Patient/carer organisation statement

A submission from the MS Society to inform the NICE appraisal of fingolimod for relapsing-remitting multiple sclerosis (November 2010)

Name: [redacted]

Organisation: MS Society

About the MS Society

Established in 1953 and with over 40,000 members and 350 branches, the MS Society is the UK's largest charity for people affected by multiple sclerosis (MS) and the largest not-for-profit funder of MS research in Europe. There are approximately 100,000 people with MS in the UK and, with 50 new people diagnosed every week, it is one of the most common neurological conditions affecting adults. We are committed to bringing high quality standards of health and social care within reach of everyone affected by MS.

Introduction

This submission has been prepared by the MS Society's policy and research directorate and is informed by:

- the results of an online survey - over 1000 people affected by MS told us about their views and experiences in relation to MS disease modifying drugs (DMDs) and relapses;
- two semi structured interviews with expert patients with direct experience of taking fingolimod;
- secondary research into the costs of MS, and;
- clinical trial data from the TRANSFORMS and FREEDOMS trials, involving 1153 and 1033 people with relapsing remitting MS, respectively.

The following six appendices are attached to this submission:

- **Appendix A:** Transcripts of interviews with two patient experts.
- **Appendix B:** A report on the perspectives of people with MS on relapses and disease modifying drugs.
- **Appendix C:** Free text responses to an open question on experiences of relapses and/or disease modifying drugs.
- **Appendix D**: Free text responses to an open question on people's main reasons for discontinuing the disease modifying drugs (Avonex, Betaferon, Extavia or Copaxone).
- **Appendix E:** Free text responses to an open question on people's main reasons for discontinuing Tysabri.
- **Appendix F:** Interview questions sent to patient experts in advance of interviews.

About the online survey

The survey attracted 1129 respondents; only 1007 responses were included in the analysis, as the report explains. It is the views of over 1000 people with MS that inform this submission. The majority of respondents (80 per cent) had relapsing remitting MS, were female (73 per cent) and were aged between 31 and 50 (67 per cent).

The survey was promoted in the following ways: the main MS Society website; the research network newsletter; the campaigns network newsletter; staff intranet and social networking websites such as Facebook and Twitter.

The survey was live for just over two and a half weeks (from 26 March until 14 April 2010). The results have since been analysed and published in a report entitled, ‘Perspectives of people with MS on relapses and disease modifying drugs’. A copy of the report can be read in full in appendix B. Open text responses to a question on people’s experiences of relapses and or taking DMDs can be read in appendix C. Appendix D contains open text responses concerned with reasons for discontinuing DMDs and appendix E contains open text responses concerned with reasons for discontinuing Tysabri.

Executive summary

The clinical trial results show that fingolimod is highly effective at reducing relapses, effective at reducing brain lesion activity and effective, to some extent, at reducing disability progression. Fingolimod therefore has the potential to improve clinical outcomes and quality of life for a significant number of people with MS and to save the NHS and personal social services money, as outlined below.

Reducing relapses

Relapses have a physical and sometimes debilitating impact on people with MS; the majority of people with MS felt relapses left them unable to do the things they wanted to do (95 per cent), slowing them down (98 per cent). As a result, 90 per cent of people with MS told us that they cannot be as independent as they want to be, with 58 per cent always or often relying on others for support.

The emotional impact of relapses should not be underestimated. A loss of independence can often mean people with MS feel they are a burden on their family (93 per cent). Relapses are often unpredictable and distressing, leaving most people feeling frustrated (80 per cent) and anxious (67 per cent). People with MS told us that relapses caused a significant disruption to their every day life. 91 per cent said that at some point during a relapse, they felt depressed with over half (52 per cent) saying they always or often felt depressed.

People with MS told us that relapses prevent them from carrying out their work duties in terms of paid employment (82 per cent). Almost 90 per cent of people were unable to carry out their usual roles and responsibilities as a direct result of a relapse. Many described taking annual leave to help cope during a relapse whilst others needed to take months off work to recover. People with MS told us that relapses make it difficult for them to sustain full time employment.

Preferred alternative method

The vast majority (95 per cent) of people with MS would prefer to have their MS drug administered via a pill. There is currently no alternative if people either do not want, or have problems with, self injecting or going to hospital for infusions.

People with MS told us that injecting was uncomfortable, with many suffering complications from injection sites and 70 per cent suffering skin reactions. Many found that their MS symptoms exacerbated difficulties with injecting such as tremors and numbness of the hands. 72 per cent found self injecting difficult and needed to rely on others.

In considering the value of the innovation of oral therapy, the inconvenience of injecting and/or going to hospital for infusions must be considered by the appraisal committee as people with MS told us this had a significant impact on lifestyle and quality of life. Injections limit people's ability to travel and, for 77 per cent of people with MS, considerably disrupt their daily life. People with MS told us they had to plan their life around infusions (85 per cent) and injecting (83 per cent). Similarly, many told us that infusions and injections affected their ability to do the things they wanted to do, affecting 66 per cent and 69 per cent of people with MS respectively.

Key concluding messages

If made available on the NHS, fingolimod would undoubtedly be the treatment of choice for many people with MS. Oral delivery in the context of MS DMDs represents a significant innovation that is particularly valued. The impact of the degree by which fingolimod has been shown to reduce relapse rate should also not be undervalued given the devastating effect that relapses can have on an individual's quality of life.

In the absence of an oral therapy, some people with MS will prefer to and choose to go untreated because of the lack of alternatives. Whilst most people described this as a drastic measure (and one they would rather avoid), some would seriously consider going untreated.

If fingolimod was not made available on the NHS, it would have the following consequences for people with MS and their carers:

1. People living with MS will experience more relapses, lowering their quality of life. As a result, fewer people with MS will be able to continue in full time employment, increasing their dependency on the welfare support system.

2. People with MS will be increasingly anxious and depressed about relapsing.

3. Treatment options will continue to involve significant planning and disruption to every day life.

4. People with MS will continue to access A&E and other healthcare services as a result of continuing to experience side effects associated with DMDs. This increases costs to the NHS and personal social services.

5. People with MS will continue to stay dependent on others to either help administer their treatment or get them to the place where they need treatment. This places added pressure on the role of the carer and increases NHS management and administrative costs.

It is therefore vital, with an increasing number of alternatives entering the market for the treatment of relapsing remitting MS, that people with MS have access to the right drug for them at the right time. NICE needs to place a strong focus on the potential to maximise quality of life for those individuals living with MS and their carers.

What do patients and/or carers consider to be the advantages and disadvantages of the technology for the condition?

1. **Advantages**
(a) Please list the specific aspect(s) of the condition that you expect the technology to help with. For each aspect you list please describe, if possible, what difference you expect the technology to make.

Fingolimod has undergone two phase III trials (the TRANSFORMS and FREEDOMS trials) involving 1153 and 1033 people with relapsing remitting MS, respectively. Within these trials, people with MS experienced the following benefits:

1. A lower annualised rate of relapse and a higher relapse free rate
The two year FREEDOMS trial compared the effectiveness of fingolimod with a placebo treatment. The results show that fingolimod reduced relapse rates by 54-60 per cent over the course of the two year trial.

The one year TRANSFORMS trial compared the effectiveness of fingolimod with that of beta-interferon-1a and found that fingolimod reduced relapse rates by 53 per cent compared with beta-interferon-1a.

A relapse is defined as an episode of neurological symptoms, lasting for at least 24 hours, that happens at least 30 days after any previous episode began. In relapses, symptoms usually come on over a short period of time and often remain for a number of weeks, but sometimes months. Relapses can vary from mild to severe. At their worst, acute relapses may need hospital treatment, but many relapses are managed at home, with the support of a GP, MS specialist nurse, and other care professionals.

Due to the varied and unpredictable nature of MS, determining an ‘average’ relapse rate is not straight forward; considering the number of people currently on disease modifying drugs it is likely that a significant proportion of people with relapsing remitting MS experience one or more relapses per year.

2. Lower risk of disability progression
Many people with MS experience a progression of disability over the course of the condition and it is estimated that around 65 per cent of people with relapsing remitting MS will develop secondary progressive MS, a form of MS that is characterised by an accumulation of disability. This progression occurs at varying rates and can lead to loss of mobility and the need to use a wheelchair. There are currently no treatments available that are proven to slow the progression of MS. Fingolimod appears to reduce the risk of disability progression, and therefore has the potential to increase the quality of life of a significant number of people with MS.

In the FREEDOMS trial, Fingolimod was shown to reduce disability progression by about 30 per cent over three to six months, as measured by the Expanded Disability Status Scale (EDSS). In the TRANSFORMS trial, fingolimod did not appear to have an effect on disability progression over the course of the trial. Both trials, however, demonstrated that fingolimod reduced brain lesion activity (as measured by MRI scanning).

These clinical benefits need to be taken into account alongside other benefits that are of value to the patient but not measured by the trial, such as the effect on quality of life and the convenience benefit of taking a pill over injections or infusions in hospital. These are the kinds of ‘benefits’ that will make a huge difference to people living with MS and their potential to have a greater quality of life, for longer. The next section considers the effect of the treatment on individuals.

(b) Please list any short-term and/or long-term benefits that patients expect to gain from using the technology. These might include the effect of the technology on:

- the course and/or outcome of the condition
- physical symptoms
- pain
- level of disability
- mental health
- quality of life (lifestyle, work, social functioning etc.)
- other quality of life issues not listed above
- other people (for example family, friends, employers)
- other issues not listed above.

In this section, we consider a number of factors which will or have the potential to deliver short and long term benefits from the perspective of people with MS. To assist us in identifying these factors and how important they are, we conducted a survey of over 1000 people with MS. Full results of this survey are attached in appendix B and open text responses are included in appendices C, D and E.

Course or outcome of the condition: impact of relapses on MS
On the trials, people with MS were between 53 and 60 per cent less likely to experience a relapse. To place this into context, we consider what it means to individuals living with MS to experience a relapse and the impact this has on their quality of life.

<u>Experiences of people affected by MS</u>
People with MS have told us that relapses have a physical and sometimes debilitating impact, affecting their ability to do day-to-day activities and lowering their quality of life. For example, in our survey, 95 per cent had experience of relapses that left them unable to do the things they wanted to do and a further 98 per cent of people felt that relapses slowed them down.

Relapses are episodes that people with MS wish to avoid and prevent as they can result in a loss of independence. For example, respondents described relapses as ‘set backs.’ As one person put it, “I want to be normal again and not have to endure debilitating relapses several times a year which set me back so far and mean I have to rely on others to help me, when I just want to be able to do the things that everyone else takes for granted” (quote 259, appendix C).

A loss of independence as a result of a relapse can make people with MS more dependent on others for help. In our survey, 90 per cent of people with MS felt they could not be as independent as they wanted to be, 91 per cent of people with MS said that they had to rely on other people for help during a relapse and a further 93 per cent felt they were a burden on their family at some point during a relapse.

One respondent provided a useful insight into the emotional impact of a relapse and the resulting loss of independence and increased dependency on family: “Relapses are not only worrying, painful and distressing at the time but can take a considerable amount of time to recover from. I have been left with residual problems from every relapse I have had and then the worry of if I have another, is the disease progressing quicker than I thought - that is always a worry at the back of my mind. I then worry about the impact on my husband and that he has to take time off work to help me. The concern that he will not cope if I become severely affected by another relapse is a genuine worry as he gets extremely frustrated with the whole MS scenario. As a very independent lady, this adds its own issues to my state of mind and the fact that I cannot be there as readily for my children and colleagues" (quote 55, appendix C).

Some respondents found the side effects of a drug favourable in comparison to the potentially debilitating effects of a relapse: "Without medical support [drug], my last relapse may have had a worse effect on my body – it could have been more disabling. The side effects of the drug are a blessing to me compared to the impact on me without having them...during my last relapse, my head was so sore I could hardly see or eat. I felt so ill, I went to bed and hoped that I would not wake up" (quote 84, appendix C).

The unpredictable and distressing nature of relapses, including the disruption they can cause to every day life, was a common theme amongst respondents. People with MS told us that relapses often left them feeling frustrated (80 per cent) and anxious (67 per cent). One person explained: "A relapse must be the most frightening thing to happen in one's life. You never know how long it's going to last and what effect it is going to have on you and all the people around you. When you are no longer in control of your body and mind you feel so lonely, depressed and vulnerable" (quote 181, appendix C). A feeling of 'loss' was a common theme amongst respondents. As one person put it, "every relapse, I lose a little bit of me" (quote 234, appendix C).

The emotional and psychological impact of a relapse should not be underestimated. In our survey, most people with MS had experienced feelings of depression (91 per cent) and anger (87 per cent) at some point during a relapse. One respondent explained: "my relapses make me feel suicidal. Fortunately, I have a child and he makes giving up an impossibility. Any chance of having a drug which would ease some of my every day difficulties and one that I could easily administer in a pill form is my one big hope. It would give me a future to look forward to" (quote 184, appendix C).

It is clear from the results and from people's experiences, that relapses can be an unpleasant and debilitating feature of living with MS, with long lasting physical and psychological effects on people living with MS including their carers. Any drug that is more effective than the current DMDs at reducing relapse rates has the potential to transform the lives of people living with MS and their ability to lead a greater quality of life.

Quality of life issues: convenience benefit of taking a pill compared to injecting and or receiving infusions

Since 2002, people with MS have been able to inject MS disease modifying drugs (DMDs). In 2007, Tysabri (Natalizumab) was approved for those with rapidly evolving severe relapsing-remitting MS. People with MS who are taking Tysabri need to attend hospital to receive regular infusions. Fingolimod therefore represents an additional opportunity in terms of how people with MS could potentially have their treatment administered in the future.

Experiences of people affected by MS

Most people (72.3 per cent) with MS who completed the survey had taken or were currently taking one or more of the following disease modifying drugs: Avonex, Rebif, Betaferon, Extavia and Copaxone. Of those who started on these DMDs, 21 per cent discontinued treatment. The reasons people gave for discontinuing can be split into the following five categories and provide a powerful argument for a future oral therapy to be made available on the NHS:

1. Injection site reactions

Skin indentation and a growing inability to cope with injecting were a common theme amongst respondents, including an increase in difficulty when injecting over long periods. One person stated: "It is getting more and more uncomfortable to inject as the original sites around my body are now dented inwards and are now unsuitable for injection. I have contacted my MS nurse who has given me ideas on suitable places to inject…the sore injection sites rub on my clothes during the day" (quote 239, appendix C).

Most people who completed the survey found injecting an unpleasant experience; 87 per cent of people with MS on DMDs at some point felt uncomfortable injecting with over 55 per cent of people finding it always or often uncomfortable to inject. A complaint among some respondents was the effect of scar tissue and fat atrophy, including injection site ulcers. Others complained that constantly injecting was not sustainable: "injections are not a long term solution – there are only so many sites a body can put up with..." (quote155, appendix C).

In some cases, complications with injection sites have resulted in emergency admissions. "One experience I had about two years ago involved an injection site becoming infected causing a cyst on my stomach. When the pain became excruciating I ended up in A&E at 2am having it lanced under local anaesthetic. This resulted in me having weeks off work (unpaid), a district nurse having to visit every day to dress the wound and I believe the incident triggered a relapse which has since left me unable to use my right hand to write with ever since. So all in all, I can't imagine a pill would cause such disruption and pain" (quote, 283, appendix C).

2. Pain and stress associated with injecting and/or receiving infusions

Most people stressed the pain of injecting and the bruising and scarring associated with this. The survey results support this finding, as 70 per cent of those who had taken DMDs had experienced skin reactions from injecting.

Respondents pointed to a relationship between the length of time spent injecting and a heightened sense of anxiety. As one respondent put it: "the stress and anxiety caused by injections has almost as much effect on my quality of life as the MS condition itself" (quote, 267), another described it as a "three-weekly dread" (quote 26, appendix C). Some respondents described how they had tried to deal with the anxiety of injecting, which they claimed had caused them to develop a 'needle phobia.' A couple of people had subsequently explored hypnotherapy.

A common theme amongst respondents was a perception that their MS symptoms exacerbated difficulties associated with injecting. One explained how "the injections are difficult with the numbness in my fingers and hands" (quote 311, appendix C). Similarly, another described the difficulty of injecting without a steady hand: "it [injecting] begins to control your life…it is against human nature to hurt yourself and even more trickier when trying to inject with a tremor" (quote 53, appendix C).

3. Side effects and experience of DMDs

The most common side effect of DMDs was a skin reaction (70 per cent) followed closely by experience of flu like symptoms (66 per cent) and headaches (56 per cent). The flu-like side effects of DMDs were described by many as a reason for discontinuing treatment with some people saying that they actually felt worse after the treatment. The side effects were described as ‘horrendous’ by some and a minority described liver problems or allergic reactions as a reason for stopping the treatment.

Seeking medical attention to help manage side effects associated with DMDs should be factored into NICE’s calculations. In our survey, three per cent of people with MS had visited A&E and a further 28 per cent had specifically booked an appointment with a healthcare professional (nurse, GP or neurologist) as a result of side effects of taking DMDs. The reported side effects associated with fingolimod are not as vast as those associated with DMDs therefore it is likely that, if it was made available, the burden to the NHS would be reduced and the quality of life of the patient improved.

Respondents described how injecting during a relapse made them feel worse about living with their MS: “I initially thought when I started injecting I would not have so many relapses but in reality, I still get them although I tell myself that I get less now. I hate injecting through a relapse because of the effort and the feeling of they are not working so why bother putting myself through the trauma. I have not missed an injection but it is more my wilful nature than what I want to do” (quote 73, appendix C).

The survey results indicate that a drug which has less severe side effects and that can demonstrate effectiveness at reducing relapses will make a dramatic difference to patient quality of life as well as potentially significantly reducing the burden to the NHS.

4. Emotional impact of injecting and/or receiving infusions

There was a growing sense amongst respondents that frequent injecting was ‘taking over their life’. A common theme was that injecting acted as a constant reminder of living with MS, making them feel depressed. One respondent, who had tried two MS disease modifying treatments, explained, “I now feel ruled by injections in a way that I do not feel by various oral tablets I take for my MS symptoms” (quote 314, appendix C).

5. Preference for a tablet over injections and infusions

With regard to how people with MS preferred their MS drugs to be administered 95 per cent favoured a pill taken daily, compared with three per cent who favoured a monthly infusion in hospital and two per cent who favoured a self administered injection given several times a week.

It seems that most respondents favoured the pill option because of its convenience in comparison to injecting. As one person put it: “It seems that a pill, like any other pill, would make life easier in terms of the practicalities of a medication and would be easier to take regularly without any trepidation and pain” (quote 158, appendix C). Another commented that, “the act of injecting three times per week was never pleasant but it had to be done. An oral version would have been welcomed” (quote 217, appendix C).

Overall, injection site reactions when coupled with the inconvenience, pain, anxiety and side effects of injecting with DMDs, all provide a powerful case for making a tablet available. Taking an oral pill rather than injecting will improve people’s quality of life in the short and long term, enabling people to feel more positive about living with their MS. It will also allow people living with the condition to take their medication in a more discreet and acceptable way to them and their carers.

Helping people with MS to remain in work

In our survey we found that, at some point, a relapse had prevented 82 per cent of people with MS from carrying out their work duties (paid employment) and that a further 89 per cent were unable to fulfil their usual roles and responsibilities during a relapse. Over half of the respondents reported that a relapse often or always has an impact on their ability to carry out their work duties.

The impact of relapses on people's ability to work can be significant as the responses to our survey illustrate. "Relapses make sustaining full time work so much more difficult as they make each day such an effort and I am exhausted, although I still manage to hold down a full time job". Another commented that she "had two relapses, one straight after the other. These relapses can be very debilitating and take away your independence. I work part time and when I have to have time off sick I feel I am letting people down. I am currently undertaking light duties as my mobility is not what it was. This greatly upsets me as I feel that due to MS, I am unable to do the job that I have enjoyed for many years" (quote 291, appendix C).

The difficulty of holding on to a job during a relapse was commented on by many of the respondents who either took annual leave to help cope during a relapse, or needed to take months off work to recover. The next two examples illustrate both of these scenarios:

"I was diagnosed in 2007 and have had three relapses since. I am a clerical assistant and when I have a relapse, I lose vision in my left eye (optic neuritis). I have pain in my arm, leg, back and chest. The first relapse caused me to be off work for 8 months. The second relapse caused me to be away from work for 4 months. The most recent relapse was – in the words of my doctor – nipped in the bud. The five day treatment of steroid infusion was a great benefit to me and I was only away from work for one week. I only work part time now as the fatigue forces this as when I am tired, I have more apparent cognitive issues at home and work. I also stumble on a daily basis as my balance is very poor" (quote 265, appendix C).

"I work full time for the NHS as an occupational therapist. To do this properly, I have to lose all aspects of life – I can't clean my home, go out and sometimes can't even make myself a cup of tea as I am so exhausted. I try to limit the impact at work by taking annual leave instead of sick leave if I feel I am losing energy which means I spend a lot annual leave in bed recovering from work" (quote 84, appendix C).

The survey findings support the argument that relapses make continuing in a permanent job a challenge for some people living with MS. For example, one commented "I am lucky that I have an understanding employer who has agreed for me to work from home part of the week when I am having problems (mobility wise). This I have found very useful from a fatigue point of view as well as allowing me to continue to work" (quote 388, appendix C).

Some people had a less than positive experience with their employers as a result of an accumulation of relapses: "I have had four bad relapses in the last 14 months causing me to have to take 6 months off work in total. I have now been made redundant and wonder if it was because of the disability?" (quote 161, appendix C).

It is evident that relapses can and do have a significant impact on people's ability to work. Unemployment among people with MS is higher than in the general population; a drug which could reduce the number of relapses enabling people to continue in a permanent job with fewer disruptions to their day to day life would not only improve people's productivity when at work, but would allow more people with MS to stay in work for longer. This would then cost the economy less in terms of the number of people becoming reliant on the welfare system and improve quality of life for people living with MS and their carers.

Impact on lifestyle and carers

The inconvenience and "paraphernalia" required to inject, especially when on holiday was remarked upon by many of the respondents. One person explained that "being able to take pills on flights would not be so intrusive as having to take injections and letters from the hospital to allow me to carry needles on the plane – one airport official asked what I felt was unnecessarily intrusive questions" (quote, 110) Another explained that, "it [injecting] does involve planning when going on holiday as a fridge is needed in hotter climates, airlines need to be notified and delivery company contacted" (quote 158, appendix C). Another related the impact to business travel: "work wise, business travel is more of a concern when I have to manage a three times a week injection schedule" (quote 42, appendix C).

Many people commented on the inconvenience of needing to attend hospital for intravenous steroids as a result of relapses. For example, one respondent wrote, " When I have a relapse, I have to go into hospital to have intravenous steroids for three days so if there was a pill available which would prevent that it would be a good thing" (quote 210, appendix C). Another person commented on the impact of steroids which they believed left them "bloated and fat" (quote 245, appendix C). Any treatment which can prevent relapses and subsequent hospital admissions, has to benefit the patient and the NHS.

Whilst 77 per cent of people considered DMDs to have significantly disrupted their daily life, 72 per cent of people agreed that administering an injection by themselves was difficult. The inconvenience of having to rely on others to inject as they couldn't inject themselves was highlighted in the responses as a problem. One respondent commented: "It has never got any easier to inject or to ask my husband to do it for me. Indeed it can cause friction between us because we both get anxious so a tablet would be just wonderful in that respect…life would become so much more normal again" (quote, 42, appendix C). One respondent remarked how taking a pill would be more discreet: "finding somewhere private to inject is not always easy. I can't inject in some parts of my body myself, so need to rely on someone else who isn't always around"(quote 294, appendix C).

People with MS told us that whether they were injecting or travelling to hospital for infusions, this was inconvenient and involved a lot of advanced planning, particularly for infusions. Of the 52 people who had taken Tysabri, the majority found infusions uncomfortable (71 per cent), inconvenient in terms of travelling to hospital (85 per cent) and, inconvenient from the perspective of needing to rely on others to get their infusions (76 per cent) - this could be transport or other support. Many spent a lot of time planning their life around their treatment; 31 per cent felt they always had to do this, and 26 per cent felt they often had to do this. In comparison, people spent marginally less time planning their life to fit around injecting; 19 per cent said they always had to do this, and a further 30 per cent said they often did this. These figures demonstrate that people with MS are spending a lot of time planning, which is both burdensome for the individual concerned and the carer. It is also disruptive; 77 per cent of those who were injecting and 79 per cent of those receiving infusions found treatment was a significant disruption to their daily life.

Respondents to the survey were split on whether they needed help with administering the drug. One explanation is that people mistakenly interpreted 'help' as meaning from a health care professional as opposed to a carer or friend and therefore the results for this question may be an underestimate. Either way, 48 per cent of people said that they always, often or occasionally require assistance with injecting.

It is clear that people with MS and their carers are fitting their lifestyles around a treatment regime. Injecting and going to hospital for infusions or steroids creates a further reliance on carers and/or healthcare professionals, whereas a treatment taken in tablet form may reduce the time a healthcare professional or carer needs to spend on helping to administer an MS drug. Fingolimod would therefore reduce the burden on the patient and the carer, but it is also likely to reduce management costs associated with delivering the drug.

What do patients and/or carers consider to be the advantages and disadvantages of the technology for the condition? (continued)

2. **Disadvantages**
Please list any problems with or concerns you have about the technology.
Disadvantages might include:

- aspects of the condition that the technology cannot help with or might make worse.
- difficulties in taking or using the technology
- side effects (please describe which side effects patients might be willing to accept or tolerate and which would be difficult to accept or tolerate)
- impact on others (for example family, friends, employers)
- financial impact on the patient and/or their family (for example cost of travel needed to access the technology, or the cost of paying a carer).

The MS Society is unaware of any difficulties in taking or using the technology. None were reported by our patient experts; they also reported no side effects (see appendix A).

The clinical trials show that some potentially serious side effects were incurred as a result of taking fingolimod at the stated doses. Trial investigators have said that people taking the lower dose of fingolimod were less likely to experience severe side effects.

Serious side effects included an increase in infections and some localised non-fatal skin cancers. Non-serious side effects included leaking blood vessels in the eye (called macular edema). There was also temporary and reversible lowering of the heart rate and blood pressure associated with the initial dose of fingolimod. Two fatalities resulted from viral infections during one of the trials (one from chicken pox virus and the other from herpes encephalitis). It is claimed by the trial organisers that in these cases the patient did not follow medical advice.

3. Are there differences in opinion between patients about the usefulness or otherwise of this technology? If so, please describe them.

The MS Society is unaware of differences in opinion between patients who have direct experience of the technology.

4. Are there any groups of patients who might benefit **more** from the technology than others? Are there any groups of patients who might benefit **less** from the technology than others?

The MS Society expects this technology to benefit people with relapsing remitting MS. We don't know of any subgroups of people with relapsing remitting MS who would benefit more or less from the technology.

Comparing the technology with alternative available treatments or technologies

NICE is interested in your views on how the technology compares with existing treatments for this condition in the UK.

The TRANSFORMS trial compared the effectiveness of fingolimod with that of beta-interferon-1a. Fingolimod was shown to be more effective at reducing relapses than beta-interferon-1a currently on the market. It is not possible to compare the effectiveness of fingolimod with other DMDs on the market.

Fingolimod is an oral therapy so side effects associated with injection of a drug are not experienced by people taking oral therapies. This also means that people who feel uncomfortable injecting a drug could potentially take fingolimod as an alternative.

Fingolimod also works in a different way to MS drugs that are currently being used to treat the condition. A specialised type of immune cell, called a T-cell, is thought to be responsible for much of the damage caused in relapsing remitting MS. Fingolimod acts by trapping these T-cells from the bloodstream into the lymph nodes. This prevents these T-cells from getting into the brain and causing damage to the protective myelin sheath, which causes the symptoms in MS.

(i) Please list any current standard practice (alternatives if any) used in the UK.

The MS Society is aware of the following current disease modifying drugs used to treat relapsing remitting MS as standard practice: Avonex, Rebif, Betaferon, Extavia, Copaxone and Tysabri.

(ii) If you think that the new technology has any **advantages** for patients over other current standard practice, please describe them. Advantages might include:

- improvement in the condition overall
- improvement in certain aspects of the condition
- ease of use (for example tablets rather than injection)
- where the technology has to be used (for example at home rather than in hospital)
- side effects (please describe nature and number of problems, frequency, duration, severity etc.)

The advantages of taking fingolimod over other licensed treatments for MS (Avonex, Rebif, Betaferon, Extavia, Copaxone and Tysabri) can be categorised as follows:

- Convenience The convenience of having an MS drug administered via tablet is favoured by the majority of people living with MS – a very small minority would prefer to have injections or infusions.

- Ease of use potentially resulting in good adherence On the trials, fingolimod was taken once a day. This makes it more likely that adherence will be higher as people with MS will only need to remember to take the pill every day.

- Potentially cheaper to administer People with MS can take the treatment at home with occasional monitoring.

- Improved lifestyle and quality of life People with MS would be more independent as they wouldn't need to rely on others to either help them to inject or to get to an infusion unit. They would also have fewer relapses and would therefore have fewer disruptions to their working life, enabling them to stay in employment for longer. A tablet would also be more discreet and would be less hassle when going on holiday or travelling for business.

- Less dependent on carer Some people with MS do not like injecting and therefore get their partners to do it; others are dependent on someone else to get them to the hospital for infusions. Taking a pill will free up the time and cost to the carer.

- Effective at reducing relapses On the trials, people with MS were between 53 and 60 per cent less likely to experience a relapse.

(iii) If you think that the new technology has any **disadvantages** for patients compared with current standard practice, please describe them. Disadvantages might include:

- worsening of the condition overall
- worsening of specific aspects of the condition
- difficulty in use (for example injection rather than tablets)
- where the technology has to be used (for example in hospital rather than at home)
- side effects (for example nature or number of problems, how often, for how long, how severe).

Research evidence on patient or carer views of the technology

If you are familiar with the evidence base for the technology, please comment on whether patients' experience of using the technology as part of their routine NHS care reflects that observed under clinical trial conditions.

The MS Society conducted semi structured interviews with two patient experts who had direct experience of taking fingolimod. The interviews have been transcribed and anonymised. A copy of the interview questions and a transcript of the interview can be read in full in appendix A and F).

<u>Background</u>

[redacted] was diagnosed with relapsing remitting MS in May 2007 and started on a trial for fingolimod four months later. Her experience of taking fingolimod on the trial has been very positive and can be summarised as follows:

[redacted] has been able to lead a very active life since starting to take fingolimod. She works as a journalist and television producer, which often involves travel abroad. She also has a 12 year old daughter and a puppy, which she has to take for a walk each day. [redacted] says that her husband and daughter don't have to do anything for her. This contrasts with [redacted] experience of being on Avonex (beta interferon 1a), also as part of the trial. Whilst on Avonex, [redacted] would experience flu-like symptoms after taking the injection and would be ‘useless’ for two days in every week.

[redacted] finds it quite difficult to compare her symptoms before and after taking fingolimod as she started taking the drug relatively soon after being diagnosed with MS. She describes some of her physical symptoms – dizziness, pins and needles, pain and fatigue – as ‘residual’ but states that they have all improved since taking fingolimod. [redacted] has had one relapse since being on fingolimod.

-[redacted] finds it easier to compare her experience of taking Avonex and taking fingolimod. She describes the weekly injection for Avonex as ‘horrible’. She doesn’t like needles and was reliant on a friend to actually administer the injection each week. The flu-like symptoms would start within three hours and [redacted] would then be debilitated for two days. Conversely, [redacted] describes being able to take a daily pill as ‘fabulous’ and hasn’t experienced any side effects from fingolimod.

- Overall, [redacted] is very positive about fingolimod and says she firmly believes it is keeping her MS at bay. She feels confident and uninhibited and ‘very lucky’ to have had the opportunity to take part in the trial.

[redacted] was diagnosed with relapsing-remitting MS in 1985. She has been on a fingolimod trial since July 2007. [redacted] used to experience relapses every few months but has not had one since taking fingolimod. Her experience of being on the trial is very positive and can be summarised as follows:

[redacted] used to have significant disability in her legs and was in a wheelchair for a long time prior to taking fingolimod. She now doesn’t use a wheelchair unless she absolutely has to and uses a stick for walking when outside the house. [redacted] says she feels ‘very well’ and thinks she is more active than before.

[redacted] describes herself as less dependent on her family since being on fingolimod. Her partner used to have to help her with taking the beta interferon injections and she was reliant on family members to push her in her wheelchair.

[redacted] finds taking a pill far more convenient than injections. Travelling abroad is now much easier and she no longer experiences the side effects of the injections, which included bad bruising and pain around the injection sites. [redacted] has not experienced any side-effects from fingolimod. No longer having relapses also means that [redacted] doesn’t have to go to hospital for intravenous steroids.

- Overall, [redacted] is very positive and says she feels ‘almost like a different person’ since she has been taking fingolimod. She feels fingolimod has the potential to improve the quality of life of many people with MS like her.

Are there any adverse effects that were not apparent in the clinical trials but have come to light since, during routine NHS care?

The MS Society is not aware of any adverse effects that were not apparent in the clinical trials.

Are you aware of any research carried out on patient or carer views of the condition or existing treatments that is relevant to an appraisal of this technology? If yes, please provide references to the relevant studies.

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MS Society (2010) *Perspectives of people with MS on relapses and disease modifying drugs.* MS Society, April 2010.

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Availability of this technology to patients in the NHS

What key differences, if any, would it make to patients and/or carers if this technology was made available on the NHS?

Making fingolimod available on the NHS would make the following key differences to people living with MS:

1. People with MS would experience fewer relapses. This would have the following impact on patients and/or carers:

- Enable people with MS to stay in employment for longer with fewer disruptions. People with MS could then contribute to the economy for longer, reducing the need for people to depend on the welfare system;

- People with MS would be less reliant on a carer and if they experienced fewer relapses, could be more independent. People with MS would stand a better chance of being able to do the things they want to do, rather than feeling physically limited by their condition;

- Lower the costs to the NHS and personal social services as more people with MS will experience fewer relapses. This would reduce the need to rely on these services as much whilst also limiting the number of emergency admissions and appointments to see healthcare professionals either because of injection site complications or due to the side effects of treatments;

- People with MS would be less anxious about experiencing another relapse. This would improve their mental and physical health more generally, giving people with MS the confidence to lead a full life and a better quality of life.

