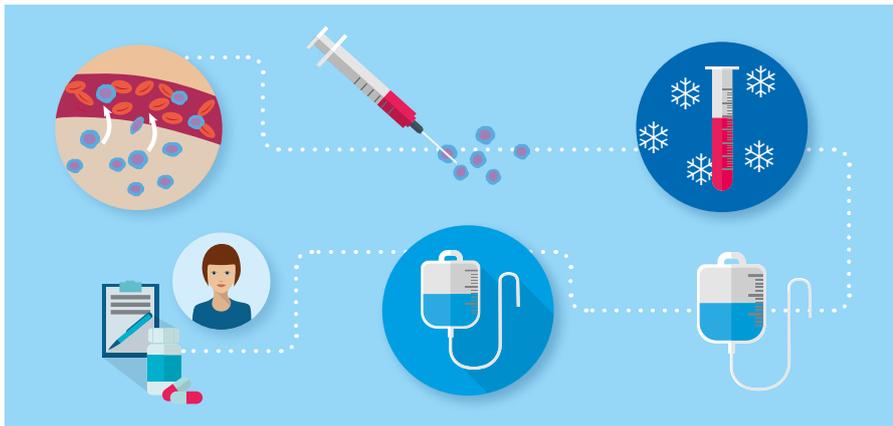


# MS in Practice

your essential update



A PUBLICATION FOR MS HEALTH PROFESSIONALS  
ISSUE 2 • SPRING/SUMMER 2018



## Promising stem cell data fuels requests for 'miracle MS cure'

**MS teams are facing an increase in enquiries about stem cell transplant treatments after preliminary results from the MIST trial suggested the procedure could improve disability.**

Initial data were presented at this year's European Society for Blood and Marrow Transplantation (EBMT) conference. They concluded the treatment was "statistically superior" to continued disease modifying drug therapy (DMD) in people with relapsing remitting MS (RRMS) who suffer two or more relapses a year.

"These results suggest that autologous haematologic stem cell transplant (AH SCT) is an effective treatment for people with highly active relapsing MS. It is important to note that this is an interim analysis and we look forward to publication of the results at the end of the study. We know people with MS are eager to get access to AH SCT but it is not suitable for all and we advise people to visit our website for more information," said Jo Sopala, Director of Health Professional Programmes at the MS Trust.

The latest data, based on a study cohort of 110 people with highly-active RRMS, are promising.

Half the participants underwent AH SCT and the remainder took one of six DMDs

— Tysabri, Tecfidera, Gilenya, beta interferons, Copaxone or mitoxantrone.

Anyone in the DMD group who experienced treatment failure, which was defined as an increase of one Extended Disability Status Scale (EDSS) point in six months, was switched to AH SCT.

At the end of the first year of treatment, there had been one relapse in the AH SCT group compared to 39 in the DMD group. In terms of disability, the AH SCT group experienced an average improvement of 1.1 EDSS point, whereas the DMD group saw an average deterioration of 0.6 points.

At an average of three-year follow up, the treatment failure rates were six per cent in the AH SCT group and 60 per cent in the DMD arm.

There were no deaths or serious side effects. Participants will be followed for another two years as part of the study.

- **Difficult conversations – how do you tell people stem cell transplantation isn't a miracle cure? See pages 4 and 5.**

## Reducing fatigue – there's an app for that

**A multidisciplinary group of MS experts has developed a telemedicine app that could be used to improve fatigue.**

Occupational therapists, neuropsychologists, neurologists and neuroscientists developed MS TeleCoach, a smartphone app designed to help people with MS fight fatigue by increasing activity levels.

It uses telemonitoring meaning it measures physical activity through the phone's in-built accelerometers, and fatigue through self-reported impact scores. It combines this with telecoaching, encompassing motivational messages and physical activity goal setting.

"Complementary to existing fatigue management approaches, the intervention aims at enhancing physical activity and thereby improving fatigue in people with MS in an accessible and interactive way, reinforcing self-management," said the team in a paper, *Improving fatigue in multiple sclerosis by smartphone-supported energy management: The MS TeleCoach feasibility study*.

The team tested the app on 75 people with relapsing remitting MS (RRMS) from 16 Belgium centres. They all had an Expanded Disability Status Score (EDSS) of four or less, and were classed as having moderate to severe fatigue as measured by the Fatigue Scale for Motor and Cognitive Functions (FSMC).

In all, 57 people completed the study. FSMC total, cognitive and motor scores changed significantly between baseline and study end, with a mean total score decrease of 3.76. →

# Welcome

## to MS in Practice Issue 2



**W**elcome to the second edition of MS in Practice, our essential update for healthcare professionals working in MS.

Firstly, thank you everyone who shared their views on the first issue. More than 71 per cent of you said the special conference edition was excellent and we hope you enjoy this one just as much.

