King's Fund

Backwards in coming Forward

The Reticence of those with Mild Relapsing Remitting MS

Users' perspectives of the new MS drugs and the MS Society

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In response to Biogen's *Patient Market Research for the UK*

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Key findings

Reasons for low uptake

As noted in the original proposal, we found that far fewer people with MS are coming forward for new drugs than had been expected. Although many potential users were vaguely aware of the new drugs, the following influences seem to be key in deterring candidates from pursuing prescription.

- No proactive discussion with a respected clinician at a critical moment in the course of the disease (e.g. relapse or diagnosis)
- Negative views of GP or neurologist about the drug
- Reluctance to experience short term side effects and anxiety about unknown long term ones
- Mild form of the disease with either infrequent or unsevere attacks

For those who do not encounter these powerful deterrents, easy access to more detailed information and the ability to overcome a distaste for self-injections can tip the balance in favour of the drug.

Role of multiple sclerosis charities

Users of Betaferon in our study were likely to be young with mild relapsing remitting MS. Although most had received information on Betaferon® from the MS Society and found it helpful, few mentioned that they were members.

Participants commented as well as raising money, they would like the following from the MS Society.

- "Hard" information should be a principal role of the MSS. Such information could consist of trial information written in lay language, lists of drugs currently in trial and their prospects, experiences of new drug users and information on the range of effects of the disease for the newly diagnosed. A science library would be a welcome addition.
- The MS Society was described as corporate and needs to become more user focused and grassroots oriented.

Introduction

Background

From October 1995 to February 1997, the Management College of the King's Fund monitored the management of the entry of Betaferon (beta interferon 1b) for multiple sclerosis (MS) on behalf of North Thames Research and Development. In particular, we were asked to identify useful lessons for health authorities which could be applied to the introduction of future high cost, controversial drugs.

While undertaking this work, we convened groups of potential and actual Betaferon users to gather information on their experiences. Although discussion focused on the managerial aspects of the drug (e.g. role of neurologists and GPs, referral processes, usefulness of the national criteria), many other topics of interest were covered.

Aims and limitations of this report

In hopes of encouraging the exchange of information between MS charities, pharmaceutical companies, the NHS and users, we have written this report in response to the document entitled *Patient Market Research for the UK* drawn up by Biogen Limited and the Multiple Sclerosis Society.

We intend to include as much relevant information as possible, although the discussion groups did not cover all of the points laid out in the above document. When reading, please keep in mind that since our objective was to obtain feedback on the managerial processes, we do not know if some of the opinions expressed on other subjects were common. Furthermore since discussion groups are self-selecting, these findings cannot be said to be representative. Finally, the drug under discussion was Betaferon not Avonex® and therefore some of the findings may not be transferable.

Purpose of this report

Having made these qualifications, we will address two questions:

1. Which factors influence people with relapsing remitting MS to come forward for new drug therapies?
2. What do these group of people with MS want from an organisation such as the Multiple Sclerosis Society (MSS)?

In addressing the first question, we discuss various discouraging factors proposed such as insufficient information, reluctance to self-inject and/or experience side effects, problems with funding, lack of interest in reducing relapses and clinician inertia. We also include other previously unmentioned factors and a short section on the few participants who proactively pursued treatment.

Our ability to answer the second question is more limited as discussion about the MSS only came up in relation to the provision of information. Nonetheless, in one group there was a lively debate on the role of voluntary agencies which also touched on current perceptions of the MSS.

Structure of the report

A methods section and participant profile precedes the main body of the report. Appendices give details on information wanted by users, messages to pharmaceutical companies and ideas for carrying out further research to substantiate the findings in this report.

Methods

Approach used

In monitoring uptake of Betaferon, we requested access to anonymous patient data on all Betaferon users prescribed from December 1995 to September 1996 from the eight North Thames prescribing centres. Two clusters of uptake were identified, one in West London and another in Essex. A letter was sent to the principal prescribing neurologists of these centres asking permission to approach their neurology nurses as intermediaries.

We then met with nurses and asked them to invite (on our behalf) all current, deferred, or discontinued users of Betaferon to a discussion group. Those who were eligible for the drug but refused were also included. By working through the neurology nurses, patient confidentiality was assured, since the King's Fund obtained no names or addresses until users contacted the researcher to indicate their willingness to take part.

