

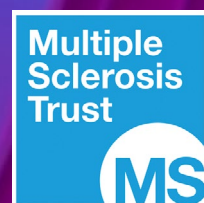


CASE STUDY COMPENDIUM

The QuDoS in MS Recognition Programme 2023

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bringing healthcare together





Introduction & Forward



Digital Innovation

MS Academy, UCLH Hospital



Outstanding MS Nurse

Nicola Hyslop, Advanced Multiple Sclerosis Nurse Champion, North Cumbria Integrated Care NHS Foundation Trust



Innovation in Practice

Samson Kayakers, Samson Centre for MS



Outstanding MS Physician

David Rog, Salford Royal Hospital



Outstanding Team

MS Preconception and Pregnancy Team, Sheffield Teaching Hospitals NHS Trust



Outstanding MS Pharmacist

Natasha Hoyle, Neurosciences Pharmacist, Sheffield Teaching Hospitals NHS Trust



Judges' Special Award

Huntingdonshire Community Multiple Sclerosis Specialist Nursing Team, Cambridgeshire and Peterborough NHS Foundation Trust



Outstanding MS Physiotherapist

Erin Cooper and Nikki Gray, Advanced Practitioner in Pelvic Health Physiotherapy, Belfast Health and Social Care Trust



Judges' Special Award

Hereford MS MDT Team, Wye Valley NHS Trust

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INTRODUCTION & FORWARD

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

QuDoS spotlights 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 2022/23 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

“The QuDoS awards in 2023 are more important than ever. This is a critical time in our services. We’re at a crossroads, and we can have a key moment to make sure that we provide an even better service for people living with multiple sclerosis.

The MS sector is fantastic. Nobody is just sitting around twiddling their thumbs waiting for this cure to come along, they’re making sure that people, those 130,000 people living with MS, are getting the best possible support they can.

With QuDoS in MS, we can shine a light on the great work being done and try to ensure some of that is replicated in other areas too. I’d love us to get to a place where that innovation, the great practice, is continually shared right across the year, right across the MS sector.”

QuDoS in MS Recognition Programme Nicola Hyslop, Outstanding MS Nurse Winner

Your name, job title, and centre

Nicola Hyslop, advanced Multiple Sclerosis nurse champion,
North Cumbria Integrated Care NHS Foundation Trust

Project / initiative name

Advanced MS champion



Challenge

- The MS service in Cumbria is continually expanding and is staffed by a very small and dedicated team. However, the patient caseload and the rurality of the local area have often made it difficult for those patients with advanced MS to be reviewed regularly.
- Through an MS Trust pilot scheme, background research illustrated that, although there are now fantastic opportunities for people to go on treatment much earlier, people that weren't in that category at that point have now developed much more complex needs, more physical symptoms, and have been unable to get into a clinic space anymore.
- Many of these patients - just by the nature of who they are - have almost plodded on. They've just got on and managed themselves and have been hitting crisis point, which was

when they were phoning the service. So, there was a clear need to reduce the risk of crisis by getting in there sooner and working with them to find out where their needs are and how we can best manage them.



“Often in this job, it’s a small change that makes a big difference.”

Nicola Hyslop
Outstanding MS Nurse Winner

Solution

Initially, I got handed a list of patients, started at the top, and worked down. It took a long time: I met them all individually to introduce myself, conduct a holistic assessment, and see where they were in their MS journey.

Because of my background as a community specialist practitioner, I already had links with the community multi-disciplinary teams (MDTs) and the Integrated Care Communities (ICC) hubs. I think I'm renowned now for saying, "I stamped my feet louder and harder, and I shout louder and harder than anyone else".

I will advocate for anybody that needs me to, to make sure that there's equality of care and service for them. They might have district nurses or physios involved, but, actually, what they need is someone to come in and coordinate all of that to ensure they're getting what they should be getting.

This approach has led to several key service improvements in order to create a better experience for patients living with advanced MS, including a pathway for patients with MS who have been admitted to acute services, which is currently under audit and is already improving communication between acute and community teams.

Results

I've had lovely feedback from patients and relatives because we are in this for not just the patient, but the relative(s) or the carers. For a lot of my patients, their family is their carer, or their carers become their family. So, it's about them knowing that the doors are open, that they can come to you when they need some advice or they've got some concerns and they've got a number they can ring, that they can email.

My area is 4,000 square miles. It's a big area, so we do utilise WhatsApp. We use text messaging, emailing, and phone calls. We use a software called Attend Anywhere, so we can do some visual links because often you can't necessarily drop everything and drive the two hours it takes to get to someone. I think that gives them confidence. Once they've got confidence in you, then they're more inclined to come back to you.

We've also conducted some education with ward staff. We did have a period of time where we didn't even know our patients had been admitted until weeks later when they were back home again. Often, it's right for the ward to ring you and say, "We've got one of your patients on the ward. Could you come and review them?" But sometimes it's not appropriate. Now, we've opened the communication between ward and community staff and, with the education that we've done, everyone has really come on board and been very supportive.