Inside, we ask the best way to have the difficult stem cell transplant conversation (pgs 4 & 5), delve into the new skill matrices developed for MS AHPs (pgs 8 & 9) and look at people-focused digital health (pg 11).

Our aim is to share best practice, so if your team is doing something worth shouting about, we want to hear from you. Please get in touch to tell us your story or let us know what you think about any of the coverage or articles in MS in Practice. You can email us on [msip@mstrust.org](mailto:msip@mstrust.org) or tweet @MSTrustforHPs

Enjoy!

**Jo Sopala,**  
*Director of Health Professional  
Programmes, MS Trust*

## It's that time of year again!

Booking for the MS Trust annual conference is now open with a number of bursary places, allocated on a first-come-first-served basis, available for MS specialist nurses and AHPs. This year's conference takes place from Sunday 4 to Tuesday 6 November and we are returning to Jurys Inn Hinckley Island Hotel, near Leicester.

- For further details and to book online visit [www.mstrust.org.uk/conference](http://www.mstrust.org.uk/conference) or email [conference@mstrust.org.uk](mailto:conference@mstrust.org.uk) to find out if you're eligible for a bursary.

## Advanced MS champions take to RiMS stage

**A project designed to ensure everyone with MS has someone to champion their cause has attracted international attention.**



in MS (RiMS) annual conference in Amsterdam.

An estimated 40,000 people in the UK have advanced MS, but a 2016 survey, *Let's Make MS Care Fair*, found they often felt abandoned by services. The champions aim to address this by coordinating care across services to provide specialist, proactive, individualised care to people with advanced MS and their families.

Megan Roberts, the charity's health professional programme manager, said: "This was a fantastic opportunity for the MS Trust to share one of the fundamental findings to come out of MS Forward View – the fact that people with MS with the

most complex needs are missing out on the vital, holistic care offered by MS specialists."

The RiMS presentation looked at the evolution of the programme, from the identification of a lack of specialists dedicated to care of those living with advanced MS, through to the funding of six band seven MS specialist practitioner roles.

The pilot programmes include a robust evaluation plan that will ultimately show the value of the roles to the NHS, with the hope of leveraging further funding in the future.

"I was delighted to be able to present on our innovative programme to address the issue, and I look forward to keeping people updated on our progress," added Megan.

- To find out more go to [www.mstrust.org.uk/advanced-ms-champions](http://www.mstrust.org.uk/advanced-ms-champions)

## MS professionals blog feed is live

The MS Trust has recently launched a new resource for health professionals – a blog feed with topics of interest to nurses, therapists and other professionals working with people with MS, with articles written for and by professionals.

One recent post featured MS specialists Nicki Abel, Denise Middleton and Lesley Catterall, discussing how health professionals can support people with MS with sexual difficulties. This can be a tricky topic to broach, but the blog contains lots of helpful tips and information.

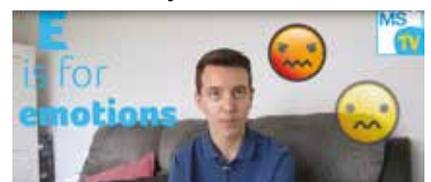
- Check it out at [www.mstrust.org.uk/health-professionals-blog](http://www.mstrust.org.uk/health-professionals-blog)

## MSTV is live

A new YouTube channel has been launched to help young people understand MS.

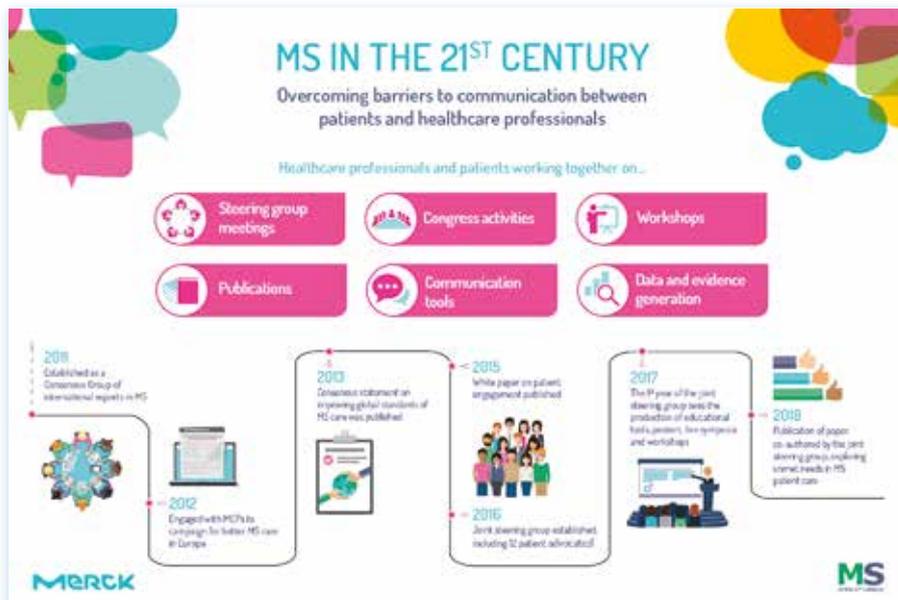
MSTV features videos on a range of topics, from symptom management to tips on looking after mental health.

