

Patient organisation submission

Ocrelizumab for treating primary progressive multiple sclerosis

Thank you for agreeing to give us your organisation's views on this technology and its possible use in the NHS.

You can provide a unique perspective on conditions and their treatment that is not typically available from other sources.

To help you give your views, please use this questionnaire with our guide for patient submissions.

You do not have to answer every question – they are prompts to guide you. The text boxes will expand as you type.

Information on completing this submission

- Please do not embed documents (such as a PDF) in a submission because this may lead to the information being mislaid or make the submission unreadable
- We are committed to meeting the requirements of copyright legislation. If you intend to include **journal articles** in your submission you must have copyright clearance for these articles. We can accept journal articles in NICE Docs.
- Your response should not be longer than 10 pages.

About you

1. Your name

Janice Sykes

2. Name of organisation	Multiple Sclerosis Trust
3. Job title or position	Information Officer
4a. Brief description of the organisation (including who funds it). How many members does it have?	<p>The MS Trust is a UK charity dedicated to making life better for anyone affected by MS.</p> <p>The MS Trust is in contact with over 40,000 people affected by MS - that's people with MS, their families, friends and the health care professionals who help manage MS. Our core belief is that the best outcomes will come from well-informed people with MS making decisions in partnership with their specialist health professionals, and our aim is to support both sides of this partnership as much as we can. We provide expert information to help people with MS manage their own condition, and, uniquely, we inform and educate the health and social care professionals who work with them about best practice in MS treatment and care.</p> <p>We receive no government funding we are not a membership organisation. We rely on donations, fundraising and gifts in wills to fund our services.</p>
4b. Do you have any direct or indirect links with, or funding from, the tobacco industry?	None.
5. How did you gather information about the experiences of patients and carers to include in your submission?	<p>We have prepared this submission based on our experience of supporting people affected by MS at all stages of the condition. We speak daily to people who are dealing with issues relating to MS: coping with the impact of diagnosis, coping with physical, emotional and financial consequences of MS.</p> <p>Working with people with primary progressive MS (PPMS) and MS specialist health professionals, we have published a book which covers the physical and emotional aspects of living with PPMS and the ongoing management of the condition. The publication can be viewed on our website: Primary progressive multiple sclerosis</p>

	<p>To gain further insight into the views of those affected, we conducted an online survey of people with PPMS, their families and specialist MS health professionals, receiving nearly 500 responses (31 January – 14 February 2018). Their experiences provide a valuable personal perspective on living with PPMS, the impact it has on quality of life, and their perception of ocrelizumab.</p> <p>All of these sources have informed our submission.</p>
<p>Living with the condition</p>	
<p>6. What is it like to live with the condition? What do carers experience when caring for someone with the condition?</p>	<p>Primary progressive MS (PPMS) is a complex and unpredictable condition which has an impact on all aspects of life - physical, emotional, social and economic. These are profoundly important not just for the person diagnosed with MS, but for their families as well. Approximately 10% of those with MS have PPMS; in England, of the 90,000 people, about 9,000 will have PPMS.</p> <p>PPMS is a form of MS in which disability increases from the outset. The rate of disability progression varies between individuals. For some, disability may progress very gradually, and may remain stable or even improve very slightly over a short period. For others the progression is more rapid and unrelenting. Although the degree of disability will vary, the uncertainty of prognosis is universal. From the early stages of PPMS, quality of life is markedly affected and deteriorates as the disease progresses. Common symptoms such as cognitive function, bladder and bowel issues, and fatigue impact on day-to-day activities and the ability to work, which in turn influence a person's mental state. Increased disability imposes a heavy burden on people with MS and on their extended families, who often act as informal carers. It also leads to substantial economic losses for society, owing to diminished work capacity for the person with PPMS as well as loss of employment for their partners who become full-time carers.</p> <p>Diagnosis:</p> <p>The majority of people with PPMS are diagnosed in their 40s and 50s¹ but can be diagnosed at a younger age; nearly 10% of our survey respondents were aged 25-44. Diagnosis can be slow as the initial</p>

¹ Rice CM. et al. Primary progressive multiple sclerosis: progress and challenges. J Neurol Neurosurg Psychiatry. 2013 Oct;84(10):1100-6. <https://www.ncbi.nlm.nih.gov/pubmed/23418213>.

symptoms, such as fatigue or difficulties with walking, can be dismissed or misdiagnosed by GPs leading to years of delay in referral to a neurologist. Indeed, several survey respondents commented that they had to see several neurologists before receiving a diagnosis. As a result of these delays, people may have already had PPMS for some time before being formally diagnosed. Since ocrelizumab is most effective in early active PPMS and cannot reverse disability already accrued, it is vital that delays in diagnosis are eliminated.