Next steps

I would like another five nurses! That would be the next step: who can we bring in? Can we bring that development role in for them? I love my job. I love the patients and the team that I work with, and to move it forward will likely require us to focus on being consistent and having the opportunity to bring in someone to develop them and for them to pick up the same role.

What has been the biggest challenge?

Some of the challenges are in relation to the GPs. Not in a negative way necessarily, but they have a tendency to just put everything down to someone's MS. I think it's about challenging that and going back and saying, "Actually, you need to see this person. Just because they've got MS doesn't mean they might have this," and getting them on board.

How did you overcome this challenge?

You've got to have some broad shoulders, and you've got to not be fearful of going to people and saying, "This is who I am. This is what my job role is. I really want to work with you to make this better. How can we do that?" Some have been very responsive, and some haven't.

I think once you've made a good change for someone – and it might be a small change – once they see that you are consistent and trying, they are more likely to get on board and go with you.

Now, I work with some really fantastic GPs that will come to me and say, "Nicola, can you come out and do a visit? We are just not sure", and I'll go back and then liaise with whoever we've got working with us at the time.

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

Be resilient, be brave, and enjoy it. We talk about baby steps a lot and to some of my patients I'll say, the smallest of change is a step. Taking that step together and supporting someone to do that and see that, actually, just because they're in a wheelchair, just because they're dependent on someone for everything that they do, doesn't mean that they don't have a quality of life.

Take a break.

Make a cup of something and enjoy an interview with Nicola Hyslop winner of the outstanding MS nurse category.



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QuDoS in MS Recognition Programme

David Rog, Outstanding MS Physician Winner

Your name, job title, and centre

David Rog, speciality lead in neurological disorders
at Greater Manchester Clinical Research Network

Project / initiative name

Transforming MS for All



Challenge

- We all recognise that issues, such as a lack of staffing and limited resources, pose significant challenges in delivering services within the NHS, exacerbated by the COVID pandemic and its aftermath.
- There is a need to address the issue of resource allocation and ensure that existing resources are utilised efficiently to optimise service delivery and meet growing demand in healthcare.
- The Transforming MS for All audit highlighted three key areas for improvement: maximising influence to drive meaningful change in MS management, enhancing operational efficiency to streamline processes and optimise resource utilisation, and harnessing the potential of routinely collected data to support and enhance services provided to MS patients.

Solution

In terms of maximising influence for change, we've continued to engage with a variety of external stakeholders as part of the Transforming MS for All programme. These include patient groups, charities, various NHS institutions coming out of NHSE, professional groups, the ABN therapists in MS, the pharmacy association, and so on. Really, we've been trying to align and identify the programmes that will affect change.

For example, NHS England recently launched a dashboard for neurological services off the back of the Getting It Right First Time, the GIRFT initiative and Transforming MS for All has been able to – and continues to – contribute to that process in terms of some MS-specific elements. That would be the first plank, if you like, in terms of influencing change.

Regarding operational efficiency, we have identified eight projects off the back of the Transforming MS for All audits. Essentially, some of those projects involve defining the roles and responsibilities of the various MS professionals that comprise the teams, identifying the fact that different teams have different compositions, and looking to see how we can expand the number of staff working in MS over time.

Results

We wrote up the audit in the form of a short report and shared that report widely with the stakeholders. So, not just with the patient societies and some of the professional groups, but also some of the MS pharmaceutical companies, and it's been obvious that, whilst we don't have a monopoly on good ideas, certainly some of the ideas may have come from a variety of sources.

Nevertheless, we've seen some of the recommendations that we've made in the report actually start to become embedded within the strategies, if you like, of other organisations. We've seen that there have been meetings that have been looking to nurture the next generation of MS consultants, for example, to support them in terms of developing business cases, and creating new roles, which will directly benefit people living with multiple sclerosis.

Moreover, colleagues have said that they've used some of the data that we've generated from the report in terms of their business cases. For example, we identified that, on average, there was about a 10% increase in this MS caseload in an average service. We've also been able to describe an average service, as well, because that really hadn't been something that was determined previously.

In the 70 centres that we identified, the average service is around 1,500 people living with MS, but, with the services we surveyed, the smallest service was fewer than 100 people living with MS, up to 5,500 people living with MS at the time. Colleagues have said that they've used some of the data from the report and the audit to inform their business cases.

Next steps

We've soft-launched phase one of the Transforming MS for All website, which is the public-facing part of the website. Now, we are working on phase two of the website, which will be the members' section. This will focus on sharing best practices and facilitating communications, so, there are a number of different elements to that, including a documents repository service map, and a forum for discussions around sharing best practice and service development.

We're also configuring a meeting of the transforming MS rural community in the autumn, which is going to focus on updates in terms of where we're at setting priorities for the future, but also looking at sustainability, so, that's been one of our key factors, really. In terms of the current climate with finite and increasingly pressurised resources, how do we continue to sustain MS services?

What has been the biggest challenge?

The biggest challenge, actually, is a lack of resource to do this and the lack of alignment in terms of the resource that is available within the MS space. One of the reasons we were able to complete the audit was largely because we did this during lockdown.

How did you overcome this challenge?