The resource, designed by the MS Trust to help young people with MS or those living with it in the family, can be found at [www.youtube.com/mstvuk](http://www.youtube.com/mstvuk)



# Tackling hidden symptoms is key to engagement

Holistic care and multidisciplinary working can help people living with MS reap the rewards of shared decision making.



What is the 'MS in the 21st century' steering group?

*Unmet needs, burden of treatment and patient engagement in MS*, published by the MS in the 21st Century Steering Group, is the result of three workshops that sought to understand current barriers to patient engagement.

They brought together 14 healthcare professionals (HCPs), patient advocacy groups and people with MS to discuss the gaps between HCP and patient perception. Participants were from the UK, across Europe, the United States and Canada.

"It is essential to involve all stakeholders in potential solutions, working in a multidisciplinary way to ensure that people with MS can participate appropriately in their care," said the paper.

It highlighted eight practical ways in which the MS community can remove barriers to shared decision making by improving disease management.

One such action was improving quality of life by placing a greater emphasis on the condition's "hidden symptoms".

"Fatigue, depression, cognition, sleep problems, sexual problems and the mental and emotional impact of MS continue to be unmet needs," said the paper.

The workshops also found that people with MS thought their "changing practical needs" in terms of disability progression and quality of life, including employment issues and social care, were not consistently met.

The steering group now wants to validate its findings in a larger cohort, and hopes shared decision making can be boosted by identifying disparities between patient and HCP perceptions.

"The engagement of patients in their own healthcare has been described as the blockbuster drug of the century," it said, adding action was required from the MS community and society at large.

"From the early stages of this disease people with MS are vulnerable to social exclusion. As disability worsens, the ability to work and interact socially becomes further restricted, meaning that efforts to enhance collaboration and develop a globalised MS community are much needed."

# Guideline seeks to standardise treatment

People with active relapsing remitting MS (RRMS) should be offered early treatment with disease modifying drugs (DMDs).

That's according to the new *ECTRIMS/EAN Guideline on the pharmacological treatment of people with multiple sclerosis* which has now been published. It was first presented at last year's ECTRIMS conference.

It recommends early treatment for people with "active RRMS as defined by clinical relapses and/or MRI activity".

The full range of available DMDs should only be available in centres with adequate infrastructure to provide proper monitoring and comprehensive assessments, as well as the capacity to detect and address possible side effects, it said.

The guideline looks at prescribing in "special situations" such as pregnancy, recommending that women with "persistent high disease activity" be advised to delay starting or growing their family.

While the document has been designed to standardise access to treatment across the continent, it does recognise its limitations.

"The recommendations have been drawn up considering its European scope, including both the outpatient and in-hospital setting, but it does not address specific organisational issues, management models or country-specific regulations required to implement the recommendations," it said.

Reference: Montalban, Xavier, et al. "ECTRIMS/EAN Guideline on the pharmacological treatment of people with multiple sclerosis." *European journal of neurology* 25.2 (2018): 215-237

What do you think

?

Get in touch to share your views  
msip@mstrust.org

# Honesty is the best policy for heightened stem cell hopes

MS services up and down the country experience an influx of calls every time a headline runs with those two magic words: miracle cure.

“The most heart-breaking part is that it’s the people who have nothing to gain from the procedure who have usually set their hopes highest.”

How do you tell someone who has pinned their hopes on a stem cell transplant that the documentary they watched or article they read wasn’t the whole story?

Honesty, consistency and as much balanced information as possible are the only options, according to the team at Salford.

MS specialist nurse Alison Bradford said: “If there has been something in the media, we will get overwhelmed with calls or people asking in clinic.”

She added that some people were “pretty clued up” and knew if they might be suitable for transplant, but that wasn’t always the case.

“The most heart-breaking part is that it’s the people who have nothing to gain from the procedure — those with progressive disease — who have usually set their hopes highest.

“It’s people who are not suitable you feel for, it’s like you are kicking them in the teeth. But as nurses, we have no option but to be honest,” said Alison.

Despite the team being very clear on suitability criteria, success rates and the pros and cons of transplant, they, like many others, have seen people spend thousands of pounds going abroad for treatment.

