THE MISSING PIECES
IDENTIFYING GAPS IN CARE & CONVERSATIONS IN MULTIPLE SCLEROSIS
Multiple sclerosis (MS) is an unpredictable, progressive, neurological condition in which the body’s own immune system attacks the nerves in the central nervous system (the brain and spinal cord). Its severity and symptoms differ from one person to the next, but anyone with MS will need care, intervention and support throughout their lives to varying degrees.

With a progressive condition like MS, receiving the right treatment and care as early on as possible is critical to ensuring the best outcome, but in the UK people with MS still face challenges in accessing both specialist care and treatment.\(^1\) The most prevalent form of MS is relapsing remitting MS (RRMS). People with RRMS experience clinical attacks (relapses) when symptoms flare up or worsen, when the relapse is resolved then the person enters a period of remission. Treatment is primarily focussed on reducing the frequency of relapses, however, given that MS attacks the central nervous system which controls the body’s movement, muscle action and balance, research suggests that it’s the impact of the disease on their ability to live their lives that’s the key concern for people with MS. They want to delay the onset of disability by maintaining their motor control, mobility and independence for as long as possible.

Available treatments, known as Disease Modifying Treatments (or DMTs) can reduce the frequency of relapses and newer treatments have also been proven to delay the onset of disability. However, in the UK only 21% of people with MS receive a DMT, one of the lowest treatment rates in Europe.\(^1\) This means in turn that we need to ensure everyone with MS has access, as early as possible, to treatments that can change the course of their disease. In addition to this fundamental requirement, people with MS should also have access to a full range of support from a multidisciplinary team of professionals, plus a regularly reviewed personalised care plan (in line with the National Institute for Health and Care Excellence (NICE) Quality Standards for MS). Unfortunately in the UK, as this report demonstrates, this is not always the case. There are “missing pieces” which means that many people with MS are missing out on the treatments and care plan that could both help deliver on their quality of life goals and best meet their clinical needs.
INTRODUCTION

Sanofi, a global healthcare leader, and its specialty care business unit, Sanofi Genzyme, strives to be a long-term partner to the MS community by delivering scientific advances that will help meet the needs of people living with MS.

Sanofi Genzyme has launched an ongoing global campaign ‘vs. MS’, which aims to shed light on and address the true physical and emotional impact of MS. The ‘vs. MS’ campaign challenges us all to think beyond the commonly understood symptoms of MS and focuses on what real MS-related disability is – what it looks like, how it feels to have MS and how it impacts everyday living.

Retention of ability/delaying disability has emerged as the major issue coming out of the ‘vs. MS’ campaign. It is one of the key areas raised by people with MS, their partners and carers. 83% of respondents living with RRMS reported that what matters most to them is taking action to prevent progression and potential disability.1

‘Missing Pieces’ is a UK specific campaign that builds on these findings. It sets out to further explore attitudes, understanding and behaviours around the treatment of MS in the UK. The objective is to identify the gaps in knowledge, awareness, treatment pathways and care plans (the “missing pieces”) that are preventing people with MS from achieving the treatment outcomes and quality of life goals they desire.

This report reveals survey data taken from specialist healthcare professionals (HCPs) and people with MS throughout the UK. It outlines recommendations for how the MS community can move towards achieving better outcomes for people with MS.

Missing Pieces Research

The Missing Pieces research was conducted by Adelphi Research UK via two online questionnaires in 2016; one survey for people with MS and one survey for HCPs. Respondents were from England (85%), Scotland (7%), Wales (7%) and Northern Ireland (1%).

The HCP survey was conducted amongst 100 respondents including neurologists, MS specialist neurologists and MS specialist nurses.

It aimed to:
- Evaluate HCP attitudes towards disability associated with MS
- Understand how frequently disability is raised by HCPs with people with MS
- Look at HCP treatment choices, specifically in relation to the importance of disability vs. relapses

The survey of people with MS was conducted amongst 120 people with either RRMS, secondary progressive MS (SPMS), or primary progressive MS (PPMS). It aimed to:
- Understand people’s attitudes towards potential future disabilities and impact on their quality of life
- Capture frequency of discussions about disability at initial diagnosis and in future consultations with HCPs
- Understand concerns at diagnosis vs. current concerns in relation to disability and relapse(s)

How MS develops

How MS develops exactly is still unknown, however it is widely accepted that it is an autoimmune disease where the immune system attacks myelin, the protein that covers the central nervous systems and helps speed up communication between neurons.2

‘Sclerosis’ means scarring or hardening of tiny patches of tissue, which is caused by relapses or distinct ‘attacks’ of symptoms. This scarring usually happens in the brain or on the spinal cord. The word ‘multiple’ is added because this scarring happens at more than one place in the brain and/or spinal cord.

