MS Society

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

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The potential of data and technology for people affected by MS

People with MS

More control over care

- It's easier for people to compare options and learn from each other online
- Interactive digital information makes it easy to find what people need and make decisions
- New digital tools produced with people affected by MS so they work for them

Accessible and coordinated care

- Data shared between services means people don't have to remember and repeat themselves
- Digital care planning and coordination helps professionals and patients to act as one team
- People with MS are confident their data will be used appropriately when they share it

The right treatment at the right time

- Automated collection and analysis of outcomes means richer data for clinicians and researchers
- Increased data collection strengthens knowledge of what treatment works best for different people
- Treatment outcomes reflect what matters to people with MS and help them make the right decisions for them

Services that better meet need

- Health services use existing data to understand what people with MS need and provide the right support
- Audits help with comparing services and drive improvement through shared learning
- Planning is improved through new data focussed on what matters to people with MS

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Stakeholders consulted throughout research

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Glossary

API	Application Programming Interface: a method of interaction between software
Anonymised data	Any way of identifying individuals is completely destroyed.
Blueteq	The company responsible for monitoring the use of disease modifying therapies in England, contracted by NHS England.
Burden of treatment	How equipped people feel to carry out tasks that help them stay well.
Clinical Commissioning Groups (CCGs)	Local organisations that are run by groups of GPs to buy healthcare services for the local population.
Commissioning	The process of deciding what services should be provided in the NHS.
Commissioning Support Units (CSUs)	NHS organisations that provide a range of support services to CCGs.
Consent	The process of explicitly asking you whether you would like your data to be shared for a certain purpose. This sometimes happens with health data, but not always.
Data security	Ensuring data is protected from corruption and access by unauthorized individuals/software.
Disease modifying therapies (DMTs)	Treatments to slow the progression of MS.
Expanded Disability Scale Status (EDSS)	A measure of disability and how it changes over time in people with MS.

Health care data	E.g. information on the number of people with MS, the types of services they're accessing, the treatment they're receiving and their outcomes.
Health literacy	A person's capacity to find, process and understand health information and make appropriate decisions regarding their health care.
Information Governance (IG)	The legal framework governing the use of personal confidential data.
Interoperability	different systems (for example IT systems) being able to operate together
Multiple sclerosis (MS)	A progressive, neurological condition with many symptoms including fatigue, mobility issues, depression and anxiety, cognitive problems and visual disturbances.
Patient activation	A person's level of knowledge, skill and confidence to meaningfully participate in their health and care.
Pharmacovigilance	monitoring the effects of medical drugs, especially to identify adverse side-effects
Pseudonymised data	Identifying information (e.g. name, address) is replaced with pseudonyms, e.g. a unique number. It is fairly standard practice when using health data for reasons other than providing care.
Secondary uses of data	Any use of health data beyond delivering direct care to a patient (primarily service improvement, service planning/commissioning and research).

Foreword – Michelle Mitchell, Chief Executive, MS Society

Introduction and technology context

Just like all of us, the 100,000 people with MS in the UK have had aspects of 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.[1]

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 new professionals from scratch because their case history has not been shared. Supermarket chains can track people's journeys through stores and use this metadata to rearrange their products to match what people are looking for, yet many parts of the NHS cannot say how many people with MS receive services in their area. The gap between policy ambition and real life experience can be huge.

With that said, we are starting to see long overdue moves to accelerate change. International examples of innovative practice like the Cleveland Clinic[2] have shown promise – empowering patients with easy, online access to their health and appointments information – while in the UK NHS England's Test Bed Programme[3] has begun to act on the Department of Health's ambition to use data and technology to deliver safer, more effective care by 2020.[4]

We welcome these initiatives precisely because the UK is so well placed to become a global leader in delivering better health outcomes and quality services through the use of technology. The UK Government's Industrial[5] and Life Sciences Strategies[6] provide the building blocks to achieve this both across the wider economy and in health care specifically – setting out commitments to invest in innovation and technological possibilities and to use the power of the NHS to support more research and real-world data.

About MS and the current state of MS services and data

Just as in other areas of their lives, people with MS rightfully want health care to increasingly respond to how they live their lives, empowering them to manage their condition and providing timely access to the right services as they are needed.

Sadly, so far for people with MS the reality is falling far short of this aspiration. Despite clear, acute need too often people with MS are still facing unwarranted variations in care and increasingly restricted access to over-burdened services. In 2016 we found that 10% of people with MS had needed to see a neurologist but had not been able to[7] and 82% had not been offered a care plan in the last 12 months.[8] The UK has some of the lowest prescribing rates in Europe: we found 44% of those who could benefit from a disease modifying therapy (DMT) were not taking any.[9]

Our report

In this context, it is perhaps tempting to dismiss innovation as a "nice to have" that MS services cannot afford to focus on in the current climate. In fact the opposite is true: what services truly cannot afford is to stand still. That's why we commissioned the Nuffield Trust to take an in-depth look at the benefits to be gained from harnessing the potential of data and technology within MS health and care and moving towards the more technology-savvy, precision medicine and personalised model of care that people with MS expect.

For the first time, this report articulates a vision of personalised, coordinated and empowering care for people with MS, enabled by effective technology, underpinned by robust data. We identify the potential "win-wins" for people with MS and for the health and care system across four key areas.

1. **Helping people with MS to take more control of their care**
    We want people with MS to able to self-manage (defined by NHS England as actions to recognise, treat or manage one's health)[10] their condition but so far few MS specific tools exist to support this, limiting engagement and effectiveness. Improved understanding of the needs of people with MS among technology developers and support from the NHS to develop targeted interventions could put self-management within the reach of many people with MS. Similarly, 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.

2. **Accessible and coordinated care**
    Technology-enabled services would allow coordination between the many professionals people with MS see, drastically improving 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, it would give professionals an easy way to refer to each other, maximising the chances that people with MS will receive all of 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[11]. 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.

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. Linking currently collected prescribing data (such as the Bluteq form in England) to the MS Register would be a stepping stone to robust and evidenced prescribing practice.

4. **Using data to better meet patient needs**
   Current MS data collection is patchy and rarely used to best effect. 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.

Achieving the vision

We are determined to make this vision a reality for everyone with MS in the UK. Alongside this report we are publishing an Action Plan to set out our role and bring together everyone needed to achieve change: governments and the NHS across the UK, health care professionals, as well as academics, researchers and – of course – people with MS themselves. We know the problems facing our community are acute and achieving our vision will not be easy. But the potential set out in this report is a cause for great optimism. By starting this conversation and setting out the case we believe we can lead the way to better, personalised and more effective care for all.

Executive summary

What is MS?

Multiple sclerosis (MS) is a progressive, neurological condition. Most people first experience symptoms between the ages of 20 and 40, which means they have to manage the condition for much of their adult life. It's a complex condition for patients and their carers to manage, from remembering to take medication at the right time to tracking symptoms and identifying relapse triggers. There is also the psychological impact of MS, from coming to terms with the diagnosis to the long term impact on how they live their life. People with MS will often need to see lots of different health care professionals, including neurologists, urologists and mental health and community teams.

This report

Recognising the potential of technology and data to transform the care and experience of people with MS, the MS Society commissioned this report from the Nuffield Trust. The report maps out what is already available, what more could be done with what is available and how data and technology could be better exploited in future to improve MS health care. This report does not cover the potential for data and technology in social care, employment or welfare for people with MS. We decided to focus on health care in the first instance as the area where there is the most evidence, but the MS Society will be taking forward work to look at other areas in the future (see our action plan Accelerating Innovation for People Living with MS).

Within health care, this report examines four key areas in the lives and care of people with MS where the potential of data and technology could be harnessed to make a significant difference. Much of the report draws on published evidence. We also spoke to eight people with MS about their experience of using technology and seven people with MS about their views on sharing their health data. Their views appear in boxes throughout the report. Participants were recruited via the MS Society.

Our review of the data landscape draws on our own desk-based research as well as interviews with data experts across the UK nations. Finally, we held two roundtables; one with MS data and commissioning experts and the other with MS and technology experts. We used these sessions to test our findings and to develop recommendations for central bodies, health care providers, commissioners, the third sector and technology companies. Our recommendations appear throughout the report.

The potential of data and technology

Technology is opening up new opportunities to people with MS to manage their condition and feel supported in doing so. We have evidence (based on a small survey) that most people with MS have a smartphone and are comfortable using the internet to find information about MS or to connect with other patients [12]. The internet and apps are already helping people better understand their MS, prepare for appointments with professionals and take steps to better manage their condition – including through connecting with other people in similar situations.

At the same time, data collected by health care organisations (such as the number of people with MS being admitted to hospital) and via initiatives like the MS Register are becoming easier to collect electronically, share and link together. This presents opportunities to better understand MS patients at a local level, including the symptoms they're experiencing, the types of services they're using and how well those services are performing. As a result, local areas could use those data to take informed investment decisions and make sure they're providing the right level of coordinated support for people affected by MS. At the moment, this information is not being used to its full potential. The data often sits in different organisations and is rarely shared with other care providers. Very few people have a good understanding of the kinds of data that are held by different organisations and, if used together, how they could improve MS services.

This report aims to identify how commissioners, planners and providers of MS care can better exploit the opportunities that data and technology offer to improve the experience and care outcomes of people affected by MS, across four areas:

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

Helping people with MS take more control of their care

There are many ways in which technology can support people with MS to take more control of their care. The internet already allows people to gather information about the disease, its causes, how it progresses, symptoms, and therapy. Some people use it to find information about ongoing clinical studies, scientific research and prepare for a consultation with a neurologist – such information is often empowering and leads to more productive consultations with healthcare professionals.

Apps and online health records have also already shown promise: online access to health records empower people to better understand and manage their health and wellbeing. 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 insightful questions of their health care professionals when they get to see them. Apps

are starting to help people manage the logistics of their condition – reminding them to take their medication or helping them manage injection sites for example. In some cases they're also helping with symptom management, such as pain and cognition.

However, more work is needed to ensure that all people with MS can make the most of these advances. The internet can leave people feeling overwhelmed by the range of advice available and not knowing who to trust, or they can be put off by overly negative information. Most apps haven't been evaluated and patients and professionals don't always know what's available to them. How confident someone feels about managing their own health and care is also something that plays a big role in their ability to make the most of digital tools.

Accessible and coordinated care

It is becoming easier to collect data electronically and to develop and use technologies to share and link that data across organisations. This presents opportunities to ensure that all professionals involved in someone's care know what is going on and people with MS see all the professionals and services that could help them.

Some local areas are already trying to share data across GPs, hospitals and social care or to make sure each person has a single record that all the people involved in their care can see. Within its vision of personalised health and care by 2020, the Department of Health set out the ambition that all care records will be digital real-time and

interoperable.[13] Technologies and digital tools are making it easier than ever before for professionals to deliver services to people with MS remotely, potentially improving access and making communication between patients and professionals swifter and simpler.

However, using data and technology to coordinate care is not widespread across the NHS and many people with MS have not yet benefitted. There is uncertainty and concern about what data can be shared among both patients and professionals while improvements in computer systems and the ability of different systems to operate together (also known as interoperability) are needed. One key example of improvement is the use of open Application Programming Interfaces (APIs): a method of ensuring interaction between software.

Improving access to the right treatments at the right time

Better use of data would help people with MS get the treatments they need at the right time. Currently, a paucity of longitudinal outcomes data aggregated across the MS population and inconsistent collection of treatment outcomes at an individual patient level mean it is often not clear which treatments work best for different people.

Better longitudinal data on the outcomes for people with MS would not only help researchers to develop new treatments but also inform better prescribing practice by neurologists, while technology could help link datasets and gather additional data, such as through remote technologies and wearables.

Using data to better meet patient needs

Maximising the potential of data requires skill. It also requires the right data. Much of the data collected by health care organisations focuses 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.

Presently there aren't any agreed, robust outcome measures for MS. Given the progressive nature of the condition, short-term and predictive measures tend to be used, rather than benchmarks for progression over time. Where data is collected, it is often not visible to those planning services to help them best understand and meet the needs of the MS population in their area.

A possible future: An MS Society view

If these recommendations are acted upon we see a future where data and technology are used to their full potential to help people with MS live full, independent lives and access the right care at the right time in a way that makes the most sense for them. This starts with technology making the lives of patients, professionals and providers easier rather than harder.

Technology, such as open APIs, shared digital care records and wearables have the potential to allow a greater quantity of data to be captured and shared with less effort and more accuracy and consistency. Apps and online platforms can help empower people with MS to take control of their condition and be an equal partner in their care. At our most ambitious, we can see emerging technologies such as Artificial Intelligence (AI), machine learning and remote monitoring of condition markers opening up more tailored and personalised care, from services to treatments.

In this vision of the future these technologies then enable commissioners, service planners and care providers to make the most of data to provide services that keep people with MS out of hospital, enable them to stay independent and provide a joined up care experience so that patients don't have to keep repeating their story whenever they see a new clinician.

People with MS are much more visible, not only to commissioners and service planners, but also to managers looking to improve their services. That means that clinics are put in place based on the needs of the local population. For example, if a large proportion of the MS population was having emergency hospital admissions following falls, the data would help make the case for fall prevention services in the community. Within primary care, if a small number of patients were identified as falling frequently, MS nurses could reach out to them specifically, to re-assess their disability level, trial the use of walking aids (e.g. a rollator) and potentially refer them for a consultant review. Investment in upstream preventive interventions has the potential to both increase a person's quality of life and reduce costs within the health service.

Data is seamlessly shared across the health system, which means all professionals can see a patients' clinical history, medications that have been prescribed and make much more informed decisions about what the best course of action to take next is. The patient feels like the system is in control of their care and the onus isn't on them to remember what has happened with their case, or what treatments they have had in the past.

Professionals also use patient and embedded technology to improve the service they're able to offer. Where technologies have been robustly evaluated, clinicians are able to use patient-generated data from apps or wearables to get an idea of how a patient has been since the last consultation. They can see trends in activity, sleep and even mental health to a degree. Software produces a synthesis of data that helps professionals to efficiently and quickly understand patterns and trends over time during a consultation, so that they can decide an appropriate treatment plan.