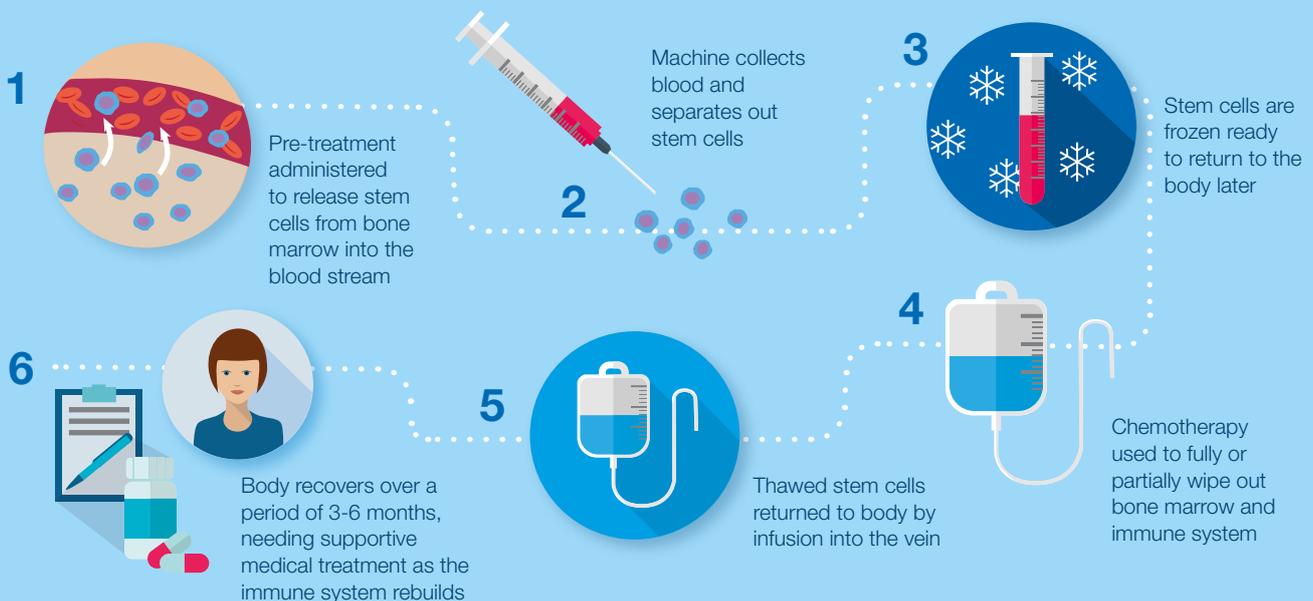
“One gentleman here spent £8,000 going to Belgrade,” said Alison. “It’s so sad when you know that it’s probably not going to make a difference, and that money could have been spent on something that might be really useful to him.”

### Clear communication

Asked how she handled such difficult conversations, Alison explained that it depended on who she had in front of her, but honesty and transparency from the outset were paramount.

“If they are not suitable, it’s about having that discussion, and giving them all the information — explaining that there is only proof that it works in people with lots of inflammation, that there have been deaths. There is no option but to be honest and straightforward, but it’s not easy,” she said.

## THE STAGES OF AHSCT



**“If they are not suitable, it’s about having that discussion, and giving them all the information. There is no option but to be honest and straightforward.”**



Everyone who enquires is referred to trusted external sources of information and is sent a standard pre-prepared, Word document. It explains the procedure, outlines the pros and cons and summarises the available evidence.

People under the care of a consultant have an appointment with their neurologist, who talks them through the pros and cons. Those who may fit the eligibility criteria are referred to Salford’s nearest trial centre, Sheffield, for assessment.

Alison said: “The media tends to portray it very positively, so we send people to look at the MS Trust, MS Society and Shift MS websites, so they can get a more balanced view.

“If after all that they are still adamant on having it privately, we try to convince them to stay in the UK. But that’s obviously more expensive.”

Anyone who still insists on going abroad for treatment is told about the importance of finding a centre that has Joint Accreditation Committee – ISCT and EEMT (JACIE) accreditation.

They are also told that they will not be eligible for NHS follow-up treatment — though this policy has not been tested since it was introduced.

- **For more information on stem cell therapy, visit [www.mstrust.org.uk/a-z/stem-cell-therapy](http://www.mstrust.org.uk/a-z/stem-cell-therapy)**

### SALFORD’S TOP TIPS FOR DIFFICULT STEM CELL CONVERSATIONS

- If someone isn’t suitable for stem cell transplantation, talk through all the other options they have available to them
- You might need back up, so make sure you are all singing from the same hymn sheet. A team meeting to set out your centre’s approach to these conversations can make sure you do not contradict each other
- Always be honest, no matter how hard it is. Anything less may inadvertently raise hopes higher
- Create a standard document that outlines the process, the pros and cons and the available evidence which can quickly be sent out
- Be aware of the details of media coverage your caseload may be exposed to

Have your say



Get in touch to share your views  
[msip@mstrust.org](mailto:msip@mstrust.org)

## Horizon scanning: stem cells in progressive disease

Many trials into the effectiveness of stem cell treatment in MS are ongoing, and more is being discovered all the time.

One such study, the Assessment of bone marrow-derived cellular therapy in progressive multiple sclerosis (ACTiMuS), is examining their effect in 80 people with primary and secondary progressive disease.

