

# Improving care for people with MS: the potential of data and technology

Summary of key conclusions



# The potential of data and technology for people affected by MS



# Introduction

Just like all of us, people with MS in the UK have had their lives dramatically changed by technology. From how we shop and run our homes to how we interact with each other and access information, technology and data have increasingly empowered us and personalised the services we use.

However, it's fair to say there is one aspect of the lives of people with MS where the pace of change has been much slower: their health and care. Websites like Amazon can offer personalised recommendations based on previous purchases, yet people with MS often find themselves having to describe their case to each new professional from scratch. Supermarkets can track thousands of people through their stores and rearrange their shelves to minimise the time people spend looking for products, yet many parts of the NHS cannot say how many people with MS receive services in their area.

Digital transformation and the possibilities it provides have not yet been realised within the care and support people with MS access. Across both the NHS and the third sector there is a long way to go to use the power of digital technology to deliver personalised and coordinated services that best meet the complex needs of the MS community.

People with MS rightly expect health care to catch up and respond to how they live their lives, empowering them to manage their condition and providing the services they need, when they need them. Sadly, there is very little evidence of this happening: too often people with MS are still facing unwarranted variations in care and increasingly restricted access to over-burdened services.

Some voluntary and community organisations providing support to people with long term conditions – including the MS Society – have begun to use data and digital technologies to enhance their offer but there is more we can do. This summary highlights examples of best practice that inspire us and that we think we can learn from.

In the context of a challenging funding environment and unchanged demand for services, it could be easy for innovation and technological improvements to be seen as low priority. But to stand still and ignore the changes that are happening all around us would be to let down people with MS. Carrying on as we are will likely mean longer waiting times and further haphazard local changes in response to squeezed budgets.

Harnessing the potential of data and technologies could improve the health and care of people with MS in four key areas:

- Helping people with MS to take more control of their care
- Accessible and coordinated care
- Improving access to the right treatments at the right time
- Using data to better meet patient needs

Here, we set out our key conclusions in each area in turn, showing the potential of data and technology for people with MS.

The MS Society has also published an action plan Accelerating innovation for people living with MS, setting out how it will respond to the recommendations of the report, which can be found [here](#).

# 1. Helping people with MS to take more control of their care

## The internet and online platforms

Patient technology is opening up a wide range of new ways for people to help manage their MS and feel supported in doing so.

Digital tools such as online platforms and information have significant untapped potential to help people with MS manage their condition and seek appropriate physical and emotional support as needed. The internet already allows people to gather information about the condition, its causes, how it progresses, symptoms, and therapy. Some people use it to find information about ongoing clinical studies and scientific research and to prepare for a consultation with a neurologist – which is often empowering and leads to more productive consultations with health care professionals. Third sector organisations are already using internet platforms and digital technology to help people with MS. For example, people who are part of online patient networks, such as the MS Society Forum, report becoming more knowledgeable and feeling more socially supported. They often have improved behavioural and clinical outcomes compared with non-users.

Improved support for people with MS to navigate their options and compare notes with each other could make it easier for them to find the solution that's right for them. However, it is important online support is easy to find and navigate and tailored to the different stages of someone's MS journey. Difficulty finding relevant information or becoming scared or anxious because of worrisome information about how MS might progress can reduce engagement.

## Action for other conditions

**HealthUnlocked** – a social media platform allowing users to find other people with similar conditions. Many conditions, such as endometriosis, lupus and rheumatoid arthritis have a specific area of this site.

**Flash Glucose Monitoring for Diabetes** – a wearable sensor which continuously monitors your blood glucose levels and allows you to access them by scanning the sensor whenever you want to.

## Existing examples within MS

In London, a social enterprise, **Salusa**, has been set up to map opportunities for physical exercise for those with long-term conditions as well as allowing them to find personal trainers and instructors.

**The MS Active Together** campaign developed by the MS Society has provided online exercise videos to help people with MS to stay active, providing tailored options for different levels of mobility.