MS is a lifelong condition which can be unpredictable in its course, meaning that the care and treatment pathways for people with MS can vary hugely from person to person and be very complex.

Disability

Disability

Time

Time

GZUK.MS.17.04.0189

Date of Preparation

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83% of respondents living with RRMS.

Around 85% of people with MS are diagnosed RRMS

About 10% of people with MS are diagnosed with this form in which disability increases from the outset11

On average, around 65% of people with RRMS will develop secondary progressive MS 15 years after being diagnosed10

9

7

65%
Symptoms of Multiple Sclerosis

Most people with MS are diagnosed in their 20s and 30s and it is the most common condition of the central nervous system affecting young adults. People who have MS experience a range of symptoms, including fatigue, problems with balance, pins and needles or problems with sight. However, the range of symptoms that are associated with MS is vast, meaning that each person’s experience is unique.

MS and relapse

MS relapses are a distinct attack of symptoms which then fade away or disappear. Relapses can usually last for more than 24 hours, and up to days or even weeks. Because of the range of symptoms that people with MS can experience, each relapse can present itself in a different way and can vary from mild to severe. MS relapses are managed at home with the support of HCPs.

Symptoms and disability

Experiencing symptoms does not necessarily equate to long-term disability in MS. Ongoing destruction of the myelin sheath and resulting nerve damage leads to disability progressing. Symptoms are a manifestation of this but may present themselves in varying severity.

MS prevalence

Over 100,000 people in the UK have MS which represents about one in every 600 people. However, prevalence rates vary throughout the UK, with Scotland having the highest rate. The current observation is that generally prevalence increases in places further north or south from the equator.

Symptoms are a manifestation of this but may present themselves in varying severity. The unpredictability of when people with MS might experience relapse, means it can be difficult for people with the condition to access the right treatment and care at the right time. They may need to navigate their way through various different health professionals and healthcare processes/systems.

Diagnosis of MS

Diagnosis of MS is usually based on clinical judgement by a neurologist with the process including several tests including:
- Magnetic Resonance Imaging (MRI) testing
- Medical or clinical history
- Neurological examination, including checks on movement, coordination, vision, balance, reflexes and other functions of the senses
- Lumbar puncture
- Evoked potentials – measurements of electrical responses of the brain

As a complex disease, each person’s experience can require multiple HCPs to help diagnose, assess and input as the disease progresses. These include MS specialist neurologists, MS nurses, occupational therapists, physiotherapists, neuro-rehabilitation consultants, speech and language therapists and neuro-psychologists. However, it is the MS nurse and neurologist that play the central roles in this multi-disciplinary team.

Managing symptoms, potential relapses, and dealing with complex care and treatment systems can take its toll on people with MS. This is particularly apparent for people with progressive forms of MS, as they are required to deal with even more complex care systems than those with RRMS. Mental health conditions such as depression are also common in people with MS.

Whilst the severity and frequency of relapses is a standard measure of MS at diagnosis, the Missing Pieces research found that this did not correspond with the main concern expressed by people with MS — 38% ranked the ‘impact of MS symptoms on everyday life’ as their biggest concern, versus only 4% that reported relapses as their biggest concern, suggesting they are concerned most with disability.

For people newly diagnosed with MS, HCPs state that disability is ‘routinely discussed’ 69% of the time. However, this number contradicts what people with MS report – only 50% recall discussing disability at diagnosis stage.

The unpredictability of when people with MS might experience relapse, means it can be difficult for people with the condition to access the right treatment and care at the right time. They may need to navigate their way through various different health professionals and healthcare processes/systems.
MS: Looking beyond the physical impact

Each person with MS has a unique day-to-day experience...

“I miss out on seeing friends as their houses and restaurants or bars aren’t accessible in a wheelchair.”