Conducted at the University of Bristol and led by Professor Neil Scolding and Dr Claire Rice, ACTiMuS has received funding from the MS Trust.

In year one, stem cells were collected from the participants’ bone marrow and reintroduced by infusion, while those in the placebo arm received a blood transfusion. In the second year, the groups were reversed.

The team then looked for changes in nerve conduction in the brain and spinal cord and any alterations in disease progression.

ACTiMuS, which built on a small safety trial that suggested the approach may affect disease progression, is expected to report later this year.



Dr Claire Rice

continued from page 1

### Using a smartphone to reduce fatigue

→ Around one third of people with severe fatigue at the start of the 12-week study saw a decrease in FSMC total and sub scores by the end.

The mean reduction in Modified Fatigue Impact Scale (MFIS) score between baseline and study end was 3.96.

**“Around one third of people with severe fatigue at the start of the 12-week study saw a decrease in FSMC total and sub scores by the end.”**

One surprise finding was that FSMC scores substantially decreased during a two-week run-in period, in which the subjects carried the MS TeleCoach device to measure activity levels, without receiving any feedback or coaching.



“This suggests that the mere fact of measuring physical activity levels and monitoring fatigue may have a positive effect on perceived fatigue,” said the paper.

“A similar effect was seen in a study where the use of activity diaries was shown to be a contributor to the self-management of fatigue and in studies of self-management programs using an interactive web-based program.”

The app will now be tested in a larger randomised controlled trial.



Reference:  
D'hooghe, Marie, et al. “Improving fatigue in multiple sclerosis by smartphone-supported energy management: The MS TeleCoach feasibility study.” *Multiple sclerosis and related disorders* 22 (2018): 90-96.

## Online mindfulness works, but requires practice

**In this Italian study, 139 participants with MS were allocated to either an online mindfulness-based meditation course or an educational course combined with exercise.**



**A**t the end of the eight-week course, those receiving the online training in meditation had greater improvement in quality of life and reduction in depression, anxiety, and sleep problems. However, six months later, both groups had returned to pre-treatment levels.

Researchers concluded that mindfulness-based meditation requires practice to maintain benefits. They recommend future studies should test ways to encourage people to practice at home so that the positive effects of meditation can be maintained.

### What does it mean?

This study showed that an online meditation course can be an effective treatment to improve psychological well-being in the short term.

Previous studies have also shown benefits of mindfulness-based therapies for people with MS but the design of these studies has been criticised, making it difficult to draw definitive conclusions.

**“Future studies should test ways to encourage people to practice at home so that the positive effects of meditation can be maintained.”**

In this study, the researchers aimed to carry out a more rigorous evaluation by using a comparison group that was also receiving an active treatment, rather than just basic medical care, and by carrying out a six-month follow-up to see whether changes were maintained.

Improvements in well-being were not maintained over time, highlighting that mindfulness-based stress reduction requires practice to obtain positive results.

Reference:  
Cavalera, Cesare, et al. “Online meditation training for people with multiple sclerosis: A randomized controlled trial.” *Multiple Sclerosis Journal* (2018): 1352458518761187.

# Smooth transition to generics poses practical challenges for MS teams

**In the current NHS climate, the switch from branded to biosimilar and generic drugs is inevitable – but it will fall to MS teams to manage the practical elements of change.**



according to its Medicines Optimisation strategy.

Rachel Dorsey-Campbell, senior neurosciences pharmacist at Imperial College Healthcare NHS Trust, said: “NHS England is encouraging all trusts to switch to generic or biosimilar products when they are available.”

In MS, Brabio is the latest example of how this change is affecting those at the coalface of managing chronic illness.

The drug, a generic version of Copaxone, was launched in the UK earlier this year.

NHS trusts signed up to the Medicines Optimisation Commissioning for Quality and Innovation (CQUIN) will have already committed to switching the majority of their patients.

“This would start with all new patients, and we certainly wouldn’t expect a trust

**B**y 2021, the health service expects to save up to £300million a year by switching to biosimilar medications to manage long-term conditions,

according to its Medicines Optimisation strategy.

to switch existing patients without first having a conversation with them.

“Clinically, there is no reason why a patient on Copaxone shouldn’t be switched to Brabio as we would expect disease control to be the same,” Rachel told *MS in Practice*.

However, the change does present practical challenges that teams should be aware of, she added.

“For example, the company providing Brabio doesn’t provide a nurse to support patients with injection training, so this task would fall to MS nurses, who we all know are already stretched,” said Rachel.

Neither does it fund a homecare service, meaning trusts must pay the delivery charges before reclaiming them from NHS England.



**“NHS England is encouraging all trusts to switch to generic or biosimilar products when they are available.”**

“In short, in the current financial climate within the NHS, the switch from branded to generic drugs is inevitable.

“However, there is work to be done by MS teams to ensure the transition is as smooth as possible for our patients,” said Rachel.