2. A tablet would give people with MS and their carers an improved quality of life. This would have the following impact on patients and/or carers:

- The ease of use of taking a tablet means that treatment can be taken in a discreet and convenient way that involves less planning for patients and carers. Taking a daily tablet would also help with compliance.

- People with MS would be less dependent on others to help administer their treatment. It would also free up the role of the carer who often either helps with injecting or ends up helping people with MS get to hospital for infusions for example.

- People with MS would not have to suffer complications associated with injecting such as site reactions potentially resulting in A&E visits and appointments with neurologists and/or nurses. This would also lower the costs to the NHS and social services.

- People with MS would have a choice; they wouldn't need to suffer the side effects of DMDs or the worry and anxiety over developing PML (in the case of Tysabri) if fingolimod was made available.

What implications would it have for patients and/or carers if the technology was **not** made available to patients on the NHS?

If fingolimod was not made available on the NHS, the following would happen:

1. People living with MS would experience more relapses. This would have the following impact on patients and/or carers:

- Fewer people with MS will be able to continue in full time employment. This means they would be less productive, and would need to start relying on the welfare system sooner;

- People with MS would be more reliant on a carer and therefore less independent. People with MS would not be able to do the things they wanted to do and would feel physically limited by their condition as their MS progressed faster;

- Increase the costs to the NHS and personal social services. The more people experience relapses, the more people with MS will increase their reliance on NHS and social care services.

- People with MS would be increasingly anxious and depressed about relapsing and the debilitating effects of relapses.

2. Without an alternative in the form of a tablet, people with MS will be limited in choice to existing treatments:

- Treatment options will continue to involve significant planning and disruption to every day life.

- Significant numbers of people with MS will continue to stay dependent on others to either help administer their treatment or get them to the place where they need treatment. This places added pressure on the role of the carer and increases NHS management and administrative costs.

- People with MS would continue to be at risk of complications associated with injecting such as injecting site reactions resulting in A&E visits and appointments with neurologists and/or nurses. This increased the costs to the NHS and social services.

It is vital that, with an increasing number of alternatives entering the market for the treatment of relapsing remitting MS, people with MS have access to the right drug for them at the right time and there should be a focus on the potential to maximise quality of life for the individual.

In the absence of an oral therapy, a proportion of people with MS will prefer to and choose to go untreated because of the lack of alternatives. Whilst most patients described this as a drastic measure (and one they would rather avoid), some of the quotes illustrate that patients would seriously consider discontinuing and going untreated:

“I hate the injection itself – it is painful. I don’t like the horrible bruising and marks all over me. Even if I thought the DMDs were doing me the world of good, I would still resent the injections and hate injecting myself and the side effects. Now that I am no longer convinced that the DMDs are doing anything of benefit, I am strongly tempted to stop altogether, but in the absence of any alternatives, this is a drastic step to take and one I am afraid to take” (quote 131, appendix C).

“I have often felt like giving up on injecting but continue as there is no alternative and I want to lessen my chance of relapses, but I would benefit so much from an oral drug. My quality of life and body would be greatly improved” (quote 314,appendix C).

Are there groups of patients that have difficulties using the technology?

The MS Society is not aware of any groups of patients that would have difficulties using the technology.

Other Issues

Please include here any other issues you would like the Appraisal Committee to consider when appraising this technology.

Appendix A: Transcripts of an interviews with a patient experts

Interview one

[redacted] is a patient expert with experience of taking fingolimod. She has been on a clinical trial for fingolimod since 2007.

[redacted] was interviewed on Thursday 28 October 2010 by [redacted], [redacted] at the MS Society.

A: When were you diagnosed with MS?

B: About 3 years ago – 2007, May 2007.

A: Was that with relapsing-remitting MS?

B: Yes. I was diagnosed in May and in September I went onto the fingolimod trial. In the first year of that – it was a double blind trial – in the first year you had a well known beta interferon, which was Avonex, or the pill and you had to take both. But only one of the ingredients was active and I happened to know that I was on the Avonex, which was the weekly injection into the thigh. And that was horrible and I know that I was on that, that that was active because I had flu-like symptoms for about three days after having the injection. Within three hours I would start to feel really bad. So, in answer to question two, yes I have, but it was part of the trial.

A: Part of the trial, ok.

B: And then I was doing the Avonex for a year and then I went onto the fingolimod. And the next year for the fingolimod trial they were just testing the efficacy at certain doses and my dosage was the low dosage, which is the one they're rolling out. So I have been taking fingolimod for two years, although I have been on the trial for three.

A: And so they gave you all this information while the trial was happening?

B: Yeah, they gave us the…each one was for a year…so now it's the third year and everyone is taking the low dosage of the fingolimod.

A: So what was your experience of actually taking fingolimod?

B: Fine, absolutely fine. It's so easy. It's a pill so there's no issue about injections and there are no side effects that I'm aware of.

A: And how often did you have to take the pill?

B: Every day. The thing about the effect on physical symptoms - fatigue, pain, disability et cetera – I still have relapses so it's not something…it hasn't…but then I don't know because I've always been on the trial really since I was diagnosed. I don't know if these are…in fact, actually, I think generally I feel better than I did before I was diagnosed.

A: Which symptoms specifically do you notice improvement with?

B: Dizziness, I get dizziness, pins and needles, pain, fatigue…

A: And they've all improved since…

B: Well, yes, they're residual. They haven't disappeared. I was rather hoping they would just disappear but it hasn't done that and sometimes, like at the moment, my bladder is really rubbish. So it hasn't prevented things happening. But I do think that it has probably…judging by some other people that I have seen…I am very lucky actually and I think maybe that part of my luck is that I am on this trial.

A: Ok.

B: So, does that make sense? I still get the symptoms but, as far as my mobility is concerned, I'm still active.

A: And can I just ask, specifically on the relapses side of things, how often have you been having those?

B: Well, last Christmas I had to go on steroids again. So that was sort of quite a big one. I was feeling quite rubbish then. It's difficult to know what's sort of a relapse and what is residual symptoms.

A: And in terms of affecting your day to day life, you said that you were able to be active still. So what sort of activities do you do? I know you work…could you maybe just talk a bit more about that?

B: Yeah, it's good. I can carry on with my work – I have to go and interview people – I write for a music magazine. And I make…I've started making promos and I'm trying to make a documentary about MS actually and about being on the trial and I've got a trailer for that. But I do feel…I mean some days are better than others…but I do feel that the fingolimod has had a very positive effect in my life. That is my feeling about it…and so I can carry on working and sometimes I get tired so my social life is slightly affected but that's not all the time. And I don't feel inhibited or anything. I mean, I have to go to Ethiopia to report on a music festival and make a film about it. And I'm making radio programmes and actually, although, Channel 4 have decided not to go ahead with moving into radio broadcasts but I was able to carry on and talk to people.

A: And, presumably, if you were travelling abroad, I would have thought that taking a pill is a lot easier?

B: Oh it's much easier actually and, as I say, I went to stay with a remote tribe in Ethiopia while I was still on the trial.

A: That's fantastic!

B: I can't say….I think that having this has enabled me. It has made me able to carry on doing things and not be scared about things.

A: Could I ask…I know you mentioned your daughter before…what is your family set-up at home?

B: Husband, daughter – my daughter is 12 now – she was nine when I was diagnosed. I have a stepson who is no longer living with us. But he was…he's older so he's gone out and started work after university. And we have a puppy.

A: So you're kept busy then?

B: It's brilliant, you know. I take her out for a walk every day.

A: And do you find yourself dependent on your family members more so than you think you would be if didn't have MS…or do you find that ok at the moment?

B: No, I find that fine. They don't have to do anything for me. I'm still the main cook, shopper…actually no, [redacted] does more of the shopping but actually that's not necessarily because…you know, the thing that makes it difficult is when I get very dizzy but I just stop then carry on.

A: And I think you said that you didn't experience any side effects from fingolimod?

B: No, not to my knowledge. I've had no side effects.

A: And presumably on the trial they have been monitoring that side of things?

B: Yeah, they have. And in every other respect I'm very healthy. I think in every other respect I would have to be very healthy otherwise I would not have been able to be on the trial.

A: So can I just ask in a bit more detail about the difference between taking a pill and having to take an injection? Did you actually have to attend the hospital to take the injections for Avonex?

B: No, I had to do it myself. But I hate needles and it wasn't like one of these little ones that you have if you've got diabetes or something. It was a big needle…it was probably two or three…it was a long needle and it had to go into your thigh muscle and I couldn't do it. I had to get my friend, [redacted], who's making the documentary with me…she did it for me every week.

A: Ok, so that was once a week.

B: Yeah, and I *hated* it so taking a pill is just, you know, fabulous.

A: And with the injections then, did you notice side effects straight away?

B: No, after three hours. Within three hours of taking the injection, it felt like I had the flu and it never got better. It was horrible.

A: Sorry, it felt like you had flu, did you say?

B: Yeah.

A: Ok, so that was presumably quite debilitating?

B: Yeah, two days…two days every week and I'd be completely useless.

A: Two days every week? Right. And, just to confirm, you haven't taken any other disease modifying treatments?

B: No.

A: Can I just go back to the question about the diagnosis? How did that come about? Did you have some symptoms that were then checked out?

B: Yeah, I was really dizzy. I felt really dizzy and quite disconnected. So people would be talking to me and I would hope that what I was replying to them was making sense in some way but I couldn't actually be certain. It was like…I wrote about it actually…did you see the link? Did I send you the link to my piece that I wrote in the Telegraph?

A: Yes, I have seen that.

B: Well, it's sort of like that really.

A: Yeah, I'll refer back to that actually because I think it would be useful as well if you're happy with that?

B: Yes, that's absolutely fine. Because, you know, it was like being in a goldfish bowl in a storm at sea, which is how I described it there. I don't want to keep repeating it…but that is what it felt like.

A: So you then went to your GP did you?

B: I went to my GP and he said, 'Oh don't worry about it, you've got some inner ear infection. Anyway, take these pills and come back.' Obviously they didn't work so he then sent me to an ENT guy who then, very luckily, sent me off to Dr M.

A: Ok, and he's your neurologist now is he?

B: Yeah, well he's my neurologist and Dr N is the one running the trial. But thankfully…because not every consultant, or neurologist, specialises in MS or even knows particularly much about it and it's so easily misdiagnosed. It's slightly easier now with MRI scans and stuff but it's, you know…there are so many people who have got it probably and didn't realise. And then there was nothing that could be done…it's just, 'oh', you know, 'come back in 30 years time when you need a wheelchair' or whatever it is. 30 years ago they were told just to come back when they needed a wheelchair. That's what the MS nurse said. Yeah, so I was very lucky to get Dr M who knew about it and knew about the fingolimod trial coming up. And he set me out a whole list of options. Because the Avonex, the beta-interferons, they don't work for everybody and they don't know why.

A: Was that all taking place at the same hospital then, the trial and..?

B: Well, no. Dr M referred me because my husband had health insurance initially so I went to see Dr M at his practice at _____. And then he referred me to the clinic at ______. And that's where the trial is taking place.

A: And do you have regular contact with an MS nurse at all?

B: Yes, there was C at the hospital. And T, who was part of the trial, who was absolutely brilliant. But they couldn't afford to keep her on, I don't think.

A: Right, so they're not there any more?

B: So, C is still at the MS clinic, the general clinic at _________. But the actual trial….

A: Oh, had a specific nurse dedicated…

B: …And she's not there anymore, which is sad, because she was absolutely brilliant. And that was great because, initially, I was quite scared, I didn't know what was going on, you know, so sometimes I'd feel really crap and I'd sort of phone up and say 'hello, what's happening to me?' And she was able to sort of put things in perspective because obviously it's something that you get used to.

A: Yes…

B: And you start realising, oh well this is probably residual or this may indicate…you know…

A: And I imagine being on a trial itself is…well there's an element of perhaps fear around that…the unknown. So it must have helped to have someone to talk things through with?

B: Yes, well you're signing all these disclaimers about sudden death and stuff (laughs)…

A: If we could perhaps move on to looking at the wider picture so not specifically related to you but to patients with MS more generally, who I understand that you've had quite a bit of contact with, what do you think the differences would be for those people if fingolimod was made available on the NHS?

B: Well, for those who are taking the beta-interferons, I think it would be absolutely amazing and it would transform their lives.

A: And do you think that's related both to the side effects and to the fact that it's a pill?

B: Yeah.

A: Conversely, so what do you think the implications would be if the technology was not actually approved by NICE? And not made available?

B: I think it would be just dreadful. I think it would be a dreadful shame actually and I think the quality of people's lives would be severely impaired. And if the country wants to keep people able to work and off sick benefits and all those kinds of things then I would suggest that they roll it out and put some more money into the NHS so they can afford it….quite frankly. And it would be cheaper in the long run because, you know, MS affects one in five people in the UK in some way, whether they've got it or whether they're carers. So, to me, having absolutely no recourse to anybody whatsoever, it would just make sense to, you know, make sure that people have the medication that can keep them active, or help to keep them active, and to keep them mobile and working and engaged in society and able to have a positive input into the economy and into their lives rather than, you know, having sickness benefits or…and unable to work…you know, it would make sense to give them something that would help them be fully paid-up members of society in every single way. I mean in terms of their mental and physical health then…what they could do.

A: Yep, absolutely agree.

B: I'm not being very articulate…

A: No, that's really really helpful. I think you've hit the nail on the head there really. And that will be a key point in our submission to NICE. Was there anything else you wanted to discuss or any other comments you wanted to add?

B: I don't know….For me, because I'd only really probably had MS for about a year…I don't know how long…six months, a year…although Dr M thought probably I had an MS episode perhaps six years ago which I'd sort of recovered from. But then…it was...or six years ago prior to my being diagnosed. And so, I spent from May to September…well I went on intravenous steroids actually. I forgot to tell you that. Initially - that was my initial treatment.

A: Sorry, intravenous steroids?

B: Steroids.

A: Right, that was at the very beginning?

B: Yeah, when I was diagnosed. And then I had liquid steroids…powder that I had to mix up, last Christmas. So that's been my other treatment, as opposed to the Avonex. But the steroids were horrible actually, I mean the way they have a very strange effect on you.

A: And so those are specifically when you're having a relapse?

B: Yeah.

A: And did you have to have those at hospital?

B: Well, the intravenous ones you do, yeah, but the ones last Christmas I had this powder that I had to mix with water or juice. They're very bitter.

A: And were there side effects to those?

B: Yeah, I think because what happens is you don't sleep, you wake up at very odd hours in the night and you're completely unable to sleep. And then you get enormously hungry.

A: And the frequency you have to take the steroids – has that changed?

B: Yeah, well you see I had them when I was initially diagnosed and then last Christmas. So that was about two years. So I didn't officially have a relapse for two years.

A: So you had the steroids initially when you were diagnosed and then there was a two year gap before you had to have the liquid steroids?

B: Yep.

A: Ok, and have you had any since then?

B: No.

A: Ok, that seems to be everything we've got on the list so unless there's anything else you wanted to add?

B: No, I just think this (fingolimod) should be made available.

END OF INTERVIEW

Interview two

[redacted] is a patient expert with experience of taking fingolimod. She has been on a clinical trial for fingolimod since July 2007.

[redacted] was interviewed on Friday 29 October 2010 by [redacted] at the MS Society.

I: Could you tell me when you were diagnosed with MS?

F: 1985.

I: And what type of MS do you have?

F: Relapsing remitting.

I: Have you been on any disease modifying treatments for MS before?

F: Yes, I was on beta-interferon.

I: And how long was that for?

F: About 18 months or a couple of years.

I: Was that quite soon after you were diagnosed?

F: No no, that was just before I started doing the fingolimod trial. I was on a trial for it at the _______…no….I was actually on the drug from the ______.

I: And how long have you now been taking fingolimod for?

F: Since July 2007.

I: Ok. And that's part of a trial?

F: I was on a trial but I'm now on the proper tablet now and I know that I was on the proper dosage when I was on the trial. So I've always been on the dosage that they're putting it out at now.

I: Is that a low dosage?

F: That's the low dosage, yes.

I: And have you been on any other disease modifying treatments as part of the trial?

F: No.

I: Ok. Could you just describe what your experience has been of actually taking fingolimod? In terms of how it has affected your MS?

F: I've not had a relapse since I've been taking it.

I: Ok.

F: And I feel very well. I seem to be a bit more active than I was before. I feel more confident because I feel it's good.

I: And so, just in terms of the relapses, how does that compare with when you were first diagnosed and the period without being on the drug?

F: I used to get relapses quite frequently.

I: Every few months or…?

F: Oh yeah, yeah.

I: And they have just stopped since being on the drug?

F: Well, touch wood, I've not had one since I've been on it. I've been on it quite a while now.

I: And could you just describe a bit more about the effect it has had on your physical symptoms? I know you mentioned relapses but could you just talk a bit more about the symptoms?

F: Well, I don't get a lot of symptoms. I still get fatigue sometimes, it depends what I've been doing, if I've pushed myself quite a lot and done a lot of walking or something like that I'll get tired. But I don't have any pain and I don't really think I've got much disability. I can't….actually I had a fall last Friday but my foot just turned over on me...but that's the only thing that's happened and that might be nothing to do with the MS at all. It might just be the way I put my foot down or something. And my general health has been good.

I: Ok, so just the same question again – how does that compare to before?

F: I feel much better now. I just feel almost like a different person since I've been taking it.

I: So did you have any pain and fatigue and any disability before taking the drug?

F: I used to have disability in my legs and I was in a wheelchair for a long time and now I'm walking. I use a stick but that's more to sort of stop people bumping into me to keep people away from me, if I'm going long distances. Around the house or anything I don't use the stick. And I don't use the wheelchair unless I absolutely have to. If I'm flying I'll use a wheelchair to get through the airport quicker.

I: So just in terms of more social and lifestyle aspects, how would you say fingolimod has affected your day-to-day life?

F: Well I don't have to think about it. I just take the drug and I just get on with my life. I go out and I meet people and do things.

I: And do you work full time?

F: No, I don't. I do voluntary work for the RSPB.

I: And so in terms of your family or support network set-up, does it have any impact on that or does that not really have an effect at all?

F: It doesn't really have an effect on them at all. It did before, because when I was having the beta-interferon, my partner used to have to help with injections sometimes. But now I can just get on with it and take the tablet in the morning and that's it.

I: Ok.

F: And they used to have to push me in the wheelchair and they don't have to do that any more.

I: And things like…you mentioned travelling, going to an airport. Do you find it's…it must be easier I imagine to just take a pill rather than worry about…

F: Yes it is, because when you were going to airports before, it was quite a palaver. You'd have to have a letter saying about you taking the injection stuff with you. And I don't have to do that now.

I: Great, ok. So I think you've summed up the main benefits of taking fingolimod. Was there anything else you wanted to add around that?

F: I don't think so. I think I'm very lucky that I was on this trial and I got on to it. It's just…I…from what I can tell and I know a couple of..somebody else who's on it at the _______ as well, and it seems to be working very well. I mean it's certainly much easier than an injection and….because you used to get bad bruises with the injections.

I: Right.

F: And it used to be quiet painful around the site.

I: And how often did you have to have the injections for beta-interferon?

F: Every other day.

I: And, just to confirm, the pill for fingolimod, is that once a day?

F: It's once a day. I take it in the morning at breakfast time.

I: And so, did you have other side effects? Sorry, firstly, did you have any side effects from taking fingolimod?

F: No, none at all.

I: And did you have any other side effects from taking beta-interferon apart from the bruising?

F: No, well, I had a relapse, a couple of relapses while I was on it. And apparently my body started rejecting the drug, it wasn't working any more.

I: Ok, and did you have to...did you always take beta-interferon at home or did you ever have to go into hospital?

F: No, I had it at home. I have had intravenous steroids when I had my relapses. And that was done as a day patient in hospital.

I: And how did you find that?

F: That was fine. You just sit there for an hour while it goes through.

I: And were there any side effects to that at all?

F: No, none.

I: Ok, so how would you say…I know that you've only been on beta-interferon…but how would you say that the treatment compares with other disease modifying treatments, if you had to sum it up?

F: Well, it's very easy to take it and you know it's much more convenient and it's sort of non-invasive. You know, you're just taking a pill. You're not stabbing yourself with a needle and…Yeah, much more convenient.

I: So what would you say if you were thinking about perhaps not just your own situation but other people with MS - what do you think the key differences would be for patients and carers if fingolimod was actually made available on the NHS?

F: Well, I think it would give people a better quality of life. I think they'd have hopefully…from my experience…they'd have less relapses so they wouldn't have to have any steroids and it would be cheaper I suppose in the long-run for the NHS and less worrying for people if they could feel confident in taking a pill and that they weren't going to have relapses so frequently.

I: And what do you think, conversely then, what would be the implications of not making the technology available?

F: Well I suppose people would know about it and they'd want to have it wouldn't they so they'd have to try and get it from other sources or from other things like cannabis and things like that to alleviate the symptoms. And I guess there would be more hospitalisation and, as I said before, a higher cost in the long run to the health service I would imagine.

I: So have you been told what happens once the trial finishes?

F: No. Hopefully I can stay on it because I am on it already. I am really hoping that NICE push it through.

I: And, in terms of the timescale for the trial then, do you know when that finishes?

F: It's in the third phase I think at the moment, I'm not sure.

I: Do you know the name of the trial you're on?

F: It's just called FTY720 and it's at the ______ Hospital.

I: That's ________ isn't it?

F: It is, yes.

I: And did you have any other comments you wanted to add at all?

F: I don't think I do actually. I sort of got it sorted out in my own head as to how I feel about it and I think it's a great thing and I just think, I know it's terribly expensive, but I think it…there's nothing they can do to sort of cure it completely but it really would help and I think it should be available to people.

I: Yes, fantastic. Well that's all very positive. Thank you.

END OF INTERVIEW.

Appendix B: A report on the perspectives of people with MS on relapses and disease modifying drugs

Multiple Sclerosis Society

Perspectives of people with MS on relapses and disease modifying drugs

MS Society

April 2010

Contents

Authors: [redacted]

Executive summary

This report documents the methods and results of a 2010 MS Society survey of people with multiple sclerosis (MS) who have or have had relapsing-remitting MS. The purpose of the survey was to capture the experiences and feelings of people with MS in relation to relapses and disease modifying drugs (DMDs). The survey had three main sections with the first asking about experiences of relapses in general, second asking about experiences of DMDs that can be self-administered by weekly injections and the third section asking about experiences of Tysabri, a disease modifying drug that is administered monthly as an infusion in a clinic. In addition to multiple choice questions, the survey contained some free comment sections.

Relapses have repercussions that go beyond the physical symptoms – they hinder people's ability to work and carry out their day-to-day responsibilities, limit their independence and increase reliance on other people. Respondents were also worried about how a relapse would impact on those around them. Finally, relapses not only have a serious impact on the practical organisation of one's life but also on an emotional level with feelings of frustration and anxiety being common.

Issues related to difficulty of use were raised with both treatments. With injected DMDs the main concerns related to the injections themselves. People found injecting to be difficult and often had to rely on other people to help them with this. Injection site reactions were not only common but often very painful too. Other side-effects also appeared common and debilitating. The frequency of the injections means that life has to be planned around the treatment to avoid socially awkward situations and to ensure injecting can be done in privacy. Overall, the treatment impacted the person injecting, those close to them, and often the person's ability to carry out their responsibilities at work and elsewhere.

Issues related to Tysabri had a slightly different emphasis. Whilst the infusion itself appeared to be tolerated better than injections, travelling to get the treatment posed problems and the person receiving the treatment was consequently more dependent on other people. The more serious side-effects, namely the viral brain infection progressive multifocal leucoencephalopathy (PML) associated with Tysabri, caused this group of respondents to be more worried about side-effects.

The final question in the survey asked for respondents' preference for administering a disease modifying drug if three options were available: an infusion administered monthly in a hospital via a drip, self-administered injection given several times a week and a pill taken daily. The overwhelming majority (95 per cent) chose the pill option, giving ease of use, convenience to everyday life and non-invasiveness as reasons for selecting this option.

The responses illustrate the practical impact relapses and using disease modifying drugs can have on a person's everyday life, giving a clear idea what

respondents would like to see improved. Both forms of treatment have strengths and weaknesses, and by identifying these strengths and weaknesses the report will draw a picture of what people with MS would want from a treatment.

The responses indicate that there was a preference for a therapy that would allow people to be in charge of their own treatment and would enable them to be independent in this sense. The treatment would easily fit in a person’s everyday life and normal activities and would not have debilitating side-effects. The treatment would enable the person to carry on with their normal life, to stay in paid employment and be able to care for their family and rather than being cared for.

1. Introduction

This report documents the methods and results of a 2010 MS Society survey of people with MS who have or have had relapsing-remitting MS. The purpose of the survey was to capture the experiences of people with MS in relation to relapses and disease modifying drugs (DMDs). Although information is available about relapses in general as well as the side-effects of disease modifying drugs, it was felt important to try and gain an understanding of what people themselves thought were the problems they have to face, what they go through during a relapse and what their own experiences of taking the DMD was. The survey was designed by the MS Society Research and Policy teams.

This chapter will give some background information about MS, what treatments are available and which treatments are expected to become available in the future. After this there is a brief section describing how the survey was carried out. The rest of the report will discuss the results of the survey.

1.1. What is multiple sclerosis?

MS is the most common disabling neurological condition affecting young adults. There are around 100,000 people in the UK living with MS. MS is the result of the body’s own immune system attacking and damaging myelin - a protective substance surrounding nerve fibres of the central nervous system. When myelin is damaged, messages between the brain and other parts of the body are distorted or lost. Over time, in addition to myelin damage, the nerve fibres themselves also become damaged leading to an irreversible accumulation of disability.

The causes of MS are unknown, though it is widely believed to be caused by a combination of genetic and environmental factors. Several genes have been associated with increasing the risk of developing MS and it is estimated that there could be as many as 50-100 genes linked to the condition. There is also some evidence linking a number of environmental factors to MS such as viral infections and vitamin D deficiency but the relative impact of these on causing the condition is yet to be determined.

There are four main recognised types of MS:

- Relapsing-remitting MS (RRMS):	Characterised as periods of relapse (acute MS ‘attacks’) followed by periods of remission (complete or partial recovery). Around 85 per cent of people are diagnosed with RRMS.
- Secondary progressive MS (SPMS):	Following an initial period of RRMS, many people develop SPMS which is characterised as a gradual accumulation of disability, either with or without relapses.

- Primary progressive MS (PPMS): Characterised as a gradual accumulation of disability from diagnosis with no distinct periods of relapse and remission. Between 5 and 15 per cent of people are diagnosed with PPMS.
- Benign MS: Is diagnosed if the condition has not got worse over a 10 to 20 year period and is associated with little or no disability.

There are many symptoms associated with MS, which include restricted mobility, chronic fatigue, bladder and bowel problems and cognitive impairment. MS is unpredictable and affects people in very different ways, with variability in severity, in rates of progression and in type and severity of symptoms. This unpredictability results in a major impact on the quality of life of people with MS and can often lead to periods of significant disability.

What are relapses?

Immune damage to the myelin sheath is believed to cause relapses, or MS ‘attacks’. Clinicians define a relapse as an episode of neurological symptoms, lasting for at least 24 hours, that happens at least 30 days after any previous episode began. In relapses, symptoms usually come on over a short period of time and often remain for a number of weeks, but sometimes months. Relapses can vary from mild to severe. At their worst, acute relapses may need hospital treatment, but many relapses are managed at home, with the support of a GP, MS specialist nurse, and other care professionals.

Due to the varied and unpredictable nature of the condition determining an ‘average’ relapse rate for RRMS is not straight forward and is an issue that has caused much debate amongst the clinical community. Although a true consensus is yet to be reached, the many thousands of people currently on disease modifying drugs (DMDs) indicates that it is likely that a significant proportion of people with RRMS experience 1 or more relapses per year

Current treatments

There are four classes of DMDs licensed for RRMS and none licensed for PPMS or SPMS. The DMDs licensed for RRMS include beta interferon 1a, beta interferon 1b, glatiramer acetate and natalizumab.

The beta interferons and glatiramer acetate are delivered by self-injection (under the skin or into the muscle) at frequencies ranging from once daily to once weekly. These are usually prescribed to people that have experienced two or more relapses over a two year period. The precise way these DMDs work is unclear but they appear to modulate the immune system in a way that reduces the damage caused to myelin. It has been shown that these DMDs reduce relapse rates on average by 33 per cent; there is limited evidence on their long term effect on disability progression. There are a number of side effects associated with these DMDs that have a significant impact on quality of life, including injection site reactions and flu-like symptoms.

Natalizumab is a monoclonal antibody treatment delivered by monthly infusion in a hospital clinic. It is prescribed for highly active RRMS where either the relapse rate or severity of relapses is considered high. Natalizumab works by preventing the immune system cells, that cause the damage associated with MS, from entering the central nervous system thereby preventing the damage to myelin. It has been shown that natalizumab can reduce relapse rates by around 67 per cent and can reduce the risk of disability progression by around 40 per cent. There are a number of side effects associated with natalizumab the most serious being a one in a 1000 risk of developing PML, a viral infection of the brain which can often lead to death.

73 per cent of the respondents to this survey had taken one or more of these drugs. As will be shown later in the report, this group of people have a wealth of first-hand experience of the benefits but also the down-sides of these treatments.

Treatments on the horizon

There is a huge need for better treatments for MS. There is no cure for the condition and no DMDs for non-relapsing progressive forms of MS. Although there are available treatments for RRMS their effectiveness is varied and the side effects can be significant.

There are a number of new potential treatments on the horizon that, from clinical trial data, look to be at least as good as if not potentially better than existing treatments. The first wave of potential new treatments for RRMS include the oral therapies, cladribine and fingolimod, that act on the immune system. Clinical trial data suggests that these reduce relapse rates by around 50 per cent. As with all DMDs these do have side effects, but they are available as a pill thereby eliminating the need to self-inject and therefore eliminating injection site reactions – a common side-effect of injecting.

The second wave of potential new treatments for RRMS may include more powerful monoclonal antibodies that suppress the immune system. These include alemtuzumab which, although associated with a number of side effects, appears to reduce relapse rates significantly and reduce disability progression by around 70 per cent, even reversing disability in some cases.

The next wave is difficult to predict but it is likely to include potential new treatments that will look to promote the repair of myelin or protect nerve fibres from damage rather than having an effect on the immune system. A combination of this type of treatment with a treatment that acts on the immune system may help in significantly reducing the effects of MS in the long term; however, this is the vision of future MS treatment which is not likely to become a reality for many years.

This report concentrates on the treatments that are currently available, betainterferons, glatiramer acetate and natalizumab.

1.2. How was the survey carried out?

Administration of the survey

The questionnaire was available online (at surveymonkey.com) from 26th March until 14th April 2010 and was advertised on the MS Society website and intranet. Information and a link to the questionnaire were also emailed to all MS Society area teams and to the directors of MS Society Northern Ireland, Wales and Scotland who all distributed the information as they saw fit. Information and a link to the questionnaire were also posted in MS Society's Facebook page (with 5000 fans) and sent to 3000 Twitter followers, and included in the Campaigns eNewsletter and MS Society eNewsletter.

Inclusion and exclusion criteria

The total number of respondents was 1129. However, only those who had or had previously had relapsing-remitting MS or who had benign MS were included in the study, whereas those who did not have MS or had primary progressive MS were excluded from the survey. One of the options in the screening question was "I have MS but do not know which type", these responses were also included. Finally, surveys that were only partially filled in were also excluded. The total number of responses included in the analysis was therefore 1007.

The average/typical respondent was female (73 per cent of all respondents), was aged between 31-50 (67 per cent), and had RRMS (80 per cent). They had experience of taking at least one of the disease modifying drugs (73 per cent). For distribution of type of MS and age of the respondents, please see figures 1 and 2 below.