**Thought Sort**, an app developed by Shift. MS following research funded by the MS Society to help people with MS access Cognitive Behavioural Therapy to manage emotions and mood.

**My MS Manager**, an app from the Multiple Sclerosis Association of America to manage all aspects of MS.

**My Multiple Sclerosis Diary**, an app to help people with MS who are using injectable medicines.

## Use of digital tools to help manage MS

Digital tools such as apps and wearable technologies are starting to help people manage the logistics of their long-term conditions – reminding them to take their medication or helping them manage injection sites for example. Some conditions have already made significant progress at developing and embedding specific technologies to support self-management and empower patients. Developments have been more limited for MS but a number of generic platforms do already exist which could benefit people with MS.

So far there are only a few digital tools that have been developed for people with MS specifically (examples on previous page). Many available digital tools focus on managing a particular symptom or set of symptoms which are often not unique to MS. However, those that do exist have not necessarily been evaluated, limiting engagement and effectiveness. This also means that many are not yet available for recommendation by the NHS or health care professionals and that people with MS may not know which digital tools might be most useful to them.

Where useful technologies already exist, these need to be promoted to people with MS who might benefit as well as their health care professionals to ensure a shared understanding. Further work is also needed to evaluate and validate these digital tools – for some symptom management tools in particular this should be done in partnership across several conditions, especially as many people with MS have other conditions as well.

An expansion of available digital tools, developed from an understanding of the technology needs and priorities of people with MS, could put self-management within the reach of many people with MS. However, people affected by MS have different lives, different priorities and different attitudes to data and technology, so rather than developing one perfect solution, we will likely need a menu of options that can work for different people affected by MS in different ways.



## 2. Accessible and coordinated care

### Coordinating between professionals

There is a wealth of evidence to show that coordination among professionals, such as having a written care plan, can both improve outcomes and help to ensure that care is driven by the priorities of a specific person with MS. However at present, care plans are under-used. In 2014, 72% of people living with a long-term condition used their care plan to manage their health every day but only 5.4% had access to a written plan. In neurology, recent figures suggest only 15% of patients have a written care plan – most of which are paper-based.

Thankfully, it is becoming easier to collect data electronically and to share and link that data across organisations, to ensure that all professionals involved in someone's care know what is going on. Rather than engage in a long struggle to bring neurology up to the level of other conditions in

terms of traditional often paper-based care plans, we see the potential to leap-frog direct to digital care plans, using the power of technology to ensure that digital plans fit much better into existing pathways (and therefore are much more likely to work) than traditional care planning.

Harnessing data and technology to analyse medical data and history – and share it more easily – would allow professionals to truly act as a team, always involving each other where needed and responsively reacting to issues as they occur. It could also drastically improve the currently complicated and confusing system of care and appointments which often mean people with MS have to repeat their stories time and again.

Better still, electronic links would give professionals an easy way to refer to each other, maximising the chances that people with MS will receive all the treatments and services that could help them. Too often where people with MS should receive things like home adaptations, the message never gets through to the team responsible for providing these. This would also enable better service design to streamline and coordinate services.

A number of NHS initiatives and action by some commissioning bodies across the UK have begun to explore how to improve coordination of care, including the role technology can play. So far though, these initiatives have reached very few people with MS and urgent action is needed.



## Action for other conditions

A number of platforms and technologies have been developed by technology companies to facilitate care coordination and information sharing between patients and health care professionals including CareTeam, CipherHealth, Patient Relationship Management (PRM) by pshealth,

Jointly app by Carer's UK helps carers keep track of medication, appointments and tasks along with the person they care for and professionals, helping coordination between all individuals.

Trafford Coordination Centre was established in 2015 in partnership between NHS Old Trafford CCG and DXC Technologies to coordinate health and social care for people with multiple needs.

Development of tools to provide digital access to patient records such as projects by Vivum Health, international examples such as the Cleveland Clinic, and initiatives within the NHS such as 'Wrapping healthcare around the patient' within Flyde Coast.