At diagnosis, many respondents described a sense of relief at finally having an explanation for the health problems they had been experiencing followed by fear for the future knowing that PPMS is a deteriorating condition and desperation at being told there is no treatment available.

Physical impact:

In the majority of people with PPMS, the spine is predominantly affected by MS lesions, leading to symptoms which affect the lower part of the body. Our survey asked people with PPMS how the condition affected them physically; out of 231 responses to this question, the symptoms most frequently selected were mobility problems (95%), balance and posture (91%) and fatigue (89%). Response to the full list of symptoms is shown below – this clearly shows the range of symptoms affecting people with PPMS:

- 95% Mobility problems
- 91% Balance and posture
- 89% Fatigue
- 74% Bladder problems
- 71% Spasticity and spasms
- 57% Pain and sensory problems
- 48% Bowel problems
- 47% Sexual difficulties
- 44% Depression and anxiety
- 36% Cognitive problems
- 18% Vision and hearing
- 20% Speech and/or swallowing

People experience multiple symptoms; on average respondents selected 7 symptoms from this list. Secondary symptoms arise as a consequence of the problems that MS brings. These may include falls due to walking or balance problems, muscle pain as a result of added strain on the back or legs caused by changes to gait, weight problems if there are mobility or swallowing issues, or the development of pressure sores due to lack of mobility.

The effect of these symptoms is compounded, leading to increasing disability: survey respondents were asked to select their physical ability:

- 21% I can walk without help for at least 100 metres and largely look after myself
- 66% I need a stick, frame or wheelchair to get around and do need help with specific activities, but largely look after myself
- 13% I am dependent on a wheelchair or spend the majority of time in bed, and need a great deal of help with daily activities

- *I have difficulty preparing meals as I am naturally right handed and I no longer have any strength in my right hand or arm. Also very little strength in my right leg and foot as I have foot drop on that foot. Dressing is also a problem.*
- *Have had several bad falls which on a couple of occasions resulted in other injuries one in particular with a damaged knee which now further affects my mobility.*
- *Bowel problems were horrible. At times not only messing myself but also bedding. Taking showers at all times of night, not being able to leave home worried of accidents. Pain and spasticity an issue until my GP found correct mix of drugs to help.*

Emotional impact:

PPMS can take a heavy toll emotionally; many respondents reported anxiety, depression, frustration, anger, isolation/abandonment and struggled to come to terms with loss of the life they had planned for.

- *I am on antidepressants often very tearful as feel such a failure as a mum and wife. I hate the progression of this disease robbing me and my family of a quality life.*
- *I get anxious, and very low and take antidepressants to help me. I have bad mood swings.*
- *From being self-confidant and self-reliant I now have to rely on others. My relationship with my husband was always of equal partners and now I feel that balance has changed.*
- *Very frustrating that I have to rely on my husband in everything I do. I can't leave the house on my own. Can't go upstairs alone.*

- *It's been a bit of a rollercoaster. I get so angry it comes out as red rage. Other times I am so sad. I'm angry about all the time and money I spent on my education, all of the missed opportunities because of work, saving for a future that will never come etc etc I feel like I wasted half of my life preparing for something that can never happen now. The other half of my life is going to be spent in a wheelchair and eventually in bed. My friends have deserted me because I'm too slow or unreliable. PPMS makes me sad and lonely.*

Others work hard to maintain a positive mental attitude, often with the support of partners:

- *With my wife as my carer we have stayed strong and positive. Together we have kept going.*
- *I haven't time to feel sorry for myself. Don't get me wrong, frustration in not being able to do things for myself can lead to a wobble, then I give myself a shake and soldier on.*
- *Initially I was very sad. Once diagnosed, my neurologist recommended I take part in an NHS run Mindfulness course - this was extremely useful for learning to control my emotions*

People with PPMS and their families go to great lengths to remain active and independent and do whatever they can to stay in work. This often involves paying privately for treatments with limited availability through the NHS, such as physiotherapy, or treatments which are not available, such as Sativex and Fampyra.

