


A large, stylized graphic element consisting of a central orange triangle pointing to the right, surrounded by a network of thin orange lines that form a complex, interconnected shape. The central triangle has a gradient from light orange to dark orange and contains the main title text.

**Accelerating innovation for
people living with MS**

A large, abstract graphic at the bottom of the page, composed of overlapping geometric shapes in various shades of orange and yellow, creating a textured, layered effect.

An action plan to unlock the
potential of data and technology
for people with MS

July 2018

Let's stop MS **together**

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Introduction

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

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

Across both the NHS and the third sector there is a long way to go to use the power of digital technology to deliver personalised and coordinated services that best meet the complex needs of the MS community.

We have developed this action plan to drive improvements in the health and care of our community through data and technology. This will involve health care providers, professionals and charities working together to take forward and achieve improvements.

This plan is underpinned by our joint report with the Nuffield Trust 'Improving care for people with MS: the potential of data and technology' [link]. We commissioned the Nuffield Trust to take an in-depth look at how better use of data and technology can lead to improved outcomes for people with MS. Their findings are summarised for each of the key areas of potential:

1. Helping people with MS to 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.

The short, medium and long-term actions we set out here respond to these findings and aim to lead change to overcome these barriers. Our plan challenges our partners and health care professionals to work with us to improve NHS services and care. But we also know that we have a role to play in providing direct access to new technology and the right services to meet the needs of our community. The report focused on the potential of data and technology mainly in a health care settings, but we think many of the findings are relevant for social care and employment settings too. We will be building our knowledge in these areas going forward, as set out in more detail below.

We set out below our key conclusions in each area in turn, along with the ways that we will act on these conclusions to realise the potential of data and technology for people with MS.

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

What we found

The internet and online platforms

Digital tools such as online platforms and information have significant untapped potential to help people with MS manage their condition and seek the physical and emotional support they need. The internet already allows people to gather information about MS, its causes, how it progresses, symptoms and therapy. Some people use it to find information about ongoing clinical studies and scientific research and to prepare for a consultation with a neurologist – which is often empowering and leads to more productive consultations with health care professionals.

Third sector organisations are already using internet platforms and digital technology to help people with MS. For example, people who are part of online patient networks, such as the MS Society forum, report becoming more knowledgeable and feeling more socially supported. They often have improved behavioural and clinical outcomes compared with non-users.

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

Use of digital tools to help manage MS

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

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

What we're going to do

New co-produced digital tools

We have already begun to use digital tools to support people with MS in managing their condition. Our MS Active Together campaign provided online exercise videos, tailored to different mobility levels, to help people with MS stay active.

However, new and different tools are needed: across the whole technology sector too few technologies and digital platforms have been developed with the involvement of people with MS. Going forward, we need to develop new self-management tools based on a good understanding of the technology needs and attitudes of people with MS, with greater engagement between the MS community and technology developers.

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

We will establish an MS Technology Forum to bring together people with MS, tech developers, health care professionals and researchers to deepen our understanding of what technologies would be useful to people with MS in helping them self-manage. Over time, the forum will look at the potential of digital tools and technology in social care and employment settings, as well as health settings.

With support from the NHS and the involvement of the research community, the insights from this forum could be developed into effective and targeted interventions. Over the next few years, we plan to identify income to **fund the development of new digital tools** with the involvement of people with MS in co-design and co-production. This will be informed by the work and insights generated by the MS Technology Forum and will include exploration of how new and innovative technology development can be supported by our research programme as part of the research strategy.

We will also explore the production of an expanded **digital self-management programme**, including, for example, an online fatigue management programme or general online self-management courses.

We hope this work will ultimately lead to **interventions that are endorsed and promoted by the health care system**, for example through the adoption of an MS specific app by NHS Digital which will be made available on the NHS through the app library.