We were basically meeting every week during the lockdown period to try and progress this. Psychologically, I think we found that very helpful because it gave us a focus during a very difficult situation. Obviously, what we wanted to do was to emerge out of lockdown stronger and perhaps better aligned than we had been going into lockdown, which I think we've managed to do.

In retrospect, we wouldn't have been able to complete this audit, or indeed, the subsequent actions from the audits, without actually having that time.

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

We've all put our hands up at various different times to do elements of the work, but I think first and foremost, it can be done. I think it requires an awful lot of effort and coordination and it would depend. If you wanted to do a national audit, for example, I think the important thing is to get down to the grassroots, to the coal face where audits have been done previously.

I think this was very much a bottom-up approach, really, where we had a number of pre-existing professional networks with MS consultants, MS nurses, pharmacists, and coordinators, and we were able to exploit those pre-existing relationships. I think that's the way to start this – very much bottom-up, but utilising existing professional networks and then trying to formalise that.

Take a break.

Make a cup of something and enjoy an interview with David Rog, winner of the outstanding MS physician category.



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QuDoS in MS Recognition Programme

Natasha Hoyle, Outstanding MS Pharmacist Winner

Your name, job title and centre

Natasha Hoyle, neurosciences pharmacist, Sheffield Teaching Hospitals NHS trust

Project / initiative name

Disease modifying therapies: A comparison of initiation timescales between patient location and medication type within Sheffield MS service



Challenge

- The duration for patients to receive treatment following Blueteq funding approval is currently unknown, which can lead to patient anxiety and an increased volume of calls to the MS service.
- A need existed to establish a baseline to determine the time it takes for patients to get treatment.
- Although a plethora of extensive patient and treatment data was available, it remained unanalysed. This lack of analysis prevented an understanding of the service's performance and identifying potential areas for improvement in order to enhance the overall delivery of care going forward.



“It’s about coming up with ways to be more efficient and making use of the staff and time that we have to produce the results that can impact on patient care, and, hopefully, improve their experiences.”

Natasha Hoyle
Outstanding MS Pharmacist Winner

Solution

- Neurosciences pharmacist, Natasha Hoyle led a large and complex audit of delays in providing disease modifying therapies to MS patients, conducted within the Sheffield MS service.
- Blueteq approval forms from October 2018 to April 2019 were reviewed to identify patients who had started or changed treatment within a six-month period.
- Data from sources, including an in-house disease modifying therapies management system known as Infolex, pharmacy dispensing records, and homecare delivery company records were analysed alongside Blueteq forms to establish a timeline from Bluteq approval date to patient receiving treatment.
- Data was also examined by geographical areas to identify any inequalities in access to healthcare.

Results

The audit found that 167 patients had started or changed to a new DMT within the sample time period. Data analysis also revealed that the median time from Blueteq approval to a patient receiving treatment was 27 and 39 days, respectively, for homecare and day case treatments. Notably, day case data showed greater variation than in the provision of DMTs through homecare.

When reviewing treatment timelines based on patient location, it was found that it took a median of 51 days for patients in Doncaster to receive homecare treatments. This was significantly longer than patients in other areas, such as Sheffield or Rotherham.

Using this information, Natasha worked with the day care unit, arranging tests and prescriptions in advance, which means that people on infusible treatments wait a median of 2.1 hours less for the treatment on the day, and can be discharged quicker.

By proactively looking at medication costs, and use of generics, the audit helped to make changes that will save millions in drug costs per year, with no change in patient safety.

Next steps

Both of these cycles were conducted pre-COVID and there was a halt to any data collection over the past few years. It is something that would be useful to start again. The landscape in DMT provision has changed a lot over the past couple of years - in our centre alone, we've had an almost 30% increase in patients on homecare treatments compared to 2019/2020, when this work was last looked at. I think we really need to establish a new baseline because we've had new treatments come along which have really changed options for patients.

What has been the biggest challenge?

The greatest challenge was just the sheer amount of work that the project was. In the first year, our documentation, although we were documenting it, it wasn't necessarily detailed and there were parts missing, so we had to use more days' resources to find out the information that we needed.

How did you overcome this challenge?

Something that I probably still need to learn from is asking others for help and making it as a team project, which I'd probably change going forward.

In the first year, I was talking to lots of different areas to collect this information, which obviously takes a lot of time, whereas in the second year because we knew the points we were looking for, it really streamlined the process and it made the second year of auditing much easier and much quicker.

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

Reach out to others to see if anyone else has an interest before you start. You can reach out to other centres, you can collate information as well, if needed, which can lead to guidance and publications and make things better around the country, rather than in pockets of certain areas.

Take a break.

Make a cup of something and enjoy an interview with, Natasha Hoyle winner of the outstanding MS pharmacist category.