- *At the moment I am paying £200 every 4 weeks for a drug for ppms.*
- *I am already paying for medication for ppms as there's not much else that helps*
- *Family support has been brilliant. Friends are very understanding and want to help with wheelchair or carrying things, though I can't go everywhere I would have done previously. I feel guilty that my husband is now my carer.*
- *Still positive, organised a weekly home visit physio, home carer three hours a week, gardener, chiropodist*
- *I have a PA weekly who can take me out in my converted car. I avoid crowded noisy places and parties as they stress me out. I have stopped distance travel and holidays. Fatigue is a major factor in my M.S. I do have a lovely big house and garden so these have become a reasonable alternative and I ask people to come to me. I enjoy shopping on Sundays (quieter). In the same way I have a list of restaurants and places to visit that can accommodate me in the wheelchair. M.S. has changed my social life but not ended it, I lived to work. I miss traveling outside U.K. the most.*
- *For the first year of my ill health retirement I was physically and emotionally exhausted and only went out once a week with my partner when she was on her days off. Most time was spent sleeping or watching television sadly. After reaching a particularly low spot for both of us, I agreed to support from a carer. This was organised through collaboration by health and social care. We also got involved with the local M S society on Wirral. Attendance at therapy classes eg. Tai Chi and Chair exercises along with psychological support from other service users and carers staff has been life saving for both of us.*

Social impact:

As PPMS progresses, people increasingly lose their independence and social activities require considerably more planning. Symptoms of PPMS, such as bladder and bowel incontinence can make activities particularly challenging; other aspects of PPMS can make people feel very self-conscious. For those who live alone, social isolation becomes a major concern.

- *I don't like being with people I don't know. I'm embarrassed because I can't use my hands properly so I have to have food cut up for me and I can't hold a glass or cup properly.*
- *I am totally isolated except for care givers visits*
- *I hardly go out socially in public as worry about falling and people looking at me*
- *It has made it impossible to go out alone and dramatically cut back on holiday and outing choices*

Economic impact:

Although NICE cost effectiveness calculations do not take account of the burden of loss of work, remaining in work is of critical importance to people with PPMS, not only for economic reasons but also for maintaining social contact and a sense of purpose. Survey respondents frequently mentioned their efforts to continue in paid employment (sometimes at the expense of social activities) or expressed regret at the loss of a working life and economic independence. Out of the 234 survey respondents, just 12% were in paid employment, a further 12% had had to reduce working hours since diagnosis, and 40% reporting that they had stopped work early or were unable to work due to ill health. A treatment which delays progression is seen as having the potential to help people with PPMS stay in work for longer.

The impact on work of the different types of MS have not been studied in the UK population but results from Scandinavian studies might be expected to apply to the UK. A Norwegian study conducted² in 2014 reported that just 14.8% of people with PPMS were employed full or part-time, compared with 66.1% with relapsing remitting MS and 24.3% with secondary progressive MS. Similarly, a Swedish study³ reported that people with PPMS had significantly lower income than people with relapsing MS.

- *My son-in-law was just 34 when he was diagnosed, my daughter was expecting their first baby. Our world was shattered. We have seen him go from a walking stick to a frame to a wheel chair. He goes to work with great difficulty*

² Boe Lunde HM et al. Employment among patients with multiple sclerosis – a population study. PLoS One 2014; 9(7): e103317. <https://www.ncbi.nlm.nih.gov/pubmed/25054972>

³ Kavaliunas A et al. Income in Multiple Sclerosis Patients with Different Disease Phenotypes. PLoS One. 2017;12(1): e0169460. <https://www.ncbi.nlm.nih.gov/pubmed/28081163>

	<p><i>and the help of the people there to get him into the wheel chair and into the office and the same at home time. My husband follows him home to help him out the car and into the house.</i></p> <ul style="list-style-type: none"> • <i>I am employed full time, so by the time I get through my work week, and the necessary household chores, I don't have much energy for much of a social life. Luckily I have an extremely supportive husband and family who understand my limitations. But I still have to be very conscious about what activities I take part in and it is a balancing act. Getting errands done requires careful planning due to my fatigue. Any decision to take part in social activities is a balancing act and something else has to be taken off of the list.</i> • <i>My position as a pharmacist was eliminated and I have been unable to find a job. My mind has not been affected, but confined to wheelchair so basically the only part of body that worked well is not being used. Loss of income, loss of motivation to keep going and reason to get up in the morning. Husband has become caregiver which has changed our relationship negatively.</i> • <i>I get so tired that I find it difficult to meet up with friends or go out socially. I use all my energy to continue in paid employment.</i> • <i>I have gone from running my own company employing over 20 people, to being unable to work and reliant on benefits within a few years. My wife has had to give up work (and a decent pension) to look after me.</i> • <i>Through losing ability to keep in employment, have struggled to have meaning in life, which leads to depressed state.</i> • <i>I stayed in employment, at a managerial level, for 5 years following diagnosis of PPMS. Thanks to the gradual erosion of abilities, particularly cognitive abilities, due to the disease, I have lost employment and cannot now even sustain employment at a junior level.</i> • <i>I want to be as active a member of society as I can be, to continue in employment and pay my taxes.</i> • <i>Through losing ability to keep in employment, have struggled to have meaning in life, which leads to depressed state.</i> <p>Caregiver impact:</p> <p>PPMS does not only impact the person diagnosed with it, but also family and friends who may provide informal care. With increasing disability, people with PPMS become more and more dependent on carers for their personal care and in order to access activities outside the home. This can strain relationships, as family members may need to take on additional responsibilities. Caregiving partners may feel uncertainty about the future, financial difficulties, social disruption and isolation.</p>
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Current treatment of the condition in the NHS