Digital personalised information and advice

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

in partnership across several conditions, especially as many people with MS have other conditions as well. **We will review and evaluate available symptom specific technologies, working in partnership with other conditions to validate them.**

More broadly, we will continue to develop targeted information and support resources including through online and digital channels. Our newly launched, redesigned website has taken us further on this journey and will allow us to do even more to segment and reach new parts of the MS community. One example is our forthcoming DMT decision-making tool (see chapter 3).

Empowering people to compare and learn from each other online

Our community forum helps people with MS access peer support, while our new website will improve our provision of targeted and tailored information. Our long-term ambition is to build on this to **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.**

To achieve this, we will continue to expand our digital support and resource offer. **We will produce content on currently available self-management technologies and further targeted and tailored information** for different people with MS at different points in their journey. Our recent [videos](#) of people with MS telling their treatment stories was a good example of the potential we see in this area.

Summary of actions

Outcomes	Actions
New digital tools co-produced with people affected by MS	<p>Launch an MS Technology Forum to bring together people with MS, tech developers and health care professionals and researchers to inform research priorities (short-term)</p> <p>Facilitate and sponsor the co-design and co-production of new digital tools with people with MS (medium-term)</p> <p>Produce a digital self-management programme (longer-term)</p>
Interactive and personalised digital information and advice	<p>Expand our digital support and resource offer - building on the success of other recent activity around this (short-term)</p> <p>Review and evaluate available symptom specific technologies, working in partnership with other conditions to validate them (medium-term)</p> <p>Continue targeted development and expansion of support and information resources for segments of our community at different points of their MS journey – supported by our new website. (ongoing)</p>

Empowering people to compare and learn from each other online	Produce online content spotlighting the experiences of people with MS of using different technologies to self-manage (medium-term)
	Provide further support for people affected by MS to compare experiences of apps, digital tools and technologies, for example through our online forum (longer-term)
	Work with NHS Digital to expand the NHS Digital App library to include an MS specific app and raise awareness of this among people with MS and health care professionals (longer-term)

2. Accessible and coordinated care

What we found

Coordinating between professionals

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

Thankfully, it is becoming easier to collect data electronically and to share and link that data across organisations, to ensure that all professionals involved in someone's care know what is going on. Rather than engage in a long struggle to bring neurology up to the level of other conditions in terms of traditional, often paper-based care plans, we see the potential to leap-frog direct to digital care plans, using the power of technology to ensure that digital plans fit much better into existing pathways (and therefore are much more likely to work) than traditional care planning.

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

Better still, electronic links would give professionals an easy way to refer to each other, maximising the chances that people with MS will receive all 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 them. This would also enable better service design to streamline and coordinate services.

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

Sharing information

Fundamental to coordinating care there must be improvements in the sharing of data across the system. Although there is a clear ambition from the NHS to enable efficient and effective data-sharing across organisations and providers, progress towards this has been hampered by a lack of incentives for commercial companies to enable software to be shared and a nervousness about the legalities of data-sharing at a professional and patient level. The Watcher Review recommended that all health care IT providers should ensure that their different systems are able to operate together (also known as interoperability). to improve data sharing.

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

We, along with others in the third sector, have a role to play in this. While we must be careful not to put people with MS in a position of being pressured to share their health data where they don't want to, we know that the more people understand about how their data is to be used and the more they see of the benefits of sharing, the more likely they are to consent to share.

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

What we're going to do

Digital planning and coordination

As set out above, we see the potential for MS services to leap-frog direct to digital care plans, using the power of technology to ensure that digital plans fit much better into existing pathways (and therefore are much more likely to work) than traditional care planning. To achieve this **we will work with the National Neurological Advisory Group (NNAG) to explore potential for digital care plans in neurology** and develop a model that can be disseminated and rolled out nationally.