These remotely captured data alongside and linked to agreed outcome measures records rate of progression over time and response to treatments. Data is aggregated nationally to make appropriate decisions about disease modifying therapies and analysed to understand where treatments are most effective – for example in the early stage of the condition, in conjunction with other therapies. The UK MS Register also has a much higher profile, and captures clinical and patient experience data for the majority of patients with confirmed MS in the UK.

Everything from apps and wearables to informational websites are made in collaboration with patients to make sure they are easy to use and take cognitive and visual impairments into account. Wearables (including smart clothing) are able to collect data in the background and do not create an extra burden for people who use them by constantly asking for data input. And apps empower patients to monitor their condition in a way that fits in with their everyday lives. The third sector plays a key role in helping technology developers work alongside patients and professionals during the development stage to ensure the technology meets their needs. It actively works to identify what patients want from technology and communicates it to industry and policy makers.

The availability of technology as well as the significant benefits if offers patients means they are motivated to use it. But they also have ongoing support when they need it. A range of professionals including MS nurses, health coaches and in some cases volunteers help patients to understand new technologies, and support them to keep using digital resources when their engagement starts to deteriorate. They work with them to understand their life goals, their social situation and their ability to take control of their health and care – and help them set short-term and long-term goals. This means they can offer the right level of support to help people maintain independence and use the tools most appropriate to them (with the acknowledgement that non-digital tools might be best-suited to some). The level of support changes over time as people become more or less able to engage with their care and technology.

However, there are barriers to achieving this vision and making the most of data and the technology available today. We propose a set of recommendations to UK national bodies, the third sector, health professionals and the technology sector to overcome the barriers and harness potential to plan and develop services more effectively for people affected by MS.

Recommendations for helping people with MS take control

Patient activation

Making the most of technology to support self-management requires patients to have a certain level of knowledge, skill and confidence to meaningfully participate in their health and care. This concept is known as 'patient activation'.

Recommendation: Clinicians across the UK need to be aware of a patient's level of activation, health literacy and understanding when they are producing a care management plan or giving them advice on how to manage their MS. The NHS should invest in an infrastructure to better understand this information and encourage the use and sustained engagement of digital tools (e.g. via health coaches).

Long-term ambition: All MS-specific technologies should be robustly tested with people with MS. The MS Society should be a link between patients, professionals, technology companies and decision makers, to ensure patients are involved in decisions about developing and evaluating patient technology. This should improve activation over time.

Information and advice

The internet can offer so many opportunities to help people with MS understand their condition, prepare for a consultation and better cope with every-day life. But there are lots of reasons why people might stop using the internet for their health care – of which one of the most prominent is people with MS becoming scared or anxious after finding worrisome information about how their condition might progress.

Recommendation: The third sector and health care providers should build on existing work to provide online information that is tailored to different stages of the condition, being mindful that patients often find overly negative information frightening and disengaging.

Personalised technology

Technology failing to meet users' needs is one of the most common reasons for people disengaging with it – and unsurprisingly we also found this to be true of MS technology. That means it's crucial to prioritise understanding how a technology will actually help people with MS during the development stage.

Recommendation: Technology companies and the third sector should build on existing work to understand what people with MS need and develop tools that work for them (see Patient Activation above).

Long-term ambition: The MS Society should provide a space where people with MS can find, access and review available digital tools to help them self-manage and decide which ones might work for them.

Recommendations for achieving accessible and coordinated care

Improving public trust

Miscommunication around large data-sharing initiatives, such as Care.Data has created a general culture of fear around data-sharing among the public and a confusion about how data is used. 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.

Recommendation: Central bodies should invest time and resource in educating and informing patients about the data that is collected about them, how it will be used, who it will be shared with and the potential benefits their data can bring. This is likely to make patients much more comfortable about sharing their data for reasons other than direct care – such as improving services.

Improved data-sharing

Data sharing offers opportunities to significantly improve care for MS patients, but at the moment it is not the norm. The main barriers around data sharing relate to interoperability and information governance (IG).

Recommendation: Central bodies should clearly communicate what is possible for data sharing in the NHS under current IG legislation and under the General Data Protection Regulation (GDPR) to help organisations make the most of the opportunities available now.

Long-term ambition: Central bodies should facilitate seamless data sharing across the NHS, including sharing with existing registries through supporting the development and use of open APIs alongside clear IG legislation. And they should publish accessible explanations of data protection requirements that empower professionals to make bold data sharing decisions.

Digital care plans

Care planning is underused in neurology and this can lead to services that are not coordinated and not focussed on the outcomes that matter to an individual person with MS – in some cases patients can miss out on services that could have helped them due to poor referral practices.

Recommendation: MS services should improve use of care planning, with a focus on digital care plans.

Raising awareness

Ultimately, as well as technology offering significant potential, there are many barriers to use – including a lack of understanding about what the benefits might be, anxieties about what engaging with technology might involve and perhaps most importantly a lack of robust data on what works and what doesn't. These aren't easy to overcome, but there are things both central bodies and the third sector could do.

Recommendation: The third sector should play an active role in engaging and educating clinicians and patients about the benefits of technology and how they could be used to improve care. For example, they should continually assess technology evaluations, and where a particular innovation has had proven success, promote it to their members and clinicians via outreach work.

Recommendation: At a broader level, as evidence develops, central bodies should collect and disseminate general learning about what has worked well when implementing patient technology, and where lessons could be learned. The third sector should ensure any MS-specific lessons are identified and acted upon.

Recommendations for improving access to the right treatments at the right time

Improving professional trust

Although Blueteq forms shouldn't be the main way to measure treatment outcomes in MS, they are necessary so that NHS England (who plan and commission the use of DMTs) can see who is receiving DMTs and in which circumstances. That means the process needs to be improved to ensure complete and useful data is captured.

Recommendation: Central bodies should clearly communicate how Blueteq forms are used, consider allowing measures other than EDSS to be used, and gain buy-in from all professionals using the system to ensure data is collected comprehensively and accurately. All of this will require resource. Blueteq alone should not be used to measure the effectiveness of particular treatments.

Ensuring treatment outcomes are captured

The MS Register could provide rich information to commissioners and planners, but given it only covers a sample of the MS population, it can't be used systematically across the country.

Recommendation: National bodies should work with the third sector and others to raise the profile of the UK MS Register and clearly communicate the value it could add in systematically monitoring treatment outcomes at population level.

Long-term ambition: Ensure the MS Register is sufficiently resourced to expand coverage and become a monitoring, assessment and planning tool to support clinical management and regulatory requirements for drug monitoring, and enhance clinical and policy decisions (i.e. pharmacovigilance).

Longer-term ambition: The MS Society should look to convene international bodies to bring MS experts together to agree on outcome measures for MS, including a broader basket of treatment outcome measures that give a more rounded picture than EDSS alone and look to eventually embed these in clinical practice.

Long-term ambition: With patient consent, stakeholders should work together to link Blueteq data to the MS Register to enable more comprehensive data collection on outcomes.

Measuring the outcomes that matter to people with MS

At the moment there aren't robust, systematic measures in place to collect outcomes across the MS population.

Recommendation: The MS Society should work with national bodies (e.g. NHS England, NHS Scotland) to bring MS experts and the third sector together to agree on outcome measures for MS. This is fundamental to using data to improve service planning and commissioning and improving MS outcomes.

Monitoring treatment outcomes and aggregating that data at population level is essential to ensure people are receiving the treatment they can benefit from the most, first time.

Recommendation: Whether through the MS Register or other means, commissioners should be monitoring treatment outcomes across their MS population – and NHS England should be collecting and using that data at a national level to inform DMT investment decisions.

Long-term ambition: explore the use of wearables for people with MS (where they are comfortable doing so) and the possibility of presenting this data to clinicians in a standardized way. This could build on presenting MS Register quality-of-life questionnaires in a standardized way in the shorter term (see above).

Recommendations for commissioners to improve service planning

Improving planning capacity

MS is a complex and long-term condition that requires specialist commissioning skills and analytical expertise. At present MS services are not planned based on an understanding of the local MS population.

Recommendation: Commissioners, planners and commissioning support units (CSUs) should invest in analytical expertise so they can better interrogate the data that already exists for their population and make informed service delivery decisions to ensure that the needs of people with MS are met.

There is a lot of MS related data currently available to commissioners, but it is not being used routinely and systematically to develop services that would help prevent crises in people with MS – which wouldn't only benefit patients and their carers, but also the health care system as a whole.

Recommendation: Planners should interrogate routinely available hospital data to better understand hospital (particularly emergency) use by MS patients, and seek to provide community services that would prevent admission, by keeping the population well and independent.

Imaging data could also be used to reduce waiting times for MRIs and improve patient experience.

Recommendation: CCGs should use data to help them understand whether their area experiences particularly long waiting times for MRIs compared to similar areas or the national average. If they do, they can start looking into why wait times are so long and put interventions in place to reduce the wait.

Improving professional practice

Current hospital coding is often poor and there are examples of it being distorted by a desire to maximise income.

Recommendation: Planners and providers need to work to ensure high quality coding. This may require data quality audits (already undertaken by some commissioners) potentially supported by specific incentives to improve data quality. Automation software that automatically interprets and codes clinic letters is already in development at Swansea University and could help with this in the future.

Ensuring treatment outcomes are captured

A detailed MS care audit has not been carried out since 2011. This leaves a significant gap in understanding of current care for MS patients.

Recommendation: An independent body should re-launch the MS audits to measure MS services and associated outcomes across the UK. This will need to be properly resourced through either central or third sector funding. There is a role for the MS Society in supporting this move and providing necessary funding.

We hope that by recommending actions for organisations across the system, we are one step closer to achieving a future where data and technology work to give people affected by MS the best care possible.

Rather than immediately reaching for technology or data solutions, the future needs to be built upon a culture and context that enables this potential to unfold. That means creating a collaborative culture between clinicians, commissioners, patients, the third sector and technology developers. If everyone works together, a better future is possible.

Chapter One: Helping people with MS take control of their care

Helping people to look after themselves can involve education, psychological strategies, support to carry on with treatments and take medicines as well as practical and social support. Researchers have concluded that self-care can have a positive impact: programmes that have aimed to support people with long-term conditions have been shown to reduce attendances at A&E[14]; help people to take their medication and complete treatment[15]; and, for some conditions, to reduce cost and use of health care services[16]. Although we know that self-care and self-management have the potential to have a positive impact, we are still not clear exactly how much effect is possible and why it works for some people and conditions and not others. Technology has great potential to help people to live better with long-term conditions including people with MS. A survey of 197 (self-selected) people with MS found over 90 per cent use the internet and have access to a smartphone. And over 85 per cent use smartphones at least once a day [17].

Encouraging patients to become engaged with their own health and care is an important ambition for the NHS. The Five Year Forward View, a 2014 policy document setting out future plans for the NHS, acknowledged that people with long-term conditions spend less than one per cent of their time with health professionals. The rest of the time, they, their families and their carers manage on their own. If someone with MS is able to manage their condition and symptoms effectively, they are more likely to maintain a high quality of life and less likely to need health services. This is important for people with MS and their families, but also for the health service which is operating within financial constraints.

The NHS has committed to providing patients with the tools they need to manage their condition well, not just in MS but more broadly too. Online resources and digital devices are a big part of that. A new health apps library has been launched containing approved apps.[18] Not only this, but there is growing work to bring patient-facing apps into the NHS. The Innovation and Technology

Tariff reimburses professionals for using a range of technologies, including an app for COPD. A framework has been developed to systematically evaluate apps and the Accelerated Access Review recommended a range of measures to help clinicians better use patient technology – such as a generic framework for prescribing apps. NHS Choices, the NHS website for health services and condition information among other things[19], has been revamped to offer new services, like an online NHS 111. And of course consumer technology is evolving all the time. This means that technology has never been so readily available to support patients to better manage their health.

Making the most of technology to support self-management requires patients to have a certain level of knowledge, skill and confidence to meaningfully participate in their health and care. This concept is known as 'patient activation'[20]. Patients who are more activated are more likely to have a regular source of care, more likely to obtain preventive care and less likely to delay getting care compared to less activated patients. High levels of activation have been associated with better outcomes, healthy behaviour, good adherence to treatment, higher satisfaction and better patient experience[21]. What's more, less activated patients are almost twice as likely as more activated patients to be readmitted to hospital within 30 days of discharge[22].

But supporting patients to engage with their health and care (and use technology to do so) isn't straightforward. It isn't clear why some patients engage with their health and care and others don't. There is no clear link between levels of activation and type of illness, symptom severity or demographic and socioeconomic characteristics[23]. Indeed, studies have found that age, level of education, income and gender explain only 5-6 per cent of variation in levels of activation[24]. That said, when activation has been studied specifically in relation to MS, low levels of education, low levels of self-efficacy (that is, self-belief in being able to overcome challenges) and depression are all

associated with lower levels of activation[25]. There appears to be no association between type of MS or quality of life and level of engagement.

Patient activation is closely linked to how equipped people feel to carry out tasks that help them stay well (known as the 'burden of treatment'). These include learning about treatments and their consequences, engaging with others and mobilising support, following treatment and lifestyle advice and monitoring treatments[26]. Where there is an imbalance between the duties a patient needs to carry out and their capacity to do so, one of the most common consequences is failure to follow medical advice[27]. However, burden of treatment is not just about a patient's capacity to cope with an ever-growing set of tasks. A systematic review of treatment burden in people with long-term conditions found that treatments were often seen to impact on 'people's sense of self, negatively affecting their emotions, their sense of freedom and their ability to engage in meaningful activities'[28]. It often put a strain on family and social relationships and led to a sense of isolation. This can result in patients taking a conscious decision to partially or completely non-adhere to treatment to minimise the level of disruption to their lives. These decisions were most often taken in secret and concealed from health care professionals[29]. The burden of treatment may help explain why only 41 per cent of MS patients in developed countries follow treatment guidance[30]. This often results in poor health outcomes, decreased quality of life and increased A&E attendances and hospitalisations[31].

The concept of 'health literacy' also plays an important role in how far patients are able to engage with their health and care. It refers to a person's capacity to find, process and understand health information and make appropriate decisions[32]. Health literacy affects a person's confidence to make decisions and use comparative information[33]. Research shows that where people are less able to understand health information, they tend to have lower levels of activation[34]. Researchers have concluded that both health

literacy and patient activation are factors in a person's ability and willingness to manage their own health and that any intervention should consider both. This is because a person with the skills to manage their own health will not necessarily be motivated to adhere to instructions or treatment and vice versa[35].