“MS means that I have to plan even the simplest of daily tasks, such as doing the shopping, putting out laundry or cooking.”

“My MS means that I cannot stand up at a party and have a conversation or a dance.”

“Standing is difficult so cooking for my children is hard.”

“Vacuuming the house can exhaust me.”

“I literally can’t keep my eyes open...it makes watching a film, or even a television programme, very difficult!”

“I love going swimming as I don’t need any crutches or a wheelchair...the only trouble is when I get out of the pool, I am exhausted.”

“MS has curtailed my career. My biggest worry is being able to financially support myself in the future.”

“I’m constantly worried I’m going to wake up tomorrow with the start of a relapse.”

“It’s hard to be intimate as I have to plan when I’ll have enough energy.”

“My MS means that I cannot carry a plate of food across a room.”
“Disability to me means both physical and mental symptoms and both visible and hidden symptoms that can have a severe impact on how you can carry out day to day living and tasks.”

Trisha Bharadwa
MS Campaigner and Blogger

Measuring progression of MS

Monitoring disease progression is an important aspect of ongoing care for people with MS. Currently progression of the disease is measured via MRI scans to see the number of lesions or ‘scarring’ on the brain, and via physical examination using a disability rating scale – the Expanded Disability Status Scale (EDSS).

The EDSS quantifies disability in eight Functional Systems (FS) and allows neurologists to assign a Functional System Score (FSS) to each of these. Higher numbers reflect a greater degree of disability, mostly in relation to mobility e.g. score 5-8 out of 10 equates to ‘severe disability, impairing your daily activities and requiring assistance with walking’.

HCPs report that ‘impact on independence’ and ‘ability to work’ are considered the main fears and concerns raised by the people they treat, above factors such as ‘impact on mobility’, which the EDSS mainly focuses on. This suggests that people with MS are most worried about not being self-sufficient in the future.

The EDSS scale

<table>
<thead>
<tr>
<th>Score</th>
<th>Description</th>
</tr>
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<tbody>
<tr>
<td>0.0</td>
<td>Normal neurological examination</td>
</tr>
<tr>
<td>1.0</td>
<td>Minimal disability</td>
</tr>
<tr>
<td>2.0</td>
<td>Relatively severe disability</td>
</tr>
<tr>
<td>3.0</td>
<td>Disability precludes full daily activities</td>
</tr>
<tr>
<td>4.0</td>
<td>Assistance required to walk</td>
</tr>
<tr>
<td>5.0</td>
<td>Restricted to a wheelchair</td>
</tr>
<tr>
<td>6.0</td>
<td>Confined to bed</td>
</tr>
<tr>
<td>7.0</td>
<td>Restricted to a bed or chair</td>
</tr>
<tr>
<td>8.0</td>
<td>Confined to bed</td>
</tr>
<tr>
<td>9.0</td>
<td>Death</td>
</tr>
<tr>
<td>10</td>
<td>Death</td>
</tr>
</tbody>
</table>

It is important to note that when a person actually becomes ‘disabled’ is very much subjective. In the UK, the word ‘disability’ is often linked to government benefits – the point at which a person is in need of these benefits is the point at which they officially call themselves ‘disabled’.

Measuring disability

The Expanded Disability Status Scale (EDSS) is the tool currently available and most commonly used by HCPs to quantify disability and monitor progression of the level of disability over time. However, only a quarter of HCPs use it at every consultation.

Both HCPs and people with MS do not necessarily think the EDSS tool measures the full extent of their experiences linked to disability, suggesting it is not fully fit for purpose.

In fact, on average, people with MS gave the EDSS tool a score of 5.6/10 in terms of how well it measures the impact of MS on their day-to-day life. Many HCPs rely on assessing disability progression simply via ‘visual observation’. This is especially true of MS Nurses where 96% state that out of all the ways to assess disability, they use ‘visual appearance’ the most. This is perhaps due to the fact that nurses see the people they are treating more often than any other HCP in the multi-disciplinary group so are better able to pick up on changes from one visit to the next.