## Six-month follow-up for those coming off Zinbryta

People previously treated with Zinbryta should be monitored for up to six months after their last dose.

That’s the advice from the European Medicines Agency (EMA) following the medication’s global withdrawal in March.

The move followed 12 reports of serious inflammatory brain disorders, including encephalitis and meningoencephalitis, in people taking the drug. Three of the cases were fatal.

“A preliminary review of the available evidence indicates that immune reactions observed in the reported cases may be linked to the use of Zinbryta. Zinbryta may also be linked to severe immune reactions affecting several other organs,” said the EMA in a statement.

“No new patients should start treatment with Zinbryta. Healthcare professionals should immediately contact patients currently being treated with Zinbryta, should stop their treatment and consider alternatives. Patients stopping treatment must be followed up for at least six months.”

● For more information, go to [www.ema.europa.eu](http://www.ema.europa.eu)

## NICE revises decision to restrict relapsing MS drugs

NICE has partially reversed a controversial decision on the use of injectable disease modifying drugs (DMDs) in MS.

The MS community reacted with dismay in December when a draft decision recommended Extavia, yet rejected Copaxone, Avonex, Beterferon, Plegridy and Rebif.

NICE has now said manufacturers dropping the price of Copaxone, Avonex and Rebif meant they would be recommended for routine NHS funding. It also recommended generic glatiramer acetate.

The MS Trust thanked the more than 500 people with MS and 100-plus healthcare professionals who contributed to the charity’s response to the original decision.

“When NICE consulted on this decision, we responded in the strongest possible terms, arguing that two vital issues, differences in ease of use of beta interferons and safety in pregnancy, had not been taken into account,” said the charity.

The new guidance does not recommend Betaferon and Plegridy will be assessed separately.

# Tool to help MS therapists deliver very best standards of care

Ensuring knowledge and skills are linked to evidence and best practice is vital to delivering high-quality care to those affected by MS, say TiMS.

Two new competency and skills matrices for MS allied health professionals (AHPs), designed to help physiotherapists and occupational therapists (OT) do just that, have been published by Therapists in MS (TiMS).

“The aim is to underpin skills and knowledge for physiotherapists and OTs so that they can manage people with MS more effectively, to standardise skills and knowledge to improve the management of MS and to ensure that knowledge and skills are linked to evidence and best practice.

“Therapists need a profession-specific, peer-reviewed, evidence-based set of competencies so that they are aware of the skills and knowledge they need to

**“Therapists need a profession-specific, peer-reviewed, evidence-based set of competencies so that they are aware of the skills and knowledge they need to manage MS optimally.”**

manage MS optimally, because people with MS and the people significant to them deserve the best, wherever they are in the UK,” said the working group behind the project.

The documents have been compiled by 25 specialist AHPs from around the UK who have many years of experience of working with people with MS as well as people with other long-term, progressive neurological conditions.

Each matrix has 20 competencies that cover all aspects of the condition and practice. They describe the depth of knowledge and skills required at each level, allowing AHPs to rank themselves as competent, proficient, specialist or highly specialist in each.

The tools can be used to identify any gaps in knowledge, and to collect evidence of enhancing their skills.

As AHPs work through the document, it provides evidence of continuing professional development (CPD) and can be used to discuss learning and training needs with managers.

The authors point out that the full lists are “aspirational”, meaning they include



everything a therapist could possibly know after working with people with MS.

“They are long because they are detailed, but they should provide a comprehensive framework that can be used by therapists at all levels to increase their effectiveness when managing people with MS,” they said.

The matrices are based on current evidence and best practice, and aim to offer AHPs a practical tool to assess and monitor their own level of expertise.

“The knowledge and skill needs of each physiotherapist or OT will vary according to their work setting. The depth and breadth of knowledge and skills correlates with experience and time spent in the job,” they said.

“It would be expected that AHPs working at a higher level or grade would have spent a number of years working with people with these conditions and

**“The framework will help the group to achieve its ultimate aim: to improve the lives of people living with MS in the UK.”**



“We hope they will be a useful tool to support therapists to improve and standardise the management and care of people with MS nationally.”

would, therefore, be able to effectively manage people with very complex presentations.

“The framework will help TIMS to achieve its ultimate aim: to improve the lives of people living with MS in the UK”, they added.

To request your copy, email [therapistsinms@mstrust.org.uk](mailto:therapistsinms@mstrust.org.uk), specifying which document you require – physiotherapist or OT – and remember to share your feedback using the evaluation sheet provided.

“After a trial period, they will be finalised and ultimately we hope they will be a useful tool to support therapists to improve and standardise the management and care of people with MS nationally,” said the working group.