Activation and engagement are not static but change over time in response to disease severity, older age and how patients report their condition at baseline[36]. And because MS is a very variable condition, levels of activation may be even more dynamic[37]. This means that clinicians and bodies offering support such as the MS Society, need to be aware of different activation levels, and how information needs to be targeted accordingly.

Improving patient activation

Recommendation: Clinicians across the UK need to be aware of a patient's level of activation, health literacy and understanding when they are producing a care management plan or giving them advice on how to manage their MS. To this end, the NHS should invest in an infrastructure to better understand this information and encourage the use and sustained engagement of digital tools (e.g. via health coaches).

Long-term ambition: All MS-specific technologies should be robustly tested with people with MS. The MS Society should act as an a **link between patients, professionals, technology companies and decision makers**, to ensure patients are involved in decisions about developing and evaluating patient technology. This should improve activation over time.

Digital tools to help people with MS self-manage their condition need to be properly designed for MS: the literature reveals that there are several barriers that can make it difficult for people with MS to use digital tools. These include difficulties due to visual impairments[38]; issues with motor skills, affecting peoples' ability to use a mouse, keyboard or smartphone; memory problems which can make remembering passwords hard and difficulties with particular websites or apps that use a small font size or flashing images for example[39]. The rest of this chapter explores three digital areas that could especially help people manage their MS:

1. The internet
2. Online patient networks
3. Apps

The internet

Many use the internet to gather health information, although this varies over time[40]. Several studies have found that when people are first diagnosed with MS they go through a period of 'frenzied searching', looking all over the internet for any information they can find. In the beginning particularly, people look for information on the condition, its causes, how it progresses, symptoms, and therapy[41]. Many eventually stop using the internet for health purposes and rely on their neurologist for information[42]. As highlighted by the people with MS we spoke to (see p. 25), some can stop using the internet because they find the information overwhelming or are scared by what they read.

Of the people who continue to use the internet, they tend to refine their searching strategies and use it for particular reasons. These include looking for ongoing clinical studies, scientific research and gathering information before and after a consultation with a neurologist[43].
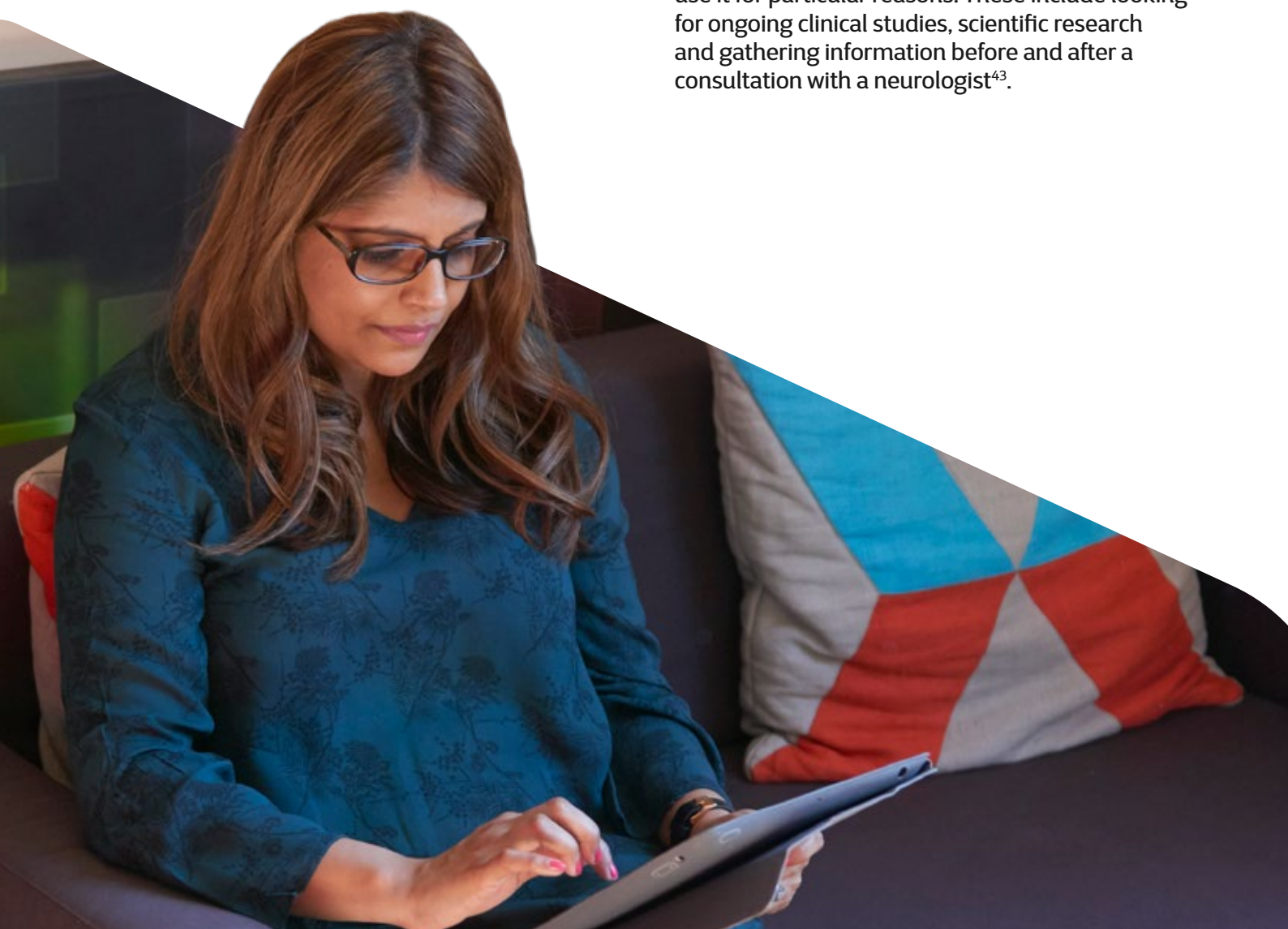
Use of the internet among the people we spoke to

Of the eight people with MS that we spoke to, everyone had used the internet in relation to their MS. This was mostly to find information from trusted websites (e.g. MS Society or MS Trust); MS-specific blogs; and online support networks, including Facebook groups. Some people used very specific Facebook groups for particular purposes like getting advice about MS and work or having MS and losing weight.

Some had also used mainstream technologies to support self-management such as Google street view – to plan the best route, including identifying drop curbs for wheelchair access; Twitter – to find others with MS or useful information; and reminders on their smartphone to remind them to take medication. Three people described using voice dictation technology for texting on their phone and typing on their computer, due to motor problems.

Another noted benefit was easy access to new information, particularly around new treatments, choosing healthcare professionals and finding guidance about claiming disability benefits, such as Personal Independence Payment (PIP). Several followed blogs to keep up to date with the latest drug developments, and used the MS Society website to find a measured interpretation of scientific findings that is easy to understand.

Barriers to using technology among the people we spoke to

Like the literature, many reported searching the internet after diagnosis and feeling scared by what they found. As a result, they tended to stick to trusted sources like the MS Society or verified blogs. A few would still Google a new symptom if it arose, but they would treat the information they found online cautiously, unless it was verified by a trusted website.

Most agreed that the internet has led to the spread of inaccurate information, particularly around miracle cures, which isn't helpful for anyone - especially friends and family who perhaps don't understand the condition as well as people living with MS.

No-one in the group particularly felt that MS symptoms stopped them using technology although they all agreed that fatigue was a barrier to all activity at times.

Concerns about data security didn't play a prominent role in stopping people using the internet or other technologies. That said, some people did express general concerns about data privacy and their data being hacked, although it wasn't specific to MS technologies or specifically using technology to better manage their MS.

The impact of apps on helping people manage their MS

Smartphone apps are beginning to help people to manage their health. For people with MS, they have the potential to play a big role in helping them to self-manage, from coping with their symptoms and reminding them to take their medication to storing information and accessing medical records. There are over 160,000 health apps on the market that can do anything from link people to support networks, to support physical activity[44].

In 2017 an NHS apps library was launched by NHS Digital, and at the moment it has over 40 apps, although none of these are MS-specific. However, there are a number of generic apps that may be of interest to people with MS such as Patients Know Best and HealthUnlocked which allows users to find other people with a similar health condition. More generally, people with MS may want to use apps

to keep track of and manage their symptoms, set medication reminders, connect with others and learn more about their condition. At the time of publication, the NHS has just announced the launch of an app to give people access to their GP record. The intention is that this will enable patients to:

- make GP appointments
- order repeat prescriptions
- manage long-term conditions
- access 111 online for urgent medical queries.

The app will become available in September and from December the intention is that every patient will be able to use it[45].

Some apps and smartphones are increasingly playing the role of allowing people to store information and easily look it up. Historically computers and personal digital assistants (PDAs) were used for this purpose – and were found to significantly improve functional performance in people with MS[46].

The box below sets out where apps can help people to better manage their MS, alongside examples of apps on the market.

Function	Example app	Description
MS-specific apps		
Receive medication reminders, track symptoms, access information about MS	My MS Manager	An app from the Multiple Sclerosis Association of America to manage all aspects of MS.
Access peer support	My MS Team	A social network and online support group for people with MS.
Manage injection sites	My Multiple Sclerosis Diary	An app to help people with MS who are using injectable medicines (e.g. Copaxone, Avonex, Rebif) to record where they have injected themselves and manage their medication stock.
Track symptoms, keep a record of notes for next neurology appointment, record walking distance through inbuilt pedometer	My Support	Specifically for patients being prescribed Rebif, to help manage their MS.
General apps		
Manage pain	WebMD Pain coach	Provides tips and goal-setting in five categories – food, rest, exercise, mood and treatments as well as pain and trigger logs
Track medications	MyMedSchedule	Medication reminder programme – including pictures of pills as visual prompt.
Improve cognition	Lumosity	Brain training games

Many apps that have potential for people with MS are symptom rather than condition specific, although most of them haven't been independently evaluated. That means we don't know how effective they are or even whether some of them are safe. There are also a number of apps that have the potential to help people with MS manage and better cope with their particular symptoms.

Mobility and physical activity

There are lots of apps that aim to improve physical activity for the general population. Several small evaluations have shown that they can be effective, but the effect size tends to be small and they are most effective when they are used as part of a bigger professional intervention. In general, bigger studies with more people and longer study periods are needed[47].

It isn't clear how effective apps to promote physical activity might be in the MS population, although a survey of over 200 people with chronic conditions found over half were willing to use a smartphone app to support physical activity[48]. Given that most people with MS have a smartphone, this could be an avenue worth exploring.

Pain

A recent review found there are 88 apps on the market that can be applied to a range of pain conditions[49]. Apart from pain relief, the most common cited app purposes included the provision of information, pain tracking and recording, to act as a diagnostic, to improve strength and flexibility, to reverse physiological factors that lead to chronic pain, to control inflammation, to assist in the dissemination of pain management research and to identify pain-related triggers[50].

A review specifically on the self-management of pain found functions included:

- pain self-care skill support e.g. muscle stretching, self-guided hypnosis, sound-assisted pain mitigation, and acupressure (this was the most common app function)
- pain education
- self-monitoring

- social support
- goal setting [51].

No apps in either review were comprehensive in pain self-management[52]. Pain apps very rarely involve health professionals in their development and very few have been evaluated[53]. However, some such as the WebMD pain coach, are based on evidence or quality guidelines endorsed by a medical board[54]. Overall though, pain apps are generally simplistic and lacking a theoretical or evidence-based foundation.

Cognition

The feasibility of an app for home-based cognitive training was recently tested for people with MS. It included games to test visuospatial working memory (like remembering a visual sequence) and processing speed, among other things[55]. It found people were highly motivated to perform well when using the app, they experienced low levels of stress and were not bored. What's more, over 80 per cent found the exercises useful and felt motivated to use the app again[56].

This is promising and suggests apps can play an important role in cognitive training for people with MS, but they still need to be fully evaluated.

Depression, anxiety and well-being

A review of apps for depression, anxiety and substance abuse found while apps can significantly reduce depression and stress, the vast majority lack scientific evaluation[57]. A recent review of apps for anxiety found the majority lacked the involvement of a health care professional in their development, and less than 4 per cent had been rigorously tested[58].

But lots of people are enthusiastic about the potential for mental health apps. Many people fail to seek mental health support when they need it, and the chance to offer support via a smartphone outside of the health care setting could offer significant advantages. The challenge is making sure people are accessing effective apps that have been rigorously tested.

Barriers to using apps

The first health apps library was launched by NHS Choices in 2012, but was withdrawn in 2015 following the realisation that many of the approved apps sent unencrypted data[59].

What's more, although patients tend to be enthusiastic about using apps for their health and wellbeing, of people who start to use a medical or fitness app, only 27–30 per cent are still using it after 90 days[60]. While this is not the only measure of whether an app has been successful (given that some may encourage people to change their lifestyle in the long-term) it does mean that even where apps look like they could have a positive impact, they may only reach a fragment of their potential in some cases.

Reasons for not using apps among the people we spoke to

As with any technology, where an app doesn't meet users' needs they will stop using it. Of the two people who had used medicine management apps in the group we spoke to, one had stopped using it because it was not customisable enough for their needs, and the other found they no longer needed it because they used pill pots instead. One of these people had also used an app for symptom tracking but had found it wasn't very functional and erased their data.

No-one had been recommended technology by a health care professional (other than being told to look at the MS Society or MS Trust website) and many were unaware of what was available to them. Most didn't know about apps to help manage MS for example, but knew there were lots of apps out there. One participant called this the "tyranny of choice".

While data security concerns didn't play a prominent role in determining app use, one person was concerned about their data from apps entering the cloud due to privacy concerns and another had worries that apps containing personal information (including MS symptoms) were not password protected and could be accessed by family members – particularly children – using the phone.

Personalised technology

Technology failing to meet users' needs is one of the most common reasons for people disengaging with it – and unsurprisingly we also found this to be true of MS technology. That means it's crucial to prioritise understanding how a technology will actually help people with MS during the development stage.

Recommendation: Technology companies and the third sector should build on existing work to understand what people with MS need and develop tools that work for them (see Patient activation above).