We also have a role in ensuring that our own services are enabled by technology and data and provided in a coordinated and intuitive manner, that people with MS find easy to navigate. This also means continuing to better join-up our services with the care and support people with MS receive from elsewhere. For this reason **we will begin work to empower our local services to use technology to better coordinate with each other and with the NHS.**

We will also evaluate current models of care for MS and other long-term conditions and produce recommendations on service design. The strong interest within the health care sector in improved coordination provides a useful platform to build on. In England, for example, we are working with NHS RightCare to examine models of care within neurology, while work is ongoing in NHS England vanguard sites to look at alternative models of care to improve coordination.

Over the longer-term, we aim to use this insight to develop a **full pilot of a technology enabled model of care** – underpinned by insight from people with MS and health care professionals and integrating our own local group support – to help coordinate care.

Improving data sharing

As set out above, progress towards data-sharing has been hampered by a lack of incentives for commercial companies to enable software to be shared and nervousness from professionals. The NHS must take further action to encourage data-sharing. The Watcher Review recommended that all health care IT providers should ensure interoperability and acting on these recommendations would provide an opportunity for real improvement. **We will work at both national and local level to ensure that best practice in data-sharing is spread and that the recommendations of the Watcher review are fully implemented.**

People have confidence to share their data

Alongside this people with MS need to be comfortable with participating and sharing their personal data, without being pressured to do so. **We will continue to work with the Richmond Group, Association of Medical Research Charities and other partners to ensure that people with MS are always clear about what their personal data can and cannot be used for** and to highlight the benefits of sharing information with professionals. This will include making sure people are aware of their own rights over their data, for example online access to their GP health record.

The MS Register is already evolving to give people with MS more control over their data. We are working to put in place a new portal where people will be able to download a copy of all their data, as well as give permission for their clinicians to view both personal and clinical data. Over time, this could become an important feature of annual reviews for people with MS, automatically highlighting key changes in people's view of their quality of life and treatments before of face-to-face discussion. **We will explore the development of an information-sharing portal that would make MS Register information easier for health care professionals to use and interpret** (where people with MS are comfortable having their data used in this way).

Summary of actions

Outcomes	Actions
<p>Digital care planning and coordination help professionals and patients act as one team focussed on what matters to people living with MS</p>	<p>Work with the National Neurological Advisory Group (NNAG) and NHS bodies to explore potential for digital care plans in neurology and develop a model that can be rolled out nationally (short-term)</p> <p>Produce recommendations on service design to coordinate care and take advantage of the opportunities of technology (short-term)</p> <p>In partnership with NHS bodies, look to pilot a service model, underpinned by technology, to help coordinate MS care (medium-term)</p> <p>Work with partners to roll out digital care planning techniques to MS services (longer-term)</p> <p>Explore opportunities to use digital approaches to coordinate support from our local groups with that of statutory services (ongoing)</p>
<p>Data shared seamlessly between services means people don't have to remember and repeat themselves</p>	<p>Work with NHS bodies to encourage data-sharing capabilities between different parts of the health care system, so that all health care IT providers ensure interoperability of systems (short-term)</p>
<p>People with MS confident their data will be used appropriately when they share it</p>	<p>Continue to work with partners to ensure that people with MS are always clear about what their personal data can and cannot be used for, giving them the assurance to share it with professionals where they would like to (ongoing)</p> <p>Develop an information sharing portal for people with MS who fill out MS Register questionnaires, as well as their clinicians (long-term)</p>

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

What we found

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

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

Separately, the UK MS Register holds data from over 15,700 people¹ who have opted in to the initiative. The register links routine hospital data, clinical information and information provided by people with MS about the everyday experience of living with MS, via a paper or online survey.

If the register could increase the amount of clinical information that is collected from sites and link with NHS data so that it is more comprehensive, it could be used to monitor treatment outcomes across an increased number of people with MS within particular regions. This would build the knowledge of both prescribers and planners who could see how well treatments are working for different types of patients.