## Sharing information

Fundamental to coordinating care there must be improvements in the sharing of data across the system. Although there is a clear ambition from national bodies like NHS England to enable efficient and effective data-sharing across organisations and providers, progress towards this has been hampered by a lack of incentives for commercial companies to enable software to be shared and a nervousness about the legalities of data-sharing at a professional and patient level.

The NHS must take further action to encourage data-sharing. The Watcher Review recommended that all health care IT providers should ensure the ability of different systems to operate together (also known as interoperability) and acting on these recommendations would provide NHS England with an opportunity for real improvement.

Alongside this we know that to make progress, people with MS need to be comfortable with participating and sharing their personal data. Miscommunication around large data-sharing initiatives has created a general culture of fear around data-sharing among the public and confusion about how data is used.

We, along with others in the third sector, have a role to play in this. While we must be careful not to put people with MS in a position of being pressured to share their health data where they don't want to,

we know that the more people understand about how their data is to be used and the more they see of the benefits of sharing, the more likely they are to consent to share.

People with MS also rightly expect information-sharing to work both ways. Online access to health records can empower people to better understand and manage their health and wellbeing. Again, not only does this mean people are better able to cope with their condition in their every-day lives but also that they can ask more informed questions of their health care professionals when they get to see them.

## Current examples in MS care

DataWell is a data-sharing scheme in Greater Manchester, East Cheshire and East Lancashire. It is already being used to improve how MS care is planned and delivered. It enables doctors and care professionals to share and view patient information to coordinate care. DataWell means that nurses can view results for monitoring disease modifying therapies (DMTs) simply by logging into the system rather than sending faxes or making telephone calls.

### 3. Improving access to the right treatments at the right time

Both data and technological innovation could play a part in deepening our often poor understanding of prescribing practice, targeting unwarranted variation and helping to improve access to the right treatments at the right time, which can slow the progression of MS.

At present data is collected on the number of people who receive a disease modifying therapy (DMT) – and in England that data is used by NHS England to make commissioning decisions on DMTs. But for various reasons, this process is viewed with suspicion by consultants and data is not always accurately collected. Outcome measures are also inconsistently captured, limiting the evaluation of how any treatment is working for an individual.

Separately, the UK MS Register holds data from over 15,700 people who have opted in to the initiative. The register links routine hospital data, clinical information and information provided by people with MS about the everyday experience of living with MS, via a paper or online survey.

If the register could increase the amount of clinical information that is collected from sites and link with NHS data so that it is more comprehensive, it could be used to monitor treatment outcomes across an increased number of people with MS within particular geographies – building the knowledge of planners who could see how well the treatments their patients are receiving are working.

We also know that this data could become even more powerful if it could be linked to more detailed data like amounts of physical activity per day, heart rate and blood pressure. Historically there has been no way of capturing this without placing a huge burden on both people with MS and health care professionals. Wearable technologies and machine learning to analyse the data they remotely collect could now solve this by providing an automatic, unobtrusive way of measuring these aspects of health in people with MS that could directly link to their records.

Better capture of prescribing data, linked to information about outcomes, could also provide people with MS with more insight to make informed decisions about treatment. As the available information increases, reliable sources to interpret it and inform people with MS will be vital.

#### Current examples in MS care

DAWN software has been purchased in some areas to help with blood monitoring information for those on treatments, providing a full robust monitoring service in secondary care to alert staff in a timely manner to patients whose blood test results are overdue, abnormal or a cause for concern.

MS Decisions, a decision-making tool for DMTs developed by the MS Trust.

#### Action for other conditions

**Precision psychiatry** is being explored for mental health conditions with the aim of identifying biomarkers which could be used to tailor treatment options. Work is underway to use machine learning and brain scans to identify patterns in treatment response.

**Skin patches for diabetes** – wearable technology being used to continuously monitor blood-glucose, deliver insulin when needed and remind people with diabetes to eat.