Long-term ambition: The MS Society should provide a space where people with MS can find, access and review available digital tools to help them self-manage and decide which ones might work for them.

Online patient networks

The internet is being used by people with MS to access online patient networks and social media. These platforms are playing important roles in helping patients share their experiences, swap lifestyle and management tips and exchange resources. People who are part of online patient networks report becoming more knowledgeable and feeling more socially supported and empowered. They also have improved behavioural and clinical outcomes compared with non-users[61]. They may be particularly important for people that have had MS for a while and are looking for support.

The literature shows people with MS benefit from patient networks in a number of ways including through[62]:

- Informational support: advice or suggestions for coping with the personal or social challenges of MS, signposting to local services; and factual or technical knowledge (from recent research findings for example).

- Emotional support: sympathy and empathy about personal situations as well as encouragement to cope with difficult situations.

- Esteem support: boosting people's self-esteem and reminding them they are not to blame for having MS.

- Network support: reminding people that they have someone there to talk to, or listen to their problems. People on social networks can go out of their way to include people who don't often join group discussions.

- Tangible support: help with tasks such as offering transport or help registering for events.

All of this means online patient networks can give people practical and emotional support to deal with their illness effectively.

There are lots of different online communities for MS, based in the UK and further afield (see box on next page for some examples).

MS Society	UK MS Society website with a forum where members can post about any topic they like.
Shift MS	A UK peer support site with over 13,500 members worldwide.
My MS Team	American social network, allowing MS patients to connect.
Overcoming Multiple Sclerosis	Australian-based site that promotes lifestyle advice (particularly diet) and provides a supportive community.
Multiple Sclerosis Facebook pages	Various groups including one run by the UK MS Society.
PatientsLikeMe (PLM)	A support community where patients share information about symptoms, treatments, and health to learn from the experience of others and improve their outcomes. These data are presented back to members as individual-level graphical health profiles and aggregated into reports accessible on the site. The data is available for research projects, with PLM as a collaborator.

PatientsLikeMe offers specific additional benefits to patients, given that it aggregates data about treatments and patient experience. An evaluation of the site found it helped patients better understand treatment side effects; make decisions about whether to start a treatment or not; and to a lesser extent take decisions about changing a medication, changing a dosage or stopping a medication. Users also found the site useful in learning about a new symptom they had experienced, managing symptoms and understanding how a treatment is working. Finally, patients are able to print reports about their symptoms and experience on a particular treatment, which many found improved health care consultations and their ability to be involved in treatment decisions[63].

Use of online patient networks among the people we spoke to

Consistent with the literature, several of the people we spoke to with MS reported feeling less isolated due to using online patient networks. For one person, online support groups were less daunting than face-to-face support groups because they didn't see people with more advanced forms of MS, and worry about their own future.

"You can't ask people if they've got MS. So much is invisible, so it's hard to meet people".

However, there can be negative consequences from engaging with online patient networks. As with face-to-face groups, some people can find it hard to be exposed to difficult aspects of MS that they haven't experienced yet. This can make people feel very uncertain about their future[64].

Some people also find it difficult to make social connections online. This can be challenging as MS is often an isolating illness[65].

Online access to records

Online access to medical records and care plans is one of the most effective ways to engage patients. Evidence shows that it can improve patient understanding, confidence, communication, adherence to lifestyle advice and a sense of involvement in their own care[66]. Record access is often used to check past activity – so patients can understand their condition better, and prepare for future consultations. This often involves using the record as a starting point to search for further information online, leading to more productive health care consultations[67].

Chapter Two: Accessible and coordinated care

There is a wealth of evidence to show that coordination among professionals can both improve outcomes and help to ensure that care is driven by the priorities of a specific person with MS. Developments in data and technology have potential to improve the coordination of care for people with MS and ensure it is more responsive to their needs.

Coordinating care between professionals

People with MS often have a wide range of service needs, from physiotherapy to urology and mental health – which means they interact with lots of different professionals across the system. At the moment, data is often not routinely shared across these professionals or settings. That means patients have to repeat their story every time they see a different professional. In addition, medications prescribed by one specialist are not visible to another so professionals rely on the patient to recount accurately the medications or treatments they are receiving. Trying to remember the sequence of events can be challenging for patients, particularly when they have had MS for a long time, and memory can be challenged by cognitive symptoms.

Without a single shared record, there is also a risk that people fall through the gaps and do not receive the care they need or that care is duplicated at significant cost to the system. This is a particular issue for the most vulnerable who may not be able to easily voice their concerns. Both scenarios represent a poor patient experience. Not only that, but it also makes patients feel like the system isn't in control of their care.

Joining up data across different organisations offers opportunities to better assess people's needs and to provide the right services. Some local areas are now trying to share data across GPs, hospitals and

social care and some places have tried to make sure each person has a single record that all the people involved in their care can see. One example of a local data sharing programme which has impacted care for people with MS is DataWell in the North West (see box below).

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. Salford Royal has around 30 patients with MS who take Lemtrada. While Lemtrada has a very good effect on quality of life, it comes with a high risk of serious side effects. That means patients taking Lemtrada need regular blood tests. At the moment, experienced nurses have to use telephone calls and faxes to follow up on blood test results and log in to lots of different systems (because they don't have easy access to the results). Salford Royal would like to offer Lemtrada to other patients. But at the moment they don't feel able to because of the monitoring it requires, and the time that takes. Accessing results via DataWell, where nurses can simply view results by logging into the system rather than sending faxes or making telephone calls, will allow nurses to see who needs intervention quickly, and will get rid of time wasted on follow-up calls.

However, such initiatives are still isolated across the NHS and are still not comprehensive even in the areas where they already operate. Acknowledging this, the NHS Five Year Forward View set out a commitment to enable better data sharing to deliver patient-centred care. The document acknowledged that progress in this area has been slow, partly because national policy has fluctuated between large-scale national programmes (such as Connecting for Health and Care.Data) that have

not been sufficiently sensitive to local contexts and a permissive approach that has allowed numerous local systems that don't link to each other to emerge. The lack of interoperability between systems has become a major barrier to better data sharing.

To correct this inconsistency, a National Information Board (NIB) was established in 2014. This body is intended to provide national enablers to ensure that locally-procured systems meet interoperability standards. Furthermore, a review led by Robert Wachter on IT in the NHS emphasised the importance of systems being able to talk to each other and recommended that interoperability becomes a "core characteristic of the NHS digital ecosystem to support clinical care and to promote innovation and research"[68]. On the back of that review, the NHS Forward View Next Steps document set out a commitment to creating fully interoperable electronic health records[69].

To deliver on this vision of fully interoperable data, there is a need to create open Application Programming Interfaces (APIs) (an API is a method of interaction between software).[70] The challenge is that APIs are, on the whole, owned by different developers and there is little incentive for commercial organisations to open them up to other companies or bodies. Although there have been many initiatives (of varying success) to create shared systems at a local level, these have generally not been scaleable at a national level.

Another important policy that is relevant to this area is that of data governance. The 1998 Data Protection Act which bound anyone holding personal data (other than for domestic use) to comply, was replaced by the General Data Protection Regulation (GDPR) in May 2018. This new legislation enforces strict legal guidelines regarding storage, maintenance and access to personal information. It expands the definition of personal data and introduces more stringent consent requirements. Importantly, it increases the power of

the Information Commissioner's Office (ICO) which will be able to impose criminal sanctions and fines for data protection breaches[71]. The new regulations also seek to clarify the meaning of consent – a term which has been open to interpretation in the past – by defining it as "any freely given, specific, informed and unambiguous indication of the data subject's wishes by which he or she, by a statement or by a clear affirmative action, signifies agreement to the processing of personal data relating to him or her" (GDPR). This clearly has far-reaching implications for those seeking to use and share data for commissioning, service improvement and research. Although provisions are made for these activities there are concerns that people will become more risk-averse when it comes to sharing data.

Sharing data for things other than patient care (e.g. for research or for planning services) can be a controversial issue. Previous attempts to improve data sharing within the NHS have had limited success. Miscommunication around large data-sharing initiatives has created a general culture of fear and confusion around data-sharing. Care.Data was a government scheme to create a giant database of medical records. It was intended to help researchers find new treatments and see how well NHS services were performing. But it was abandoned in 2016 after a series of high profile mistakes.

People with MS are key partners in improved coordinated care and need to be comfortable with any sharing of their personal data. It is important that people understand how their data is to be used and see the benefits of sharing – that encourage them to continue to give their informed consent to share. Evidence suggests that there are very mixed attitudes to the sharing of health data among patients. Surprisingly, despite the increased use of the internet and smartphones, public attitudes to data sharing have not changed much in recent years[72]. People are generally happy for their data to be shared between professionals who are caring for them. Many studies have found that a lot of people

are also supportive of information being used for research and for improving services[73]. However, when asked about their level of willingness to share their own health information for research and planning, views are very mixed[74]. For example, a large survey carried out in London found high levels of support for electronic health records (EHRs) for personal health care provision (89.7 per cent) but there was less enthusiasm for a data being used for multiple purposes, such as research and service planning (62.5 per cent)[75].

One clear message is that although many people may be happy to share information about their health, they are much less willing to share if it is linked to other personal information such as income, education level or employment status[76].

Attitudes to data sharing among the people we spoke to

Our discussion session with seven people with MS revealed a high degree of agreement in attitudes to data sharing and their attitudes largely reflected the findings of the literature review.

In general, the group were willing to allow different providers of care to share their health records between them. The group felt the benefits of health care providers sharing data was twofold: to improve the care they themselves receive and to advance clinicians' knowledge of MS as a condition.

"I can't see any point in not sharing my data … the more we share, the more knowledge there is [about a possible cure]"

Some of the group expressed surprise that health care providers didn't already have access to their complete health records. When participants were asked how they would feel if their personal information (such as employment status, education level or income) were linked to their health records, they were all less willing to share their data.

They described such data-sharing as 'intrusive' and they failed to see that there could be a benefit. There was particular nervousness around employment data being linked, in case that meant their employer may be granted access to their health records.

Participants talked about the importance of feeling 'in control' of their information and that it should be up to them to decide who knows about their employment or if their employer should know about their health status. People were particularly uncomfortable with the idea of sharing personal information with commissioners. The general feeling was that it would be very intrusive, although a small number in the group did say that if the data (in aggregate form) could be used to address variation in service provision or access, they could see some benefit, for example by reducing variation in access to consultants.

Unease about sharing appeared to be due to a nervousness about where "it could lead … could it be used to decide contributions to medical care as we move towards a privatised health service?"

There was a willingness to allow research organisations from any sector to access their data for the purposes of research. However, there were caveats to this: the group were willing to share only aggregate data (with the exception of drug trials) with researchers as long as the purpose of the research was clear.

If the data was to be identifiable, people would want more information about the purpose of the work and they would expect to be asked for explicit consent for its use. There was general openness to commercial and pharmaceutical companies having access to anonymised data as long as the purpose would be to look for patterns or information that could help develop a cure or treatment.

Members of our discussion group were open to sharing their data with the NHS bodies that plan and commission services (CCGs) because the purpose is to improve service provision. However, there was slightly more caution expressed around this. The majority of the group felt that their data should be available to CCGs only in aggregate form as they would feel uncomfortable about their specific named data being made available. They felt there was no reason for CCGs to access their identifiable data.

Attitudes to data sharing among the people we spoke to continued

When asked how they would feel if an organisation external to the NHS (e.g. a private consultancy hired to undertake data analysis) was given access to their data for the purposes of service improvement, there was a general consensus that they would be happy for that to happen as long as the NHS was gaining insight from it and on the condition that the private company did not use the data for any other purpose.

One member of the group expressed confidence that procurement rules dictate that companies comply with NHS organisations' requirements around data governance. This open attitude to sharing data with a private company slightly contradicts the wider literature that mostly finds people to be more nervous around sharing their data with a commercial company that stands to gain from access to data.

Uncertainty also extends to health care professionals involved in MS care: The Caldicott review[77] found a 'culture of fear' among professionals that they may mistakenly misuse data and a lack of clarity over who they are lawfully able to share information with and for what purpose. This lack of clarity among the public, commissioners, service providers and researchers poses a significant barrier to service improvement and integration[78].

Improving public trust

Miscommunication around large data-sharing initiatives, such as Care.Data has created a general culture of fear around data-sharing amongst the public and a confusion about how data is used. 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.

Recommendation: Central bodies should invest time and resource in educating and informing patients about the data that is collected about them, how it will be used, who it will be shared with and the potential benefits their data can bring. This is likely to make patients much more comfortable about sharing their data for reasons other than direct care – such as improving services.

Improved data-sharing

Data sharing offers opportunities to significantly improve care for MS patients, but at the moment it is not the norm. The main barriers around data sharing relate to interoperability and information governance (IG).

Recommendation: Central bodies should clearly communicate what is possible for data sharing in the NHS under current IG legislation and under the General Data Protection Regulation (GDPR) which came into effect in May 2018, to help organisations make the most of the opportunities available now.

Long-term ambition: Central bodies should facilitate seamless data sharing across the NHS, including sharing with existing registries through supporting the development and use of open APIs alongside clear IG legislation. And they should publish accessible explanations of data protection requirements that empowers professionals to make bold data sharing decisions.

Online access to records

While computer systems to enable effective data sharing are ultimately needed, other technologies also have the potential to improve the coordination of care and smooth some of the current gaps in data sharing. The literature suggests that online access to medical records and care plans is one of the most effective ways to engage patients. In addition to facilitating better patient involvement and ownership of their own care, personal health records – that is, records owned by the patient

rather than a health care organisation and usually hosted online, also mean that patients can share their health data with all health providers delivering their care, improving the coordination of care across different professionals and settings and facilitating seamless care provision across community, primary, secondary and tertiary care.

Such records are already becoming increasingly common. GPs have been required to give patients online access to detailed coded information held in their patient records since 31 March 2016. This includes diagnoses, medications and treatments, immunisations and test results, but not free text entered by clinicians. Official figures reveal that over 95 per cent of GP practices are now set up to offer online access to detailed GP records.[79]

However, at the moment patients don't have access to their secondary care record, which is likely to be of considerable interest to people with MS. A recent survey of the general population found just 0.6 per cent of respondents had accessed their medical record online in the previous six months[80].