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

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

¹ Mostly people with MS, although a confirmed diagnosis is not required to opt in to the register

What we're going to do

Agreed treatment outcomes

There are no agreed measures of clinical outcomes for people with MS. Bringing the MS and health community together to agree the most important treatment outcomes is the necessary first step to embedding these and improving data collection. The MS Society has already convened an Outcomes Working Group, led by Prof Frederick Barkhof, to work with people with MS to agree the most appropriate measures for future clinical trials. **There is potential to build on this work for the evaluation of existing treatments through real-world evidence with the same or similar measures.**

Expanded data collection

Alongside work to drive agreement of clinical outcome measures across MS care, including for medicines and treatments, **we will take action to encourage the linking of prescribing data with primary and secondary care datasets.** This may be most usefully and easily done via an expanded and better promoted UK MS Register or another mechanism. We will discuss this with health care bodies to understand the best way to pursue this – one example from England is the potential to link MS Register records to the Blueteq prescribing system, so that a much broader range of outcome data is directly linked back to official prescribing data.

We provide support to people with MS to help them navigate the various treatment options available to them and make informed decisions about their care. As part of this we are developing a DMT decision-making tool. **We will build on this to provide a broader menu of options, using the possibilities of digital technology.** As we see improved data collection on prescriptions, we will evolve these materials to help people with MS understand new insights.

As with wider capture of data in MS services (see chapter 4) there are currently issues with the quality and consistency of recording of DMT decisions and associated outcomes. **We will identify the possibilities from current practice of DMT monitoring to improve this and disseminate best practice.** For example, in some areas the use of DAWN software may have improved the data captured about a patient's experience of DMTs.

Automated collection and analysis of data

To drive better monitoring of treatment outcomes, in the longer term **we will look to identify opportunities to use our research grants programme to explore the potential of artificial intelligence to improve MS care.** We co-fund a Progressive MS Alliance project harnessing the power of machine learning to enable earlier detection of MS through MRI. The project is looking use machine learning to detect signs of MS on MRI earlier than a clinician would be able to. If we can achieve the expanded data collection set out above, there could be potential to analyse metadata on treatments to find new ways of predicting what treatments are likely to be successful for particular types of patients.

Wearable technologies could provide much expanded outcome data but further research and testing is needed. **We will explore opportunities to gather information on how these could be used for people with MS and test the possibilities and how these may link with MS Register data.**

Summary of actions

Outcomes	Actions
Treatment outcomes aligned to what matters to people with MS	Convene key stakeholders to agree outcome and quality measures for MS services, focussed on the areas that matter to people with MS. (short-term)
Expanded data collection maximises knowledge of what treatment works best for specific patients	<p>Work with health care providers to improve linking of prescribing data with secondary datasets and the MS Register. (short-term)</p> <p>Build on our planned DMT decision-making tool to expand our support to help people with MS make choices about symptoms (medium-term)</p> <p>Explore possible systematic processes and supporting incentives to improve monitoring of DMTs. (medium-term)</p>
Automated collection and analysis means richer data for clinicians and researchers	<p>Explore opportunities to pilot the use of wearables in clinical and research settings (ongoing)</p> <p>Through our research grants, explore the potential for technologies, such as remote monitoring and machine learning, to drive precision medicine in MS. (longer-term)</p>

4. Using data to better meet patient needs

What we found

Improving data and planning capacity

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

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

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

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

We reviewed the types of data that are collected as part of routine care, how they might be used to improve MS services and identified the obstacles to making this happen at the moment. Some of those obstacles include a lack of comprehensive health care data, an issue in all the four countries of the UK (particularly in primary care), poor quality coding in some datasets (e.g. outpatients) and low recording of MS diagnoses.

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

Focussing services on what matters to people with MS

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

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

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

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

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

What we're going to do

Better use of existing data

While the data we have for MS services is far from perfect, the Nuffield Trust report also demonstrates that what we do have is not used to its full potential. We see scope for us to produce our own analysis of MS services in local areas, focussing on under-analysed areas such as MRI capacity and emergency admissions data. This can help us to make the case to commissioners and others for specific service interventions that more appropriately meet the needs of people with MS.