Figure 1

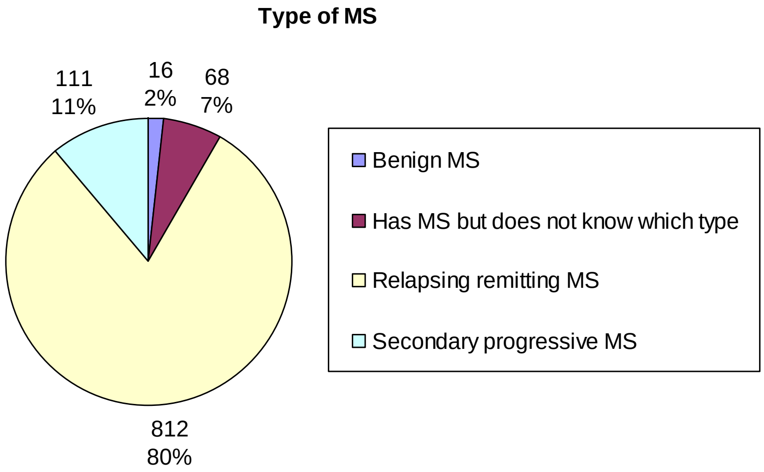
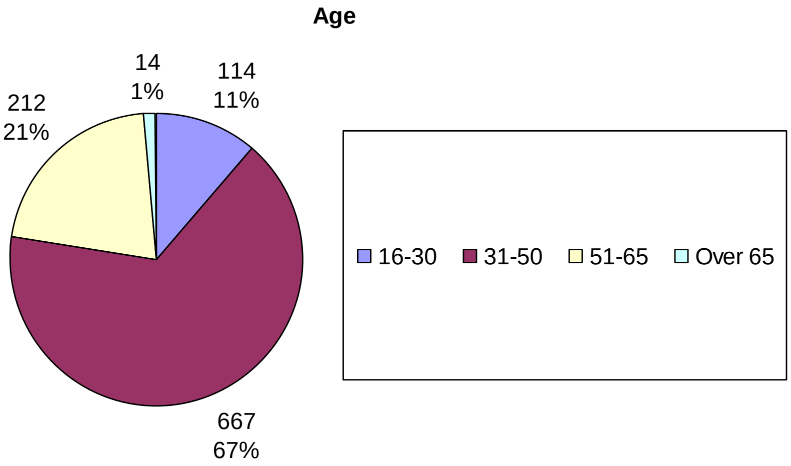


Figure 2



Analysis

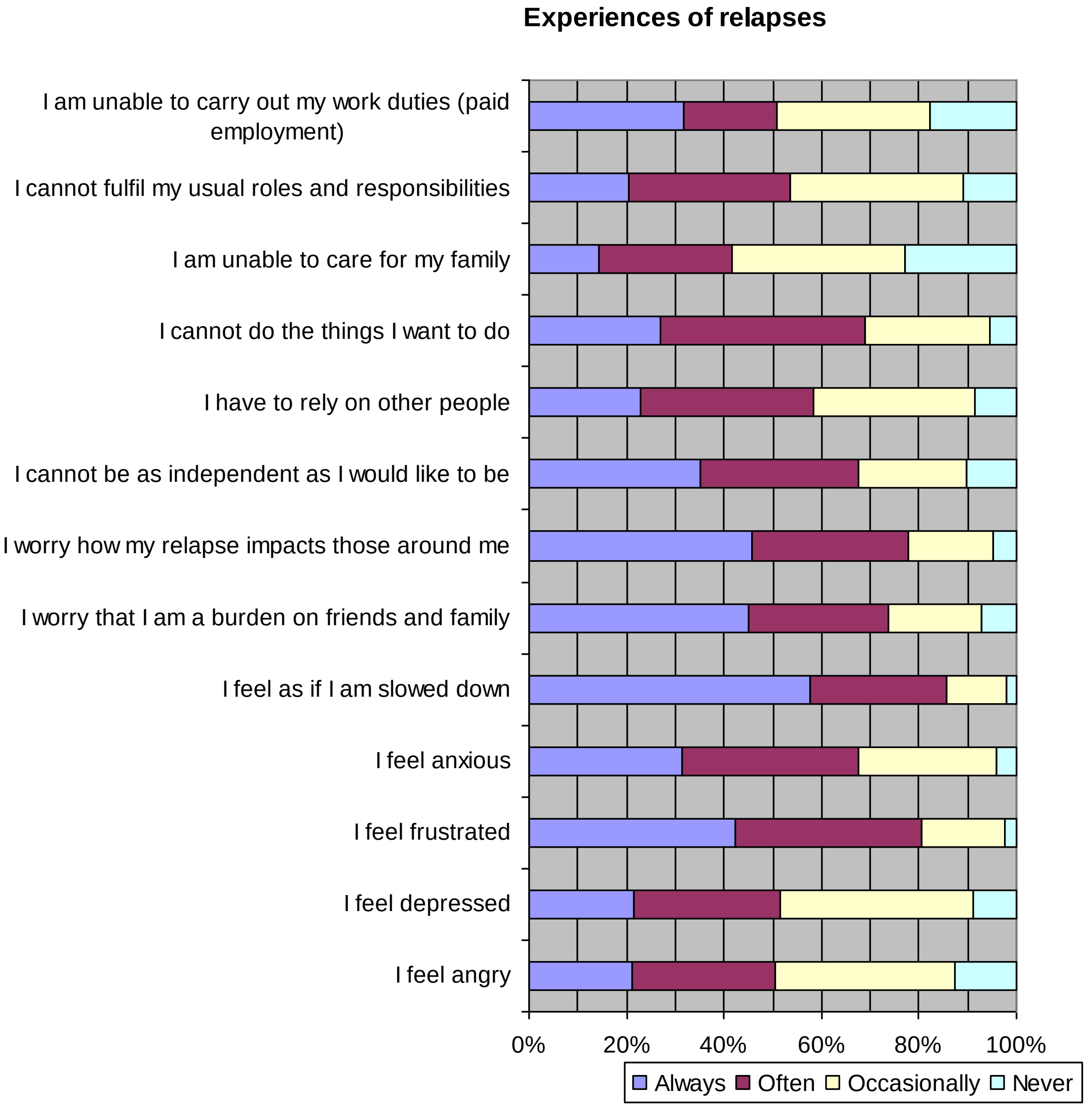
Descriptive statistics were used to analyse the results of the survey. Due to rounding, the percentages for each questions do not always add up to 100 per cent. Quotes from the free comment sections were extracted to illustrate the results of the survey, but no systematic analysis was conducted on the free text answers.

2. Experiences of relapses

All those who qualified to take part in the survey were asked about their experiences in relation to relapses. The total number of respondents for this section was 1007.

The respondents were first presented with statements related to relapses and asked to rate them according to how closely the statements reflected their own experiences. The response options were 'always', 'often', 'occasionally' and 'never'. The statements ranged from ones dealing with the practical impact of relapses on the respondents' everyday life to ones scoping emotional impact of relapses. The statements and the distribution of responses to them are presented in the table below (figure 3).

Figure 3



Work and other responsibilities
On being asked whether a relapse prevents the respondent from carrying out their work duties (particularly in reference to paid employment), the most frequent response (32 per cent) was 'always' (Figure 3). If response categories 'always' and 'often' are combined, over half of the respondents (51 per cent) reported that a relapse has an impact on their ability to carry out their work duties.

The impact of relapses on work was also reflected in the answers given in the free comment section:

> *"Relapses make sustaining full-time work so much more difficult as they make each day such an effort and I am exhausted, although I still manage to hold down a responsible job."*
>
> *"I had two relapses last year one straight after the other. These relapses can be very debilitating and take away your independence. I work part-time and when I have to have time off sick I feel I am letting people down. I am currently undertaking light duties as my mobility is not what it was. This upsets me greatly as I feel that due to MS I am unable to do the job I have enjoyed for many years."*

The difficulties of holding on to one's job were also visible in the responses. Adjustments are sometimes needed to enable someone with MS to stay working. This was clearly something where some respondents were more fortunate than others:

> *"I am lucky that I have an understanding employer who has agreed for me to work from home part of the week and when I am having problems (mobility wise). This I have found very useful, helping me from a fatigue point of view as well as allowing me to continue to work."*
>
> *"I try to limit the impact at work by taking annual leave instead of sick leave if I feel I am losing energy which means I spend a lot of annual leave in bed recovering from work."*
>
> *"I have had 4 bad relapses in the last 14 months causing me to have to take 6 months off work in total. I have now been made redundant and wonder if it was because of the disability?"*

18 per cent of respondents indicated they were never unable to carry out their work duties due to a relapse. It is worth noting that unemployment among

people with MS is higher than in the general population, and this might go some way to explain the number of responses in category ‘never’.

Finally, being unable to carry out one’s responsibilities is not just restricted to employment. When asked about fulfilling one’s roles and responsibilities in general, over a half of the respondents (53 per cent) thought they were ‘often’ or ‘always’ unable to fulfil their usual roles and responsibilities because of a relapse.

Independence

Some of the statements scoped respondents’ perceptions of independence in relation to a relapse. Overall, the great majority (some 91 per cent) felt that they have to rely on other people at least occasionally, with nearly 60 per cent reporting they had to rely on other people either always (23 per cent) or often (35 per cent).

> *“I have had awful relapses, where I have been unable to do anything for myself for months, until relapse passes, leaving you weak, feeling dreadful and depressed.”*
>
> *“If there was a high risk treatment which could potentially cure my MS I would seize the opportunity with both hands as I want to be normal again and not have to endure debilitating relapses several times a year, which set me back so far and mean I have rely on others to help me, when I just want to be able to do the things that everyone else takes for granted.”*
>
> *“I have persevered with the inconvenience of injections because the relapses would be worse. The injections require a bit of planning and some symptoms on the day of injection, but I feel this is worth suffering to minimise the likelihood of another relapse, and the inevitable worry and complete dependence on family to care for me that would result.”*

When presented with the statement “I cannot be as independent as I would like to be”, 35 per cent of respondents felt that this reflected their experience always, with a total of 89 per cent of respondents feeling that this reflected their experience at least occasionally.

> *“I found relapses very frightening and upsetting, having to take time off work, deal with new symptoms, losing control of my life and independence and the uncertainty of not knowing what residual damage would be left when the relapse ended.”*

Worry about other people

There were two statements scoping whether respondents were worried how their situation impacts those around them. It was very clear that this was a concern to many, with 46 per cent indicating they were always worried about how their relapse impacts on others and 45 per cent saying that they always worrying that they are a burden to their friends and family.

A relapse does not only affect the person with MS but also those around them.
Particularly with a reduction in independence, families are often closely involved with care but the relationship can become strained under concerns for a loved one, the carers own needs and the unknown:

> *"Relapses change your life completely - not the same person at all any more. DMD are difficult to handle at time because of the bad side effects (not each week but for me I would say 3/5 weeks are a problem to me and I have had to live my life around this which is sometimes difficult, not only for me but my family too."*
>
> *"Relapses are not only worrying, painful & distressing at the time but can take a considerable amount of time to recover from, I have been left with residual problems from every relapse. I then worry about the impact on my husband and that he has to take time off work to help me. The concern that he will not cope if I become severely affected by another relapse is a genuine worry as he gets extremely frustrated with the whole MS scenario. As a very independent person this adds it's own issues to my state of mind, as well as the fact that I cannot be there as readily for my children and colleagues."*
>
> *"I am fortunate that I haven't had to take drugs as yet but I do know that relapses make me feel awful and debilitated and it is very hard to explain to you family why you feel like you do."*
>
> *"It has never got any easier to inject myself or any easier to ask my husband to do it for me. Indeed it can cause friction between us because we both get anxious."*

Emotional well-being

Finally, there were several statements relating to general feelings during a relapse. The feeling of being slowed down was certainly one that respondents recognised, with a majority of 58 per cent claiming this to reflected their experience always. The feeling of frustration also seemed to closely reflect the respondents' experience of a relapse, with 42 per cent saying this was the case always and a further 38 per cent saying this was the case often. Finally, feeling anxious reflected nearly 67 per cent of respondents experiences either always or often. The feelings (anxiety, frustration, depression) can stem from a number of things:

> *"I feel frustrated as I am very independent and I am very scared losing functionality."*
>
> *"Due to the change in feeling in my legs I no longer felt safe to work in my original job role when diagnosed therefore left for an office job. This lead to an episode of anxiety and mild depression which still bothers me from time to time."*

> *“I felt extremely nervous and frightened when first told I would need to take the drugs - I became depressed at this time as the enormity of my diagnosis hit home, that this was it for life until the drugs stopped working.”*
>
> *“I suffered Post-natal depression which stemmed from my absolute fear of having a relapse and not being able to look after my child. This was coupled with anxiety attacks caused by fear of not getting enough sleep, becoming run down and then having a relapse. This desperately impacted my first 8 weeks after birth, which I'll never get back.”*

Relapses have repercussions that go beyond the physical symptoms – they hinder people’s ability to work and carry out their day-to-day responsibilities, limit their independence and increase reliance on other people. Respondents were also worried about how a relapse would impact those around them as friends and family are also affected by the uncertainty of the condition. Finally, relapses not only have a serious impact on the practical organisation of one’s life but also on a person’s emotional well-being.

3. Experiences of disease modifying drugs

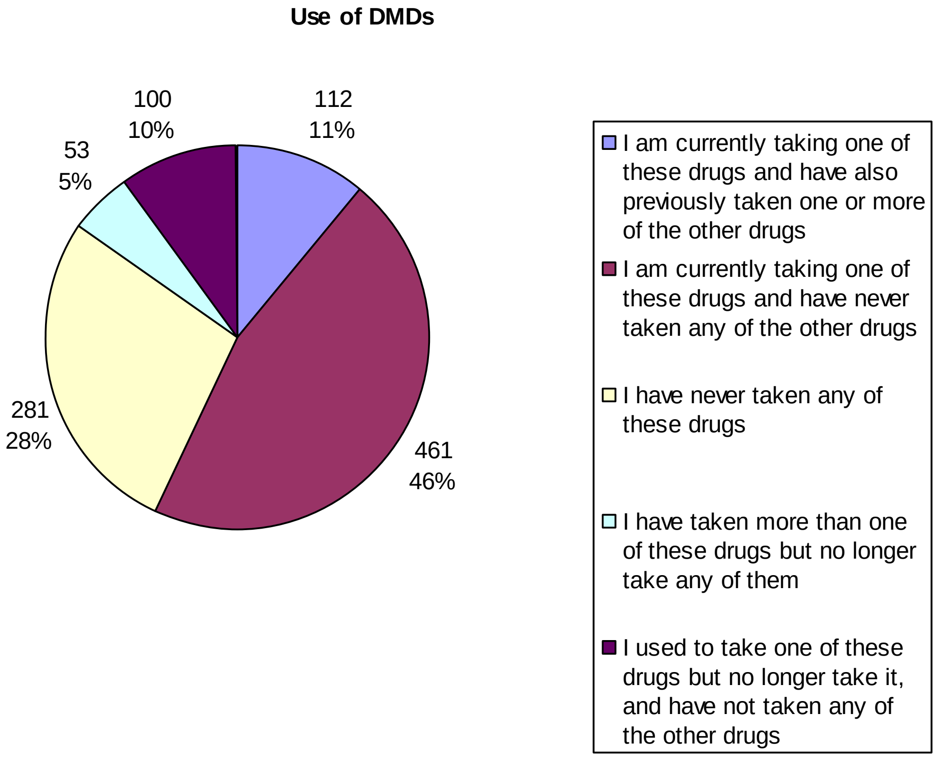
The survey also sought to find out about experiences specifically related to injecting disease modifying drugs (Avonex, Rebif, Betaferon, Extavia or Copaxone) or taking Tysabri. People who had experience of using at least one of these drugs at some point were invited to answer these sections, whereas those who had not used either at any time were excluded from this stage.

Overall, 73 per cent (N=736) of the respondents had taken at least one of these disease modifying drugs at some point in time.

3.1. Injecting disease modifying drugs

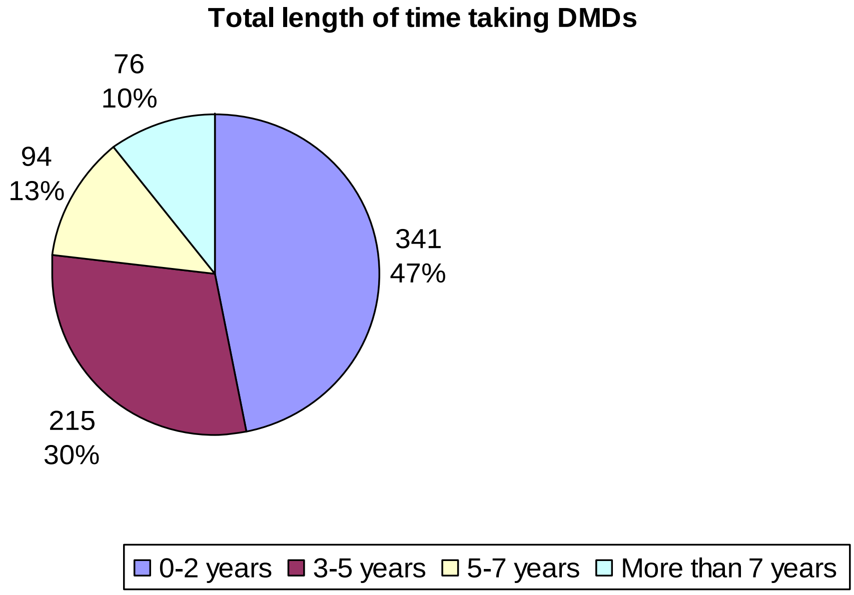
72 per cent of the respondents had taken at least one of the injected DMDs at some point in time. Of those who responded to this section, 57 per cent were currently taking one of these DMDs. 15 per cent of the respondents had tried at least one of these drugs but were no longer taking any. 26 per cent had discontinued taking one of these drugs earlier on (figure 4). Reasons for discontinuing drugs are discussed further below.

Figure 4



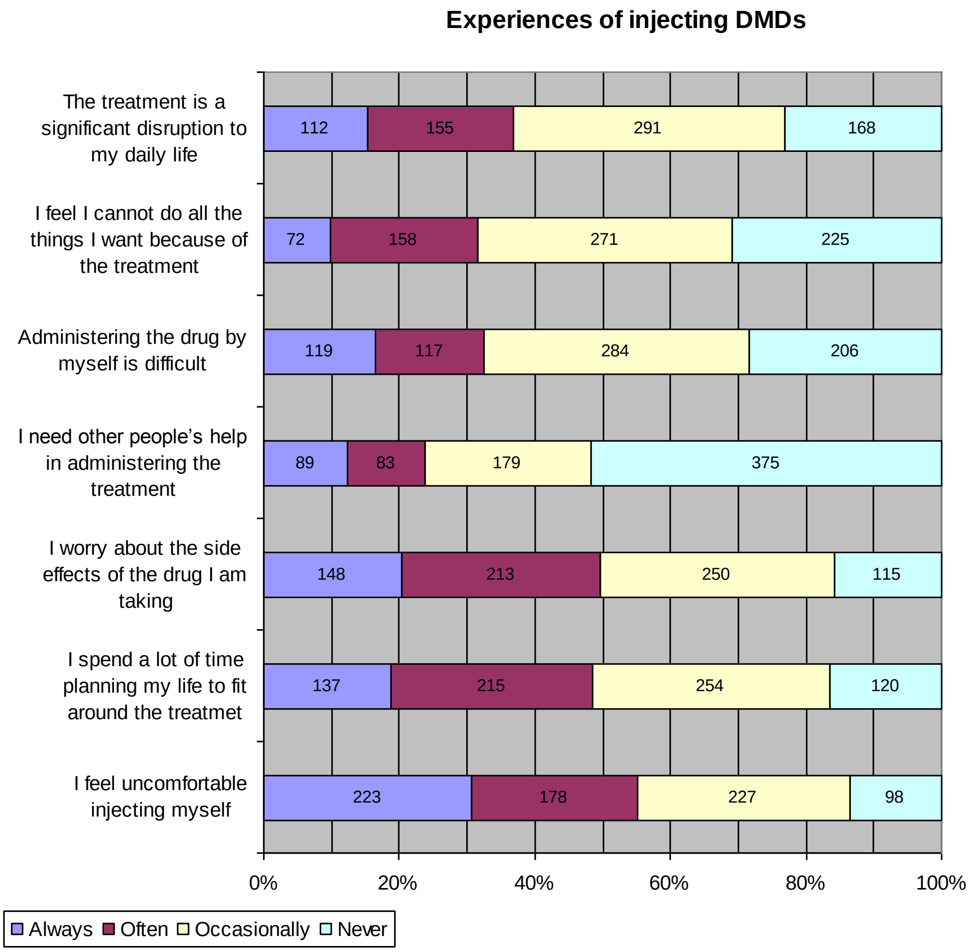
For a breakdown of the length of treatment on injected DMDs, please see figure 5.

Figure 5



Respondents were presented with statements about practicalities and experiences of injecting DMDs, and asked to rate them on a scale of Always-Never, according to how the statements reflected the respondents' experiences. Please see figure 6 below for the statements and the distribution of responses.

Figure 6



Experiences of injecting DMDs

Independence

Over half of the respondents reported that they never needed other people's help in administering (mixing etc.) the drug and in a separate statement, 28 per cent found self-administration never to be difficult. Although it should not go unnoticed that there were also a significant proportion of respondents who found these areas problematic at least at times, it appears that self-administering the drug allows for more independence. This was certainly the view of some of the respondents:

> *"I would not want to go to hospital monthly for a drip – you spend enough time there or with other medical professionals. It isn't just the the time it takes for the drip, it's the recovery time too and having someone to go with you."*
>
> *"I feel very lucky to have the ease of use with the Rebismart and not having to be the 'patient', I can do all of my injections myself. However, my arms and legs are dotted with skin reactions, when I wear a swimming costume on holiday, I feel I need to cover up all the time. I would welcome an oral drug, so long as the side effects were similar, so that I could lead a more normal life."*

Independence enabled by self-injecting becomes even more apparent when compared with Tysabri which cannot be self-administered, and this will be discussed later in the report.

While injected DMDs may be easy to administer without other people's help, nearly 50 per cent of respondents thought they spent a lot of time planning around the treatment either always or often (figure 6). The need for planning is well illustrated by the comments describing everyday situations that are familiar to everyone, but that become problematic when you have to fit in everything that goes with the treatment:

> *"Needing to give myself an injection after a long day (e.g. after a party, night out, long journey) can be difficult. Carrying all the paraphernalia - cool box, injector, sharps box, et al - when going away can be a nuisance, frankly. Finding somewhere private to inject isn't always easy. I can't inject in some parts of my body myself, so need to rely on someone else (who isn't always around)."*
>
> *"It does involve planning when going on holiday as a fridge is needed in hotter climates, airlines need to be notified and delivery company contacted."*
>
> *"There is also the hassle of keeping the drug in the fridge (away from the children). There is all the paraphernalia with the equipment needed. Sharps box, auto injector. Having to think about taking it all on holiday. Will there be a fridge to keep the Rebif in? A place to store it at home. Being in when the delivery van comes every month."*

Although self-administered DMDs appeared to allow for more independence, they also have their problems, and need some planning to be compatible with an active life.

Injections

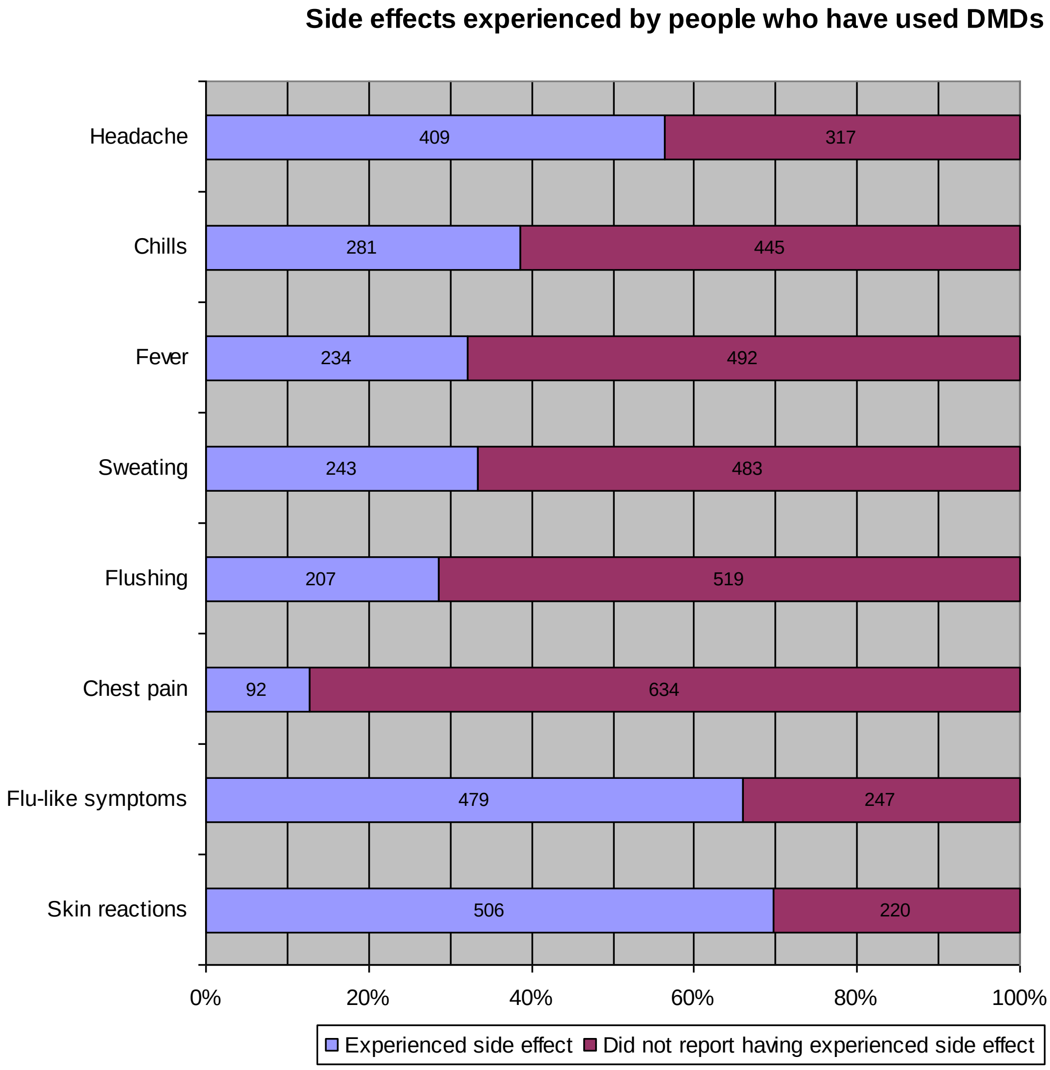
A little over 31 per cent of respondents felt always uncomfortable about injecting oneself. Overall, nearly 90 per cent of the respondents reported feeling uncomfortable injecting at least occasionally. The self-injection, which many respondents found difficult, featured often in the comments:

> *"It is a frightening thing being told that DMDs are only available via an injection and that you have to do it. To begin with, it controls your life as it is against human nature to hurt yourself and even trickier when trying to inject with a tremor."*
>
> *"Injecting daily is both painful and inconvenient. It is something that daily I dread."*
>
> *"It's not pleasant experiencing the flu-like symptoms, but I think this would be far easier to cope with if you didn't have to inject as well."*

Side-effects

In addition to the difficulty of injection itself, injection sites can develop painful skin reactions and this was the most commonly experienced side effect, as reported by 70 per cent of respondents (see figure 7). Other commonly experienced symptoms were flu-like symptoms (66 per cent) and headache (56 per cent). Overall, 64 per cent of the respondents had sought some form of medical advice because of the side-effects (figure 8).

Figure 7



It is not surprising then, that nearly 50 per cent of respondents said they worried about the side-effects often or always (figure 6). The impact of the side-effects was described in the free comments:

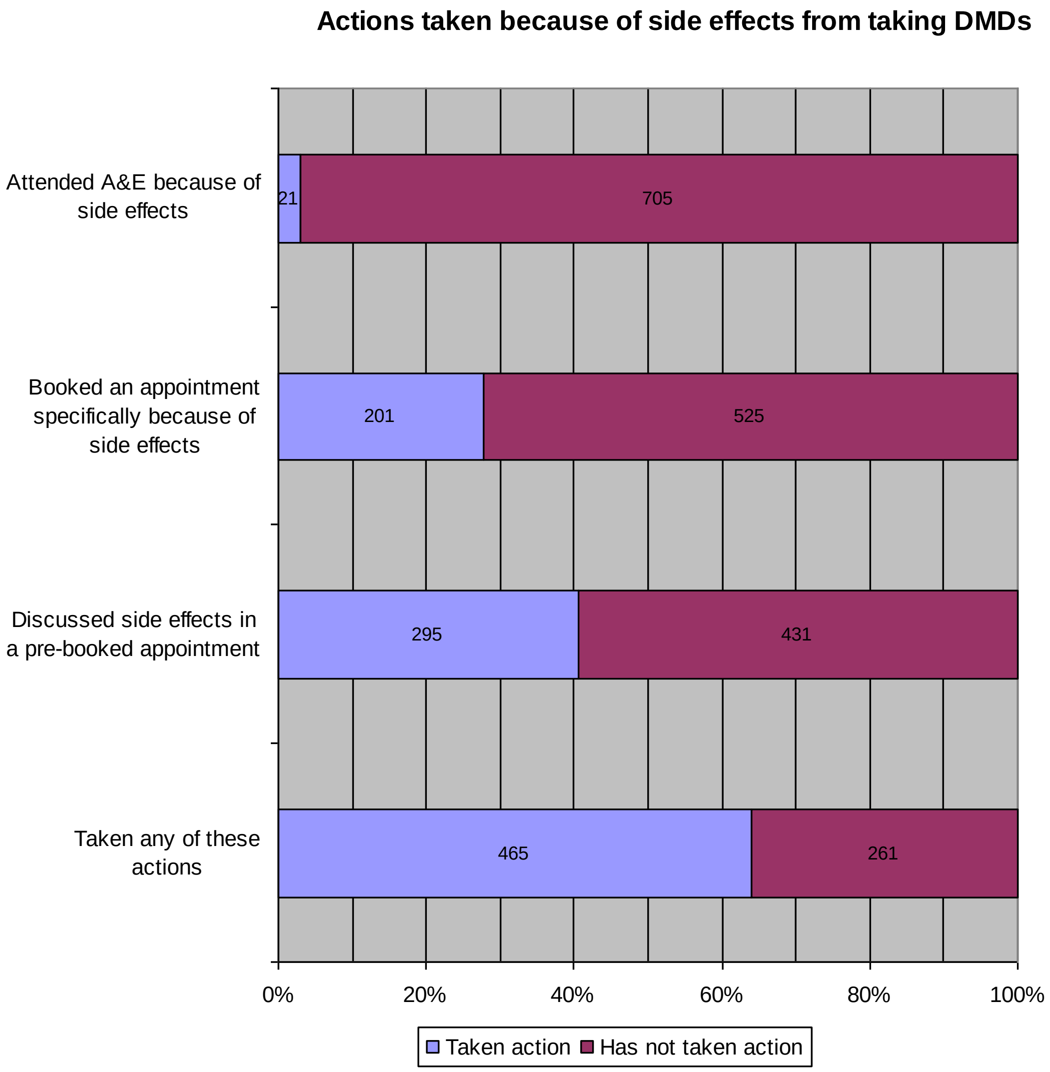
> *"I am a young woman and I feel this disease limits my life in ways it should not, I want to take my medication to stay well but I hate having to take injections, they hurt and make a mess of my skin."*
>
> *"Sometimes the side-effects are worse than the symptoms of a relapse."*

> *"I take a weekly injection. I don't suffer strong side effects but the following day is a bit of a write off - like a minor flu, tiredness and headaches etc and difficulties in concentrating. I can do very little on that day. To help ensure I can continue with work I inject on Friday evenings which means that I get a 1 day weekend (the Saturday being a write off). I live with this but it can be very tiring and draining - physically, mentally and emotionally."*

Finally, those who had discontinued one of these treatments at some point were asked for a reason for this. Common reasons were to do with the side-effects, fear of needles and ineffectiveness of treatment. Skin reactions was a side-effect that was particularly singled out and reported frequently as a reason for discontinuing a treatment.

> *"I found the self injection too stressful. I could not come to terms with it having a deep fear of needles."*
>
> *"I couldn't inject myself. It was taking over everything else in my life!!"*
>
> *"I hated the needle, the bruises and needle marks and the side effects."*

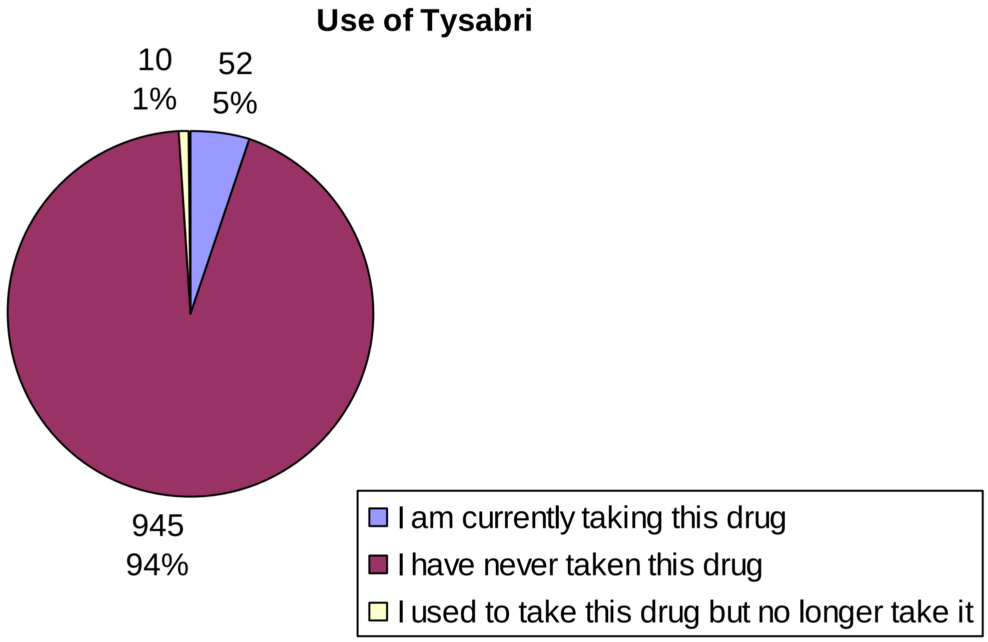
Figure 8



3.2. Taking Tysabri (natalizumab)

Tysabri is the brand name for natalizumab, a disease modifying drug recommended by NICE for adults with “rapidly evolving, severe, relapsing-remitting MS”. Unlike injected DMDs, Tysabri cannot be self-administered but is given as monthly infusions by a health care professional.

