King's Fund

Management of the Introduction of Betaferon®

A Developmental Evaluation

Final report

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by

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Executive Summary

Background

In the next few years, an expensive, clinically persuasive, high demand drug will come on to the market with the power to seriously disrupt health authorities' budgets. Contrary to initial expectations, beta-interferon 1b for multiple sclerosis was not that drug.

However, as the first drug to be actively managed, the introduction of Betaferon® - Schering's trademarked beta-interferon 1b - has provided the opportunity to pilot many helpful approaches and evaluate their usefulness. Our project followed the process in one region (North Thames) from early autumn 1995 (a couple of months before Betaferon was licensed in December 1995) until just over a year after its introduction.

Key messages

- **Many of the approaches used in managing the entry of Betaferon were successful** and could be applied to future similar drugs with minimal modification.
- **National clinical guidelines** have been widely appreciated by GPs, neurologists, and users. When introducing future 'managed' drugs, some mechanism should be devised whereby central guidelines, which are drawn up by a respected clinical source, are issued, and **supported by a local process** of review, adaptation, agreement and adoption into routine clinical use.
- **Severe and unanticipated side effects** were apparently not picked up by the existing yellow card system, although two of our sample of 21 Betaferon users reported them in our discussion groups.
- **Involving users** should receive a higher priority in order to get an idea of potential demand and patient concerns, through discussions both pre- and post- licensing.
- **Better auditing mechanisms** need to be developed and put in place for high-impact new drugs, to assess early uptake and conformance with guidelines.
- **The role of lead purchaser** was not followed through although it had been valuable in the very early stages. In future if the lead purchaser approach is to be used again, **CEOs and region should clarify their expectations of the lead purchaser role**, and make proper arrangements for resourcing it.
- **Some sort of co-ordinating body would be useful to lead** the development of more systematic processes for managing the introduction of significant new drugs, and provide some of the positive guidance supplied by the NHS Executive for Betaferon, which will not be produced for future drugs. Current work done by the Drug Information Network could form a starting point, but it would need secure funding and further development.
- **Issues of equity,** both between patients within a particular health authority and between patients in adjacent health authorities, should be discussed and the implications of *not* funding a drug explored by a wide range of interested parties, including CHCs and GPs, both regionally and locally.
- **The role played by the King's Fund** in the evaluation process was welcomed by our project steering group. They valued our independence, our role as a focal point for communication, and the mix of support and challenge we provided which was seen as developmental as well as evaluative.

Contents

Main Findings

Introduction

This section summarises approaches which worked well (and not so well) and offers suggestions for the management of future neurological drugs and perhaps, in some cases, drugs for other conditions. Further details are provided later in the Project Report section later in this document.

Summary of useful approaches in managing Betaferon

Health authorities

- Early financial commitment by health authorities helped focus energy on good management. (see paragraph 6. in the Project Report section for further information)
- Key stakeholders within providers, including sources of influence such as Clinical Directors, were identified by managers leading on Betaferon at an early stage to establish a climate of collaboration. Discussions with clinicians were valuable to gain a sense of their opinions about the drug, specifically its degree of clinical effectiveness, potential health gain and possible extent of prescription. (§7. 8.)
- GPs were involved appropriately in the process. GP letters, which included information on all aspects of the drug as well as recommended prescription routes, were particularly appreciated by GPs. (§9.)
- In general, GPs, neurologists and patients were happy with consultant only prescription *for this drug* since GPs know little about the condition of MS and even less about interferons, the long term effects are not known, the clinical effectiveness of the drug is questioned and the expense is high. (§10. 11.)
- Tertiary centres worked well in limiting prescription to the most appropriate candidates. Consultant prescription has not occurred without prior agreement with the health authority. (§14. - 16.)

Regional level

- The lead purchaser provided useful information by liaising with the NHS Executive and the pharmaceutical company in the early stages, but other implicit expectations of the role were never properly clarified and were not met. (§27. 28. 29.)

National level

- The Executive Letter EL 95(97) highlighted the importance of Betaferon for those health authorities where little planning of its management had previously taken place. (§30.)
- The EL also importantly indicated that this drug was expected to be available on hospital prescription only, not GP prescription. This was seen as extremely helpful by HAs and widely accepted by GPs (at least for the early years), hospital neurologists, and people with MS. (§31.)
- The clinical guidelines issued by SMAC were appreciated by GPs, neurologists and users. Including users in the process of consultation was very positive. (10. 11. 32.)

