



Patient Group Submission Form

The Scottish Medicines Consortium (SMC) is committed to working in partnership with patient groups to capture patient and carer experiences, and use them to inform decision-making.

Before you make a submission

You are required to complete a patient group partner registration form before you make a submission. The registration form requests general information about your organisation. It only needs to be completed once (and annually updated) and should save you time with any further submissions to SMC. If you have not already completed a registration form, please do this before you make your submission.

You will find it helpful to read our *Guide for Patient Group Partners*, which gives details about the type of information you need to capture in the submission form. **Please read this before you make your submission and use it to help you complete each question.**

You can find the registration form and *Guide for Patient Group Partners* in the [Public involvement](#) and [Making a submission](#) sections of our website.

Contact us

If you have any more questions after reading the guide, the SMC Public Involvement Team can support you throughout the submission process. You can email us at:

hcis.SMCPublicInvolvement@nhs.net or phone: **0141 414 2403**.

Please do not hesitate to get in touch, as we are here to help you.

Name of medicine:

Fampridine (Fampyra)

Indication: (what the medicine is used for)

Improvement of walking in adult patients with multiple sclerosis with walking disability

Submission date:

3 September 2018

Name of organisation making submission:

Multiple Sclerosis Trust

Who is the main contact for submissions to SMC?

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Summary of key points

Please summarise the key points of your submission which you would like to emphasise to SMC Committee – bullet points may be helpful.

(See P11 of *A Guide for Patient Group Partners*)

300 words maximum

Walking problems affect a large proportion of people with MS and can have a major impact on all aspects of work, social and family life. Increasing mobility problems lead to greater dependence on informal carers, leading to poorer quality of life and economic burden not only for the individual, but also for their family, friends, work colleagues and wider society.

Fampridine is currently the only licensed medicine for mobility problems in people with MS. There are a number of causes for walking problems and not all will be resolved by fampridine. A two week trial of fampridine can identify responders. A relatively small clinical improvement in walking ability can have a more significant perceived benefit for the person with MS. Improving mobility also increases the opportunity for people to take part in activities which lead to improved physical fitness and emotional well-being.

In the words of someone with MS: “I've been on Fampyra for a year now. Fampyra is amazing. It helps me walk, swim, get up the stairs and much more.”

Please provide details of any individuals who have had a significant role in preparing your submission and who have an interest to declare.

(See P11 of *A Guide for Patient Group Partners*)

300 words maximum

The views of a range of people were taken into account for this submission, but no individual with an interest to declare undertook a significant role in preparing it.

Please tell us how you gathered information about the experiences of patients and carers to help inform your submission.

(See P11 of *A Guide for Patient Group Partners*)

300 words maximum

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.

We have prepared this submission based on our experience of supporting people affected by MS, through our telephone and online enquiry service and through the involvement of people with MS at all stages of the condition, in helping us prepare our information materials. Many of these individuals are struggling to cope with the effect of impaired mobility. We have also asked for testimonies from people who have taken fampridine, but as this is currently only available via private prescription, the number of people who have been able to give us their experience is very limited.

We have reviewed information and extracted comments received via our Enquiry Service and social media channels to understand and appreciate the perspectives of people with MS.

1. How does this condition affect the day-to-day lives of people living with it?

(See P11 of *A Guide for Patient Group Partners*)

500 words maximum

Multiple sclerosis (MS) is a life-long, progressive neurological condition affecting the central nervous system and is the most common cause of neurological disability in young adults. It can result in a wide range of symptoms that can occur in many combinations. For most, MS does not have a significant effect on life expectancy but for some it may mean facing 50 years of disability and distress.

Walking around the house, the garden, to the shops and in the office should be automatic and effortless and is something that we all take for granted. The value we place on our mobility is reflected by the fact that walking problems and consequent loss of independence is one of the greatest fears of people diagnosed with MS.

Walking problems affect a large proportion of people with MS. One study suggested that 15 years after diagnosis, people with MS face a 40% probability of needing some form of walking assistance.

Walking problems can affect a person's independence and can have a major impact on all aspects of work, social and family life. They often compound other MS symptoms such as increased fatigue due to the effort of walking, bladder and bowel incontinence because it becomes difficult to reach the toilet in time, increased risk of falls leading to further complications, general weakness and social isolation through becoming housebound.