Figure 9

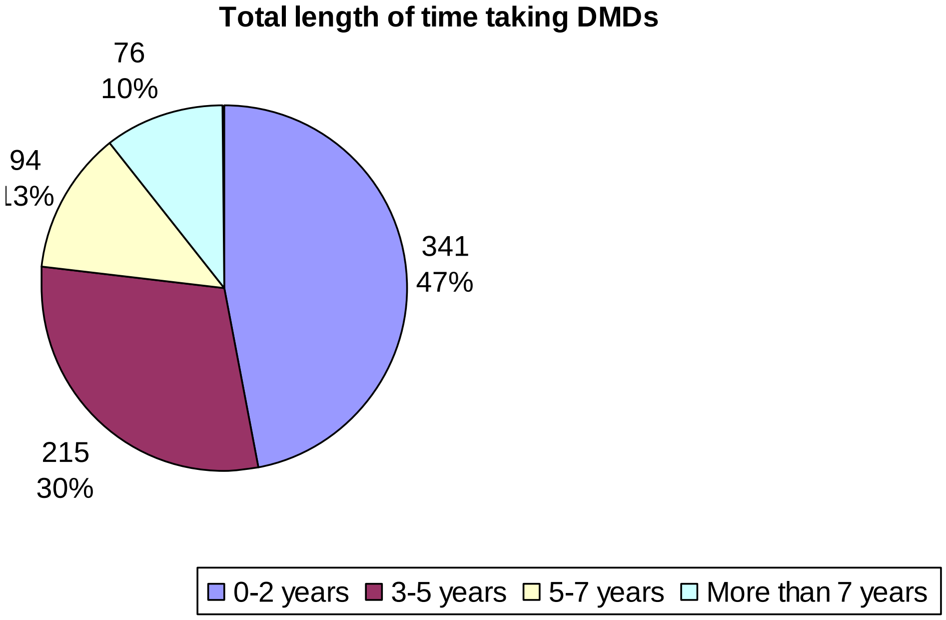


The number of people using Tysabri (figure 9) is lower than the number of those using injected DMDs and this was also reflected in the number of responses to this section – a total of 62. Of the 62, 52 were currently taking Tysabri and a further 10 people had taken Tysabri at some point but discontinued the treatment. Reasons given for discontinuing the treatment were risk of PML, a viral brain infection that can be fatal, and clinician's decision. There has been one large study suggesting that the chance of developing PML for someone using Tysabri for 18 months is around one in 1000. This study looked at over 3400 people taking natalizumab, but they did not all have MS. The risk of PML with Tysabri use increases after 2 years of therapy. The long-term risk is thus not yet known, but it seems this risk might affect decisions about treatment as the following comment exemplifies:

> *"I have been told by my consultant that I have to come off tysabri by the end of this year, so getting new treatments licensed as soon as possible is important because tysabri has changed my life for the better and to lose that is going to be very hard. The only thing is that I have been told that I have to be off tysabri for a minimum of six months so not looking forward to that period with no meds."*

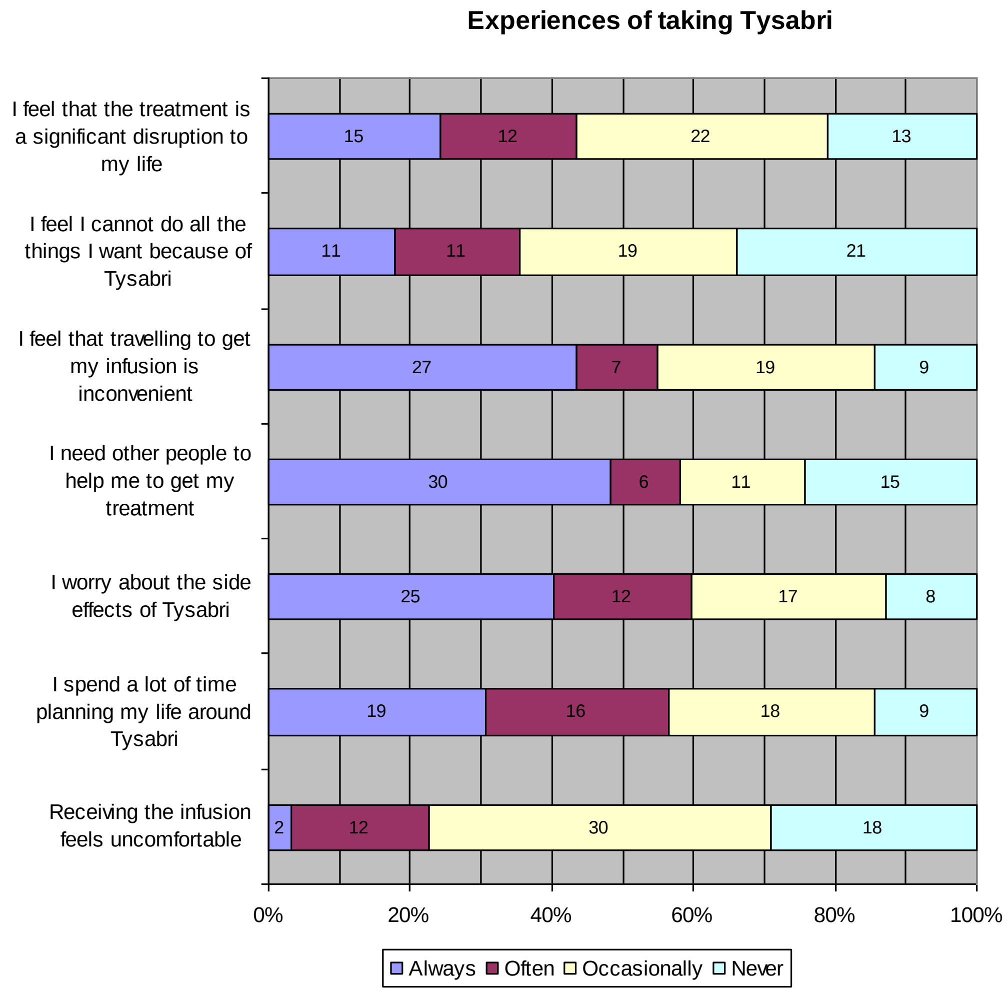
For a break-down of the duration of treatment with Tysabri, please see figure 10.

Figure 10



The respondents were presented with similar statements scoping experiences of being on Tysabri, as in the section about injecting DMDs. The statements were modified to better reflect the practicalities of Tysabri-taking, whilst keeping them as similar as possible to enable comparison (see Figure 11).

Figure 11



When comparing the responses to statements between the two different types of disease modifying treatment, some interesting differences emerge. For the distribution of responses related to Tysabri, please see figure 11.

Practicalities around Tysabri, which is administered monthly by a health care professional, are very different from self-injecting. Receiving one’s infusion requires the person to travel to a hospital or a clinic, and this was found to be inconvenient with nearly 50 per cent of respondents finding this to be the case always.

> *“Early days for tysabri. the main difficulty is the travel to hospital (but maybe i'll get used to that) and the time off work required for the treatment. but I remain hopeful.”*
>
> *“Shame I wasn't forewarned of how long the hospital visit would take (patients are told 1 hour infusion + 1 hour obs - first visit was 7.5 hours, subsequent ones never less than 4 - not a problem now I know to take packed lunch + work, but very annoying on first visit when I was unprepared)”*

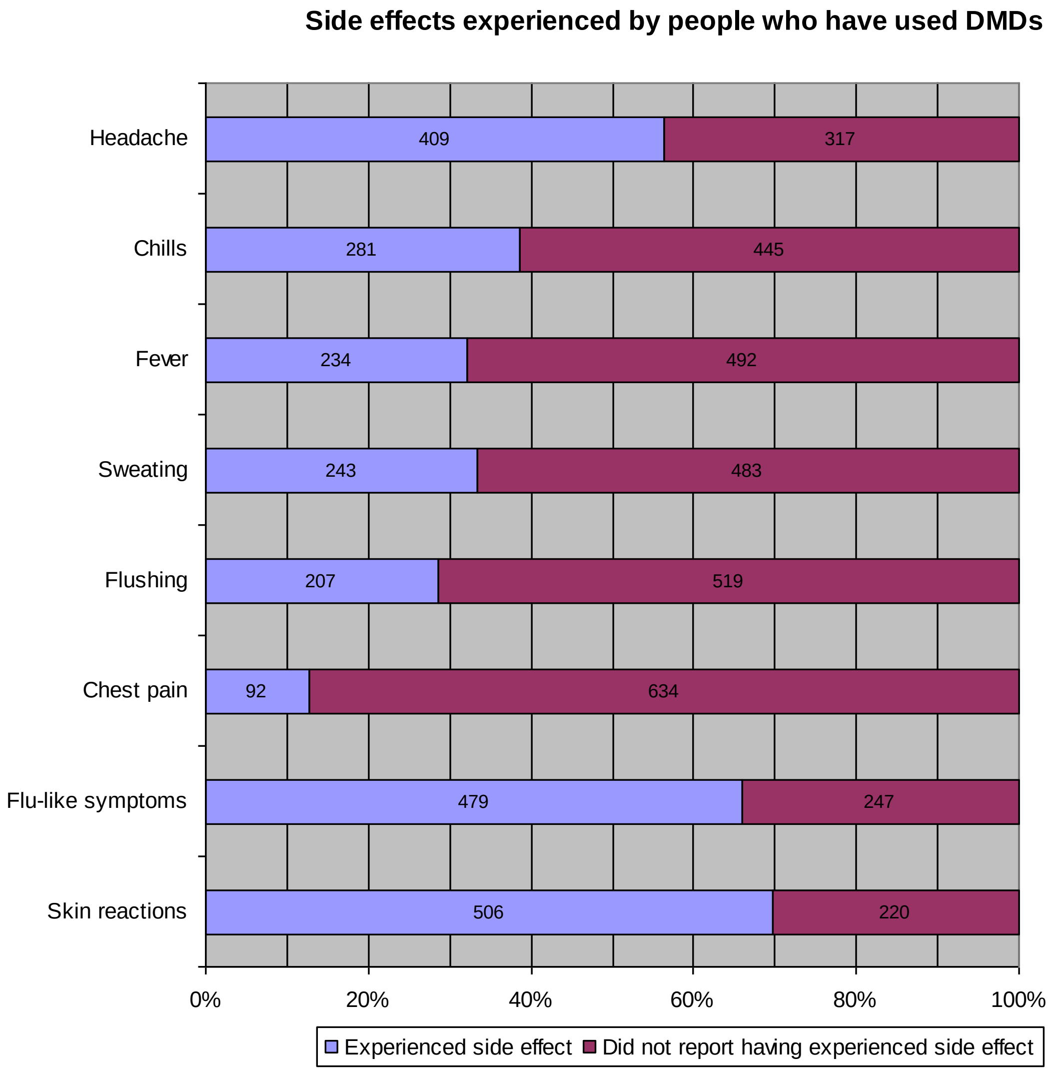
> *“Copaxone has left 'dipping' all over my body, (legs on both sides, buttocks on both sides) and although Tysabri seems to be working, although it does take two days out of my month.”*

There are some side-effects, such as shivering, feeling sick or dizzy, that can be experienced during or directly after the infusion. There were similar statements asking about discomfort for each of the treatments – the one asking about feeling uncomfortable when receiving the infusion and the other whilst injecting. 22 per cent of respondents felt receiving the infusion felt uncomfortable either always or often, and this was relatively low compared to the discomfort of the injecting oneself with 56 per cent reporting this to reflect their feeling always or often. Whereas problems and discomfort of injecting were commonly commented, there were no comments made about the discomfort of infusions.

Side-effects

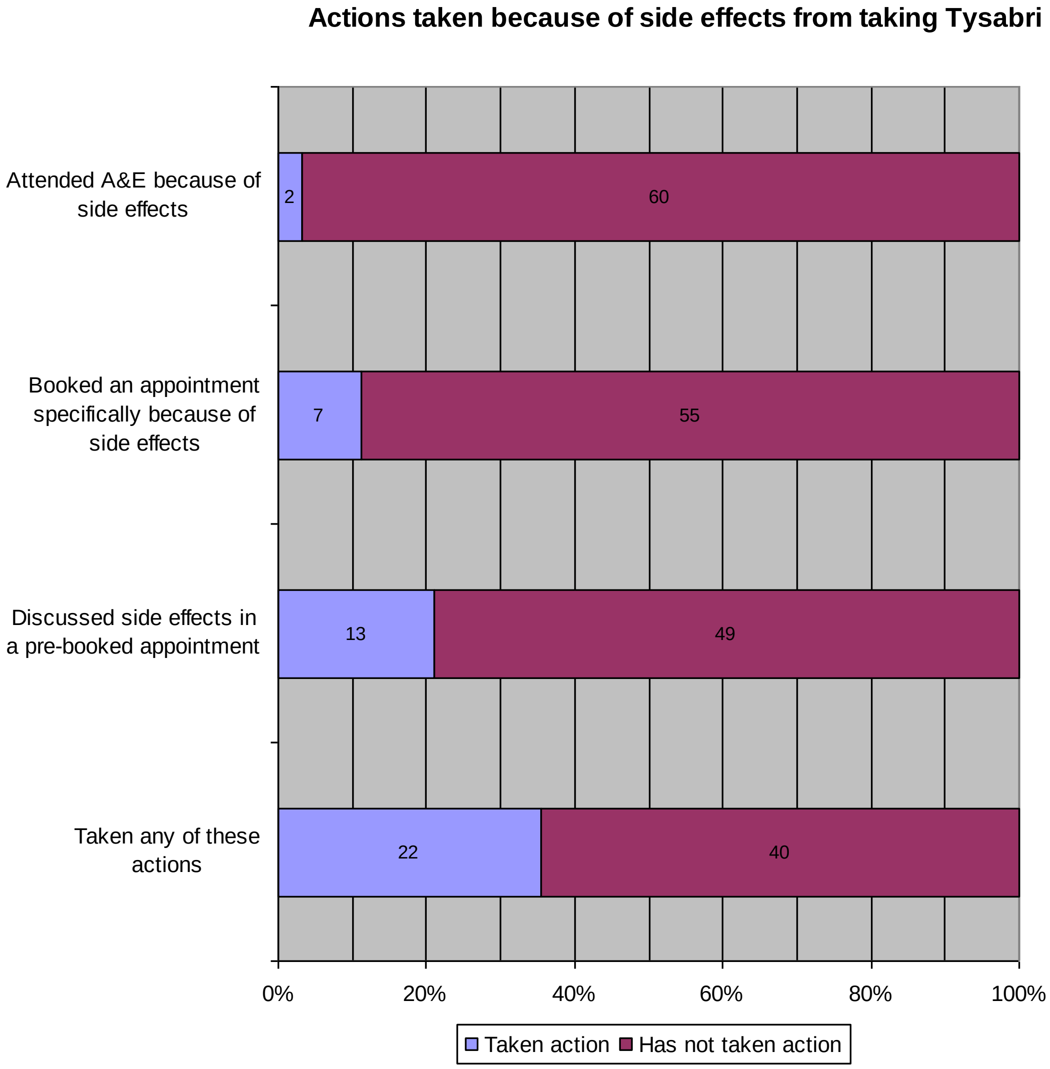
The most common side effects experienced after taking Tysabri are joint pain, fever, tiredness, a runny or blocked nose, sore throat, feeling nauseous, headache and dizziness. All of these side-effects were familiar to the respondents of this survey. The most common side-effects experienced were tiredness (53 per cent of respondents) and headache (39 per cent) (see figure 12).

Figure 12



Some 35 per cent of respondents who had taken Tysabri had sought medical help because of their side-effects (figure 13). This appears to be a lot lower than in self-injected DMDs where 60 per cent of respondents had sought medical help due to side-effects.

Figure 13



Worry about side effects

In addition to the side-effects listed above, taking Tysabri increases the risk of PML, a viral brain infection which can be fatal. In light of this, it is not completely surprising that over 40 per cent of respondents (figure 11) always worry about the side-effects:

> *"I now have very few new symptoms and have only had 2 relapses whilst taking this drug (Tysabri) - although I do worry about PML. As I expected, none of the drugs have improved my disability, but I feel at last that I have plateaued."*

although the fear of PML can be mitigated by being closely monitored:

> *"One of the nasty side effects of tysabri is PML but at least I am surrounded by doctors/nurses when I take drug and I am closely monitored as well."*

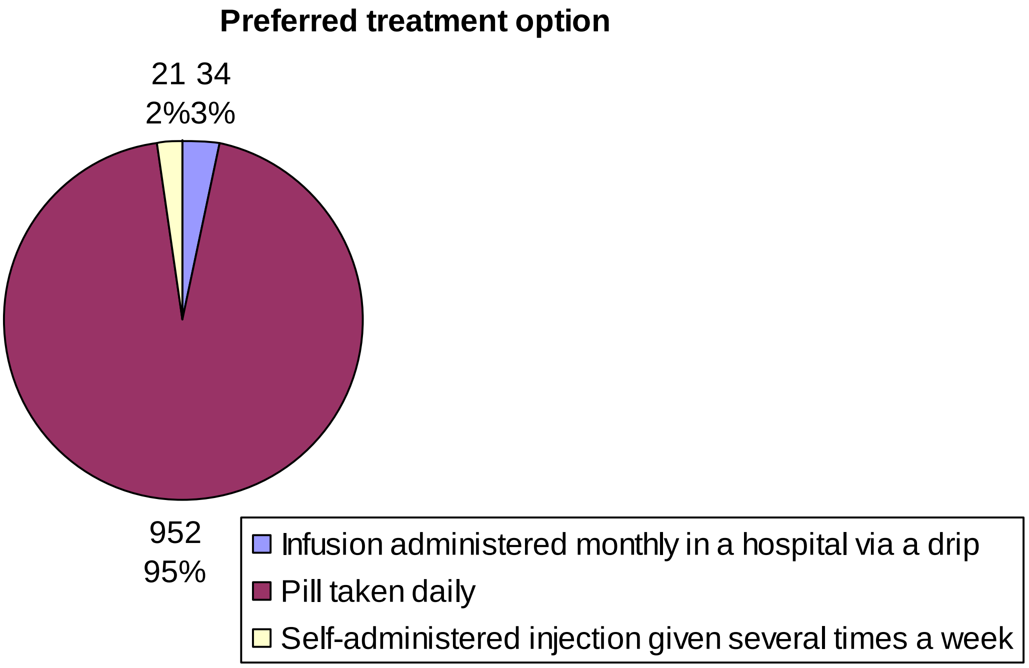
As already discussed, the risk of PML was also commonly given as a reason for discontinuing the treatment. However, despite this, the free comments relating to Tysabri told a very different, more positive story overall compared to those related to injected DMDs:

> *"I was diagnosed with rapidly evolving MS in Feb 2009. I started on Tysabri in March 2009 and I have not had a relapse since. I still have problems with my mobility and speech from my previous relapses but after 17 months of sickness absence from work I am finally stable enough to go back to work. That's all thanks to the Tysabri."*

4. Preferences for disease modifying therapies

The final question in the survey asked for respondents' preference for administering a disease modifying drug if three options were available: an infusion administered monthly in a hospital via a drip, self-administered injection given several times a week and a pill taken daily (see figure 14). Everyone who was qualified to take part in this survey was asked to answer this question, and the total number of responses was 1007.

Figure 14



The overwhelming majority (95 per cent) chose the pill option, giving ease of use, convenience to everyday life and non-invasiveness as reasons for selecting this option:

> *"Taking a tablet I could get on with my every day living, as I should be able to do even though I have MS."*
>
> *"I am trying to maintain a normal life and stay in employment. My work means that I sometimes need to be away from home. Having to inject at specific days/ times means my flexibility while I am away is much reduced. A drug administered orally would make working life much easier."*
>
> *"It would be the easiest and least obtrusive method, would fit in better with my lifestyle and would enable me to control my illness in a way which does not draw attention to my disability. It's bad enough living with the illness, coping with the symptoms and trying to get on with life without having to add to the stress with hospital visits and injections."*

Respondents to this survey have shown that the impact of MS is not only limited to people with MS but extends to their friends and family as well. Whilst helpful at times, treatments can also unnecessarily complicate lives and be a constant reminder of one's condition. Just like everyone else, respondents to this questionnaire want to live independently, stay in employment, take care of their families and go on holidays without having to plan, worry and deal with physical and emotional discomfort. It is vital that disease modifying drugs are effective, easy to use and fit around a person's every day life.

> *"If there was a high risk treatment which could potentially cure my MS I would seize the opportunity with both hands as I want to be normal again and not have to endure debilitating relapses several times a year, which set me back so far and mean I have rely on others to help me, when I just want to be able to do the things that everyone else takes for granted."*

Appendix C: Free text responses to an open question on experiences of relapses and/or disease modifying drugs

Perspectives of people with MS on disease modifying drugs

If you would like to tell us anything else about your experiences of relapses and/or taking disease modifying drugs you can use the space below.	
Answer Options	**Response Count**
	421
answered question	**421**
skipped question	**709**

Number	Response Date	Response Text
1	Mar 25, 2010 12:11 PM	xxxxxxxxxxxxxxxxx
2	Mar 26, 2010 9:15 AM	I feel I am at this moment in time expieriencing a relapse. It seems to be lasting longer than ever, I would be so grateful to receive tablets that would aid my recovery. I have suffered with MS for 20 years, I think I deserve a break.
3	Mar 26, 2010 9:27 AM	Since starting the DMD's I haven't had a relapse, but I am unsure whether the drugs are having an affect or it is just coincidence.
4	Mar 26, 2010 9:30 AM	I is painful when done in the same spot. My thighs are dented, red and scarred from injections. Relapses are awful and I have been taken to A&E by my family before and then had to have an hour long steroid drip everyday for three days.
5	Mar 26, 2010 9:34 AM	I would hope that any treatment for MS patients now or in the future is free as it is for other conditions.
6	Mar 26, 2010 9:37 AM	I have recovered well from my relapses, with small symtoms remaining. So I know I'm a great candidate for DMT. I havent relapsed since I've been on Rebif, so cannot comment if my relapses are less severe with it. My relapses have always reqiured hospitalisation, and I am lucky to have recovered quickly from them, although my last 2 relapses were very close and took longer to recover from. I am hopeful the DMT will prolong my remissions etc. I have been injecting Rebif via the Rebismart for a week, and am begining to understand all of my perameters with the drug - site reactions have caused some pain, redding, tenderness and flu-like side effects, which I am learning to manage - but evidently I'm only on 8mg now! So, how I react on more, remains to be seen. I find it frustrating that when I take the drug it governs what I do - I'm only in my early 30's and whilst I may not be able to stay out as long as I would like to any more, I would still like to be able to partake in all the activities, without thinking when I have to inject.....
7	Mar 26, 2010 9:41 AM	I have been left with red marks and dry skin where I have injected for several months after the treatment and my skin has not recovered fully yet.
8	Mar 26, 2010 10:31 AM	I am getting worse everyday,they say I have RRMS but I believe I have SPMS has my systoms are always the same everyday the pains are getting worse,feel like a spastic,can,t get my words out & finding hard to cope.I am a x-addict which I think stops them giving me meds for my ms,I,ve been put on Gabapentin but haven,t noticed much change yet! only started them a wk ago,got to slowly take them to take 3 a day.Had a infusion for 3 days didn,t help,don,t want to have them as being a x drug addict my veins are scared,took a while to find a vein.I am also on methadone,is this the reason I don,t get much help,I feel like I,m left to rott away with the ms.
9	Mar 26,	I found that while in a relapse my skin was very tough, I had a visit by a specialist

	2010 10:31 AM	nurse from the company who supplied my drug and she saw how difficult it was for me, she thought the needle may be blunt but after checking the batch they were perfectly fine it was just my skin was like the hide of a Rhino. I tried the injector pen but it was so sore and far to quick - it made a snap sound which I would try not to jump from but it was hard, I would bleed and bruise at the site of the injection from the pen, my legs (thighs) have become scarred from the injections - I stopped after giving them a good try, I felt that they were beneficial in helping my fatigue and memory but the side effects were as bad as the ms for me, my theory was why hurt myself more when I have a disease that can do that I'm just adding more pain and suffering to it. A pill would be like a God send!
10	**Mar 26, 2010 10:47 AM**	I have been on Avonex for just over 4 years & I still suffer very bad side-effects after injecting. This includes flu like symptoms, joints aching, chest pains, breathing problems. This starts in the night after injecting & goes on for the next 3 days. I'm losing half my week ALL the time!!!!
11	**Mar 26, 2010 10:48 AM**	i am on my first relapse after being diagnosed four years ago. I have now been off work for 3 months and looking to start back in the next couple of weeks on reduced hours for a while.
12	**Mar 26, 2010 10:56 AM**	A s a nurse i feel for both myself and other sufferer's of RRMS i have to work with some people who have to suffer with the problems on a day to day basis. There is not enough support out there from professionals as much as i would like there to be. I am not needle phobic normally but since having to inject myself regularly i have hot flushes sickness feelings before injecting as i know i am going to hurt myself!!! I have told my neurologist on a regular basis that i would gladly take about 14 pills a day if they got rid of the injections, so anybody who does not agree with this, needs their head examined because if they had to do it then they would think twice!!!!!!!
13	**Mar 26, 2010 11:05 AM**	I was incredibly sick when having a relapse and it lasted a period of 5 weeks being off work - it has always left me a side effect i.e unable to use my right hand and leg as it has always had knock on effect, My balance has also been affected after a recent relapse. I do not enjoy taking the injections as I inject them intra muscularly and I feel so ill after I have taken it.
14	**Mar 26, 2010 11:27 AM**	I gives me hope anf the motivation to carry on .
15	**Mar 26, 2010 11:35 AM**	When I have relapsed I was given Dexamethasone
16	**Mar 26, 2010 11:46 AM**	Relapses are awful because just when you start to cope with how you are, a relapse comes along and knocks you for six, both mentally and physically. Some relapses make old disabilities reappear, or bring along new symptoms. The fear is always there, that you wont recover from this relapse or be left with a more permanent visable disability and then there is the relapse time and the additional recovery time on top. What is the point in these oral drugs getting trials if in the end, only certain people will get them, if NICE decide they can have them at all. It shouldnt be about money but what a person needs to have a decent life and if taking a pill everyday gives me that life, then i would take it.
17	**Mar 26, 2010 11:56 AM**	I have only been on Rebif 22 for 8 weeks and I am having problems with the side effects not sure how long I will continue with this treatment
18	**Mar 26, 2010 11:58 AM**	taking Rebif using the Rebismart device is simple and i would not consider anything else at present.
19	**Mar 26, 2010 12:01 PM**	I have been offered DMD's by my consultant but due to the possible side effects and having to self inject I have so far resisted. If there was an oral alternative then I would seriously considered this option.

20	Mar 26, 2010 12:12 PM	My first relpase lasted for 6 months, sight loss paralysis etc, very frightening!! Couldn't to to work as needed help to live day to day and care for my 18 month old baby and 7 year old. Didn't know what was happening, however, now diagnosed my relpases haven't been as severe but still bad enough to prevent me carrying out normal activities and need to take time off work.
21	Mar 26, 2010 12:19 PM	I have found that any relapes I had while taking Avonex where much milder and shorter than before.
22	Mar 26, 2010 12:33 PM	im currently in the process of seeing my neurologist to receive the disease modifying drugs as i feel like some of my symptoms have worsened and i am now starting to experience new ones. Although I have not had a serious relapse I'm not sure if I have in fact suffered a relapse as I'm still trying to distinguish between a relapse and a symptom.
23	Mar 26, 2010 12:49 PM	I have always resisted DMDs due to potential side effects.
24	Mar 26, 2010 12:55 PM	I continued to have major flu-like symptoms throughout the 4 years on Avonex. In addition, the DMD was stopped because there was a concern it was causing more grief to my legs where I was constantly injecting. My legs have improved quite a lot since stopping, but I have had a relapse, which is the first for 4 and a half years. So in my opinion, the DMDs work, but if there could be a better method of having them (ie orally!) then that would be the best all round!
25	Mar 26, 2010 1:15 PM	I as would I am sure most MS patients (especially those on Interferons and similar) be extremely happy to take the new drugs (i.e. cladribine) as soon as possible as until we try these new medications we will not reach the ultimate aim of ridding the world of MS (or indeed managing its effects) [redacted]
26	Mar 26, 2010 1:19 PM	I've had RRMS for 8years now and have had frequent relapses with steroid infusions in and out of hospital. Rebif x3 weekly was an instant no no for me. side effects every night and skin reactions along with more disruption to my life. I administer avonex myself once weekly and don't find it a problem but still have occasional side effects. I've been offered Tsybari, but feel the risk of PML too high. I'm still walking and working, so i'll have to wait and see what else is offered. Why is there no research in the UK for CCVSI, I understand that this is very effective in America!
27	Mar 26, 2010 1:20 PM	Tysabri has been brilliantly effective and I am working full-time. Shame it took 5 and a half months of continually worsening symptoms to get the treatment after diagnosis. Shame I wasn't forewarned of how long the hospital visit would take (patients are told 1 hour infusion + 1 hour obs - first visit was 7.5 hours, subsequent ones never less than 4 - not a problem now I know to take packed lunch + work, but v annoying on first visit when I was unprepared)
28	Mar 26, 2010 1:27 PM	i just wish they would bring out a tablet to cure MS which would be good rather then injecting all week! the relapse i had last year was horrnedous as i did not know what was wrong with me!
29	Mar 26, 2010 2:41 PM	Injecting yourself every other day does become part of your routine but at times it's tricky if you're travelling and have to carry equipment/sharps bins etc with you.
30	Mar 26, 2010 3:00 PM	I have only recently started on Rebif - I feel a lot better for taking it (taking control) but it is a 3-weekly dread for me each time I remember I have to inject that day
31	Mar 26, 2010 3:14 PM	Easier to administer than injections No skin reactions ie; dimpled skin, sore/red rashes on skin, bruising, lumps under

		skin, pain, blood, unsightly skin on thighs, stomach, forearms, sides
32	**Mar 26, 2010 3:14 PM**	They should be available to people diagnosed with MS upon diagnosis.
33	**Mar 26, 2010 3:21 PM**	The only thing that gets me back on track after a serious relapse has been steroids.
34	**Mar 26, 2010 3:32 PM**	In the almost two years since I started on rebiff I have had one very minor relapse (which may have been stress rather than a relapse) but in the two years prior I had 3 serious relapses. In my opinion DMDs work. However injecting is often painfull and the bane of my life.
35	**Mar 26, 2010 3:57 PM**	I have had several experiences of being on a 3 day steroid drip to treat a relapse - I have preferred it when it has been possible to stay in overnight, rather than go back and forth to the hospital for 3 days. This is tiring when suffering a relapse and also makes me dependent on someone to get me to the hospital 3 days in a row.
36	**Mar 26, 2010 3:58 PM**	I must admit that I am fairly new to the DMD therapies so cannot offer much experience commentary however I know that a pill or liquid medicine to be taken orally would be much safer and more pleasant to take. I am not squeamish about injections but doing a jab myself every week does give me the jitters.
37	**Mar 26, 2010 4:06 PM**	rehelapses are less frequent now i am on dmd tho when they do occur they disrupt my life completely the last relapse i had lasted for a couple of mths.thats 2mths of bed rest and not being able to do anything for myself.this is really hard on my family.
38	**Mar 26, 2010 4:12 PM**	Please see comments on previous page. I feel all with MS who require these drugs are in effect guinea pigs and everyone should do their research and then make informed choices.
39	**Mar 26, 2010 4:15 PM**	Diagnosed with aggressive r/r MS, I was fortunate to be given Azathioprine at a time when disease-modifying drugs were not allowed. From being admitted to hospital around four times a year with long relapses, I never again suffered such a devastating relapse and did not and do not require in-hospital treatment any more.
40	**Mar 26, 2010 4:29 PM**	The DMD follow-up blood tests never take place. I get an annual check-up and that's the only time blood samples get taken!
41	**Mar 26, 2010 4:49 PM**	Too many side effects with Rebiff; switched to Copaxone but often find myself not injecting as I developped a mental block against the injection needle
42	**Mar 26, 2010 5:04 PM**	I have used Betaferon for 12 years now. It has nver got any easier to inject myself or any easier to ask my husband to do it for me. Indeed it can cause friction between us because we both get anxious so a tablet would be just wonderful it that respect. But an injection also often hurts and caused unsightly marks that never really dissappear Plus when going on holiday or away you always have to think about how you will cope with the injections - this will not be an issue with a tablet. Life would become so much more normal again
43	**Mar 26, 2010 5:05 PM**	I hear from others that regular injections are very uncomfortable. MS is an awful illness and everything must be done to make life more bearable.
44	**Mar 26, 2010**	After 12 months of taking a DMD I am a lot more accepting of the injections however I still have periods where I have injection site problems. I also find that if I will do

