



## Transforming MS for All

### **Transforming MS 4 All Summit. Solving the MS care paradox: Progress. Priorities. Planning. Participation.**

The inaugural **Transforming MS 4 All Summit**, held on the *8th of September 2023* at The King's Fund, London, marked a significant milestone in the journey to improve Multiple Sclerosis (MS) care across the United Kingdom. This first-of-its-kind event brought together a diverse array of stakeholders, including MS experts, healthcare professionals, and senior representatives from the pharmaceutical industry. The shared mission was to address the complex challenges and paradoxes that have increased over time in the field of MS care.

### **Opening Session - Welcome and Objectives: Jane Galloway & David Rog**

In her welcoming remarks, facilitator **Jane Galloway** set the tone for the event by emphasising **TMS4All**'s mission to solve the **MS Care Paradox**;

- *We can do more to affect the natural history of MS - through therapeutic advances.*
- *We can do less to affect the natural history of MS - through capacity and other issues.*

The objectives included progressing towards better MS care, outlining **TMS4All** plans and priorities, and encouraging active participation from all attendees.

In his role as a presenter, **David Rog** introduced the agenda and unveiled the vision and objectives for **TMS4All**. The vision was clear: to prioritise the efficiency of patient care and the sustainability of staff in MS care. The summit saw an impressive and diverse turnout from across the UK, with MS practitioners ranging from consultants and specialist nurses to pharmacists, therapists, coordinators, patient group representatives and senior pharmaceutical industry colleagues.

The **TMS4All** leadership and operational team, consisting of **Joela Mathews, David Rog, Jeremy Hobart and Sian McKay**, seized this unique opportunity to unite colleagues from all corners of the UK. Their goal was to facilitate the exchange of experiences in MS care solutions, including stakeholders with senior roles and expertise in the NHS and industry, and foster brainstorming and knowledge-sharing to improve services.

## Panel Discussion: Addressing the MS Care Paradox

Chaired by **Jane Galloway**, the first panel featured prominent figures in the field - **Jeremy Hobart, Penny Dash, and Martin Wilson**. Their central task was to explore how the MS community could effectively engage with national structures to address the MS care paradox.

**Jeremy Hobart** initiated the discussion by highlighting the recent strides made in MS research, which have significantly improved patient diagnosis, long-term care strategies, and overall health outcomes. Notably, he emphasised improved diagnostic criteria, enabling earlier diagnosis and treatment, new disease-modifying treatments and symptomatic therapies. However, Jeremy also pointed out a glaring disparity: the NHS has not kept pace with these advancements. Managing long-term MS care, with increasing monitoring requirements and evolving roles for healthcare professionals, has become increasingly complex. Patient expectations have also evolved, adding to the challenges. Jeremy outlined three key areas of focus to address the **MS care paradox**:

1. Maximising influence for change.
2. Improving efficiency and resilience.
3. Maximising the benefits of data

**Penny Dash**, Chair of North West London Integrated Care System (ICS), brought her wealth of experience in improving healthcare quality and efficiency to the discussion. She emphasised the need for cost-effective approaches to MS care, using NW London ICS as a case study. Penny highlighted the importance of nationally coordinated care systems for MS and the necessity of better coordination in primary care networks and mental health services. She acknowledged challenges such as workforce shortages and the slow adoption of digital technology. Investment in healthcare has increased, whereas productivity has not, to the same extent; however, she also presented successful examples of healthcare transformation and workforce redesign, underscoring the role of clinical leadership in driving change.

**Martin Wilson**, Consultant Neurologist at The Walton Centre NHS Foundation Trust, Chief Clinical Information Officer at Cheshire and Mersey ICS, Deputy Chair of NHS England's Neurology Clinical Reference Group (CRG) and Clinical Adviser for NHSE neurosciences transformation programme, delved into the Neurology Strategic Transformation Programme (NSTP), which seeks to transform neurology services nationwide. He introduced a new commissioning model that shifts most services, including MS care, to be commissioned at the Integrated Care System (ICS) level, with only highly specialised services and high-cost drugs remaining nationally commissioned. Martin also emphasised the importance of national neurology dashboards, such as the recently launched NHSE Adult Neurology dashboard, which includes national MS metrics.