## Levels of competency:

### Competent

Basic awareness/  
understanding  
Band\* 5

### Proficient

Good understanding  
Band 6

### Specialist

Thorough understanding  
Band 7

### Highly Specialist

Expert understanding  
Band 8

\* Band may not reflect current practice in all organisations, but the levels should resonate with most work settings and hierarchies

What do you think



Get in touch to  
share your views  
[msip@mstrust.org](mailto:msip@mstrust.org)

## The competencies

<b>Competency 1</b> Knowledge of condition	<b>Competency 11</b> Continence
<b>Competency 2</b> Disease modifying treatments	<b>Competency 12</b> Cognition, behaviour and mental health
<b>Competency 3</b> Nutrition and hydration	<b>Competency 13</b> Palliative care
<b>Competency 4</b> Respiratory	<b>Competency 14</b> Activities of daily living and social care
<b>Competency 5</b> Swallowing and communication	<b>Competency 15</b> Roles and relationships
<b>Competency 6</b> Balance and mobility	<b>Competency 16</b> Vocation and participation
<b>Competency 7</b> Posture and skin integrity	<b>Competency 17</b> Self-management
<b>Competency 8</b> Tone, tremor and ataxia	<b>Competency 18</b> Education and research
<b>Competency 9</b> Fatigue and sleep	<b>Competency 19</b> Service management and development
<b>Competency 10</b> Pain and sensation	<b>Competency 20</b> National guidelines and legislation



## From audit tools to podcasts – there’s a lot going on at TiMS

**Welcome to the first MS in Practice Therapists in MS (TiMS) column, which we will use to inform you about the work we are doing.**

To give you some background, TiMS is an organisation for Health and Care Professions Council-registered allied health professionals (AHPs) with an interest in MS. Our aim is to improve the lives of people with MS by supporting, strengthening and promoting the role of therapists, as well as sharing expertise and developing knowledge and skills.

Since we were formed in 2004, we have developed several resources for AHPs and we are currently working on some exciting new projects.

These include a self-assessment form for use during the annual reviews recommended in the 2014 NICE Guideline for MS. It helps professionals identify topics or symptoms people with MS wish to talk about during their review. The form will be piloted in the coming months and we hope to have it available for general use before the end of the year.

TiMS is also updating its service evaluation audit tool to utilise the MS Trust’s MS Forward View statements and other sources, such as the NICE Guidelines. The previous tool was based on the quality standards set out in the National Service Framework 2005.

Training podcasts which cover subjects such as spasticity management and handling are also being developed.

We will keep you up-to-date on these projects through *MS in Practice*, but please do get in touch if you would like more information.

- **For more on joining TiMS and accessing our resources, email [therapistsinms@mstrust.org.uk](mailto:therapistsinms@mstrust.org.uk) or visit [www.mstrust.org.uk/TiMS](http://www.mstrust.org.uk/TiMS)**



## Whistle-stop tour of nurses in action

**The UKMSSNA is very pleased to contribute to MS in Practice. In this, our first contribution, we want to give you a whistle-stop tour of just some of the things we do.**

Updating the website has been one of our major projects over the last year, and we continue to make it easier to access and navigate. We hope you like it.

Closely linked to the website is our continuing work to update the care plan and slide library. Each project is led by a working group of volunteer UKMSSNA members who are working to make them user friendly and easily accessible.

We are also currently reviewing all the protocols and pathways on the website to ensure that they are still relevant and fit for purpose.

The UKMSSNA regularly meets with the MS Trust, MS Society and Shift MS, and, when required, we work in collaboration in terms of response and endorsements related to MS.

On your behalf, we responded to NICE’s technology appraisal for the disease modifying drugs.

We also continue to endorse the neurological examination course at Greater Manchester Neuroscience Centre, Salford.

After a hiccup last year, we are now working with the IOMSN to re-establish the international exam at the MS Trust conference this November. We will keep you posted.

We have a committee and strategy planning meeting in June, so will update you on our plans for the next 12 months in the next edition of *MS in Practice*.

- **If you aren’t a member and wish to join, please contact us via [www.ukmssna.org.uk](http://www.ukmssna.org.uk)**

# Digital health should focus on the patient not the technology

While technology holds massive potential to solve some of the problems faced by MS teams, we should not lose sight of how it could benefit the end-user.

That was the message that came out of a webinar on the use of technology in MS services, held as part of the Quality in the Delivery of Services (QuDoS) in MS recognition programme.

**“We need to think about the problem we are trying to solve rather than focus on a fancy bit of technology and how it can be implemented – it might not be suitable for the purpose.”**

## Capacity, capacity, capacity

That MS teams face capacity challenges in a world of finite resource and increasing medication monitoring is well documented.

In 2016, MS Forward View highlighted two particular tech-related problems:

- 1) Lack of IT systems or databases to track DMD monitoring
- 2) Lack of integrated systems between providers that share the care of people with MS

Ben Dorward, lead neurosciences pharmacist at Sheffield Teaching Hospitals NHS Foundation Trust, tackled both by setting up a monitoring database and ensuring it was integrated across the region.