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QuDoS in MS Recognition Programme Outstanding MS Physiotherapist Winner

Your name, job title, and centre

Erin Cooper and Nikki Grey, advanced practitioner physiotherapists in pelvic health,
Belfast Health and Social Care Trust

Project / initiative name

Pelvic health physiotherapy pilot programme

Project start date

2020



Challenge

1. Pelvic health problems can be embarrassing and challenging to live with, causing a barrier to social integration and reduced quality of life.
2. Although patients with MS are more likely to develop pelvic health complications, such as bladder and bowel dysfunction, there was no dedicated pelvic health team for MS patients within the Belfast Health and Social Care Trust to help individuals manage their symptoms and offer advice and support.
3. Instead, patients were referred to the continence service for assessment for intermittent self-catheterisation and pads. However, consultants realised that patients required more in-depth answers to their questions.
4. A need existed to establish a dedicated pathway for neurology to send patients to a pelvic health team, which would be able to help educate patients about their pelvic health before it reached a point where intervention would be more difficult.

Solution

A two-year pelvic health physiotherapy pilot programme – led by Erin Cooper with assistance from Nikki Gray during maternity leave – was established to bridge the gap between neurology and pelvic health for MS patients.

Education sessions were delivered for patients, neurologists, MS nurses, and the wider physiotherapy service to raise awareness of the role of a pelvic health physiotherapist and the role that physiotherapy can play in helping patients to overcome and manage issues such as urinary and faecal incontinence.

Results

Since the service was established in 2020, it has received more than 200 referrals. Patients now have earlier input, so their pelvic health conditions are getting seen earlier and they're getting addressed earlier, so that hopefully they can manage for longer and with more independence in the future.

From a patient satisfaction survey, 100% of patients felt it was beneficial to have a dedicated MS pelvic health physiotherapy service, with 96% of respondents reporting that they would recommend the service to others.

We were very sensitive about the topic that we were discussing and one of our patients said it made a great difference to their confidence in dealing with their pelvic health condition.

Next steps

Every patient is an individual, and they all need an individual treatment plan and input. Currently, I am not trained in intermittent self-catheterising (ISC), so if a patient has retention of their bladder when we do a bladder scan, we have to refer them to the continence team, and there is a really long waiting list.

The next stage is to undergo ISC training and hopefully develop the service to give a patient one journey.

What has been the biggest challenge?

When my job would've been starting, COVID hit. Everything went on to telephone assessments, advice over the phone. I think, for a lot of us, the pandemic made us realise that we can adapt when we want to, but it was probably one of the biggest changes we all had to respond to.

At that point of time, I also was pregnant, so I had to go off shielding at 28 weeks, which was a month and a half into my role.

How did you overcome this challenge?

Very quickly I realised how much work there was and how much I could do on my own. It was really good for my confidence.

Nikki took over for those 10 or 11 months while I was off on maternity leave. She did a really great job of holding the service together because, obviously, two months in going on maternity leave, I suppose that's when the service could have fallen down around us.

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

I think the big thing is look at your area and see what other people are doing. Research what's currently happening to see if there is a need, and if you can fulfil that need.



“We do what we can. It's just always focusing on the service user; what do they want and how can we help them achieve that?”

Erin Cooper

Outstanding MS Physiotherapist Winner

Take a break.

Make a cup of something and enjoy an interview with, Erin Cooper winner of the outstanding MS physiotherapist category.



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QuDoS in MS Recognition Programme Dr Wallace Brownlee Digital Innovation Winner

Your name, job title, and centre:

Dr Wallace Brownlee, clinical lead for MS, UCLH Hospital

Represented by:

Sarah Gillett, managing director, Neurology Academy

Jamie McGregor, director of policy, intelligence and operations, Neurology Academy

Project / initiative name: MS Academy

Project start date: 2016



Jamie McGregor (left) and **Sarah Gillett** (centre) accepting the award for Digital Innovation on behalf of Dr Wallace Brownlee, MS Academy, UCLH Hospital.

Challenge

- When COVID struck, there was a lack of accessible education as the pandemic necessitated postponement and cancellations, and lockdowns impeded traditional face-to-face meetings.
- The rapid transition away from face-to-face meetings left both patients and MS professionals isolated from the wider community, with an unmet need for peer support at a particularly difficult time.
- Rapid digital adoption created a gap for online education via webinars, and online learning programmes and webpages, all available without barriers and free of charge to the MS community.

Solution

The MS Academy responded to the unique challenges of COVID restrictions by delivering live webinars, which included panel discussions and open Q&A sessions.

We provided a platform where people could come together at a time of need, communicate, bounce ideas off one another, and just share best practice.

Those sessions were created specifically on the needs of the environment at the time. It was ever-changing, and we were delivering education almost weekly at that stage and making it available online.

Since then, the MS Academy has been able to build upon this and continue providing a digital learning platform that runs concurrently with face-to-face sessions. This allows people

who were previously not able to attend a face-to-face training programme because of caring responsibilities or geography the benefit of the very best in MS education and the support of feeling encouraged within a learning community.

Results

Since the transition to digital learning at the time of the COVID pandemic, the Academy has produced 51 webinars with 89 speakers: a total of 54 hours of education on MS.

Webinars produced by the MS Academy have been viewed more than 30,000 times, with 26,600 hours of teaching being provided to healthcare practitioners in MS care. The MS Academy website has amassed almost one million page views.