## Key Takeaways from the Panel

- **The MS Care Paradox:** This paradox underscores the contrast between the potential for better care and treatment for MS patients, thanks to advancements in research and treatments, and actual care provided, due to the challenges posed by overstretched services, staffing issues and patient backlogs, within the MS healthcare system.
- **Service Developments:** It became evident that MS service developments have not kept pace with advancements in MS research and treatment. Issues such as staffing shortages, inadequate strategic planning, lack of regional resource coordination, and changes in the roles of MS professionals were highlighted.
- **Maximising Influence for Change:** The panel emphasised the need to maximise influence and awareness of MS care at the national level. This includes creating opportunities for more storytelling, knowledge sharing and case studies, something which the newly launched **TMS4All** website hopes to achieve.
- **Efficiency and Resilience:** In the context of MS care, discussions centred around streamlining processes, optimising resource utilisation, and adapting to changing patient needs.
- **Maximising Data Insights:** The importance of leveraging data and technology in MS care was highlighted numerous times. All participants agreed that data approaches are underutilised and that existing data could be used to help improve patient outcomes and the overall quality of care, particularly in the context of patient medical trial eligibility.
- **Integrated Care Systems (ICS):** The transition to ICS and the delegation of commissioning responsibilities from national to regional levels were discussed. This change is intended to improve the delivery of healthcare services, including MS care, and promote equity of access. There are opportunities for existing NHSE programmes to be linked to pilots in ICSs.
- **New Models of Care:** Developing a new model of care, including tiered service categories, will impact how MS care is provided and funded. This includes primary services, speciality clinics, and highly specialised services.
- **Focus on Equity:** The shift towards ICS is expected to emphasise equity of access to MS care services, ensuring that patients across different regions receive consistent, high-quality care.
- **Feedback from devolved nations:** Representatives from Wales, Scotland and Northern Ireland broadly agreed with the issues identified but highlighted additional challenges due to large catchment areas and low population density, rural challenges, attracting staff and, in some instances, even longer waiting lists and lack of a functioning devolved government.

## UK MS Pregnancy Register Update

**Ruth Dobson** presented the journey of the **MS Pregnancy Register Initiative** over the past five years. This collaborative effort within the MS community has highlighted the critical need for consensus and guidelines and showcased the value of interdisciplinary expertise.

The initiative has set a new standard for comprehensive MS pregnancy patient care by bringing in experts from various fields, including maternal physicians and pharmacists. The launch of the pregnancy register, supported by an enthusiastic and multi-professional team, has marked a significant milestone. With nearly 200 people with MS already on board, the register is gradually shaping our understanding of pregnancy in MS patients across the UK.

Crucially, this collaborative effort has begun to yield tangible results in clinical practice. Consistency in recommendations, especially regarding the use of disease-modifying therapies (DMTs) during pregnancy, is emerging as a clear benefit. Ruth's presentation served as a powerful reminder of the impact that collaboration and consensus-building can have on improving the lives of people with MS.

## Participants Workshops

A series of workshops followed the day's panel and guest presentations. Workshops focused on sustainability, including making MS an attractive career choice, improving MS teams' roles and responsibilities, measuring care, improving access and efficiencies towards pharmaceutical trials and championing MS care.

**Workshop 1:** *How to maximise the benefits of MS clinical trials and real-world evidence (RWE) generation in the UK?*

This workshop was dedicated to exploring how to maximise the benefits of MS clinical trials and real-world evidence (RWE) in the UK. The following expert speakers presented their experience of the difficulties in undertaking clinical trials to generate discussion:

- Andy Blight
- Klaus Schmierer
- Jeremy Chataway
- Rod Middleton

These presentations led to interesting and thought-provoking discussions among all present, which will be written up in detail and circulated separately. Key points from the workshop included:

- Calculating potential savings for the NHS resulting from drugs used in clinical trials at the national level.
- The importance of incorporating MS clinical trials modules into the early training of Specialty Registrars (SpRs) to attract them to the field of MS.
- The development of one-year fellowships in MS, including clinical trials post-completion of Core Training (CCT). This approach offers a multi-regional perspective and aims to reduce consultants' apprehensions about taking on the workload associated with Disease-Modifying Therapies (DMTs).

- The necessity to promote research participation in all new MS job plans which are akin to the approach adopted by Owen Pearson in Swansea.
- The exploration of a regional delivery model for clinical trials, drawing lessons from successful approaches in cancer research.
- The replication of the MS SMART study within the UK MS Register.
- Establishing a sign-up list for OCTOPUS, both currently and in response to future changes in inclusion/exclusion criteria.
- Acknowledging the value of real-world evidence (RWE) from the UK MS Register in initiatives such as smoking cessation and reducing disability rates, anxiety, and long-term disability outcomes compared to clinical trials.
- Highlighting the precedent set in cancer research by the FDA's acceptance of virtual real-world data control arms, potentially accelerating studies. The emphasis was on the consistency of outcome measures and the possibility of scaling this approach across the UK.
- Post Brexit, the new regulatory approvals through the MHRA are an opportunity for early regulatory approval, but patients still may not get access to the treatments due to backlogs.
- Look at leveraging Blueteq data as an initial RWE dataset.