Response rate

In total, sixty two invitations went out. Twenty nine people with MS replied that they would be interested in attending, of whom twenty four actually came. Nineteen were current users of Betaferon; three had declined the drug and two had discontinued its use due to side effects. Sixteen carers also were present.

Details

Two groups took place at the King's Fund in Oxford Circus and three were at a local hospital. All sessions took two hours and were convened between September and November 1996. The smallest group involved three people and the largest had twelve. Recording of information was done through notes and tapes, but the tape from the first group was inaudible.

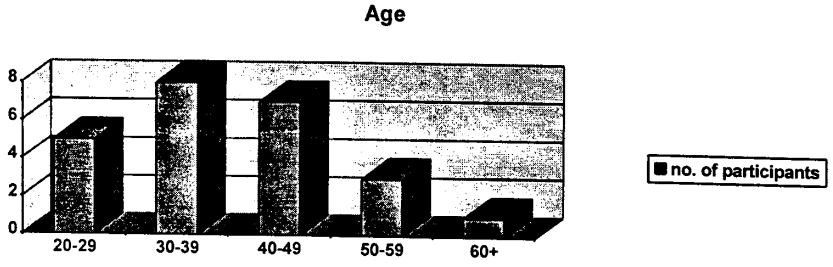
Participant profile

Disease type

As only people with the relapsing remitting form of MS are eligible to receive Betaferon, all participants had confirmed diagnosis of this type of the disease.

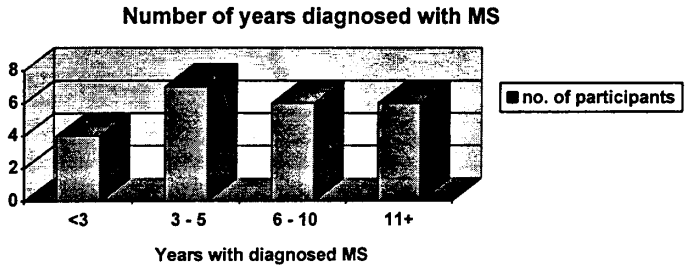
Gender and age

Five men and nineteen women with MS attended. The youngest was 23 and the oldest 63; the average age was 39.



Number of years with diagnosed MS

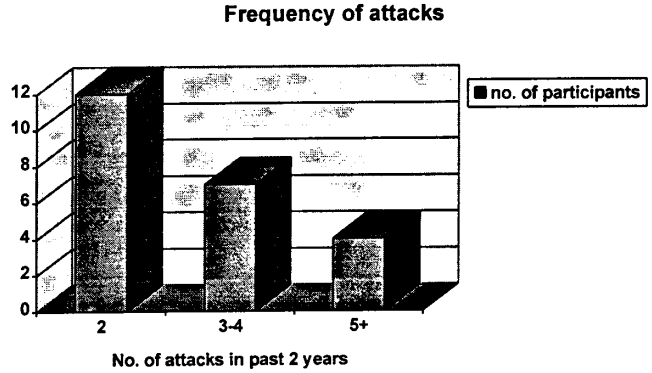
The number of years with diagnosed MS ranged from less than one to 33. Roughly half of the participants had been diagnosed for five years or less.



NB Data for one participant not available.

Severity of disease

National criteria specify that all candidates must have had at least two attacks in the past two years. The majority of the participants with MS had experienced just this minimum number of attacks. The most severely affected had twelve attacks in the past two years. The average was 3.5.



NB Data for one participant not available.

Participants' comments tended to support the assumption by the data that this particular group of people have a milder form of MS which does not greatly affect their daily lives.

> *I tend to put my MS away from me. It's not a major part of my life.*
>
> *I go 6 months and I think 'I'm fine now' and you forget what it's like to have a relapse.*

Which factors influence people with relapsing remitting MS to come forward for new drug therapies?

Factors with an unknown or confounding effect

Funding difficulties

Since everybody who participated in these groups would have been funded to go on the treatment, it is impossible to gauge the extent to which financial pressures deterred possible candidates. Nonetheless, one participant did encounter some problems.

> *My neurologist dangled it in front of me, but there were problems of finance so it had to wait until April. Then I was told to go to my local hospital and I could get it there.*

Almost all were aware that Betaferon is expensive, but for most it did not influence their decision to take up treatment. Nonetheless, it did affect how candidates interpreted information and influenced many participants' views on equity of access.