Evidence from the general population shows that patient access to medical records is highly valued, leading to improved satisfaction and perceived savings in time and money (through savings on transport costs and telephone calls)[81]. A recent systematic review found that patients were more satisfied with the automatic communication of test results and with online information about their treatment or condition compared with those who accessed this information in person or by telephone[82].

None of the people with MS we spoke to accessed their health record online, and in fact there was an appetite for better access to health data particularly full blood test and MRI results.

That said, some professionals have concerns about giving patients access to their own records including leaving vulnerable patients open to exploitation by others and sharing third party data via free-text fields. What's more, some people are concerned about patients' ability to interpret their records and the impact record access might have on the health care service (one large study found patient access to records and clinicians via email increased GP visits, telephone encounters, A&E visits and hospitalisations[83]).

Remote technologies including smartphone apps, wearables and online platforms could also increasingly allow improved data capture – and enabling patients to input this data in their record may be useful for clinical care (providing safety requirements are met – see apps section for barriers to use).

Many patient record platforms, such as Patients Know Best allow patients to add in their own data from wearables and apps as well as record their symptoms and how these change over time. Apps also exist that allow patients and carers to track symptoms and appointments. For example, the Jointly app by Carers UK[84] helps carers to keep track of medication, appointments and tasks on behalf of the person they are looking after. It also allows a 'circle of care' to be created among people responsible for caring for someone, allowing information to be shared. Some online platforms enable patients to print reports about their symptoms and experience on a particular treatment, which many found improved health care consultations and their ability to be involved in treatment decisions.

Digital care plans

Digital technology provides the opportunity for all patients to be able to access a written care plan, which they can share with their entire health care team as well as carers and relatives. A recent report[85] by the Professional Record Standards Body, in conjunction with NHS Digital and other partners, set out the following expected outcomes from standardised digital care plans:

- Improved continuity of care by communicating relevant information more quickly, which should help people to get the right information and support when they need it.

- Greater patient empowerment by enabling them to direct their care and support.

- A holistic picture of an individual's strengths, needs, goals and actions, enabling individuals, carers, next of kin, as well as health and care professionals to provide appropriate support to enable people to remain healthier for longer.

- Improved safety by reducing transcription errors through re-use of key data.

- Improved safety by recording and sharing information about what to do in a deteriorating or crisis situation.

- Improved individuals' experience by ensuring key information about them is available to care professionals wherever and whenever it is needed.

The potential for an app to coordinate MS care

All eight of the people with MS we spoke to about using technology agreed that an app that helped them track their symptoms and share the data with their health care team would be beneficial – and that they would like to use such an app. But when asked if they would like their health care team to be able to see data from a wearable device about physical activity, most agreed that would be too intrusive.

However at present, care plans are underused. In 2014, seventy-two per cent of people living with a long-term condition used their care plan to manage their health every day but only 5.4 per cent had access to a written plan.[86] In neurology, recent figures suggest only 15 per cent of patients have a written care plan – most of which are paper-based[87].

Portals that give patients access to both their online record and their care plan can improve empowerment and where patients share them they help to keep everyone informed (see Online access to records on p. 39). They can also be particularly important in case of an emergency, so that all health care professionals and carers know what to do.

This would be enhanced even further if there was seamless record sharing across the NHS, so not only could professionals see the agreed care plan but they could also see what symptoms, diagnoses and treatments the patient has had to date.

Electronic links would also give professionals an easy way to refer to each other, maximising the chances that people with MS will receive all of the treatments and services that could help them. There is anecdotal evidence that where people with MS should receive things like home adaptations the message never gets through to the team responsible for providing these.

Digital care plans

Care planning is underused in neurology and this can lead to services that are not coordinated and not focussed on the outcomes that matter to an individual person with MS – in some cases patients can miss out on services that could have helped them due to poor referral practices.

Recommendation: MS services should improve use of care planning, with a focus on digital care plans

Making care more accessible through digital tools

In addition to using better data sharing to coordinate care, an array of digital tools are emerging to help professionals to work more responsively with people with MS in new ways to manage the condition together.

Email and messaging

Expanded use of email and secure messaging have been found to improve communication with professionals, save patients' time and increase overall satisfaction. Patients often feel more comfortable to ask questions and welcome the ability to save the clinician's message and return to it at a later time[88]. Patient satisfaction tends to improve when professionals respond to their queries quickly[89]. This offers real opportunities for people with MS to engage with their MS nurse or GP when they have an issue, rather than when their routine appointment is.

Remote consultations and telerehabilitation

The provision of remote consultations in primary care is becoming increasingly common, although patient uptake remains low. NHS England has invested £45 million to promote the uptake of online consultations (email, online messaging and video) in general practice[90]. Now, health care providers are starting to think about where remote consultations could be used in outpatient settings – in routine follow-up appointments for example.

Video consultations have been generally well received – particularly by people who struggle to access health care services[91]. Video consultations with health care professionals might work particularly well for people with MS who have mobility issues – and in fact many evaluations of web-based interventions describe how people with MS welcome the convenience of remote interventions. These might be particular well-suited to follow-up appointments – particularly as people with MS see their neurologist and MS nurse fairly infrequently anyway.

In general, evidence of health outcomes associated with remote consultations is fairly inconclusive[92].

Health care professionals are increasingly using the internet to deliver care remotely to people with MS. Lots of different interventions have been developed including online courses to improve depression, anxiety and fatigue; educational and self-management programmes, providing tools like symptom diaries; and behavioural programmes to encourage physical exercise. A lot of interventions have several components, and in addition to online content, allow patients to connect with health professionals via video, telephone or online messaging services.

The advantage of these sorts of programmes is that they can be completed from a patients' home. A lot of people with MS think that is an important benefit – particularly if they have mobility issues[93]. The downside is that engagement with the programmes tends to dwindle over time. But supporting people with e-mails or scheduled telephone calls can help sustain engagement[94].

Web-based physiotherapy

This is a professionally-led intervention using a website to introduce patients to different types of exercises. Some websites use videos as well as textual instructions so patients can comfortably complete the exercises from home. Physiotherapists use the different exercise options to create tailored programmes for patients. In one study which tested this intervention, physiotherapists also phoned participants weekly, and changed the exercise programme as needed (see Paul and others, 2014).

Overall there is some low-quality evidence that remote interventions (sometimes referred to as 'telerehabilitation') can reduce short-term disability and improve symptoms such as fatigue and depression[95]. There is some evidence they can also improve quality of life in the longer-term[96].

Many of the studies referred to in Annex 1 are small in terms of sample size and duration. Evaluating MS interventions ideally requires a large sample size with long-term follow-up given that the condition is so variable under normal conditions. This means the results should be interpreted with caution.

There are also a range of specific interventions using digital tools around key areas of symptom management. In general there is some evidence that these approaches can be effective, but the evidence base is quite immature so it is difficult to draw firm conclusions about specific interventions. See Annex 1 for a detailed consideration of the evidence around use of digital tools for:

- mobility and physical activity
- pain
- cognition
- depression, anxiety and wellbeing.

Raising awareness

Ultimately, as well as technology offering significant potential, there are many barriers to use – including a lack of understanding about what the benefits might be, anxieties about what engaging with technology might involve and perhaps most importantly a lack of robust data on what works and what doesn't. These aren't easy to overcome, but there are things both central bodies and the third sector could do.

Recommendation: The third sector should play an active role in engaging and educating clinicians and patients about the benefits of technology and how they could be used to improve care. For example, they should continually assess technology evaluations, and where a particular innovation has had proven success, promote it to their members and clinicians via outreach work.

Recommendation: At a broader level, as evidence develops, central bodies should collect and disseminate general learning about what has worked well when implementing patient technology, and where lessons could be learned. The third sector should ensure any MS-specific lessons are identified and acted upon.

Chapter Three: 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.

Longitudinal data on outcomes could also be used by researchers for generating research hypotheses about which treatments or interventions might be most effective in which patients – particularly where lifestyle and social information is captured.

Getting treatment right first time

Given that GPs are the gatekeeper to the rest of the health system, GP records are the only dataset where the full spectrum of MS symptoms are recorded for any one patient – and their severity is logged over time. That means primary care records provide a longitudinal dataset to understand how MS is progressing within a particular patient population – and potentially whether certain patient characteristics, treatments or co-morbidities are associated with better or worse outcomes. Although these rich datasets already exist, the problem is that primary care records at the national level are incomplete for most of the country and not linked directly to treatment datasets. Instead, GP data generally sits in individual practice systems from which it is both costly and complex to extract information. Information is most comprehensive in Wales. The comprehensive primary care GP dataset collects data from approximately 80 per cent of practices and provides information on the signs, symptoms, test results, diagnoses, prescribed treatment, referrals for specialist treatment and social aspects relating to the patients' home environment. That means there is potential for this data to be manipulated to see which patients are receiving which treatments, their disease course, and their outcomes.

Similarly, the Scottish Primary Care Information Resource (SPIRE) draws on data from all GP practices in Scotland. SPIRE is not an existing national dataset, rather an initiative which aims to pull data from relevant GP records in Scotland, to answer particular questions. The data is not stored beyond answering those questions and is destroyed after use – so is of more use to researchers than commissioners. However, there is potential for this data to be better used by commissioners, which could have direct implications for making sure people with MS get the right treatment first time, based on their characteristics, social environment and MS stage.

There are two datasets (the Clinical Practice Research Datalink (CPRD) and The Health Improvement Network (THIN)) that capture a sample of GP data in the whole of the UK. But these are not comprehensive nor publically available. There is potential for them to be more effectively analysed for MS-specific data and this could produce aggregate findings, but there would not be potential for person-level records to be used. Although there is widespread agreement in the research and practice community that a comprehensive national GP dataset would have great value, there are no current initiatives to create one.

Evaluating treatment outcomes

Evaluating treatment outcomes (how a particular treatment affects the progression of MS and patients' quality of life) at a population level is important as it may reveal patterns in how particular therapies work in different patients. For example, one DMT may be particularly effective if MS is at an early stage but less effective at slowing progression later on. Unless we systematically evaluate treatment, it is harder for clinicians to make informed, bespoke decisions.

Unfortunately, at the moment there aren't robust, systematic measures in place to collect outcomes across the MS population. Given the progressive nature of the condition, 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. The existing dominant measure of progression (EDSS) was the key outcome measure in clinical trials underpinning the use of existing DMTs, so it is unlikely to be replaced in the short term. However it is possible to round out this measure with a focus on other important treatment outcomes such as upper limb function and the MS Register questionnaire, which covers a wide array of aspects of quality of life.

In the longer term, we recommend the MS Society push for a consensus on comprehensive outcome measures – particularly challenging national bodies to convene meetings with all relevant stakeholders (see recommendation box on p. 47). Because of their relevance to clinical trials, such a set of measures is only likely achievable through an international consensus (potentially building on the MS Brain Health initiative[97]). We are already seeing some efforts to move beyond EDSS in clinical trials, including a new phase 3b trial for ocrelizumab focused on upper limb function. However such measures will take time to embed as outcomes for real-world evidence.

In England, Scotland and Northern Ireland national prescribing data counts prescriptions in units – so commissioners can see how many units of for example, Lemtrada or Copaxone have been prescribed in their area, but not the patients they have been prescribed to. That means there isn't an easy way of seeing how many patients the treatments are for, why new treatments have been prescribed, how people with MS have experienced them and what the outcomes have been.

Improving data collection and professional trust

In England, the process for collecting data on disease modifying therapies (DMTs), via a clinician form, is problematic. Firstly, the form asks for a measure of disability, which not everywhere routinely collects. This means some of the data is incomplete or even inaccurate, where centres are estimating the result. This is a particular concern given the data is not audited. Secondly, information is only captured while patients are being prescribed the DMT – when it is first prescribed and annually after that. Many DMTs are only given two or three times, and therefore there is a risk of long-term outcomes not being captured. Thirdly, some clinicians worry that the form is overly focussed on criteria for stopping treatment, in a bid to save money. This combined with the fact that patients don't give consent for their data to be shared with Blueteq, the company that administers the form, has made some clinicians suspicious of the whole process.

NHS England have recently published a consultation on the algorithm for DMT use that underpins the Blueteq system[98], which anticipates only a modest saving from implementing stopping criteria. This is an important step towards transparency, but must be followed up by proactive communications with professionals at regional and local level.

Improving professional trust

Although Blueteq forms shouldn't be the main way to measure treatment outcomes in MS, they are necessary so that NHS England (who plan and commission the use of DMTs) can see who is receiving DMTs and in which circumstances. That means the process needs to be improved to ensure complete and useful data is captured.

Recommendation: Central bodies should clearly communicate how Blueteq forms are used, consider allowing measures other than EDSS to be used (see above) and gain buy-in from all professionals using the system to ensure data is collected comprehensively and accurately. All this will require resource. Blueteq alone should not be used to measure the effectiveness of particular treatments.

That means other mechanisms are needed to systematically collect treatment outcome data. The UK MS Register and audits could fill this gap, with a few amendments. The UK MS Register holds data from a sample of people with MS who have opted in to the initiative. They don't need to have a confirmed diagnosis of MS. At the moment over 15,700 people have opted in. 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 be expanded so that it is more comprehensive, it could be used to monitor treatment outcomes across the whole MS population and within particular areas – so that planners can see how well the treatments their patients are receiving are working.

If the current collection of prescribing data (such as the Blueteq form in England) was improved and linked to richer information on outcomes like the UK MS Register, the resulting metadata relating to thousands of patients would be a significant step towards more robust and evidenced prescribing practice.

This data may be more powerful if it could be linked to more detailed patient-level data like amounts of physical activity per day, heart rate and blood pressure[99]. A one-year study of smartphone use to actively and passively measure symptoms in people with MS found it could collect very useful data, particularly symptom fluctuation over time which is difficult to measure through annual tests with professionals[100].

However anecdotal evidence suggests that, historically, there has been no way of capturing this without placing a huge burden on both people with MS and health care professionals. In the future, wearable technologies and machine learning to analyse the data may help to 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 on the MS Register - providing richer data on treatments (and other aspects of MS care).

Ensuring treatment outcomes are captured

The MS Register could provide rich information to commissioners and planners, but given it only covers a sample of the MS population, it can't be used systematically across the country.