7. What do patients or carers think of current treatments and care available on the NHS?

Management of PPMS focuses on four key areas: symptom management; prevention of complications; maintaining function and promoting general health and wellbeing.

Given the wide range of symptoms that people with PPMS may experience, it is important that there is access to a range of therapies delivered by skilled allied health professionals, competent in MS care. These health professionals are generally engaged according to patient need for episodes of treatment focussed on individual problems and goals.

In reality, access to NHS and social care interventions to support people living with PPMS such as physiotherapy or neurorehabilitation are limited, sporadic or even non-existent. The quality of and access to care is highly dependent on where someone lives. Calculation of the cost of providing "established clinical management" cannot assume an ideal situation where these services are readily available.

Our survey asked people with PPMS about contact with MS specialist health professionals in the last 12 months.

- 70% had seen a neurologist
- 63% had seen an MS nurse
- 9% had seen neither, but would have liked to
- 5% had seen neither, but by choice

We are aware that in some areas, people with PPMS have been effectively 'discharged' from MS services, either due to a perception that there is no 'treatment' available for PPMS or due to limitation in service capacity. Overwhelmingly, the message that people receive from MS health professionals is that there is no treatment available for PPMS.

Our survey respondents also reported how often they had used other NHS services; those most frequently accessed include:

- 17% A&E
- 27% Continence advisor
- 14% Community/district nurse

- 14% Other specialist nurse
- 10% Rehabilitation medicine team
- 73% Family doctor
- 45% Physiotherapist
- 32% Occupational therapist
- 12% Orthotist
- 15% Chiropodist

A number commented that access to care, particularly physiotherapy, was inadequate or they had to pay for private treatment.

- *I'm on so many waiting lists I've lost track (some have been months)*
- *Long waiting time if I need to see someone.*
- *Poor provision for services in the area. i see a physio privately, private hydrotherapy, private reflexology, private medication. Without this I feel I would definitely be more disabled.*
- *Access to physiotherapy, dietitian etc just doesn't happen on NHS. I have had to seek these privately. Or via the local MS Therapy Centre*

“Established clinical management” is not defined in the final scope, but it is clear from the data collected in our survey that people with PPMS have a high level of need for NHS care. There is currently no research or professional consensus on what “established clinical management” is or how much it costs; any definition will be idealistic. It is unrealistic to assume that all people with MS have access to high quality care that fully meets their needs. The reality is that people with MS often have very limited access to services. The quality of and access to care is highly dependent on where an individual lives. An MS Society report found that 40 per cent of MS specialist centres failed to offer people with MS a truly multi-disciplinary clinic⁴. This was also reflected in the Royal College of Physicians national audit of services for people with MS which found only 43% of people said they knew they had access to specialist neuro rehabilitation and 57% said that they had access to specialist MS physiotherapists.⁵ In 2011 the National Audit Office report for services for people with neurological conditions found that the case loads of MS

⁴ MS Society, MS 2015 Vision, (2011)

⁵ RCP and MS Trust, National Audit of services for people with Multiple (2011)