King's Fund Role

The project group felt that there were several helpful aspects to the King's Fund involvement. They asked us to note in this report particularly:

- the study design and feedback processes which provided a very useful mechanism for reflection during and immediately after key meetings and decision points.
- our simultaneous support of and challenge to participants with whom we worked - providing a source of 'critical appraisal'.
- our role as a focal point for communication and sharing of information.
- our independence of vested interests, and our organisation's reputation and credibility with a wide range of actors.
- the potential to use our report as an 'external lever' within and outside the HA.

Suggestions for management of future neurological drugs

Lead managers

Lead managers were those who took on the practicalities of the work and in the case of Betaferon included pharmaceutical advisors, medical advisors and public health consultants.

1. Discussions should be initiated with users via national *and* local branches of patient organisations to ascertain their priorities pre-launch. Keeping in mind that it typically takes approximately two years for a drug to reach its full market potential in the UK, even more valuable contact with users could be initiated post-launch to discuss expected demand, once more information is available. (§25.)

2. Key stakeholders within the authority, especially commissioning and contracting staff, should be brought into the arena early on to look at ways of negotiating contracts. (§6. 7. 17.)

3. Lead managers from health authorities without host providers could look at ways of agreeing protocols together in order to avoid a single centre working to different purchaser guidelines. (§13.)

4. Future planned introductions could make more use of the regular contact between potential users and usual neurologists to discuss new drug treatments. (§12.)

5. Letters to GPs could be written in such a way that they include or can serve as information for patients, providing that they are jargon free and easily understood. (§26.)

6. The interface between tertiary and secondary care, particularly the process of follow up, should be more clearly developed before final contracting takes place. (§14. - 16.)

7. Side effects, particularly serious or unanticipated ones, should be more closely monitored and reported. When a small total number of patients receive a new drug (such as Betaferon), this information will need to be actively sought by HAs, and specially collated at a supra-regional or even national scale. (§24.)

8. Auditing mechanisms should be required by HAs from providers (some of whom have been reluctant to disclose any information at all about the patients they are treating). Processes should be set up using the expertise of local MAAGs and public health information departments and in consultation with clinical and contracting staff from purchaser and providers. A key individual within the authority should be responsible for routinely checking on returns from providers and reporting back to the authority, and where appropriate a supra-regional (or national) collating centre. There should be a role for GPs in reviewing or providing input to the audit process. (§22. 23. 18.)

Chief Executives

1. A regional mechanism (The Drug Information Network) exists for gathering and digesting available information on emerging drugs, and disseminating it to lead managers in health authorities. However, its funding needs to be secured, so that its work can be more systematically planned and followed through. Any other work that helps to predict potential uptake of new drugs and its consequent cost should be encouraged. (§3.)

2. Issues around equity of access need to be thought through more fully and the implications of not funding a new drug discussed with a wide range of interested parties, including CHCs and GPs, both regionally and locally. Potential consequences may need to be identified and contingency plans arranged. (§38. 42.)

3. If a lead purchaser approach is thought to be appropriate, this role should be discussed at regional CEO meetings (§27.- 29.) with the explicit definition of:

    - which tasks are to be done
    - who is to do them
    - how their work will be paid for
    - when the work should be done

4. To avoid over-reliance on any single individual in any HA, lead manager responsibility should be supported more strongly by active involvement from at least two departments: for example, public health, prescribing, and contracts/finance. (§8.)

5. Chief Executives as a group might wish to consider quite quickly extending the approach suggested here to managing beta-interferon 1a and co-polymer 1. Some of the features found helpful in managing Betaferon are absent or weak for these new drugs, raising the risks and the requirement to manage them actively locally - there is no equivalent of the Betaferon Executive Letter, GP prescription remains a real possibility, no clinical guidance has been produced, and to date there is very limited information available.

NHS Executive

1. Several of the NHSE's actions which were seen as helpful in this instance are not likely to be repeatable for future drugs in the same way by the NHSE itself. (§30. 32.) There seems to be a need for some form of co-ordinating body which could provide a supportive lead to HAs, including at least:

- an independent and credible source of information about significant new drugs nearing licensing.
- clinical guidelines from a respected body of clinicians.
- a focal point for communications about selected recently introduced drugs, including collation of information about side effects, and processes for supporting local adoption of clinical guidelines.