Recommendation: National bodies should work with the third sector and others to raise the profile of the UK MS Register and clearly communicate the value it could add in systematically monitoring treatment outcomes at population level.

Long-term ambition: Ensure the MS Register is sufficiently resourced to expand coverage and become a monitoring, assessment and planning tool to support clinical management and regulatory requirements for drug monitoring, and enhance clinical and policy decisions (i.e. pharmacovigilance).

Longer-term ambition: The MS Society should look to convene international bodies to bring MS experts together to agree on outcome measures for MS, including a broader basket of treatment outcome measures that give a more rounded picture than EDSS alone and look to eventually embed these in clinical practice.

Long-term ambition: With patient consent, stakeholders should work together to link Blueteq data to the MS register to enable more comprehensive data collection on outcomes.

Measuring the outcomes that matter to people with MS

Unfortunately, at the moment there aren't robust, systematic measures in place to collect outcomes across the MS population.

Recommendation: The MS Society should work with national bodies (e.g. NHS England, NHS Scotland) to bring MS experts and the third sector together to agree on outcome measures for MS. This is fundamental to using data to improve service planning and commissioning and improving MS outcomes.

Monitoring treatment outcomes and aggregating that data at population level is essential to ensure people are receiving the treatment they can benefit from the most, first time.

Recommendation: Whether through the MS Register or other means, planners should be monitoring treatment outcomes across their MS population – and NHS England should be collecting and using that data at a national level to inform DMT investment decisions.

Long-term ambition: explore the use of wearables for people with MS (where they are comfortable doing so) and the possibility of presenting this data to clinicians in a standardized way. This could build on presenting MS Register quality-of-life questionnaires in a standardized way in the shorter term (see above).

Chapter Four: Using data to better meet patient needs

The collection of comprehensive and robust MS data would allow services to be planned and commissioned based on a complete picture of MS population needs.

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.

Agreed outcomes for MS care (see Chapter Three) 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 need.

In England, most health services are commissioned and paid for locally by bodies known as clinical commissioning groups, or CCGs. But where services are needed for conditions that are complex and affect a relatively small number of people, a national body, NHS England, is responsible. This is known as 'specialised commissioning'.

What is commissioning?

Commissioning is the process of deciding what services should be provided in the NHS. It involves looking at what the population needs and identifying a provider to deliver the best services to meet those needs within a set budget. It then involves monitoring those services to ensure they are of high quality and are meeting the needs of the population.

Who does commissioning in the NHS?

This process is different across the different UK nations. Both Wales and Scotland give all health planning responsibilities to devolved health boards. In Northern Ireland, the Health and Social Care Board makes planning decisions for the country's five trusts. GPs are represented on local commissioning groups in each of the five health trusts.

In England, there are two main levels of commissioning in the NHS:

1. NHS England is a national organisation that makes decisions about services for conditions that are quite rare. So, for example, services for a condition that affects small numbers of people are commissioned by NHS England. NHS England spends around £15bn per year on these services. For MS, this includes services delivered in specialist neuroscience centres (if from a consultant referral or a GP referral pre-April 2015), DMT ingredients, specialised rehabilitation services and specialist communication equipment (see Multiple Sclerosis Trust, 2016).

2. Clinical Commissioning Groups (CCGs) are local organisations that are run by groups of GPs. They vary in size but cover an average population of around 200,000. CCGs are given a budget to buy all the services that the population need that aren't commissioned by NHS England. This amounts to around £73bn per year. In recent years, responsibility for more MS services has shifted from NHS England to CCGs (The MS Trust 2016). For MS, this includes services delivered in designated neuroscience centres (if from a GP referral post-April 2015); tests, scans and imaging ordered by GPs; community and generalist rehabilitation services; mental health services and wheelchairs

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 per cent 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 disease 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 interests, the size of the local hospital and the scale of resource it has.

Here we set out what the main areas of untapped potential are (please see Appendix 1 for a full description of routinely collected health data of relevance to people with MS). However, to really exploit any of the opportunities detailed here, planners will need to either invest in their own analytical capacity or invest in commercial organisations that can help them make sense of the data.

Improving planning capacity

MS is a complex and long-term condition that requires specialist commissioning skills and analytical expertise.

Recommendation: Commissioners, planners and commissioning support units (CSUs) should invest in analytical expertise so they can better interrogate the data that already exists for their population and make informed service delivery decisions to ensure that the needs of people with MS are met.

The rest of this chapter focuses on:

- keeping people with MS out of hospital
- reducing waiting times
- monitoring the progression of MS.

Keeping people with MS out of hospital

Every UK nation has a dataset which captures inpatient and outpatient hospital activity. Inpatient data usually provides rich diagnostic information, allowing commissioners to identify people with MS, how frequently they are admitted to hospital, their reason for hospital admission, and details about any treatments or investigations they receive in hospital. Where MS is not the primary cause of admission though, there is always a risk that it will not be

captured as a secondary diagnosis, particularly if the patient is reasonably well (although it should be, as hospitals receive an increased fee for treating someone with a long-term condition).

Outpatient data is much less detailed in all four of the datasets. It doesn't include diagnostic information, which means people with MS aren't identifiable from outpatient data alone. It is possible to link inpatient and outpatient data, but people with MS would only be identifiable in outpatient data if they have had an inpatient stay. This is a significant limitation for how the data could be used because it means that those people with MS who use outpatient services but had never had an inpatient stay are effectively invisible to commissioners. Furthermore, the way the data is coded is a broader challenge when using hospital data. Where they lack the details of an encounter, hospital coders often code procedures or interactions inaccurately – defaulting to the one the hospital receives most money for. This risks giving an inaccurate picture of service use and expenditure to commissioners.

Improving professional practice

Current hospital coding is often poor and there are examples of it being distorted by a desire to maximise income.

Recommendation: Planners and providers need to work to ensure high quality coding. This may require data quality audits (already undertaken by some commissioners) potentially supported by specific incentives to improve data quality. Automation software that automatically interprets and codes clinic letters is already in development and could help with this in the future.

If coding was improved and commissioners used available hospital data effectively, they could better understand why people with MS are using emergency hospital services as well as outpatient services – which means there would be potential for services to be commissioned which sought to keep people with MS healthy and independent and therefore prevent crises that require an inpatient admission.

For example, if a large proportion of the MS population was having emergency hospital admissions following falls, the data would help make the case for fall prevention services in the community. These might include MS-specific exercise programmes to help patients improve their balance and core strength (see for example, exergaming in Appendix 1) or support to ensure people with MS have necessary adaptations in their home and workplace to prevent falls. Within primary care, if a small number of patients were identified as falling frequently, MS nurses could reach out to them specifically, to re-assess their disability level, trial the use of walking aids (e.g. a rollator) and potentially refer them for a consultant review with a view to alter medication. Investment in upstream preventive interventions has the potential to both increase a person's quality of life and reduce costs within the health service.

MS audits are also likely to be useful here. To date, three national MS audits have been carried out by the Royal College of Physicians – in 2006, 2008 and 2011. They cover England and Wales, and review how organisations are performing against the NICE clinical guidelines of care for people with MS. These measures include local access to neurological specialist and rehabilitation services, access to key specialists, information on mobility and falls, and equipment provision. Audits are really helpful in understanding variations in service across the country, and where services are failing to meet people's needs. If audits were

carried out more regularly, there would be potential for commissioners to identify and address any inappropriate regional variation and ensure equitable access to services.

Finally, focus packs put together as part of the RightCare initiative give commissioners in England a better understanding of how adults with a neurological condition are using services at a local level. For people with MS, these measures include admission rate, length of stay following emergency admission and elective and non-elective spend on MS. If commissioners are able to use focus packs alongside other available data as discussed, they would be able to build up a rich picture of their MS population and be able to make informed and cost effective decisions about services.

None of this is the norm at the moment, and the onus falls on patients to seek out additional help if they need it – and it may or may not be available in the local area. The result is that, too often, people with long-term conditions like MS are not able to access the preventive care that would prevent deterioration and they end up being admitted to hospital as an emergency. This is both costly to the system and a poor experience for the individual.

Improving planning capacity

There is a lot of MS related data currently available to commissioners, but it is not being used routinely and systematically to develop services that would help prevent crises in people with MS – which wouldn't only benefit patients and their carers, but also the health care system as a whole.

Recommendation: Planners should interrogate routinely available hospital data to better understand hospital (particularly emergency) use by MS patients, and seek to provide community services that would prevent admission, by keeping the population well and independent.

Ensuring treatment outcomes are captured

A detailed MS care audit has not been carried out since 2011. This leaves a significant gap in the understanding of current care for MS patients.

Recommendation: An independent body should re-launch the MS audits to measure MS services and associated outcomes. This will need to be properly resourced through either central or third sector funding. There is a role for the MS Society in supporting this move and providing necessary funding.

Reducing treatment waiting times

In England, the diagnostic imaging dataset provides information on imaging activity by type, source, count and waiting times for various imaging techniques (such as MRI scans). A one-off publically available summary with information about people with MS was produced for 2012-2013. Data at this granular level is not routinely provided, although it does exist – and there is potential for it to be linked to inpatient and outpatient data[101].

If this data were accessed at a granular level, it could be used by CCGs to help them identify whether their area experiences particularly long waiting times compared to similar areas or the national average. If they do, they can start looking into why the wait times are so long in their patch and whether anything could be done to address the wait. It may be a staffing shortage, an equipment shortage or a bottleneck causing delays somewhere in the process. Once the delay has been identified, measures could be put in place to address it – for example additional investment in radiographers, or novel staffing solutions which increase radiographer capacity by pairing them with assistant staff[102]. This would mean people with MS (or suspected MS) wouldn't have to wait so long for an MRI scan, offering a more positive experience for people with MS and enabling them to more rapidly access preventive care and assistance to prevent deterioration.

Improving planning capacity

Imaging data could be used to reduce waiting times for MRIs and improve patient experience.

Recommendation: CCGs should use data to help them understand whether their area experiences particularly long waiting times for MRIs compared to similar areas or the national average. If they do, they can start looking into why wait times are so long and putting interventions in place to reduce the wait.

MS Society view: the difference our recommendations could make

This report has highlighted where people are already bringing data together to improve care (the development of the recent RightCare packs for example) and using technology to manage their MS better (like through exergaming). But it has also pointed out that there is room for improvement. There are lots of things a range of professionals and organisations across the system could do to improve how data and technology are used to manage MS. If all the actions we recommend here are taken, the future will look very different.

Below we have set out a common experience of services for someone with MS currently, followed by a potential experience in the future if the recommendations in this report are implemented.

A common experience now

Natalie is 43 and has relapsing remitting MS. During her annual review, her neurologist tells her that her MS has become more active and he recommends moving from her current beta interferon treatment to a more aggressive second-line treatment. The news is a huge shock to Natalie and she struggles to process the names of new treatment options in the short appointment time available.

Before the next appointment, Natalie googles MS treatments but she can't remember exactly which ones she was eligible for and it's hard to compare so many possible treatments, each with different pros and cons.

When she sees her neurologist again the appointment starts late because he has had to deal with an urgent case and she only has 20 minutes to further discuss her treatment options. Most of the time is taken up by the neurologist explaining the generic pros and cons of the specific treatments that could work, so there is no time to discuss her priorities and how different options fit into her life.

Natalie feels like she doesn't fully understand the options, but decides to trust her neurologist and opts for his treatment recommendation of alemtuzumab. The neurologist says he will write to her GP with the treatment plan and copy her in, then has to rush off to deal with another urgent case.

Natalie starts on alemtuzumab, after six months she has not had a relapse, but she is having more trouble moving around and her fatigue has gotten worse, with more trouble thinking clearly, which is affecting her job. She googles ways of managing these symptoms and decides to try an app to improve fatigue. She also reads that physical activity is an important way of combating MS so signs up to a motivational website that encourages her to update it with the exercise she does.

Unfortunately, the app for fatigue seems to make a lot of assumptions about her that simply don't chime with the reality of her MS – it says things like "dance your way to fitness!" and "drop down and give me 10!". The motivational website for exercise also seems geared towards extremely active people and entering the data each day is an extra reminder of her MS, when often she would rather not think about it.

At her next annual review Natalie spend most of the time talking to her MS nurse about how her treatment is going and telling her about her experience of the app and website. She also mentions her mobility problems and that she's worried about falling, as well as the impact her cognitive difficulties are having on her work. Her nurse is very sympathetic and recommends contacting local social care services for an assessment as they may be able to help.

Natalie calls her local council but they say she's got through to the wrong place, they give her someone else to try but they say the right person is on holiday and she'll get a call back. After waiting two weeks she calls again and is able to schedule an initial assessment for several weeks later.

Unfortunately in the meantime she slips over in the shower and badly fractures her arm and hip. This is a harrowing ordeal in itself as Natalie lives alone and has to keep shouting until a neighbour finally hears her and calls an ambulance. After falling Natalie finds she has less confidence about moving around and her daily life is much more of a struggle, especially as she requires a lot of painful rehabilitation to try to get back to where she was.

A possible experience in the future

When Natalie gets the recommendation to move onto a different DMT her neurologist tells her "I know this can be a shock but there is lots of help to think about your options". He tells her that the MS Society website has a decision-making aid that asks questions about her MS, her life now and her priorities – and then provides tailored advice based on the experiences of thousands of other people with MS and the outcomes they've experienced on different DMTs in similar circumstances.

When she sees her neurologist again the appointment starts late but she is armed with specific tailored information about each of her options and she spends her limited time with him asking specific questions about how each would fit into her life and priorities.

Together they agree the best option is fingolimod, because it's difficult for her to make time for the infusions related to alemtuzumab and its risk of thyroid problems could be a big problem with her job. At the end of the appointment they briefly discuss ways of managing her other symptoms. The neurologist doesn't have time to go into options in detail but mentions that there is a dedicated section on the MS Society website for people with MS to compare notes on different digital tools that can help manage symptoms – and that the local MS clinic runs regular sessions to help people get to grips with this kind of technology. The neurologist updates her digital care plan so all the other professionals involved in her care are aware of Natalie's new treatment and possible side-effects, as well as the symptoms she wants to manage more actively.