	5:10 PM	swim or other exercise these site marks are unsitely.
45	Mar 26, 2010 5:10 PM	Work wise, business travel is more of a concern when I have to manage a 3 times a week injection schedule. I hate needles which dosen't help. Avonex gave me a severe flu side affect which effectively romoved one day a week from my life while I took it. Copaxone still give me a rash.
46	Mar 26, 2010 5:14 PM	I know I am worse when not well, when overheated and when stressed
47	Mar 26, 2010 5:21 PM	i currently am lucky enough to be able to take Sativex. Unfortunately, it is still unlicensed and I do live with the possibility that it will never get licensed and may be taken away at some stage. It does me a lot of good and I would hate to see it go. I understand that it isn't a dmg as such, but it makes me feel better in myself in order for me to get out and about and keep fit and not be a burden on my family or society. i wish the government had more thought about prevention rather than cure with illnesses per se not just MS. If they could see that i currently lead an average kind of life, which is very good after 20 years, and that it may mean that I won't be a drain on resources later in life.
48	Mar 26, 2010 5:21 PM	Just not a pleasent experience. MS is bad enough without having to organise your life around your medication. Which in turn is not very pleasent and not very effective.
49	Mar 26, 2010 5:26 PM	Injecting just once a week disrupt your whole life and sometime it can be excruciating
50	Mar 26, 2010 5:30 PM	I take baclofen 3 x 10mg daily and I do not know how this is affecting me. I also take fesoterodine fumerate 2 x 4mg daily and this helps with bladder control. Although I was only diagnosed in August 2009 I think I have had this disease for at least 20 years.
51	Mar 26, 2010 5:40 PM	It is utter hell and there is no support if I want to carry on with a normal life. A relapse is so individual and unpredictable that it is impossible to get help without taking time off work for a long period and actively seeking help, which involves many different agencies and people. Even small disability help is hard when you're just able enough not to fufil the criteria. The most difficult thing I do every day is wash and get dressed, but because I can, I don't tick the right box for example.
52	Mar 26, 2010 5:53 PM	They just did not work for me - currently undergoing chemotherapy every 3 months, but appears to be having no effect - something for secondary progressive urgently needed
53	Mar 26, 2010 5:59 PM	It is a frightening thing being told that DMDs are only available via an injection and that you have to do it. To begin with, it controls your life as it is against human nature to hurt yourself and even more trickier when trying to inject with a tremor. It's not pleasant experiencing the flu-like symptoms, but I think this would be far easier to cope with if you didn't have to inject as well.
54	Mar 26, 2010 6:02 PM	i have been frustrated with rebif as I still relapse 3 or 4 times a year which causes a lot of disruptioon in my life, however since starting this drug I have not had the severe relapses i used to have which often involved a stay in hospital and me being very ill at home and unable to look after myself.
55	Mar 26, 2010 6:11 PM	Relapses are not only worrying, painful & distressing at the time but can take a considerable amount of time to recover from, I have been left with residual problems from every relapse I have had & then the worry of if I have another is the disease progressing quicker than I'd hoped, & that is always a worry at the back of my mind. I then worry about the impact on my husband & that he has to take time off work to help me. The concern that he will not cope if I become severely affected by another relapse is a genuine worry as he gets extremely frustrated with the whole MS

		scenario. As a very independant lady this adds it's own issues to my state of mind & the fact that I cannot be there as readily for my children & colleagues.
56	**Mar 26, 2010 6:19 PM**	My consutant thinks that the side efects would outweigh the benefits of the drugs at the moment, even though I'm having quite a few relapses, so won't prescribe any desease modifying drugs. I worry that the progression of thre disease would be better controlled if i was on the drugs tha as i am now.
57	**Mar 26, 2010 6:19 PM**	Betaferon was a big hope for me at the time - but I just COULDN'T inject myself. Ghastly. My relapsing/remitting is now secondary progressive. Sad.
58	**Mar 26, 2010 6:25 PM**	Only diagnosed 2.5 years and my decision not to take DMDs initially - hoping (unrealistically) relapses would not happen or if they did would not be as bad as original - the fact that oral medication was not an option definately figured in decision.
59	**Mar 26, 2010 6:30 PM**	Relapses are absolutely soul-destroying, so having to put up with a few flu-like symptoms is neither here nor there(especially as MS tends to make you feel awful most of the time anyway). Side effects like this are a small price to pay for the benefits these drugs can bring.
60	**Mar 26, 2010 6:34 PM**	Find a big problem having to remember when to take injections is a bit easier with new battery powered injector which store all info on machine
61	**Mar 26, 2010 6:35 PM**	It causes me a lot of pain and discomfort.
62	**Mar 26, 2010 6:39 PM**	Avonex gave me almost unacceptable side effects (totally out of action for 24 hours with MS type side effects). it helped reduce relapses but didn't eliminate them. Early days for tysabri. the main difficulty is the travel to hospital (but maybe i'll get used to that) and the time off work required for the treatment. but I remain hopeful.
63	**Mar 26, 2010 6:39 PM**	No MS related comments
64	**Mar 26, 2010 6:47 PM**	My experience of Copaxone has been life changing but I would still not choose to administer the drug in the form of injection. I have had so far only the initial expected relapse since injecting this drug.
65	**Mar 26, 2010 6:51 PM**	Relapses can make it difficult to plan ahead except in a tentative way.
66	**Mar 26, 2010 6:55 PM**	Usually feel quite ill especially head pains and pressure, aching, flu symptoms about 4 hrs after and may last a day and a half. It would make my life so much better to know that I would not have to inject each week as I dread it now that I get the pains when injecting. My eyesight is getting worse and that worries me with the injections too.
67	**Mar 26, 2010 6:57 PM**	Occasion ally I make a little buise, but keeping the relapsing down is worth it, and the stiffness and flu klike systoms
68	**Mar 26, 2010 7:00 PM**	I personally have found Copaxone to keep me almost true relapse free since I began taking it. My fatigue levels which were affecting my life before starting on Copaxone also seem to be improved in a great way, it was noticable from very early days of starting.
69	**Mar 26, 2010 7:08 PM**	I find injecting very painful and always get skin reactions - I now have lipoatrophy which is very unsightly but have no choice but to carry on because I do not want my MS to progress further.
70	**Mar 26, 2010 7:09 PM**	while on Rebif the flu like symptoms never changed, and that made life difficult as the flu like symptoms would last into the next day, so that would be three days lost out of a week
71	**Mar 26, 2010**	That I have received great care from my consultant

	7:11 PM	
72	**Mar 26, 2010 7:19 PM**	I like Tysabri (so far ...) and feel better than I have for years!
73	**Mar 26, 2010 7:37 PM**	I initially thought when I started injecting I would not have so many relapses but in reality I sill get them although I tell myself I get less now. I hate injecting through a relapse because of the effort and the feeling of they are not working so why bother putting myself through the trauma. I have not missed an injection but it is more my willfull nature than what I want to do. I had to fight so hard to get on the drugs that whether they are working or not I am determined to take them.
74	**Mar 26, 2010 7:44 PM**	ms consult
75	**Mar 26, 2010 7:47 PM**	it's horrid having a relapse and not to be able to do things that in the past were easy, and done without thinking I feel very thankful that I have injections and that they are helping, I hope
76	**Mar 26, 2010 7:50 PM**	life is a struggle
77	**Mar 26, 2010 7:52 PM**	Have never taken any.
78	**Mar 26, 2010 7:53 PM**	The effects that the drugs were supposed to have on me - i.e weaker relapses and longer remission periods - appear to be happening in my case. My MS. is getting progressively worse but few if any noticeable relapses.
79	**Mar 26, 2010 7:53 PM**	I have been on Copaxone for six months. I was havng a relapse every few months and I have had nothing since taking the drug. This might not sound too severe to some people but some of my relapses have affected my mobility and scared me. Copaxone has given me confidence that my relapses are slowing down. To have this, or indeed a pill, makes me think I will be able to work longer and hold MS off longer. I am 35 and have two children. These drugs are working for me and I would like it to stay that wa,y with me being able to get any drugs that I need. Surely, keeping me fit enough to work and live a 'normal' life is a benefit to the people paying for these drugs?
80	**Mar 26, 2010 7:55 PM**	I work full time for the NHS as a band 7 Occupational therapist - to do this properly I have to lose all aspects of life - I can't clean my home , go out and sometimes cant even make myself a cup of tea as I am so exhausted. I try to limit the impact at work by taking annual leave instead of sick leave if I feel I am losing energy which means I spend alot of annual leave in bed recovering from work. I would fall into depression about the lack of life if I had not got such wonderful family, friends and colleagues.
81	**Mar 26, 2010 8:02 PM**	Please work hard to source this, it will mean so much. Thank you as ever.
82	**Mar 26, 2010 8:09 PM**	Relapses are scary never knowing how long they will last and how disabled I will be left after the relapse.
83	**Mar 26, 2010 8:15 PM**	as i said I would like to use the injection you take once a week
84	**Mar 26, 2010 8:20 PM**	I am a normal human being like everyone else who has this disease. I still work full time, pay my tax and national insurance. I never wanted to be a burden on the economy and still don't want to be. If I can get the best medication to help me and to help keep me well, to continue to contribute to the economy, then that can only be good. If I stay well, this should help reduce the impact on the economy - If I become unwell, not only will I need to stop working, but perhaps my carer / carers will need to reduce working hours and so claim Financial support from the govt, a further

		burden on the economy. The drugs are a means to an end - I don't want them but need them and so appreciate all the help I can get. Without medical support my last relapse may have had a worse effect on my body-it could have been more disabling. The side effect of the drugs are a blessing to me compared to the impacts on me without having them. I will persevere with whatever comes. During my last relapse, my head was so sore I could hardly see / eat - I felt so ill. I went to bed and hoped that I would not wake up. I have had MS for many years, but was only diagnosed almost 5 years ago aged 20 (after going private). I had to wait two years for access beta interferon treatment as it wasn't avilable for everyone in my province.
85	**Mar 26, 2010 8:24 PM**	
86	**Mar 26, 2010 8:52 PM**	In my experience (5 Years since dx) I had 3 obvious relapses in the first year. Since starting treatment on DMD I have only had 1 relapse on vision which commenced a few weeks before starting DMD. It has worsened over the last few years despite continueing with DMD. Other symptoms have slowly progressed or worsened over th last two years. I am still trying to work (Self Employed) but output is greatley reduced.
87	**Mar 26, 2010 8:59 PM**	DMD's have kept me mobile and working but the process of getting the drugs into the system is wrecking my body. Came off 2 treatments due to subcut. atrophy and when off treatment experienced a damaging relapse. Praying I will not get atrophy of muscle or I may be out of options.
88	**Mar 26, 2010 8:59 PM**	I would love to be on a drug with a greater efficacy so I can live my live, pay my mortgage and taxes and be happy.
89	**Mar 26, 2010 9:13 PM**	Not sure if DMDs are effective.
90	**Mar 26, 2010 9:18 PM**	Drugs for health conditions should improve your quality of life, not hamper it more. Injecting is horrible & I dread every other day.
91	**Mar 26, 2010 9:20 PM**	Since taking the drugs I have felt that the disease is being eased. Maintaining a regular exercise three or four times a week is helping me combat the balance issues, stamina and building strength in my overall body.
92	**Mar 26, 2010 9:34 PM**	drug woud be easier to tollerate, orally.
93	**Mar 26, 2010 9:37 PM**	I haven't really had any relapses since being on copaxone, other than minor flare up of symptoms after I've had a cold etc. Ive been injecting for 2 years. I am sometimes concerned about skin reactions and if these got worse then I would consider a pill provided there were no severe side effects.
94	**Mar 26, 2010 9:49 PM**	I find the day after my injection(im on betaferon) I get headaches.I also dont sleep well the night I have had the injection,and dont want to do much the next day,just stay in bed or watch tv. I had a major relapse in 2008,this is when I was diagnosed.which left me unable to work as I was a carer and always on my feet. Now I can only walk short distances. I started injecting in november 2008 after watching the betaferon dvd but I was disapointed as I didnt improve much.Ive been told that its just ment to slow down the progression but things have got worse quickly since ive been on betaferon.
95	**Mar 26, 2010 9:56 PM**	i have taken rebif, avonex and copaxone, side effects with each were different but just as disrupting to daily life.
96	**Mar 26, 2010**	My GP refused me Sativex.

	9:59 PM	I take bacolen - it does no good.
97	**Mar 26, 2010 10:07 PM**	I have had MS for 20 years and for the first 10 years it was relapsing/remitting. I have never been offered disease modifying drugs. I found relapses very frightening and upsetting, having to take time off work, deal with new symptoms, losing control of my life and independence. The uncertainty of not knowing what residual damage would be left when the relapse ended
98	**Mar 26, 2010 10:12 PM**	Relapses have been quite debilitating, affecting my ability, for instance, to get on with my work. However, I've not had any relapses since diagnosis, 6 months ago, so I'm not sure how I'd cope now that I know what it is, and have the support of an MS nurse. I feel like I've been lucky in terms of Rebif side effects, but an equally efficacious tablet would be easier to manage.
99	**Mar 26, 2010 10:29 PM**	I started taking Avonnex three years ago and had side effects at first that lasted 3-4 days every week for the first 3-4 months then 2 days for the next month. I really didnt want to continue to use this medication however my old Neurologist refused to allow me to stop. I felt that the side effects were taking over my life and I was ill for half the week and mostly bed bound. When the side effects lessened, it became bearable though it had had a dreadful effect on my working life and home life. I felt totally out of control of my life and not listened to by those who were supposed to care and support my decease and my health. Now thing are better and I only have 1 day of feeling unwell. I now have Secondary Progressive MS.
100	**Mar 26, 2010 10:33 PM**	They need to be more effective and less of a burden on daily life
101	**Mar 26, 2010 10:41 PM**	I used to inject Rebif 3 time a week but had so many reactions to the drug. It seemed to react with other foodstuffs like Chinese, Indian takeaway food. I went out for my best friends stag night had a few too many drinks but was fine when I went to bed. When I woke I was unable to walk. This had never happened before Rebif.
102	**Mar 26, 2010 11:45 PM**	I do not have relapses
103	**Mar 26, 2010 11:47 PM**	I had a course of Mitoxantrone over a number of years and then my treatment was transferred to Copaxone. This regime has worked well for me and I am very pleased about that.
104	**Mar 26, 2010 11:56 PM**	The actual act of injecting , fills me with dread, even though it has now been 18 months since I started.I have been phsically sick the day before and the day after injecting. An alternative, oral drug, would give me back 7 days a week, instead of 5.
105	**Mar 27, 2010 12:08 AM**	having the start of a second relapse within two years of last one and obviously you worry how much more damage is being done scarring wise. sounds as if there are so many more now on the market.
106	**Mar 27, 2010 12:12 AM**	I feel fortunate to have been on Avonex at all, I have no idea what my condition would be without it.
107	**Mar 27, 2010 12:12 AM**	I am one of the lucky ones who is on Betaferon as before I started this medication when I had a relapse I ended up in a wheelchair. Now touch wood when I have a relapse they are not as bad. People need to stop moaning and be thankful if they are getting the treatments they need whether injections or tablets. Life is too short some people are not so lucky.
108	**Mar 27, 2010 12:31 AM**	HAVING TO INJECT 3 TIMES A WEEK MEANT MS WAS CONSUMING MY LIFE AND I TOTALLY WAS AGAINST THIS .IT MADE ME PERCEIVE MYSELF AS BEING ILL WHEN I WASN'T .HAVING TO GET TRAVEL LETTERS .

109	**Mar 27, 2010 1:05 AM**	they tell you that you will experience flu like symptoms for about the first 6 months i have been on rebif for four years now and i still get the flu like symptoms so constantly have to take painkillers 3 times a week when i do my injections
110	**Mar 27, 2010 7:14 AM**	Q3 -none of the answers available were relevant but I have had to called NHS Direct when I had a particularly severe reaction. I have also discussed the reactions with the Copaxoen helpline and with my Specialist MS Nurse and consultant at routine appointments. Being able to take pills on flights would not be so intrusive as having to take injections and letters from the hospital to allow me to carry needles on the plane -one airport official asked what I felt was unecessarily intrusive questions. My relapses are now irregular but life affecting when they happen -usually affecting my legs. My determination to not make me stop my usual responsibilities -even when I perhgaps should -means some of my responses are 'occasionally' when they should be 'often' but I refuse to give in. Life with MS is a battle.
111	**Mar 27, 2010 8:57 AM**	Decided not to take disease-modifying drugs because I hated the thought of injecting myself on a regular basis.
112	**Mar 27, 2010 10:10 AM**	I'm scared to travel abroad with needles I find injecting difficult & most times painful I take diease modifying drugs because its the only option
113	**Mar 27, 2010 10:18 AM**	I have had steriods, firstly in tablet form which worked very well and stopped my relapse speedily secondly I had a three day intravenous course of steroids, this just make me feel worse.
114	**Mar 27, 2010 10:24 AM**	I have had 5 relapses in the last 6 months each getting worse and leaving me with more spastistity each time. Can't take too many steriods as I have osteoporosis. Have already had 5 courses in the last 6 months and this relapse Gabapentin has been increased to help with the pain.
115	**Mar 27, 2010 10:28 AM**	Avonex was taken every Friday night which meant anxiety all day beforehand, then forced myself to do it and then 'lost' the entire weekend (mainly in bed) due to the side effects In the end, I abandoned the treatment as it was worse than the disease
116	**Mar 27, 2010 10:34 AM**	I have recently started taking Amantadine, and am very pleased with the result so far.
117	**Mar 27, 2010 10:50 AM**	I have always got on with things with the help of my GP as I was told I do not have enough relapses to warrant medication.
118	**Mar 27, 2010 10:54 AM**	Because Rebif has to be kept refrigerated transportation eg going on holiday is very difficult. Making sure it is kept at the correct temperature on the plane and in the hotel while still having access is a problem.
119	**Mar 27, 2010 10:56 AM**	When having a relapse if it is bad I have had to take steroids , which do then mean that I am unable to function normally until the steroids wear off. I hated having to be injected with beta interferon and used to get very distressed and hate the day knowing an injection was coming.

120	**Mar 27, 2010 11:45 AM**	Tysabri has changed that for me as my relapses have reduced and it is a relief to have only;y one infusion every 4 weeks rather than 3 injections a week. The injections make me ill and although there was a slight reduction in relapses, the side effects of the drugs made day to day living very tough.
121	**Mar 27, 2010 12:00 PM**	Obviously you get more proficient with the injections as time goes on, but it is fiddly and trying to remove air bubbles can be difficult. I have had the syringe/ needle fall apart in the auto-injector once because the needle assembly had worked loose.
122	**Mar 27, 2010 12:06 PM**	i would appreciate a drug or something that would keep me at the position I am now. I feel if maybe I had been given something earlier I would not be as bad as I am now.
123	**Mar 27, 2010 12:27 PM**	I am currently on Rebif and have not had a relapse since I started treatment - nearly a year now, so the treatment seems to be working well for me, so I'm happy about that. I just hate the injections, so if I was able to change to pills and they would work as well as the Rebif, then I'd be over the moon!
124	**Mar 27, 2010 12:39 PM**	I have experienced bad relapses and been in hospital. I don't want my MS getting any worse. I have had relapse attacks but they have got better in a few days and my MS Nurse has given my husband and mother advice.
125	**Mar 27, 2010 12:56 PM**	I do not wish to take a drug that does not have a positive effect, I feel that the arrangement with Avonex is very successful and has kept me working and living as normally as I can at present. I would not take a drug that had serious, permanent side effects. Although if it was a definate cure I would take the chance!
126	**Mar 27, 2010 12:59 PM**	I currently take DMD, and may move from Betaferon to Tysabri as I have suffered with a new relapses since starting Betaferon as suggested by my Consultant
127	**Mar 27, 2010 2:03 PM**	I have had very few relapses since being on the injections. However, it is hard to know if this is because of the injections or because I have gone into secondary progressive MS.
128	**Mar 27, 2010 2:15 PM**	I WOULD DEARLY LOVE A CHANGE TO TABLET FORM AS DESCRIBED PREVIOUSLY.
129	**Mar 27, 2010 2:37 PM**	I started on rebif 22 after a big relapse which left me sightless for a few months. The rebif treatment was going very well, and I experienced no further major relapses whilst on it, only slight niggles such as tingly fingers, wobbly leg and slight vision issues The formulation of the rebif changed early last year, and after a few months of being on that, I started getting back ache, which worstened when moving up to 44 in september. At the same time I moved from the rebiject to the rebismart. The site reactions were supposed to be a lot less, but I found them even worse. I also got stomach/constipation issues, which got so bad and constant that I was taken off the injections. I still have the stomach aches but to a lesser degree (only stopped rebif in february) and hopefully they will be better in a few months when the rebif is fully out of the system. I do worry though what comes next. I have been advised that tysabri might be good - but the thought of possibly taking tablets instead gives me hope.
130	**Mar 27, 2010 2:40 PM**	Rebif provided no change in the pattern, frequency or severity of relapses. I had approximately four relapses in the 18 months I took it, which was the same number of replases I had when not on any DMD. I have been taking Copaxone for over two and a half years and have not had an acute relapse in that time.
131	**Mar 27, 2010 2:45 PM**	Relapses are a nightmare, particularly as they are so unpredictable. I know that employers are deeply sceptical about employing someone with RRMS, and frankly I don't blame them. Who wants an employee who could get sick at any time, and who could be off for months with a potentially reduced ability upon their return. I still work but while I think the DMD may have initially helped with reduction of relapses, they

132	**Mar 27, 2010 3:37 PM**	may not have done and certainly aren't now. I find the injection a horrifying experience, I get cold, sweaty and shaky - this is before I inject! I think it is called terror! I hate the injection itself; it is painful. I don't like the horrible bruising and marks all over me. Even if I thought the DMDs were doing me the world of good I would still resent the injections and hate injecting myself and the side effects. Now that I am no longer convinced that the DMDs are doing anything of benefit, I am strongly tempted to stop altogether, but in the absence of any alternative, this is a drastic step to take and one I am afraid to take. My experience of relapses mean that I struggle to cope each day during one as I have to constantly consider the impact of the disease modifying drug on my insulin as the control of my diabetes is significantly affected during a relapse. An illustration of this is that once when I went hypo - as my insulin had become out of control due to the MS relapse- I was in the house on my own and I totally lost the use of my legs. I managed to drag myself on the floor from the lounge to the kitchen but I was unable to pull myself up to reach any food - luckily I was able to get a chocolate biscuit from my briefcase. I also once went to the toilet and then my legs collapsed and I was unable to stand up. I had not been hypo but I became so due to the stress caused as I could not open the toilet door either; luckily, on this occasion, my husband heard me and was able to help.
133	**Mar 27, 2010 3:47 PM**	I feel although I don't particularly like the injections, they are not really a problem and currently I have been a year without a relapse! First time since being diagnosed 6 years ago! So because of that I'm more than happy with taking the injection.
134	**Mar 27, 2010 4:10 PM**	I have never found a problem with taklng daily injections of copaxone and have travelled often abroad with no problems.
135	**Mar 27, 2010 4:11 PM**	I constantly suffer from chronic fatigue
136	**Mar 27, 2010 4:19 PM**	It is impossible to say how beneficial they have been to me personally which I find difficult. I would like to feel that it was definitely worth the tender blotches , muscle pain etc
137	**Mar 27, 2010 4:25 PM**	Since starting Rebif I have experienced a lot of nasty side-effects including unpleasant site reactions that last for weeks. From the research I've done the DMD's don't seem to have a great effect on either reducing relapses or disease progression in the long-term, so I often wonder why I'm putting myself through it all!!
138	**Mar 27, 2010 4:28 PM**	To date I have resisted taking medication as I have been fortunate enough not to have prolonged relapses. However, were my situation to worsen I would rather taken oral medication than any other form.
139	**Mar 27, 2010 5:01 PM**	Self injecting has become routine now after 9 years and seems to be working well for me.
140	**Mar 27, 2010 5:48 PM**	I have been on the drugs trial for Fingolimod for over three years now, and on the whole I have been quite "well". I feel I am doing something positive against this disease, as when I was offered DMD's originally it just filled me full of dread the thought of either me or a loved one having to inject me regularly.
141	**Mar 27, 2010 6:01 PM**	I am fortunate that I havent had to take drugs as yet but I do know that relapses make me feel awful and debilitated and it is very hard to explain to you family why you feel like you do.
142	**Mar 27, 2010 6:07 PM**	When experiencing a relapse this has an impact on my whole life and that of those closest to me. There is always the underlying fear/concern that a relapse may occur and how or whether this will affect my level of functioning and deterioration in the long term if recovery is not complete.

Taking disease modifying treatment has now become part of my routine, though there has been the rare occassion I have just considered maybe discontinuing the treatment as I am unsure whether there is an overall benefit and wheher the experience of the itchiness and soreness is worth it. However those are the days when I feel particularly sorry for myself!
Dear MS Group,

I have Multiple Scleros MS + Trigeminal Neuralgia TN. There is also a TN website

Currently take Amytriptiline and Tegratol Retard to try to control the pain. Please forgive me for any spelling errors.

Apart From trying to monitor my Jaw pains right hand side.

I have problems with my balance. I also wear a splint on my right leg. MS Currently use a walker to get about. I try to rely on this rather than use a wheelchair while I am able.

I try to regulate the tablets which I take for TN. I feel that the tablets I take can and do upset the usage of my leg/balance. Whilst I have cut down. Currently seem to have more usage in my right leg. I can still bend my right knee though it is rather stiff and hard going. My right ankle hardly works at all and the splint helps the right foot from dropping.

I hope that I am able to/allowed to use the recently develeoped tablets. Also if I am allowed to, my symptoms do not get worse. Hopefully my condition will improve.

Thank you for reading my email.

I am not very good at using/getting on to this computer.

Best wishes to all sufferers. Also I hope that there will be further scientific develeopments, and that we can be optimistic for the future.

Yours faithfully,

143 **Mar 27, 2010 6:16 PM** AEDMUSCODE

144	**Mar 27, 2010 6:39 PM**	[redacted] I have only had very slight side effects from the medication and that was at the early stages of taking it.
145	**Mar 27, 2010 6:58 PM**	The flu like symptoms I get from avonex does alter what I do on the day I take it and the following day I also experience a relapse every couple of years. Compared to some people Im lucky but if there was another safe drug to take that was more effective and had less side effects that would be great.
146	**Mar 27, 2010 7:32 PM**	no info on coming off effects. and fear of not getting back on the scheme because of the cost.
147	**Mar 27, 2010 7:34 PM**	loss of vision in a relapse. Mix up getting delivery of copaxone. Fab service from connextion team (Copaxone) always call me to see how things are going and if I need anything or just want to talk about the treatment. Good experience with Mitoxantrone in stabaising my MS. I hate injecting and hate having to get my husband to inject me too
148	**Mar 27, 2010 8:11 PM**	Relapses change your life completely - not the same person at all any more. DMD are difficult to handle at time because of the bad side effects (not each week but for me I would say 3/5 weeks are a problem to me and I have had to live my life around this which is sometimes difficult, not only for me but my family too.
149	**Mar 27, 2010 8:14 PM**	The drug I was on did reduce my relapses - a third of 4 or 5 per year was/is worth all the bother of injections. Life is much better than it was. Before being on my first drug I had in one year - double vision, then one leg not working as it should, then falling/tripping due to feet having strange feelings and not going where they should, then half face becoming numb and scratching eye leading to problems in eye .... I felt that MS was really taking over my life. My first course of injections I felt was really working and I was very unhappy when MS Nurse told me to stop injecting as my blood was being affected. I had no idea what was happening to my blood, but I felt the drug was really helping to reduce the relapses. When I met with my consultant I told her I was very disappointed as it been the first time I had anything to help my MS. She Has now put me on another drug - still injecting.
150	**Mar 27, 2010 9:32 PM**	My initial response, when I heard these new tablet form drugs were to become available and I immediately contacted my MS nurse, to ask if I would become eligible when the drugs became available. She could not guarantee that I would be give these....but I am hopeful...
151	**Mar 27,**	Relapses really suck!!!

	2010 10:19 PM	
152	**Mar 28, 2010 3:50 AM**	My symptoms and relapses have been relatively mild to date, but I they are becoming more frequent and severe, but so far I have manged not to take any drugs. My neurologist offereed beta-antiferon, but we agreed that this stage it was not necessary. My symptoms consist of permanent numbness/pins & needles in my right arm and over the last week a feeling like I have a 10kg weight strapped to my legs. This is the third time I have experienced the "heavy" legs. First time I took a short course of steroids, but the second time I let it run its course.
153	**Mar 28, 2010 9:14 AM**	I tried Rebif for a short while, but did not stay on it long enough to feel any benefit as it hurt too much. I then went onto Copaxone, which worked fantastic and enabled me to walk properly again, but I could not carry on with it, because the longer I used it the worse the pain got, which was causing me to be very anxious. It was making taking the drug by injection truly impossible. I was gutted.
154	**Mar 28, 2010 9:48 AM**	preparing people to manage the usual side effects of Bet Interferon= fever and importance of injection site rotation is key to them starting off well and continuing on their meds - the MS Specialist Nurse is key to this preparation. With the new pills I am concernned that people may assume that a pill is easily popped but not appreciate that these are heavyweight compounds which may have nasty side effects and that close monitoring bloods etc will need to be in place for their safe use.
155	**Mar 28, 2010 10:13 AM**	Injections are not a long term solution - there are only so many sites a body can put up with and after 3 years of daily injections, I have discussed with my MS nurse whether to give up the treatment for this reason. She persuaded me to keep going as the treatment (Copaxone) seems to help but I don't feel I can keep doing this much longer. I tried Avonex prior to Copaxone but had bad reactions in terms of flu symptoms & depression, so cannot try an Interferon based treatment again even if it does mean fewer injections.
156	**Mar 28, 2010 11:41 AM**	Since I have been taking Rebif (6 months), I have not had any relapses, whereas before starting the treatment I had several relapses one after the other.
157	**Mar 28, 2010 11:53 AM**	they help
158	**Mar 28, 2010 11:59 AM**	My relapses are mainly sensory so do not affect my ability to go about my day to day living greatly. Due to the change in feeling in my legs I no longer felt safe to work in my original job role when diagnosed therefore left for an office job. This lead to an episode of anxiety and mild depression which still bothers me from time to time. I have no problem injecting 3 times a week. I learnt to inject other people for my role some time before I started on interferon so easily moved to self injecting without any auto injector. It does involve planning when going on holiday as a fridge is needed in hotter climates, airlines need to be notified and delivery company contacted. I experience pain when injecting into my thighs and get skin reactions. More recently I have experienced flu like symptoms bad enough to require a day off work. It seems that a pill, like any other pill would make life easier in terms of the practicalities of a medication and would be easier to take regularly without any trepidation and pain.
159	**Mar 28, 2010 12:30 PM**	The thought of self-administering a drug by injection was, initially, very scary. This was also at a time when I was recovering from a disabling relapse and was very worried about my future so it was an extra worry I could have done without.

160	**Mar 28, 2010 1:38 PM**	I feel I have benefited greatly from the drug Rebif 44 mg over the past nearly 7 years. Relapses have not ceased but they are less severe and disabling than in earlier times (my MS was diagnosed in 1982 and has been a constant factor affecting my work and life over the years. I do not feel that strongly about the pill option but if i had to inject daily rather than 3x a wk then I certainly would!
161	**Mar 28, 2010 1:44 PM**	I would welcome any drugs that could be prescribed. I have had 4 bad relapses in the last 14 months causing me to have to take 6 months off work in total. I have now been made redundant and wonder if it was because of the disability? Anything to make life easier would be very beneficial to me and my family & friends.
162	**Mar 28, 2010 1:51 PM**	I even had some hypnosis sessions once to try to overcome the fear that I felt leading upto my weekly injection. Worked for a while but eventually the effect waned. I also have to work myself up to it, since giving yourself an injection deep into your muscle can be parelled with stabbing yourself. Not a natural human action to do 'damage' to yourself. I can be very down around injection time which you cannot necessarily share with others.
163	**Mar 28, 2010 2:58 PM**	I was diagnosed in 1998 with relapsing remitting ms, which proved to be very aggressive; I used to have about 10 severe relapses a year before I began my Rebif treatment. Unfortunately for me an awful lot of nerve damage occurred during those initial first years, resulting in me becoming very disabled, very quickly, leading to my early retirement. I have always had side effects; they are sometimes mild, sometimes awful! My ability is always diminished the following day after an injection, I have to take ibuprofen or paracetamol to counteract the worst of it! Rebif has definately slowed down my relapse rate, and my relapses are a fraction of the severity that they used to be. I really hope that a less bothersome treatment becomes available very soon…
		my relapses have been frequent un warned and has affected my ability to function independently and has had severe impact on my ability to work. I am currently unable to feel the right side of my body and cannot use my writing right hand and i am relying on the use of my left hand which i had lost sensation last year. I am also unable to lift my right leg nor move my toes so mobility is poor. I am wholly reliant on my partner to function within my home and the thought of a new drug which would reduce the relapses would be greatly welcomed
164	**Mar 28, 2010 4:06 PM**	I was meant to start rebif injection a couple of months ago however a suffered a rare blood clot in my brain which has led me needing to take warfarrin daily which rebif will interact with and injections will be more problemayic
165	**Mar 28, 2010 4:19 PM**	My relapses became more severe and more frequent after taking Avonex for 9 months. I continued to take it for a further 12 months but the side efects were interferring with my daily life and I couldn't see the benefit in aking it any longer. I lost faith in these dmds and now take nothing but Gabapentin for the pain and a vitamin D supplement.

166	**Mar 28, 2010 4:21 PM**	i was on copaxone first and had side effects like painful breast which i had for 4 months and several other side effects but then it was causing skin damage that was 18 months that i was on that injection, i have been on Avenex for just over 2 years but from the first day i started taking them i have a bad bad headache right after i have had my injection which lasts for about 4 days then i'm ok for 2 but then it's time again for it again i had night sweats and feeling cold, flu type syptoms, bad hallucinations, difficult sleeping. bad muscle cramps, pains in legs there have been many side effects from both of the injections which were not very pleasant at all. There is also the hassle of keeping the drug in the fridge (away from the children). There is all the paraphinalia with the equipment needed. Sharps box, auto injecter. Having to think about taking it all on holiday. Will there be a fridge to keep the Rebif in? A place to store it at home. Being in when the delivery van comes every month.
167	**Mar 28, 2010 4:47 PM**	Taking a tablet would be so much more convenient.
168	**Mar 28, 2010 5:41 PM**	I feel well on Copaxone and have not had a relapse since taking it but it is gradually ruining the areas where injected by leaving a permanent cellulite effect and there is less fat left to use for future injections so I can't view it as a long term treatment in the future
169	**Mar 28, 2010 5:55 PM**	When I was originally diagnosed in 1976, I was injecting every day with ACTH. The experience I had with that has put me off injecting myself for ever!!!!
170	**Mar 28, 2010 6:07 PM**	Disease modifying drugs have allowed me to keep working (along with sheer bloody determination). Injecting myself is a skill I have learnt and side effects are small price for me to pay. I do worry that having developed a resistance to Avonex the same will happen with Beta-feron.
171	**Mar 28, 2010 7:02 PM**	G.Ps could be better informed and take things a little more seriously than your usual 4 minute appointment allows.
172	**Mar 28, 2010 7:07 PM**	i have been fortunate to have been given the drug Campath for my acute MS. I used to suffer from very bad relapses at least one big attack every few months most of them leaving me unable to walk for weeks on end. Just when I had started to recover from one bad attack and it was normally the beginning of yet another relapse. Since taking Campath in 2007 I have had a new lease of life, and havent experienced a bad relapse since August 2007. I still have residual symptoms and sometimes I suffer from very minor relapses, normally only lasting between 24 and 48 hours but nothing as bad as I used to get in the past. Access to the latest Drugs and the continuation of effective research is vital for all us MS suffferers as it provides us with options and for hope.
173	**Mar 28, 2010 7:28 PM**	i know it is not a cure but i will try anything that might help, and that i might be able to feel normal
174	**Mar 28, 2010 8:24 PM**	I hate injection night even after all these years..... and the 24 hours after!!
175	**Mar 28, 2010 8:24 PM**	Regular appointments to discuss the drug and monitor for side effects was reassuring.
176	**Mar 29, 2010 7:15 AM**	Whilst injecting is fairly straightforward, it can be quite uncomfortable and taking a tablet daily would be so much easier and simpler.
177	**Mar 29, 2010 8:27 AM**	Before I was put on Copaxone I had several major relapse that had left me compleatly paralysed in both arms and legs, unable to talk or eat normal food and severe double vision. The last major relase kept me in hospital for three months. I also had a DVT while in hospital because of lack of movement in my limbs. Since

		being on this drug I have had minor ups and downs but nothing to hospitalise me.
178	**Mar 29, 2010 8:39 AM**	I take Avonex on a weekly basis, and although my relapses feels under control I feel that I have to give up a day every week to deal with the side effects of Avonex, this is invariably at the weekend which means I have to give up 24hrs of my free time each week to dealing with the side effects. In addition the injecting process can be quite a strain mentally.
179	**Mar 29, 2010 9:03 AM**	People don,t realise how debilitating this desease is, and in a lot of cases can,t be seen on the outside. The treatments I have had over the last thirty years have been Steroids, Tegretol and now I'm taking Gabapentin and Destrusitol for my bladder. I have relapsing remitting MS although it's been more relapsing in the last 12 months.
180	**Mar 29, 2010 9:23 AM**	Initially the injections are scary, they are painful & leave your skin bruised. Going on holiday is a nusiance getting your medication through the airport, all your equipment has to be searched!!! A pill would be amazing, please, please hurry
181	**Mar 29, 2010 9:46 AM**	A relapse must be the most frightening thing to happen in one's life. You never know how long its going to last and what effect it is going to have on you and all the people around you. When you are no longer in control of your body/mind you feel so lonely, dpressed and vulnerable.
182	**Mar 29, 2010 10:39 AM**	I didnt realise how bad the rebif injections were making me feel until I stopped taking them. I am unsure if they assisted with decreasing relapses as I wasnt on them for very long due to the reactions andmy relapses are not hugely frequent although obviously I met the criteria for the treatment
183	**Mar 29, 2010 10:49 AM**	I am hypersensitive to medication side effects, so although, I believe that being on DMTs has reduced my number of relapses over the years, I have at times been unable to manage the side effects and have had to come off interferron completely. Now that I'm on Copaxone I feel well, but have a lot of pain after the injection and I worry a lot about eventual lipoatrophy. I am eager for a DMT in the form of a tablet to be approved, though I worry that I would not be able to take it because of its side effects.
184	**Mar 29, 2010 10:50 AM**	My relapses make me feel suicidal. Fortunately, I have a child and he makes giving up an impossibility. Any chance of having a drug that would ease some of my everyday difficulties and one that I could easily administer in a pill form is my one big hope. It would give me a future to look forward to.
185	**Mar 29, 2010 11:07 AM**	Once or twice I have been able to have a short course of steroids to clear up some symptoms of a relapse, but I am not keen to take them too often. I do not have many relapses and for the most part I am fit and well and able to carry on with a normal life with no problems. I feel that Rebif is helping and if I was not taking it I could be having more relapses.
186	**Mar 29, 2010 11:16 AM**	Relapses are a constant reminder of the progression of the disease. You are always aware that you will be less able after one and that it is a progressive disease. Injecting medication requires a lot of planning ,particularly when going on holiday.Access to fridges for storage isn't always available. You are also at the risk of syriges or injectors not working as they should.
187	**Mar 29, 2010**	i don't know if it is because of taking the rebif or just luck, but no significant relapses since taking it.