We've also delivered education specifically for patients and families, giving them access to healthcare professionals when it wasn't possible through normal measures.

To address the high rate of burnout seen in HCPs, we also ran MIND health sessions, some for those with MS and for nurses and practitioners.

Providing those sessions and having them as open access online gave patients and families an extra bit of support, but also supported the healthcare professionals to be the best they could be at that time.

Next steps

We started with live webinars and then moved to make them available on demand. This has now been expanded into completely virtual online courses, a number of resource sections, and collaborating with other organisations to ensure that their content is accessible directly from ours so that we can bring together the community.

This is something that we will just continue to expand on and seek feedback from delegates, and the healthcare professionals delivering the education, to ensure that we can progress and ultimately provide a broader range of virtual education to those who want to access it.

Additionally, we've developed a number of our in-person courses or masterclasses into hybrid offerings to create a greater sense of inclusion in networking so that they're not just attending online and there's no engagement.

They are able to interact with the room, interact with the speakers, and it's just more equitable access for people. People have various barriers or obstacles in life that may prevent them from attending in-person education. By countering these, we are just making a greater service for people with MS.

What has been the biggest challenge?

At the beginning of COVID, we had to adapt very quickly. We didn't deliver anything virtually prior to this, and it was a quick shift to: "How are we going to be able to educate people when we can't meet?"

Standing out from the crowd was also quite difficult because as soon as we'd done a number of educational things, a lot of other people started jumping on the same idea, and I think everybody got Zoom fatigue at one point.

How did you overcome this challenge?

We are very hands-on. All of our courses generally are small groups that interact with each other. Trying to find something that was able to bring that interaction between the people to make them feel as though they were still a part of a network was very difficult. Also, it was ensuring the education was always relevant and up-to-date with the ever-changing environment.

We also adapted webinars to be able to run the symposium sessions for the pharma companies and sponsors so that they actually got a platform to be able to have a voice as well because they weren't allowed into hospitals to meet.

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

Look at what everyone in your community wants and needs: the 5Ws, who, what, where, why, when, give a great understanding of what is required. Ultimately in our position, this is those working in MS services and, most importantly, the people with MS who are accessing those services.

It needs deep thought; it needs multiple different opinions. Ultimately, that should create a greater idea and sense of understanding of what is required and what will be of most benefit.

Take a break.

Make a cup of something and enjoy an interview with, Sarah and Jamie who represented Dr Wallace Brownlee for winning the Digital Innovation category.



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QuDoS in MS Recognition Programme Innovation in Practice Winner

Your name, job title, and centre:

Sara McGowan, lead physio at Samson Centre for MS

Project / initiative name:

Samson Kayakers

Project start date:

Initially began in 2019, but expanded in 2021



Samson Kayakers being presented their award by Tania Burge (right), MS Trust.

Challenge

- Exercising can be a difficult task for those living with MS, particularly as common symptoms of MS, such as fatigue, weakness, and poor coordination, may make the prospect of exercise daunting.
- Group exercise is known to encourage regular participation and regular exercise can enhance wellbeing and mental health.
- The Samson Centre and the Wey Kayak Club have shared a building since 2000. Each organisation uses the same facilities at different times of the day and shares running costs. An opportunity existed to explore a collaboration between the two organisations to help people living with MS to improve their fitness and strength.

Solution

The Samson Kayakers vision came about over coffee in a kitchen shared by the Samson Centre and the Wey Kayak club, while discussing how people living with MS could benefit from using a Kayak Ergometer.

Kayak Ergometers (ergos) are indoor kayak machines. The Kayak Ergo allows the user to practice correct paddling technique against resistance to simulate the feeling of pulling the paddle through water. It gives the user an opportunity to have a cardio-vascular workout whilst maintaining good upright posture, so they develop core stability, co-ordination, balance, and strength, as well as improve their cardio-vascular fitness and endurance.

We use High-intensity Interval Training (HIIT) as the foundation of the training. It allows rest, it allows them to get the most out of their exercise whilst they're here with us. People with MS find it a really great way of improving their cardiovascular fitness. They can have quite a hard workout on the machines, but at the end of it, although their legs have had to do some work, they're not so completely exhausted that they can't stand up, get to the coffee area, get to the car, and get on with the rest of their day.

It really is a joint project. There are physiotherapists advising on posture and positioning. We had the gym instructors assisting with warm-up cool-down and being extra pairs of hands during the class, and then we have Paul the kayak coach who advises on the more technical sides of the kayak paddling, stroke, and techniques.

It also allows for those factors of MS, that when they're exercising hard they're not overheating, that we're not overexerting them. We are working them in a safe and appropriate manner so that there's all that physiological side of it, which they really enjoy.

Results

Samson Kayakers now has 15 members attending weekly who have developed into a tight-knit social group of people with MS providing support to each other.

The friendships forged through the Samson Kayakers extend outside of the classes, with team members going for drinks at the pub and organising fancy dress kayaking sessions.

In 2022, team members from Samson Kayakers arranged an on-the-water session to translate the skills they had learned on dry land to piloting wider, more stable kayaks on the water of a local lake. The event was so successful that the members have gone on to organise trips independent from the Samson Centre.