Natalie finds the MS Society "digital tool library" and is able to search for tools that can help her with the symptoms she's most worried about and read reviews from other people with MS detailing their experiences with it. The most popular app for physical activity is one that was developed with people with MS, in a partnership with a technology company brokered by the MS Society. She decides to try this and a tool for fatigue management that seems most popular with people with MS doing similar jobs to her.

At her next annual review her MS nurse is already aware that Natalie has switched to fingolimod and that she was looking for better ways to manage fatigue and get more active. She asks about this and Natalie tells her that knowing other people with MS had found the same tools helpful made her more confident of success and that the clinic she attended on fatigue management was really helpful. She also likes the way her physical activity data is collected automatically in the background, rather than her having to enter it as a regular unwelcome reminder of her MS.

Natalie also fills out a questionnaire for the MS Register every six months and has agreed for this information to be shared with her nurse. The nurse says she's noticed that her score for fatigue has improved somewhat compared to the previous questionnaire, but her score for anxiety is worse. She asks what might be behind this and Natalie explains that one reason is that with her mobility problems she worries about falling down at home – she lives alone so what would happen? She also mentions that her symptoms are having an effect on her work but she doesn't know how to tell her boss about her MS, so she worries her symptoms are seen as poor performance.

The nurse is very sympathetic and explains that local service planners had analysed lots of data about people with MS and found that they were relatively likely to fall down at home. This had led to them putting in place a new "fast-track" falls prevention service for situations like Natalie's. The nurse digitally refers Natalie direct to the falls prevention service – managed by the Local Authority – on her tablet. She also explains that lots of people with MS struggle with their symptoms at work and the local MS service is trialling a new software programme that can digitally adapt existing letters from neurologists to GPs so people with MS can get a personalised letter to take to their employer explaining their symptoms and the likely impact on their work. Natalie thinks this would be a huge help in broaching the subject with her boss.

Towards the end of the appointment the nurse's tablet beeps and she says "oh good, you'll have an assessment for falls prevention in two weeks". Following the assessment Natalie receives free adaptations to her home via the Disabled Facilities Grant and is also given a "panic button" to call local services if she ever does fall down when she's alone. She also receives the adapted letter the next day and takes it to her boss to explain about her MS diagnosis and what it means.

Six months later, Natalie feels more in control of her condition and treatment decisions, and is doing well on her new treatment and symptom management tools. Her work is going better as her symptoms have eased and are managed and her boss has been very understanding since she explained about her MS diagnosis.

How do we get there?

None of this will be easy and these are not short-term goals. But this report has set out where we are now and what the challenges to achieving this vision in the future are. We hope that by recommending actions for organisations across the system, we are one step closer to achieving a future where data and technology work to give people affected by MS the best care possible.

Rather than immediately reaching for technology or data solutions, the future needs to be built on a culture and context that enables this future to unfold. That means creating a collaborative culture between clinicians, commissioners, patients, the third sector and technology developers. If everyone works together, a better future is possible.
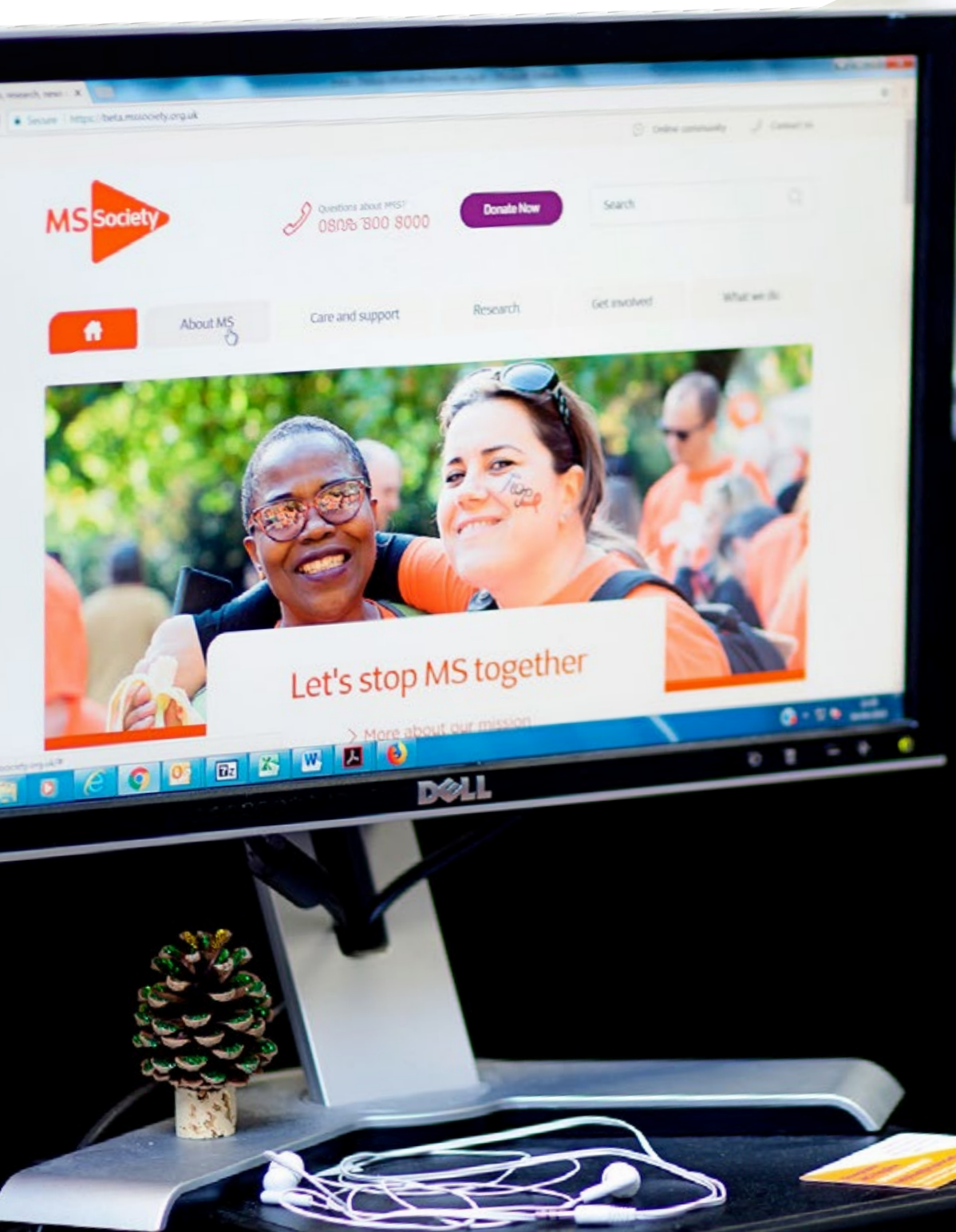
Annex 1: Summary of evidence for professionally-led services that use digital tools

Mobility and physical activity

Specific interventions for mobility and physical activity include web-based exercises, online exercise diaries and remote monitoring via pedometers or accelerometers. There is good evidence that these interventions can have a large effect on physical activity when compared to no treatment, usual care and minimal treatment without technology[103]. But they don't appear to have a significant impact on walking mobility, psychological outcomes or quality of life[104]. Similarly, some interventions specifically for strength and balance, for example through web-based physiotherapy, can have a positive impact on muscle strength and level of physical activity, but they don't appear to influence wider outcomes like fatigue or quality of life in MS[105].

It isn't clear how consumer wearable devices like Fitbits might impact on physical activity. While evidence suggests they are just as accurate as professional pedometers[106], if health care professionals are not monitoring activity, engagement is likely to be lower.

'Exergaming' is becoming more prominent in interventions to improve physical balance, strength and gait in people with MS. It involves using consumer platforms like the Wii Fit and commercially available games. It has been used in lots of different ways, and there is no real agreement about the types of games that should be used or how long training sessions or programmes should last[107].

Studies that have compared traditional exercise to exergaming in people with MS have either shown better or comparable outcomes for exergaming[108]. Importantly though, people tend to prefer exergaming to traditional exercises. One randomised control trial (RCT) which

compared exergaming to both traditional balance techniques and no care in MS patients not only found comparable improvements in balance, but also that patients believed exergaming actually improved their balance over and above traditional approaches[109]. A belief in the benefits is a strong predictor of whether people will use technology and suggests exergaming is more motivating than traditional approaches to exercise – and therefore likely to produce better results in the long-term.

Fatigue

Some work has found that physical activity can improve fatigue in MS, suggesting the technology set out above is also relevant here. But more recent evidence suggests that effectiveness depends on whether fatigue at the start of the intervention is classed as 'clinically-relevant' – i.e. whether or not it has a significant effect on daily life[110]. Where fatigue is severe, interventions are more likely to be effective[111].

Online interventions for MS patients experiencing fatigue typically consist of self-management programmes (usually including activities and weekly sessions on topics such as the importance of rest, arranging worktops and desks to avoid prolonged standing and setting priorities). Some are based on cognitive behavioural therapy (CBT) (see box).

Fully automated online programmes based on CBT can substantially reduce fatigue in people with MS, although they are most effective when patients are supported by professionals via email. This is primarily because professional engagement helps to reduce drop-out rates[112]. However, evidence suggests online CBT for MS-related fatigue is ultimately less effective than CBT delivered by a therapist in person[113].

Pain

According to guidelines by the International Association for the Study of Pain (IASP) and the National Institute for Health and Care Excellence (NICE) CBT should be the first line of treatment for pain management. Importantly, evidence shows CBT is effective specifically in relation to neuropathic pain - a common MS symptom[114].

There isn't much evidence about the impact on pain of psychological therapies like CBT delivered via the internet specifically in relation to MS, although there is evidence from other conditions that is likely to be transferrable.

For example, one systematic review of internet-interventions on pain found positive results on improving pain, activity limitation and cost associated with treatment[115]. A second systematic review found improved results on pain – although the effect was small[116]. Another, which focused on online psychological therapies for children and adolescents with chronic pain, found there is some evidence that they can reduce the severity and intensity of pain in the short-term[117].

There are also other web-based interventions that can impact on pain. Websites and online networks that offer social support can empower patients with chronic pain to self-manage and seek further social support offline[118]. And there is evidence from one study that an online behavioural intervention to improve physical activity (see Physical activity above) improved pain symptoms – but this needs investigating further[119].

There is also a growing number of smartphone apps to support pain management (see section on apps below).

Cognition

Some evidence suggests that physical activity can improve cognitive function in MS – meaning technology to improve physical activity could impact on cognition too. But a recent review found the connection could easily be confounded by other factors and that the evidence of a connection is equivocal[120].

Evidence suggests that memory rehabilitation can improve cognitive performance in people with MS, and the effect continues for some time after the intervention has finished[121]. It can also improve quality of life in the short-term[122]. Memory rehabilitation approaches emphasize the importance of repetition, stepwise learning and providing learning materials in a variety of formats[123] – and therefore lends itself to an online format, particularly in the form of games and 'brain training'.

Online tools are beginning to show positive results in improving the cognitive function of people with MS. Early findings from a study using Lumosity[124], a tool with lots of brain training games, revealed a trend towards significant improvement in cognitive function, particularly visual memory, executive function and attention[125].

Another study compared brain training with normal computer games and also found brain training led to significant improvement in cognitive function for people with MS – including processing speed, working memory, verbal and visual learning and visual scanning[126]. People played the games in their own home and compliance was high which is significant, because drop-out rates for online interventions are usually substantial. Nevertheless, more research is needed about the how effective brain training is and in which contexts.

Some people have also tested the impact of mindfulness meditation, delivered via the internet, on cognitive function in MS with positive results. It was found to improve cognitive measures of information processing. Secondary outcomes included reduced fatigue and depressive symptoms[127].

Depression, anxiety and wellbeing

Face-to-face CBT has proven effective in reducing depressive symptoms in people with MS, although there isn't a consensus about how long it should be delivered for or the best way of delivering it[128]. Computerised CBT is now starting to show some positive results. Fischer and others[129] found that a fully automated CBT programme not only reduced severity of depressive symptoms, but also increased quality of life and decreased fatigue. Online problem-solving therapy has also been shown to reduce depressive symptoms[130]. But more recent work on CCBT found that while the intervention seemed to reduce depressive symptoms, symptoms also reduced in the wait-list control – suggesting further research is needed to understand which aspects of CCBT are effective[131]. That said, evidence consistently shows patients are satisfied with CCBT and would recommend it to others[132].

Mindfulness interventions delivered remotely have also shown some positive effects. One study found mean scores for pain, fatigue, anxiety, depression and impact of MS were reduced as a result of mindfulness intervention delivered via Skype compared with a control group at post-therapy and follow-up[133]. Similarly, a small study of motivational interviewing by a nurse over the telephone showed positive outcomes – and the intervention was well received by patients[134].

Annex 2: Factors influencing attitudes towards data sharing

Researchers have tried to establish whether willingness to share health data is associated with different personal characteristics (e.g. age or gender or income level) but the results are not very clear. For example, in some studies, people who described themselves as groups other than white British were more cautious about sharing their data and were more likely to want to be asked for consent before their data was used for any purpose[135]. But a large survey in London found the opposite[136]. Research into links with age or education levels has also found mixed results[137]. It might be assumed that because younger generations have grown up with social media that they would be less worried about data sharing but a large piece of research found that they were actually no less concerned than older people: "the expansion of social networking sites such as Facebook does not mean that young people do not care about privacy or what happens to their personal information"[138].

Although the existing research has not provided clear links between personal characteristics and willingness to share data, it has identified three factors that do influence people's attitudes. These are:

1. What the data is and how sensitive the individual thinks it is

While there is support for unidentifiable information being used in research and service improvement, people are more nervous about use of identifiable data and there is an expectation that they would be asked explicitly for permission to use their identifiable information[139].

People's willingness to share also varies according to what the information is. For example, people are generally not very concerned about the sharing of information if they have a contagious illness but less willing to share their data if they consider themselves to have a sensitive condition, such as a mental health issue[140]. Also, the severity of

an individual's condition has an impact on their willingness to share data: the more severe the illness, the more willing they are[141]. One MS-specific study found that those with benign relapsing remitting MS were more likely to ask for their data to be removed from the register compared with the prevalent population[142]. There is some research to suggest that the more a person uses health services, the more accepting they are of implicit consent for use of de-identified data[143].