	11:26 AM	I felt extremely nervous and frightened when first told I would need to take the drugs - I became depressed at this time as the enormity of my diagnosis hit home, that this was it for life until the drugs stopped working. I think that if I was told that I could take a pill, it would have made life easier and less daunting, rather than having to decide how many times a week I wanted to be injected. With the Rebif (3 times a week) injections I had to plan my week to fit them in, it's easy to say it only takes 5 minutes to do the injection, at times it would take up to 30 mins to calm myself down enough to have the injections.
188	Mar 29, 2010 11:27 AM	Travelling is made more stressful as you have to ensure that 1) you can take the drugs with you on teh plane etc. and b) that your accomodation is suitable for storing the drugs. Also, you then have to plan your holiday around the injection.
189	Mar 29, 2010 11:47 AM	Relapses are an intrusion to normal life and the drugs are only partly effective. Sometimes the side effects are worse than the relapse symptoms. Medication needs to be effective and unintrusive, medication that can be self-adminstered at home gives greater independance to the patient.
190	Mar 29, 2010 12:10 PM	I have been taking Rebif now since the year after diagnosis, it however has never been a problem to me, my family have always said they wouldnt be able to inject me, so with the new oral medication, it seems more suitable for me and my family. I am thinking of my family in the long term, and the oral medication is more suited to them, I am however fearful that they do not work as effectively as the Rebif, but for my family I want/wish to change to the pill form as soon as possible.
191	Mar 29, 2010 12:17 PM	I suffered Post-natal depression which stemmed from my absolute fear of having a relapse and not being able to look after my daughter. This was coupled with anxiety attacks caused by fear of not getting enough sleep, becoming run down and then having a relapse. This desperately impacted my first 8 weeks after birth, which I'll never get back (was my first child). I haven't taken any steps for drugs as yet because injections seem so drastic and to be honest scares me.
192	Mar 29, 2010 12:25 PM	Take avonex - still have cold/flu like symptoms almost 3 years on since starting treatment. Tried Copaxone instead, but only lasted a week as the skin site reactions were awful. Lump like size of an egg, must have had an allergy to the ingredients. so went back on Avonex, trying to live with the side effects again as not other drugs at this time. However, had no relapses while on Avonex (could be coincidence but cannot be proven either way)
193	Mar 29, 2010 12:33 PM	I have relapsing remitting MS at present, but I feel that I am getting worse generally. I am to see a neurologist this week, and have been led to believe (by my MS nurse) that he will suggest a self-injected drug. I don't want to face it.
194	Mar 29, 2010 1:03 PM	I haven't had many relapses and disease hasn't really progressed - since taking Betaferon
195	Mar 29, 2010 1:42 PM	It becomes increasingly difficult to identify what is a relapse, (due to progression) and therefore monitoring the effectiveness of a taken medication is difficult/impossible.
196	Mar 29, 2010 1:55 PM	Rebif can only reduce th number of relapses. I have had a few relapses during the past two years. One, I'm convinced, brought on by stress in the work place, 25 years in the NHS. One brought on by a very heavy cold and now I'm told that my medication is under threat as I'm unable to walk 100m. unaided. I wish! So I'm

		feeling a little low at the moment and fighting my way through my current relapse. Since being on Rebif I've not suffered the dreadful fatigue that used to be my lot
197	**Mar 29, 2010 2:26 PM**	Travel with syringes, esp airports and flying, often difficult. Intramuscular injection is tiresome.
198	**Mar 29, 2010 2:28 PM**	I feel generally frustrated with there being so much said about MS but so little apparent recorded facts of the illness throughout the country where comparisons can be made and steps or lack of them justified.
199	**Mar 29, 2010 2:47 PM**	Weekly intramuscular injections are unpleasant. I imagine daily injections would be equally unnerving. The whole process is fairly hard to do when it is not actually making you feel better afterwards (generally worse for 24hrs), just slowing down the process of getting worse. If you have a head ache you take a pain killer and you feel better an hour later. Disease modifying drugs don't make you feel better or improve you, they just help your prognosis long term.
200	**Mar 29, 2010 2:56 PM**	I hated taking Betaferon - every other day the injection loomed and reminded me that I have MS. It was so painful! My bottom ended up covered in red wheels, puckered, with deep dips and very sore. The fat displacement is also unattractive. I still have these deep, irregular, subcutaneous pits and they are sensitive to sit on, 5 years after I stopped injecting the drug!
201	**Mar 29, 2010 3:01 PM**	The benifits of the Capaxone to my MS have been wonderful. It was difficult injecting every day but I am used to it now and only need help to inject where I can not reach. The only problem was going on holiday and keeping our fridge cool enough in our caravan while we were travelling. Hopefully this will be sorted out this year. I have not had the courage to fly with my needles etc as I dont feel confident taking every thing with me and having to keep the temperature correct for the Capaxone. Also having to explain everything to customs is a cause of concern.
202	**Mar 29, 2010 3:05 PM**	I am just using 22mg and yet I have a my high liver Enzyme is slightly high. I was advice by my doctor to keep injective beta interferon rebif
203	**Mar 29, 2010 3:41 PM**	I personally have serious side effects from taking rebif (peripheral neropathy, severe, headaches, worsening of raynauds diseas) I felt I was not taken off rebif early enough despite my reports to my MS nuses on my 3 monthly checks of the symptoms I was experiencing listed above. I was on rebif for 8 years. Unfortunately despite comming off rebif 12 months ago the side effects from this drug have left permenant damage. In my view the monioring of this drug treatment was inefficient.
204	**Mar 29, 2010 3:47 PM**	I felt my relapses were sometimes difficult to deal with, they left me feeling very lethargic with no energy to do thing. I felt that taking the drugswould make me feel better, but they didn't.
205	**Mar 29, 2010 4:06 PM**	I THINK TABLETS ARE A GOOD IDEA, AS THEY CAN EASILY BE FITTED INTO YOUR DAILY ROUTINE AND YOU PROBABLY WON'T NEED HELP TAKING THEM. THEY ARE ALSO DISCREET. I WAS'NT SQEAMISH ABOUT INJECTING MYSELF AFTER THE FIRST COUPLE OF TIMES, BUT DID NEED HELP WHEN IT CAME TO INJECTING MY BOTTOM. SO SOMEONE ELSE MAY BE SQEAMISH, EVEN WITH AN AUTO-INJECTOR. WHEN YOU GO AWAY IT CAUSES PROBLEMS - DO YOU GO SELF CATERING FOR A FRIDGE OR DO YOU ASK YOUR HOST TO STORE IT FOR YOU? THEY MIGHT NOT LIKE YOU INJECTING YOURSELF? I WOULD NOT WANT TO GO TO HOSPITAL MONTHLY FOR A DRIP - YOU SPEND ENOUGH TIME THERE OR WITH OTHER MEDICAL PROFFESSIONALS. AND IT ISN'T JUST THE TIME IT TAKES FOR THE DRIP, ITS THE RECOVERY TIME TOO. AND HAVING SOMEONE TO GO WITH YOU.
206	**Mar 29, 2010 4:34 PM**	I have been fortunate enough to have been one of the very first people on the risk-sharing scheme for Copaxone. I have never had a relapse and I believe that is thanks to the medication I take. I would want to be assured that any new drug would be as effective and suitable for me as Copaxone has been.

207	**Mar 29, 2010 4:52 PM**	The relapses are frightening and I never am quite sure what will happen in the future. Also, I am not sure my medicine is actually going to help me or is helping and I worry about it.
208	**Mar 29, 2010 4:57 PM**	I havent suffered a relapse for a while I dont think hopefully the drug and lifestyle may be helping. I am taking Avonex again after stopping for a while because of possible misinterpreted side effects. Since restarting the drug and administering by use of an autoinjector in the legs and taking Brufen half an hour before administerinmg the side effects are gone to my knowledge. I have found forgetting Brufen means the side effects return for that injection period (strange but true). I take Avonex because without it there is absolutely no defence against the disease apart from injecting more often!! The new oral therapes would make a magnitude of difference for every reason.
209	**Mar 29, 2010 5:22 PM**	I developed MS in 2007 and from May to October, both legs were numb from below the knee, it was horrible, like walking on stilts, I could see my toes but was not able to move them. I watched Benny Hinn on the television in October 2007 and he said, "somebody who is watching has been cured of their numbness." A fortnight later, the feeling came back in both my legs so I am convinced he healed me throught the television. I had a stage at Easter 2008 when my fingers became very stiff and it was hard to write so I made myself write e-mails every day and now they are fine. In January the muscles in my back became very stiff but happily I am staying with my family in Dubai till July 6th and with the sun and warmth out here, they are slowly beginning to unstiffen. I was prescribed Gabapentine for burning sensations but after about a week of taking it, I was admitted to Margate hospital as I thought I was having a heart attack as I could not breathe, felt faint and had cold sweats so I am never going to take it again!
210	**Mar 29, 2010 5:46 PM**	As i said previously i am really scared of needles so would be glad of a pill being available. Also when having a relapse i have to go into hospital to have intrevenous steroids for three days so if there was a pill avalible which would prevent that it would be a good thing,
211	**Mar 29, 2010 5:48 PM**	I've been injecting for several years now but I was terrified of self-injecting when it was first suggested and am very thankful to my MS nurse for the help and support she gave me
212	**Mar 29, 2010 6:15 PM**	My MS has improved since I started LDN in Nov.2008.Why don't you do a survey on that?
213	**Mar 29, 2010 6:41 PM**	is sore and i HATE doing it
214	**Mar 29, 2010 6:53 PM**	GP's take a reactive rather that proactive line of treatment. Their lack of knowledge of MS symptoms (even if they have the MRI results) does not inspire confidence. If I visit a GP when I have a relapse the first thing they ask is if I would like steroids. More education please.
215	**Mar 29, 2010 7:29 PM**	I was given Copaxone whilst having Mitoxantrone (which also involved steroids). There was very little information about either of the drugs (I relied on the internet). I had no idea, when I started using Copaxone, how bad the bruises would be up to 12 months after having chemo and would have given the Copaxone up only I thought "persevere, there are people worse off than you". There was nobody to show me how to use the Copaxone as my MS nurse had gone on maternity leave. I had to reply on the DVD in the bag and my own GP nurse (who tried to take the air bubble out). She had never heard of it before. My cognitive problems meant I had to rely heavily on my husband to make sure I was administering it correctly.
216	**Mar 29, 2010 7:47 PM**	First drug used was Copaxone, which caused "scary" post-injection side effect: shortness of breath, tightness in chest, tightness going rapidly up arms, seemed to lose awareness for short time and was unable to speak (even though I though I was speaking). Also daily injecting was annoying as it seemed to take over my life.

		Now on Rebif. Three times weekly injecting is better and can alter the days if necessary to suit what I'm doing. The downside is I'm still experiencing flu-like side-effects 18 months on - which also takes over my life. Difficult to tell if frequency of relapses has changed as I can nearly always detect something going on, but severity is much reduced. Taking Rebif from October 1994 until May 2006 at first was very effective in reducing frequency of relapses. From Feb 2004 forward relapses returned with their previous frequency, and when I experienced abcesses that ulcerated on the injection sites, it was agreed that I stop taking the drug.
217	**Mar 29, 2010 8:10 PM**	The act of injecting 3 times per week was never pleasant but it had to be done. An oral version would have been welcomed.
218	**Mar 29, 2010 8:26 PM**	I was diagnosed with rapidly evolving MS in Feb 2009. I started on Tysabri in March 2009 and I have not had a relapse since. I still have problems with my mobility and speech from my previous relapses but after 17 months of sickness absence from work I am finally stable enough to go back to work. That's all thanks to the Tyasbri.
219	**Mar 29, 2010 8:32 PM**	I have had MS 17 years, 12 years Betaferon 1B. Age 38,years old.
220	**Mar 29, 2010 8:33 PM**	I absolutely loathe taking injectable DMDs. I fid that If I have had a bad day at work and am feeling stressed and tense then te injection itself is painful -this is followed by approx 48hrs of flu symptoms. Due to these symptoms I have had to go part time at work. It is hard to explain the impact that having a weekly dose of flu has on your life - suffice to say that it is not a positive one!
221	**Mar 29, 2010 8:40 PM**	The skin reaction at the site of the injection a couple of days after administering Copaxone leads to uncomfortable itching, redness and pain when touched.
222	**Mar 29, 2010 8:49 PM**	Just push for the oral drug to be made available on the nhs.
223	**Mar 29, 2010 9:06 PM**	various problems with my liver enzymes which I understand is due to the drug treatment (rebif)
224	**Mar 29, 2010 9:21 PM**	As I never know when the relapses are going to occur, I am afraid to arrange anything in advance - last year I had to cancel 3 summer trips (including a cruise) because of the fear of being unable to cope, which was caused by a relapse just before I was due to go; this resulted in a breakdown. Relapses make sustaining full-time work so much more difficult as they make each day such an effort and I am exhausted, although I still manage to hold down a responsible job. In 10 years of having RRMS I have not been able to pin down one thing which causes, prolongs or eases my symptoms, which are now starting to include random, sometimes severe, pain.
225	**Mar 29,**	I found that taking paracetamol prior to injecting mitigated the side effects. I took

	2010 9:33 PM	paracetamol during the period of titration and for the first month of taking Rebif at the full strength.
226	**Mar 29, 2010 10:27 PM**	I've been on Rebif for about 7 months. No definite relapse during this time. However I have felt MS symptoms have flared up for a approx 3 week period during this time. Discussed with MS Nurse and we decided not to take any intervention action. Will discuss with Neurologist at next appointment. Its unpleasant having to store my injections (copaxone) in the fridge and having to have a sharps box in my house and to take one on holiday if there could be an effective alternative to injections that would be wonderful !!!
227	**Mar 30, 2010 1:45 AM**	I have been newly diagnosed with relapsing remitting MS and as yet have not needed medication. But between the last two relapses it has only been 10 months with an increase in symptoms. I am constantly scared about my future as am only 26 and nobdy can give you an answer to how exactly it will progress for me. If there was medication which was available and proved to slow down the occurances of relapses then I feel this should be made available to sufferes.
228	**Mar 30, 2010 4:01 AM**	Having to deal with the stress of wondering when will the next new symptom appear or reappear one has to deal with the scheduling of medication, pain of the injection and time comsumption of administration once one adds the time to use heat or ice before and after the injection. (40 to 60 mins per day) Then one has to worry about the tissue damage and the ever decreasing number of sites over time. The same would be true of IV administration. Also the rare but nevertheless possibility of infection anytime one breaks the integrity of the skin.
229	**Mar 30, 2010 6:47 AM**	Only one minor relapse in 9 years - Rebif works for me!
230	**Mar 30, 2010 7:52 AM**	I have tried hypnotherapy to deal with my phobia of hypodermic needles, but this didn't help. I have seen a therapist/psychiatrist about my phobia, but with limited success. Although my relapses have been less frequent and less severe while taking DMDs, I often wish I could stop taking them, just to get some of my life back. I would much rather take a pill once a day instead of having to remember to do injections.
231	**Mar 30, 2010 9:32 AM**	Tysabri has stabalised my aggressive MS and for that I am so grateful and now I would like my life to continue without hospital visit after hospital visit if possible
232	**Mar 30, 2010 9:33 AM**	One of the nasty side effects of tysabri is PML but at least i am surrounded by doctors/nurses when i take drug. I am closely monitored as well - this wont happen taking a pill especially if that pill works in the same way as tysabri.
233	**Mar 30, 2010 9:45 AM**	My eyesight was very good until I went on Beta Interferon, and then my eyesight deteriorated. After coming off the drug, my eyesight has stabilised, but has not recoved it's previous standard.
234	**Mar 30, 2010 9:46 AM**	Every relapse I lose a little bit of 'me'.
235	**Mar 30, 2010 9:52 AM**	In 2007/early 2008 one relapse seem to merge into another and I must have had at least six of varying intensities. Since beginning Copaxone in March 2008 I have had one relapse in July that year but took steroids and carried on working (I had only just returned to work after a break of 18 months). As far as I am concerned, Copaxone has given me back my life although, in some ways it has backfired! While I was poorly in 2007, plans were set in motion to return to my native Yorkshire where I have family to support me and, frankly, I was not expecting to be able to

236	Mar 30, 2010 10:20 AM	return to work let alone maintain it if I did manage to go back. However, problems with the property market delayed my move for many months and I did not move until March last year (2009). At this point I felt disinclined to quit my job and put myself at the total mercy of the benefits' system so I opted to continue in the "short-term" doing a weekly round trip 500 mile commute from my home in Selby (near York) to Canterbury in Kent. Being an English teacher in Further Education and living a short (mobility) scooter ride from my local FE College I expected the arrangement to be short-lived but I find myself still doing this weekly journey (and staying 2 or 3 nights in a B&B) with no sign of an end. (This is both very tiring and expensive!) The problem is that my teaching job in Canterbury has been so diluted - under "reasonable adjustments" - that all chances of career progression have been halted along with slight possibility of new employment. Frankly, it's all rather a mess and, whilst I would not choose to give up the Copaxone, and remain extremely grateful for it, my regret is that I was not prescribed it sooner, opposed to waiting - under NICE Guidelines - for the disabling attacks (which have left me struggling to walk[I use a powered office chair at work and a mobility scooter outside]). With earlier prescribing I would have stood a better chance of maintaining my former teaching role and increasing my hours within one institution (I was previously doing a number of fractional contracts with separate employers over different locations) and following "Plan A". This plan was to increase my mortgage and purchase a flat close to Canterbury College (at the time new appartment blocks were being built opposite). So, to sum up, my main concern is for earlier prescribing! My specialist has not explained or offered them to me.
237	Mar 30, 2010 10:36 AM	I take Copaxone. I felt it started to partially work within a few weeks making the relapses less continuous and with breaks in between in which I felt totally normal and not tired, previously I had felt as if something was happening all the time and was continually tired. The relapses gradually reduced to 5-6 week intervals then after 8 months stopped altogether. After a year on the drugs I began to develop serious hives which only stopped when the dose was reduced to 6 times a week, missing 1 day. A daily pill would be great but it would have to have for me at least as good an effect as copaxone but without the hives. Traveling is sometimes a problem as the injections have to be refrigerated when away.
238	Mar 30, 2010 10:44 AM	As previosuly stated, injecting daily is both painful and inconvenient. It is somthing that daily I dread, It has howver, seemed to reduce my relapses but it is only an average of 30 per cent The new drugs offer a lot of hope to RRMS sufferers and should be made available to anyone who is eligible for them
239	Mar 30, 2010 10:56 AM	It is getting more uncomfortable to inject as the original sites around my body are now dented inwards and are now unsuitable for injection. I have contacted my MS nurse who has given me ideas on suitable places to inject. Unfortunately they are sites I have avoided previously - the sore injection site rubs on my clothes during the day. I injected Beta Interferon (Avonex) for 2 or 3 years as a weekly injection and I was suffering from flu like symtoms and relapsed on a regular basis. Have been on Copaxone for last six years and rarely relapsed, but injections is now uncomfortable on a regular basis. I put Anthisan on the injection site after injectioning which releaves some of the soreness and again the next day.
240	Mar 30, 2010 11:33 AM	When i first started REBIF i was happy that i had started some kind of treatment that would reduce my relapses. After a few months my wife repeatedly commented on my low mood including severe mood swings. After reading and speaking to other MS sufferers i came to the conclusion that it was the REBIF that was making me feel this way, so after 3 years of taking the medication i decided to stop injecting my DMD's (without telling anyone). After 2 months has elapsed my wife commented that i seemed happier and easier to live with in general. I then told my wife and MS Nurse

		of my decision to stop taking REBIF. My MS Nurse was fully supportive of my personal decision and so was my wife. I feel that if i had not stopped taking the REBIF then my marriage would have desolved. I now only take PROVOGIL for my fatigue and have not had a major relapse now since i stopped my REBIF in 2007.
241	**Mar 30, 2010 12:39 PM**	I have noyt had a relapse for many years. Now I worry about my future and the fact that at 68 years old, I am probably too old for treatment.
242	**Mar 30, 2010 2:02 PM**	the benefits of taking the drug has to outway the side effects
243	**Mar 30, 2010 2:20 PM**	The worst relapse i had was when i was taken off the drugs after the trial I felt that more damage was caused following relapses during this time
244	**Mar 30, 2010 2:41 PM**	Avonex was horrendous - it made me ill for two days every week, I was so ill I would have to pay someone to sleep over with me. Side effects would mean my legs would collapse so I would be unable to get to the toilet in the night, I would sweat, shake, my teeth would chatter, every muscle would hurt - awful. Copaxone doesn't give me any side effects, but it's a daily intrusion into my life and makes going away difficult.
245	**Mar 30, 2010 4:04 PM**	I have had awful relapses, where I have been unable to do anything for myself for months, until relapse passes, leaving you weak, feeling dreadful and depressed. Taking steriods makes you bloated and fat,
246	**Mar 30, 2010 4:07 PM**	spoke about when was on rebif
247	**Mar 30, 2010 4:47 PM**	The injections have definitely worked for me as i havent had a major relapse for 2 years but i still get caught out with fatique which is hugely frustrating and limiting my activities with the children the fatique just comes on whether i do to much or not. i still have sensations in face legs and feet and legs play up drag or limp or give way but if rest it subsides. i shouldnt complain as there are friends who have very bad mobility probs. fatique is the main prob for me i am overall pleased with treatment but would love a tab instead of inj. I was going to do a trial at walton for one of the tabs but my blood pressure was too low so couldnt do it.
248	**Mar 30, 2010 8:34 PM**	As understand my illness will worsen the more relapses I experience. Currenly Avonex reduces my relapse rate by @30 per cent and so any drug that could reduce my relapse rate even further will improve the quality of my future life.
249	**Mar 31, 2010 7:55 AM**	My relapses are fairly infrequent and I am sometimes given steriods for bad ones.
250	**Mar 31, 2010 8:23 AM**	The relapses I get with my Progressive Relapsing MS are cognitive and the one I am still experiencing was brought on by stress and lack of sleep.
251	**Mar 31, 2010 9:08 AM**	I have injectewd betaferon for 10 years now and I regard it as 'my friend'. It certainly appeared to reduce my relapse rat and together with intravenous steroids most of the relapse I experienced were short lived and even though a few symproms remain after a relapse I honestly believe things would be much worse had the relapses been more frequent and allowed to run their course.
252	**Mar 31, 2010 2:35 PM**	I undertstand these oral therapies are more effective than the existing DMDs. This is why I want access to these drugs. Also I recognise that as the years go on my abilty to inject may reduce.
253	**Mar 31, 2010 2:45 PM**	I have never been given any medication by my Hospital nureologist and only receive stemetil from my Dr during a relapse.
254	**Mar 31, 2010 2:49 PM**	I do find that relapses are only a couple of times a year, while administering rebif. I am sure this has helped me to lead a near " normal" life. I do still suffer with flu like symptoms, which i take ibroprofen for.

I recently had a very bad relapse after a bout of the seasonal Flu. Administering Rebif
was difficult as I had little strength to load my medication into the rebiject. A pill
would have been so much better.
You do not appear to differentiate between an attack and a relapse. They are quite
different. A relapse can occur literally from sitting on a hard chair which upsets my
system and I then find walking difficult. This tends to ameliorate fairly quickly. An
attack (T cells?) is scary. I have in the past lost the use of my legs, my arm, my sight
and the ability to go to the toilet. Most of these functions have returned, but not all.
Mar 31, Minor disabilities and tiredness are constant. Any tablet which has no, or very limited
2010 side effects and stops residual damage is good by me. I have, as yet, never taken
255 3:37 PM desease modifying drugs for MS.
My relapses have become shorter and less severe since taking copaxone-from 7-8
wks to 2 wks.

Mar 31,
2010 I still put off doing my injection because inserting the needle hurts and the copaxone
256 3:39 PM stings after I have done it. It is unpleasant and sometimes I just don't want to do it.
Relapses have become more sevre over time, although taking Rebif has minamised
these to nil within the last 14 months. Commencing rebif I suffered flu like symptoms
after each injection for a period of 2-3 months, that was 3 times per week. These
Mar 31, decreased after I began to take paracetamol 4 hours prior to, and at the same time
2010 as injection administration. Now I have no side effects at all. This does noy stop me
257 3:40 PM occassionaly worrying about possible future long term effects.
Mar 31,
2010
258 5:16 PM I hate having MS
I feel frustrated as I am very independent and I am very scared losing functionality.
If the risks are proportionate then I am very willing to try new treatments if it means
I am able to maintain a more normal life.

If there was a high risk treatment which could potentially cure my MS I would seize
the opportunity with both hands as I want to be normal again and not have to endure
debilitating relapses several times a year, which set me back so far and mean I have
rely on others to help me, when I just want to be able to do the things that everyone
else takes for granted.

More than anything else I WANT MY PRE-MS LIFE BACK, I want my energy, stamina,
ability to travel at the drop of a hat, to no longer suffer chronic unending pain, which
medication only dulls rather than relieves.

I want to live my life without worrying about waking up unable to move, or to be
unable visit certain places due to heat or humidity for fear I will be unable to move or
suffer more severe symptoms or suffer a relapse.

Mar 31, I am a young woman and I feel this disease limits my life in ways it should not, I
2010 want to take my medication to stay well but I hate having to take injections, they
259 5:42 PM hurt and make a mess of my skin, which me unhappy with my medication.
Mar 31,
2010 Have had MS for 12 yrs, diagnosed at 16. I have never been offered any of the
260 6:19 PM treatments?
Mar 31, The first two weeks of starting avonex I had the flu like symptoms. Since then my
2010 symptoms have been more like a period that is due. Since taking the Avonex I
261 6:23 PM haven't had any relapses
Mar 31, It can be difficult to recognise a relapse and when taking DMT it is disappointing if
262 2010 you do have one. Feel physio support would be beneficial at point of relapse to try to

	6:45 PM	minimise progress of disability.
263	Mar 31, 2010 7:07 PM	4-6 week intervals is fine
264	Mar 31, 2010 7:32 PM	Often my relapses came at night and would be like fireworks going off in my head. I had to walk up and down with the TV on until they went away. Afterwards I felts like I could sleep for a month. At the time my doctoe prescribed Carbamazepine to control the "explosions" and later Amitriptyline to help me sleep.
265	Mar 31, 2010 8:24 PM	I was diagnosed in 2007 & have had 3 relapses since. I am a clerical assistant & when I have relapse I lose vision in my left eye - Optic Neuritis, I have pain in my arm, leg & back & chest. The first relapse caused me to be off work for 8 months. The second relapse caused me to be away from work for 4 months. The most recent relapse was - in the words of my Doctor "nipped in the bud". The 5 day treatment of steroid infusion was a great benefit to me & I was only away from work for 1 week. I only work part-time now as the fatigue forces this. When I am tired I have more apparent congitive issues at home & work. I also stumble on a daily basis as my balance is very poor. My next appointment is with my consultant on 19th April & I am hoping he will change the current medications to prolong remissions between relapses. I take 225mg Pregabilin twice daily. Also 1 Modafinil tablet daily & 25mg Amytryptaline & .2micrograms of Desmopressin at night. I hope this will help with your study.
266	Mar 31, 2010 8:49 PM	I have only been taking Avonex for six months and, so far, it has been effective. Being told I would have to inject was probably harder for me than being told I had MS. Even though you have to get used to it and appreciate being offered the drug, it doesn't make it a pleasant treatment experience and the side effects generally mean that one night a week is written off as you feel lousy.
267	Mar 31, 2010 9:13 PM	The stress and anxiety caused by injections has almost as much effect on my quality of life as the MS condition itself.
268	Mar 31, 2010 10:22 PM	Feel injections may trigger relaspse
269	Apr 1, 2010 12:44 AM	What a nice section that you've put here, so I can tell you what I really think. I'm far from being alone, though. The MS Society can ONLY redeem itself, if they get on-board with the rest of the world in regards to CCSVI and the treatment to fix this VASCULAR CONDITION. That way, and ONLY that way, you can really prove yourselves as being there for MS Patients, and really wanting a cure. Come on, folks, get with it. Read Facebook... We're there and we're completely FED UP!! Look at the ms-ccsvi-uk page... you'll learn more than you ever imagined about the people you supposedly are supposed to be looking out for.
270	Apr 1, 2010 6:59 AM	I live overseas with no family support around me so simply have to just get on with life and do everything for myself. With a positive frame of mind it's entirely possible. When my legs get so heavy and walking is difficult, I shake it off and force myself to carry on. I feel injecting with Rebif is keeping the MS under control (to a point). I obviously don't know much about the new pills because if the drugs being injected are 'disease modifying', aren't the pills a 'disease modifying' drug as well? For me, it's purely if the pills do the same job then 100 per cent I'm all for it as there are very few parts of my body left to inject without pain.
271	Apr 1, 2010 10:10 AM	I would be very resistance to any suggestion to move from Rebiff to one of the oral compounds as I have not had a relapse for over three and a half years and whilst I still suffer from side effects, flu like symptoms and injection site reactions these are easily managed. I have great concerns tha the oral drugs are going to be pushed as the best treatment available but am concerned about there safety.
272	Apr 1, 2010	I hate the pain of the injection, then the side effects, it is an awful experience and so disruptive.

	10:33 AM	I found the flu-like side effects a major issue, all the other inconveniences and side effects were bearable. So for me, administering the injection, was NOT my biggest concern. If the drugs worked and didn't have such awful side effects (for me) then I would happily inject on a dialy basis.
273	**Apr 1, 2010 11:17 AM**	In the 2 1/2 years I took interferons I had no relapses - since stopping I have had many - I now take LDN which definitely helps and has no side effects. If the new tablet has the same side effects, the fact that it was a tablet not an injection would not encourage me to take it again.
274	**Apr 1, 2010 12:29 PM**	It was very frustrating when I had to wait the six weeks coming off Avonex (by the time I started on Tysabri I was in the middle of another relapse). That was the last relapse I had a year ago (fingers crossed it continues for a long time like this).
275	**Apr 1, 2010 12:38 PM**	I take a weekly injection. I dont suffer strong side effects but the following day is a bit of a write off - like a minor flu, tiredness and headaches etc and difficulties in concentrating. I can do very little on that day. To help ensure I can contnue with work I inject on Friday evenings which means that I get a 1 day weekend (the Saturday being a write off). I live with this but it can be very tiring and draining - physicaly, mentally and emotionaly.
276	**Apr 1, 2010 12:56 PM**	I was taking Avonex briefly but found the weekly stress of worrying about doing my injections was too much. I know can't even let anyone else inject me. I could cope with the side effects of taking the DMDs but just not the physical act of injecting. It now worries me that I am not on any medication at all.
277	**Apr 1, 2010 1:46 PM**	I've often been prescribed steroids for relapses, and even with the extra side effects that come with taking this orally I am very please that I haven't had to go to hospital influsions that I so often see people taking
278	**Apr 1, 2010 2:03 PM**	too scared for the injections !
279	**Apr 1, 2010 3:02 PM**	Am awaiting to see about drug therapy after my diagnosis in December last year.
280	**Apr 1, 2010 3:51 PM**	I cannot stress enough the problems that revolve around holding down a busy and stressful job and the effect that medication has on this. The injections never improved for me and I took time off due to the flu reactions, as the benefits never outweighed the bad reactions. A pill would allow people to manage to retain their jobs for longer - I am currently struggling to hold manage my job and would not be covered for a hospital appointment every month - I would have to take 12 days out of my holiday to cover this (or a minimum of 6 days - 12 half days). With my relapses increasing and the fatigue symptoms ever growing, help managing MS is vitally important.
281	**Apr 1, 2010 4:12 PM**	I have only recently been diagnosed with MS (4 months), however have retrospectively been diagnosed as having it for 5 years. The fact that there is disease modifiying drugs out there is wonderful. The fact that most are injections is less so. I have had varying side effects with my avonex, but realise its worth the perseverance in order to sustain my current level of health for as long as possible. I have been told by several medical proffesionals that I should be able to lead a 'normal' life, while this isnt strictly true as I have to loose part of my weekend to avonex side effects, a pill based drug would potentially re address this.