## 4. Using data to better meet patient needs

### Improving data and planning capacity

At the moment, many people with MS are invisible to commissioners and service planners. Although it is possible for planners to identify those with MS in some routine datasets, this is rarely done. Research by the Neurological Alliance in 2015 found that only 20% of CCGs had assessed the number of people using neurological services in their area.

That means that designing MS services at a local level is not based on an understanding of:

- how many people have MS
- the services they need
- the services they might need in the next few years
- how the condition is changing and progressing within the population group.

In turn, this means that it is often down to chance whether someone with MS will have access to the necessary specialist support, for example a GP with a special interest in MS, a team of MS nurses, or secondary care MS clinics. It often depends on a consultant's knowledge, the size of the local hospital and the scale of resource it has.

We reviewed the types of data that are collected as part of routine care and how they might be used to improve MS services. We also identified the obstacles to making this happen at the moment. Some of those obstacles include a lack of comprehensive health care data, an issue in all the four countries of the UK (particularly in primary

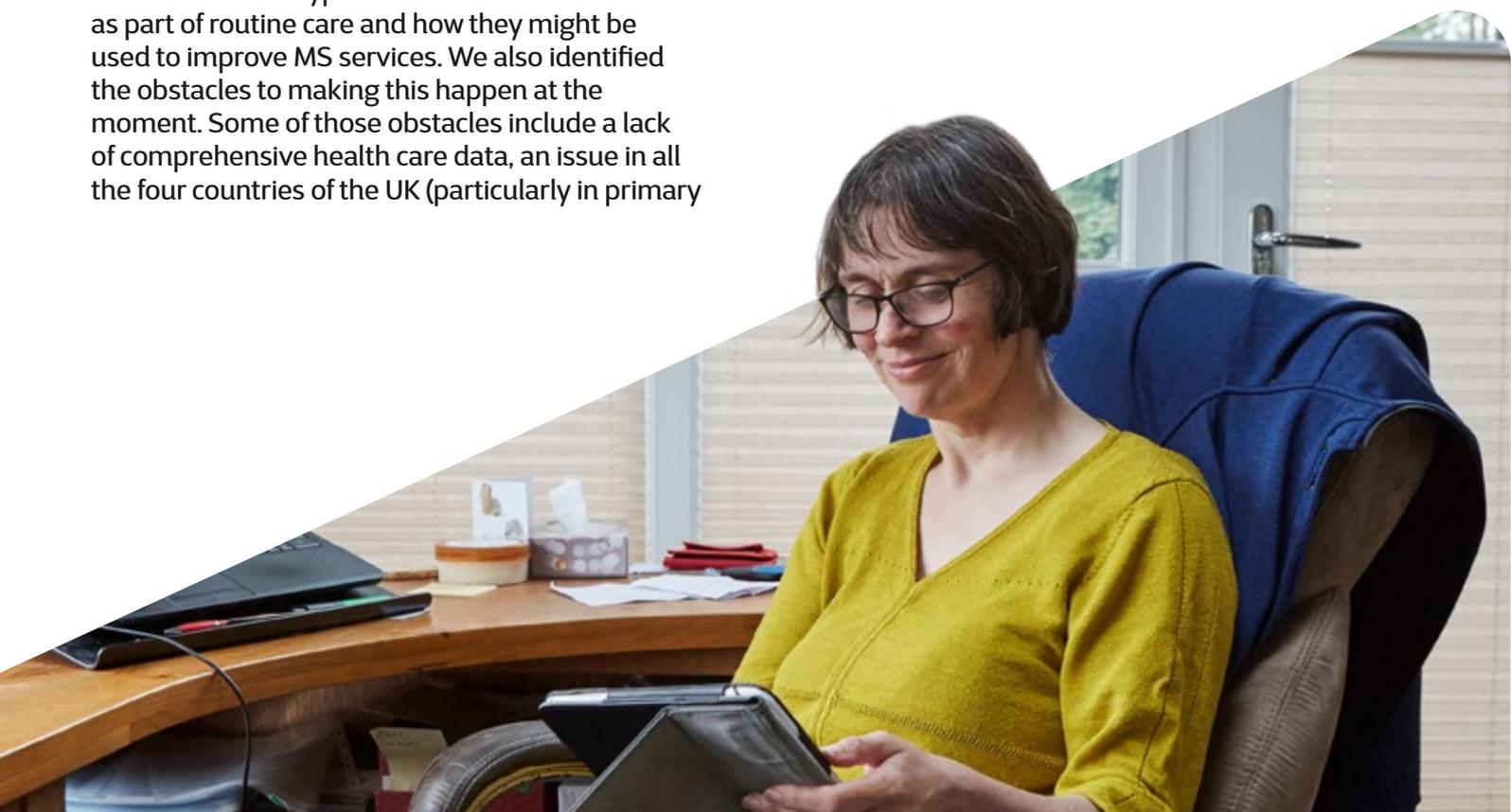
care), poor quality coding in some datasets (e.g. outpatients) and low recording of MS diagnoses.