British Canoeing has provided support to the Samson Kayakers, offering advice on drills and warm-up and specialised seating. And Olympic gold medallist, Liam Heath MBE joined a kayak ergo session at the Samson Centre for Multiple Sclerosis.

“When I reached out and asked for some specialist help, I was really thrilled that people felt that they were more than happy to help.”

Sara McGowan
Lead physio, Samson Centre for MS

Next steps

The boats that we have access to here are very narrow and very tippy; they're not ideal for people with MS. My aim would be to have some more accessible kayaks, which are wider and more stable, maybe two-person kayaks. This also means getting people in and out of the water safely from the banks at the river, which might necessitate a different type of jetty and, certainly, a hoist for some of our members.

That would be the icing on the cake, though, to see it all the way through so that people could come here to the centre, learn on land, but also have the opportunity to go out on the water.

What has been the biggest challenge?

As physios and clinicians, we tend to err on the side of caution, whereas the kayakers, on the other hand, are completely opposite. They would just throw someone in a boat and hope for the best.

That's one of the challenges really because the kayakers are very much like: "Let's just get on and give out a go and see what happens and sort out the problems as and when they arise," whereas I always like to try and pre-empt that.

How did you overcome this challenge?

It's definitely a two-way process. We've always looked at the sessions monthly to see how they're going and make sure we've got the right mix of people in each group. Plus, although Paul the kayak coach is a fantastic and experienced kayaker, he hasn't worked with people with MS before. Getting that understanding of how hard you can push people, the importance of keeping the environment cool and well-ventilated, allowing plenty of rest – it's been a learning process.

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

I'd say just give it a go and do a risk assessment. Always go back to those movement analysis skills and look at what people need to be able to move effectively and functionally in an effortless way. Then, think about what activities you have available to you, what people with MS could benefit from, and using other people's skills and expertise as well because most people want to help.

Take a break.

Make a cup of something and enjoy an interview with, Sara McGowan for winning the Innovation in Practice category.



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QuDoS in MS Recognition Programme Outstanding Team Winner

Your name, job title, and centre:

Dr Azza Ismail, consultant neurologist, Royal Hampshire Hospital
Daisy Cam, MS specialist nurse, Royal Hampshire Hospital

Project / initiative name:

MS Preconception and Pregnancy Team

Project start date:

2021



Challenge

- Multiple Sclerosis affects individuals at their reproductive age, affecting family planning decisions for the majority of people affected.
- Pregnancy management in MS starts pre-pregnancy, and the decisions we make on treatment with our patients can have long-term implications. We also know that it's really important that we provide personalised care because every patient is different.
- It was apparent that the care of pregnant women with MS was not joined at all. Our patients had to have lots of different appointments with lots of different teams, which needed to then be conversing with each other. We felt that bringing the teams together to have our patients being seen by one team would stop the misinformation and would give them a much better journey through their pregnancies.

Solution

We started off with discussions within our MS team, but then also discussions within the wider neurology team and our management team. In Sheffield, we're very lucky to have a really excellent and established epilepsy maternity service. We thought it would be really nice to adopt the model that's already been around for patients for many years. It's been proven to be very successful.

We personally approached Dr Tessa Bonnet, who is the consultant obstetrician running that clinic, who recognised the importance of this area. From there, we began the clinic as a pilot programme for a few months to see how it performed.

Daisy Cam compiled two different patient leaflets, one for the preconception clinic and then one for the pregnancy clinic, which consultants and nurses could hand out to patients.

We also decided that it would be good to have a checklist that covered the maternity side of things, which would go in their clinical notes. The checklists would cover everything from preconception to appointments when they were pregnant, and also during the postnatal period.

Results

Since the clinic began, 80 patients have been seen by the MS Preconception and Pregnancy Team. We've had really excellent feedback from our patients, both formally and informally. For example, in a patient survey conducted as a part of the service evaluation, the majority of our patients were very satisfied with the clinic and very happy with the outcome.

One of the rewarding parts of this clinic was identifying that quite a significant proportion of patients had difficulty planning their families and had fertility issues. Through this clinic, these issues were identified and addressed. It was nice to see a positive outcome, people who have actually been struggling and then having a baby within a year or 18 months - that was great because many of our patients shy away from talking about this.

Next steps

We would now really like to expand this clinic to reach out to as many patients as we can, particularly at the district general hospitals. This is our next step now, and this is where we're negotiating as to how we can coordinate having this specialist clinic, but across the whole region.

Incorporating maybe a three-monthly menopause clinic alongside the preconception clinic is also something we would be interested in doing because women's health, in general, has been so overlooked for so long. Menopause is a huge aspect of women's lives and can affect them in so many different ways. A lot of the symptoms are very similar to MS symptoms, so that's the next aim, to incorporate menopause care as well.

What has been the biggest challenge?

One of the most challenging aspects was coordinating the time. Because obviously, we all work and have very busy schedules, so it's actually just to find the time to bring this all together into one clinic.

How did you overcome this challenge?