		Its clear even to me that a pill would be 'cheaper' to distribute, administer and ingest/recieve. It seems to me like a win win situation for everyone involved.
282	Apr 1, 2010 4:22 PM	I did take a break for a year from injecting Copaxone but was persuaded by my family to start back on it due to a relapse at the end of last year. I had forgotten how difficult it is to inject and now realised that my reasons for coming off it have not changed but I will continue for the sake of my family and the hope it is doing me some good in reducing relapse rates. I do not like the sore lumps and stinging from each injection and have been told they will reduce over time which I seem to remember I was told last time.
283	Apr 1, 2010 5:23 PM	One experience I had about 2 years ago involved and injection site becoming infected causing a cyst on my stomach. When the pain became excruciating I ended up in A&E at 2am having it lanced under local anaesthetic. This resulted in me having weeks off work (unpaid), a district nurse having to visit every day to dress the wound and I believe the incident triggered a relapse which has left me unable to use my right hand to write with ever since. So all in all, I can't imagine taking a pill would cause such disruption (and pain!)
284	Apr 1, 2010 5:56 PM	I have always gone 'in denial'. If I would realise what was happening maybe I could alleviate some of the effects and pain. I have never taken drugs but Anandin extra does not get at the pain.
285	Apr 1, 2010 6:58 PM	When using avonex I became very anxious about the jag and how I would feel the next day after using it. I recently changed to rebif, but don't know if the muscle pain in my legs is a relapse or caused by the drug.
286	Apr 1, 2010 6:58 PM	Injections can be very painful at times, they have caused unsightly lipoatrophy - they have been difficult to transport when on holiday, as we spend our holidays camping We have had to limit where we went camping in Europe to camping sites where we could have electricity to connect to a reliable fridge which we needed to buy transport the drug. We had a fridge failure in a heatwave year (that is the only couple of weeks I have missed taking the drug) and upgrading the fridge and electrical connections was expensive and takes up a lot of space to transport it all. Not at all convenient.
287	Apr 1, 2010 7:25 PM	I take Rebif and have had 2 relapses in the last year.
288	Apr 1, 2010 8:32 PM	I have been taking Avonex for six years but I still get flu like symptoms after injecting and also a red skin reaction at the injection site. My Neurologist says that this proves that I have not developed neutralising antibodies. This does not make me feel better about it! I dislike injecting because no-one else I know has to take medication in this way, it can also be quite painful. It makes me feel different from everyone else and there is no sign that it works. Occasionally I forget to inject before I go to bed by which time it is too late to do it that day. A pill would be so much more convenient as it would not need 30 minutes to come to room temperature.
289	Apr 1, 2010 9:40 PM	I like taking my disease modifying drugs . I feel at least I am doing something to fight this horrible disease.
290	Apr 2,	Th intervals of my relapses has been so close lately having been confined for almost

	2010 2:50 AM	twice a month.My Neurologist can't easily bring me back to Betaferon or Interferon or any MS disease modifying drug available in either Europe, U.S. or Canada because aside from we still have to order the med abroad, the cost of the med when it arrives here in the Philippines becomes skyrise. The irony of it all, Philippine government doesn't support patients of unknown specialty disease like MS.
291	Apr 2, 2010 10:51 AM	I had two relapses last year one straight after the other. These relapses can be very debilitating and take away your independence. I work part-time and when I have to have time off sick I feel I am letting people down. I am a Staff Nurse and am currently undertaking light duties as my mobility is not what it was. This upsets me greatly as I feel that due to MS I am unable to do the job I have so enjoyed for the last 8 years. I feel at the moment I will not be going back to my role as a 'Nurse' but taking on other tasks within the nursing team, I know this will be better for my health at this time. I am currently taking Avonex and have been on this for the past 3 years. I do these injections myself as I prefer it that way. It is not a pleasant experience and when I do have relapses I sometimes wonder whether this medication is working for me and is it worth the pain!!!! I am really hoping that oral medication would be available for me in the future.
292	Apr 2, 2010 11:51 AM	A reaction to Copaxone I have had three times in a year and is the scariest thing I have ever experienced. Afterwards it does make you feel wary when the next injection is due.
293	Apr 2, 2010 3:10 PM	each week on injection day i am allways reminded of my ms and the anxicety returns. it would be so easy to pop a pill.as im sure it would for anyone who has tio inject.
294	Apr 2, 2010 5:19 PM	Since starting daily injections of Copaxone I have had no relapses at all, whereas prior to this I had many relapses in close succession. Needing to give myself an injection after a long day (e.g. after a party, night out, long journey) can be difficult. Carrying all the paraphernalia - cool box, injector, sharps box, et al - when going away can be a nuisance, frankly. Finding somewhere private to inject isn't always easy. I can't Inject in some parts of my body myself, so need to rely on someone else (who isn't always around).
295	Apr 2, 2010 7:55 PM	Although I have had few relapses, I feel that the treatment with steroids which I received caused permnent damage - i.e. digestive problems, thinning of the skin and of the veins. I feel that the medical profession is often reluctant to explain the problems which can be experienced with treatments. The more clear the explanations the better.
296	Apr 2, 2010 8:35 PM	I have only recently been diagnosed and as of yet I don't know what type I have. At the moment I am very worried about my future and that of my family. I have recently moved a hundred miles away from my family and friends to start a new job and a new life.
297	Apr 3, 2010 10:16 AM	I had symptoms of Optic Neuritis on 20 Nov 2009 with white lesions shown up on my MRI. I was told that I could be given Cladribine but only within a 90 day period. I was also told that I might not even have MS and might not have any further symptoms. When I asked the question - when I have my second MRI in 90 days and if there is further white lesions could I start Cladribine I was told that this was not possible. I have now had my second MRI and it shows new lesions, I now cannot have the treatment that I want (Cladribine) so have to wait up until maybe a year when it might be legal to prescribe in this country - in the mean time my disease is as my neurologist puts it "slowly bubbling away" Please make this drug available so people like me can continue to get on with our lives with the reassurance that we are taking the best drug available in slowing down

		the progression of this disease. Thankyou.
298	Apr 3, 2010 10:30 AM	The DMD I am on has not worked and I cant take the others due to the side effects that I worry about. My recent relapse has meant I now cant walk, but maybe i would be walking if these better new drugs were available faster. I don't believe any of the DMD are good enough to help with my MS
299	Apr 3, 2010 12:06 PM	I find it very hard to deal with self injection and would be extremely happy if I could take a dmd orally.
300	Apr 3, 2010 2:21 PM	I had my second attack last year in october, i was given steriods which helped greatly reduce my symptoms and stabilize me, i however still feel fatigue and run down a lot but wont go to the doctor unless i get severe pain and numbness because i have a far of facing the injections frequently and the thought of the lack of options available makes me not want to discuss my problems with joint pains, sometimes numbness etc.
301	Apr 3, 2010 2:56 PM	I am a resident in Scotland. The treatment I have recieved has been excellent. The service from Clinovia and BUPA over delivery of the drug has also been first class. There is regular dialogue between the drug company and the specialist MS nurses. m Further i have moved inScotland from one health board to another area and the MS specialist NHS treatment was absolutely seamless and straightforward.
302	Apr 3, 2010 3:01 PM	Injections are painful I have ended up with bruises, red marks and blotchey skin. I also got asked if I was a drug addict by one lady.its inconvenient and it constantly reminds you about your illness.during a holiday I had to go back to the hotel to adminster my injection, then there's having to get a letter and getting taken aside at the airport like a criminal.
303	Apr 3, 2010 3:21 PM	Must admit I am happy to use Copaxone as prviously I was experiencing a lot of relapses ant these have lessened a great deal since I started on Copaxone. It is a great drug for me. I would love use a a pill as giving myself injections is so unpleasant---- and leaves me with sore patches
304	Apr 3, 2010 3:38 PM	I have had bad ractions from taking my rebif in injection form and on the evenning of taking it,my body wants to shut down and not let me do alot,so it becomes very frustrating and i am becoming resentful of it,as i would like to be able to go out in the same evenng...
305	Apr 3, 2010 4:00 PM	I am very pleased I am using Tysbri as it was my only option when my MS started to get Progessive Remitting Relapes. But I have to take a day off work every 4 weeks and travel to London which is expensive. I also worry about the risks and what it is doing. We need these drugs to be cleared by NICE to get my life back.
306	Apr 3, 2010 8:00 PM	I had a very good relationship with copaxone and suffered very few and only mild relapses whilst I was on it. I felt I was almost cured. But I had sudden occasional attacks of chest tightness palpitations flushing and finally severe muscle spasms and pain in the muscles of my back and base of back causing me to worry about my safety if I continued to take the drug
307	Apr 4, 2010 7:23 AM	I'm not currently on any disease modifying drugs becasue I haven't been diagnosed very long and we are waiting to see how frequently I have relapses. I currently take medication to help treat some of the symptoms I am left with permanently, but they don't help at all when I have a relapse. My specialist is hopeful that the tablet version of the medication will be available once we are in a position to make a decision about diease modifiers. I want MS to have as little impact on my life as possible - but that's proving to be a real challenge. Trying to hold down a job with MS (and employer's and colleagues' attitudes towards it) the debilitating effects of relapses and trying to live a normal life is very difficult. I'd welcome anything that would make it easier and 'normalise' it.
308	Apr 5, 2010 8:29 AM	die genannten medikamente sind eher schädlich,da ms keine autoimmunerkrankung ist sonder venösen ursprung ist

309	**Apr 5, 2010 10:28 AM**	i take ldn but not being well off i strugle paying for script and ldn could do with help thanks mjherbert
310	**Apr 5, 2010 11:33 AM**	I have no side effects using Copaxone - however I do not feel any effects at all, and has not stpped my condition worsening slighty
311	**Apr 5, 2010 7:11 PM**	The relapses are very distressing and completely disrupt my life. I find it difficult to plan anything such as a holiday due to the uncertain nature of MS. Taking syringes abroad is a nightmare, an oral drug would be much better. The injections are difficult with the numbness in my fingers and hands.
312	**Apr 5, 2010 7:47 PM**	Copaxone bruises me and gives me very hard itchy skin.
313	**Apr 5, 2010 8:53 PM**	I had taken Avonex for 19mths and then experienced tripping up and leg stiffness and loss of balance came off the drug for 10months and started Rebif and took it for 13months still have leg stiffness. Stopped Rebif 3 months ago and my walking is much the same but my balance has improved, but I am experiencing more numbness in my fingers hands and feet. I may have to start back on Rebif, but I would prefer if it was in tablet form for the long term medication.
314	**Apr 5, 2010 9:27 PM**	Avonex was so wrong for me ,I became scared of the deep injection & my husband often had to do it for me.The side effects were awful & I was so miserable in the end I had a break of around 4 months then went on to copaxone. I now feel ruled by injections in a way that I do not feel by various oral tablets I take for ms symptoms.I have often felt like giving up on injecting but continue as there is no alternative & I want to lessen my chance of relapse,but I would benefit so much from an oral drug.My quality of life & body would be greatly improved. Surely an oral drug will be cheaper too in the long run.
315	**Apr 6, 2010 4:09 AM**	I was on beta seron, never fellt any benefit from the drug, but experienced many side effects
316	**Apr 6, 2010 9:45 AM**	I do think the medication works as I haven't been hospitalised for s few years.
317	**Apr 6, 2010 12:29 PM**	just been diagnosed
318	**Apr 6, 2010 2:31 PM**	I
319	**Apr 6, 2010 4:18 PM**	only had about 2 relapses but have had cancer twice over last 9 years slowed me down a bit more.
320	**Apr 6, 2010 6:41 PM**	when i have relapses the dmd makes the relapse worse after administration.
321	**Apr 6, 2010 7:09 PM**	Since using these drugs my MS has improved and I have spent more time in remission than previously this was also shown when I stopped taking the medication for 3 months and then experienced my first relapse in 18 months
322	**Apr 6, 2010 7:40 PM**	Copaxone has left 'dipping' all over my body, (legs on both sides, buttocks on both sides) and although Tysabri seems to be working, it doe take two days out of my month, so a tablet would be so much easier to manage. It would also allow me to manager my life a little further. However..................Tysabri works for me and does seem to be preventing this from getting un-manageable, so unless the tablets does

323	Apr 6, 2010 8:46 PM	the same would stick with Tyasbri. I am also aware, this does not work for all, but it does for me!! I have tried rebif and liver function was out to often then tried copaxonne but had to stop due to injection site reations.Later found out i have diabetes which may have contributed to skin taking longer to heal. I now take no diesese mod drug and am having a relapse for the first time in a few years. A pill would be a wonder.
324	Apr 6, 2010 8:55 PM	The effect of the unpredictability of relapses is at times challenging and distressing. The impact is not only on myself but on family and friends. I find the treatment of steroids for relapses extremely unpleasant. I often have a low lymphocyte count (which brings different side effects) as a result of the Avonex and have occasionally had to have a break from treatment. The decision to continue with Avonex is 'on balance' with the hope that it reduces frequency and severity of relapses, as the side effects of the Avonex also impact on daily living. Any opportunity to reduce these negative results would enhance my life. I remain very active and have a positive approach to life but believe if there are alternative treatments that reduce the negative aspects of both relapses and current treatment this has to result in a reduction of costs to the NHS and Social Care system as a whole.
325	Apr 6, 2010 10:23 PM	I would like my life and my future back.
326	Apr 6, 2010 11:29 PM	The relapses have not ceased. I was free for a while when having treatment with Mitoxantrone and just after. It is milder but there's a gradual downturn again. There MUST be something better. What is the comparative cost? I wonder...
327	Apr 7, 2010 8:20 AM	Really bad side effects, bruising horrific that leave lasting bruises and soreness - looks wierd and makes people look at you funny.
328	Apr 7, 2010 8:46 AM	I never really experienced major relapses per se, even before the drugs. Have been dxed 20 years. I used to get flare ups for the first 5 years or so whilst taking meds I would get the standard symptoms but nothing major. Have been without meds for 2 years and not had any major incidents. Very scared about where this is going......
329	Apr 7, 2010 10:39 AM	My drugs work at slowing the eventual, and guaranteed, development of my MS. In this situation I'm VERY prepared to feel crap for 3 days rather than 7 per week
330	Apr 7, 2010 11:12 AM	I have questions about whether the drug is working versus the relapse is not as bad / not as frequent as it could be if I weren't on the drugs.
331	Apr 7, 2010 11:27 AM	needles also scare/worry others
332	Apr 7, 2010 11:56 AM	Still having side effects even though i have now been using avonex for six years.
333	Apr 7, 2010 11:58 AM	I administer Rebif manually on a Monday, Wednesday and Friday, and always feel more poorly on these days, i.e. more headahes and even Migraines which I never suffered from before. I am currently relapsing and feel very poorly. I am currently taking Pregabalin to ease the pain, but I feel I'm getting worse, not better. I see my MS nurse on Friday, and will raise these issues with him. I am going to enquire about LDN, as this seems to be the only drug which is having any positive effect on MS symptoms.
334	Apr 7, 2010	I use hyperbaric oxygen and have only had two or three relapses While using it for the last ten years

	12:13 PM	
335	Apr 7, 2010 1:21 PM	I have only been taking Copaxone for 6 months, but it has made a significant difference to my overall health, and I have felt much better since taking it. It hasn't solved all my relapses, but it has certainly helped. I don't find the injections arduous, although remembering to take it out of the fridge in time to come to room temperature can be a challenge!
336	Apr 7, 2010 1:46 PM	from being on these ijections for 5 years I have lumps, bumps & redish/purplish marks over my buttocks and abdomin, they are quite sore and very unsightly. It is very often painful on injecting. I am not 100 per cent sure what course my disease would of taken without these drugs but I, myself do feel they have helped immensley.
337	Apr 7, 2010 3:14 PM	I have been taking Copaxone for 7 months and am just experiencing my first relapse since commencing the treatment. Previously, relapse 1- May 2004, relapse 2- Dec 2008, relapse 3 -April 2009, relapse 4- March 2010. There has been a wider gap between relapses since Copaxone than immediately prior to starting injections. I make an assumption that I may have relapsed before now and/or that relapse could have been more severe than without Copaxone. This currnet relapse has been described by a neurologist as a bad brain-stem relapse and has therefore affected several aspects of my daily life including marked speech slurring, pain, mobilty and severe fatigue. Aside from itchy, raised lumps on injection site that are just beginning to be less pronounced, I feel that I have not experienced any side effects.
338	Apr 7, 2010 3:43 PM	I have been on Copaxone for nearly a year now and during that time I have suffered a few relapases, which have required IV steriods. I think Copaxone has probably helped reduce the severity of the relapses but I need to self inject every day and use different sites each day which takes some planning and organisation.
339	Apr 7, 2010 4:26 PM	Relapse are horrible. They scare me and my husband. We are never sure how much more disability I will gain or whether I will improve at all. They take months and months ut of my life and often a year or more to get better.
340	Apr 7, 2010 4:47 PM	I had a total of 13 relapses over the first 2 years of being dx I was on Avonex for 1 of those years but I was still having relapses I started Tysabri on August 08 and haven't had a relapses since the Tysabri has giving me my life back
341	Apr 7, 2010 5:17 PM	injections frighten a lot of people even my children know I do it but will not see me do it so taking a pill would be great. Plus, you can take the pills out with you.
342	Apr 7, 2010 6:40 PM	i started taking avones combined with metylperdeniloson in high dosag from 2001 as i get diognised as the same year in 2005 i lost my eyesight which again having streoid injection for 5 days in hospital 2 times a day i got back to normal.in 2007 i stopped taking the treatment comletlyin 2010 i started having trigiminal neuroligia which lookes like another relaps because i became paralise in my left side of my body
343	Apr 7, 2010 7:28 PM	I have been told by my consultant that I have to come off tysabri by the end of this year, so getting fingolimod licensed as soon as possible is important because tysabri has changed my life for the better and to lose that is going to be very hard. The only thing is that I have been told that I have to be off tysabri for a minimum of six months so not looking forward to that period with no meds.
344	Apr 7, 2010 8:53 PM	I would like to be able to try LDN as it seems to have worked for so many MS sufferers, so far no drug treatment I have expreienced has had any positive effect on my MS symptoms
345	Apr 7, 2010 10:04 PM	I feel very lucky to have the ease of use with the Rebismart and not having to be the 'patient', I can do all of my injections myself. However, my arms and legs are dotted with skin reactions, when I wear a swimming costume on holiday, I feel I need to

		cover up all the time. I would welcome an oral drug, so long as the side effects were similar, so that I could lead a more normal life. Lack of support from GP (pleads ignorance), instead referred to specialist (a long journey away) for answers - cannot get appointment with specialist just have to wait my turn months ahead. Regular contact from somebody/anybody would be good - just a phone call. Support is needed generally for people with MS - it can be very lonely.
346	**Apr 8, 2010 9:39 AM**	
347	**Apr 8, 2010 10:09 AM**	I AM NOW 53 HAD MS SINCE i WAS 16
348	**Apr 8, 2010 2:57 PM**	To date and extremely fortunately, I only have monthly B12 injections
349	**Apr 8, 2010 3:52 PM**	Every time I have a relapse I worry that i won't recover from it. Always leaves me physically worse off than I was before, so it's really important to me that I am on the drug that most effectively prevents relapses.
350	**Apr 8, 2010 3:59 PM**	I was stopped from taking Betaferon due to attempting suicide after 6 months of being on the drug. I was then commenced on Copaxone, but continued to have regular relapses despite being on it. It was then decided that commencing Tysabri would be the best option. I now have very few new symptoms and have only had 2 relapses whilst taking this drug - although I do worry about PML. As I expected, none of the drugs have improved my disability, but I feel at last that I have plateaued.
351	**Apr 8, 2010 4:29 PM**	I can be kept awake at night unable to sleep, due to the side affects of my Rebif. Therefore making me much more tired the following day.
352	**Apr 8, 2010 5:00 PM**	i always tolerated the drugs pretty well
353	**Apr 8, 2010 6:18 PM**	Mot convinced these drugs actually work
354	**Apr 8, 2010 9:55 PM**	One of my relapses that i had a few years ago was in my eyes. Everything was out of focus and i couldn't see anything past a certain point at the corners of my eyes. I felt very frustrated and depressed as i had only just gotten over a previous relapse in my leg and couldn't feel or use it properly for a few weeks. Having to try to inject myself only made me feel worse.
355	**Apr 8, 2010 11:53 PM**	Capoxone has had such a positive impact on my illness in terms of fatigue and my general well being. I'd love to take a drug that improved my health to this extent, with minimal side effects in oral form.
356	**Apr 9, 2010 6:05 AM**	In all examples a MS sufferer including myself feels isolated - there is no practical support system and very little understanding amongst others about this disease.
357	**Apr 9, 2010 10:53 AM**	Please live our lives for a day.
358	**Apr 9, 2010 11:26 AM**	i worry about drug dependency for this illness and especially if efficacy has yet to be proven.
359	**Apr 9, 2010 12:10 PM**	Each injection site becomes sore and swollen. I have had horrific skin reactions with my skin coming apart, being infected and now scarred. I do believe in the medication which is the only reason that I can continue with the injections because it is keeping me well but it does takes its toll on all aspects of my life. Im am truely hoping that it will become available to me in tablet form.
360	**Apr 9, 2010**	I have never had any side effects with taking this drug. I just cannot bare injecting my self and a pil would be so simpler.

	12:36 PM	
361	Apr 9, 2010 1:02 PM	when I first started to inject with avonex I had mild side effects but after injecting for 18 months the side effects returned with a vengance I was completely unable to function for 3 to four days after injecting. I was then put on copaxone but I had severe injection site reactions which resulted in having to take steriods to clear up the injection sites. As a result of this I haven't been taking any modifying drugs for approximately 2 years and boy do i know about it because the relapses are coming thick and fast.
362	Apr 9, 2010 1:45 PM	Re relapses - unpredictability of them - dont know whats round the corner. Re Avonex - often experience mega 'hangover' feelings morning after, but not moaning as know Im one of the luck ones who've been given chance to take it.
363	Apr 9, 2010 1:52 PM	in my case , eventually my blood readings became abnormal. I am actually quite gratefull that there is a treatment that has worked for me (15 months no relapses) , on betaferon. Although you wonder , in this day and age a pill cannot be made more available. Betaferon is a delicate substance. My job and lifestyle require(d) extensive travelling and this is curtailed by MS and carrying betaferon. If there could be a "normal" stable version i.e. a pill , i could potentially go back to having a normal lifestyle and contribute again.
364	Apr 9, 2010 2:51 PM	I am saddened that i inject every day knowing that the drug i am injecting can only reduce relapses by a third....which seems a small return for the pain, trauma and anxiety I put myself and those around me through to get it into my system!
365	Apr 9, 2010 3:26 PM	I expected it to have worked by now but the MS nurse said it may be working where I can't see it
366	Apr 9, 2010 3:44 PM	i dont think we get told enough about why a consultant has chosen the 1 he puts you on , and i dont think you get enough support after a relapse and you can never get a ms nurse at weekend and its not like to plan to have a relapse at weekend
367	Apr 9, 2010 3:54 PM	I have been very fortunate. During the time I have been taking REBIF I have had no major relapses and this followed a few years of relapses and steroids etc. I am not oblivious to the fact that I may still have relapses in the future and I do have to endure the effects of things that have happened in the past. I am also astounded by the industry that is around the medication. Private nurses coming to the house to train you to use it. Refrigerated delivery vans to the house. Dedicated phone lines with the manufacturer and distributer. Monthly sharps boxes and disposals. My GP told me, because it came up on his system, even though he was not paying, it cost nearly a thousand pounds a month. That is a lot of money to pay out on any person in a credit crunch! And that does worry me. This drug has helped change the course of my MS and I have the distant worry that it might be withdrawn.
368	Apr 9, 2010 4:17 PM	disease modifying drugs have been very helpful for me but injecting is uncomfortable and i have had some side effects and skin problems, however i feel it is a small trade-off for the effect of being well. i would be very interested in taking a pill instead of injecting but would also be anxious now about changing my treatment in case it affects my health and causes a relapse.
369	Apr 9, 2010 4:29 PM	The Rebif was unsuitable for my body to cope with the awful side effects. I then went on Capaxone which to date I tolerate, but due to injecting I am getting problems. These range from injection site swelling, irritation, redness, and muscle loss. I have found due to taking Capaxone I have suffered far fewer relapses.

370	**Apr 9, 2010 4:56 PM**	I have been on Betaferon since Sept 1996. I used to have 3-4 relapses a year I have not suffered any since starting the treatment. My walking ability has slowed down over the years and I tire easily when doing housework but this is nothing compared to the way a relapse affected me.
371	**Apr 9, 2010 5:59 PM**	I am at the moment in a very bad relapse i can hardly walk now and in a lot of pain and bad spasticity
372	**Apr 9, 2010 6:07 PM**	After experiencing really nasty site reactions, panic attacks, fainting and therapy sessions and seen the stress this has caused to my family (and to myself), the thought of being free of all this fills me with hope. Every time i have to inject I wish there was another way.
373	**Apr 9, 2010 6:20 PM**	I was very fortunate, in that I was given the opportunity to try Rebif quite soon after diagnosis. It has worked incredibly well for me and has (in my view) reduced my relapses by 80 per cent. I have never had bad side-effects, but just get big red blotchy marks. That's nothing. I used to have to pay for it and it cost a great deal of money. The risk-sharing scheme was a life-saver. I have only 3 more lesions in the last 10 years and 4 significant relapses. t relapse causes permanent damage - so for me, relapses=damage=progression. The damage is slight, compared to so many other more disabled people. I have balance problems, memory loss, neuropathic pain, hemiparesis and some vision problems and fatigue. I can't work as a classical musician any more as I just don't have the inner strength. The invisible symptoms of MS can be awful and as they are invisible, how can you quantify them? I would not like to try to apply for benefits as I can't prove to someone how much MS has changed my life. Without Rebif, I am sure that I would not be able to walk. I also take LDN which has given me back full bladder function, which is an incredibly important factor for people with MS. Removing the risk of having to use catheters may even save me from an early death. At the time of my diagnosis in 2000, the MS Society was not a big part of my life. The perception of the MSS was that it is very medically conservative and only interested in paliative care. Things have improved. Thanks to the message forum, we can swap information and experiences and I have learned a huge amount about MS. Back in 2001, the 'other' MS charity with a magazine (New Pathways) was very anti-DMD and this was a cause of great emotional discomfort. I still haven't forgiven them for their attitude and probably never will. At least the MSS discusses other treatment options and although it can't endorse

		alternative therapies or drugs as nothing works for everyone, at least they have had the open-mindedness to discuss drugs and therapies and for that I thank you. For me, Everyday Living is a lifeline. I would like to say a million thanks for this website.
374	Apr 9, 2010 7:04 PM	waiting for liberation treatment...hoping to forget about the drugs
375	Apr 9, 2010 7:12 PM	I am currently on the Dacluzimab drugs trail.
376	Apr 9, 2010 8:06 PM	Although I was offered disease modifying drugs in 2005, having at that stage had enough relapses to qualify, in consultation with my GP I decided that it was not appropriate for me. I went instead to the Royal London Homeopathic Hospital, who discovered a vitamin deficiency which is now being treated, as well as prescribing homeopathic remedies. I have not had a significant relapse since.
377	Apr 9, 2010 8:20 PM	I have never been offered any DMD's in the 7 years I have been diagnosed. It saddens me that I now find that they arent recomended for people after 6 years DX and feel I have "missed the boat".
378	Apr 9, 2010 8:47 PM	To take a pill would be more comfortable, than having an injection, and dreading the side-affects that you know come next. My children would benefit from this as well i think, as they know what to expect from their mum on my chosen day. This injection always affects me the next day.
379	Apr 9, 2010 10:48 PM	you have nothing to compare it to so difficult to judge what impact it is having you just hope it is having some effect on reducing the number and severity of relapses. A pill would be wonderful.
380	Apr 10, 2010 2:57 AM	our neuro and their nurses should be supportive, I know our NHS is going through rough times but things are changing slowly but surely i hope
381	Apr 10, 2010 8:28 AM	Infections and bruising in the injection sight.
382	Apr 10, 2010 8:45 AM	I have had to seek help for depression and feelings of worthlessness, due to a feeling that there was no way to cope with this debilitating disease. Any treatment that would improve all MS sufferers quality of life must surely be considered as worthwhile. Pain and fatigue can be almost unbearable. I know what it's like to have to stay in hospital for drug treatment (steroids), and to have the option to self medicate, without needles or stayover, would be immensely positive.
383	Apr 10, 2010 10:26 AM	Only as per the last question box.
384	Apr 10, 2010 10:40 AM	A relapse for me is overwhelming, affecting my physical mobility by 75 per cent+ e.g. I can't even crawl very well to get to the toilet
385	Apr 10, 2010 12:10 PM	I'm afraid of needles so self-administering Rebif/Copaxone was a horrible experience for me. I experienced the post-injection reaction associated with Copaxone (feels like a mixture of heart palpitation - asphyxia - anaphylactic shock!) which was pretty terrifying. The tissue on and around injection sites is permanently damaged from sub-cutaneous injections. Switching to weekly intra-muscular injections (Avonex) has been better but I need to go to my GP for the injection as I cannot bring myself to do it. I also suffer muscle spasms and debilitating flu-like symptoms after the treatment, this still occurs regularly despite being led to understand that the side effects would disappear over time (I have been taking Avonex for over 2 years now).