2. How well do medicines which are currently available in NHSScotland help patients manage this condition? (See P12 of *A Guide for Patient Group Partners*)

500 words maximum

Difficulties with walking can be caused by balance or coordination problems, dizziness, numbness or other sensory changes in feet or legs, muscle stiffness (spasticity) or weakness. Because of the range of possible causes of walking difficulties, a multidisciplinary team of specialist health professionals may be involved in managing this aspect of MS. Input from a specialist physiotherapist is particularly important. Access to neurophysiotherapy is highly dependent on where someone lives and often limited to just a few sessions. A recent caller to our enquiry service reported a 10 week waiting list to see a physiotherapist for assessment of walking problems.

Medicines are available through NHSScotland to treat spasticity and some other causes of walking difficulties. Apart from walking aids such as walking sticks and frames, there are no other treatments. Fampridine is currently the only medicine with a marketing authorisation for treating mobility problems in people with MS.

3. Have you been able to consult with patients who have used this medicine?

(See P12 of *A Guide for Patient Group Partners*)

Yes

No

4. Would this medicine be expected to improve the patient's quality of life and experience of care, and if so, how?

(See P12 of *A Guide for Patient Group Partners*)

500 words maximum

Fampridine works by allowing electrical signals to continue travelling along damaged nerves to stimulate muscles and is particularly effective for people whose walking impairment has been caused by reduced nerve transmission. An initial two week trial of the drug can identify those who respond to it. In clinical trials, responders to fampridine experienced an average improvement of about 25% of walking speed. However, this outcome fails to capture the impact that this improvement can have on quality of life, as these testimonies demonstrate:

"I have been taking Famprya for 13 months of which i can walk twice as quick over 25 feet, i have no bladder/bowel problems (do not have to wear urisheaths anymore), can go out of the house confident that i am not going to have an accident. This drug has changed my whole quality of life."

"Had my free trial and went back for a walking test. I'd made a 50% change to my walking. Fatigue had lessened too. I've been self funding since January 2013, now I'm finding it very hard to fund! I know without this drug I would not have the same quality of life. I would not be able to work, therefore cost the government lots more in benefits."

"I've been on Famprya for just over 6 weeks. It has changed my life. I'm on one stick again, sleeping at night only, in charge of my bladder. My walking speed has improved by a quarter."

After clinic visits for initial assessments to determine whether someone's walking speed is improved by taking fampridine, further doses of fampridine are taken at home, minimising the time and cost of travelling to and from a hospital clinic.

5. What kind of impact would treating a patient with this medicine have on the patient's family or carers? (See P13 of *A Guide for Patient Group Partners*)

500 words maximum

As walking problems can have a major impact on all aspects of work, social and family life, any improvement in mobility will bring many benefits to the individual as well as to their family and carers. MS is associated with high rates of unemployment and depression compared to the general population. Improvement in mobility helps people stay engaged in the activities which matter to them which is likely to have a positive effect on the person and on their relationships with family and carers.

Increased independence and the ability to remain in employment, both for the individual and informal carers, reduces the financial burden of MS and improves the psychological and emotional impact that MS can have on relationships.

Improved mobility enhances participation in family commitments, day-to-day activities and social life. Improvements in mobility which help with other problems such as incontinence will reduce the role which a carer may need to play.

Someone with walking problems will need housing adaptations and equipment such as walking frames or wheelchairs. In addition to the cost of providing these, they can also have a big impact on family life as they make the house feel less like a home, may be difficult to accommodate when floor space is limited and affect how other members of the household perceive the person with MS.

6. Are there any disadvantages of the new medicine compared to current standard treatments? (See P13 of *A Guide for Patient Group Partners*)

500 words maximum

As with any drug, we understand that there are a number of potential side effects of fampridine. Urinary tract infections are very common. Other common side effects include dizziness, headache, back pain, difficulty sleeping, feeling sick and stomach upsets.

We also understand that it is important not to exceed the recommended dosage of one tablet taken 12 hours apart as there is an increased risk of seizures and other side effects if doses overlap or higher doses are taken.

Given the impact of walking problems on daily activities and the lack of alternative treatments, we would expect most people to view these side effects as an acceptable risk. However, there will always be individual preferences about benefit and risk balance and practicalities linked to daily routines.

7. Is there any additional information you think may be useful for the SMC committee to consider? (Optional)

500 words maximum

8. Do you consent for a summary of your submission to be included in the Detailed Advice Document for this medicine?

Yes

No

Thank you for completing this form.

Please email it to: hcis.SMCPublicInvolvement@nhs.net

If you are unable to email this form to us, please send by post to the address below:

Public Involvement Team
Scottish Medicines Consortium
Healthcare Improvement Scotland
8th Floor
Delta House
50 West Nile Street
G1 2NP

The Public Involvement Team is available to advise you on how to complete this form to ensure the patient and carer experience is fully captured, to help inform the SMC decision making process. If you have any questions about completing this form call us on: 0141 414 2403.