We're very lucky. We do have really excellent members of our management team who actually dedicated the time to coordinate this clinic and to make sure everything is running very smoothly. Without them, we couldn't have done that clinic. So, they're doing a massive, excellent job.

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

I'd encourage all MS specialist centres to try and establish this really rewarding service. If we can do it, I'm sure everyone else can do it. It's very rewarding. It just needs a bit of patience, excellent communication, and a good working relationship with the MS maternity services.

It's also about having good working relationships with your immediate colleagues. Within the MS team itself, having a nurse, a consultant neurologist, and a consultant obstetrician, we all look at things from a very different angle. That mix of professionals is vital.



“Our long-term aim is hopefully to see this as a nationally established service in every centre in the UK.”

Dr Azza Ismail

Consultant neurologist, Royal Hampshire Hospital

Take a break.

Make a cup of something and enjoy an interview with, Dr Azza Ismail and Daisy Cam for winning the Outstanding Team category.



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QuDoS in MS Recognition Programme Judges' Special Award Winner

Your name, job title, and centre:

Sarah Roderick, Queen's Nurse and MS Specialist Nurse,
Cambridgeshire and Peterborough NHS Foundation Trust

Ellie Garlick, Queen's Nurse and MS Specialist Nurse,
Cambridgeshire and Peterborough NHS Foundation Trust

Project / initiative name:

Huntingdonshire Community Multiple Sclerosis Specialist Nursing Team



Challenge

- There is a growing awareness in MS healthcare of the importance of advanced care planning, but many clinicians do not feel confident supporting their patients to think ahead.
- In our area, there were lots of people living with MS who weren't managing and were struggling a lot with their condition. We were almost just putting out fires here, there, and everywhere, with lots of people and families in crisis.
- We recognised a need for a resource for people with MS to provide information on advance care planning.

Solution

For patients who are newly diagnosed, we felt that those patients, those people needed more support than somebody who hopefully had been living with MS for a while and was maintaining their condition or having a good quality of life and managing their symptoms. We split our caseload up into different categories, and that then gave us almost a basis for how to support our patients.

We see people who have complex needs or whose condition might be progressing and are in a difficult phase of their condition more often, as well as those patients who might be coming to the end of their life or in the palliative phase.

Our main goal is to help people live as well as they can with their MS, but also to be as independent as they can, so that they can manage their MS independently and live as well as they can.

We've worked really hard to develop really strong links with the multidisciplinary team (MDT). Our team is part of the community neuro rehab team locally. We have good relationships with our neuro-occupational therapists, neuro physios, speech and language therapists, and the bladder and bowel service locally, so that we have that local knowledge to refer to and signpost people onto other services. They also get feedback from those teams, so that we can oversee and coordinate things for the care of people with MS in our area.

Plus, we do a lot of education of our patients, so that we're hopefully helping them develop the skills to self-manage their MS and then, hopefully, not need us quite so much or quite so frequently, but always being there as their support in the background to call on when they need to.

We also approached the MS Trust with an offer to collaborate on creating an information booklet for patients. The result was "Thinking Ahead – setting out your wishes for your future care and treatment", published in March 2022..

Results

A large percentage of our patients see us as collaborators. We're there alongside them and their families. Through education, we teach them when they need to contact us and when they don't need to, and how they manage their symptoms before they need to contact us. We teach them red flags and things like that, which then helps them to be in control, really.

I think we've also empowered our patients. There are a number of support groups that have been set up throughout the region, so they're able to support each other, as well as call on us to support them.

The other part of the feedback that we have had is the work with the MDT. If a patient needs an intervention from, for example, a speech and language therapist, we often do joint visits with them, which means then that they'll do their piece of therapy. Then, we join them when they're almost at the end of that, so that they can hand it back over to us, and we, the patient, and the family, know what the plan is going forward.

“It's been very satisfying for us when we meet someone, and they're in crisis, and we can do some really intensive work with them and really be led by their needs.”

Ellie Garlick
Queen's Nurse and MS Specialist Nurse,
Cambridgeshire and Peterborough NHS Foundation Trust

Next steps

We want to see if we can replicate our work further across the county and work with the teams that already cover Cambridge and Peterborough, and expand and collaborate more.

We've got big ambitions, having seen the difference we've made to the people we've had contact with. We've recently discovered that the number of people living with MS in the area that we do cover doesn't match up with our caseload, so we need to try and go and be more proactive in identifying people who should have access to us that don't at the moment.

What has been the biggest challenge?

One of the main challenges was identifying those people who've been living with MS for many years and aren't known to MS services.

We run clinics locally within all the different areas, so people can easily see us. We also offer home visits, and since COVID, we do a lot of video calls, phone calls, and emails.

We were both new to that whole area, and we had to find all the other members of the multidisciplinary team, build relationships with them, and find out how we could work together. Also, finding, linking with GP surgeries, and working out how they work was a challenge. I think that COVID has helped with communication for us, our patients, and other professionals.

How did you overcome this challenge?

We work in quite a rural area. It covers a large geographical area, so having the ability to do a joint visit with a speech and language therapist and a dietitian, online with the patient and the family member who might be in a different area, has also helped us.