2. The difficulty in managing to set priorities locally and ensure equity of access nationally needs to be addressed urgently. (§31.)

Project Report

Background

1. Throughout 1994 and early 1995, health authorities were becoming increasingly aware of the need to manage the introduction of new drugs. With the issuing of EL(94)72 and constant reminders of the imminent launch of Betaferon for multiple sclerosis, many began to seriously look at the issues.

2. Partly in response, the North Thames Organisation and Management Group commissioned the King's Fund to monitor the management of the introduction of Betaferon. Work began in October 1995, two months before the product was licensed, and continued for just over one year.

Why Betaferon?

3. At the time Betaferon was selected as the topic for this study, anxieties about its launch were very high and there was widespread consensus that its introduction would need to be actively managed. Not every new drug necessitates this, but Betaferon had almost all of the characteristics of drug that warrants a careful entry, as the model below shows. Thinking about new drugs in this way may help to identify potential budget busters in advance and select an appropriate degree of management. Further discussion with North Thames pharmaceutical advisors in March may help to develop these ideas.

No management required	→	**Active management required**
Cheap		Expensive
Robust evidence		Disputed evidence
Multiple treatments available for condition		First treatment available for condition
Uncontroversial		Controversial
Low demand anticipated		High demand anticipated

Aims of the Project

4. By working with the principal stakeholders in the introduction, pharmaceutical and medical advisors, public health consultants, finance mangers, provider operations managers, neurologists, GPs, users, the pharmaceutical company and the Multiple Sclerosis Society, we hoped to identify the approaches to the management of Betaferon which were most or least successful. The long term goal was to determine which approaches could potentially be used when managing future drugs.

Structure of the Report

5. The rest of this report has two main sections. The first looks at the strategies which were used and evaluates them. The second offers some observations on rationing that came to light during the management of Betaferon.

Strategies Employed in the Management of Betaferon

Local Level - Health Authorities

In the early stages (before licensing)

Financial commitment

6. Early stages of the introduction were facilitated by the commitment of health authorities to fund Betaferon, subject to prescription being made in accordance with the product licence and detailed clinical guidelines, despite restricted budgets and pressures to blacklist the product. This commitment dispelled fears of explicit rationing, which could have led to negative media attention and increased patient demand. Instead energy was concentrated on learning how to introduce new drugs successfully.

Early negotiations

7. Pre-licensing contact between purchasers and providers was mentioned by both as productive. A common goal of "how can we best manage this drug" provided a forum for those with previously opposed agendas to work together and, in some cases, healed old wounds. An added bonus was the sparking off of organisation-wide discussion of the issues within health authorities and trusts. Purchasers were also able to gain an understanding of clinical attitudes towards the drug and its potential for uptake. Some purchasers adopted a low key, informal one-to-one approach while others set up multi-disciplinary groups.

Difficulties

8. Both techniques worked well but it was initially difficult to identify the "right" people within trusts regardless of the approach. A further complication with the one-to-one method was that in one health authority the lead manager left before finishing the process and to date no one has carried on her work. Over-reliance on one individual to manage the introduction of a drug is not to be recommended as turnover amongst NHS staff is significant.

Clinician involvement in the process

GPs

9. The degree and ways of involving clinicians, both GPs and neurologists, were appropriate. GPs were sent letters about Betaferon encouraging them not to prescribe. In a small survey conducted with GPs from two health authorities, those who remembered the letters described them positively with one commenting, "perfectly pitched". Interestingly, only one GP from the inner London authority recalled the letter, which may indicate that in the future other communication methods may need to be employed with the hardest pressed GPs.

GP versus hospital prescription

10. All GPs contacted were happy with initiating the drug on a consultant prescription basis and, except in one case when a GP began prescribing Betaferon before it was licensed, health authorities reported that all other North Thames GPs had complied with this guideline. GPs gave many reasons for this including their lack of knowledge about the disease and the drug, uncertainty of long term effects and the controversial nature of the drug, both from a clinical effectiveness and funding perspective. Patients also added a further incentive for consultant only prescription in that GPs may not have the time or staff to provide adequate resources for a Betaferon user. Although participating GPs were satisfied with initial hospital prescription, a few argued for a more 'shared care approach' a few years down the line.