	<p>nurses varied extensively in each Strategic Health Authority⁶. A more recent survey⁷ conducted by the MS Trust in 2016 found that on average, people with progressive MS are seeing MS specialists much less often than people with relapsing MS.</p>
<p>8. Is there an unmet need for patients with this condition?</p>	<p>Time and again respondents to our survey commented that there is currently no treatment to delay the progression of PPMS, nothing that can change the prognosis of their condition. Many people are doing all that they can to minimise the impact of PPMS, but they are all too aware that there is nothing that will slow down the progression of their disease.</p> <ul style="list-style-type: none"> • <i>I was told a slow gradual decline towards a wheelchair with no drugs to help on the way</i> • <i>Took ages to get a diagnosis. Over 2 years. Then got told nothing could be done and likely to be in a wheelchair within 10 yrs. Thanks, bye, next! No support, no help.</i> • <i>My neurologist goes through the motions but there is nothing he can prescribe for PPMS</i> • <i>The NHS services can diagnose PPMS and inform you that you have a life changing incurable neurological condition that at present they have no treatment for. This is devastating. My daughter was diagnosed with MS over a year ago (she is 34 now). Although she was assessed by a very experienced neurologist he told us there was presently no licenced drug treatment for PPMS and therefore there was nothing he could do other than monitor her symptoms.</i> • <i>Very poor, my daughter has not seen a consultant for over two years, she has district nursing care and drugs to deal with symptoms but nothing to stop or slow down the deterioration</i> <p>In the absence of a treatment that will stop or slow down deterioration, the biggest unmet need remains access to the full range of NHS services on demand and coordination of services to ensure rapid referrals at times of critical need.</p> <ul style="list-style-type: none"> • <i>Until suitable drugs are available, I feel that REGULAR and adequate physiotherapy should be offered as a matter of course, along with counselling.</i>

⁶ National Audit Office. Services for people with neurological conditions (HC 1586). TSO, 2011

⁷ MS Trust. [Is MS care fair?](#) MS Trust; 2016

Advantages of the technology

9. What do patients or carers think are the advantages of the technology?

The clinical trial data⁸ have demonstrated the effectiveness of ocrelizumab at delaying progression in PPMS:

- Fewer people taking ocrelizumab had an increase in disability, compared to placebo. An increase in disability which lasted 12 weeks was seen in 32.9% of those taking ocrelizumab and 39.3% of those taking placebo. In addition, increased disability which lasted at least 24 weeks was seen in 29.6% taking ocrelizumab and 35.7% taking placebo. Comparing the two groups, people taking ocrelizumab were 24% less likely to have an increase in their disability than those taking placebo.
- After 120 weeks of treatment, walking speed over 25 feet was 39% slower for ocrelizumab compared to 55% slower for placebo. Brain lesion volume decreased by 3.4% with ocrelizumab and increased by 7.4% with placebo. Loss of brain volume was 0.9% for ocrelizumab and 1.09% for placebo.
- Ocrelizumab treatment lowered the risk of progression of upper extremity disability, as measured by the 9 hole peg test, compared with placebo.⁹

The overwhelming majority of people with PPMS are delighted that there is, at last, potential to slow down the progression of their condition; over the years as the number of treatments available for relapsing MS have grown, people with progressive MS have felt that their needs have been forgotten. Many respondents to our survey recognised that their PPMS may be too advanced to gain a benefit, but believed others should be given the opportunity to take a medication that would slow down progression. The benefits of slowing down progression are seen as maintaining mobility and independence for longer, allowing people to continue to work for longer, and saving costs for the NHS in the long term by preventing progression and the need for MS services and social care.

⁸ Montalban X, et al. Ocrelizumab versus placebo in primary progressive multiple sclerosis. New England Journal of Medicine 2017; 376: 209-220. <https://www.ncbi.nlm.nih.gov/pubmed/28002688>

⁹ Fox EJ, et al. Effect of ocrelizumab on upper limb function in patients with primary progressive multiple sclerosis in the ORATORIO study. [ECTRIMS Online Library. Fox E. Oct 27, 2017; 200891.](#)

While some have high expectations, anticipating improvement in mobility and other symptoms, others are more realistic about what it could offer them. There is a general recognition that ocrelizumab is not a cure for PPMS.