386	**Apr 10, 2010 1:46 PM**	Can not add anything at the moment as due to embark on a course of disease modifying drugs
387	**Apr 10, 2010 2:01 PM**	the issue of delivery means you have to plan and arrange, life would be easier if you could pop down the chemist for a few pills.
388	**Apr 10, 2010 2:12 PM**	At present I am waiting to see my consultant regarding injection side-effects (Betaferon). After a number of years injecting, I seem to be having side effects (legs seem to be extremely heavy and awkward to move and sometimes I cannot move at all, like I am paralysed. This makes me feel very angry and takes away my independence. I am told that nobody else as reported any similar problems (I am aware however, of other patients coming off the injections due to similar problems). The injections now cause me to have a bad day, every other day, this as a massive impact on my working life and more importantly my home life. I am lucky that I have an understanding employer who has agreed for me to work from home part of the week and when I am having problems (mobility wise). This I have found very useful, helping me from a fatigue point of view as well as allowing me to continue to work. My independence is very important to me, as is my family. I have no problems with needles and although sometimes awkward I am not bothered about injecting myself. In saying that not all people are as easy with needles or injecting (as a personal friend of mine, panics every time they have to inject). Therefore, an oral form of medication would seem an easier solution to the current form of injection.
389	**Apr 10, 2010 4:41 PM**	ms is very life limiting and if you have ms you need all the drugs available to deal with this condition and taking a tablet would be so much better
390	**Apr 10, 2010 5:30 PM**	I'm 25, I started on avonex and stayed on it for as long as I could even though I missed two days out of every week because I suffered really bad migraines, felt sick and was really nasty, so I had to stay in bed all because I'm scared of needles and did'nt want to have to inject myself. Then I plucked up the courage and stared copaxone, I kept getting infections, It got to the point it was one every week, then I went on rebif and I got really depressed and when I was'nt depressed I was really nasty so I'm off them now and not doing well at all, I can't do much and when I try and do the tiniest thing I'm exhauted, like just having a shower or just getting dressed, my legs are bad, balance is bad, my lower back is sore all the time, sometimes can't hear well, get blurred vision, sometimes can't smell or taste much if anyone has had that, I never use to have pain but I do now all the time, I would just like something simple like a pill to help me and none of these scary treatments like needles and infusions and so on, please nomore pain!!
391	**Apr 10, 2010 8:35 PM**	Flu like side effects bad at first when injecting disease modifying drug. Concerned taking too many ibuprofen to combat the side effects MS Fatigue increasing relentlessly.
392	**Apr 10, 2010 10:23 PM**	Relapses are seriously worrying as you don't know if it will be permanent damage, how soon and when you recover. or how long the relapse will last. I worry about having to rely on the DMD more so the way it is administered at present and just how helpful it would be for me.
393	**Apr 11, 2010 5:25 AM**	i have been dignosed with ms for 13 years & recently had eurodynamics which showed up stress related bladder i dont understand this as wen i get urge to go to toilet i cannot get there without part or full leakage,i cannot hold my urine in at all,and because i havent got urgency the specialist will not perform bottox op on my

		bladder but maybe streaqtch bladder in my thoughts wouldnt this make my bladder worse as in not being able to hold urine
394	**Apr 11, 2010 7:36 AM**	I am only ever given steroids for ms flares and i hate the side effects of them.
395	**Apr 11, 2010 9:44 AM**	I am scared about the side effects of taking any drugs.
396	**Apr 11, 2010 10:58 AM**	Travelling abroad can be a concern with the need to carry additional items; find a fridge etc
397	**Apr 11, 2010 12:49 PM**	I started taking beta interferon 3 years ago and suffered 2 relapses, shoirtly afterwards. These relapses were disabling and I was unable to walk for 5-6 days. My GP prescribed steroids, at the latter of these attacks. I have been relapse free for over 2 years. I recently received vaccinations(5 months ago) prior to a holiday in Eygypt and unfortunately I have been unwell since. My MS symptons have all returned and are only now beginning to ease. I can still walk independently for a short distance, with regular and frequent breaks. Despite seeking medical advice prior to these vaccinations, when I was told it would be ok to take these vaccinations whilst receiving interferon, my body reacted badly both physically and mentally.
398	**Apr 11, 2010 1:24 PM**	I have persevered with the inconvenience of injections because the relapses would be worse. The injections require a bit of planning and some symptoms on the day of injection, but I feel this is worth suffering to minimise the likelihood of another relapse, and the inevitable worry and complete dependence on family to care for me that would result. A daily tablet, although also likely to have side effects, would be so much simpler. I also have needed to work from home on the day of the drugs delivery as there is no one to leave refrigerated drugs with, thus taxing my employer's patience since they do not really allow working from home. I am lucky that I am able to do this, since they respect the DDA.
399	**Apr 11, 2010 1:57 PM**	When I was on copaxone, my blood suagrs wwere not under control (Type 1 diabetic), when I spoke to the MS nurse and the Consultant that couldnt help me. It was only when i pushed that the MS nurse wrote to the drug comapny and they said that the absorption rates could be affected if both drugs were injected in the same area. i never injected insulin where I injected copaxone, but it was close, say at least 3 cms away. I dont inject insulin in my legs anymore and I came off copaxone becasue of this and also becasue my leges were so sore with lumps and swellings from the injections. I think that becasue my Neurologist doesnt know the answers to my questions and neither does the nurse, they are pretty useless and wheras I once had faith in them i now cosnider them to be superfluos to my requirements. there is no cure, there is no treatment, there is no hope. Sorry about my spelling, my ON has left me unable to see propeerly.
400	**Apr 11, 2010 5:15 PM**	I am very grateful that I get a disease-modifying drug. After managing pretty well for many years, my MS had started rapidly to worsen, with relapses happening every four months of so. I had to stop going into the office to work, though was fortunately able to continue to work, albeit for reduced hours, from home. I could see all to well if the progression had continued, I'd soon be unable to walk at all. These days I can still walk around the house (and have not yet been forced to move) and, on a good day, I might be able to walk some distance outdoors too. It's not much, and my life is very limited compared with how it used to be, but it's something. The interferon has stabilised the disease for now and, although some symptoms continue to worsen, I have not had a major relapse for several years now. If only it didn't mean sticking needles in myself...
401	**Apr 11, 2010 10:14 PM**	I am only recently diagnosed, and have not yet had the consultation at which we will discuss treatment options. However, as my impairment due to MS is still relatively mild, I'm concerned that the conventional self-injected or hospital-administered DMDs would have a greater impact on present quality of life than the symptoms of the

		disease itself. This may discourage me from accepting treatment. I think I would be much more open to the idea of treatment if I knew it would not involve relatively unpleasant modes of administration, such as injections or infusions.
402	Apr 12, 2010 6:48 AM	I have never been afraid of needles so the injhecting bit is only painful rather than frightening. I do suffer terribly from localised bruising at the site of the injection. They are painful and very unsightly. I cannot imagine the freedom and relief from these issues a pill would give me.
403	Apr 12, 2010 1:26 PM	Whilst i am grateful to be on DMD's, it is a burden to be injecting copaxone everyday
404	Apr 12, 2010 2:19 PM	Would love to have more freedom with the drugs as having to deal with the ms itself.
405	Apr 12, 2010 4:16 PM	Although injecting myself daily is not a buddle of fun I feel it is a small price to pay, in the absence of oral drugs, to keep any relapses to a minimum. I look forward to oral treatment being available in the near future.
406	Apr 12, 2010 4:57 PM	Have been lucky to have very few relapses and have only ever taken Amitryptiline.
407	Apr 13, 2010 7:20 AM	When having a relapse i am unable to inject myself due to not being able to hold the injection or grip. The tablet would help me as well as my family, as i am still able to take tablets on my own and not being a burden to others.
408	Apr 13, 2010 9:39 AM	I really haven't had a great experience of injecting. Avonex in particular but Copaxone has cause long waste of muscles and uneven skin. It also make it a lot harder to travel with these medications.
409	Apr 13, 2010 10:21 AM	I had a sarcoma in my thigh 4 years ago in the exact spot I often used to administer Rebif at the time (I did rotate the site but used my leg quite often as it was easiest to do myself). Although no doctors have said that the injection was the reason for the cancer, it seemed very coincidental that it was that exact location. Last week I had a very severe allergic reaction to Copaxone after injected, on both Tuesday and Wednesday nights, which caused an extremely itchy red rash over my entire body and face and made my lips, eyelids and throat swell up painfully. I have therefore now stopped taking Copaxone!
410	Apr 13, 2010 11:15 AM	My experience with Avonex lasted almost 3 years, the very first time I ever took it I said to my wife that ive been given the wrong drug it was that harsh. However I stuck with it the side effects never really stopped more I just got used to them, I used to dread Fridays as that was injection day. It took until Wednesday to recover then ied have Thursday then the whole thing would start again. Anyway after nearly 3 years I experienced exactly the same really harsh side effects as when I first took it I was at home alone and to be honest it really scared me, so I decided to stop taking it. Since ive stopped taking it I have taken a single Aspirin a day and a Krill oil supplement and although incredible small I have had more of a response to these than I ever did to Interferon, I had a repeat mri when I moved and my Neurologist has told me there is no active lesions, so ime sort of at a loss really yes I would take another medication preferably a pill but it has to show some sort of benefit as I am no lokger up for torture.
411	Apr 13,	The main issues with injecting daily is the skin site reactions, Lipoatrophy and getting

	2010 12:35 PM	help when injecting at sites that are hard to get to.
412	**Apr 13, 2010 1:50 PM**	when I have a relapse and receive IV steroids I always suffer sever side effects for 5-7 days post completion, followed by a slow recovery.
413	**Apr 13, 2010 5:55 PM**	HAving MS is like suddenly being drawn into running a life long marathon. Ok, so the challenge is on and it appears that for me there is no opting out. Having relapses along the way makes it more like an obstacle course or steeple chase. Having treatment or interventions that have side effects is like having to run uphill as well. I am blessed in having a family who cheer me on, who will even run alongside me and hold me up when I stumble ... and they would rather I ran as smooth a marathon as possible.
414	**Apr 13, 2010 6:18 PM**	I am certain that the drugs have stabilised my ms and have therefore improved the quality of my life.
415	**Apr 13, 2010 6:41 PM**	I am having a relapse at the moment and the reality of my illness taking over my life so much so that I cannot function without an immense amount of support from all those around me is very scary. I want to beat this illness, but know that there are times when I cannot. I know that I may soon need to start using disease modifying drugs, it has been discussed with my consultant, I have been put off by the method of administration.
416	**Apr 13, 2010 7:21 PM**	they make my body sore and red it hurts when injecting and i find it hard to do as i can never find a place on my arms legs or bum with enough fat and i have scars on my stomache so cant go there so overall a nightmare.
417	**Apr 13, 2010 9:12 PM**	Having only been diagnosed less than a year ago (and whilst encountering a trying 20m period in the run up to diagnosis) the fear of intravenously or self-injecting treatments has really put me off taking any dmd's. The taking of a pill for the condition would more likely satisfy the least level of change I feel I can cope with in dealing with this condition.
418	**Apr 14, 2010 8:23 AM**	I have had problems with my blood tests since taking Rebif. I have had continual problems with my liver function, although this has settled down, is still higher than the norm. The rebif has affected my thyroid function also. I am unsure that the Rebif is effective, as I have still experienced exacerbation of symptoms and mild relapses.
419	**Apr 14, 2010 12:15 PM**	Today is the best I will ever be as my condition deterates dialy.
420	**Apr 14, 2010 12:53 PM**	If it is safe, without major side effects and effect full I would clearly prefer daily pills, or better pills taken less than once a day, but they better be far more effective than interferon. It seems to be relative safe. By the way, I am a danish patient with MS, but I hope this survey could benefit MS patients in the hole of the EU
421	**Apr 14, 2010 3:33 PM**	in my opinion, having been diagnosed with ms is bad enough,having to take time out for to attend appointments for infusions, or having to have painful injections and feeling unwell afterwards,would not be my choice of treatment if i could take a wee pill every day!

Appendix D: Free text responses to an open question on people's main reasons for discontinuing the disease modifying drugs (Avonex, Betaferon, Extavia or Copaxone).

Number	Response Date	Response Text
1	Mar 26, 2010 9:19 AM	The Stress of injecting myself and did not seem to made a difference
2	Mar 26, 2010 9:38 AM	Injection site reactions
3	Mar 26, 2010 9:47 AM	Neurologist removed me as I kept forgetting to inject,
4	Mar 26, 2010 10:23 AM	there were a number of reasons from allergic reactions and hardened skin
5	Mar 26, 2010 10:24 AM	Side effects.
6	Mar 26, 2010 10:26 AM	Contraindicated by blood results - low white cell count and problem with liver. Also feeling low on Rebif.
7	Mar 26, 2010 10:44 AM	Rebif- i suffered scar tissue and many skin reaction sites
8	Mar 26, 2010 10:53 AM	It caused liver damage
9	Mar 26, 2010 11:27 AM	could not cope with self injection
10	Mar 26, 2010 12:07 PM	i developed a slight phobia of neddles and felt sick when i thought of taking my injection
11	Mar 26, 2010 12:07 PM	severe side effects
12	Mar 26, 2010 12:21 PM	Avonex , was getting too many relapses
13	Mar 26, 2010 12:28 PM	taken off it
14	Mar 26, 2010 12:47 PM	I moved from RRMS to Secondary Progressive
15	Mar 26, 2010 12:50 PM	Neurologist suspecting SPMS
16	Mar 26, 2010 12:51 PM	I couldn't inject myself, it was taking over everything else in my life !!
17	Mar 26, 2010 1:08 PM	I went from RRMS to secondary progressive

18	**Mar 26, 2010 1:09 PM**	side effects
19	**Mar 26, 2010 1:13 PM**	chage from copaxone to betaferon
20	**Mar 26, 2010 1:37 PM**	flu-like side effects
21	**Mar 26, 2010 2:03 PM**	undesirable side effects
22	**Mar 26, 2010 3:14 PM**	BETAFERON STARTED TO UPSET MY LIVER AND WAS TOLD BY DOCTOR TO STOP USING IT.
23	**Mar 26, 2010 3:53 PM**	Development on NAB's and increase in relapse rate
24	**Mar 26, 2010 4:03 PM**	Stopped Rebif as I was still relapsing twice a year, so after 2 years on it I was changed to Copaxone
25	**Mar 26, 2010 4:23 PM**	Allergy
26	**Mar 26, 2010 4:46 PM**	Side effects
27	**Mar 26, 2010 5:05 PM**	Side effects
28	**Mar 26, 2010 5:07 PM**	Had a severe bad reaction to it.
29	**Mar 26, 2010 5:07 PM**	Avonex left me with severe side affects.
30	**Mar 26, 2010 5:16 PM**	Felt generaly poorly. Aches,Stiffness,Depressed. Had two further relapses.
31	**Mar 26, 2010 5:44 PM**	side effects
32	**Mar 26, 2010 5:49 PM**	copaxone (5yrs) & rebif (3 yrs) had no effect
33	**Mar 26, 2010 5:51 PM**	Intolerance resulting in skin abcesses and lowering of white blood count
34	**Mar 26, 2010 6:07 PM**	I have recentley started taking Avonex but not been on it long enough to comment as yet.
35	**Mar 26, 2010 6:15 PM**	couldn't inject myself - despite hypnotherapy!
36	**Mar 26, 2010 6:29 PM**	I found the self injection too stressful. I could not come to terms with it having a deep fear of needles

37	**Mar 26, 2010 6:31 PM**	Drug worsened my crohns disease
38	**Mar 26, 2010 6:32 PM**	side effects (raised liver function)
39	**Mar 26, 2010 6:33 PM**	transferred to tysabri
40	**Mar 26, 2010 7:00 PM**	Consultants advise
41	**Mar 26, 2010 7:03 PM**	I started taken Tysabri (natalizumab)
42	**Mar 26, 2010 7:03 PM**	neutralising antibodies - Rebif
43	**Mar 26, 2010 7:04 PM**	Bad reactions to injection site, anxiety at having to inject
44	**Mar 26, 2010 7:12 PM**	sise affects of rebif unbearable i now take copaxone
45	**Mar 26, 2010 7:12 PM**	kept having relapses
46	**Mar 26, 2010 7:41 PM**	no impact
47	**Mar 26, 2010 7:46 PM**	Wanting to have a baby
48	**Mar 26, 2010 7:47 PM**	Cosultant felt that drug was no longer effective
49	**Mar 26, 2010 7:58 PM**	Avonex wiped my white cell, fatigue, suicidal
50	**Mar 26, 2010 8:21 PM**	side effects
51	**Mar 26, 2010 8:41 PM**	Fat atrophy at injection site
52	**Mar 26, 2010 8:49 PM**	NABs on Rebif
53	**Mar 26, 2010 8:56 PM**	antibodies in blood results meant a change needed to DMD
54	**Mar 26, 2010 9:12 PM**	reaction to inections
55	**Mar 26, 2010 9:17 PM**	Allergic reaction to Copaxone

56	**Mar 26, 2010 9:23 PM**	got on trial plus poor efficacy
57	**Mar 26, 2010 9:52 PM**	side effects
58	**Mar 26, 2010 10:18 PM**	MS nurse & consultant's advice
59	**Mar 26, 2010 10:19 PM**	I had more relapses, although short lived, whilst on Rebif than without it
60	**Mar 26, 2010 11:40 PM**	Consultant didn't think it was helping me- I agreed
61	**Mar 27, 2010 12:22 AM**	INCREASE IN RELAPSES AND NEW BRAIN LESIONS.
62	**Mar 27, 2010 2:05 AM**	liver funtion
63	**Mar 27, 2010 7:50 AM**	avonex was not very effective in controlling my relapses so i was transfered on to rebif 44mg.
64	**Mar 27, 2010 8:08 AM**	I took Rebif following participating in a trial for Cladrabine but it made me feel sick.
65	**Mar 27, 2010 8:32 AM**	it made me depressed
66	**Mar 27, 2010 10:03 AM**	Side effects
67	**Mar 27, 2010 10:24 AM**	Side effects and horror at self injection
68	**Mar 27, 2010 10:47 AM**	It was not stopping my relapses, caused me distress taking it. Now on Tysabri every four weeks.
69	**Mar 27, 2010 10:51 AM**	advised to stop due to blood abnormalities
70	**Mar 27, 2010 11:40 AM**	side effects
71	**Mar 27, 2010 1:59 PM**	rebif - causing more pain than helping. Reaction marks & stomach/bowel issues too painful to continure
72	**Mar 27, 2010 2:06 PM**	I hated the needle, the bruises and needle marks and the side effects
73	**Mar 27, 2010 2:10 PM**	extra pain with Copaxone
74	**Mar 27, 2010 2:31 PM**	Allergic reaction with Betaferon

75	**Mar 27, 2010 2:35 PM**	Rebif: had as many relapses per annum as not taking any drugs at all
76	**Mar 27, 2010 3:41 PM**	change from Betaferon to Rebif on hospital advice
77	**Mar 27, 2010 4:01 PM**	severe reaction to betaferon in my leg left me unable to walk.
78	**Mar 27, 2010 4:08 PM**	Neurologist agreed it wasn't helping
79	**Mar 27, 2010 6:05 PM**	side effects
80	**Mar 27, 2010 6:13 PM**	allergy to avonex
81	**Mar 27, 2010 6:32 PM**	I wanted to change to a drug that I only ad to take once a week.
82	**Mar 27, 2010 7:28 PM**	injection site ulcers
83	**Mar 27, 2010 7:29 PM**	NAB (Rebif)
84	**Mar 27, 2010 7:42 PM**	Had problems with my blood. Consultant decided to stop previous drug.
85	**Mar 27, 2010 7:43 PM**	Could not afford it and hated shots
86	**Mar 27, 2010 8:10 PM**	It affected my Kidneys.
87	**Mar 27, 2010 9:26 PM**	I had to inject and found this impossible because of pain and after effects etc
88	**Mar 28, 2010 8:56 AM**	It was far too painful.
89	**Mar 28, 2010 10:05 AM**	depression (Avonex)
90	**Mar 28, 2010 12:35 PM**	started tysabri
91	**Mar 28, 2010 1:59 PM**	Side Effects
92	**Mar 28, 2010 3:31 PM**	side effects and injection skin damage
93	**Mar 28, 2010 4:11 PM**	didn't work for me

94	**Mar 28, 2010 4:31 PM**	I didn't like giving myself the big injection (Avonex) once a week, I ended up injecting into my thigh bone by mistake and that WAS painful!!
95	**Mar 28, 2010 5:33 PM**	just on steroids for 5 days
96	**Mar 28, 2010 5:54 PM**	I developed a resistance to Avonex & no longer effective
97	**Mar 28, 2010 5:57 PM**	had a reaction to it
98	**Mar 28, 2010 8:20 PM**	was found to have more lesions and so started on Tysabri
99	**Mar 28, 2010 8:21 PM**	Was not working
100	**Mar 29, 2010 3:26 AM**	side effects
101	**Mar 29, 2010 8:38 AM**	trying for a baby
102	**Mar 29, 2010 8:41 AM**	My difficulties gradually stopped
103	**Mar 29, 2010 10:10 AM**	the side affects, and they did not reduce the relapse rates
104	**Mar 29, 2010 10:13 AM**	copaxone wasn't working for me and with rebif I was have severe site reactions
105	**Mar 29, 2010 10:33 AM**	bad reaction at injection sites
106	**Mar 29, 2010 10:35 AM**	I changed from Avonex, which did not seem to be working so well, to Rebif which it was thought would work better.
107	**Mar 29, 2010 10:39 AM**	side effects
108	**Mar 29, 2010 10:52 AM**	swollen ankles, injection site psoriasis
109	**Mar 29, 2010 11:09 AM**	injection site reactions on Rebif - inflammation on site & muscle athrophy, now on Avonex
110	**Mar 29, 2010 11:09 AM**	Negative reaction to medication
111	**Mar 29, 2010 11:31 AM**	ms worsened
112	**Mar 29, 2010 11:43 AM**	No longer effective in preventing relapses

113	**Mar 29, 2010 12:01 PM**	Increased relapse rate
114	**Mar 29, 2010 12:19 PM**	copaxone - skin site reactions were severe
115	**Mar 29, 2010 1:30 PM**	still getting regular relapses
116	**Mar 29, 2010 2:23 PM**	Disease progression
117	**Mar 29, 2010 2:39 PM**	Pain of injection sites, fat displacement,scarring, anxiousness of alternate day injections
118	**Mar 29, 2010 2:52 PM**	adverse reaction
119	**Mar 29, 2010 3:30 PM**	caused serious side effects
120	**Mar 29, 2010 3:35 PM**	I became secondary progressive and they didn't seem to have and benefit
121	**Mar 29, 2010 3:55 PM**	I FELT IT DID NOT SUIT ME AT THAT TIME (TRIAL MEDICATION)
122	**Mar 29, 2010 6:11 PM**	allergic to rebif,copaxone stopped working
123	**Mar 29, 2010 7:39 PM**	Disturbing post-injection side-effect
124	**Mar 29, 2010 7:40 PM**	Became Immune to Rebif and Copaxone side effects made my life extremely difficult and uncomfortable, more than the relapses.
125	**Mar 29, 2010 7:41 PM**	Rebif ,it was not working for me !!
126	**Mar 29, 2010 7:50 PM**	Iatrogenic hepatitis
127	**Mar 29, 2010 7:59 PM**	I was experience frequent relapses and reactions on the injection sites.
128	**Mar 29, 2010 8:32 PM**	side effects
129	**Mar 29, 2010 10:18 PM**	I took betaferon previously for two years and the side effects did not reduce I felt I had enough to contend with without the flew like symptoms .
130	**Mar 30, 2010 1:45 AM**	neutralizing antibiodies
131	**Mar 30, 2010 2:09 AM**	My Dr wanted to try something different to see if I would have fewer relapses

132	**Mar 30, 2010 8:43 AM**	Side effects
133	**Mar 30, 2010 9:25 AM**	Didnt seem to work and stop relapses
134	**Mar 30, 2010 9:27 AM**	Side effects
135	**Mar 30, 2010 9:33 AM**	condition improved after a course
136	**Mar 30, 2010 9:39 AM**	poor reactions to them
137	**Mar 30, 2010 11:08 AM**	Depression, mood swings.
138	**Mar 30, 2010 12:39 PM**	side effects
139	**Mar 30, 2010 12:54 PM**	I continued to have relapses on Rebif, roughly every 6 months
140	**Mar 30, 2010 1:05 PM**	They became neutralized in my body and ceased to work!
141	**Mar 30, 2010 1:55 PM**	side effects
142	**Mar 30, 2010 2:33 PM**	NAB +ve
143	**Mar 30, 2010 2:35 PM**	Horrendous side effects of Avonex
144	**Mar 30, 2010 3:58 PM**	continued relapsing and got fed up of injecting daily
145	**Mar 30, 2010 4:05 PM**	intensity in nerve pain
146	**Mar 30, 2010 5:16 PM**	on tysabri now
147	**Mar 30, 2010 6:11 PM**	not working
148	**Mar 30, 2010 6:12 PM**	rebif nearly killed me every time i took it
149	**Mar 30, 2010 6:41 PM**	flu like symptoms and painful injection sores
150	**Mar 30, 2010 6:59 PM**	side effect

151	**Mar 31, 2010 2:15 AM**	i used avonex for 2 years but could not cope with side effects, and changed to rebif
152	**Mar 31, 2010 11:40 AM**	started new drug tysabri
153	**Mar 31, 2010 12:08 PM**	advised by specialist
154	**Mar 31, 2010 2:27 PM**	Nurologist recommended stronger DMD because of relapse
155	**Mar 31, 2010 2:58 PM**	breathing problems with rebif
156	**Mar 31, 2010 3:22 PM**	Injection
157	**Mar 31, 2010 3:26 PM**	rebif no longer working. copaxone, site probs and disease progressing.
158	**Mar 31, 2010 3:33 PM**	the way my body reacted to them.
159	**Mar 31, 2010 3:57 PM**	medical advice that it was not effective
160	**Mar 31, 2010 5:14 PM**	Felt worse after injecting Rebif
161	**Mar 31, 2010 6:55 PM**	Tysabri - and pleased I changed...
162	**Mar 31, 2010 7:32 PM**	Side effects
163	**Mar 31, 2010 8:57 PM**	stress of self injecting
164	**Mar 31, 2010 9:44 PM**	Affected my liver
165	**Mar 31, 2010 10:17 PM**	Too painful and left bruises.
166	**Mar 31, 2010 10:17 PM**	Anxiety
167	**Apr 1, 2010 12:36 AM**	I hate needles and puncture marks, and I don't want to fill my body with toxins
168	**Apr 1, 2010 8:07 AM**	drug didnt work (betaferon)
169	**Apr 1, 2010 8:49 AM**	Having been re-assessed as having Secondary Progessive MS, the use of the drug would not have benifited me

170	**Apr 1, 2010 9:31 AM**	caused problems with my white blood cells and liver
171	**Apr 1, 2010 9:58 AM**	ms moved from RR to secondary progressive
172	**Apr 1, 2010 10:59 AM**	Didn't feel happy relying on drugs
173	**Apr 1, 2010 11:06 AM**	tried a new treatment that had no affect
174	**Apr 1, 2010 11:09 AM**	unacceptable side effects
175	**Apr 1, 2010 11:54 AM**	Copaxone wasnt working so well after 3 years
176	**Apr 1, 2010 12:06 PM**	was on avonex, had 3 relapses in year,started on tysabri a year ago
177	**Apr 1, 2010 12:32 PM**	x
178	**Apr 1, 2010 12:51 PM**	Problems with injecting myself
179	**Apr 1, 2010 3:44 PM**	Never got over the problems with injections and struggled with the "flu" symptoms - although had taken for around 4 years
180	**Apr 1, 2010 4:12 PM**	Side effects too debilitating for long term use
181	**Apr 1, 2010 6:41 PM**	It wasn't working, so I was put on Tysabri instead
182	**Apr 1, 2010 7:58 PM**	Kept relasping
183	**Apr 1, 2010 8:14 PM**	symptoms remained the same for 10 months
184	**Apr 2, 2010 2:37 AM**	Economic
185	**Apr 2, 2010 8:39 AM**	Relapses frequent on both avonex & copaxone. Now on tysabri.
186	**Apr 2, 2010 10:33 AM**	Betaferon, I had an allergic reaction and injection sites were extremely painful
187	**Apr 2, 2010 2:37 PM**	Over active thyroid, neurologist said I had to change from Rebif to Copaxone
188	**Apr 2, 2010 5:05 PM**	Was in Republic of Ireland taking Rebif. On return to UK was not then available to me.

189	**Apr 2, 2010 6:31 PM**	Had avonex, went to tasabri for 2 years and now on copaxone
190	**Apr 2, 2010 7:41 PM**	side effects i.e.one day a week of misery,for years
191	**Apr 3, 2010 2:35 PM**	I started taking tysabri as i was told rebif was not effective for me.
192	**Apr 3, 2010 3:51 PM**	I now have Tysbri infusions
193	**Apr 3, 2010 4:32 PM**	weight gain and depression
194	**Apr 3, 2010 4:39 PM**	betaferon did not seem to help me
195	**Apr 3, 2010 7:55 PM**	I developed bad reactions to copaxone after five years of few MS symptoms
196	**Apr 3, 2010 9:19 PM**	side effects and injection
197	**Apr 4, 2010 8:57 AM**	I was put on another treatment
198	**Apr 4, 2010 10:37 AM**	injected into a nerve
199	**Apr 5, 2010 8:21 AM**	ohne wirkung
200	**Apr 5, 2010 10:32 AM**	Side effects
201	**Apr 5, 2010 11:27 AM**	Stopped taking Avonex as it made mmy symotoms worse
202	**Apr 5, 2010 12:26 PM**	consultant changed drug
203	**Apr 5, 2010 12:51 PM**	ineffective
204	**Apr 5, 2010 6:05 PM**	My body started to reject the drugs
205	**Apr 5, 2010 6:11 PM**	i was advised by my medical team
206	**Apr 5, 2010 8:25 PM**	leg stiffness with avonex and rebif
207	**Apr 5, 2010 8:35 PM**	Made me sick

208	**Apr 5, 2010 9:06 PM**	avonex affected my mood & side effects & injection unpleasant
209	**Apr 6, 2010 4:05 AM**	side effects
210	**Apr 6, 2010 9:57 AM**	I was allergic to all of them
211	**Apr 6, 2010 12:00 PM**	I had a bad allergic reaction to Rebif, consultant took me off it.
212	**Apr 6, 2010 1:25 PM**	Pregnancy
213	**Apr 6, 2010 5:17 PM**	Lack of result and difficulty injecting regularly
214	**Apr 6, 2010 5:51 PM**	i did not like injecting and felt that it was nt working
215	**Apr 6, 2010 6:30 PM**	reacted badly to rebif
216	**Apr 6, 2010 6:54 PM**	side effects
217	**Apr 6, 2010 7:27 PM**	RRMS progressed to Aggressive RRMS so moved to Tysabri
218	**Apr 6, 2010 8:42 PM**	side affects(slow healing of skin areas) now poss due to diabetes
219	**Apr 7, 2010 8:35 AM**	Plateaued on Avonex - kept getting celulitis from Betaferon
220	**Apr 7, 2010 11:25 AM**	became needle phobic
221	**Apr 7, 2010 11:53 AM**	no longer able to tolerate side effects and skin tissue broke down
222	**Apr 7, 2010 12:59 PM**	Betaferon had lower percentage of relapse than Avonex
223	**Apr 7, 2010 1:21 PM**	My husband couldn't deal with giving me injections
224	**Apr 7, 2010 2:37 PM**	pregnancy
225	**Apr 7, 2010 4:36 PM**	I was taken Avonex for a year but it wasn't stopping relapses I'm now taking Tysabri and it been great no relapses in almost 2 years
226	**Apr 7, 2010 6:16 PM**	my ms was remiting replsing after 6 years my neurologist told me my ms has become secondery progresive so he stopped me from taking the drogs.

227	**Apr 7, 2010 7:11 PM**	Betaferon was no good for me because I have aggressive relapsing and remitting so I went onto Tysabri
228	**Apr 7, 2010 8:29 PM**	to begin tysabri
229	**Apr 8, 2010 10:33 AM**	self injecting
230	**Apr 8, 2010 3:47 PM**	continuing relapses - commenced on Tysabri
231	**Apr 8, 2010 4:51 PM**	stopped working
232	**Apr 8, 2010 8:17 PM**	side effects
233	**Apr 9, 2010 12:05 AM**	the flu like probs with this drug made me feel very ill.
234	**Apr 9, 2010 5:59 AM**	Ineffective and exacerbated my symptoms
235	**Apr 9, 2010 10:16 AM**	Developed neutralising anti-bodies
236	**Apr 9, 2010 10:23 AM**	MS NOW PROGRESSIVE NOT RR & HAVE BEEN ON FOR 5 YEARS
237	**Apr 9, 2010 10:37 AM**	skin reactions
238	**Apr 9, 2010 11:04 AM**	didn't seem to work and had site reactions
239	**Apr 9, 2010 11:43 AM**	did not work
240	**Apr 9, 2010 11:45 AM**	I now recieve Tysabri
241	**Apr 9, 2010 12:55 PM**	severe reactions to avonex and copaxone
242	**Apr 9, 2010 2:26 PM**	decision of dr
243	**Apr 9, 2010 2:43 PM**	Felt it had stopped working after nearly 4 years!
244	**Apr 9, 2010 3:05 PM**	avonex-due to mood problems copaxone-skin problems. Also I did not really believe I had MS.
245	**Apr 9, 2010 4:01 PM**	Rebif did not suit me ; made me so ill

246	**Apr 9, 2010 5:56 PM**	I got very painful site reactions and had panic attacks
247	**Apr 10, 2010 10:03 AM**	stopped working & alot of relapses
248	**Apr 10, 2010 11:21 AM**	severe side effects
249	**Apr 10, 2010 11:54 AM**	Reb/Cop - bad inj site reactions, distress of self-injecting
250	**Apr 10, 2010 1:41 PM**	all had adverse effects but currently on mitoxantrone
251	**Apr 10, 2010 5:04 PM**	did'nt agree with me at all
252	**Apr 11, 2010 1:49 PM**	Cpaxone interfeered with insulin absorption, Avonex made me feel so ill for 2 days a week even after being on it for 12 months
253	**Apr 11, 2010 2:28 PM**	more side effects from Rebif. changed to Avonex only 1 injection a week instead of 3 with Rebif , less side effects with Avonex.
254	**Apr 11, 2010 4:42 PM**	my consultant felt I needed "stronger" dose
255	**Apr 11, 2010 4:57 PM**	Avonex - Very low white cell count - now on Cop.
256	**Apr 12, 2010 11:38 AM**	I could not tolerate the side effects after 9 months of use
257	**Apr 12, 2010 2:11 PM**	frequency of relapses
258	**Apr 12, 2010 4:10 PM**	Relapses increased not decreased
259	**Apr 12, 2010 6:31 PM**	was told that it was no good for me .
260	**Apr 12, 2010 6:46 PM**	I am now receiving tysabri
261	**Apr 12, 2010 7:16 PM**	Bad reaction
262	**Apr 12, 2010 10:51 PM**	too many relapses on 1 affecting my liver on other 1
263	**Apr 13, 2010 8:46 AM**	capaxone - not effective (enough)
264	**Apr 13, 2010 9:32 AM**	Scan still showed activity, didn't lessen relapses, needles cause indentations in my skin

265	**Apr 13, 2010 10:15 AM**	Flu-like symptoms of Rebif were intolerable, had severe, dangerous allergic reaction to Copaxone
266	**Apr 13, 2010 11:04 AM**	skin reactions, joint pain, actual injecting itself
267	**Apr 13, 2010 12:01 PM**	developed antibodies to rebif
268	**Apr 13, 2010 1:42 PM**	Copaxone discontinued due to reaction to my skin
269	**Apr 13, 2010 5:44 PM**	Side effects horrendous - worse than MS symptoms
270	**Apr 13, 2010 7:12 PM**	i became allergic to copaxone i could not walk my legs doubled in size
271	**Apr 14, 2010 12:46 PM**	Started taking Tysabri instead
272	**Apr 14, 2010 2:33 PM**	i was on copaxone and had 2 flare ups a year and had site discomfort

Appendix E: Free text responses to an open question on people's main reasons for discontinuing Tysabri.

Number	Response Date	Response Text
1	**Mar 28, 2010 12:37 PM**	wanting to start a family
2	**Mar 30, 2010 1:06 PM**	I became allergic to it.
3	**Apr 1, 2010 11:10 AM**	doctors decision
4	**Apr 2, 2010 6:33 PM**	consultant was worried about further complications after 18 months of use
5	**Apr 2, 2010 7:44 PM**	fear of possibility of brain virus after 2 years
6	**Apr 5, 2010 10:35 AM**	Side effects
7	**Apr 7, 2010 8:38 AM**	fear of pml
8	**Apr 8, 2010 4:54 PM**	didn't work
9	**Apr 10, 2010 1:42 PM**	side effects so bad
10	**Apr 12, 2010 6:35 PM**	was told it was no good for me.

Appendix F: Interview questions sent to patient experts in advance of interviews

Thank your for agreeing to be interviewed on Tuesday 19 October at 12.00pm. The interview will be recorded and typed up and attached as an appendix to the MS Society's submission to NICE on fingolimod.

The purpose of the interview is to find out, in more detail, what difference fingolimod has made to you. What difference do you feel it has made to your MS, and how has taking fingolimod affected your day to day life? What have been the main advantages and disadvantages of the treatment?

Below are a set of questions I may ask you – these will be useful in preparing for your interview on Tuesday. In the mean time, if you have any questions, please do not hesitate to drop me an email – [redacted]

Opening questions:

1. When were you diagnosed with MS – what type of MS do you have?

2. Have you been on any other MS disease modifying treatments before? (Avonex, Rebif, Betainterferon, Extavia, Copaxone, Tysabri)

3. How long have you been taking fingolimod for?

Key questions to reflect main questions in submission:

4. What has been your experience of taking fingolimod – how do you feel it has affected your MS?

   Prompts:
   - Effects on physical symptoms eg. fatigue, pain, disability, general health

5. In your opinion, how has taking fingolimod affected your day to day life?

   Prompts:
   - Ability to work
   - Social life
   - Lifestyle
   - Impact on carer and/or family

6. In your opinion, what are the main benefits of taking fingolimod?

7. What have been the side effects of taking fingolimod? How have these been managed?

8. Other MS drugs are injectable or have to be taken via an infusion in hospital – what difference does it make to you to be able to take a tablet? What difference does it make to your quality of life?

9. Follow up: how does this treatment compare with other DMTs?

Closing questions

10. What key differences, if any, would it make to patients and/or carers if this technology was made available on the NHS?

11. What are the implications of not making the technology available on the NHS?

12. Any other comments?