> *The cost didn't cross my mind at all.*

> *I was worried that English neurologists would think about the cost. The press went on and on about how it was going to be rationed and that was just not helpful.*

> *I suppose the only way it could be available to more people is if they lowered the cost.*

First treatment licensed

Several participants mentioned that they were interested in Betaferon as it was the only drug for MS available at the time.

> *It was the first thing I'd heard of and the only thing available so I grabbed it.*

For at least one other candidate however, the fact that Betaferon was the first MS drug was a deterrent.

> *If this is just a first generation drug, imagine what they could come up with in ten years time.*

Drug treadmill

Keeping in mind that many people with this type of MS have limited contact with the NHS, a few commented that Betaferon would be the first step onto a "drug treadmill". One woman who refused the drug stated,

> *There was a thing in my head that said once you're in the mentality you take this drug and then the next one and the next one...I didn't want to get into that.*

For a couple of others introducing themselves to the NHS as potential candidates for future drugs was an important factor in taking Betaferon.

> *One of the reasons I decided to go for this one was so I'd be here ready and waiting for the next.*

> *I went on Betaferon because I'm waiting for a cure. And here we are, it's Friday night and there's still no cure.*

Factors that in combination with other influences have a strong effect

Lack of further information

Although one participant said that Betaferon was not well known, almost all of the participants commented that they had heard of the drug long before considering treatment. The most common sources of initial information were: television, national press (both newspapers and magazines), the MSS and friends with MS. Several said they first heard of it from relatives abroad, in particular the United States and Ireland.

The majority tended not to act after this initial awareness of the drug. A few that did found obtaining further information quite difficult. One looked on the Internet and found the original trial data; another requested a medical literature search from a university where her mother worked. Three candidates were even more resourceful.

> *I had to ring neurologists abroad because you can't get the same kind of information out of an English neurologist. They (neurologists abroad) are much more frank with you.*
>
> *I asked a friend who was a pharmacist to get information from the drug company.*
>
> *A nurse from Wales advertised in the 'Nursing General' asking to speak to anyone with MS, so I wrote to her and she said she'd just started with Betaferon and she was having a wonderful experience.*

Other participants disagreed and said that finding further information was not difficult.

> *There was quite a lot about once you started looking for it. My family's a bit like the Mafia and we had press cuttings coming in from everywhere.*

Another mentioned that satisfaction with information depended more on finding the right answer to a particular question than the quantity available.

> *You can have something ten pages long, but if it's got the one paragraph that you've been looking for it can put your mind at rest.*

Lack of explicit information about a drug does seem to deter some users from taking up new treatments. One participant, in talking about her possible recruitment to a trial for another MS drug therapy, commented

> *I am very wary to go on this new drug when there's so little information about it.*

Self-injections

Injections were not popular.

> *I didn't like the injections or the thought of the injections.*
>
> *I'm not all that keen on sticking needles into me. I look like a map of the Channel Islands. (said by a nurse)*
>
> *If it were in tablet form, everyone would want it.*

The distaste for injections was so strong that some felt it would lead to them refusing any future drugs provided in injection form.

Nonetheless, none of the decliners mentioned that self-injections was a factor in their decision and those that were users found ways to become easier about self-injecting.

> *The video was good because it made me feel better about injections.*

I felt better about it once I saw the nurse inject herself. It sounds funny, but she just stuck it in her thigh and said, 'See it's not a problem'.

My husband said, 'Let's take some of the anxiety out of this. You mix 'em and I'll whack 'em."

Factors with a powerful influence

Short and long term side effects

Participants were very well versed in possible side effects to the drug and most mentioned that they had to be considered carefully.

Me and my husband thought about it quite deeply. I just felt that by that stage I could try the drug, see what the side effects were and if they were too bad give up. Or, not try the drug and not know and then six months down the line have a bad relapse and wish I had taken the drug. I really didn't feel I had a choice. I had to give it a go.

One of the participants who declined the drug stated that possible short term side effects played a large part in her decision.

In some ways, the side effects were worse than some aspects of the MS. Quite honestly, it didn't sound like it would be an improvement for me.