We know that with action, comprehensive and robust MS data could be collected and shared, allowing services to be planned and commissioned on a complete picture of the needs of the MS population. Services would be responsive and tailored to local need – drastically improving the experiences of people with MS.

### Action for other conditions

Asthma UK's report *Connected Asthma* sets out remote monitoring to develop predictive algorithms to alert those with environmental triggers as well as risk stratification tools to benefit primary care management and resource allocation.

NHS England's National Cancer Programme has included work to improve clinical standards and metrics with five pilot sites testing a new diagnostic standard and five alliances piloting a new quality of life metric.



## Focussing services on what matters to people with MS

Much of the data collected by health care organisations focus on processes – for example the number of people admitted to hospital or the number of people receiving outpatient care, rather than outcomes. While this is useful, it doesn't provide any insight into which services might be most effective at achieving things that truly matter to people with MS, such as delaying progression of disability, staying out of hospital, and receiving prompt and comprehensive care when something unexpected happens.

Presently there aren't any such agreed outcome measures for MS collected as part of routine practice through a centralised system. Instead, short-term and predictive measures tend to be

used, rather than benchmarks for progression over time. Common disability measures used for people with MS are often sensitive to error at the lower end and insensitive to change at the higher end. And of course, actually accessing data and analysing it effectively requires resources and appropriate skills – currently available data is not consistently analysed or used.

Bringing the MS and health community together to agree the most important outcomes of an MS service is the necessary first step to embedding these and improving data collection.

Agreed outcomes for MS care could underpin regular audits to understand quality of services and identify gaps – eventually these could include social care and employment to provide a much fuller understanding of the lives of people with MS and the services they require.

### Current examples in MS care

The UK MS Register holds data from a sample of people with MS from over 15,700 people who have opted in. They don't need to have a confirmed diagnosis of MS. The register links routine hospital data, clinical information and information provided by people with MS about the everyday experience of living with MS, via a paper or online survey.

NHS England's RightCare neurology focus packs include a wider range of outcome measures and information on the most common procedures and diagnoses for neurological conditions. They help CCGs begin work on phase two of the NHS RightCare approach 'What to Change' by using indicative data to identify improvement opportunities.

Swansea University are developing and testing natural language processing technology. This

is a way that a computer picks out important information from a clinic letter. This would allow greater and quicker upload of information into the UK MS Register and would rely less on the human inputting which would save time and reduce error.

Royal Preston Hospital MS and the Walton Centre run a telephone clinic – patients register for an appointment and are called back at agreed time.

Research projects including The Trajectories of Outcomes in Neurological Conditions (TONIC) – which has developed a questionnaire for people with neurological conditions – and the South West Impact of MS (SWIMS) – which has collected longitudinal data from patients – have begun to demonstrate how contextual data could be collected for use by commissioners to improve services.



## **We're the MS Society.**

Our community is here for you through the highs, lows and everything in between. We understand what life's like with MS.  
**Together, we are strong enough to stop MS.**

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