there are also several research programs planned where new treatments will be investigated. For example, there are three new trials of MS medicines and one for stem cell transplant.

What was the biggest challenge?

Dealing with the increase in demand (increasing MS patient caseloads) with the same amount of resources.

How did you overcome the challenge?

Bringing a new DMARD Coordinator on board to look at processes and strip out any inefficiency was helpful; a new trainee pharmacist has also helped to make pharmacy processes more efficient too. However, it is a continuously ongoing challenge.

What would be your advice to others wanting to replicate this project?

Look at processes and keep asking the question 'do we need to do this?' and 'can we do it better?' Talk to the management team about extra staff who could help to streamline non-clinical time so that physicians and nurses can spend more time with patients.

Testimonial quote



From a nominator

David Paling has improved access and equity provision of care for people with MS in Sheffield and the wider area. He has been instrumental in developing services, alongside nurse colleagues, to provide a holistic approach to care of people with MS. He has guided and supported the nurses to introduce different aspects of care, such as providing acupuncture and joint-led continence clinics.”

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QuDoS Multiple sclerosis: NHS case studies 2019

Innovation in practice

Name, job title and centre

Dan Kucharczyk and Gail Shore, MS clinical nurse specialists, Royal Wolverhampton Trust (RWT) MS Nurse Team

Project / initiative name

Relapse management pathway

Project start date

June 2018



Challenge

1. When the current team inherited the service, there was no defined pathway on managing relapse.
2. This lack of a written process meant that some patients were not receiving timely care. Patients who thought they were having a relapse would call the service, and the MS team would ask them to take a urine sample to their GP. It could take anything up to 10 days to diagnose an infection and initiate antibiotics or decide upon alternative treatment.
3. These problems were compounded by the team's rapidly expanding geographical patch, and the associated uptick in caseload.

Solution

At RWT we worked innovatively and in collaboration with other services to expand our capabilities as an MS Nurse Service. Put simply – we squeezed every ounce of willingness, goodwill and energy from other health professionals. Using best practice guidance, we harnessed this support to create treatment pathways. The relapse pathway is one example of these documents which have given structure to our services.

1. The team mapped out a relapse management pathway based on the MS Trust's Eight Steps to Managing Relapse and the NICE guidance.

Solution cont...

2. To speed up access to care, the team made links with the local community-based Rapid Intervention Team (RIT). The MS team now refer suspected relapse patients to RIT, which is made up of advanced specialist nurses, who carry out a home visit. This usually happens within four hours. RIT nurses either rule out infection, or, if they are unable to do this, collect blood/urine samples.
3. The team sought and were granted governance approval for the pathway.

Results

1. The link with RIT has reduced the time it takes to diagnose an infection from 10 days to overnight.
2. Relapses and potential relapses are dealt with quickly and effectively.
3. The pathway has standardised the service's approach to relapse management.

Next steps

The relapse pathway was just the start for the RWT MS team. We have also produced a dysphagia pathway and have many more processes we wish to formalise in the coming months.

These include working with obstetrics and gynaecology colleagues on a pathway for pregnant women with MS, and with tissue viability nurses on a pathway to prevent pressure ulcers.

Ultimately, we would like to formalise all our processes into "one pathway to rule them all", or 'global' overview of the service.

What was the biggest challenge?

One issue we had was ensuring the service covered Cannock, an area which was taken on by RWT quite recently and doesn't have the same RIT community services as we have here in Wolverhampton.

This was a challenge as we wanted services to be fair and equitable across areas, even though some people didn't have access to the same team.

How did you overcome the challenge?

To overcome this, we spoke to the team at Cannock Hospital, where there is a minor injuries and walk-in centre. After negotiating with the sister on the ward, we now have an arrangement where patients can attend the walk-in centre if they think they are having a relapse and staff there will screen for infection and collect the sample.

Although it's not an exact replica of the service we can offer in Wolverhampton, it is still infinitely faster than us trying to get patients to send their samples to GPs.

What would be your advice to others wanting to replicate this project?

Firstly, go looking for the services in your trust that you might be able to work with and use them. They tend to be just as keen on joint working as you are.

Also, remember that it's a long process and you have to keep at it. When you send off your first email to say that you are interested in doing X, Y and Z it might be a month before you get an answer. Sometimes, you don't get an answer at all until you send six emails. Keep plugging away because it is worth it.

- The RWT MS Nurse team are happy to share their pathways with fellow services. Please contact rwh-tr.msnurses@nhs.net

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QuDoS Multiple sclerosis: NHS case studies 2019 Judges special award

Name, job title and centre

Maureen Ennis, MS Specialist Nurse, Co-Chair, SELKAM

Project / initiative name

The South East London Kent and Medway (SELKAM) Regional MS Nurse Advisory Group

Project start date

1990



Challenge

MS specialist nurses and therapists can often work in isolation. This can make it difficult to:

1. Share best practice
2. Access updates on drugs, disease management and day-to-day practice
4. Access clinical supervision

Solution

The South East London Kent and Medway (SELKAM) Regional MS Nurse Advisory Group was established 20 years ago. It now has around 20 members, all of whom feel part of a valued team. They meet regularly to support each other through challenging times and celebrate each other's successes. SELKAM also operates an email members' enquiry service which allows members to ask questions and stay in touch in between meetings.