11. The majority of neurologists who responded to a questionnaire also stated that they were happy with hospital based prescription.

Neurologists

12. Most indicated they were satisfied with the way in which they had been involved in the process of introducing Betaferon although the role of the usual consultant in frequency of contact and follow up was somewhat overlooked. As the best placed person to initiate discussion about the benefits (or otherwise) of a new drug treatment, this point of contact could be expanded on when looking at managing future drugs.

13. One source of potential conflict between clinicians and purchasers was identified at a centre which receives a great many outside referrals. Clinicians here are treating patients from seven different health authorities, some of which have insisted on different cessation criteria. This could lead to a situation in which one patient is taken off the treatment while another with the same circumstances continues. In managing future drugs, the issue of multiple purchaser guidelines for the same treatment at a single centre may need to be addressed more fully.

Tertiary centres

Advantages

14. Tertiary centres with specialist clinics run by one or two designated clinicians worked well; all neurologists who have prescribed Betaferon so far did so with prior agreement from the respective health authority. Patients were in favour of this approach as they felt the same type of candidate was likely to be prescribed and the selection process was fairer. Other advantages mentioned were that prescribing neurologists can become experts in the drug and it fostered good control and monitoring. Nurses were also happy as they (usually) only needed to set up networks within one hospital and could keep track of results from blood and other tests more easily.

Disadvantages

15. Dissenters amongst neurologists and patients commented that tertiary centres are not convenient for follow up, further prescription or picking up supplies. A further complaint from both was that the established relationship between usual neurologist and patient is threatened. In introducing future drugs, both patients and neurologists have suggested that health authorities better organise the interface between tertiary and secondary care before finalising any contracts.

Strategies employed to curb inappropriate prescription

Role of tertiary centres

16. Although overall uptake of Betaferon was low, mechanisms were incorporated to limit excessive or unsuitable prescription. One that was activated, and found useful, was the designation of tertiary centres as places of assessment to hinder over enthusiastic neurologists from prescribing. A further limiting factor, which may have been unintentional, was that the majority of prescribing clinicians at these centres were cautious about the clinical benefits of the drug and so were careful to whom they actually prescribed.

Contracting arrangements

17. Scrutiny of each candidate's eligibility either through ECR procedures or with the submission of auditing forms prior to prescription were strategies used by several health authorities. Once the initial procedures were in place and approval given however, many did nothing more to monitor prescription.

Other planned strategies

18. Other potential mechanisms, which are being tested or have yet to be tried, include capping initial numbers of patients with review once that limit is met; convening a committee of clinicians, including GPs, to evaluate the application of prescription criteria amongst two providers within one area and, in the case of the GP prescriber, the application of the caveat that GPs who prescribe Betaferon will not be entitled to contingency funds.

Untried three tier referral system

19. Not one of the twenty four people with MS in the user discussion groups (of whom all but three were taking or had tried Betaferon) experienced the expected three tier referral process from GP to usual neurologist to prescribing neurologist and only four were GP referrals. Consequently, little can be evaluated directly in this area.

20. If a three stage referral approach is to be used for future drugs, there need to be checks built into the system to ensure that eligible candidates have the opportunity to be properly assessed. Many patients in our sample first had the drug brought to their attention by their neurologist, not their GP, either at the time of initial diagnosis of MS, or at a regular follow up appointment with their usual neurologist for those with established MS.

Areas of potential improvement

Fall off in active management

21. One worrying finding was that once initial demand for Betaferon was found to be lower than expected, active management of the drug declined, even though historically it takes at least two years for a drug to reach its market potential in the UK. As a result, most health authorities did not get to the stage of developing useful tools for audit.

Lack of auditing mechanisms

22. In the case of Betaferon, there are potentially four principal stages of audit: 1) devising forms, 2) ascertaining that the right questions are being asked, 3) checking that returns are being completed by providers and 4) monitoring the returns. Nine months after the drug had been marketed, only four health authorities had completed stage 1, no one seemed to be undertaking stage 2, and stages 3 and 4 were only sketchily carried out. By not devising and applying these mechanisms, evaluating the effectiveness of Betaferon, both in clinical and financial terms will be severely limited.