Participants also pointed out that those suitable for Betaferon are generally only affected by their disease when having a relapse and the rest of the time consider themselves to be quite healthy. By injecting every other day and suffering nausea, joint aches, fevers, headaches and so forth, they no longer perceive themselves as well but ill. Since amongst people with MS there is a great belief in being positive and remaining as active as possible, this redefinition of their self-perception could be a major drawback to using Betaferon.

Unknown long term side effects also heavily influenced two young women's decision to refuse the drug. Interestingly, both were childless.

Who knows? I might want to have babies and how does this drug affect them? Does it do something to their genes? That kind of stuff scares me.

Mild form of the disease

Participants were well aware that the principal effect of Betaferon was a reduction in relapses and this was valued highly by those who suffer vicious and/or frequent attacks. What's more, unlike clinicians who do not necessarily make an association between the two, some users felt that in decreasing the number of relapses, the progression of the disease would be delayed.

I wanted a break from this downward spiral because every time I have a relapse something else packs up.

Let me try the drug and let me see if it will help me and postpone going into a wheelchair.

The relative infrequency and mildness of attacks did contribute to two women's decision to refuse the drug.

I wouldn't take it at the moment because I haven't had an attack in over a year. But if I had lots of attacks or worse ones I would.

Clinicians' negative attitudes and inertia

Clinicians' attitude to the drug was one of the key factors in influencing candidates. Clinicians affected the process in many ways.

For a few people, the initial source of information was a GP, or more likely a neurologist. For others, who had heard about the drug but did not pursue it, the neurologist (or a member of the MS team) proactively proposing the drug was a very strong motivator.

> *My neurologist told me about it and said there was no reason why I couldn't take this on.*
>
> *I was phoned by (a member of her neurologist's team) and she informed me that there was a new drug and would I be interested in coming to a meeting to discuss it.*

In fact out of the twenty four participants with MS, only a quarter said they actively sought prescription. The rest would not be on treatment if they had not been approached by a medical professional and told of their suitability as candidates.

Just as positive attitudes from clinicians can encourage uptake, negative GPs and neurologists can severely limit the number of candidates coming forward.

In a separate piece of work with GPs, we found that far fewer patients enquired about Betaferon than had been anticipated (15% of the overall MS population). Furthermore, only about half of those requested referrals from GPs to a neurologist (7%) and only a quarter actually received referrals (4%). The main reasons for the drop-off were ineligibility according to the criteria and a lack of interest once further information was provided.

Two GPs also admitted that they were not convinced of the benefits of the drug and gave negative opinions to four or five of their patients. It is worth bearing in mind, however, that most of the participants in our group bypassed the GP and sought only their neurologist's views. For further details of this survey, please see Appendix 1.

Totally negative neurologists were even more likely than GPs to influence potential users against taking a new drug.

> *If you come up against a brick wall, a neurologist who doesn't hold with the drug, you think this man is knowledgeable, this is his field and he thinks this drug is not right. So you go away and don't ask for a second opinion.*

Timing of discussion with clinician

Several participants commented that the neurologist told them about the drug when they were first diagnosed or soon after an attack, which is a particularly vulnerable time for someone with MS.

> *I think when I was introduced I was still in shock from the diagnosis....My dad died from chronic progressive MS two years ago so anything that came along I'd grab it.*
>
> *I had a relapse and I thought I'll take anything to not have this again.*
>
> *When you've just come out of an attack they could have been injecting me with water and I wouldn't have cared.*

Since most participants only saw their neurologist at diagnosis and during relapses, they felt that this was an appropriate time to learn of the drug, but not necessarily to make a decision about taking it.

I feel you have to come to terms first with your MS before you go on this drug, which is not easy.

Making a rational decision when you've just been diagnosed is very difficult. Your whole life has just been turned upside down....I'd only been diagnosed six months ago and I'd already had so much grief I decided not to give myself anymore. But if the drug had come out during my second attack, I would have taken it but that wouldn't have been good because it wasn't a rational decision.

Experiences of those actively seeking treatment

Of the six who actively sought treatment, only one reported experiencing difficulties.

My neurologist said, "I wouldn't stick something strange like this into myself". And I said, "But you don't have MS." I had to have a tantrum to get it, but I think it was more a case of him not knowing me well enough than him not wanting me to have the drug.

In one group, where two people had actively sought the drug, both stated they would have fought harder to receive treatment if they had met resistance. Several more from the same group, who did not proactively seek treatment, remarked that at the first sign of any obstacle the matter would have been dropped. This suggests that those who expect resistance are more willing to try to overcome it than those who anticipate a smooth run.