There is also a role for us to use our connections with MS health care professionals to influence and improve practice. **The Neurology Intelligence Collaborative** brings together key partners to align priorities around data and intelligence projects in neurology to avoid duplication and ensure different partners are more than the sum of their parts. **We will use our membership of this forum to work with others to facilitate and encourage improved coordination and dissemination of data** for planning services.

Over time, we will seek to **launch a portal of anonymised data**, using data from an expanded MS Register and other sources. This would provide people with MS, health care professionals, commissioners and researchers with an easy way to compare their area to others and identify aspects of local services that could be improved or adapted.

New data focussed on what matters to people with MS

As mentioned above, there are no agreed measures of clinical or health outcomes for MS services. However even the process data we have is often poor quality and not used to its full potential due to lack of consistent coding – especially in outpatient settings – and analysis practice. Presently much of the data collection on delivery of MS services across the NHS is focused almost exclusively on processes and activity. This means that we have some picture of the number of people treated in different settings such as those admitted to hospital or receiving outpatient care. However, we have very little data to help us to understand the outcome or impact of this care.

Over time, we will look to work with partners to build on work to agree the most important treatment outcomes to **agree an expanded set of outcome measures that can define a quality MS service locally.**

We also know that NHS services for MS are not the only areas of outcomes that matter to people with MS and that other care settings, such as social care, are also incredibly important. For this reason, we will explore improving our understanding of available social care data and look to undertake work to **develop and agree outcomes across social care and employment.**

We also sponsor the MS Register (see chapter 3). One excellent way to improve data capture would be for **clinicians to more routinely promote the MS Register** so that there is an increasingly robust and standardised dataset across a range of information.

Audits of services

Once improved coordination of analysis and the development of consensus about possible outcome measures for services has given us a more complete dataset and picture of collection, **we aim to drive work to revive regular audits of MS services.** Audits allow for regular monitoring of how services are being delivered for our community and the impact they are having. This understanding provides an up-to-date picture for commissioners to improve service provision and better meet the needs of the community and third sector organisations to understand and take action to address unacceptable variation.

Summary of actions

Outcomes	Actions
Better use of existing data means people with MS are more visible and the right services are in place	<p>Produce our own analysis of MS services in local areas, focussing on under-analysed areas and share these with local commissioners to drive better planning. (medium-term)</p> <p>Launch a portal of anonymised data for health care professionals, commissioners and researchers, using data from an expanded MS Register. (longer-term)</p> <p>Use our membership of the Neurology Intelligence Collaborative to work towards improved coordination between national bodies on analysis and use of data. (ongoing)</p>
New data focussed on what matters to people with MS	<p>Build on work around treatment outcomes to agree an expanded set of outcomes that define quality MS services (medium-term)</p> <p>Look to agree outcomes for social care and employment services (longer-term)</p>

	Promote the UK MS Register to encourage people with MS to sign up (ongoing)
Audits of services to help drive improvement and comparison between services to learn from each other	Work with key partners to revive regular audits of MS services on the basis of agreed outcome and quality measures. (medium-term)