The group:

1. Meet regularly throughout the year providing specialised education opportunities to the group members, both new and old
2. Provides access to clinical supervision, networking, and sharing of best practice
3. Work on policy and procedure development in collaboration with consultant colleagues
4. Organises a regional MS multidisciplinary one day conference
5. Work to support new practitioners as they are appointed
3. Continue to evolve to meet the demands of the changing MS practice landscape

Results

1. Over 20 years, SELKAM has grown from small beginnings to an alliance of around 20 highly skilled, highly informed MS healthcare professionals.
2. SELKAM initiated one of the first sets of MS relapse management guidelines in 2008. These have since developed and now form the basis of the NICE guidelines
3. Complete online diaries and health questionnaires noting changes in their condition which they can share with their clinical care teams.
4. SELKAM has worked consistently towards supporting its members to develop and maintain their specialist skills, keeping members informed and educated on new drugs as they become available, as well as identifying and responding to specific learning needs
5. SELKAM has worked MS Specialist Consultants from across the region and with Deborah Clark, pharmacist at King's College Hospital NHS Foundation Trust, to develop and audit regional disease modifying therapy guidelines.

What was the biggest challenge(s)?

Over the last 20 years, the group membership has changed a lot. We often find we have to repeat information as new members come in. It's really important that all new specialists develop their skills and have access to all the knowledge that they need.

Some people work on their own, which can be isolating. That can also be a challenge.

How did you overcome the challenge(s)?

We keep on top of what needs refreshing by keeping abreast of which new drugs are coming out and working with pharma companies to get training in place. We also work hard to keep on top of member queries which give us an idea of training needs.

To overcome isolation, we offer peer support via face-to-face meetings and email, as well as provide clinical supervision.

What would be your advice to others wanting to replicate this project?

- Identify peers in your area/region who will benefit from and enrich your group
- Set dates for meetings a year to 18 months in advance and ring-fence these dates in your diary
- Set a robust agenda and involve pharma companies for the education sessions. They will often provide really excellent speakers and even whole learning programmes

Testimonial quote



I am proud to be part of such a proactive, professional and knowledgeable group of people. We share best practice, are instrumental in developing and auditing guidelines and it is an opportunity for clinical supervision which is not offered to us elsewhere."



When I started my role as an MS nurse I would not have been able to cope with the management of my caseload without the help and support of the SELKAM nurses."

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QuDoS Multiple sclerosis: NHS case studies 2019

Outstanding MS nurse Karen Vernon

Name, job title and centre

Karen Vernon, Salford Royal NHS Foundation Trust

Project / initiative name

Neurological Examination Course – Training for MS nurses

Project start date

2012



Challenge

1. The role of the MS nurse has evolved considerably in recent years.
2. As relapse management started to become more nurse led, Karen was aware of a lack of skills in terms of physical neurological examinations.
3. This lack of knowledge can impact on the quality of neurological examination reports and holistic relapse management.

Solution

1. A practical course was developed with the input of expert nurses and consultants and with sponsorship from Teva UK.
2. The programme runs over a Friday evening and all day Saturday, twice a year. It utilises a slide deck, case scenarios and workbooks developed by the team.
3. The course is delivered by consultants and MS nurses.
4. The Friday session is theory based, covering the basics of why a neurological examination is carried out and what to look for. It also includes interactive case study learnings.

Solution cont...

5. The Saturday session, held in the hospital's clinical skills lab, is more practical. A consultant goes through the examination and nurses can then "practice" on each other. In the afternoon, volunteer patients attend the course. The nurses then carry out neurological examinations on the patients under the close supervision of medical staff.
6. The course was piloted among nurses in the northwest of England before being offered nationwide.

Results

1. The course is so popular that it consistently has a waiting list.
2. It is an example of an effective way to upskill the nurse workforce on taking a holistic approach to relapse management.
3. The team consistently receive very positive feedback – people say the course has had a very positive impact on their practice.
4. The course contributes to effective succession planning by ensuring the next generation of MS nurses have the skills they need to deliver holistic care.

Next steps

We would like to develop an advanced neurological assessment course. It is likely that this will take the form of an online learning module or e-learning package.

What was the biggest challenge?

Logistics – arranging travel and accommodation for the attendees and ensuring there are enough staff and volunteer patients to run the course.

How did you overcome the challenge?

Teva UK, the course's pharmaceutical company sponsor, does a lot of the organising.

The team are fortunate to have a group of patients who are willing to give their time up for this course as they can see the importance of this in upskilling MS nurses.

What would be your advice to others wanting to replicate this project?

- Use the facilities at the hospital if you can.
- If using patient volunteers, chose them carefully. You need people who understand your vision and are easy to work with.
- Secure buy in from the consultants at the very start.

Testimonial quote



**From a
colleague**

Karen continually develops and transforms services. She's grounded, approachable, straight talking and simply an amazing person."

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OVERVIEW OF THE QUDOS 2020 PROGRAMME

QuDoS-MS (Quality in the Delivery of Services in Multiple Sclerosis), now heading for year five, is a programme that recognises innovation in the care of patients with multiple sclerosis (MS) and communicates it to the broader UK MS medical community (neurologists, nurses and other support teams), making a real difference to the lives of patients and their families/carers.

The innovation and recognition programme is run by pharmpforum, one of the world's biggest healthcare media companies (monthly audience of circa 150k visitors), in collaboration with the MS Trust. In addition, these organisations leverage their respective networks to partner with additional companies and channels as media partners for the QuDoS-MS programme.

QuDoS-MS launches in the first half of the year to encourage submissions of innovative work from across the UK MS medical community. Submissions are then referenced and judged by an expert panel, including esteemed MS key opinion leaders, prior to recognising the most innovative work at a ceremony held during the MS Trust annual conference in November. Media activity then continues until early the following year to disseminate the innovative work submitted.

The QuDoS-MS programme is made possible through sponsorship from a number of pharmaceutical companies, whose support is recognised by the UK MS medical community throughout the activities.

Find out more about the programme and the great work of the UK MS medical community by visiting our website qudos-ms.com or contact the programme manager [Lynette Arnell](#).



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