23. One tertiary centre has virtually refused to supply information to the commissioning health authority about patients treated, on the grounds that patient confidentiality will be breached. Negotiations are continuing to see if an acceptable arrangement can be reached.

24. Another consequence of limited monitoring is that it is potentially dangerous to patients. Of twenty one Betaferon users who participated in our discussion groups, two had experienced severe and previously unreported side effects of paralysis from the neck down and subsequent loss of bladder control. Although these events should be reported to the pharmaceutical company via the yellow card system, a representative from the company to whom we reported the side effects said that the company had not previously been aware of these two cases. If health authorities do not request these data from their providers and share it with other authorities or check that the yellow card system is rigorously applied, assessing the safety of a new drug is seriously hampered.

Limited user involvement

25. As crucial stakeholders in the introduction of new drugs, the very limited user involvement in the process was also disappointing. Apart from one meeting with the Director of Welfare from the national Multiple Sclerosis Society (MSS), little other contact with users was made, despite the fact that local branches of the MSS exist in every health authority and at least two other charities have members with MS. Since patient demand has enormous influence in managing a new drug and health authorities, unlike pharmaceutical companies, have the advantage of direct access to patients' views, users could be incorporated more into the process.

Lack of information

26. Although it is debatable whether charities, providers or purchasers should be primarily responsible for informing users, it was unfortunate that many health authorities did not develop any patient information whatsoever. Information to GPs, on the other hand, ranged from summaries on all known aspects of the drug (i.e. side effects, method of administration, benefits and criteria for prescription) to brief notes discouraging GPs from prescribing. In managing future drugs, comprehensive information to GPs covering key points (including what is not known about a drug), which could be given to, read and understood by patients, would be helpful.

Regional Level - Chief Executives

Lead purchaser approach

27. Approximately nine months prior to licensing, North Thames Chief Executives designated East London and the City Health Authority as *lead purchaser.* As the terms of being *lead purchaser* were never made explicit, staff who took the practicalities of the work on board were confused as to what East London and the City were actually supposed to provide. One useful output was the gathering of information from central sources and the pharmaceutical company, but expectations of clinical guidelines, patient information or strategies for negotiating contracts were not met.

Suggested modifications

28. One Chief Executive suggested that in the future the role of the lead purchaser should be defined in North Thames Chief Executive meetings. He proposed that the tasks should be identified (e.g. information, clinical guidelines, patient information, negotiating contracts, establishing a uniform region-wide approach) and suitable people within each health authority be nominated as representatives to take the work forward, with one taking on an overall co-ordinating role. Once the previously agreed tasks had been completed, discussion amongst Chief Executives would determine whether further work was necessary.

29. Another Chief Executive agreed that this could work, but added that the resource commitment of the lead purchasing authority would need to be calculated. In another region where a similar approach was used successfully, the unexpectedly great time commitment of the lead purchaser and the lack of financial contributions towards her time by other health authorities was found to be problematic.

National Level

NHS Executive

Executive Letter

30. Central guidelines were helpful at a time when managing the entry of new drugs was almost a completely new concept. The Executive Letter helped to galvanise some reluctant health authorities into action and was particularly useful in setting the precedent of hospital

based prescription, thereby resolving the debate of GP versus consultant prescription for Betaferon.

31. The "local priorities" aspect of the EL, however, was problematic in that it effectively eliminated the possibility of achieving equity of access across the nation. Unsurprisingly, once the NHS Executive discounted this as a chief priority, health authorities also relegated it to a secondary position. Neurologists, GPs and especially patients have all pointed out that this was a major managerial failing. Chief Executives are also concerned as they fear those authorities which fund expensive treatments will see prospective candidates moving into their area. Without a coherent, central framework, health authorities cannot prioritise locally while allowing for equity of access nationally. This will be a recurring problem in the introduction of new drugs, unless some moves are made to address the issue in the near future.

Clinical guidelines

32. Stakeholders who were questioned about the clinical (SMAC) guidelines were uniformly positive. Users commented that the criteria were objective since the guidelines were set out pre-licensing and not in response to a financial crisis. Neurologists and GPs were also positive as they felt the clinical guidelines gave them support when faced with unsuitable but demanding candidates. The wide acceptance of the clinical guidelines by many types of stakeholders could be due largely to the extensive consultation process undertaken by their author, Professor McDonald, Chair of the Association of British Neurologists. In particular, he should be commended for including patient group representatives in the process.

