

**Transforming MS For All (TMS4All):  
Solving the MS care paradox  
Summary of Proposed Projects**

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## Overview

The UK MS audit of 70 centres concluded the need for three work streams:

- Maximising influence for change
- Maximizing efficiency and sustainability
- Maximising the use of data

In this document we outline 8 projects addressing issues primarily around the second and third work streams: maximise efficiency and sustainability; and maximise use of data. Our primary suggestion for the first work stream (maximizing influence for change) is that we appoint a specific senior person to work with, and on behalf of, the broader MS community to enable changes in service development to be realised. The aim being a sustainable flexible and evolving model of service delivery. We recognise the skillset for this role has yet to be fully defined, and the process of identification, recruitment and funding will take time. In addition, we envisage that role starting after some of the projects listed below have progressed.

## The UK MS audit: findings in a nutshell

The MS UK Audit exposed an MS care paradox. Year on year, advances in our understanding of MS and treatment options means there is more we can do for people living with MS (PLwMS) to reduce disease impact and protect brain health. In reality, year on year there is less we actually do for people as services are not advancing in parallel. As a result, the gap between theoretic and actual achievements for PLwMS increases year on year: ***the MS care paradox***.

We think this paradox can be solved. Not by simply expanding MS teams but by addressing the way MS teams work, how MS care is delivered and how those actions are realised. Naturally, there will be a requirement for investment. But this should be evidence-led, strategically-driven, cost-effective, co-ordinated and accountable. Here, we outline a proposed set of projects aimed at achieving that goal.

We expect the MS care paradox is, or will be, a common finding in other disease areas – both neurological and non-neurological. As such, we believe MS care offers the opportunity to be an exemplar for advancing health care across specialities.

## Proposed projects: generic issues

All the projects listed below aim to improve care for UK PLwMS. While each project is a stand-alone piece of work, the projects are inter-related. We have listed the projects in a priority order, from our perspective, but recognise different stakeholders may have different priority orders.

Our hope is that multiple collaborators will support projects. A collaborator can choose to support any one or more project/s. Collaborators can combine to support one or more project. Ideally, we would like to see equity in contribution, transparency and accountability. For that reason, we have costed all projects as £50000 and timed them at 12 months duration, even though their individual costs and time requirements might vary. Our accountability strategy is to provide progress reports to collaborators at 1,3,6,9 months so that they can see progress across the projects, and determine whether they consider progress adequate and value for money. If so, collaborators can decide whether to continue funding beyond 12 months, if further work is required. If not, funding can be discontinued.

All funding will be via a non-for-profit community interest company (CIC). This initiative – Transforming MS for All - is a collaboration with an established CIC, Transform MS. Transform MS CIC is a community interest company incorporated in 2019 with a stated social purpose of supporting people with Multiple Sclerosis and their community. Transform MS CIC delivers its social purpose through a combination of its own projects and contributing to, facilitating and investing in other projects, that align with the Transform MS CIC social purpose.

As a CIC, Transform MS operates within a regulatory framework and has an established asset lock; there is assurance that income and activities deliver its declared social purpose. This framework includes annual reports to a formal regulator who reviews and ensures that the CIC is operating appropriately.

#### TMS4All: Project proposals for solving the MS paradox

To provide support to the *Transforming MS for All* initiative, a separate project account will be created within the Transform MS CIC accounting structure. This ensures that all income and costs are managed separately from the Transform MS CIC business with complete transparency; 100% of the monies received will be invested in project delivery. Within the *Transforming MS for All* project account, separate sub-accounts for each of the projects outlined in this proposal would be created. This provides the ability for regular reporting to sponsors of the overall financial management of the Transforming MS for All initiative, as well as meeting any audit requirements for specific projects.

For each project the £50000 for 12 months funding will support a full time project lead, associated administration support, a contribution to an overarching more senior project manager and pro-rata reimbursement for contributions from individuals within the MS community. The reporting structure is at 1,3,6,9 and 12 months with justification for ongoing investment if required.

## **Project 1: Roles and responsibilities of MS team members - clarifying expectations of people delivering MS care**

### **Rationale:**

The UK MS audit showed that:

- UK MS teams have inconsistent staffing structures;
- MS team member roles and responsibilities varied substantially;
- there was notable acting down and also acting up;
- Most MS teams were understaffed when compared with theoretic standards.

To solve this, MS teams must work as efficiently as possible to ensure their personnel and skills are used maximally.

### **Aim:**

To identify and formalise the components of MS care and how they can be undertaken efficiently and effectively within an MS team.

### **Method Overview:**

- Identify existing work
- Identify key partners and stakeholders for collaboration
- Draw on experience of good practice within MS teams and other disciplines
- Identify components of MS care, how are they delivered, how they can be delivered?
- Examine roles of MS team members
- Explore new ways of working
- Set standards
- Examination of current workforce
- Generalisability to other clinical specialities

## **Project 2: MS team support mechanisms – website, communication and repository**

### **Rationale:**

The MS UK Audit demonstrated that MS teams had limited:

- knowledge of care processes at other MS teams;
- access to successful approaches to service development;
- access to exemplars of good practice,
- advice and peer support.

To solve this, a single point of contact for the MS community would facilitate and simplify access to information and communications.

### **Aim:**

To develop a single point of contact for UK MS teams and patients for information, communication, and access – a way in to all MS information – up to date peer reviewed advice for MS clinicians and patients (new patients, research opportunities. COVID guidance, recruitment to academic or commercial studies).