2. Who will be using their data and how much the individual trusts that user

A major factor determining people's willingness to share data is the extent to which they trust the end user. A consistent message in the evidence is that the public is generally willing to share data if it is to be used to improve the public health system or for clinical research but they are very unwilling to share data if it is to be used, or they suspect it might be used, by a commercial body[144]. If there is high trust in the end user and a feeling that there is transparency around who the end user is, the public is more willing to share their data[145]. Assurances about privacy and security increase trust[146].

3. What the data will be used for and how informed the individual feels about that

As a general rule, the more clarity and understanding an individual has around how their data will be used, the more willing they are to share[148]. This suggests that patient and public engagement and education are worth investing in to ensure that clarity is achieved.

Clarity around how consent works and what the patient is consenting to share is also very important. Many people assume that they will be asked for consent for use of even de-identified

data[149]. Different models of consent have been proposed and explored with Caldicott calling for an opt-out model and others favouring an opt-in approach[150]. Others have explored what is known as a 'dynamic consent' model whereby an individual gives ongoing consent that they can set at different access levels and change at any time[151]. Such a model, it is argued, increases people's engagement in the process and thus increases their feeling of control over their data and, in turn, their willingness to share[152]. The important message from the literature is that the greater a person's understanding of what they are consenting to, the more willing they are to share their data.

Furthermore, if people are given feedback about how their data is used or if they benefit directly or indirectly from the work, their enthusiasm for sharing is increased[153]. Relatedly, the research notes how important it is to ensure a match between individuals' expectations and what a database can deliver. A paper that explored attitudes to the forthcoming MS Register, for instance, found that people's expectations of what the register might deliver was unlikely to be matched in reality and that there was a risk of high drop-out rate which could limit the register's long-term usefulness[154]. This is a particular concern for databases that rely on individuals registering themselves.

Ultimately, it is difficult to predict attitudes towards data sharing by looking at socio-demographic characteristics, and it is especially important not to assume that one group (e.g. young people) might be more or less willing than others to share data. Most people have an altruistic attitude towards data use for service improvement and research but it is important not to assume that everyone will willingly consent to the use of their data. 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.

Appendix 1: Routinely collected data for improving MS service planning and commissioning

Data source and stream	Are PwMS identified?	What could you learn about PwMS?	About the data	Data access	Notes
Hospital activity data					
NHS Digital Hospital Episode Statistics, Inpatient data	Yes	Understand more about why people with MS (those with a recorded diagnosis) use inpatient care. Such as how many hospital visits, reasons for hospital visits, details about the patient and stay in hospital.	**Granularity:** Person level or England summaries **Frequency:** Real time or annual summaries **Country:** England	This depends on the publication type. Annual publications with summary information are publically available. Person-level data requires high levels of permission.	Patient level data requires high levels of permissions and would need a research team with data access and skills to conduct analysis.
NHS Digital Hospital Episode Statistics, Outpatient data	Possibly – see notes	Outpatient data summaries provide information on what specialists people see and how many appointments people have under a neurology speciality. Linked inpatient and outpatient data would also allow you to identify pwMS from diagnostic information.	**Granularity:** Person level or England summaries **Frequency:** Real time or annual summaries **Country:** England	This depends on the publication type. Annual publications with summary information about neurology specialities are publically available; person-level data requires high levels of permission.	Diagnostic information in outpatient data is very poor – for example in 2015–16 95% of outpatient attendances recorded a diagnosis of 'Unknown and unspecified causes of morbidity'. To identify pwMS data would need to be linked to inpatient data where diagnostic information is more reliable. Summaries only give information related to 'neurology' specialty.

NHS Digital **Referral to treatment waiting times**	Neurology only	Treatment waiting times (median wait time and performance against waiting times targets) for all neurology specialities, how this compares to other specialties and how these change over time.	**Granularity:** England and PCT level **Frequency:** This publication is annual but data exist monthly **Country:** England	A publically available neurology and Neurosurgery specialty breakdown was provided in 2012–13. It is unclear if this is published regularly, but the data exist.	This does not identify pwMS directly but could be useful for contextual information about how people are accessing neurological care.
NHS Digital **Diagnostic Imaging Dataset**	Neurology and some MS specific information	This dataset provides information on imaging activity by type, source, count and waiting times for various imaging techniques (such as MRI scans) for neurology specialty and some specific to pwMS.	**Granularity:** England and local level commissioner/ provider **Frequency:** Monthly **Country:** England	A one-off publically available summary with information about pwMS was produced in 2012–13. Data at this granular level is not routinely provided and permissions are needed to access the full dataset. This dataset can also be linked to inpatient/outpatient data.	The MS breakdown is not routinely provided but the data are collected and could be useful in understanding more about the pathway to diagnosis.
Information Services Division Scotland **Scottish Morbidity Record (SMR)**	Yes	This dataset contains information on outpatient activity, inpatient and day case activity, the number of NHS beds, and information on hospital diagnoses and operations/procedures in hospitals in Scotland.	**Granularity:** Person level **Frequency:** Real time **Country:** Scotland		

SAIL databank Patient Episode Database for Wales (PEDW)	Yes	The NHS Wales hospital admissions (Inpatients and day cases) dataset comprises attendance and clinical information for all hospital admissions and includes diagnoses and operations performed.	**Granularity:** Person level **Frequency:** Real time **Country:** Wales	Requires permissions	
SAIL databank Outpatient Dataset (OPD)	Neurology specialty	Attendance information for all NHS Wales hospital outpatient appointments. Information collected includes specialty of care, appointment date and attendance status.	**Granularity:** Person level **Frequency:** Real time **Country:** Wales	Requires permissions	Appointments are classified by area/type of care – such as 'neurology specialism' – rather than by diagnostic information which isn't well completed in outpatient data.
Patient administration system data held in data warehouse Inpatient data	Yes	Understand more about why people with MS (those with a recorded diagnosis) use inpatient care in Northern Ireland. For example, how many hospital visits, reasons for hospital visits, details about the patient and stay in hospital.	**Granularity:** Person level **Frequency:** Real time (refreshed daily) **Country:** Northern Ireland	Requires permissions	
Patient administration system data held in data warehouse	No	Outpatient data summaries provide information on what specialists people see and how many	**Granularity:** Person level **Frequency:** Real time (refreshed daily)	Requires permissions	

| Outpatient data | | appointments people have under a neurology speciality, in Northern Ireland.

Linked inpatient and outpatient data would also allow you to identify pwMS from diagnostic information – but outpatient data systems do not capture diagnosis coding and coverage of procedure coding is sporadic | **Country:** Northern Ireland | | |

Data source and stream	Are PwMS identified?	What could you learn about PwMS?	About the data	Data access	Notes

Primary care activity data

Data source and stream	Are PwMS identified?	What could you learn about PwMS?	About the data	Data access	Notes
NHS National Institute for health research Clinical Practice Research Datalink (CPRD)	Yes	This dataset provides anonymised primary care records which could be used to understand more about how pwMS use primary care services, for example what symptoms they report, lifestyle information and tests.	**Granularity:** Person level sample **Frequency:** Real time **Country:** UK	Person-level data requires high levels of permissions.	Sample covers approximately 8.8% of the UK population from 684 GP practices, including practices in England, Northern Ireland, Scotland and Wales.
UCL The Health	Yes	THIN dataset captures anonymised information about patients (such	**Granularity:** Person level sample		Sample covers 6.2% of the UK population from 562 practices in the UK.

Improvement Network (THIN)		as age or sex), medical diagnoses, prescriptions and any additional health data such as vaccinations etc.	**Frequency:** Real time **Country:** UK		
Scottish Primary Care Information Resource (SPIRE) Processed by NHS National Services Scotland (NSS)	Yes	Draws on data from all GP practices in Scotland. Could be used to see how many times people with MS see their GP, what they are seeing their GP for and whether that care could be delivered elsewhere.	**Granularity:** Person level **Frequency:** Real-time **Country:** Scotland	Requires permissions	SPIRE is not an existing national dataset, rather an initiative which aims to pull data from relevant GP records in Scotland, in order to answer particular questions. The data is not stored beyond answering those questions and is destroyed after use.
SAIL databank Primary Care GP dataset	Yes	For GP practices in Wales this dataset captures the signs, symptoms, test results, diagnoses, prescribed treatment, referrals for specialist treatment and social aspects relating to the patients home environment.	**Granularity:** Person level **Frequency:** Real time **Country:** Wales	Requires permissions	It covers 80% of GP practices in Wales
Eclipse database	Yes	This dataset includes 13 million patient records (including free text), which is currently used for managing performance within certain conditions.	**Granularity:** Person level **Frequency:** Real time **Country:** England	Not publically available at present	Could build a MS resource hub within the dataset

| Northern Ireland Local Enhanced service (NILES) Medical care planning for patients with chronic conditions data returns | No | Data collected on primary care planning for people with LTCs | **Granularity:** Practice-level Frequency: Annual

Country: Northern Ireland | Available to commissioners but not publically available | |
| Ipsos Mori

GP patient survey | Those with a long term condition and identifies long-term neurological problem | The GP patient survey collect information on people's experience of GP services. For those who say they have a long-term condition, data are collected on how supported they feel to manage their condition. | **Granularity:** GP practice/ CCG and England

Frequency: Annual | Publically available, more detail may be accessible on request | This does not identify pwMS directly but could be useful contextual information about how people living with a long-term condition access primary care. Although at practice level, small numbers make practice-level analysis difficult. |

Data source and stream	Are PwMS identified?	What could you learn about PwMS?	About the data	Data access	Notes

Mental health activity data

| NHS Digital

Mental health services dataset | Possibly (depending on coding) | Collects person-level data on all mental health activity – including services provided in hospitals, outpatient clinics and community services. | **Granularity:** Person-level

Frequency: Real time

Country: England | Requires permissions

Commissioner extracts available | |

| Welsh Government

Admissions to mental health facilities | Possibly | Contains information on patients admitted to NHS mental health facilities and independent hospitals during the year. | **Granularity:** Data is available by gender and legal status (on admission and changes in status during year). It is available down to hospital level for NHS patients and Wales level for independent hospitals.

Frequency: Annual reports

Country: Wales | Reports publically available | |

Data source and stream	Are PwMS identified?	What could you learn about PwMS?	About the data	Data access	Notes

Treatment data

| NHS Digital

NICE Technology Appraisals in the NHS in England, Innovation Scorecard | Includes MS specific medications | This dataset collects information on the use of MS medicines positively appraised by NICE reporting the daily dose per 100,000 population. | **Granularity:** England and CCG level

Frequency: Quarterly since 2011/12

Country: England | Quarterly scorecard

Publically available | |
| ISD, Scotland

Monthly | Includes MS specific medications | This dataset details items dispensed in the community at | **Granularity:** General practice or health board | Publically available | |

prescribing activity data		prescribing location code level for General Practice data and aggregated by NHS Board for other prescriber location types	**Frequency:** Monthly **Country:** Scotland		
HSC, Business Services Organisation Pharmaceutical statistics	Includes MS specific medications	Counts and costs of prescriptions; prescribing by GP practice. Data on the activity of prescribing for individual drugs is available to purchase from the Family Practitioner Services, Information and Registration Unit of the Business Services Organisation	**Granularity:** unknown **Frequency:** unknown **Country:** Northern Ireland		
Blueteq	Yes	The ability to track pwMS treatment course and changes in EDSS scores.	**Granularity:** Person level **Frequency:** Real time **Country:** England	Access to this data is currently unclear	
MS drug monitoring return	Yes	Track the number of people who started MS drug therapy; number of patients who stopped therapy; number of patients waiting for therapy in Northern Ireland	**Granularity:** Aggregate information **Frequency:** Monthly **Country:** Northern Ireland		

Data source and stream	Are PwMS identified?	What could you learn about PwMS?	About the data	Data access	Notes
Registers, audits, one-off publications and other					
MS Society UK MS Register	Yes	The Register links routine hospital data, clinical information and information pwMS provide about the everyday experience of living with MS.	**Granularity:** Person level, CCG **Frequency:** Real time since 2011 **Country:** UK	Available to researchers with appropriate permissions.	Covers people who opt in (currently over 15,500) but they do not need a confirmed MS diagnosis from a neurologist.
Information Services Division Scotland and NHS National Services Scotland Scottish MS Register/ MS Audit	Yes	The Register collects information about new cases of MS, including information on demographics, employment status, family information, diagnosis details, date of first symptoms and referral and Investigation types used (Brain MRI, Spinal Cord MRI, Evoked Potentials and Lumber Puncture).	**Granularity:** Scotland and some at Scottish NHS Board level **Frequency:** Annual reports **Country:** Scotland	Publically available	
MS Society My MS, My Needs	Yes	Patient survey data that captures information on access to treatment and health care in UK.	**Granularity:** Survey includes information from a sample of pwMS across UK **Frequency:** Two time points, 2011	Available to MSS and national data tables are publically available	

			and 2016 **Country:** UK		
Royal College of Physicians **MS National Audit**	Yes	Data collected in these audits review how organisations are performing against the NICE clinical guidelines of care for pwMS. These measures include local access to neurological specialist and rehabilitation services, access to key specialists, information on mobility and falls, and equipment provision.	**Granularity:** England and Wales **Frequency:** Infrequent, three time points **Country:** England and Wales	2006, 2008 and 2011 reports available in pdfs	
Public Health England/ NHS England **Neurology Focus Packs**	Yes and some additional neurology level information	These data were collated to give commissioners at a local level a better understanding of how adults with a neurological condition were using services. For pwMS, these measures include admission rate, length of stay following emergency admission and elective and non–elective spend on MS. Some further information on neurology outpatient appointments and spending.	**Granularity:** England CCGs **Frequency:** Three time points: 2012/13, 2013/14, 2014/15 **Country:** England	Publically available	These are historic data captured at three time points but potentially shows which hospital measures may be useful to understand more about MS service use. These data also provide a useful perspective of variation across England.

| NHS Digital NHS Outcomes framework | Neurology only | This dataset provides information on the long-term impact of having a neurological disorder. The measure is potential years of life lost from causes considered amenable to health care. | **Granularity:** England **Frequency:** Annual **Country:** England | Publically available | This does not identify pwMS directly but could be useful contextual information about the impact of long-term neurological conditions. |

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