The drive for earlier treatment

It is recognised by professional bodies, such as the Association of British Neurologists (ABN), that measurement of disease progression and offering treatment as soon as possible is important.\(^{14,15}\)

The NICE Quality Standards for MS recommend that people with MS have access to care from a multidisciplinary team with expertise in MS and access to a comprehensive review of their treatment and care annually.\(^{20}\) The MS Forward View: A Consensus on the Future of MS Services, published in November 2016, also stated that MS teams should offer everyone with MS a comprehensive annual review with an appropriate health professional who has specialist expertise in MS.\(^{21}\)

Despite these recommendations it is reported that 36% of people with MS had not seen a neurologist in the past 12 months and overall one in ten said they’d not seen a neurologist recently but felt they needed to.\(^{1}\)

The fact is, people with MS are in contact with a multidisciplinary team which can make it challenging for them to identify or access the right healthcare professional to help them with their treatment decisions. The most common key contact for healthcare and support in relation to MS is a specialist nurse but it is the MS specialist neurologist that would initiate, for example, a DMT treatment.\(^{18}\)

Key contact for healthcare and support\(^1\)

The new NICE Quality Standards in MS,\(^{11}\) published in 2016, set out the level of services expected and recommend that people with MS:

- Are given support at the time of diagnosis to understand the condition, its progression and the ways it can be managed by the consultant neurologist making the diagnosis.
- Are offered a face to face follow-up appointment with a HCP with expertise in MS so take place within six weeks of diagnosis.
- Have a single point of contact who co-ordinates access to care from a multidisciplinary team with expertise in MS.
- Are offered support to remain physically active if they have problems with mobility or fatigue.
- Are offered treatment as soon as possible and within 14 days of the onset of symptoms, if they have a relapse.
- Are offered a comprehensive review at least once a year by HCPs with expertise in MS.

The NHS Quality Improvement Scotland published national standards of care for neurological conditions in October 2009. The local Department for Health, Social Services and Personal Safety Northern Ireland considers NICE Guidance, and any endorsements are published on its website.\(^{22}\)
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that over the last three years, access to DMTs in England across the UK (one of the biggest MS surveys ever) showed disparities in the services offered from one part of the country to another. The My MS, My Needs Surveys by the MS Society and the My MS, My Needs 2015 survey conducted by Adelphi Research highlighted the importance of holistic annual reviews by an MS specialist, as NICE recommends and also further care planning resulting from these reviews. It is clear that disability is an important concern for people with MS. Over half (54%) of people with MS said they were worried and 45% said they were scared at the prospect of becoming disabled. It needs to be more support for both people with MS and carers on the emotional burden that the uncertainty of MS can bring.

With the arrival of DMTs, people with MS are becoming more aware of monitoring their own condition and want to be involved in their treatment decisions. In fact, 40% of discussions about disability are actually initiated by the person with MS. But a large proportion (42%) would prefer to discuss disability more frequently with their HCPs. These ongoing conversations will help empower and reassure people with MS that the likelihood of disability progression is being tracked and managed. This is linked to the importance of holistic annual reviews by an MS specialist as NICE recommends and also further care planning resulting from these reviews.

Access to recent MS treatment advances

Since becoming available, DMTs have changed the RRMS treatment landscape. They can reduce the number of relapses as well as reduce the severity of relapses, and some can also slow down disease progression and disability. There are 11 drugs approved for use by the NHS in the UK. It is important to note that in the UK, DMTs are only prescribed to those with RRMS or secondary progressive MS who meet certain criteria.

With the recent treatment advances, access through a multidisciplinary team of HCPs has become a widely-debated topic. The My MS, My Needs Surveys by the MS Society, focused on access to treatment in the UK, and revealed big disparities in the services offered from one part of the country to another. Recently, a follow-up survey involving 11,024 people with MS across the UK (one of the biggest MS surveys ever) showed that over the last three years, access to DMTs in England among those who could benefit has increased. However, the UK still has one of the worst rates of DMT use in Europe, with regards to people with MS receiving a DMT. With more choice of DMTs becoming available, it is now more important than ever that people are able to talk to an MS specialist as soon as possible after diagnosis about the treatment option that would best suit them.