### **Method Overview:**

- Identify existing work
- Identify key partners and stakeholders for collaboration
- Develop website content
- Provide access
- Link and signpost to other MS relevant internet resources for HCPs
- Develop repositories
- Work with stakeholders to meet their needs

## **Project 3: Where is the care – UK MS care map development**

### **Rationale:**

It is difficult to know what MS services exist where in the UK. Knowledge is often outdated as services and teams change frequently. Likewise, we do not know where PLwMS are distributed in the UK. MS care, service delivery, communications and service development would be facilitated by prospectively interactive updated “maps” of UK MS services and patient distributions.

### **Aim:**

To build a set of relevant prospectively updated Maps that serve the needs of different stakeholders including PLwMS, MS Teams (e.g. for transferring patients’ care), patient Groups, Commissioners and Service Planning and others.

### **Method Overview:**

- Identify existing work
- Identify key partners and stakeholders for collaboration
- Establish information governance requirements, permissions and accessibility
- Engage Map developer
- Work with services to map services and patients
- Include therapies and rehabilitation facilities
- Work with NHS commissioners to Map patient postcodes (first part) as heat map.
- Establish mechanisms and processes to ensure longevity and prospective updates

## **Project 4: Recording care – MS team documentation**

### **Rationale:**

MS teams do not use consistent methods of documentation. Templated documentation will improve information gathering, consistency, communication and efficiency whilst reducing administration costs. It should improve information for PLwMS, and ensure MS teams are more efficient in providing guiding documentation and methods of providing data that link to benchmarking, expectations, performance and key metrics.

### **Aim:**

To develop consistent methods of documentation, including a core dataset, that support and maximise care and data availability, reduce administrative team requirements, maximise efficiency, minimise person time and improve digital maturity and literacy.

### **Method Overview:**

- Identify existing work
- Identify key partners and stakeholders for collaboration
- Collect exemplars from a wide range of HCPs.
- Identify what is required from documentation and how some of this could be automated
- Identify the core/minimum data set that services need to collate on each PLwMS
- Gain consensus
- Pilot exemplars.



## **Project 5: Measuring outcomes – MS expectation frameworks**

### **Rationale:**

The UK MS audit highlighted near ubiquitous difficulties instigating MS service developments locally, despite persuasive business cases built on a sound understanding of how to influence the pathophysiology of MS. All services were struggling to deliver high quality care to PLwMS. New developments will compound those problems. Patient expectation outcome frameworks provide a different outcome-focussed approach to influence service development. Here, reasonable expectations of care and care pathways are defined, consensus agreed and articulated as an outcome measure. Services are then benchmark against these criteria.

### **Aim:**

To collaboratively develop patient outcomes expectation frameworks to enable services to be benchmarked and to guide MS service development.

To explore the development of MS team and NHS outcome expectation framework as a methods of service delivery accountability.

### **Method Overview:**

- Identify existing work
- Identify key partners and stakeholders for collaboration
- Collaborative partnership with shift.MS, *agreed in principal*.
- Identification, review and collation of existing patient experience work in MS.
- Patient interviews, focus groups and surveys.
- Clinician interviews, focus groups and surveys.
- Engagement with NHS (ICSs, NHSE, commissioners) to develop agreements for implementation, accountability and action on results.
- Pilot work.

## **Project 6: Maximising core activities – making Blueteq indispensable**

### **Rationale:**

Blueteq form completion is mandatory for MS DMT prescribing. It is one process common to all MS services in England. We believe it is underutilised in terms of supporting MS care and in the data it provides. This project aims to maximise the value of Blueteq to the care of individuals with MS, MS teams and the NHS.

### **Aim:**

Develop the Blueteq process into a clinical management Dashboard.

Develop a “living” probabilistic algorithm to support and guide MS DMT choice.

### **Method Overview:**

- Identify existing work
- Identify key partners and stakeholders for collaboration
- Strength and formalise existing partnerships with NHSE (commissioners) and Blueteq
- Work with clinical teams to ensure needs met
- Develop front end as clinical management Dashboard
- Partner with statistical group to develop back end - a prospectively updated probabilistic outcome tool.
- Explore linkage to other NHS systems
- Pilot work
- Roll out the key learnings and outputs to the other home nations

## **Project 7: Advancing data value – improving HES data quality and routine use**

### **Rationale:**

Hospitals collect vast amounts of data, most of which is not readily available to, or used by, MS teams. There are long standing concerns of the data quality of HES (hospital episodic statistics) and coding variability that limit its value to NHS care development. We have been working in partnership to develop a HES dashboard that is clinically useful to MS teams

### **Aim:**

- To improve HES data quality
- To improve MS data coding consistency.
- To maximise the use of HES data in routine care and service development.

### **Method Overview:**

- Identify existing work
- Identify key partners and stakeholders for collaboration
- Determine the data MS teams need to assist care, service development and national auditing.
- Examining data quality of coding variances
- Propose and pilot consistent coding method.
- Scoping out how we can further maximise the use of HES data (eg social determinants of health, co-morbidities, link to Blueteq etc)

## **Project 8: Ensuring the future - making MS an attractive career option**

### **Rationale:**

Good quality and sustained MS care relies on the next generation of MS HCPs. Currently, MS is not a popular career choice, perhaps due to the work pressures and difficulties developing services.

### **Aim:**

To make MS care an attractive career option for neurologist, specialist nurses, pharmacists, therapists and admin support staff.

### **Method Overview:**

- Identify existing work
- Identify key partners and stakeholders for collaboration
- Work with juniors to define what is attractive to come into MS
- Work with existing MS teams and national bodies, to determine how to maximise attractiveness for those in post
- Develop career structures paralleled by educational programmes.
- Recruitment drive, eg succession planning and advertising vacancies