Pharmaceutical company

Successes

33. Schering Health Care, the pharmaceutical company which developed and marketed Betaferon, had a difficult role in breaking down the mistrust between the NHS and drug companies. Trust was fostered through the company's willingness to organise events in which both the good and bad aspects of the drug were disclosed. Requests for information were consistently met and additional help was given to many, both inside and outside the NHS, while they grappled with the implications of introducing Betaferon. An indication of Schering's success is that several people from the NHS described them as "ethical".

Misjudgements

34. Suspicions were aroused when Schering sponsored a parliamentary briefing. Constant updates on Betaferon also irritated staff in the NHS and after a time they were regarded as sales propaganda.

Future approaches

35. Further progress towards a more collaborative approach could be made through learning much more about the daily pressures and concerns of NHS staff .

Multiple Sclerosis Society

36. As the principal patient group organisation involved in the introduction of Betaferon, the Multiple Sclerosis Society was seen by many in the NHS as allies. With the publication of the cautious charities' leaflet, the MSS helped to dampen down unrealistic patient expectations. They consistently stressed that their priority was equity of access and successfully co-opted the launch of Betaferon to highlight their own agenda of better services for people with MS in some parts of the country.

Contributions to the Rationing Debate

Explicit versus Implicit Rationing

Lack of central funding

37. Although there were rumours of central funding for Betaferon, in the end health authorities were expected to pay out of growth money. Indications are that future drugs will also be managed within existing budgets.

Explicit rationing of Betaferon

38. Despite this reality and arguments for cost effectiveness, purchasers cannot be seen to be explicitly rationing in the present climate. With Betaferon, although many health authorities queried its potential health gain, only one did not commit funding within North Thames. This was justified on the basis that the HA had no allocated growth money. Negative media attention ensued. Eventually their provider paid for treatment with some bitterness resulting.

Implicit rationing of Betaferon

Waiting lists

39. Implicit rationing was widespread with Betaferon. In two health authorities, approximately 70 - 100 people are waiting assessment while purchasers and providers are in a stalemate about funding for a Betaferon/MS clinic. Neither side has said Betaferon will not be funded, but while disagreements continue eligible and interested candidates cannot get the drug.

Role of neurologist

40. Implicit rationing also became evident through user group discussions. Most patients became interested in the drug *after* their neurologist first suggested it to them, even though they had heard about it before through the media. Since many neurologists were not convinced about the benefits of Betaferon, they did not propose it to their patients and uptake has been correspondingly low.

Role of GP

41. GPs also indirectly rationed access as around 20-25% of potentially suitable patients who enquired about Betaferon were discouraged from seeking referral in one survey. Key stakeholders - in this case neurologists and GPs - who are unconvinced of the effectiveness of a drug play a crucial role in rationing by default. This has implications both for pharmaceutical companies, which want to market their products, and for purchasers who need to manage potentially widespread prescription.

Central or local judgements on cost-effectiveness vs. equity?

42. A tension emerged between some public health departments' views on cost/effectiveness, and users' and clinicians' views on equity. The users and clinicians took the view that if a drug was licensed, it had been assessed for safety and effectiveness, so they felt it was unreasonable for an Authority to refuse completely to fund the drug. Public health departments looked at the balance they saw between cost and marginal health gain, and some would have preferred to spend their money on other treatments or patient groups, initially being very reluctant to fund Betaferon for patients in their HA.

Alternative treatment options

Other ways of improving patients quality of life

43. One live issue early in discussion dropped out of serious consideration later - alternatives to Betaferon for improving the quality of life of people with MS. Spending on the drug is seen by most neurologists as from a "different pot of money", and there were no obvious ways for HAs or providers to offer choices to patients - even those who could have been prescribed Betaferon - between drug treatment and alternative forms of support - e.g., social care, physiotherapy, help with transport, or aids and household adaptations.

44. The MS Society has been campaigning for more assistance to be provided to people with MS, and there are mixed views about the value of devoting financial resources to a drug whose clinical benefits are not overwhelming.