Disability and treatments

As well as difficulty in prompt access to treatment, many people with MS are still not receiving advice about delaying disability from their HCP. Many people naturally learn about relapses when they are diagnosed but not about potential disability. When asked, two thirds (65%) of people with MS say maintaining independence is their main treatment goal, followed by reducing relapses. However 22% of people with MS say the HCP they see does not discuss treatment goals with them.4 There is also a lack of clarity and information surrounding MS. Over a quarter of people with MS (28%) are not aware that the number of relapses in MS (that measures worsening of MS) is not directly linked to disability progression (e.g. difficulty working or performing everyday tasks such as walking, concentrating, etc.). When aware of this, 66% saw delaying disability as a more important treatment goal than reducing the frequency of relapses. Additionally 24% of people with MS are not aware that treatments help to delay disability.5 Those who do not have adequate access to the right care may be missing out on treatments that could put off disability, allowing for a more fulfilled life for longer. Around three quarters of HCPs think people with MS face delays in being initiated onto a DMT in particular, with the main reason being limited access to MS specialist neurologists.6 This means that even if people with MS do have treatment goals, the care system in the UK does not necessarily allow them to be met. The NHS Five Year Forward View highlights that prevention is a key priority to making the NHS more sustainable, and early access to MS specialist neurologists and treatments something that could contribute to this sustainability.7 In order to ensure no-one with MS misses out and everyone is given the best chance to live their life independently for as long as possible, we need to move from the current watch and wait system to a more proactive preventative care model – each person must have an individualised care plan with their treatment goals as the focus.

Summary key points:

• People with MS are concerned about disability but that concern may not be addressed during the consultation with their HCPs.

• Modern therapies, particularly DMTs, can play a critical role in delaying the onset of disability allowing people with MS to continue to live full and productive lives.

• It has been shown that the UK is failing to make these therapies available to people that need them. This means there is a danger of the NHS not being able to prevent people with MS becoming more sick in the long term and therefore risking putting further strain on NHS finances.

The Missing Pieces research was funded by Sanofi Genzyme and conducted by Adelphi Research UK.

Adelphi Research UK

Date of Preparation July 2017

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Sanofi is committed to working with the whole of the MS community to ensure that every person in the UK with MS receives a standard of care that, at a minimum, matches that delivered in other major European countries such as Germany, France, Spain and Italy. We know that there are missing pieces in both the conversations people are having with their healthcare professionals and in the care plans and treatments they are receiving – we are committed to support those to be filled in. And we will focus on ensuring that the care delivered to people with MS is centred around the things that matter most to them.

This includes:

**TODAY**

01. Understanding what type of MS has been diagnosed, how ‘active’ it is, what symptoms may be experienced and what impact this may have both now and in the longer term on both physical and mental ability.

**THE AMBITION:**

Every person with MS should be offered a follow-up face to face appointment six weeks after diagnosis with a HCP with expertise in MS as per the NICE Quality Standards for MS. They should also be talked through, or directed towards sources of information on the care pathway, in order to understand who may be involved, at what point, and what mandates are in place that govern their care.

02. Every person with MS should have knowledge and understanding of the different treatment options available to them and be given the opportunity to express what their personal goals are for treatment – this should inform shared-decision making.

**THE AMBITION:**

At an appointment six weeks post diagnosis, every person with MS should be encouraged to express their treatment goals and jointly agree a treatment plan with their HCP.

**FUTURE**

03. Starting on DMTs as quickly as possible

Every person with MS should have prompt access to treatments that can change the course of their disease (DMTs).

**THE AMBITION:**

Every person with MS should have access to DMTs from diagnosis, or at minimum within 14 days of the onset of symptoms if they have experienced a relapse (in line with the NICE Quality Standards for MS).

04. Having access to a multidisciplinary team who can deliver integrated care centered around the individual

People with MS should have prompt and simplified access to a multidisciplinary team that can provide the three key pillars of MS care: symptom management; disease modification; and neurorehabilitation. Care should be centred around the needs of the individual with MS, as opposed to being centered around organisational structures.

**THE AMBITION:**

Every person with MS should have a single point of contact, in line with the NICE Quality Standards for MS, who can effectively coordinate their care.

05. Having an individualised care plan and regular reviews

MS is a heterogeneous disease therefore every person with MS needs an individualised approach to their disease management. With MS being a progressive and lifelong disease, regular reviews of the care plan are essential to ensure they are delivering in line with changing needs.

**THE AMBITION:**

Every person with MS has an individual care and treatment plan in place, which is discussed and reviewed at least once a year with a HCP with a specialism in MS, in line with the NICE Quality Standards for MS.
REFERENCES


7. Sanofi data on file, May 2016.