***Workshop 2: Building sustainability in MS teams by maximising efficiency.***

This workshop provided valuable insights into enhancing sustainability within MS teams by optimising efficiency. Key takeaways encompassed:

- The pressing need for greater standardisation of MS care practices.
- The standardisation of outpatient correspondence, including the creation of templates using smart phrases and a broader database, catering to all individuals with MS, not just those on Disease-Modifying Therapies (DMTs).
- Strategies to make specialised MS careers more appealing at an early career stage for professionals from diverse backgrounds involve the revision and standardisation of job descriptions, participation in career fairs, and broader advertising.
- The recognition that one-size-fits-all does not apply to the core MS team requires customisation based on the needs of each 1000 persons with MS (PwMS).
- The importance of defining various care models and adapting the roles of team members accordingly, with consideration for varied access to healthcare professionals outside the core team.
- The demand for more administrative roles and positions dedicated to handling data to alleviate the workload of healthcare professionals.
- The emphasis is on improved data sharing and enhanced collaboration among healthcare professionals.

## Summit Conclusion & Participant Feedback:

### A Call to Action

The day's event drew to a close with a strong call to action, encouraging participants to commit to at least one advocacy initiative. This involved sharing or prompting **TMS4All** among peers, offering access to valuable resources such as peer-to-peer knowledge sharing, successful case studies, real-world data, and helpful patient care letter templates.

### Feedback from the Summit:

The feedback from the summit attendees was overwhelmingly positive, highlighting the enthusiasm and engagement:

- 98% of attendees would be interested in attending a future **TMS4All** summit meeting.
- 87% of participants found the topics covered at the summit meeting useful to their practice and service.
- The two biggest benefits of the event were:
  - The opportunity to collaborate and exchange ideas with like-minded colleagues provides a valuable space for considering improvements in their services.
  - A renewed sense of optimism and positivity about the potential achievements within the TMSFA community, demonstrating the power of collective efforts in advancing their shared goals.

## Future Meeting Topics

During the **TMS4All** summit, several topics and action items were suggested by participants via a virtual brainstorming board. These include regularly updating results achieved between meetings and key summits, providing an update on national MS data access, defining what "good" looks like in the context of services, sharing audit results to identify areas for improvement, updates on addressing geographical inequalities in service provision, ensuring DMT access, staying informed about wider NHS changes, sharing success stories, updates on identifying what an MS 'core' team looks like and frequent updates on relevant industry developments and initiatives. Many participants were also keen to have an organised trip to Wales after hearing of the successful case studies from Swansea!

## TMS4All Core Operational Team Key Actions

- A written report of the summit is to be shared with all attendees and posted on the **TMS4All** website.
- To organise a follow-up webinar with Penny Dash and Martin Wilson to continue and expand the discussions on *"How can MS teams, ICS and NHS England work collaboratively to develop services and advance care?"*
- Initiate discussions with interested colleagues to advance the concept of post-completion of Core Training (CCT) fellowships for trainee neurologists, providing them with enhanced opportunities for professional development.
- Scope out the possibility of **TMS4All** creating a devolved nations task force to explore how we can ensure **TMS4All** offers broad support across the UK.

- Foster continued engagement with pharmaceutical industry colleagues and patient organisations to discuss future collaborations.
- Undertake an assessment to calculate the cost savings to the NHS resulting from clinical trials of MS. Calculate the savings to the NHS from clinical trials of MS DMTs
- Socialise Owen Pearson's schema for including a PA for research in each new MS consultant's job plan.
- Continue to engage with NHSE regarding dissemination and feedback of blueteq data.
- Establish standardised documentation for clinic letters.
- Develop **TMS4All** website to share best practice exemplars, audit templates and a "who's who" as not everyone in the MS community knows everyone else.
- Consider taking an exhibitor's stand at the MS Trust Conference 2024.

### **Actions for All**

- Develop an accurate understanding of your MS patient population as a fundamental requirement to enable service planning, business cases and research.
- Sign up for the **TMS4All** website to start creating the community.
- Submit documents for the **TMS4All** website repository that may benefit HCPs working in UK MS services. (These might include best practices, protocols or job descriptions).
- Send the **TMS4All** team your service contact information to be added to the service map function on the website.
- Estimate clinical trial drug savings to the NHS and share so we can estimate at a national level.

### **Opportunities to Help and Volunteer**

- Contact a member of the **TMS4All** operational team if interested in getting involved with the post-CCT fellowships for trainee neurologists concept.
- Contact a member of the **TMS4All** operational team if interested in any of the other topics and action items listed above.
- If anyone is willing to join a team to create templates and identify useful documents to share within the **TMS4All** document repository, please contact [joela.mathews@transformingmsforall.org](mailto:joela.mathews@transformingmsforall.org).

## **Contributions & Sponsors**

The core operational team would like to take this opportunity to thank all our generous hosts, presenters, speakers and attendees of the inaugural **TMS4All** summit.

Parts of the running costs of this meeting have been sponsored by Biogen Ltd, Janssen, Merck, Novartis, Roche Products Limited and Sanofi. The sponsors have had no control or input into the content of this meeting.