People on DMDs can have their monitoring blood tests done at sites in the community that have been connected to the hospital laboratory IT systems. It generates a log of all homecare prescriptions which is available to all members of the multidisciplinary team, including pharmacy.

The integrated system of blood monitoring and prescription generation enables the hospital pharmacists to easily access the most up-to-date results.

Patient advocate, Trishna Bharadia said: “Solutions need to be problem-driven. We need to think about the problem we are trying to solve rather than focus on a fancy bit of technology and how it can be implemented – it might not be suitable for the purpose.”

Jo Sopala, director of development at the MS Trust, also took part in the live debate.

“This is about how we can improve patient experience, not using digital for digital’s sake,” she said, adding there was lots of work going on to learn from.

The webinar, which was sponsored by Biogen, was produced by pharmaphorum with the support of the MS Trust.

- **To read an overview of the webinar, see [www.mstrust.org.uk/tech-webinar-blog](http://www.mstrust.org.uk/tech-webinar-blog)**

## Helping the hard to reach

Rachel Morrison, MS specialist nurse, covers the large, rural region of Scotland’s Western Isles and uses technology to increase access to services to those in the most remote areas.

One example is Florence, or ‘Flo’, a web-based system that collects clinical information direct from the person with MS, allowing for symptom, adherence and activity monitoring.

Another is Attend Anywhere, a video consultation platform – perfect for people who might otherwise have to travel for days to attend an appointment on the mainland.

Rachel emphasised that there was no “one-size fits all” approach, and that solutions relied very much on the individual.

- **For more on Rachel’s use of technology to provide care to hard-to-reach patients, see [www.mstrust.org.uk/tech-webinar-blog](http://www.mstrust.org.uk/tech-webinar-blog)**



*Ben’s monitoring database is integrated across the region, giving team members access to blood results.*

- **To see more examples of best practice, see [www.mstrust.org.uk/team-case-studies](http://www.mstrust.org.uk/team-case-studies) or get in touch to share your own case study. Contact [education@mstrust.org.uk](mailto:education@mstrust.org.uk)**

# Get involved!

Thank you very much to all of you who held awareness and fundraising activities during MS Awareness Week in April.

We can only continue our work thanks to fantastic people like you who help to support us. If you or anyone you know would like to get involved in any fundraising events or activities, please do get in touch.

- Contact our fundraising team on 01462 476707 or [fundraising@mstrust.org.uk](mailto:fundraising@mstrust.org.uk) or visit [www.mstrust.org.uk/get-involved](http://www.mstrust.org.uk/get-involved)



## Can you help us find friends?

We are looking for supporters to become the face and voice of the MS Trust in their local community. Becoming a Friend of the MS Trust is a great way to meet new people, have fun, gain new skills and support our work.

Whether you organise a fundraising event, place collection boxes in local shops or run a stall at a community event, you can make a huge difference by raising the profile of the services we offer and the money we need to reach more people.

- If this sounds like you please contact us on 01462 476707 or email [fundraising@mstrust.org.uk](mailto:fundraising@mstrust.org.uk) for an information pack. If you know anyone else who might be interested, please pass our details on to them.



## Are you looking for an adventure?

Want to trek the Great Wall of China? Or cycle from London to Paris? We offer a range of amazing sponsored experiences that you can participate in to support the work of the MS Trust.

After a three-year break, our exclusive ski challenge Monster Ski returns for 17-21 March 2019. We're looking for experienced skiers and snowboarders to join us in the popular French resort of Chamonix for a ski experience like no other. The goal is to ski 30,000ft of vertical descent — the equivalent of Mount Everest — every day.

We're also recruiting for the Freedom Trail Trek from 4-9 July 2019. This stunning but demanding trek in the Pyrenees starts in France, and follows the route of the Chemin de la Liberté. The route follows in the footsteps of servicemen and refugees escaping France during the Second World War and takes in memorials to some of the local people who risked their lives to help them.

- To find out more about any of these trips, or to see what else we have on offer, visit [www.mstrust.org.uk/adventure](http://www.mstrust.org.uk/adventure)

## SAVE THE DATE

**MS Trust Conference**  
4-6 November 2018  
Jurys Inn Hinkley Island Hotel,  
Leicestershire  
[www.mstrust.org.uk/event/ms-trust-conference](http://www.mstrust.org.uk/event/ms-trust-conference)



Follow us on Twitter  
**@MSTrust**  
**@MSTrustforHPs**

Contact us:  
**01462 476700**  
**info@mstrust.org.uk**

MS in Practice published by  
 Editorial: Amanda Barrell  
Design: Emily Wilkinson  
[www.lemonade-studio.co.uk](http://www.lemonade-studio.co.uk)  
Printed by Pureprint  
on behalf of the MS Trust

 **Multiple Sclerosis Trust**  
Spirella Building  
Bridge Road  
Letchworth Garden City  
Hertfordshire, SG6 4ET  
  
Registered charity  
number: 1088353