Interestingly two of those six who actively sought out treatment decided against it once they were given further information in the assessment interview.

Before it was licensed, I wrote to everyone under the sun about it: my health authority, my GP, the MSS. Once I was offered it, I wasn't interested anymore.

I went in there (to the assessment interview) determined to have it, but when he said I could I didn't want it anymore.

There is a possibility that this particular neurologist was negative about the drug, but since many candidates reported that he presented the benefits and risks fairly and left the decision very much up to the patient this is probably not the case.

Summary of key factors influencing take up

As noted in the proposal, we found that far fewer people with MS are coming forward for new drugs than had been expected. Although many potential users were vaguely aware of the new drugs, the following influences seem to be key in deterring candidates from pursuing prescription.

- No proactive discussion with a respected clinician at a critical moment in the course of the disease (e.g. relapse or diagnosis)
- Negative views of GP or neurologist
- Fear of short term side effects and anxiety about unknown long term ones
- Mild form of the disease with either infrequent or unsevere attacks

For those who do not encounter these powerful deterrents, easy access to more detailed information and the ability to overcome a distaste for self-injections can tip the balance in favour of taking up the drug. For details on the type of information people with MS want, please see Appendix 2. For messages from users to drug companies, see Appendix 3.

What do these group of people with MS want from an organisation such as the Multiple Sclerosis Society (MSS)?

Attitudes to the MSS

A couple of participants volunteered that they were members of the MSS, but the majority did not seem to belong although we cannot be sure as these data were not collected.

Discussion about the MSS was always in relation to the provision of information and one participant in particular felt very negative about the MSS as a whole. Many of the quotes below are hers and caution should be exercised as her feelings may not apply to the majority. Nonetheless, she was very articulate in expressing the dissatisfaction that some young people with mild MS may feel.

> *They (the MSS) raise a lot of money which I'm delighted about, but I don't like the way they portray MS. You tell someone you've got MS and they automatically think you're going to die or fall over and dribble at the mouth and that's because of those MS posters. I remember going up the tube, I'd just been diagnosed (Spring 1996) and I went past those posters and I was hysterical by the time I got to the top. How I was going to lose my sight, how I wasn't going to be able to walk. And it's a lie. The statistics are that it's one in five that get hit to hell and they give the impression everyone is.*

Feedback on Betaferon leaflet

Discussion about the charities' Betaferon leaflet took place in all five groups. Most were positive.

> *I was impressed by the leaflet because it gave lots of information and didn't over simplify.*
>
> *I thought it was a very good leaflet which surprised me as I am not the most enormous fan of the MS.*

A few made less encouraging comments.

> *Like everything else I read, it was a bit on the fence.*
>
> *It didn't really tell me anything I didn't already know.*

Further information wanted

Users always want more information but getting the balance right in amount and tone is not easy, as users themselves are aware.

> *I don't want to know much. You on the other hand want to know everything.*

Many talked about the different stages of information and the type and quantity of information required. Initially, users indicated that they needed to know the minimum of who the drug is for, benefits and risks, side effects, method of use and where it can be obtained. In the next stage, when assessing their candidacy with clinicians and trying to make a decision, users requested more detailed information, preferably in written form.

> *I would have liked more written information. You can't take it in when they're talking to you.*
>
> *Maybe if we'd been given statistical information about the trial in the USA...it might have given us a better idea. It would have been quite useful.*

I would have liked the chance to hear other people's experiences on the drug. It might not have changed my mind because there's nothing else out there and steroids are useless. More information, more easily available.

I'd like to know more than the superficial stuff. I want to know exactly what it's doing and why. I probably wouldn't understand it but I'd like to try.

I feel I should have been told about this (the antibodies) before I went on the drug.

After having made a decision to take Betaferon and before the first injection, users needed and received a great deal of information on self-injection techniques and dealing with side effects from Innovex and NHS nurses. Once the first two months of severe side effects are over, information is required on how to incorporate the drug into your life long-term so travelling tips and information on contraindications are useful.

Even though the participants were amongst the first to use Betaferon, they commented that they would always like to hear more about other people's experiences on the drug. Any subsequent information on short or long term side effects would also be useful.