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

When you move into an area where there's an unmet need for people living with MS, it can be quite overwhelming because there are just people coming from all angles, asking for help and support. The way we initially started was just putting things down on paper, writing a plan, and prioritising what needed to be done first.

Getting to know the other members of your team is also really important. We collaborate with professionals, but also family members and our patients, and see ourselves as a team, as a whole, as opposed to patients and professionals. We see ourselves as working together.

Take a break.

Make a cup of something and enjoy an interview with, Ellie Garlick and Sarah Roderick for winning the Judges' Special Award.



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QuDoS in MS Recognition Programme Judges' Special Award Winner

Your name, job title, and centre:

Del Thomas, lead MS CNS and Neuro CNS manager, Wye Valley NHS Trust

Project / initiative name:

Hereford MS MDT Team



Del Thomas (right), Hereford MS MDT Team being presented their award by **Christine Singleton** (far right), Consultant Physiotherapist (FES), West Midlands Rehabilitation Centre (chair of judging panel)

Challenge

- Herefordshire is a large, rural county with an ageing population and substantial MS patient cohort. Yet, the area has very few specialist services and relies on a general neurologist who attends the county weekly from the QE Hospital in Birmingham.
- An unmet need existed for a multidisciplinary team that could work with commissioners and the health community to develop local approaches to MS care.

Solution

We've established a core community-based, non-medical model MS team, comprising two MS nurses, an MS occupational therapist (OT), and an MS co-ordinator, plus a wider multidisciplinary team (MDT), which includes neuro OT, neuro-physiotherapy, speech and language therapists, dieticians, and wheelchair services.

Within collaborative MDT sessions, the whole team comes together to discuss patients of concern, plan joint working/home visits and case conferences, and plan newly diagnosed sessions, FACETS courses, and exercises.

The whole MDT has been involved in developing a local website, which is a well-being hub full of information for those living with MS and their families.

While other allied health professionals and GPs access the information, it's ultimately local services with local clinicians giving advice about the local centre.

Results

I did a few interviews with patients recently about the value of services, and one patient said very clearly that they'd had a relationship with the nurse, the OT, and the physio. They knew the direction of when I was doing the referrals and that they were going to have a burst of treatment and then come back to me. He knew we were all communicating with each other.

When we had all spoken to him independently, he knew that we'd had a multidisciplinary team meeting, and he felt that we had a really cohesive approach to his planned care. Everyone was communicated to within that, and he was really reassured by that. If we take that approach, it permits people to dip in and out, and they have the confidence that we'll react in an appropriate way.

Next steps

There is always an evolving element to a website. Recently, we worked with the web designers to build a strapline for breaking news.

Now that it's up and running, we have a working party group meeting four times a year, and everyone has a role and a responsibility to go through each section and build on it, just add things.

That's a huge amount of people, including speech and language therapists, dieticians, the patients themselves, and the third sector charity. There's a lot of input, and there are a lot of links to external stuff nationally. Shift.ms has written pieces for us, MS Together, as well as the MS Trust, but there's also the pregnancy registers and the tissue bank. Overall, there's a huge amount of information on the site that needs to be reviewed. I don't want it to just lie stagnant.

“I'm just immensely proud of getting it to the point of it being patient-focused because there has been a challenge along the way.”

Del Thomas
Lead MS CNS and Neuro CNS manager,
Wye Valley NHS Trust

What has been the biggest challenge?

It can be quite a challenge because if somebody's got an idea, some other people don't want to go down that pathway. Some people like to self-read on a Kindle, some people like to read in a booklet, and some people like to see a video, so it's an opportunity to give a variety of formats of information because we know that everyone's so different. The challenges were engaging people to understand the drivers and what the future would look like.

How did you overcome this challenge?

We developed a dedicated section on the website called Patient Stories, where individuals living with MS can share their experiences, such as travelling with a wheelchair or using an intermittent self-catheter, how they've embraced it, and how actually their life has changed since then.

We're not giving advice. We're signposting people. We're giving very basic information on a wide range of things, pointing people to where exercise and places may be around the county, and videos from our physios about a conversation about what exercise is.

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

If it's going to be an internal thing, make friends with your IT team and get them to realise that NHS Digital has an agenda going forward and these types of initiatives eventually are going to lead into the main NHS app. If you were doing it independently like I have, going forward, you have to think about licenses and surrounding fees.

If you've got this vision and you want to do it, you've got to think of how to keep it running after launch because it's not just a one-off thing. It can't stay still. You still have to plough money into it for updates and things like that because technology changes all the time.

Take a break.

Make a cup of something and enjoy an interview with, Del Thomas for winning the Judges' Special Award.



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OVERVIEW OF THE QUDOS 2023 PROGRAMME

QuDoS-MS (Quality in the Delivery of Services in Multiple Sclerosis), returning for the first event since the start of COVID-19, 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 organised and run by pharmaphorum, a leading healthcare media company with a monthly audience of approximately 150,000 visitors, in partnership with the MS Trust. Together 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 welcome submissions of innovative work from the UK MS medical community. Entries 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. Media activities continue in the months after the event 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.



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