- *if I could preserve my hand function it would mean I could remain mainly independent which would benefit everyone.*
- *Although I have limited mobility it is my hands deteriorating that I would like to slow or stop*
- *Ocrelizumab is the first treatment EVER for PPMS, I have done everything I can for myself, without this treatment, I will be accumulating disabilities much faster if I am not allowed to have this treatment.*
- *Yes I think it should be prescribed by the NHS. Any hope of delaying the onset of worsening symptoms would improve not only my prospects but also of my wife and children - aged 11 & 14.*
- *It should be prescribed by the NHS because it is the only current medication which has been shown to slow the progression of PPMS. Quite apart from the benefit to the patient, it would be cost-effective for the NHS, since it would lessen the chances of further treatment and/or social care being needed further down the line.*
- *Ocrelizumab should definitely be prescribed on the NHS. The evidence to date indicates it can have an effect on slowing progression. Progression must be slowed to ensure individuals can remain active, can remain in employment and can remain as productive members of society. The existing bleak outlook of no treatment and no hope can be challenged by ocrelizumab as it is being challenged in other countries where ocrelizumab is now being used.*
- *Even a marginal improvement in my mobility would have a significant impact on my QOL and ability to work & earn.*
- *Could be life changing for me, may be able to stay in full time employment and still pay tax*
- *As someone with very early stage PPMS i believe ocrelizumab should be prescribed by the NHS as studies have shown it can ease progression of MS. My neurologist tells me the earlier this treatment is available to people like me the better to delay any progression. It is very hard to be told you have a progressive illness where no treatment is currently available*
- *I do think ocrelizumab should be prescribed on the NHS. I want the chance to have the progression of my MS slowed, this would enable me to continue in paid employment in a job I enjoy. I want to remain mobile and to be able to look after myself.*
- *I of course think it should. I have no other drug available to me for PPMS to help slow progression. At this stage, I don't need support from health care providers (although I would like more). I can walk unaided and generally live a full life, with a positive attitude. However I am aware my symptoms are getting worse, my mobility and cognition are in decline, which in is increasing anxiety and depression. This will only get worse. If I am not able to access something to slow progression I would imagine I will require more medical intervention costing the NHS in the not too distant future. Whilst I still have some mobility it makes sense to help me to maintain it for as long as possible so it takes longer for me to become a burden on NHS resources. I would hope this alone would make the drug cost effective.*

Disadvantages of the technology	
<p>10. What do patients or carers think are the disadvantages of the technology?</p>	<p>Very few people expressed reservations about ocrelizumab. One person expressed concerns about risk of cancer, another felt the treatment effect was small and not enough to consider taking the drug.</p> <p>Expectations of treatment will need to be managed; people will need to be counselled that ocrelizumab will not necessarily make them better, but will slow down the rate at which they get worse.</p> <p>Undoubtedly, there will be disappointment when some people learn that they are not eligible for ocrelizumab.</p> <p>Experience gained from MS teams in the United States and other countries where ocrelizumab has been approved for PPMS will be invaluable to manage expectations and identify potential risks.</p>
Patient population	
<p>11. Are there any groups of patients who might benefit more or less from the technology than others? If so, please describe them and explain why.</p>	<p>Ocrelizumab has been licensed by the EMA for early, active PPMS. Active PPMS is defined in terms of MRI evidence. However, “early” PPMS is not defined other than by reference to the ORATORIO inclusion criteria.</p> <p>We anticipate that the definitions of “active” and “early” will be further refined during the course of the appraisal. To ensure people have access to treatment early in the course of their PPMS, it is paramount that delays in diagnosis are minimised.</p>

Equality	
12. Are there any potential equality issues that should be taken into account when considering this condition and the technology?	None.
Other issues	
13. Are there any other issues that you would like the committee to consider?	<p>The dosing schedule consisting of two initial infusions, followed by infusions every six months offers a very practical regimen which will minimise the impact on family and work commitments, reduce the impact of side effects. Experience from treatments for relapsing remitting MS has shown that this type of treatment pattern is often preferred over more frequent dosing (such as taking tablets daily) and ensures a higher level of adherence.</p> <p>Side effects are limited to a day or two following an infusion (and became milder after the first infusion).</p>
Topic-specific questions	
14. To be added by technical team at scope sign off. Note that topic-specific questions will be added only if the treatment pathway or likely use	

of the technology remains uncertain after scoping consultation, for example if there were differences in opinion; this is not expected to be required for every appraisal.]

if there are none delete highlighted rows and renumber below

Key messages

15. In up to 5 bullet points, please summarise the key messages of your submission:

- Primary progressive MS is a life-long condition which is characterised by increasing disability from the outset
- Increasing disability has an impact on physical and emotional well-being for the individual and on family members who act as informal carers, causing anxiety, depression, and leading to breakdown in relationships
- PPMS has significant social and economic impact as people are less able to work and contribute to society in a way that has meaning for them
- Current management of PPMS is inconsistent as access to appropriate therapies is difficult or only available through private healthcare – which for those unable to work or on low incomes is not an option

- Ocrelizumab is the first treatment which has been shown to slow down progression, which in turn improves health outcomes and thus alleviates the impact of PPMS

Thank you for your time.

Please log in to your NICE Docs account to upload your completed submission.