Role of the charities

The few participants who spoke about the role of multiple sclerosis charities felt that information provision was the most important task, especially as some doubts were expressed as to the degree of bias from clinicians and inaccessibility of pharmaceutical companies.

The MSS don't even have a science library. Explaining that stuff and going through the science in layman's terms is their job....This generation now are Thatcher's babies and tea and sympathy and Thatcher's babies just won't mix. We want hard information and the MSS just hasn't moved with that.

A few participants spoke of how they had found other charities very helpful.

The Myelin Project are very good. I got in touch with them when I first got diagnosed.

My sister rang the ARMS Society and they sent her the info and they are fantastic.

In this country we're not as pushy and it's kept under wraps. I got very fond of Americans when I was diagnosed because I would ring them and they'd say, "OK what information do you want? Where do I send it to?". Over here it's "he's out of the office and I don't know when he'll be back".

In a subsequent discussion with the participant who voiced her dissatisfaction with the MSS most strongly, she elaborated that the MSS's job was to inform even if it "pissed people off". She praised the literature of the MSS in the USA as they provided a brochure on all the drugs for MS currently in trial and their potential usefulness. Furthermore she stated that she would be just as happy with information photocopied in A4 sheets as glossy brochures as she was interested in facts not presentation.

Finally, she added that the MS needed to become more grassroots focused.

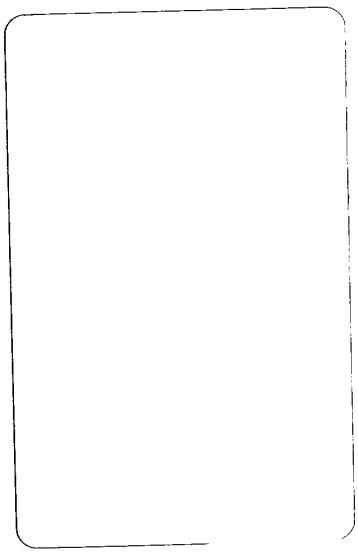
The MSS's attitude to patients is patronising. If you go to Terence Higgins Trust, their attitude to sufferers is completely different from the MSS because the HIV patients are seen as the client, the focus. The MSS is almost corporate. Their 'Reaching for the Stars' was awful - something about we must bring the concerns of the MS sufferers more to the centre. And I thought, "Why are you saying this now? Isn't that what you're there for?"

Summary

Keeping in mind that very few participants spoke about the MSS, the information we gathered on perceptions of the charity is cursory at best. Their principal contact with the society had been through the provision of information, which most had received and found helpful.

Participants commented as well as raising money, they would like the following from the MSS.

- "Hard" information should be a principal role of the MSS. Such information could consist of trial information written in lay language, lists of drugs currently in trial and their prospects, experiences of new drug users and information on the range of effects of the disease for the newly diagnosed. A science library would be welcome.
- The MS Society was described as corporate and needs to become more user focused and grassroots oriented.



Appendix 1

Table 1

General Practitioner Profiles for East London and City HA and East and North Hertfordshire HA

	All practices	Single	2 partner	3-6 partner	7+ partners	Fundholder	Multifundholder	Non-fundholder
ELCHA	369	17% (62)	20% (74)	55% (203)	8% (30)	2.5%	17%	80%
E&N Herts	280	4.5% (13)	4% (12)	60% (168)	31% (87)	76%	-	24%

Table 2

Sample Numbers

	Total sample number	Single	2 partner	3-6 partner	7+ partners	Fundholder	Multifundholder	Non-fundholder
ELCHA	28	4	6	16	2	1	5	22
E&N Herts	21	1	1	12	7	16	-	5

Table 3

Referral Patterns and Outcomes

	Expected numbers with MS in total popul-ation (1:1000)	Estimat-ed actual number s with MS in total pop.	Number s with MS in sample popula-tion	Sees GP		Self refers to neurologist	Sees Neurologist				
				Initial enquiry	Referred to neurologist		Not suitable	Joint decision no Rx	Waiting assess-ment	Outcom e not known	Prescribe d
ELCHA	585	533	40	8	4		3		1		0
E&N Herts	488	1266	95	9-10	1	2	1	1		1	0

Appendix 2

Questions asked by participants during the discussion

Medical questions on Betaferon

1. Is Betaferon a life long drug?
2. What happens after two years? Does your body get accustomed to it?
3. What does it actually do inside my body?
4. What are these neutralising antibodies and why isn't there a test for them when there was one on the trial?
5. How long will it take before you actually begin to feel better?
6. Do younger people respond better to the drug (anecdotal evidence that they do)?
7. Can you take steroids while on the drug or not?
8. Could more severe reactions be due to bad doses?
9. What other drugs are contraindicated (e.g. contraceptive pill and analgesics)?
10. Have any other side effects cropped up now that it has been on the market for longer?