Appendix: table of all actions

Outcomes	Actions
<p>New digital tools co-produced with people living with MS</p>	<p>Launch an MS Technology Forum to bring together people with MS, tech developers, health care professionals and researchers to inform research priorities (short-term)</p> <p>Facilitate and sponsor the co-design and co-production of new digital tools with people with MS (medium-term)</p> <p>Produce a digital self-management programme (longer-term)</p>
<p>Interactive and personalised digital information and advice</p>	<p>Expand our digital support and resource offer - building on the success of other recent activity around this (short-term)</p> <p>Review and evaluate available symptom specific technologies, working in partnership with other conditions to validate them (medium-term)</p> <p>Continue targeted development and expansion of support and information resources for segments of our community at different points of their MS journey – facilitated by our new website (ongoing)</p>
<p>Empowering people to compare and learn from each other online</p>	<p>Produce online content spotlighting the experiences of people with MS of using different technologies to self-manage (medium-term)</p> <p>Provide further support for people affected by MS to compare experiences of apps, digital tools and technologies, for example through our online forum (longer-term)</p> <p>Work with NHS Digital to expand the NHS Digital App library to include an MS specific app and raise awareness of this among people with MS and health care professionals (longer-term)</p>
<p>Digital care planning and coordination help professionals and patients act as one team focussed on what matters to people affected by MS</p>	<p>Work with the National Neurological Advisory Group (NNAG) and NHS bodies to explore potential for digital care plans in neurology and develop a model that can be rolled out nationally (short-term)</p> <p>Produce recommendations on service design to coordinate care and take advantage of the opportunities of technology (short-term)</p>

	<p>In partnership with NHS bodies, look to pilot a service model, underpinned by technology, to help coordinate MS care (medium-term)</p> <p>Work with partners to roll out digital care planning techniques to MS services (longer-term)</p> <p>Explore opportunities to use digital approaches to coordinate support from our local groups with that of statutory services (ongoing)</p>
<p>Data shared seamlessly between services means people don't have to remember and repeat themselves</p>	<p>Work with NHS bodies to encourage data-sharing capabilities between different parts of the health care system, so that all health care IT providers ensure interoperability of systems (short-term)</p>
<p>People with MS confident their data will be used appropriately when they share it</p>	<p>Continue to work with partners to ensure that people with MS are always clear about what their personal data can and cannot be used for, giving them the assurance to share it with professionals where they would like to (ongoing)</p> <p>Develop an information sharing portal for people with MS who fill out MS Register questionnaires, as well as their clinicians (long-term)</p>
<p>Treatment outcomes aligned to what matters to people with MS</p>	<p>Convene key stakeholders to agree outcome and quality measures for MS services, focussed on the areas that matter to people with MS (short-term)</p>
<p>Expanded data collection maximises knowledge of what treatment works best for specific patients</p>	<p>Work with health care providers to improve linking of prescribing data with secondary datasets and the MS Register. (short-term)</p> <p>Build on our planned DMT decision-making tool to expand our support to help people with MS make choices about symptoms (medium-term)</p> <p>Explore possible systematic processes and supporting incentives to improve monitoring of DMTs (medium-term)</p>
<p>Automated collection and analysis means richer data for clinicians and researchers</p>	<p>Explore opportunities to pilot the use of wearables in clinical and research settings (ongoing)</p> <p>Through our research grants, explore the potential for technologies, such as remote monitoring and machine learning to drive precision medicine in MS (longer-term)</p>

<p>Better use of existing data means people with MS are more visible and the right services are in place</p>	<p>Produce our own analysis of MS services in local areas, focussing on under-analysed areas and share these with local commissioners to drive better planning (medium-term)</p> <p>Launch a portal of anonymised data for health care professionals, commissioners and researchers, using data from an expanded MS Register (longer-term)</p> <p>Use our membership of the Neurology Intelligence Collaborative to work towards improved coordination between national bodies on analysis and use of data (ongoing)</p>
<p>New data focussed on what matters to people with MS</p>	<p>Build on work around treatment outcomes to agree an expanded set of outcomes that define quality MS services (medium-term)</p> <p>Look to agree outcomes for social care and employment services (longer-term)</p> <p>Promote the UK MS Register to encourage up-take by people with MS (ongoing)</p>
<p>Audits of services to help drive improvement and comparison between services to learn from each other</p>	<p>Work with key partners to revive regular audits of MS services on the basis of agreed outcome and quality measures (medium-term)</p>

We're the MS Society.

Our community is here for you through the highs, lows and everything in between.

We understand what life's like with MS.

Together, we are strong enough to stop MS.

mssociety.org.uk



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 **Let's stop MS together**