Practical questions

1. What procedures do you need to follow when going abroad with the drug?
2. If you stop taking it, what happens to the doses you don't use?
3. Do you need a pre-payment certificate?

General questions

1. Why are they so expensive?
2. Why is the drug only available for those who meet the criteria?
3. How do they know that it cuts down relapses by a third when MS is such a variable disease?
4. Why is it in injection form?
5. Why do we have to mix it up?
6. Why is the American name different?
7. How are other users of the drug coping?

Questions on other drugs

1. Is it true that they are working on a drug that is injected into your body and goes into your brain and goes to the places where you need to be repaired?

Appendix 3

Messages to pharmaceutical companies

Some were anxious that overall investment in MS may slacken as the uptake of new drugs is so low. One of the commonest worries was unease at the long term future of the beta interferons.

> *I feel that they could well chop it because it's expensive and not enough people are on it.*

One participant was angry because

> *...they (drug companies) don't talk directly to patients and I understand that's government regulations but that's wrong ...and I read in a science magazine about the neutralising antibodies and they were playing that down. That's way out of order.*

Other participants were also confused about neutralising antibodies and felt that any tests like the ones for neutralising antibodies should be sorted out before marketing the drug.

In two groups, there was a short discussion on why the sufferers with the mildest form of the disease were being offered the first MS drug therapies. Most were merely puzzled, but one participant felt that it was morally incorrect, as well as a mistake from a marketing viewpoint, not to produce drugs for the worst off first.

Finally advice was offered on how to gauge potential uptake.

If you want to know the number of people who are going to take a drug, talk to the people with the disease who are the least badly affected and then you'll know the bottom line - the fewest number of people you can expect.

Appendix 4

Suggestions for further research

In assessing the representativeness of findings on low uptake

Three questions are raised by this work which need to be answered before Biogen take any further action. They are:

1. are these findings true in other places in the country?
2. are they representative for larger groups of those with mild relapsing remitting MS?
3. can they be applied to Avonex as well as Betaferon?

We suggest two possible approaches in answering them. The first is to convene focus groups of those who have gone through the process of assessment for Avonex throughout the country. As well as generating further clues, discussions would give partial answers to 1 and 3.

Of particular interest would be individuals who decided not to take the drug as they can give much more information on the weight of each factor than the small number of declimers in our study. A short questionnaire would then be helpful to test out the representativeness of the findings in the larger population of those with mild relapsing remitting MS.

With regards to recruitment, it is unlikely that people would come forward as a result of a radio or television advertisement as some have not yet told key individuals (e.g. bosses, friends) that they have MS and therefore may not respond to such a public invitation. Neurologists' lists would be the ideal source, but in order to take part, neurologists need to see that their patients or the service will benefit.

One possibility is to work with neurologists who conducted trials of Avonex or have prescribed it frequently once licensed. Another option is to identify those areas where the MS Society has a strong branch with good links with the local neurologist. We found that building up good relationships with neurological nurses and other support staff and asking them to recruit on our behalf also worked well.

It is probably advisable to recruit only people who have been through the assessment process since they will have deliberated the implications of taking a new drug fully. Trial participants might also be suitable, but there could be possible biases. Recruiting individuals who have never seriously considered taking the drug or who would not meet the criteria is not helpful as they usually give an over-optimistic picture of their interest.

In assessing the findings on the MS Society

Much more work needs to be done in this area as only one group really discussed the role of the MS Society. Again, we would highly recommend focus groups to gather initial information on possible incentives to joining the MSS followed by questionnaires to test for respresentativeness. Participants would need to be young with mild to very mild MS, although they do not necessarily need to have gone through the process of assessment for new MS drugs. Recruitment channels could be similar to the above; particular stress on the need to meet the information requirements of people with MS might interest some clinicians in participating as they could then gear their own information provision accordingly.